CHRONIC KIDNEY DISEASE AND SELECTED DOMAINS OF HEALTH EQUITY (RURALITY, SOCIOECONOMIC STATUS, CAREGIVERS)

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Thesis
Submitted to Flinders University
for the degree of

Doctor of Philosophy

College of Medicine and Public Health

13 June 2025

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ABSTRACT

Chronic kidney disease (CKD) is an abnormality of kidney function or structure lasting at least 3 months. It is associated with poor quality of life, increased morbidity and mortality, and globally is an increasingly frequent cause of death. It is also an expensive disease, particularly in its most severe form, kidney failure, when managed with kidney replacement therapy (KRT).

Health equity is the absence of unfair differences in health status because of differences in opportunities to achieve optimal health. CKD incidence and outcomes are strongly associated with health inequity. Many factors may impact health equity, and this thesis focusses on three domains described in the "PROGRESS-Plus" framework: (1) rural residence ("Place"), (2) socioeconomic disadvantage ("Socioeconomic status" (SES)), and (3) caregivers of people with kidney failure ("Plus").

This thesis includes original contributions to knowledge of the characteristics, disease impacts, and outcomes in each of these groups. A lower incidence of KRT was shown among non-indigenous Australians living in rural areas, along with poorer survival on dialysis but not with transplantation. Peritoneal dialysis was shown to have comparable outcomes between urban and rural areas. Rural workforce attraction and retention is critical to improving access to care for rural residents. This thesis details nephrology training, medical workforce distribution, and exposure to regional and rural medicine during training which is associated with future practice outside cities. An exploratory case-matched study showed comparable blood pressure control and kidney function with long term care of CKD and transplant recipients managed with telemedicine compared with standard care. This increased confidence that the barrier of travel for rural residents could be mitigated with technology, one step in improving health equity.

A Registry analysis of the impact of lower SES on dialysis outcomes in Australia showed poorer survival among residents of the two lowest socioeconomic quartiles, with greatest impact for those aged <65 years. This was in the absence of any significant dialysis quality of care indicator differences between SES groups, suggesting other causes for the disparity in outcomes. Private hospital use, which is associated with higher SES, was found to provide dialysis to an older population than public hospitals but to have similar haemodialysis survival. Lower education attainment is one measure of lower SES and is associated with poorer health literacy. Health literacy is required to navigate the health care system, make positive health choices, and implement change in behaviour to improve outcomes. A quality improvement activity showed poor knowledge about CKD among outpatient clinic attendees, with no improvement over 12 months with standard nephrology care suggesting alternative education models are required.

Caregivers are in a temporary situation of disadvantage, socioeconomically disadvantaged and more likely to be rural residents. A large systematic review of caregivers of dialysis recipients found significant burden and quality of life (QOL) comparable to caregivers of people with other chronic diseases. A second systematic review of caregivers of people choosing conservative kidney management also demonstrated significant burden and QOL comparable to caregivers of dialysis recipients. Lastly, by linking a caregiver sub-study to a larger randomised controlled trial of extended hours haemodialysis, this thesis reports characteristics and QOL of caregivers of dialysis patients in China. These caregivers had similar mental QOL and higher physical QOL than the dialysis patients they cared for, and lower personal well-being than the general Chinese population. The 12-month follow-up reported the impact of extended dialysis hours on caregivers, showing lower utility-based quality of life compared with standard haemodialysis hours.

The published works have provided new knowledge into CKD and three domains of health equity. The work has translated to regular inclusion of rural residence and SES in analyses using the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). The most important consequence has been the development of an extended suite of quality indicator reporting by ANZDATA in collaboration with the Australian and New Zealand Society of Nephrology.

DECLARATION

I certify that this thesis:

1. Does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university

2. The research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. To the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Date: 5/4/2025

ACKNOWLEDGEMENTS

Professor Rathika Krishnasamy for encouraging my application at a time in my career when I thought the opportunity to complete a PhD had passed.

My supervisors, Professor Jonathan Craig and Professor Stephen McDonald, for selflessly finding time to support me through this process, providing thoughtful reviews of my work and focussing me on the task.

Thanks to the medical students, junior doctors and colleagues who have been co-authors on the impactful work we have completed. Special mention needs to be made of the research nurses at Sunshine Coast Health, especially Andrea Pollock, who have walked this path from the very beginning.

I would like to acknowledge the support from Sunshine Coast Health and local grants from the Private Practice Trust Fund and Wishlist Foundation. This support facilitated the development and completion of much of this research.

I am also grateful to the Flinders University for admitting me as a Research Higher Degree candidate, and subsequently awarding me a Research Training Program fee offset, in the form of an Australian Government Research Training Program Scholarship.

To my patients and their caregivers who have endured the burden of chronic kidney disease but still found time to participate in research. You have taught me so much over the years and honoured me with the privilege to care for you.

Finally, and most importantly, my family. To my parents for valuing and supporting my education and seeing me through my formative years. My exceptional children, who have witnessed the challenges and rewards which accompany being part of a medical family, and who are my constant source of inspiration to be my best self. Most especially, my love Nicole, who despite making personal sacrifices has been my unwavering champion and supporter. You are my foundation for which I am eternally grateful.

LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACTIVE	A Clinical Trial of Intensive Dialysis
ADLs	Activities of daily living
AIHW	Australian Institute of Health and Welfare
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
ANZSN	Australia and New Zealand Society of Nephrology
AU	Australia
AU$	Australian dollar
CA$	Canadian dollar
CARI	Caring for Australian and New Zealanders with Kidney Impairment
CKD	Chronic kidney disease
CKM	Conservative kidney management
Co-ACTIVE	Caregivers of ACTIVE (A clinical trial of intensive dialysis) study
Co-TIMELY	Caregivers of the Infirm Elderly study
eGFR	Estimated glomerular filtration rate
EMR	Electronic medical record
EQ5D-3L	EuroQol 5 Dimensions 3 Level
FHN	Frequent Hemodialysis Network
GFR	Glomerular filtration rate
IRSD	Index of relative socio-economic disadvantage
IRSAD	Index of relative socio-economic advantage and disadvantage
KRT	Kidney replacement therapy

NHANES	National Health and Nutrition Examination Survey
NT	Northern Territory (of Australia)
PD	Peritoneal dialysis
QI	Quality Indicator
QOL	Quality of life
RCT	Randomised controlled trial
SEIFA	Socio-economic Indexes for Areas
SEP	Socioeconomic position
SES	Socioeconomic status
SF-36	36-item short form survey
UK	United Kingdom
UKRR	United Kingdom Renal Registry
USRDS	United States Renal Data System
US	United States
US$	United States dollar

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CHAPTER 1: CONTEXTUAL STATEMENT

1.1 Introduction

1.1.1 Chronic kidney disease (CKD)

Chronic kidney disease (CKD) is defined as any abnormality of kidney function or structure that is present for a minimum of 3 months and has implications for health (1). These abnormalities may include glomerular filtration rate (GFR) <60ml/min/1.73m^2 or any marker of kidney disease including albuminuria, urine sediment abnormalities, kidney related haematuria, tubular disorders, histologic and structural disorders. CKD is classified according to cause, GFR category (G1 – G5), and albuminuria category (A1 – A3). The most severe form of CKD is kidney failure defined as GFR <15ml/min/1.73m^2 with many people requiring kidney replacement therapy (KRT) in the form of dialysis or transplantation to avoid death from kidney failure.

The global prevalence of CKD is estimated at 9.5% (IQR 5.9-11.7) with the highest rates in Eastern and Central Europe (2). In the Ausdiab study completed in Australia, 16% of people aged 25 years or older had either proteinuria, haematuria and/or reduced GFR (3). Globally, CKD was estimated to cause over 26 million years of life lost in 2016 and is predicted to double by 2040. Further, CKD was estimated to cause 1.2 million deaths in 2016, increasing to 3.1 million by 2040. As a result, CKD will increase from the 16th most common cause of death in 2016 to the 5th by 2040 (4). In general, CKD prevalence increases with age and in developed countries is more common among people with diabetes, obesity, and hypertension.

The growth in CKD has resulted in a growth in the incidence and prevalence of KRT (Figure 1). In Australia, this growth has mainly been among those aged >65 years (Figure 2).

Figure 1: Australian incident kidney replacement therapy rates over time (5)

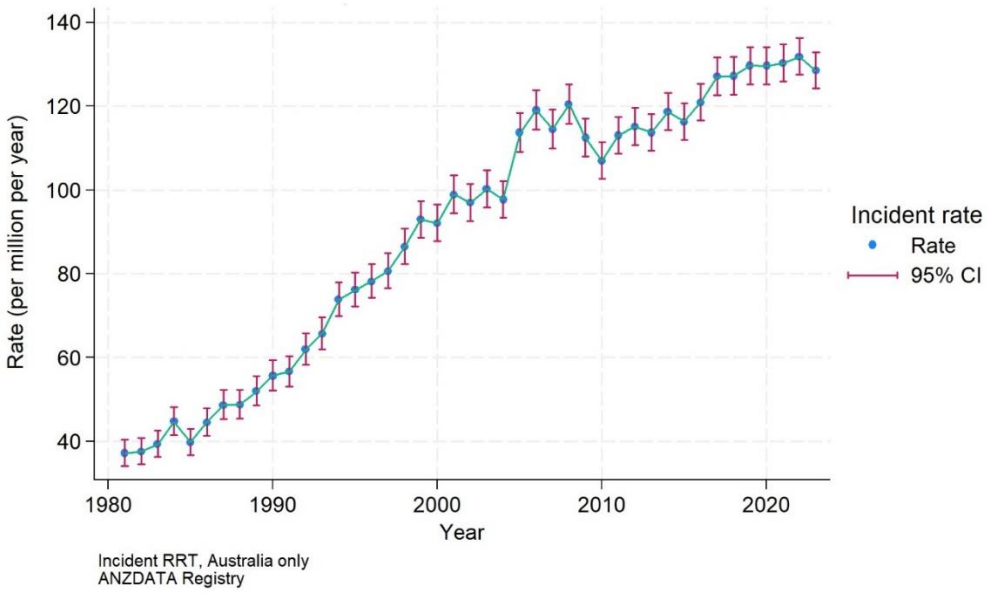
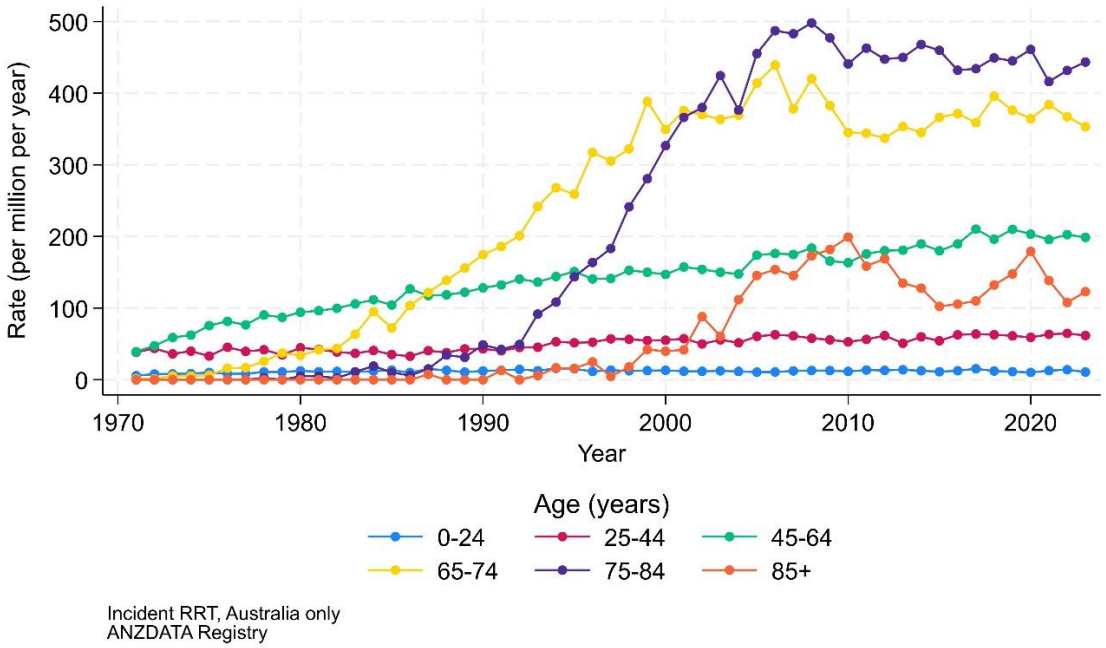


Figure 2: Australian age specific incident kidney replacement therapy rates over time (5)



The effects of CKD are not limited to mortality and years of life lost. Even mildly reduced GFR or increased albuminuria has been associated with increased rates of cardiovascular events, mortality, and hospitalisations, with more advanced stages of CKD associated with higher risk (6). The greatest impact is seen among those undergoing dialysis. CKD is also associated with increased hospital acquired complications (7), chronic pain (8), depression (9), fatigue and poorer quality of life, commonly worse among people requiring dialysis than those with less severe CKD (10). Ability to work is also impacted with a systematic review finding employment rates of 26.3% for dialysis patients and 38.2% for transplant recipients (11).

There are significant cost impacts of CKD on the health system. Annual per person estimated costs for KRT across the world are haemodialysis (US$19,380), peritoneal dialysis (US$18,959) and first year of transplantation (US$26,903) (2). In Manitoba, Canada, in 2018 the cost of in centre haemodialysis was estimated at CA$64,214 annually per patient and the comparable figure for peritoneal dialysis was CA$38,658 (12). A costing study in the Northern Territory (NT) of Australia in 2019 found annual per person costs for haemodialysis of AU$85,919, rising to over AU$120,000 for haemodialysis in remote areas (13). There are important differences between the NT and elsewhere in Australia which limit extrapolation, but contemporary national figures for Australia are not available.

There are also significant healthcare costs for people with CKD related to the increased prevalence of comorbidities and complications. A study from the NT found a progressive increased cost of

healthcare with more advanced CKD not yet requiring dialysis, mainly due to hospitalisation costs. This cost was AU$53,000 annually more among CKD G5 compared with people without CKD (14). This progressive increase in healthcare costs with advancing severity of CKD has also been found among the Ausdiab study cohort where annual costs were AU$1829 for those without CKD increasing to AU$14,545 for those with CKD G4-5 (15). A study from Queensland, Australia, found people with CKD were ten times more likely to require hospital admission and each admission was twice as costly (AU$9060) than people without CKD (16).

1.1.2 Health equity

The World Health Organization defines equity as "the absence of unfair, avoidable or remediable differences among groups of people" regardless of how they are defined (e.g. ethnicity, gender, disability). Therefore, health equity is when everyone can attain their full health potential (17). Examples of health inequalities due to unavoidable or non-remediable factors include genetic and biological variations or choice of individuals or groups. However, unfair remediable factors that are mainly outside the control of individuals or groups can lead to uneven health outcomes such as higher incidence of disease and lower access to healthcare. These factors include where people are born, live, grow, and work and may require broad policy changes to reduce the health impact.

An acronym frequently used to encompass these aspects impacting health equity is "PROGRESS Plus" (Table 1). The acronym "PROGRESS" was first described in 2003 (18) and then expanded to "PROGRESS-Plus" in 2008 (19, 20).

The justification of the elements in "PROGRESS" with examples of differences in health in both low- and middle-income, and high-income countries has been described (21). As a further example in the Australian context, people living in rural areas are under-represented in clinical trials and hence unable to access new and emerging therapies. Health equity may be improved by implementing decentralised clinical trials (22) and the Australasian Teletrial Model (23).

"PROGRESS-Plus" includes a domain of socioeconomic status (SES). This term does not have a clear definition nor standardised methodology for measurement (24) and other terms have been used as synonyms such as socioeconomic position (SEP) (25, 26). In general, the United States literature has used the term SES and European literature has used SEP. For consistency with previously published manuscripts included in later chapters, this thesis uses the term SES.

Table 1: Factors impacting health equity (PROGRESS-Plus)

Acronym	Characteristic
P	Place of residence (e.g. urban/rural, community characteristics, country)
R	Race, ethnicity, culture, language
O	Occupation (e.g. type, unemployment, informal employment, working conditions)
G	Gender, sex
R	Religion
E	Education
S	Socioeconomic status
S	Social capital – relationships and social networks
Plus	Personal characteristics associated with discrimination (e.g. disability, age)
	Features of relationships (e.g. excluded from school, parents who smoke)
	Time dependent relationships (e.g. respite care, other occasions when a person is at a temporary disadvantage)

1.1.3 Chronic disease and health equity

Chronic or non-communicable diseases include cardiovascular disease, cancer, chronic respiratory disease, and diabetes (including CKD) (27). These conditions are a result of non-modifiable factors such as genetics, as well as modifiable factors including the environment and behaviour. There is a close association between chronic disease, poverty, and vulnerable populations. "PROGRESS-Plus" provides a broad framework for health equity, however this thesis will focus on three of these domains.

Place of residence, in particular living in rural areas is associated with poorer health outcomes compared with those living in urban areas. In Australia, examples include higher stillbirth and infant mortality among premature births (28), increased prostate cancer mortality with lower rates

of prostatectomy (29), greater mortality following heart failure hospitalisation (30) and cardiovascular events, increased cancer mortality (31), and increased injuries causing death (32). Rural areas of Australia are not unique in experiencing poorer health outcomes, with similar findings reported from New Zealand (33) and Canada (34).

The health equity impacts associated with lower SES (also referred to as socioeconomic disadvantage) has been described around the world. In the United States, the highest rates of chronic disease in adults, or children with less than good health, are among the poorest families by income, with a graded reduction as income increases. Lower education attainment is associated with higher infant mortality, reduced life expectancy, and poorer health among Blacks, Hispanics, Asians, American Indians, and Whites in the United States, again with a graded reduction as educational attainment increases (35). In Australia, despite a universal health care system, deaths per 100,000 population are highest for men and women among the lowest Index of Relative Socio-economic Disadvantage quintile with a graded reduction to the highest quintile (36). Notably, other countries with universal health care also have poorer health outcomes for the lowest SES members of society, examples including the United Kingdom despite the introduction of the National Health Service, and European countries (35). This has been explained by socioeconomic factors outside the health care system impacting outcomes and that the more well-off are better able to make use of health care services (37).

Another population greatly impacted by the burden of chronic disease is caregivers. Often overlooked, unpaid or family caregivers provide essential support for people with chronic disease to manage in the community (38). Aligning with the “PROGRESS-Plus” framework, health equity is an issue for caregivers due to being in a time dependent relationship when at disadvantage (the “Plus” domain). There may be further risks associated with other domains including the informal unpaid caregiving role (occupation), restricted employment and income opportunities (SES), and isolation (social capital). There are 3 million caregivers in Australia, of whom 38.6% have a disability themselves, 29.9% were born overseas, and 24.2% live in an area of most socioeconomic disadvantage. For those aged 15-64 years, median gross income is 10% lower than non-carers and fewer are employed (70.4% vs 79.3%) (39). Of Australian primary caregivers, 30% rely on a government pension or allowance as the main source of income compared with 7.3% of non-caregivers. In the United States, 21.3% of the adult population is a caregiver (40) where the financial burden has been estimated at US$6954 annually (41). Financial strain is experienced by 18% of United States caregivers, who are more often Black, Hispanic or have not attained university education (40). Further, when compared with urban counterparts, rural caregivers in the United States have lower SES (42), provide more hours each week caregiving, and are more likely to be a caregiver (43, 44). Therefore, caregivers are socioeconomically disadvantaged and more likely to live in a rural area, characteristics which predispose to poorer health outcomes themselves. A German study reported caregivers have poorer subjective health,

more frequent history of depression, higher stress, more obesity, and more annual general practitioner visits (45). In summary, caregiving can be associated with significant burden which is associated with anxiety (46) and impacts on quality of life (QOL) and poorer perceived health (40), although there does not appear to be an adverse mortality impact (47).

CKD in disadvantaged populations was the focus of International Society of Nephrology World Kidney Day 2015 (48) with a position statement linking disadvantaged communities with an increased burden of undiagnosed and untreated CKD. Note was made that disadvantaged groups are present in low-, middle-, and high-income countries. Possible mechanisms for poorer CKD outcomes in these groups include health behaviours, access to health care, and biological and environmental factors (48). These groups are not only impacted by increased CKD prevalence and complications, but often by poorer access to and outcomes from KRT even in countries with universal health care. More recently, a review of inequities in kidney health and care pointed to the need for leadership and advocacy among the nephrology community to implement solutions (49).

1.1.4 Thesis motivation and outline

During my postgraduate training I was fortunate to practice medicine in remote and regional areas of Australia including Cairns, Cape York, Darwin and the "Top End" of the NT. This gave me firsthand exposure to the challenges and health inequities faced by rural residents, socially isolated, those of low SES, and Aboriginal and Torres Strait Islander people.

Following completion of training, I moved to Nambour, Queensland, at the time classified as an inner regional area. There was only one nephrologist between my location and Townsville over 1000km to the north. This highlighted the lack of access to care for rural people and resulted in me spending many years in service provision until workforce challenges improved. Only then was I able to turn some effort to understanding and publishing the challenges faced by people with CKD living in rural Australia. The relationship between rural residence and low SES was apparent early, while the significant demands on caregivers as more healthcare has been provided in the community became apparent over time. It is these three domains of health equity and CKD that are the focus of this thesis.

The manuscripts included in this thesis have been published between 2012 and 2022. Where possible, I have tried to facilitate involvement of early-stage researchers (commonly a registrar or early career nephrologist). Contributions from co-authors and my personal contributions are outlined in chapters 2-4 along with impact factors, citation metrics, and concise statements of original contributions to the literature. A total 13 papers are included of which I am first author on 5 and last author on 8. In general, I have developed and designed the study concept, written protocols and ethics applications, sought grant funding where necessary, contributed to data

collection (including as a reviewer for titles, abstracts and manuscripts of systematic reviews), analysis and interpretation, and either written or extensively revised the final manuscripts.

This chapter will continue detailing the findings, significance, and original contributions of the publications in the context of the literature. Chapters 2 to 4 contain my relevant published manuscripts bundled into three domains of health equity including: 1) rural residence; 2) low SES with subsequent development of quality indicators (QIs) for KRT care, and 3) caregivers of people with CKD. Chapter 2 includes epidemiological work using the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) to describe the state of KRT care in regional and rural Australia while the second manuscript explores peritoneal dialysis in greater detail. This chapter includes a paper on nephrology medical workforce and a single centre clinical trial to prove CKD and transplant care can be safely delivered by telemedicine, thereby improving access to care for rural residents. Chapter 3 includes epidemiological work using ANZDATA to provide original contributions to the literature on the impact of SES on mortality and quality of care among people undertaking dialysis in Australia. This work has been translated into a suite of KRT QIs for Australia and New Zealand. Finally, two manuscripts detailing patient knowledge about CKD, including the lack of impact of standard nephrology care to educate patients are included. Chapter 4 covers the impacts on caregivers and includes two systematic reviews describing the impacts for caregivers of dialysis patients and caregivers of those choosing conservative kidney management. The chapter includes cross sectional and longitudinal data on caregiver QOL linked to the ”A Clinical Trial of Intensive Dialysis” (ACTIVE) study (50). This includes the first data on caregivers of dialysis patients in China and the first publication detailing QOL of caregivers of patients undertaking standard or extended hours haemodialysis. The final chapter outlines my conclusions and future directions.

1.2 Rural residence and CKD

Australia is a big country with a relatively small population concentrated in large urban centres. Beyond the cities, distances are vast and access to medical services is often difficult. These problems are not new. As far back as 1968, the Medical Journal of Australia reported concerns about rural doctor issues (51). The challenges of attraction and retention of a medical workforce to rural areas, high patient contact hours, limited opportunities for continued education, difficulty attracting locums and professional isolation were also recognised in the 1970s (52-54). By the 1990s, and in response to several committee reports, a Rural Health Taskforce was established and an inaugural National Rural Health Conference. One recommendation was for greater undergraduate medical training in rural areas with large regional areas as an important factor being integral to success. The Rural Incentives Program was announced in 1992 to facilitate this (55) and Monash University established the first rural health academic unit (56). Rural clinical

placements for medical students have subsequently been shown successful in increasing the medical graduates pursuing future career paths outside urban areas (57-59). The issues effecting medical workforce have also been recognised among other health professionals.

Workforce challenges and lack of access to services contribute to poorer health outcomes for people in rural Australia. However, there are many contributing factors including personal behaviours such as excess alcohol and smoking, trauma/accidents, obesity, physical inactivity (36), and community issues such as unemployment, occupational/environmental exposures, and low SES (60). Patients in rural areas also report other challenges such as difficulty navigating the health care system, separation from family and community to attend health care appointments, and the time and financial burden of travel and accommodation away from home (61). It is apparent that with so many factors impacting health outcomes in rural areas there is not a simple solution, and improvements require a holistic approach.

1.2.1 Australian dialysis and transplantation incidence and outcomes

There was little information about the impact of rural residence on people with CKD in Australia or elsewhere in the world in my early career. A significant proportion of Aboriginal Australians live in regional and remote areas and publications from the late 1990s to 2000s highlighted the very high incidence of kidney failure in this population. This was especially for those resident in the NT (62), and further work demonstrated significant regional variation in kidney failure but persistently higher rates in remote compared with urban areas (63). The ANZDATA Registry was used to demonstrate that First Nations people having KRT in Australia and New Zealand had a 70% higher mortality than other patients and were less likely to receive a transplant, although geographic location was not considered (64). Work had also been published, again using ANZDATA, to show higher rates of graft loss and poorer patient survival among Aboriginal people who had kidney transplantation (65). Further, Aboriginal Australians having peritoneal dialysis had higher rates of peritonitis (66) with those in regional and remote regions having higher peritonitis related complications and mortality (67).

Although this work examining Australian Aboriginal health had been published, the impact of rural residence on KRT had not been explored. ANZDATA had commenced collection of postcode data for each patient at start of KRT, and that enabled the use of the Australian Standard Geographical Classification produced by the Australian Bureau of Statistics (ABS) (68) to allocate at postcode level the area of residence (major city, inner regional, outer regional, remote and very remote) for each person in the Registry. Given the previously published data on the First Nations population, and uncertain postcode data in this group (due to the postcode of the hospital at dialysis start often being provided to ANZDATA rather than the postcode of the remote community of patient origin), my work in the area focused on the non-indigenous population. The work was initially performed

on data from 1996-2005 and presented at the Australian and New Zealand Society of Nephrology (ANZSN) annual scientific meeting in 2005 where I was awarded the Rural Science Award. The data was extended to 2009 for the final publication (69).

My Australian analysis showed a lower incidence of commencing KRT outside major cities, with more remote regions having the lowest incidence. Dialysis survival was lower outside major cities, except for the remote group where patient numbers were small. Lastly, transplant patient survival was not different by remoteness although outer regional areas had poorer graft survival at 1 year (69).

Regional and remote areas may have limited options for haemodialysis due to lack of a facility dialysis unit (e.g. at a hospital or community centre) within reasonable travel distance, or challenges to undertake home haemodialysis due to water purity and supply issues, power, or patient characteristics. Peritoneal dialysis is a less resource intensive dialysis modality with flexibility to be undertaken in remote locations without the need for power or large volumes of high purity water. It therefore seemed important to explore the uptake of peritoneal dialysis outside major cities and its outcomes. My manuscript was published in 2013 and demonstrated that uptake of peritoneal dialysis was higher with increasing remoteness, technique failure (i.e. haemodialysis transfer) was less common outside major cities for the first 6 months and comparable thereafter, and peritonitis rates and mortality did not differ by remoteness (70). This data suggested peritoneal dialysis was a good treatment choice for kidney failure in regional and remote Australia.

It is noteworthy that my work examined area of residence at a postcode level which was mapped to statistical local areas. Some postcodes may have more than one statistical local area in which case the postcode remoteness was allocated to the most populous area. While this methodology fits the ABS remoteness model, it does not indicate travel distance from the patient's home to the nearest medical care and/or haemodialysis unit. Further, it is not possible to apply the results to every individual within a regional or remote location using this methodology due to ecological fallacy. The literature in this field includes both remoteness determined by distance needed to travel for medical care (71-74), and classification of residential regions similar to that used in my work (75-78).

In the period between initial presentation and final publication of these manuscripts, data examining the impact of rural residence on CKD and outcomes had been published from the United States and Canada and showed mixed effects. The first used the United States Renal Data System (USRDS) and ZIP code to classify people as urban, large rural, small rural, and remote residence (78). This study reported an increased uptake of peritoneal dialysis outside urban areas. Ethnic group affected survival and time to transplant with rural Black populations having better dialysis survival but being much less likely to be transplanted than urban Black residents. The

white non-Hispanic population had a small survival disadvantage on dialysis in rural and remote regions but were more likely to be transplanted.

A later paper from the United States again used USRDS but determined rural residence using rural-urban commuting area associated with ZIP codes, classifying patients as urban, micropolitan or rural (76). This study found no difference in survival by remoteness for haemodialysis, increased mortality for non-urban peritoneal dialysis patients, and increased transplantation for non-urban patients. My work also demonstrated an increased prevalence of transplantation outside major cities, and this was replicated in the United States with incident transplantation rates both by travel distance to transplant centre and rural-urban commuting area (74). Interestingly, another paper from the United States found non-urban residents were less likely to undergo transplantation but this study did not consider differences in transplant suitability by remoteness (75). United States rural dialysis residents are older with more comorbidities than urban counterparts (78).

Among peritoneal dialysis patients, a Canadian study of travel distance to the treating nephrologist's practice found an increased incidence of peritoneal dialysis when travel distance was greater than 50km, but also increased mortality (73). A USRDS study found micropolitan and rural residence was associated with increased mortality on peritoneal dialysis (76). An Australian study using ANZDATA found a shorter time to peritonitis and increased rates of peritonitis among those living >100km from the peritoneal dialysis unit (72).

Overall, my work expanded the literature of the impact of CKD on rural residence beyond a North American perspective. It highlighted the disparity in KRT based on remoteness in Australia, adding dialysis to the conditions and treatments associated with poorer outcomes in regional and rural Australia. The work was not able to identify the underlying causes for the disparities but work to address the complex issue of poorer health of rural residents in Australia remains ongoing (79-81).

1.2.2 Medical Workforce

One area of focus to address rural health challenges has been workforce. The 2008 Australian Institute of Health and Welfare (AIHW) workforce report found rates of medical practitioners per 100,000 population based on a 40-hour week were 376 in major cities, 217 inner regional, 187 outer regional, and 196 remote/very remote areas. For medical specialists the respective rates were 132, 64, 44, and 23 (82). A 2007 survey of nephrologists in Australia (83) found 88% reported their primary place of practice as a major city compared with 9% inner regional, 2% outer regional, and 0.4% remote (for context, approximately 70% of Australians live in major cities). Furthermore, the secondary sites of practice of those in major cities were typically also in a major city rather than outreach to a regional centre (84). In this context, I then turned to understanding

the medical nephrology workforce as Chair of an ANZSN Workforce workgroup (85) and training of new nephrologists (86). Other healthcare professionals such as nurses, allied health, and dialysis technical staff are also important in providing care for people with CKD but were outside the scope of my work.

In the early 2000s there was concern about the adequate exposure of nephrology trainees in Australia to clinical scenarios. This was associated with an increase in registered trainees from 22 in 2000 to 84 in 2010. Over the same period there was a significant reduction in the number of dialysis patients, renal biopsies and dialysis catheters inserted per trainee (87), suggesting less clinical exposure. The first workforce survey of nephrologists published in 2007 raised concerns about inadequate supply (84), however 8-10 years after its publication there were concerns about an oversupply of medical professionals and nephrologists. Indeed, the number of medical graduates in Australia was forecast to double between 2005 and 2012 (88) and predictions were of an oversupply of 7000 doctors by 2030 (89).

By 2016 the number of nephrology trainees in Australia had increased to 120 and projections for nephrologist numbers by 2025 suggested an oversupply. In response to this, my work found 42% of newly completed trainees were enrolling in a higher degree, 77% had either commenced or completed a higher degree, and over half of these were doing a higher degree for career development rather than wanting a research career (86). However, a positive impact of the increased supply had been a growth in nephrologists from 11% practising in regional areas to 19% by 2016 (85), perhaps due to more employment opportunities in regional and rural areas compared with cities and the change to training with increased rural exposure at medical school. A survey similar to my original work of trainees and early career nephrologists was repeated in late 2020 and early 2021 and found 85% were mainly working in a major city but 31% of early career nephrologists had completed some training in a regional or rural area (90).

On reflection, this work was undertaken at a time when there were grave concerns of an oversupply of doctors in Australia. Perhaps it should have been more accurately described as a maldistribution. Increasing workforce may help to improve the undersupply outside major cities, but many other policy changes and initiatives have been made over many years to help achieve better rural resident health outcomes. Examples include:

- Rural Incentives program (55)
- Establish an Australian Rural Health Research Institute (91)
- Establish an Australian College of Rural and Remote Health (92)
- National Rural Health Conferences (93)
- National Strategic Framework for Rural and Remote Health to guide a national approach to policy, planning, design and delivery of healthcare in rural and remote Australia (94)

- Rural health student placements (58, 59, 95, 96)
- Rural clinical schools (57, 97)
- Preferential admission of rural students to medical school (98)
- Workforce incentive program doctor stream (99)

1.2.3 Telemedicine

The issue of rural residents' health status, access to care and impacts of travel for specialist services has not been resolved (100). For example, the challenges of people travelling or relocating from home for radiation treatment include burden of travel, living away from home, financial burden, and distant from family and friend support (101). With the increased availability and acceptability of telemedicine which can reduce travel for rural people, I conducted a case matched trial to demonstrate feasibility and quality of care with this model in the CKD and transplant population (102).

Telemedicine (also called telehealth) is defined as medical information that is exchanged between sites through electronic communication to improve a patient's health. The communication may be clinician to clinician (email, video, on-line result/report portals), clinician to patient (phone, video, email, internet, remote wireless monitoring), and patient to mobile health technology (smartphones, mobile apps, email, web portals, wearable monitors) (103). The evidence for benefit has been slowly accumulating, although a map of 58 systematic reviews covering 965 studies between 2007 and 2015 showed effectiveness for remote monitoring, psychotherapy, and counselling for chronic conditions but further evaluation required for the effectiveness of telehealth consultation (103).

In nephrology, early experience with telemedicine (or as the term was coined, telenephrology) was mixed (104-107). By 2017 there was increasing interest in telemedicine for nephrology but evidence of its quality and safety compared with standard in-person care was limited (108). Despite this, its use in Australia for clinician-patient consultation was growing.

In the absence of data showing safety and quality of care for telemedicine in nephrology, I completed the next study (102). This study was longer in duration of patient follow-up (2 years) compared with many studies of telemedicine, examined important clinical outcomes including blood pressure control and kidney function, and included groups of people with CKD or a functioning kidney transplant. The patients already had an established relationship with the nephrology service. The study showed feasibility, high patient satisfaction in both standard care and telemedicine groups, equivalent clinical outcomes between groups, and a significant reduction in travel with telemedicine. Although only single centre, telemedicine has grown progressively at this centre due to trust in the patient quality of care that can be delivered. The paper has been well

cited. Larger studies (109) and broader uptake of telemedicine in nephrology have followed, partly driven by necessity related to COVID-19 (110, 111).

1.3 Socioeconomic status, quality indicators and CKD

There are many reasons why people in rural and regional areas have poorer health outcomes than those in urban areas. A significant contributor to these poor outcomes are the social determinants of health, whereby where people are born, grow, live and work are closely associated with health outcomes (112). Social determinants may be considered the underlying causes of the health behaviours (e.g. obesity, inactivity, smoking, alcohol, poor diet) that lead to disease and increased morbidity and mortality (36). The main social determinants have been characterised as (112, 113):

- Early life: Health behaviours during pregnancy such as smoking, alcohol, poor diet, and nutrient deficiencies can impact the development of an unborn child, leading to low birth weight which is associated with increased disease in later life. Low birth weight has been associated with low nephron number, and increased risk of albuminuria, hypertension, and CKD (114-116). As an infant, inadequate cognitive, emotional, and sensory input can impact growth, learning, behaviour, and positive health habits such as good diet, exercise, and not smoking.
- Social exclusion: This describes social disadvantage and lack of skills and opportunity which impacts ability to participate fully in society. This may be associated with discrimination based on gender, ethnicity, culture, or sexual orientation which contributes to psychological damage and anxiety. Social inclusion involving both family and the community, may benefit health by creating networks that provide support in times of economic, personal or health difficulty. Social isolation has consistently been associated with increased cardiovascular and mental health disease (117). Loneliness has been associated with an increased risk of CKD among people with diabetes (118), and a Chinese cohort study found social isolation predicted both rapid decline in GFR and new onset CKD (119).
- Social capital: This is the bond between members of communities and each other, often reflected by the availability of community resources such as sporting or other facilities. The “liveability” of a location such as open space, parks, playgrounds, and walkability to services may all contribute to health.
- Employment and work: Unemployment is a risk for poorer health outcomes and is associated with poorer education attainment and opportunities. However, even among those employed, the degree of autonomy, working hours, demands and conditions may impact physical and mental health. For example, less job control is associated with increased cardiovascular disease (120).

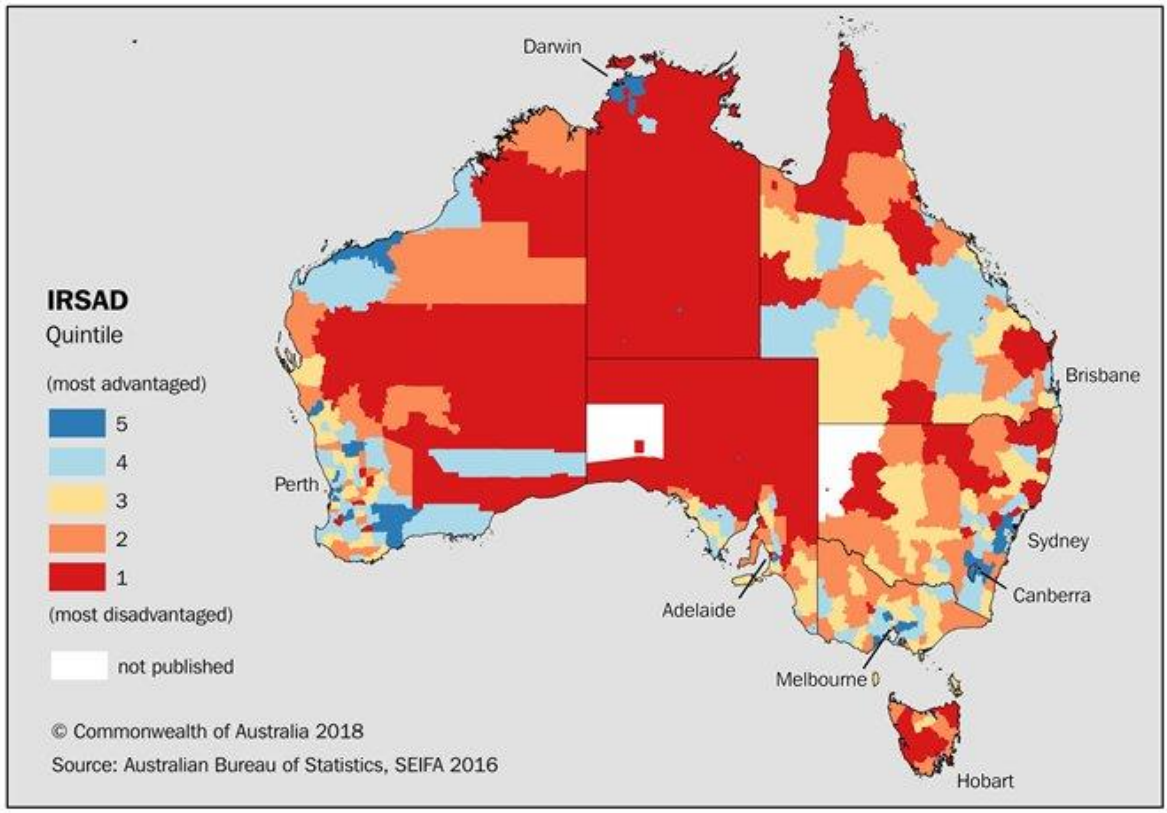
- Housing: Safe and affordable housing is associated with better health.
- Residential environment: Communities that are safe, socially cohesive, have access to quality food and transport, and a pleasant environment are associated with better health outcomes. For example, living in a socioeconomically disadvantaged neighbourhood in the United States is associated with higher rates of cardiovascular disease (121).
- Socioeconomic position: People who are from poorer social or economic backgrounds in general have increased rates of disease and its complications, including shorter life expectancy. Common measures of SES include education level, occupation, and income. Composite measures are also available such as the Scottish Index of Multiple Deprivation 2020 (122).

The ABS reports the Socio-Economic Indexes for Areas (SEIFA) based on census data every 5 years (123). The ABS defines relative socio-economic advantage and disadvantage in terms of people's access to material and social resources, and their ability to participate in society (123). There are four indices reported: The Index of Relative Socio-economic Disadvantage (IRSD); The Index of Relative Socio-economic Advantage and Disadvantage (IRSAD); The Index of Education and Occupation; and The Index of Economic Resources. IRSAD is generated using census data including household income, education level, unemployment or type of employment, internet access, separated/divorced/single parent family status, households with children <15 years and no working parents, no car ownership, rent costs per week, and mortgage repayments.

SEIFA is a much broader measure of SES than measures such as income or employment. However, as it is generated from census data there are some weaknesses to consider including there is no measure of a household's wealth or the social infrastructure available in the local community. The measures are also not relevant for an individual but reflect the SES of the area which at the smallest is Statistical Areas Level 1 which generally have a population of 200-800 with an average of 400 people.

The most advantaged local government areas are in the eastern and northern suburbs of Sydney and beachside in Perth, while the most disadvantaged are rural communities often with large Aboriginal populations in Queensland and Northern Territory. In general, the most advantaged areas are in large cities (especially Melbourne, Sydney, and Canberra) and regional and rural areas are more disadvantaged (Figure 3).

Figure 3: Index of relative advantage and disadvantage (IRSAD) quintiles for Local Government Areas of Australia map (124). Reproduced under the Deed - Attribution 4.0 International - Creative Commons



The earliest reports of the association of SES with dialysis outcomes were in the 1990s. The Michigan Kidney Registry was used to demonstrate that survival for Black but not White Americans undergoing dialysis was worse as the ZIP code of residence level of income reduced (125). The USRDS used incident cases of treated kidney failure from 1983-1988 and average per person race specific county of residence income to demonstrate that for both Black and White Americans, there was an inverse association between income and incidence of treated kidney failure (126). A smaller study from New York State at the same time found an inverse association between median family income in the patient's ZIP code and incidence of diabetic and hypertensive glomerulosclerosis for Whites but not for Blacks (127). A study from California used Medicare or Medicaid insurance status to demonstrate that those excluded from Medicare (and hence poorer minority groups) are less likely to be listed for transplantation (128).

Research output increased in the first decade of the 21st century, exploring the impact of SES (determined using various methodologies) on incidence of kidney failure, transplantation access and rates, progression of CKD, and dialysis modality selection, mainly from the United States and United Kingdom. Selected publications are shown in table 2.

Table 2: Publications exploring socioeconomic status and chronic kidney disease

Year Published	Author	Country	SES methodology	Outcome
2001	Garg P et al (129)	US	Neighbourhood income	Higher income associated with lower mortality and higher transplant listing
2002	Stack AG (130)	US	Employment, education	Greater use of PD among better educated & employed
2005	Merkin SS et al (131)	US	Area level income, wealth, education, occupation	Greater risk for CKD progression among poor White males, but not White females or Blacks
2006	Caskey FJ et al (132)	England, Wales	Townsend Index*	Social deprivation associated with poorer survival in incident KRT patients which resolved after adjusting for comorbidity
2008	Keith D et al (133)	US	Minority race and education	Minority race and low education associated with longer time on dialysis prior transplant waitlisting
2008	Volkova N et al (134)	US	Neighbourhood poverty	Neighbourhood poverty strongly associated with higher KRT incidence, more marked in Blacks than Whites
2009	Gore JL et al (135)	US	ZIP code income and personal education	Lower area income or personal education level associated with lower

				living kidney donor transplant rates
2010	Axelrod N et al (136)	US	ZIP code	High SES patients had greater access to transplant (especially living donor) and lower post-transplant mortality
2010	McClellan WM et al (137)	US	Household and neighbourhood income	Household poverty associated with CKD (non-dialysis)
2010	Udayaraj U et al (138)	England, Wales	Townsend Index	Socially deprived have reduced access to transplantation
2010	Udayaraj U et al (139)	England, Wales	Townsend Index	Increased KRT incidence with social deprivation
2011	Choi A et al (140)	US	Education	Poorer education attainment associated with increased risk of CKD and albuminuria
2011	De Andrade Bastos et al (141)	Brazil	Household income	No association with PD technique or patient survival

SES = socioeconomic status, PD = peritoneal dialysis, US = United States, KRT = kidney replacement therapy

*Townsend Index – incorporates unemployment, non-car ownership, non-home ownership, household overcrowding

The published data suggested low SES was associated with higher rates of CKD, higher incidence of KRT, poorer dialysis survival and less access to transplantation. Although there had been significant work in the United States and United Kingdom, both have different health care systems to Australia. In the United States, healthcare is mainly funded by private insurance, with smaller portions of the population covered by Medicare (government funded for age >65 and those <65

with permanent disabilities or kidney failure), Medicaid (government funded for those below the poverty line), or Veteran's Affairs. A significant portion in the United States have no medical insurance and co-payments for care are common among all patients. In the United Kingdom, the National Health Service is a universal healthcare provider and there is also a small private healthcare sector. There are some patient co-payments. Australia has a universal healthcare provider (Medicare), but 45% of the population (September 2024) (142) also choose to pay for private hospital health insurance (there is a subsidy for private insurance for low income earners and an increased tax liability for high income earners without insurance). Australians may choose to use publicly funded hospital care or elect to use private hospitals (either with insurance, self-funded, or funded by Department of Veterans' Affairs for ex-servicepeople). Co-payments for health care are common. Of note, Australia also has a much greater geographical spread of population than the United Kingdom.

1.3.1 Socioeconomic status and Australian kidney replacement therapy outcome

The first Australian papers examining SES and CKD were published in 2012 and included my work comparing people having dialysis in public and private hospitals in Queensland (143). Ideally this work would have included all of Australia, but models of care vary significantly between states and may include no private haemodialysis, or private haemodialysis units which provide care to public hospital patients on an outsource contract. For this reason, Queensland alone was examined as the patients in private haemodialysis units were privately insured or Department of Veterans' Affairs patients. Public hospital patients are usually uninsured but may include people with private insurance who choose a public hospital or cannot access their preferred dialysis facility or dialysis modality (typically peritoneal dialysis or home haemodialysis) in a private hospital. Data were not available to examine how many had private insurance but were having dialysis in a public hospital. However, ABS has shown private insurance rates of 34% among IRSD most disadvantaged regions compared with 77% of people in the least disadvantaged areas (144), suggesting that overall the people having dialysis in private hospitals have higher SES than their counterparts in public facilities. The study showed no difference in patient survival on haemodialysis between public and private hospitals (but poorer survival on peritoneal dialysis compared with haemodialysis in public hospitals), although significant differences in patient characteristics and dialysis care.

At the same time as my analysis using ANZDATA, the Registry published its first work examining SES and incidence of KRT in Australia (145). Unlike many previous studies, this study used IRSAD, a much broader measure of SES than income or educational attainment alone. The Australian data again showed an increased incidence of KRT among those living in lower SES areas, most marked for diabetic nephropathy. People commencing KRT from lower SES areas

were younger with more comorbidities. The study did explore the interplay between SES and rural residence, finding a greater impact of SES on incidence rates of KRT in major cities than regional and remote areas, and noting that postcodes in major cities had higher SES overall than more remote areas.

These first Australian publications lead to more work exploring the impact of SES on KRT care. Transplantation rates (both pre-emptive and living donor) in Australia were shown to be higher among higher SES areas, but deceased donor transplantation rates were shown equivalent by SES area. This suggested the health of potential donors of people living in low SES areas may preclude them from donating rather than an issue of equity of access (146). I then co-authored an analysis exploring the impact of SES on uptake of home dialysis modalities (147), finding a lower incidence of peritoneal dialysis among people from high SES areas and no variation in uptake of home haemodialysis. People from high SES areas undertaking haemodialysis were far more likely to have this in a private hospital. In Australia, private hospitals are not usually funded for home dialysis therapies, and it is possible that people who attend private physicians with private health insurance may be recommended to undertake private hospital haemodialysis, or alternatively may choose to do so to continue a therapeutic relationship with the treating nephrologist. As a result, uptake of peritoneal dialysis may be lower among the high SES areas. In contrast, uptake of peritoneal dialysis in England and Wales is lower among low SES groups (132). It is possible the absence of a significant private hospital system in the United Kingdom results in all people having similar treatment options. Further, a Canadian study reported similar patient desire for peritoneal dialysis regardless of SES, but people of lower SES faced barriers that prohibited undertaking peritoneal dialysis such as physical space and family and social supports (148).

The next work I undertook in this program was to investigate the impact of SES on dialysis survival in Australia (149). This examined non-indigenous Australians categorized by IRSAD and reported similar findings to other studies with lower SES being associated with increased comorbidities, rural residence, and lower transplantation rates. Mortality was higher in lower SES areas, comparable to results from the United States (129, 150) but inconsistent with England/Wales which had similar survival by SES in an adjusted analysis (132). The difference between Australia and England/Wales is interesting and suggests that access to a universal health care system alone cannot alleviate differences in outcomes. Despite Australia having a universal health care system, there remain significant out of pocket costs for patients, and a systematic review has found that costs inhibit adherence to CKD treatment and dialysis attendance with the poorest being impacted the most (151). Australia has a greater geographic distribution of population than England/Wales and rural residence may mean a very long travel distance for healthcare which may impact outcomes. Further, other factors such as education, income distribution, and health behaviours have been proposed as reasons for smaller inequalities in overall mortality between low and high

SES populations in European countries (152), and similar factors may help explain the differences between Australia, the United States, and England/Wales for dialysis.

My work was important as it demonstrated the greatest association of lower SES on poorer dialysis survival was among the young, with the difference not seen in people aged >65 years. A similar finding for KRT was reported from England/Wales (132) and a more recent study of non-dialysis CKD from Scotland found poorer care and outcomes in deprived areas, greater among those aged <65 years (153). A study from the United States examined mortality among young adults on dialysis and found poorer survival among Blacks compared with Whites living in areas of poverty, a difference that was attenuated in high SES areas (154). However, this study did not explore the impact of poverty by all age groups. A recent cohort study with 18 years follow-up found people living in low SES neighbourhoods during young and middle adulthood (compared with later adulthood) suffered the greatest impact on all-cause mortality (155). My data only reported postcode at entry to KRT and therefore data on SES of area of residence in young and middle adulthood was unknown for those >65 years. It is also possible that the social determinants of health and health behaviours have a greater impact in earlier life whereas with age and kidney failure, the disease process has a much greater and overwhelming impact on prognosis.

Multiple measures may be used to examine the impact of SES on healthcare. The work with ANZDATA used IRSAD, a broad measure at postcode level. Studies from other countries have used household income, educational attainment, or occupation and have generally confirmed an association between lower SES and higher mortality in people receiving maintenance dialysis irrespective of the measure used (156). ANZDATA does not collect household income, education level or health literacy data of individuals making these analyses impossible using Registry data. However, the AIHW has reported the lowest mortality from CKD among those who completed university education and households with the highest income (157).

1.3.2 CKD health knowledge

Health literacy describes an individual's ability to obtain, understand, process and apply information to make effective decisions about health care (158). Low health literacy in the general population has been associated with poorer health outcomes including more hospitalizations and greater mortality, and less uptake of preventative health measures such as vaccination and breast cancer screening (159). In the non-dialysis CKD population, poorer education has been associated with higher rates of CKD and/or albuminuria (140, 160). Interestingly, a comparison of the United States and Netherlands found a strong association with CKD and income but not education in the United States, and the opposite in the Netherlands (161), postulated to be related to the user-pays nature of United States healthcare. Further, low educational attainment in the setting of non-dialysis CKD is associated with increased vascular events and mortality (162). This

led to my next studies examining the knowledge of people with CKD about kidney disease and the impact of standard care on changes over time (163, 164). These projects were conducted as surveys at a single centre.

The first paper explored knowledge about kidney disease among people newly referred to a nephrology outpatient clinic (163). Of 210 surveyed patients, 70.5% had education to primary or secondary school level and 54.3% were on a government pension for income. Overall knowledge of CKD with regards to causes, symptoms and treatment was poor. There was little education in primary care and hence despite being referred for kidney disease it is likely the survey found knowledge levels comparable with the Australian general population which is also known to be insufficient (3). Poor kidney disease knowledge among people with CKD is not unique to this population. Data from a United States population of people with CKD who had seen a nephrologist at least 4 times in the previous year found a third had poor understanding of CKD and half did not know about haemodialysis, peritoneal dialysis or transplantation (165). A study from Singapore also found limited CKD knowledge in a primary care population (166). In a nested sub-study of the Ausdiab study, people with CKD were asked risk factors for kidney disease and the most common answer was alcohol, comparable with my work. Knowledge was poor even among those with diabetes or hypertension, and the authors called for public and patient education (167).

The next paper explored the change in knowledge about CKD over a 12-month period when patients had been attending the nephrology outpatient clinic (164). At the time, the nephrology clinics at my hospital provided individual education to people with estimated GFR (eGFR) <20ml/min/1.73m^2, mainly focussed on treatment plans for kidney failure and delivered by nurses and allied health staff. All patients had access to pamphlets, explanation from the treating nephrologist, and some with eGFR > 20ml/min/1.73m^2 were referred for individual education at the discretion of the medical staff. Despite a median 4 visits to a nephrologist over 12 months, improvements in knowledge were small and disappointing. For example, the most common causes of CKD nominated were unsure and alcohol. Only 6% had eGFR <20ml/min/1.73m^2 and only 8.4% had seen a nurse educator making analysis of the impact of focussed individualised education impossible. However, there was no difference when examining those with more frequent outpatient visits than those with less, nor those who did versus did not report collecting pamphlets. Overall, the data showed a disappointing outcome at 12 months with the current model of care.

The literature at the time showed both poor knowledge about kidney disease among the general population and people attending nephrology clinics, and it seemed standard nephrology care had limited beneficial effects. Indeed, a recent study from a well-resourced multi-care kidney clinic in Canada found only moderate knowledge of CKD (168). This leaves the questions of how to deliver education, what impact can education have on patients' knowledge about kidney disease and how

does this impact outcomes. In 2007, the Caring for Australian and New Zealanders with Renal Impairment (CARI) guidelines on pre-dialysis education for patients with CKD were published (169). The author noted level 2 evidence that education is an important part of a pre-KRT management strategy and may have beneficial effects (reducing temporary access at start of dialysis, psychosocial well-being), and that all patients should have access to a pre-KRT education program. The Guideline also noted that there were few reports of the effects of education on progression of CKD, with many being limited by having selective populations included and being retrospective. Nevertheless, the Guideline included implementation and audit recommendations for Australian and New Zealand renal units. My work demonstrated that despite following the CARI Guideline with pre-KRT education (eGFR <20ml/min/1.73m^2), only a small fraction of the CKD population received personalised education and hence the majority were no better off.

Two Cochrane reviews summarise the progress in the field of patient knowledge and education about CKD over the next decade. The first included 120 studies (107 randomised controlled trials (RCTs) and 13 non-randomised, 21,149 participants) published up to July 2022 examining the benefits and harms of interventions to improve health literacy in people with CKD (170). The authors noted the very broad field which included educational interventions, self-management interventions, and a combination of the two. When compared to usual care, low certainty evidence showed educational interventions may increase CKD related knowledge, self-management interventions may improve self-efficacy and QOL physical component score, and a combination of these may increase knowledge, self-efficacy and self-care behaviour. Moderate certainty evidence suggested little impact on rate of eGFR decline although a combination of education and self-management probably decreases the risk of death. Overall, the authors suggested that these interventions are probably of benefit, but evidence had high heterogeneity and hence was of low certainty.

The second Cochrane review included 8 RCTs and quasi-RCTs (840 participants) published up to July 2024 examining the benefits and harms of education programs for people with CKD and diabetes (171). The authors found education compared with usual care probably decreases glycated haemoglobin and may improve general knowledge of diabetes and some self-management practices. Evidence for other benefits is uncertain.

The area of health literacy, kidney disease knowledge, education and self-management is complex and evidence heterogeneous or weak. Overall, there is possible benefit and little evidence of harm. The cost-benefit of intervention for a large population needs to be better understood as nephrology services in Australia are generally inadequately resourced to provide detailed education to all and will most likely continue to target selected individuals and those approaching KRT. Although a CKD knowledge tool has been developed in the past (172), its use did not become widespread. More recently another CKD knowledge instrument has been developed and

may offer the opportunity to monitor and assess the impact of different interventions in improving patient knowledge (173). On reflection on my work, it was a useful real world quality initiative in an Australian centre that highlighted the challenges at the time and was relevant to other Australian sites. The use of a validated tool for CKD health literacy would have strengthened the work although none were available at the time of the study. Measuring health literacy and targeting people with low health literacy rather than all patients may have also been a valuable strategy. Overall, the heterogeneity of interventions is similar to the variation in learning methods of individuals and reflects the many different approaches that are required to improve knowledge among the patient population and broader community.

1.3.3 Quality Indicators

The final area I examined with regards the effects of low SES on outcomes was quality (of care) indicators (QIs) (174). QIs have been defined by the United States Agency for Healthcare Research and Quality as standardised, evidence-based measures of health care quality that can be used to measure and track clinical performance and outcomes (175). This work was an ANZDATA analysis of biochemical, haematological, peritoneal dialysis and haemodialysis adequacy, and vascular access markers of care according to guidelines. Having a functional vascular access (arteriovenous fistula or graft) was less common among the disadvantaged compared with the advantaged IRSAD quartile. Otherwise, differences were few and it seemed that QIs were not the reason for poorer survival among socioeconomically disadvantaged people having dialysis in Australia.

In nephrology, QIs have been reported in the past and are commonly the remit of clinical quality registries such as United Kingdom Renal Registry (UKRR), USRDS, or ANZDATA. Published work regarding QIs and low SES had come from North America and England/Wales. A selected summary is shown in table 3.

Table 3: Literature review of low socioeconomic status and CKD quality indicators

Year Published	Author	Country	SES methodology	Outcome for lower SES group
2006	Caskey et al (132)	England/Wales	Townsend Index	More referred late to nephrology, less likely to achieve Hb or phosphate targets

2008	Keith et al (133)	US	Medicare insurance, education attainment	Less pre-emptive transplantation wait listing
2009	Udayaraj et al (176)	UK	Townsend Index	Better achievement of calcium and phosphate targets
2009	Gore et al (135)	US	Education attainment	Less live donor kidney transplantation
2015	Nee et al (177)	US	Medicare-Medicaid dual eligibility and ZIP code household income	Individual and area level poverty associated with less likely to start haemodialysis with an AVF
2015	Tang et al (178)	Australia	SEIFA	Higher risk of peritonitis associated hospitalisation or death
2015	Hao et al (179)	US	Educational attainment	Lower rates of pre-KRT nephrology care
2016	Kumar at al (180)	US	Household income	No association with phosphate levels
2019	Kim SJ et al (181)	Canada		No association with referral rates for transplantation
2019	Naylor KL et al (182)	Canada	Neighbourhood income	No association with transplant graft survival

Hb = haemoglobin, SES = socioeconomic status, UK = United Kingdom, US = United States, SEIFA = Socio-economic indexes for Areas, KRT = kidney replacement therapy

*Townsend Index – incorporates unemployment, non-car ownership, non-home ownership, household overcrowding

The international evidence showed some associations between lower SES and late referral to nephrology care. This was confirmed in a systematic review (183). A recent systematic review found early referral is an indicator of good pre-dialysis care, and is associated with lower mortality, shorter hospitalisation, less use of dialysis catheters, and a higher rate of transplantation (184). This suggests that timely referral as a QI is associated with outcomes and may explain some of the effect seen in low SES groups.

In the United States, low SES was associated with less living kidney donor transplantation. A possible explanation is that potential donors may be at higher risk of poorer health related to their SES and therefore unsuitable as donors. On the other hand, a factor which may deter potential donors could be the costs for the donor. A small Australian study found donors faced indirect costs of AU$7249 and direct costs of AU$1682 (185). In Ontario Canada, where a program of reimbursement of costs for living donors is in place, a gap remained of CA$1313 for direct costs and CA$1802 in lost income for donors (186). For people with limited financial means, these personal costs may make living donation prohibitive, and hence impact donor rates for socioeconomically disadvantaged people with kidney failure. Telemedicine for living donation evaluation has been reported to help reduce the financial and geographic barriers for donors (187) which may improve health equity.

While most published work has explored the association between dialysis and transplantation QIs and SES, the treatment of kidney failure often represents a small portion of a long health journey for people with CKD. It is this pre-KRT period that may contribute most to health outcomes once people commence dialysis. A study using the National Health and Nutrition Examination Survey (NHANES) found modifiable factors such as health-related behaviours (smoking, diet, alcohol consumption, sedentary time), comorbid conditions (obesity, diabetes, hypertension) and access to healthcare contribute to the association between CKD and low SES (188). This suggests that effort delivered early to improve health may have a far greater impact than once people reach kidney failure. However, we should strive to deliver equitable care to people experiencing socioeconomic disadvantage regardless of their stage of CKD.

QIs are used widely by individuals, government, and non-government agencies. Australian examples include the Australian Council on Healthcare Standards, National Aged Care Quality Indicator Programme, National Cancer Control Indicators, and the Australian Commission on Safety and Quality in Healthcare (189). The Commission has developed the Australian Framework for National Clinical Quality Registries 2024 (190), which supports registries such as ANZDATA to collect, analyse and report clinical data with a view to better patient outcomes across Australia. ANZDATA commenced in the 1960's and produced its first report in 1977. It aims to "encourage and enable the highest quality of care for people in Australia and New Zealand with end stage

kidney disease by providing information that is complete, accurate, clear, relevant, readily available and timely" (191).

At the same time as my work on the impact of SES and rural residence on KRT outcomes, I was Chairperson of the Key Performance Indicator working group of the ANZSN. The report of that committee which I drafted (192), reviewed and recommended change to QI reporting by ANZDATA. Until this point, ANZDATA had been producing individual hospital reports which included data on patient characteristics compared with the national data as well as standardised mortality ratio and transplant graft survival. A separate report included QIs with regards to peritonitis rates and permanent vascular access at first haemodialysis, and this reporting had not been reviewed or updated for a long period.

Through my work with ANZDATA, I have led the implementation of the committee recommendations. The first of the new QI Reports was published in 2021 (using data from the 2020 calendar year) and has been reported annually since, supplemented with semi-annual reports using "real-time" data to provide contemporaneous information to contributing sites. QIs reported include peritonitis rates, dialysis access planning at commencement of KRT, transplantation wait listing, KRT modality, and annual data survey timeliness. Reports can be found at the ANZDATA website (191).

More recently, we have explored patient perspectives of public reporting of ANZDATA centre-specific results through a qualitative study of patients (n=27) conducted with on-line focus groups (193). The study identified five themes: 1) complexity of quality, 2) surrendering to the health system, 3) benefits for patient care, outcomes, and experience, 4) concern about risks and unintended consequences, and 5) optimising the impact of the data. The participants encouraged the public availability of centre specific QI reports supported with provision of context by trusted clinicians while framing data positively.

1.4 Caregivers of people with kidney disease

Health equity for caregivers is impacted by being in a time dependent relationship that leads to temporary disadvantage. They are adversely impacted by kidney disease without being directly afflicted. Caregivers are more often at socioeconomic disadvantage (39), rural residents (42), ethnic minorities, and face significant personal costs and lost opportunities in the role. As a result, they experience a burden of caregiving, poor life satisfaction (194), anxiety, depression and poorer mental health (195). Risk factors for caregiver burden include female sex, depression, social isolation, low educational attainment, more hours caregiving, financial stress, and lack of choice in being a caregiver (196). Further, the therapeutic relationship is between the health professional

and the patient, while the caregiver may be excluded or not provided adequate information or support to function in their role. The caregiver has been described as “suffering in silence” and the “invisible patient” (196).

This thesis includes two systematic reviews of the burden experienced by caregivers of people with CKD (197, 198) and two publications from the Caregivers of A Clinical Trial of IntensiVE Dialysis (Co-ACTIVE) (199, 200), a sub-study of caregiver QOL linked with the ACTIVE dialysis study (50). Much of the background for this section is drawn from my book chapter narrative review (201).

A caregiver can be described as someone who provides a broad range of assistance for a person with a chronic or disabling health condition (38). A caregiver may be either a formal trained specialist (either paid or from a volunteer organisation) or informal (typically family members and friends). Australia has an estimated 3 million caregivers (39) and replacing informal caregivers with paid employees would cost an estimated AU$60.3 billion, equivalent to 3.8% of gross domestic product (202). Not only do informal caregivers save significant healthcare costs, but they make personal sacrifices to complete their role including out of pocket costs, increased work-related stress trying to balance their roles, and reduced work hours which further adds to financial stresses. Caregiving has been shown to reduce employment productivity by one third, or an estimated AU$5600 per employee (203). Often minority populations suffer the greatest impact (41).

The roles of caregivers are generally classified into activities of daily living (ADLs) which may include bathing/showering, dressing, feeding, toileting, mobility; instrumental ADLs which may include shopping, housework, cooking, transport, finances, medication management; and other activities which may include advocacy, interactions with health professionals, and medical/nursing tasks (40). For those providing care for people with CKD there may be unique demands such as frequent transportation to and from a dialysis unit, injection of erythropoietin, setting up and managing home haemodialysis or peritoneal dialysis, changing dressings, ordering dialysis fluids, ensuring dietary compliance, and navigating a complex health system (204-206). A study of people aged over 65 years receiving haemodialysis reported 42.6% required caregiver assistance with instrumental ADLs and another 52.5% needed assistance with both ADLs and instrumental ADLs (207). With the ageing population, particularly the increased incidence of dialysis among the elderly who often have associated comorbidities, demands on caregivers are likely to increase.

Caregiver burden is the “extent to which caregivers perceive that caregiving has an adverse effect on their emotional, social, financial, physical, and spiritual functioning” (208). There is a strong association between caregiver burden, depression and QOL (209-211). In general, caregiver burden is correlated with the time spent caregiving and increasing needs for assistance with ADLs and instrumental ADLs (38). Those at greatest risk to suffer caregiver burden include female gender, under financial stress, social isolation, low education attainment, lack of choice about

caregiving, residing with the care recipient, and those suffering depression (196). Given the long-term nature of CKD and extended impact on caregivers, I sought to better understand burden and QOL of caregivers of people with kidney disease from the multitude of publications in the field through two systematic reviews.

The first systematic review examined caregivers of adults undergoing dialysis (197). The literature at the time was extensive but not clearly distilled. The focus of the systematic review was quantitative studies in caregivers of people undertaking dialysis with the primary aim being to report caregiver QOL and burden. Secondary aims included reporting the profile of caregivers, the instruments used to record burden and QOL, and compare caregiver QOL across different dialysis modalities and with non-dialysis caregivers and the dialysis patients themselves. The database search identified 1072 citations of which 86 underwent full text review and 61 were included. Most studies were cross-sectional and 70 different scales were used to assess caregiver QOL and burden. Most care recipients were having facility haemodialysis (72.3%) or peritoneal dialysis (20.6%). In general, caregiver QOL was comparable to caregivers of people with other chronic conditions and was better than the dialysis recipient. No difference was found between dialysis modalities although few studies compared the groups. Overall study quality was generally poor and heterogeneity in design made quantitative meta-analysis impossible and between study comparison difficult. The study suggested a need to better explore the impact of home haemodialysis, extended hours haemodialysis, and changes in caregiver QOL and burden over time. The systematic review did not examine supports and interventions for caregivers.

This was the first systematic review I had undertaken and there were many challenges and learnings. I was unprepared for the rigour required and on reflection an initial smaller project may have been a better starting point. The large number of papers, challenges of data extraction, heterogeneity of studies, and inability to complete a quantitative meta-analysis were some of the hurdles. This project also introduced me to record management software, and governance around systematic reviews including PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses), PROSPERO (International Prospective Register of Systematic Reviews) and study quality tools (in this case the Newcastle-Ottawa Scale). Due to the steep learning curve and challenges, the project completion was delayed resulting in the review needing to be updated prior to submission, further increasing the workload. Nevertheless, the systematic review clearly brought together the evidence, drew attention to caregivers impacted by kidney failure, and detailed areas for future research. The work has been heavily cited.

The second systematic review reported experiences of caregivers of people choosing conservative kidney management (CKM) rather than KRT (198). With increasing age and comorbidity, the benefits of KRT over CKM without dialysis become more marginal. As an example, a United States Veterans study among people aged >65 years with eGFR <12ml/min/1.73m^2 who were not

suitable for transplantation found commencing dialysis was associated with an extra 77 days survival over 3 years, but 15 days fewer at home (212). With limited survival advantage and increasing trade-offs with other priorities including quality of life, CKM is a frequent choice for many people with kidney failure. For example, a Canadian community-based cohort study found rates of kidney failure not treated with KRT increased with increasing age and roughly half of cases of kidney failure were not managed with KRT (213). Data from Australia has similarly reported that for every person treated with KRT, another is managed with CKM (214). The rates of people with kidney failure who do not receive KRT are higher in low- and middle-income countries where the primary barrier to KRT is cost, although other factors include geographical (distance to care), physician related (availability, access and knowledge), patient related, and health care system related (capability, availability, access) (215).

The practice of CKM has been widely recognised and provided although treatment options and goals vary (216-221). The impact on caregivers of people choosing CKM has been less well studied. For this reason and given that 50% of people with kidney failure (typically elderly with more comorbidities) in high income countries choose CKM, I chose to expand understanding of caregiver experiences beyond dialysis with the second systematic review (198). The systematic review included both quantitative and qualitative studies, but only 6 were identified for inclusion and all were from high income countries. Although concluding that caregivers of people choosing CKM suffer comparable impacts on QOL and burden as caregivers of people having dialysis, and describing the causes of anxiety among caregivers, the study had significant limitations restricting its generalisability. Foremost was the limited data published in this field restricting the systematic review to just six single centre studies with small caregiver numbers (total 133). There was no data from low- or middle-income countries where the population requiring, and the challenges for caregiving may be quite different. Nevertheless, this was the first systematic review on the topic and demonstrated significant caregiver impact but also the need for future work. My work expanding this field is detailed in the final chapter of this thesis covering future directions.

The systematic review of caregivers of dialysis patients identified several areas where more data would improve understanding of caregiver QOL. The areas included longitudinal data, caregivers of people having home haemodialysis, comparing QOL between patient and caregiver, and the impact of increased weekly dialysis hours on the caregiver. The ACTIVE Dialysis trial (50, 222) provided an opportunity to develop a caregiver's sub-study to address some of these questions. The ACTIVE Dialysis trial randomised 200 people to either standard (up to 18 hours/week) or extended (minimum 24 hours/week) haemodialysis for 12 months. There was no difference between groups in the primary outcome, QOL, as measured by the EuroQol 5-dimension instrument (3 level) (EQ-5D-3L). There were improvements in biochemistry and pill burden and no differences in blood pressure, vascular access complications or left ventricular mass index.

Recruitment was across 4 countries and could include both facility and home haemodialysis patients.

The Co-ACTIVE study was developed after the ACTIVE Dialysis trial was already funded and progressing. The trial was designed to describe characteristics of caregivers, compare caregiver and dialysis patient QOL, compare caregiver personal wellbeing with the population, and explore the impact of extended hours dialysis on caregiver QOL. Because the ACTIVE Dialysis trial commenced prior to the Co-ACTIVE sub-study, recruitment in Australia, New Zealand and Canada was almost complete, and hence most caregivers and patients were from China. Only 54 and 40 patient/caregiver pairs respectively were included in the baseline and longitudinal datasets. As a result, the studies were smaller than planned and generalisability was impacted. Further, although other countries recruited people undertaking home haemodialysis, the predominantly Chinese recruitment led to no home haemodialysis patients being included. Nevertheless, the Co-ACTIVE study was the first study to report characteristics and QOL of caregivers of people having dialysis in China.

Importantly, Co-ACTIVE reported the impact of extended hours dialysis on caregiver QOL in a randomised study. At the time of the study, some patients were choosing extended hours haemodialysis for benefits of improved biochemistry, reduced pill burden (223, 224) and better blood pressure control (225, 226). Others were hopeful of improved survival which had been reported from some observational studies (227-231) but not others (232). The Frequent Hemodialysis Network (FHN) Daily Trial (233) randomised patients to 6x/week haemodialysis or 3x/week haemodialysis for 12 months and found better outcomes for the frequent dialysis group for both co-primary outcomes; death or change in left ventricular mass over 12 months and death or change in the physical-health composite score of the RAND 36-item health survey. The trial confirmed increased frequency haemodialysis was associated with better phosphate and hypertension control. These benefits were seen with total weekly dialysis hours of 10.4±1.6 vs 12.7±2.2 and haemodialysis treatments each week of 2.88±0.39 vs 5.17±1.11 in the control and frequent groups respectively. While the difference in dialysis hours each week was small, the increased sessions may have a significant impact on caregivers with regards transportation to dialysis (or setting up home haemodialysis). In contrast, the under-powered FHN Nocturnal Trial randomised 87 patients to standard haemodialysis (mean 12.6±3.9 hours/week) or nocturnal haemodialysis 6x/week (mean 30.8±9.1 hours/week) and did not find a difference between groups for the same co-primary outcomes (234).

The FHN trialists considered the impact of the interventions on caregivers and used the 10-question Cousineau perceived burden scale to measure the degree to which patients consider themselves as a burden on their caregiver (235). The FHN baseline data reported 57% had caregivers and those patients had more comorbidity, higher Beck Depression scores (indicating

greater depression), and lower physical functioning than those without caregivers. Predictors of greater perceived caregiver burden included poorer physical and mental health and higher Beck Depression score among the dialysis patients (236). Over the 12-month trial, perceived caregiver burden for frequent facility haemodialysis compared with standard dialysis did not differ between groups, but there was a suggestion of increased burden among caregivers of nocturnal home haemodialysis patients (237).

The main difference between the FHN trials and Co-ACTIVE was that rather than measuring perceived caregiver burden, Co-ACTIVE measured actual caregiver QOL by completion of EQ5D-3L, short-form 36 (SF-36), and the personal wellbeing index (238). The populations between FHN and Co-ACTIVE are different, and hence it is not possible to compare study results directly. However, Co-ACTIVE found poorer utility-based QOL as measured by EQ5D-3L during follow-up in the extended hours group compared with the standard hours group. Although this finding was not replicated using SF-36 measured QOL, the suggestion of a possible negative impact on caregivers of patients undertaking extended hours dialysis is consistent with the FHN data.

One of the challenges with studies of caregivers is the consent process. As mentioned previously, the therapeutic relationship is between health professionals and the patient, not the caregiver. As a result, enrolment of caregivers in Co-ACTIVE required a stepped consent process whereby patients, after consenting to the main ACTIVE Dialysis trial, completed a second consent form to allow the investigators to approach the caregiver, and then caregivers completed another consent process. While this process allows direct responses from caregivers, it is laborious and risks non-consent at each step which can impact recruitment. This process also highlights the potential disconnect between caregivers and health systems in managing chronic disease.

Another challenge in both the FHN and ACTIVE Dialysis trials is patient recruitment. It is challenging to recruit a population of haemodialysis patients agreeable to randomisation to either extended hours/frequent sessions or standard dialysis. This leads to a study population that is not representative of the general dialysis population. For instance, in ACTIVE Dialysis mean patient age was 51.8±12.1 years, similar to the FHN Daily trial, but inconsistent with the more advanced mean age among KRT cohorts. As a result, the patients and caregivers recruited to Co-ACTIVE were also not representative of the broader dialysis population with ages of 49.5±13.2 and 53.4±11.3 years respectively. On the other hand, is quotidian (either increased frequency or extended hours) haemodialysis undertaken frequently by patients? An analysis of ANZDATA of people who had ever undertaken quotidian dialysis found only 7% of people ≥75 years had ever done so, compared with 48% of people aged 18-54 years (239). This suggests the question of impact of quotidian dialysis on caregivers of patients of advanced age is less relevant than the impact on those caring for patients having conventional haemodialysis. The impact on caregivers of the elderly is an ongoing project (240) discussed below in future directions.

Co-ACTIVE is a small study, but it has provided information for health professionals, patients and caregivers when considering frequent or extended hours dialysis. It has done this as a sub-study of a larger randomised study, helping to reduce selection bias from observational studies. Used alongside the results of the systematic reviews, the studies provide important evidence to help guide patients, caregivers, and health professionals with an informed decision-making process.

There have been many publications about caregivers of people with CKD following my work. One finding of my initial systematic review was the multiple instruments used to measure burden or QOL. A systematic review is underway to provide an overview of the measurement properties of available tools and possibly identify the most appropriate instrument for assessment of caregiver burden into the future (241).

The work also demonstrated that as part of the instrumental ADLs undertaken by caregivers, food sourcing and preparation is common. While much time is spent educating patients about CKD and its management, it is often the responsibility of the caregiver to provide meals. In collaboration with dietitians, we have explored caregiver nutrition knowledge and their perceptions of their role in meal provision for people with CKD (242). The study is only single centre but found moderate nutrition knowledge using the revised General Nutrition Knowledge questionnaire. Qualitative interviews revealed caregivers wanted to provide healthy meals for the CKD care recipient and a desire to follow disease specific dietary recommendations. Caregivers are an important avenue for patient management.

Unfortunately, most literature regarding caregivers is descriptive and reports of interventions to improve caregivers of CKD patients burden or QOL are few. A systematic review in 2008 found just 3 studies that examined the impact of an intervention aimed to support caregivers, and all these were evaluating an educational intervention. The studies all showed an educational intervention increased caregiver knowledge (243). Another systematic review covered the period 2009-2020 and found a further 6 studies which reported group interventions including an empowerment program, psycho-educational intervention, education, coping strategies and relaxation. All studies reported the group session either reduced caregiver burden or improved QOL (244). A small study from Iran has also reported peer support groups may reduce caregiver burden (245). More recently, a randomised trial of the impact of a patient navigation program for children aged 0-16 years with CKD from remote areas or low socioeconomic backgrounds was reported (246). The primary outcome was self-rated health of the child which did not improve after 6 months, however qualitative results found improvements in mental strain on caregivers, strengthening their capacity to care and decreasing family tension.

Although there is insufficient published literature for supporting caregivers of people with CKD, data is available on other chronic conditions and can be used as the starting point for people with CKD and source of potential further trials. A systematic review of interventions to support

caregivers of people with Alzheimer's disease and neurocognitive disorders found benefit for multicomponent psychoeducational interventions such as mindfulness and communication training, cognitive reframing and professionally led support groups (247). Another systematic review of support interventions for caregivers of people with end-stage chronic illness reported positive outcomes for psychosocial interventions (248). For caregivers in rural areas, telemedicine has been shown beneficial by decreasing psychological stress, increasing care efficiency, and improving social supports (249).

Although other chronic conditions may provide some guidance for interventions for caregivers of CKD, the specifics of CKD make this an important area for future work. One challenge is that some support measures are already available but with unproven efficacy. Nevertheless, engagement with patients and caregivers (250) and identifying their unmet needs such as inadequate information and social isolation (251) will be important in guiding research in this field and improving QOL.

CHAPTER 2: CKD AND RURAL RESIDENCE

2.1 Renal Replacement Therapy in Rural and Urban Australia

Gray NA, Dent H, McDonald SP.

Nephrol Dial Transplant 2012; 27(5): 2069-2076

DOI: 10.1093/ndt/gfr584

Journal Impact Factor 3.371 in 2012. 4.8 in 2023. 37 citations and Field-Weighted Citation Index (FWCI) of 1.22 (27/3/25)

Co-Authorship statement: H Dent assisted with statistics. S McDonald provided guidance and senior oversight. I conceptualised and designed the study, analysed and interpreted the data, and wrote the manuscript.

Original contribution to literature: Description of incidence, prevalence, and outcomes of KRT in rural compared with urban Australia.

Nephrol Dial Transplant (2012) 27: 2069–1969
doi: 10.1093/ndt/gfr584
Advance Access publication 9 October 2011

Renal replacement therapy in rural and urban Australia

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Abstract

Background. Australians living in rural regions have poorer health outcomes than city residents. This study compares rural and city patient access to and outcomes of renal replacement therapy (RRT) in Australia.

Methods. Non-indigenous Australians aged ≥16 years who commenced dialysis or underwent renal transplantation between 1996 and 2009 and were registered with the Australia and New Zealand Dialysis and Transplant Registry were included. Each patient's location was classified according to a remote area index as major city (MC), inner regional (IR), outer regional (OR) or remote/very remote (REM).

Results. A total of 24 068 commenced dialysis and 5399 received a renal transplant during the study period. Patient distribution by remote area index was 71.3 and 70.8% MC, 19.1 and 18.6% IR, 8.4 and 9.1% OR and 1.1 and 1.5% REM for dialysis and transplant patients, respectively. RRT incidence per million population after adjusting for age and gender was 124 [95% confidence interval (CI): 122–126] MC, 106 (95% CI: 103–110) IR, 100 (95% CI: 96–105) OR and 96 (95% CI: 84–109) REM. After controlling for

demographic variables, comorbidities and other covariates, hazard ratios for dialysis survival compared to MC were 1.08 (95% CI: 1.03–1.14) IR, 1.19 (95% CI: 1.11–1.28) OR and 1.03 (95% CI: 0.84–1.25) REM. Transplant patient survival was not statistically different by remoteness.

Conclusions. Rural Australians have lower incidence of RRT. Whether the causes of the lower RRT reflect lower disease rates or differential treatment access is not known. Differences in outcomes were seen for dialysis but not transplantation.

Keywords: dialysis; mortality; rural; transplantation; urban

Introduction

People living in rural areas of Australia have poorer health outcomes than those living in cities. Mortality rates in regional areas are higher than major cities (MCs) and increase further with increasing remoteness [1]. This variation remains after correcting for the greater indigenous population in remote Australia. Possible explanations include access to health services, physical inactivity, excess alcohol, poor nutrition, unemployment and lower socioeconomic status. Rural residence has been associated with increased mortality rates for cancer [2, 3], circulatory disease, chronic obstructive pulmonary disease and trauma [1]. Furthermore, rural residents undergo fewer diagnostic [4–6] or therapeutic interventions [7, 8] than Australians in MCs.

There are few studies examining rates of end-stage kidney disease (ESKD) in rural areas. United States data reports rural dialysis patients are older, less racially diverse, have more comorbidities and undertake peritoneal dialysis more frequently than city patients. In a multivariable model, dialysis patient survival in rural areas compared to cities was better for non-Hispanic white and black patients but worse for Hispanic patients [9]. Mortality among peritoneal dialysis patients in Canada has been shown higher in rural locations than cities [10]. The impact of rural residence in the USA on transplantation is mixed, with one study reporting lower waiting list registration and transplant rates in rural areas [11] but another study reporting similar or greater likelihood of renal transplantation when living further away from a transplant centre [12].

The specialist field and nature of the technology involved to deliver renal replacement therapy (RRT) would suggest that rural people with ESKD may be at risk of less access to and poorer outcomes from RRT than city patients. The aim of this study was to compare RRT incidence and prevalence rates and dialysis and transplant patient characteristics and survival in rural and city locations in Australia.

Materials and methods

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects observational data on all patients receiving RRT in Australia and New Zealand, including postcode at entry to the programme. All data are collected and submitted to ANZDATA by the treating nephrologist or renal health team at each local site. This study included all non-indigenous patients aged ≥16 years registered with ANZDATA who commenced dialysis or received a transplant in Australia between 1 January 1996 and 31 December 2009. Indigenous patients (those who self identify when asked their racial origin) were excluded from this analysis because work in this area has been completed previously [13].

The Australian Bureau of Statistics used 2001 Census data to produce the Australian Standard Geographical Classification of remoteness areas. This classifies all statistical local areas according to a remote area index. The remote area index is determined by measuring the road distance from a statistical local area to five classes of service centre. There are six remote area index classifications: MC, inner regional (IR), outer regional (OR), remote, very remote and migratory [14]. Urban areas include the MC category, while rural areas include regional, remote and very remote Australia (Figure 1). In Australia, travel from rural areas to the nearest renal service may be many hundreds of kilometres. We allocated a remote area index category to every Australian postcode using the statistical local area data. Where a postcode contained statistical local areas from two or more remote area index classifications, the postcode was allocated the remote area index that had the greatest population. New Zealand and international patients do not have postcode data and were excluded from the analysis. Australian patients without postcode data recorded at commencement of RRT were excluded. Patient numbers in the remote and very remote areas were small so these groups were combined into a single remote (REM) category.

Statistics

Population estimates by remote area index, age, gender and indigenous status were obtained from the Australian Bureau of Statistics Census data 1996, 2001 and 2006. For other years, population estimates were linearly interpolated (1997–2000 and 2002–05) and extrapolated (2007–09). These population estimates were used to directly standardize RRT incidence and prevalence rates by remote area index for age and gender. Poisson regression was used to compare incidence and prevalence rates while adjusting for age and gender.

Baseline characteristics at commencement of dialysis or at time of transplant were compared between remote area index categories using the chi-square test for categorical data and Kruskall–Wallis test for continuous non-normally distributed data.

Survival analyses were performed using multivariable Cox proportional hazards models. For patient survival on dialysis, covariates included in the model were age, gender, racial origin, body mass index, primary renal disease, peripheral vascular disease, cerebrovascular disease, ischaemic heart disease, chronic lung disease, diabetes, smoking status (never/former or current), late referral (<3 months before commencing dialysis) to a nephrologist, dialysis modality and state. Models for graft and patient survival of transplant recipients included age, gender, race, body mass index, primary renal disease, smoking status, peripheral vascular disease, cerebrovascular disease, ischaemic heart disease, chronic lung disease, diabetes, duration of dialysis prior to transplant, donor source by total ischaemia time (living donor, deceased donor <12 h, deceased donor 12–18 h, deceased donor ≥18 h or deceased donor unknown ischaemia time), peak panel reactive antibody, number of human leucocyte antigen (HLA) mismatches and state.

Data were censored for renal transplantation (dialysis patients only), recovery of renal function, loss to follow-up and end of study (31 December 2009). Proportional hazards assumptions were checked by Schoenfeld residuals and scaled Schoenfeld residuals, examined by formal hypothesis test and graphically. Data were analysed using Stata/IC 11 (College Station, TX). P-values <0.05 were considered statistically significant.

Results

Baseline characteristics

A total of 24 068 people commenced dialysis during the study period; patient characteristics at commencement of dialysis by remote area index are shown in Table 1. There were significant differences between city and rural

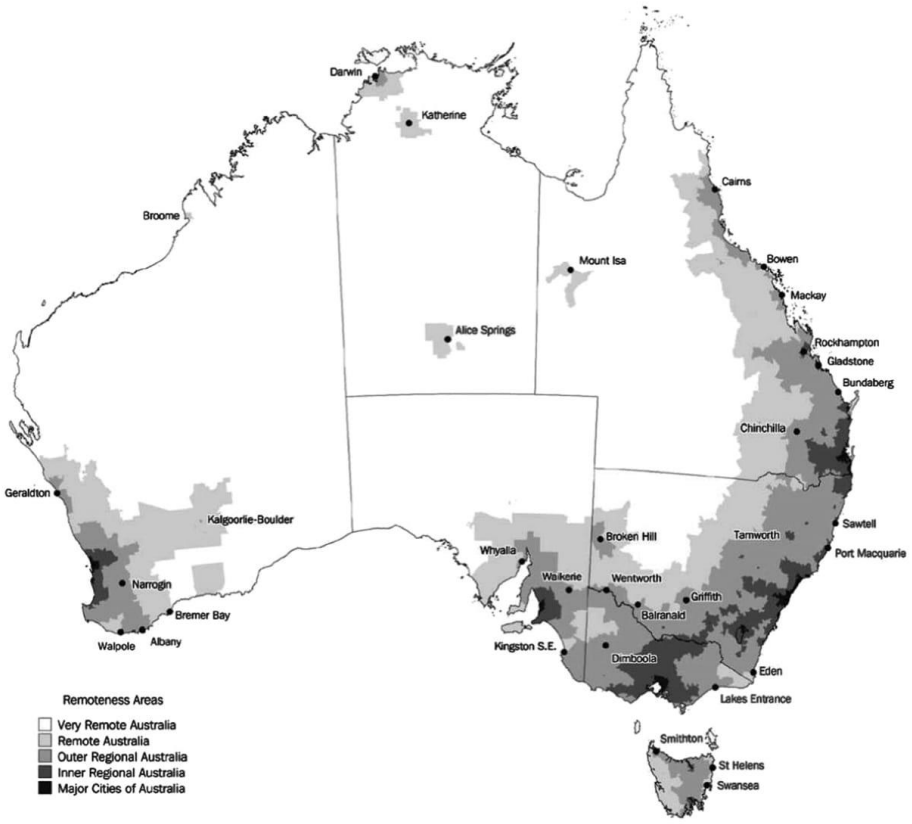

Fig. 1. Australian standard geographical classification of remoteness 2001 (source: Australian Bureau of Statistics).

patients. MC patients were least likely to be current smokers, referred to a nephrologist <3 months from commencement of dialysis or be treated with peritoneal dialysis as initial modality. MC patients were most racially diverse with the lowest prevalence of Caucasians and the highest prevalence of Asian race. Diabetes was less common among the rural categories. Dialysis patient primary renal disease by remote area index is shown in Table 2; although rates of glomerulonephritis, hypertension and diabetic nephropathy did vary between remoteness groups, there was no consistent gradation.

A total of 5399 underwent renal transplantation during the study period. Transplant patient characteristics by remote area index are shown in Table 3. There were fewer differences between city and rural patients in this group than the dialysis group. There were no differences in age, co-morbidities, dialysis duration prior to transplantation, living donor rates, pre-emptive transplantation, peak panel reactive antibody or HLA mismatches. As expected, total ischaemic time for rural patients receiving deceased donor kidneys was longer.

Incidence and prevalence

Figure 2 shows the standardized incidence rates adjusted for age and gender for all patients commencing RRT by remote area index, with higher incidence rates in MCs than all rural areas. Figure 3A and B shows the standardized prevalence rates adjusted for age and gender for dialysis and transplant patients, respectively. Compared with MC, prevalence rates for dialysis were lower in OR and REM areas. In contrast, prevalence rates for transplant patients were higher in IR and OR areas compared with MC.

Patient outcomes

There were 10 739 dialysis patient deaths during the study period. Table 4 shows that compared with the MC group, dialysis patient survival in IR and OR areas was worse. There was considerable variation in the remoteness effect between different states. OR and REM dialysis patients were more likely to have a cardiac death and less likely to withdraw from dialysis (Table 5). There was no difference by remote area index for reason for withdrawing from dialysis ($P = 0.62$).

Table 1. Dialysis patient characteristics by remote area index[a]

	MC	IR	OR	Remote/very remote	P-value
Number (n = 24 068)	17 167 (71.3%)	4597 (19.1%)	2030 (8.4%)	274 (1.1%)	
Age (median ± IQR)	64.4 (51.2–73.7)	64.7 (52.2–72.9)	63.4 (50.6–72.1)	61.2 (48.1–70.9)	<0.001
Males (%)	60.6	61.2	62.7	68.3	0.018
Ethnicity					
Caucasian (%)	84.6	98.0	94.5	95.6	<0.001
Asian (%)	10.5	1.3	2.5	2.6	
Other (%)	4.9	0.7	3.0	1.8	
Creatinine (μmol/L) at entry (median ± IQR)	662 (508–860)	667 (509–860)	722 (560–904)	750 (580–923)	<0.001
BMI (kg/m^2)					
Underweight (<18.5) (%)	4.5	3.4	4.2	3.0	0.002
Normal (18.5–24.9) (%)	39.8	38.7	38.9	43.2	
Overweight (25–29.9) (%)	32.7	33.0	33.5	25.5	
Obese (30+) (%)	23.0	24.9	23.5	28.4	
Peripheral vascular disease (%)	27.0	27.5	25.5	24.1	0.259
Cerebrovascular disease (%)	16.2	17.0	13.3	12.8	0.001
Ischaemic heart disease (%)	41.7	41.2	37.5	35.0	0.001
Diabetes (%)	36.8	31.2	32.7	34.7	<0.001
Chronic lung disease (%)	15.7	17.8	15.3	18.3	0.003
Late referral[b] (%)	23.1	24.9	26.0	27.1	0.002
Current smoking (%)	10.6	11.8	13.9	18.6	<0.001
Initial modality peritoneal dialysis (%)	24.6	27.9	28.0	38.0	<0.001

[a]IQR, interquartile range; BMI, body mass index.
[b]Late referral defined as referred to a nephrologist <3 months before commencing dialysis.

Table 2. Dialysis patient primary renal disease by remote area index

	MC	IR	OR	Remote/very remote	P-value
Glomerulonephritis (%)	27.5	26.4	28.8	24.8	<0.001
Diabetes (%)	26.8	21.4	21.1	27.4	
Hypertension (%)	8.5	9.3	9.0	13.1	
Polycystic kidney disease (%)	6.5	7.6	6.6	6.9	
Reflux nephropathy (%)	5.0	6.7	4.7	6.6	
Miscellaneous (%)	5.9	7.2	9.3	5.1	
Uncertain (%)	19.8	21.4	20.5	16.1	
Total (%)	100 (n = 17 167)	100 (n = 4597)	100 (n = 2030)	100 (n = 274)	

Table 6 shows the transplant patient outcomes by remote area index. MC patients were least likely to have acute rejection in the first 6 months post-transplantation. There was no difference in delayed graft function needing dialysis or creatinine >200 μmol/L at 6 months by remote area index. Patient and graft survival were similar in MC, IR and REM groups. Compared with MC, graft survival was worse in OR and there was a trend to worse patient survival. For transplant patients, there was no difference between cause of death (P = 0.75) or graft failure (P = 0.38) by remote area index.

Discussion

This study has shown that the incidence of RRT in rural areas of Australia is lower than in MCs. The prevalence of dialysis is lower in OR and REM areas, but transplant prevalence is higher in IR and OR Australia. Commencing dialysis in IR or OR Australia is an independent predictor of mortality. Except for poorer graft survival in OR areas, transplant patient outcomes are not affected by geographical location.

There are several possible explanations for the lower incidence of RRT in rural areas. ANZDATA records postcode information at the time of commencement of RRT. Dialysis, in particular, may not be available in a rural location and as a result some rural patients approaching treatment may relocate to cities prior to starting RRT. These patients will then be recorded under the MC category. While there is anecdotal evidence that the ill and elderly may migrate to urban areas, there is little published data [1].

The incidence data may suggest that ESKD is less common in rural Australia. This seems highly unlikely. Like other renal registries, ANZDATA only records patients who commence RRT. There is no record of patients with ESKD who are managed with a non-dialysis (palliative) pathway. It is plausible that patients in rural areas may choose palliation rather than dialysis more frequently than those in cities. Possible reasons to choose palliation may include the burden of travel to dialysis or specialist care, non-referral to specialist care and poor education about RRT options. Canadian data show that local access to treatment is important and building satellite haemodialysis units in rural areas results in a significant increase in the number of elderly receiving RRT [15].

Table 3. Transplant patient characteristics by remote area index[a]

	MC	IR	OR	Remote/very remote	P-value
Number ($n = 5399$)	3824 (70.8%)	1002 (18.6%)	490 (9.1%)	83 (1.5%)	
Age (median ± IQR)	47 (35–57)	47 (36–57)	47 (37–56)	48 (37–56)	0.908
Males (%)	61.2	65.6	68.0	68.7	0.003
Ethnicity					
Caucasian (%)	84.8	97.8	94.5	98.8	<0.001
Asian (%)	11.1	1.2	3.3	1.2	
Other (%)	4.2	1.0	2.2	0.0	
Creatinine (μmol/L) at entry (median ± IQR)	780 (610–998)	780 (610–1000)	813 (651–1010)	840 (661–1045)	0.083
BMI (kg/m^2)					
Underweight (<18.5) (%)	4.4	1.8	2.5	2.4	0.003
Normal (18.5–24.9) (%)	44.4	44.5	40.8	41.0	
Overweight (25–29.9) (%)	34.3	37.4	37.3	33.7	
Obese (30+) (%)	16.9	16.3	19.5	22.9	
Peripheral vascular disease (%)	5.2	4.5	3.5	6.0	0.339
Cerebrovascular disease (%)	2.9	3.0	2.9	4.8	0.793
Ischaemic heart disease (%)	9.3	8.2	8.8	8.4	0.727
Diabetes (%)	11.3	8.6	10.0	12.1	0.093
Chronic lung disease (%)	4.5	5.4	3.5	2.4	0.270
Smoking at entry (%)	9.4	10.8	13.7	9.6	0.024
Biopsy at entry (%)	53.9	52.8	55.0	51.3	0.830
Dialysis duration prior to transplant					
Pre-emptive (%)	12.3	13.8	12.2	8.4	0.354
0–1 year (%)	22.9	23.3	22.5	26.5	
1–3 years (%)	34.9	34.6	38.0	44.6	
3+ years (%)	29.9	28.3	27.4	20.5	
First transplant (%)	97.4	97.2	95.1	95.2	0.027
Living donor (%)	45.0	49.3	43.3	48.2	0.058
Donor total ischaemic time					
Living donor (%)	45.0	49.3	43.3	48.2	<0.001
DD <12 h (%)	19.1	14.6	11.4	8.4	
DD 12–18 h (%)	26.6	26.2	28.2	21.7	
DD >18 h (%)	8.8	8.4	16.1	21.7	
Unknown (%)	0.7	1.6	1.0	0.0	
Peak panel reactive antibody					
0–10%	76.9	78.0	81.1	85.5	0.098
11–50%	15.8	14.8	12.1	6.0	
>50%	7.2	7.2	6.8	8.4	
HLA mismatches					
0 (%)	7.1	8.1	8.2	9.6	0.383
1–2 (%)	31.4	33.5	34.4	30.1	
3–6 (%)	61.5	58.4	57.4	60.2	

[a]IQR, interquartile range; BMI, body mass index; DD, deceased donor.

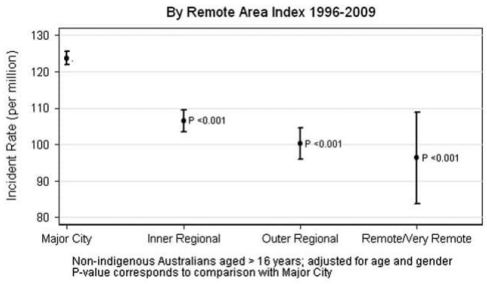

Fig. 2. Standardized incidence—ESKD patients.

A major barrier to medical care, including RRT in rural Australia, is distance and travel. In our study, the rate of peritoneal dialysis was higher in rural regions, reflecting both the benefits of home therapies in this group and likely poor access to satellite haemodialysis units. An increased rate of peritoneal dialysis in rural regions of the USA has also been shown despite rural facilities being less likely to offer peritoneal dialysis training [9]. While peritoneal dialysis rates were higher among rural patients in our study, haemodialysis remained numerically the main treatment modality. One option to reduce travel is home haemodialysis, but there may be barriers to this modality in rural Australia that are not encountered in cities, particularly water quantity and quality. In the USA, rural facilities were less likely to offer home haemodialysis training [9] and had lower rates of home dialysis (peritoneal and home haemodialysis combined) among rural compared with city patients [16]. Our study did not examine where training for peritoneal dialysis or home haemodialysis occurs, but it is likely that many rural patients may need to live away from home for some period to complete training. This may be a significant disincentive to undertake home dialysis therapies and if

a haemodialysis facility is not located nearby, patients may chose a palliative pathway.

If home dialysis is not an option for a patient, they must travel (or relocate) to the nearest facility for maintenance haemodialysis. Travel can add several hours to the treatment and result in dialysis taking all day. Transport to and from dialysis is a problem if the patient cannot drive; across Australia, approaches to government support of travel costs vary widely. A study of regional Australian patients needing to travel to a city for radiotherapy treatment identified concerns with the burden of travel, difficulties in living away from home, financial concerns, distance from family and friends and feelings of being a burden on others [17]. Data from the Dialysis Outcomes and Practice Patterns Study found longer travel time to dialysis was associated with a greater mortality risk and decreased health-related quality of life. Interestingly, this was not because patients with further to travel decided to withdraw from treatment [18], results confirmed by our study. In summary, distance is a marker for both a lower incidence of treatment for ESKD and reduced survival after commencing dialysis in rural regions.

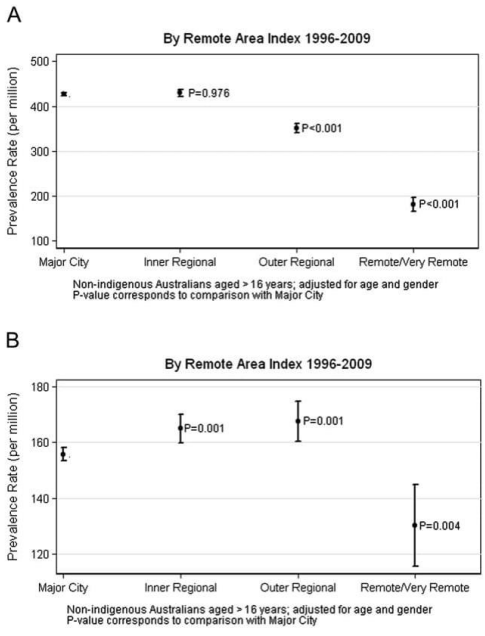

Fig. 3. (**A**) Standardized prevalence rates—dialysis patients. (**B**) Standardized prevalence rates—transplant patients.

Access to health care providers is a significant problem for rural patients. The Australian Institute of Health and Welfare studied the medical workforce in 2003 [19]. After correcting for clinical care performed outside the primary practice location, the number of full-time equivalent medical staff per 100 000 population by remote area index was 316 MC, 181 IR, 161 OR, 166 remote and 157 very remote. In 2007, a survey of the Australian nephrology workforce was completed [20]. Eighty-eight per cent of respondents reported their primary site of practice was an MC, with only 9% IR, 2% OR and 0.4% REM. Furthermore, many nephrologists reported other sites of practice, but for those with a primary site in an MC, their other sites were also usually within an MC. Thus, Australian data suggest people with kidney disease in rural regions have less access to a nephrologist unless they travel to an MC. Canadian data have shown that people with kidney disease who live >50 km from a nephrologist have poorer outcomes than those who live <50 km away. Canadian patients with chronic kidney disease not on dialysis living >50 km from the nearest nephrologist, when compared with patients living <50 km from the nearest nephrologist, are less likely to receive specialist care, recommended laboratory testing and appropriate medications. They were also more likely to die or be hospitalized [21]. Similarly, Canadian studies examining the impact of distance between the home of a dialysis patient and practice of the treating nephrologist have found that a distance of >50 km was associated with an increased risk of death for haemodialysis [22] and peritoneal dialysis [10] patients compared with distances of <50 km.

There may be other factors that may contribute to the poorer dialysis survival we found in IR and OR Australia. For example, we did not compare key performance indicators such as dialysis adequacy, dialysis hours, vascular access at first dialysis, haematology or biochemistry between city and rural groups. However, in the USA, similar haematocrit targets were achieved and rural units achieved target urea reduction ratios more frequently than city units [9]. Patient compliance may be different between rural and

Table 4. Dialysis patient survival by remote area index[a]

	MC	IR	OR	Remote/very remote
Australia (HR[b] and 95% CI)	1.0	1.08 (1.03–1.14)	1.19 (1.11–1.28)	1.03 (0.84–1.25)
New South Wales/Australian Capital Territory (HR[c] and 95% CI)	1.0	1.09 (1.01–1.18)	1.07 (0.93–1.24)	1.00 (0.69–1.45)
Victoria (HR[c] and 95% CI)	1.0	1.17 (1.06–1.29)	1.31 (1.10–1.55)	0.98 (0.24–3.96)
Queensland (HR[c] and 95% CI)	1.0	0.99 (0.88–1.11)	1.12 (0.98–1.27)	1.05 (0.68–1.62)
South Australia (HR[c] and 95% CI)	1.0	1.23 (0.93–1.62)	1.37 (1.08–1.73)	1.10 (0.61–1.97)
Western Australia (HR[c] and 95% CI)	1.0	0.92 (0.76–1.12)	1.23 (0.98–1.54)	1.18 (0.79–1.77)

[a]Patient numbers in Northern Territory were too small to analyse. HR, hazard ratio.
[b]Adjusted for age, gender, race, body mass index, primary renal disease, comorbidities, late referral, current smoking, peritoneal dialysis as initial therapy and state.
[c]Adjusted for age, gender, race, body mass index, primary renal disease, comorbidities, late referral, current smoking and peritoneal dialysis as initial therapy.

city patients with regard to medications and possibly dialysis hours. Patients often request a reduction in dialysis hours, and this may be more common among patients who already have significant travel time for each dialysis session. There may be difficulties attracting and retaining qualified and skilled staff in rural areas. Rural areas may have problems with ongoing education of health professionals, maintenance of equipment or patient travel for vascular access.

Our data showed transplant prevalence in IR and OR Australia was higher than in MC. This is consistent with previously published data showing an increased likelihood of transplantation in rural areas [12]. Transplantation is the best management option for most patients with ESKD, but particularly rural patients as it resolves the problems of regular travel for dialysis. Pleasingly, transplant patient and graft survival were comparable to MC for all groups except graft survival in OR areas. Possible reasons for these similar outcomes include the patient being under the care of a transplant nephrologist or transplant centre with standardized care or that transplantation is less affected by distance than dialysis.

There are a number of options to reduce the gap between rural and city RRT incidence and dialysis outcomes. Developing satellite haemodialysis units in rural areas has been shown to increase access for elderly patients and reduce travel time and distance [14]. This may reduce the gap in incident RRT rates between OR and REM areas and the city. Other ways to reduce travel time such as dedicated transport services that minimize the idle time between arriving at the dialysis unit and commencing dialysis and finishing dialysis and leaving the unit may assist. Efforts to increase the medical workforce have been ongoing [23] and full-time equivalent staff numbers have increased [24], but it remains to be seen if this will improve the health of rural Australians. Whether improving nephrology outreach clinic services or permanent placement of a nephrologist in a rural area improves access and outcomes is not proven but seems highly likely to be beneficial. Provision of training for both peritoneal dialysis and home haemodialysis in rural areas and encouraging patient uptake of these home therapies may improve access to RRT. Telehealth is being used to improve rural patient outcomes and access to specialist care [25, 26]. Efforts to educate rural primary health care providers may improve referral rates and appropriate care of chronic kidney disease patients. Education and behaviour change among rural residents, such as stopping smoking, may also assist.

Our study has several limitations. Firstly, postcode data at entry to RRT were used in this study. We do not know how many or how often patients relocate to access health care for kidney disease prior to commencing RRT. Relocation after commencing RRT was low. ANZDATA has collected current postcode data since 2005 and only 0.3% of patients moved from one remote area index classification to another, with movement equal in both directions. Secondly, patients who commenced RRT in Australia but did not have a postcode recorded were excluded. This would not have affected our analysis as only 0.04% ($n = 10$) had no postcode data recorded at entry. Thirdly, the method used to classify a postcode by remote area index relied on data from statistical local areas and some postcodes had several different remote area index classifications of statistical local areas. Our classification of each postcode may thus have created a bias, although we used the most populous remote area index allocation for each postcode. Fourthly, we have no data on patients who were managed conservatively and never commenced RRT. Finally, the data are observational and there are confounding variables that may contribute to our understanding. Rural residence and distance to treatment are not the cause for poor outcomes but mark for other factors which are.

In conclusion, our findings show Australians living in rural areas compared with cities have poor access to RRT and many have worse outcomes on dialysis. We recommend that efforts be made to improve access to nephrology care through primary care practitioners, specialists, nursing and allied health staff and dialysis at the local level to reduce travel and the burden of a chronic disease in rural areas. Any changes to service provision should be used as an opportunity to study the effects on rural patient health.

Table 5. Dialysis patient cause of death by remote area index

	MC	IR	OR	Remote/very remote	P-value
Cardiac (%)	37.3	36.1	40.3	49.5	
Vascular (%)	9.1	9.3	10.1	8.4	
Malignancy (%)	6.1	7.3	7.5	10.3	0.006
Infection (%)	11.3	11.2	12.0	8.4	
Withdrawal (%)	30.9	30.8	25.3	17.8	
Other (%)	5.3	5.3	4.8	5.6	
Total (%)	100	100	100	100	
	($n = 7564$)	($n = 2125$)	($n = 943$)	($n = 107$)	

Table 6. Transplant patient outcomes by remote area index

	MC	IR	OR	Remote/very remote	P-value
Delayed graft function needing dialysis (%)	14.0	11.4	13.1	14.5	0.180
Acute rejection <6 months (%)	22.9	24.7	23.7	36.1	0.029
Creatinine >200 μmol/L at 6 months (%)	8.2	7.8	9.0	8.4	0.889
Transplant patient survival (HR[a] and 95% CI)	1.0	1.17 (0.89–1.55)	1.34 (0.97–1.86)	0.58 (0.22–1.53)	
Graft survival (HR[a] and 95% CI)	1.0	0.93 (0.76–1.13)	1.29 (1.03–1.63)	0.70 (0.38–1.29)	

[a]Adjusted for age, gender, race, body mass index, primary renal disease, current smoking, comorbidities, repeat graft, duration on dialysis, donor source by total ischaemia time, peak panel reactive antibody, number of HLA mismatches and state. HR, hazard ratio.

Acknowledgements. The authors gratefully acknowledge the contributions of the Australian and New Zealand nephrology community in providing information for and maintaining the ANZDATA database.

The data reported here have been supplied by ANZDATA. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the ANZDATA.

Conflict of interest statement. None declared.

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Received for publication: 16.6.11; Accepted in revised form: 1.9.11

2.2 Peritoneal dialysis in rural Australia

Gray NA, Grace BS, McDonald SP

BMC Nephrol 2013; 14: 278

DOI: 10.1186/1471-2369-14-278

Journal Impact Factor 1.52 in 2013. 2.2 in 2023. 18 citations and FWCI of 0.72 (27/3/25)

Co-Authorship statement: B Grace assisted with statistics. S McDonald provided guidance and senior oversight. I conceptualised and designed the study, analysed and interpreted the data, and wrote the manuscript.

Original contribution to literature: Description of peritoneal dialysis uptake and outcomes in rural compared with urban Australia.

Gray et al. BMC Nephrology 2013, 14:278
http://www.biomedcentral.com/1471-2369/14/278

BMC Nephrology

RESEARCH ARTICLE Open Access

Peritoneal dialysis in rural Australia

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Abstract

Background: Australians living in rural areas have lower incidence rates of renal replacement therapy and poorer dialysis survival compared with urban dwellers. This study compares peritoneal dialysis (PD) patient characteristics and outcomes in rural and urban Australia.

Methods: Non-indigenous Australian adults who commenced chronic dialysis between 1 January 2000 and 31 December 2010 according to the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) were investigated. Each patient's residence was classified according to the Australian Bureau of Statistics remote area index as major city (MC), inner regional (IR), outer regional (OR), or remote/very remote (REM).

Results: A total of 7657 patients underwent PD treatment during the study period. Patient distribution was 69.0% MC, 19.6% IR, 9.5% OR, and 1.8% REM. PD uptake increased with increasing remoteness. Compared with MC, sub-hazard ratios [95% confidence intervals] for commencing PD were 1.70 [1.61-1.79] IR, 2.01 [1.87-2.16] OR, and 2.60 [2.21-3.06] REM. During the first 6 months of PD, technique failure was less likely outside MC (sub-hazard ratio 0.47 [95% CI: 0.35-0.62], $P < 0.001$), but no difference was seen after 6 months (sub-hazard ratio 1.05 [95% CI: 0.84-1.32], $P = 0.6$). Technique failure due to technical (sub-hazard ratio 0.57 [95% CI: 0.38-0.84], $P = 0.005$) and non-medical causes (sub-hazard ratio 0.52 [95% CI: 0.31-0.87], $P = 0.01$) was less likely outside MC. Time to first peritonitis episode was not associated with remoteness ($P = 0.8$). Patient survival while on PD or within 90 days of stopping PD did not differ by region ($P = 0.2$).

Conclusions: PD uptake increases with increasing remoteness. In rural areas, PD technique failure is less likely during the first 6 months and time to first peritonitis is comparable to urban areas. Mortality while on PD does not differ by region. PD is therefore a good dialysis modality choice for rural patients in Australia.

Keywords: ANZDATA, Australia, Dialysis, Mortality, Outcomes, Peritoneal dialysis, Remoteness, Rural

Background

Among non-indigenous Australians, the incidence of renal replacement therapy and survival on dialysis are lower in rural compared with urban areas [1]. Peritoneal dialysis (PD) prevalence in Australia has fallen from 27% in 2000 [2] to 21% in 2009 [3]. However, the uptake of PD among dialysis patients living in rural areas of Australia [1] and USA [4,5], and Canadians living more than 50km from the treating nephrologist [6], has been shown to be higher than urban dwellers.

The impact of rural residence on PD outcomes is less well understood, particularly outside North America. Canadian patients living more than 50 km from their treating nephrologist were less likely to suffer technique failure and transfer to haemodialysis (HD), but suffered increased mortality [6]. A smaller study from Ontario, Canada did not show a difference in technique failure or mortality with PD in rural areas [7]. In the USA, rural PD patients have a higher mortality risk than those in urban areas [5]. In Australia, technique failure, peritonitis and mortality have been shown to be higher among remote living indigenous PD patients compared with urban dwellers [8]. Time to the first episode of peritonitis among Australian PD patients living more than 100km from the treating centre is shorter than those living within 100km [9]. Different management practices for peritonitis for patients living distant to the treating centre have also been reported [9].

Many studies have examined distance from the treating centre rather than rural residence per se. However,

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rural residence has been shown to be directly linked with multiple poor health outcomes [10]. This paper describes non-indigenous PD patient characteristics, complications, and outcomes in rural Australia.

Methods

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects observational data on all patients receiving chronic renal replacement therapy in Australia. All data are collected and submitted to ANZDATA by the treating nephrologist or renal health team at each local site. This study included all non-indigenous patients aged > =18 years registered with ANZDATA, who commenced renal replacement therapy between 1 January 2000 and 31 December 2010, and underwent PD at some stage during this period in Australia. Indigenous patients (those who self-identify as Australian Aborigines or Torres Strait Islanders when asked their racial origin) undertaking PD were excluded from this analysis because work in this area has already been completed [8,11].

The Australian Bureau of Statistics used 2006 Census data to produce the Australian Standard Geographical Classification of remoteness areas [12]. This classifies all statistical local areas according to a remote area index which is determined by measuring the road distance from a statistical local area to five classes of service centre. There are six remote area index classifications: major city (MC), inner regional, outer regional, remote, very remote and migratory. Urban areas include the MC category, while rural areas include regional, remote and very remote Australia. Where a postcode contained statistical local areas from two or more remote area index classifications, the postcode was allocated the remote area index that had the greatest population. Australian patients without postcode data recorded at commencement of renal replacement therapy were excluded. Patient numbers in the remote and very remote areas were small so these groups were combined into a single remote category.

Time to first use of PD was analysed for all patients who started renal replacement therapy by either continuous ambulatory PD (CAPD) or automated PD (APD). The use of icodextrin among PD patients was recorded during annual surveys in 2007 – 2010. We analysed use of icodextrin at the survey closest to 1 year after commencing renal replacement therapy for patients who commenced PD in this period.

Technique failure was defined as any change of modality from PD to HD that lasted more than 30 days. Reasons for technique failure were only recorded after 2006 and were coded as infectious (related to peritonitis, tunnel or exit site infection), technical (dialysate leak, hydrothorax, scrotal oedema, catheter difficulties, hernia, pain, surgery, adhesion), dialysis related (ultrafiltration or solute clearance), non-medical (patient choice for personal reasons), transplantation, death, and miscellaneous.

The date of first episode of peritonitis was recorded from 2000, but more detailed data related to peritonitis (type of organism, treating antibiotics, outcomes of treatment) was only routinely collected after October 2003. Peritonitis outcomes were classified as resolution of peritonitis with continuation of PD, removal of Tenckhoff catheter, permanent transfer to HD, and death within 90 days.

Patient death on PD was defined two ways: death during PD treatment; and death while on PD or within 90 days of transferring to HD. Patient death following transplantation but within 90 days of ceasing PD was considered a transplant related death. Causes of death were categorised into: cardiovascular causes (cardiac complications, ischaemia, infarction, aneurysms, haemorrhage), infectious, non-medical (suicide, withdrawal from dialysis for any reason, accidental death), malignant or miscellaneous. Patient survival was analysed using an "as treated analysis."

Statistics

All analyses were adjusted for the following factors at commencement of renal replacement therapy: age category (18–44, 45–54, 55–64, 65+ years), body mass index category (< 18.49, 18.5-24.9, 25–29.9, 30+ kg/m^2), smoking status, comorbidities (diabetes, chronic lung disease, coronary artery disease, peripheral vascular disease, cerebrovascular disease), primary kidney disease (glomerulonephritis, diabetes, hypertension, polycystic, reflux or others), late referral (commencing renal replacement therapy within 3 months of referral to nephrology care), gender, race (Caucasian, Asian or other), and size of initial treating centre. The size of the initial treating centre was divided based on the number of incident patients from 2000–2010; small (1–49 patients), medium (50–199 patients), and large (200+ patients).

Uptake of all forms of PD, as well as patient and technique failure, and time to first episode of peritonitis were all analysed using competing risk regressions, using the methods of Fine and Gray [13]. The assumption of constant proportional sub-hazards was checked by plotting Shoenfeld-like residuals and by investigating a remoteness: time interaction term within the model. For analyses of PD uptake from time of commencing renal replacement therapy, death and transplantation were competing risks. Death, transplantation and APD were competing risks for CAPD. Death, transplantation and CAPD were competing risks for APD.

All cause technique failure from the time of commencing PD was analysed with transplantation as a competing risk. Because the hazard ratio varied over time, this

analysis was stratified. Technique failure within the first 6 months was examined separately to subsequent failure. Technique failure due to a specific cause was analysed with other causes as competing risks. Patients were encoded as either MC or other when small numbers of cases were present (individual causes of PD technique failure and cause of death). Time to first peritonitis episode analyses included death and transplantation as competing risks. The incidence of peritonitis was analysed using Poisson regression, with total time on PD per patient as an offset.

The outcomes of each case of peritonitis were investigated using mixed-effects logistic regression, with infection number nested within patient as random effects. Separate models investigated the proportion of peritonitis cases that resulted in a permanent change to HD, removal of the peritoneal catheter, or death within 90 days. The use of icodextrin at the survey closest to one year after commencing renal replacement therapy was analysed using logistic regression. Specific causes of death were also compared between remoteness areas using logistic regression.

Results are presented as either sub-hazard ratios (analogous to hazard ratios from Cox regressions) from competing risk survival models, or odds ratio from logistic regressions, with 95% confidence intervals [95% CI].

All analysis was carried out using Stata IC 12.1 (StataCorp, College Station, TX, USA). This study was approved by the Prince Charles Hospital human research ethics committee.

Results

Figure 1 shows a flow chart of the study population. PD patient distribution was 69.0% MC, 19.6% inner regional, 9.5% outer regional, and 1.8% remote. Patient characteristics at commencement of renal replacement therapy are shown in Table 1. Diabetic kidney disease was more common in MC while current smoking, chronic lung disease, obesity and Caucasian race were more common among patients from rural areas.

The uptake of PD increased with increasing remoteness (Figure 2). However, among patients who ever used PD, patients from outer regional and remote areas were less likely to commence renal replacement therapy with PD (Table 1). Compared with MC, sub-hazard ratios [95% confidence intervals] for uptake of PD after adjustment for age, gender, body mass index, smoking, comorbidities, late referral, race, and centre size were 1.70 [1.61-1.79] inner regional, 2.01 [1.87-2.16] outer regional, and 2.60 [2.21-3.06] remote. This was largely due to increasing uptake of APD, although CAPD also increased with remoteness. Use of icodextrin did not vary significantly with remoteness (P = 0.9).

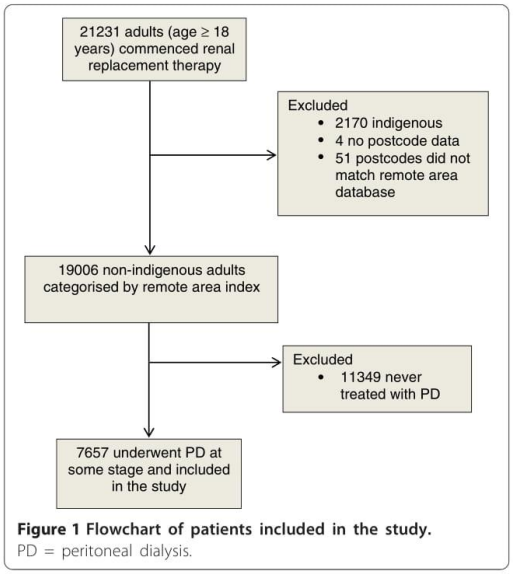

Figure 1 Flowchart of patients included in the study. PD = peritoneal dialysis.

Technique failure rates in rural areas were low so inner regional, outer regional and remote patients were grouped. Overall technique failure was less likely during the first 6 months of PD for this rural group compared with MC after adjusting for other variables, but technique failure was not associated with remoteness after 6 months of PD (Figure 3). Patients living outside major cities were less likely to be transferred to HD due to technical or non-medical causes (Table 2).

There were 5159 cases of peritonitis over 9328 person-years at risk, giving a rate of 0.55 cases per year. Time to first peritonitis episode did not vary with remoteness (P = 0.8), but total peritonitis cases per year did (Table 1). Compared to small centres, medium-sized centres (50 – 199 incident patients) and large centres (200+ incident patients) had lower rates of peritonitis (sub-hazard ratio [95% CI] for time to first peritonitis 0.64 [0.50-0.81], P < 0.001; and 0.60 [0.45-0.74], P < 0.001 respectively). Patients living outside major cities were more likely to suffer culture negative or methicillin sensitive *Staphylococcus aureus* peritonitis (Table 3). Remote patients were less likely to transfer permanently to haemodialysis after an episode of peritonitis (Table 4).

Patient survival while on PD or within 90 days of stopping PD did not differ significantly by region overall (P = 0.2). Cause of death between major cities and grouped rural areas did not differ for infectious (P = 0.7), non-medical causes including withdrawal from dialysis for any reason, accident, or suicide (P = 0.1), or miscellaneous causes (P = 0.8). There was a trend towards increased cardiovascular (sub-hazard ratio 1.13 [95% CI: 0.98-1.29],

Table 1 Characteristics of adult non-indigenous Australian patients who commenced renal replacement therapy (2000–2010) and underwent PD at some stage

Factor	Major city	Inner regional	Outer regional	Remote	p-value
N	5285	1503	731	138	
Age, median (IQR)	63 (50, 72)	64 (52, 71)	64 (52, 72)	64 (51, 72)	0.64
Male	57.8%	57.7%	59.2%	60.9%	0.80
Body mass index (kg/m^2)					<0.001
Underweight (<18.5)	4.2%	2.5%	3.4%	1.4%	
Normal (18.5–24.9)	40.3%	38.9%	37.2%	43.5%	
Overweight (25–29.9)	33.9%	34.0%	36.6%	22.5%	
Obese (> = 30)	21.6%	24.5%	22.7%	32.6%	
Chronic lung disease	13.7%	15.9%	14.1%	21.0%	0.02
Coronary artery disease	34.7%	34.9%	32.1%	33.3%	0.60
Peripheral vascular disease	20.0%	20.7%	17.8%	22.5%	0.30
Cerebrovascular disease	14.3%	15.6%	13.3%	16.7%	0.40
Diabetes	40.2%	32.5%	33.9%	33.3%	<0.001
Primary renal disease					<0.001
Glomerulonephritis	1422 (26.9%)	430 (28.6%)	184 (25.2%)	34 (24.6%)	
Diabetes	1633 (30.9%)	341 (22.7%)	176 (24.1%)	38 (27.5%)	
Hypertension	523 (9.9%)	149 (9.9%)	78 (10.7%)	25 (18.1%)	
Polycystic	313 (5.9%)	103 (6.9%)	47 (6.4%)	8 (5.8%)	
Reflux	243 (4.6%)	75 (5.0%)	26 (3.6%)	6 (4.3%)	
Other	1151 (21.8%)	405 (26.9%)	220 (30.1%)	27 (19.6%)	
Late referral	21.2%	23.4%	24.2%	25.4%	0.10
Current smoking	10.6%	12.0%	13.7%	14.5%	0.03
Race					<0.001
Caucasian	77.4%	97.0%	94.7%	94.2%	
Asian	12.9%	1.7%	3.1%	2.2%	
Other	9.7%	1.3%	2.2%	3.6%	
Creatinine (umol/L) at entry, median (IQR)	631 (490, 827)	635 (490, 813)	673 (536, 855)	729 (540, 910)	<0.001
PD at commencement of dialysis	3446 (65.2%)	1002 (66.7%)	433 (59.2%)	82 (59.4%)	0.002
PD facility size (incident patients in study period)					<0.001
1–49 patients	139 (2.6%)	86 (5.7%)	53 (7.3%)	26 (18.8%)	
50–199 patients	314 (5.9%)	488 (32.5%)	266 (36.4%)	32 (23.2%)	
200+ patients	4829 (91.4%)	929 (61.8%)	412 (56.4%)	80 (58.0%)	
Peritonitis cases per year (Poisson mean and 95%CI)	0.55 (0.53–0.56)	0.55 (0.51–0.58)	0.59 (0.54–0.64)	0.71 (0.59–0.84)	0.014
Time per patient spent on PD in months, median (IQR)	16.4 (7.1–29.3)	15.8 (7.7–29.3)	17.0 (7.6–27.8)	17.0 (7.8–31.7)	0.81

IQR interquartile range, late referral = commenced dialysis < 3 months from first referral to a nephrologist, PD facility size was categorised by the number of patients commencing PD during the study period, *CI* confidence interval.

P = 0.09) and malignant (sub-hazard ratio 1.49 [95% CI: 0.99-2.27], P = 0.06) deaths in rural areas.

Discussion

This study has shown that among non-indigenous Australians, the uptake of PD increases with increasing remoteness; time to first peritonitis in rural areas is comparable with MC; PD technique failure rates in the first 6 months are lower in rural areas due to less technical and non-medical causes; and overall death rates do not vary between regions. There is a suggestion that more cardiovascular and malignant deaths occur in rural areas.

Incidence rates of renal replacement therapy among non-indigenous people have previously been shown to be lower in rural Australia [1]. PD is suited to many

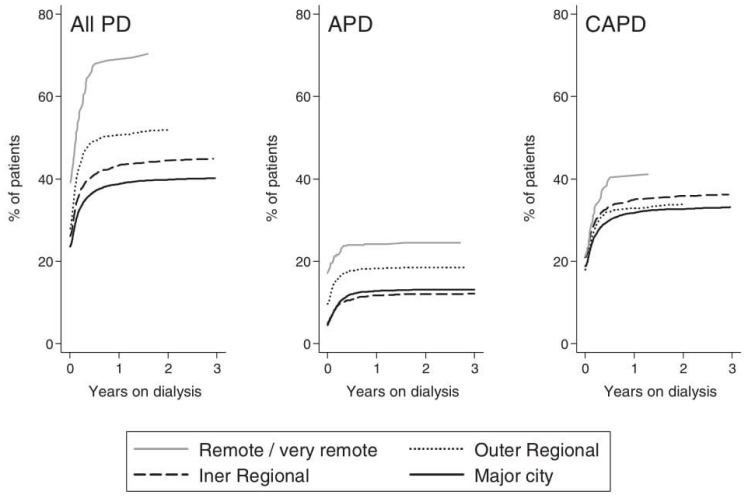

Figure 2 Uptake of all PD, CAPD and APD over time, by remoteness categories.

patients living in remote areas, where regular travel to HD units is not practical. In addition, PD does not need large quantities of clean water and/or reliable power which may limit home haemodialysis as an option for some rural patients. It is therefore not surprising that PD uptake increases with remoteness. Our data confirms findings from other studies [4-6].

Importantly, our data showed no difference in mortality among PD patients across all regions. This is reassuring for non-indigenous rural patients that they can safely undertake PD and not be disadvantaged. Given the overall increased mortality risk for dialysis patients in rural Australia [1], these findings suggest PD is a preferred modality. While these findings are supported by a Canadian cohort of incident PD patients [7], in the USA PD patients had higher mortality in micropolitan and rural areas [5]. The prevalence of PD is much lower in USA and there are likely many other country specific and patient selection factors that may explain the difference. A limitation of our study is that we did not

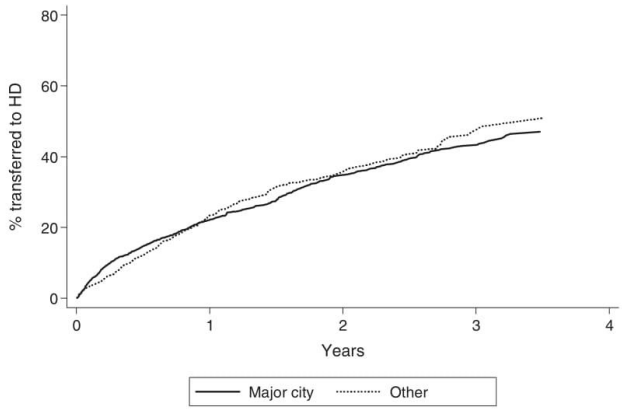

Figure 3 Cumulative incidence of technique failure, with transplantation and death as competing risks. Inner regional, outer regional and remote areas have been combined to a single "other" group due to small numbers.

Table 2 Competing risk sub-hazard ratios [95% confidence intervals] for technique failure, by reason for failure

	Major city	All other regions*
All cause – first 6 months	1 (reference)	0.47 [0.35–0.62], P < 0.001
All cause > 6 months	1 (reference)	1.05 [0.84–1.32], P = 0.6
Infection	1 (reference)	1.15 [0.80–1.67], P = 0.5
Dialysis	1 (reference)	1.05 [0.73–1.52], P = 0.8
Technical	1 (reference)	0.57 [0.38–0.84], P = 0.005
Non–medical	1 (reference)	0.52 [0.31–0.87], P = 0.01
Transplantation	1 (reference)	1.12 [0.82–1.53], P = 0.5

*Inner regional, outer regional and remote were grouped due to small numbers.
Each cause of failure has all other causes and death as competing risks. Data for reason for technique failure was only available after 2006.

measure distance to the treating centre which has been associated with increased PD patient mortality [6] or peritonitis risk [9]. Furthermore, our data do not apply to indigenous patients in rural areas of Australia who have been shown to have higher mortality rates than non-indigenous, possibly due to a shorter time to first peritonitis and that 79% of indigenous in rural Australia live in remote areas, whereas most non-indigenous in rural Australia are in regional areas [8].

Technique failure rates in rural areas were lower during the first 6 months, similar to Canadian data [6]. In our cohort this was mainly due to fewer technical and non-medical reasons for failure. It is understandable that if a rural patient has a significant distance to travel for HD there may be greater incentive to persist with PD rather than abandon for personal reasons. Furthermore, travel time has been associated with increased mortality on haemodialysis [14], so it is sensible to continue with PD when possible. The reason for fewer technical complications causing technique failure in rural PD patients is uncertain, but may relate to greater persistence in rural areas to resolve technical problems and continue PD. Importantly, PD failure for dialysis reasons such as inadequate clearances or ultrafiltration were similar between regions, suggesting that dialysis adequacy was not compromised. Furthermore, although more people underwent PD, the total duration of PD treatment in months did not differ by region. PD technique failure after 6 months did not differ by region, perhaps due to the greater uptake of PD among rural patients resulting in people less suited to self care commencing PD than in urban areas.

Time to first episode of peritonitis and peritonitis as a cause for technique failure were not different by remoteness area. We did find a difference in overall peritonitis rates by region, with higher rates in remote areas in particular. However, peritonitis data submitted to ANZDATA for second and subsequent episodes may not be as accurate or complete as for the first episode. Previous work has shown an increased rate of peritonitis and shorter time to first peritonitis for patients living >100km from the treating centre in Australia [9]. It seems that distance from the treating centre and possibly remote residence is therefore associated with increased peritonitis rates in Australia. This may reflect difficulties with home visits with increased distance and suggests a possible role for telemedicine.

Our study confirms previous findings [9] that there is an increased rate of *Staphylococcus aureus* peritonitis in rural areas, especially in outer regional and remote Australia. The causes for this finding are uncertain but may be affected by higher *Staphylococcus aureus* colonisation rates and possibly inadequate decolonisation procedures in remote areas. Decolonisation with topical mupirocin has been associated with a 70% reduction in *Staphylococcus aureus* peritonitis rates [15].

Table 3 Distribution of agents causing first episode of peritonitis, by remoteness area

	Major city	Inner regional	Outer regional	Remote	p-value
Culture negative	257 (14.5%)	103 (19.9%)	42 (16.3%)	9 (16.4%)	0.03
Coagulase negative *Staphylococcus aureus*	432 (24.4%)	110 (21.3%)	50 (19.4%)	9 (16.4%)	0.4
Methicillin resistant *Staphylococcus aureus*	26 (1.5%)	13 (2.5%)	5 (1.9%)	3 (5.5%)	0.4
Methicillin sensitive *Staphylococcus aureus*	138 (7.8%)	38 (7.4%)	33 (12.8%)	5 (9.1%)	0.01
Other gram positive	307 (17.3%)	77 (14.9%)	37 (14.3%)	7 (12.7%)	0.9
Gram negative	481 (27.1%)	129 (25.0%)	69 (26.7%)	15 (27.3%)	0.8
Anaerobes	4 (0.2%)	4 (0.8%)	0 (0.0%)	0 (0.0%)	0.04
Fungi	45 (2.5%)	14 (2.7%)	10 (3.9%)	1 (1.8%)	0.6
Mycobacteria	7 (0.4%)	2 (0.4%)	2 (0.8%)	0 (0.0%)	0.6
Other	73 (4.1%)	25 (4.8%)	10 (3.9%)	5 (9.1%)	0.09
No culture taken	3 (0.2%)	2 (0.4%)	0 (0.0%)	1 (1.8%)	0.6

Percentages are for each column and can be > 100% because of multiple organisms cultured for some patients.

Table 4 Peritonitis outcomes

	Major city	Inner regional	Outer regional	Remote
Transfer to haemodialysis	1 (reference)	0.89 [0.73–1.10] P = 0.3	0.91 [0.70–1.18] P = 0.5	0.49 [0.28–0.88] P = 0.02
Catheter removal	1 (reference)	0.93 [0.76–1.14] P = 0.5	0.96 [0.75–1.24] P = 0.8	0.75 [0.45–1.22] P = 0.2
Death within 90 days	1 (reference)	0.94 [0.58–1.53] P = 0.8	1.13 [0.60–2.12] P = 0.7	1.08 [0.32–3. 61] P = 0.9

Data presented are odds ratios [95% confidence intervals] and P values, produced from mixed–effects logistic regression. Models were adjusted for age, body mass index category, smoking status, comorbidities, primary kidney disease, late referral, gender, race, and size of treating centre, with infection number nested within patient as random effects.

Our data show that while PD uptake is more common in rural areas, those living in outer regional and remote Australia are less likely to commence dialysis with PD than in major cities. This finding is different to Canadian [6] and American [5] data which shows people in remote areas are more likely to commence dialysis with PD than city dwellers. However, in USA the uptake of PD at commencement of dialysis was less than 10% of incident patients, much lower than Australia. The Canadian study was different to ours because it examined patients commencing dialysis in an earlier time period (1990–2000), examined distance from the treating nephrologist rather than rural residence, and included indigenous patients. The lower dialysis initiation with PD in outer regional and remote areas was not explained by a difference in late referral to a nephrologist by remoteness area. However it remains possible that people in these areas did not seek nephrology care until late in the course of their kidney disease, perhaps due to the smaller medical [16] and nephrology [17] workforces compared with urban areas.

Our study has several limitations. Postcode data at commencement of renal replacement therapy was used and we do not know how many or how often patients relocate to access health care for kidney disease prior to commencing dialysis. Socio-economic status was not examined in this analysis. Previous work has demonstrated increased PD technique failure with lower neighbourhood education level [7]. Furthermore, lower socioeconomic status has been associated with increased PD patient peritonitis and mortality in China [18] and peritonitis associated hospitalisation and death in Australia [19]. The method used to classify a postcode by remote area index relied on data from statistical local areas and some postcodes had several different remote area index classifications of statistical local areas. Our classification of each postcode may thus have created a bias, although to minimise this we used the most populous remote area index allocation for each postcode. There is no data on patients who were managed conservatively and never commenced dialysis, although treatment rates have been shown similar by remoteness [20]. The data is observational and there are many variables such as exit-site infection, local protocols, use of telehealth, and local available expertise which are unavailable for this analysis. Lastly, the data collected by ANZDATA is submitted voluntarily and has only been subjected to a small audit [21], although all units in Australia and New Zealand participate and assert that reporting is complete.

Conclusion

This study has shown an increased uptake of PD with increasing remoteness in Australia. PD technique failure rates are lower in rural areas while peritonitis rates and mortality do not vary by region. PD therefore appears to be a good treatment choice for patients living in rural Australia. Efforts to maintain and improve quality care in rural areas such as adherence to guidelines, use of outreach clinics and telehealth may further enhance the health of rural patients.

Abbreviations

PD: Peritoneal dialysis; ANZDATA: Australia and New Zealand Dialysis and Transplant Registry; MC: Major city; IR: Inner regional; OR: Outer regional; REM: Remote/very remote; CI: Confidence intervals; HD: Haemodialysis; CAPD: Continuous ambulatory peritoneal dialysis; APD: Automated peritoneal dialysis.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

NG conceived the study, participated in its design and coordination and drafted the manuscript. BG participated in study design, performed the statistical analysis and participated in drafting the manuscript. SM participated in study design and statistical analysis. All authors read and approved the final manuscript.

Acknowledgements

The authors gratefully acknowledge the contributions of the Australian and New Zealand nephrology community in providing information for, and maintaining the ANZDATA database.
The data reported here have been supplied by ANZDATA. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of ANZDATA.

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Received: 8 January 2013 Accepted: 26 November 2013
Published: 20 December 2013

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doi:10.1186/1471-2369-14-278
Cite this article as: Gray *et al.*: Peritoneal dialysis in rural Australia. *BMC Nephrology* 2013 **14**:278.

2.3 Nephrology training in Australia and New Zealand: A survey of outcomes and adequacy

Beaton TJ, Krishnasamy R, Toussaint ND, Phoon RK, Gray NA

Nephrology (Carlton) 2017; 22(1): 35-42

DOI: 10.1111/nep.12720

Journal Impact Factor 2.178 in 2017. 2.4 in 2023. 13 citations and FWCI of 0.22 (27/3/25)

Co-Authorship statement: T Beaton was a basic physician trainee at the time. He helped with data collection and drafted the initial manuscript. R Krishnasamy assisted with statistics. N Toussaint and R Phoon provided advice based on their roles as previous Chairs of the training committee for nephrology for the Royal Australasian College of Physicians. As senior author, I designed the study, developed the survey and methodology, interpreted the data, provided supervision, and extensively edited the manuscript.

Original contribution to literature: Description of training adequacy and career pathways for nephrologists in Australia.

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NEPHROLOGY

Nephrology **22** (2017) 35–42

Original Article

Nephrology training in Australia and New Zealand: A survey of outcomes and adequacy

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KEY WORDS:
Australia, curriculum, nephrology, New Zealand, training.

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Accepted for publication 23 December 2015.
Accepted manuscript online 6 January 2016.

doi: 10.1111/nep.12720

Conflict of Interest and Disclosure: None

SUMMARY AT A GLANCE

Nephrologists who had recently completed their training in Australia and New Zealand were surveyed to determine their views on adequacy of advanced training in Nephrology. By comparing self-determined competency and skill relevance. Nephrology training generally meets percevied clinical needs, with most trainees securing their desired employment. Additional exposure to research and management skills were areas identified for improvement.

ABSTRACT:

Background: **Advanced training programmes in nephrology should provide broad exposure to all aspects of nephrology. In Australia and New Zealand (ANZ), the Advanced Training Committee in Nephrology oversees training, and recent increases in trainee numbers have led to concern about dilution of experience.**

Aim: **To investigate early career paths of nephrologists in ANZ and determine the adequacy of training by comparing self-determined competency and skill relevance among recently graduated nephrologists.**

Methods: **In 2015, the Advanced Training Committee in Nephrology administered an online survey during the annual subscription for members of the Australian and New Zealand Society of Nephrology. Nephrologists who were awarded Fellowship after 2002 were invited to participate.**

Results: **The survey was completed by 113 Fellows with 8 respondents excluded (response rate 44.1%). Initial post-Fellowship work included full-time public hospital appointments (34.3%) or undertaking full-time higher research degrees (41.9%). The majority reported securing their desired employment. Respondents indicated adequate training in most clinical skills; however, responses of 'well trained' in home haemodialysis (41.8%), conservative care (42.9%), automated peritoneal dialysis (38.8%), and assessment of kidney transplant recipients (48%) and living kidney donors (34.7%) were less adequate. Although considered highly relevant to current practice, responses of 'well trained' were low for management and research skills, including complaint management (16.3%), private practice management (2%), health system knowledge (14.3%) and regulations (6.1%), ethics approval (23.5%), research funding (11.2%) and quality assurance (26.5%).**

Conclusion: **Nephrology training in ANZ generally meets clinical needs and most secure their desired employment. Training in management and research are areas for improvement.**

The number of nephrology advanced trainees in Australia and New Zealand (ANZ) has increased significantly in recent years. In 2014, there were 106 nephrology trainees across Australia compared with 23 in 2000.[1,2] New Zealand reported growth from 19 trainees in 2010 to 30 in 2014 (Advanced Training Committee in Nephrology, pers. comm., August 2015). Reasons for this increase include efforts to promote nephrology training due to concerns of insufficient numbers of nephrologists in the workforce and the ability to cater for future community demand, introduction of safe work practices limiting hours doctors can work and a significant increase in the number of medical school graduates.[2,3]

Nephrology trainees in ANZ are eligible for specialist recognition in nephrology after a minimum of 3 years of advanced training following completion of the Royal Australasian College of Physicians (RACP) basic physician training programme and examinations. Prior to 2014, nephrology advanced training was composed of two core clinical years and one elective year that could be clinical or research based. Currently, the nephrology advanced training programme involves three core clinical

years and is supervised by the Advanced Training Committee in Nephrology, a subdivision of the RACP.[4]

Increasing numbers of graduating doctors and nephrology trainees have resulted in decreased clinical exposure. It has been reported that junior doctors in Australia spend only 15% of their day in direct patient contact.[5] A specific concern for nephrology training is that the increase in trainee numbers is disproportionally greater than the increase in patients with end-stage kidney disease (ESKD) over the same time period. This has resulted in decreased clinical exposure, particularly to dialysis and renal transplant patients.[2] The number of procedures performed by trainees, such as kidney biopsies and insertion of temporary vascular access catheters, has also reduced.[2] These issues raise concerns that the traditional advanced training in nephrology undertaken in ANZ may not continue to meet the needs of trainees and new Fellows.

There has been limited research investigating the effectiveness of nephrology training. In the United States of America (USA), perceived gaps in training were reported by nephrologists in a number of areas of the curriculum, many of which also had significant relevance to current practices.[6] To date, there has been no similar study in ANZ. This study aimed to identify the adequacy of current nephrology advanced training in ANZ in meeting the needs of nephrologists once they were awarded Fellowship of the RACP (FRACP).

METHODS

A cross-sectional study, involving an online survey, was conducted after approval by the Human Research and Ethics Committee of the Prince Charles Hospital, Queensland, Australia (HREC/14/QPCH/277). The survey (Appendix 1/Table S1) was developed after review of relevant literature and the current curriculum in nephrology. The survey was reviewed by the Advanced Training Committee in Nephrology and administered online using Survey Monkey™. Distribution was to eligible participants in early 2015 at the time of annual subscription renewal for membership of the Australian and New Zealand Society of Nephrology. Nephrologists awarded their FRACP in Nephrology after 2002 were directed to a statement explaining the study and invited to participate in the optional survey after providing consent. Participants who completed their Fellowship training internationally were excluded. Data was obtained from the RACP regarding the total number of nephrologists who were awarded FRACP in Nephrology after the year 2002, including information on where the Fellows trained (Australia, New Zealand or internationally).

Data collected in the survey included age, gender, marital status, location of medical school, year graduated from medical school, year awarded FRACP, whether any training was completed in a rural setting (as nominated by the respondent) and if the Fellow was accredited in another specialty area. Respondents were asked if they had completed, or commenced but not yet completed, a higher degree. Details for those undertaking or those who had undertaken a higher degree included why they chose the higher degree, whether completed post-Fellowship or not, whether it helped employment opportunities and if they were still involved in research. Respondents were asked about their expectations of their career as they approached the end of training and how this compared with actuality. The survey also focused on the nephrologists' perceived competence in a number of key learning objectives set by the RACP for training and how relevant those learning objectives were to current practice.[7] Respondents were asked to rate their nephrology training as either 'well trained', 'some training' or 'little/no training' for each learning objective. They were then asked whether those learning objectives were 'very important', 'somewhat important' or 'not important' to their current practice. This format was modelled on a previous non-validated USA study.[6] For the purpose of analysis, training was considered adequate for post-Fellowship needs if reported as 'well trained' and importance was considered significant if participants reported 'very important' or 'somewhat important'.

Data was de-identified and stored on a password-protected computer. Descriptive statistics were used to report participants' characteristics. Results were expressed as frequencies and percentages for categorical variables, mean ± standard deviation for normally distributed variables and median (interquartile range) for non-normally distributed variables. To further assess the adequacy of training as trainee numbers increased, participants were divided into two time periods; group one included participants awarded FRACP from 2002–2009 and group two included those awarded FRACP from 2010–2014. Differences between the two groups were analysed by chi-squared test for categorical data and Wilcoxon rank sum test for continuous non-normally distributed data. Data were analysed using standard statistical software program (STATA 12; http//www.stata.com/). *P* values of less than 0.05 were considered statistically significant for all described analyses.

RESULTS

One hundred and thirteen survey responses were received. Eight respondents were omitted from the analysis due to achievement of FRACP prior to 2002 or completing their training internationally. Information from the RACP revealed 306 nephrologists gained Fellowship between 2003 and 2014 inclusive, of whom 68 trained internationally. This resulted in a response rate for ANZ trained nephrologists of 44.1%. Of the 105 responses, seven did not complete the survey in full. A majority of respondents were men, married and had completed medical school in Australia (Table 1).

Table 1 shows that post-Fellowship plans closely matched actual employment for respondents. The majority was employed full time in a public hospital (34.3%) or undertook a higher degree (41.9%) immediately post-Fellowship. A significant proportion of respondents completed (56.2%) or had commenced (21%) higher post-graduate degrees, primarily

Table 1 Participants' characteristics

Baseline characteristics	$N = 105$
Age (years) (IQR)	41 (37–44)
Gender (male)	66 (63%)
Marital status (married/partner)	93 (89%)
Medical school	
- Australia	62 (59.1%)
- New Zealand	7 (6.7%)
- India	16 (15.2%)
- Others	20 (19.0%)
Year graduated medical school (IQR)	1999 (1995–2002)
Year awarded FRACP (IQR)	2009 (2006–2011)
Completed some training in a rural area of ANZ	37 (35.2%)
Qualified training in other specialty area	26 (24.8%)
-General medicine	21 (20.0%)
- Others	5 (4.8%)
Post-Fellowship employment plans	
- Full-time public hospital	38 (36.1%)
- Full-time private practice	1 (1.0%)
- Higher Degree	42 (40.0%)
- Mix public/private practice	9 (8.6%)
- Other	15 (14.3%)
Post-Fellowship actual employment	
- Full-time public hospital	36 (34.3%)
- Full-time private practice	3 (2.9%)
- Higher Degree	44 (41.9%)
- Mix public/private	6 (5.7%)
- Other	16 (15.2%)
Higher Degree	81 (77.2%)
- Completed	59 (56.2%)
- Commenced	22 (21.0%)
Reasons for Higher Degree	
- Career development	35 (43.2%)
- Desire to do research	34 (29.6%)
- Suit lifestyle	2 (2.4%)
- Expectations	3 (3.7%)
- Only option for employment	1 (1.2%)
- Others	6 (7.4%)
Types of Higher Degree	
- PhD	54 (66.7%)
- Masters	18 (22.2%)
- Others	9 (11.1%)
Higher Degree helped to obtain position	30 (37.0%)
Still active in research following completion of higher degree	35 (59.3%)

Data expressed as mean ± SD, median (IQR) or number (%). ANZ, Australia, New Zealand; FRACP, Fellowship of the Royal Australasian College of Physicians; IQR, interquartile range; RACP, Royal Australasian College of Physicians; SD, standard deviation.

because of a desire to pursue a research career or to enhance career opportunities. Most respondents reported their initial employment as their preferred place of work (74.2%), what they expected (81.2%) and an enjoyable experience (91.4%). The average working week (including those employed part time) was 37.1 ± 15.6 h with most time in clinical work (Table 2).

The current primary workplace setting and hours spent on clinical work, nephrology and research reported by respondents reflected their initial work post-Fellowship (Table 2). Currently, 62.3% are employed at a single workplace, 29.2% are employed at two workplaces and 8.5% are employed at three workplaces. In their current practice, the average hours spent per week on teaching, administrative tasks and supervising nephrology advanced trainees were reported as 3.0 ± 2.5, 3.4 ± 4.1 and 3.0 ± 3.6 h, respectively.

Table 2 Comparison between initial primary workplace and current primary workplace

	Initial workplace	Current primary workplace
Country		
- Australia	87 (82.9%)	88 (83.8%)
- New Zealand	8 (7.6%)	4 (3.8%)
- Other/did not respond	10 (9.5%)	13 (12.4%)
Setting		
- Teaching/university hospital	76 (72.4%)	76 (72.4%)
- Other public hospital	15 (14.3%)	12 (11.4%)
- Private practice	5 (4.8%)	6 (5.7%)
- Research centre	8 (7.6%)	3 (2.9%)
- Other	1(1%)	8 (7.6%)
Working hours/week (mean ± SD)		
- Total hours/week	37.1 ± 15.6	35.7 ± 19.2
- Clinical hours/week	24.9 ± 16.0	26.5 ± 17.9
- Nephrology hours/week	21.3 ± 16.3	22.2 ± 15.1
- Research hours/week	12.7 ± 14.7	11.5 ± 14.0

SD, standard deviation.

Training adequacy and importance

A majority of respondents reported adequate training in most areas of ESKD, including transplantation (Fig. 1a). Teaching and exposure to the use of immunosuppressive agents were also predominately adequate (83.7%). Less than half of respondents reported adequate training for conservative care management (42.9%), automated peritoneal dialysis (38.8%), home haemodialysis (41.8%), continuous renal replacement therapy (CRRT) (23.5%), and the assessment of transplant recipients (48%) and live donors (34.7%).

Areas of ESKD (dialysis and transplantation) were reported as highly important to current practice (Fig. 1b). Conservative care (96.9%), CRRT (82.5%), use of immunosuppressive agents (99%), assessing transplant recipients (93.8%) and donors (91.8%) were also considered to have significant importance to clinical practice.

There were mixed responses for reported adequacy of skills training (Fig. 2a). Adequate training was reported by a majority of respondents for performing native (79.6%) and transplant (76.5%) renal biopsies and non-tunnelled haemodialysis catheters (64.3%). Responses were lower for interpreting kidney biopsies (43.9%) and prescribing plasmapheresis (37.8%). Very few reported adequate training in performing peritoneal dialysis catheter insertion (11.2%) and interventional haemodialysis access procedures (10.2%).

Skills considered most important to current practice by the respondents were interpreting a kidney biopsy (95.9%) and prescribing plasmapheresis (89.8%). The skills considered least important to current practice were tunnelled haemodialysis catheter (50%), peritoneal dialysis catheter (36.7%) and interventional haemodialysis access procedures (35.7%).

Managerial training was generally reported as poor with low responses of nephrologists receiving adequate training across

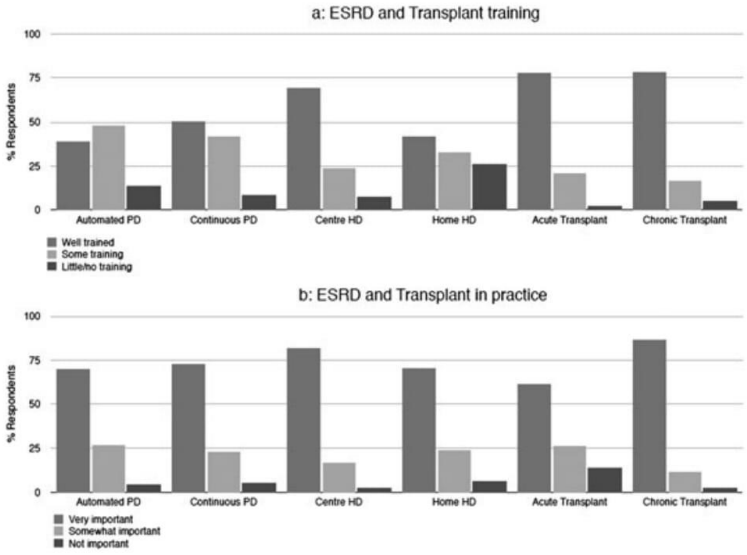

Fig. 1 Reported adequacy of training (a) and importance to current practice (b) of management of end-stage kidney disease and transplantation for Australia and New Zealand nephrologists awarded Fellowship from 2003–2014 ($n = 98$).

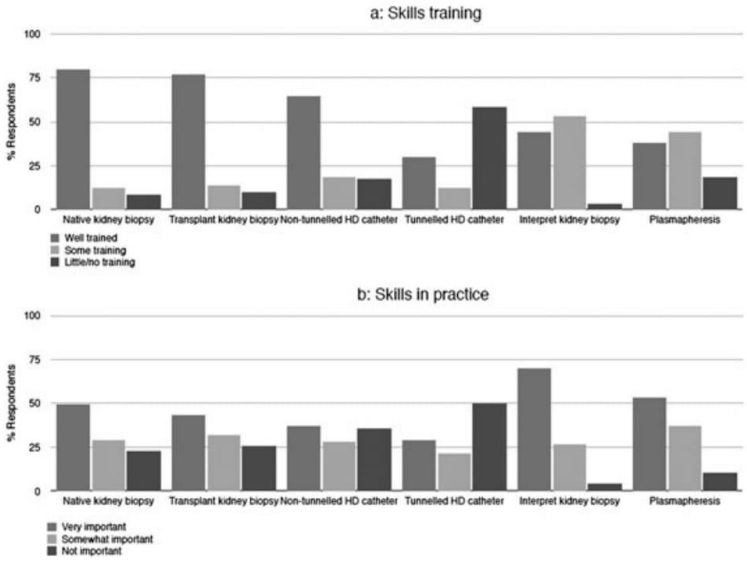

Fig. 2 Reported training adequacy (a) and importance to current practice (b) of nephrology skills for Australia and New Zealand nephrologists awarded Fellowship from 2003–2014 ($n = 98$).

all categories (Fig. 3a), a significant mismatch when comparing rated importance with practice. Managerial skills were considered to be of significant importance to current practice by most respondents across all categories (Fig. 3b).

Only a minority of nephrology Fellows reported adequate training in research (Fig. 4a). The best response was for interpretation of medical literature where 45.9% reported adequate training. Respondents reported significant importance to their practice in the areas of clinical research (91.8%), ethics approval (88.7%), interpretation of literature (96.9%), access and use of the Australia and New Zealand Dialysis and Transplant Registry (92.9%) and quality assurance (99%) (Fig. 4b).

Table 3 shows a comparison between Fellows who completed training from 2003 to 2009 and 2010 to 2014. As illustrated, there was little difference in reported rates of training adequacy between the two time periods.

DISCUSSION

Our study is the first to examine career paths and training adequacy of recently graduated nephrologists in ANZ. We report that a majority complete a higher degree in research and follow their preferred career choice. Nephrology training in clinical areas is generally adequate, but trainees report being underprepared in management and research skills.

From 2014, nephrology trainees in ANZ were required to complete a minimum of 3 years of core clinical nephrology, which compares with previous training requirements of two core clinical years and one non-core or elective year.[4] This change ensured nephrology training in ANZ was more aligned with other international nephrology training programmes such as the United Kingdom and Ireland and was also in response to concerns regarding decreased clinical exposure during nephrology training with increasing advanced trainee numbers.[2,8,9]

Despite concerns regarding possible reduced clinical exposure, our study does not support a difference in quality of training between the periods 2003–2009 and 2010–2014. There were no areas of clinical training that were reported as less adequate by trainees between the two time periods. This is despite increased numbers of nephrology advanced trainees in ANZ over that time while clinical exposure and procedures performed by trainees has decreased.[2] Despite a lack of current evidence for diminished adequacy of training, future concerns regarding quality of training remain, particularly regarding reduced work hours for junior doctors, increasing numbers of medical graduates, reduced doctor–patient contact time, and increased flexible training such as part-time appointments and job sharing.[5,10–13] Although there have been valid concerns raised, our data is consistent with other published reports of inadequate evidence that these issues (particularly reduced junior doctor working hours) have led to less adequate training.[14,15]

Nephrology trainees have expressed concerns that increasing trainee numbers will impact employment opportunities; however, most respondents in our survey reported being able to secure their desired positions. Most have also expressed satisfaction in their role. Notably, few work in private practice after completion of training. Our results showed that 24.8% had trained in general medicine or another specialty, and a significant portion of working time was spent in non-

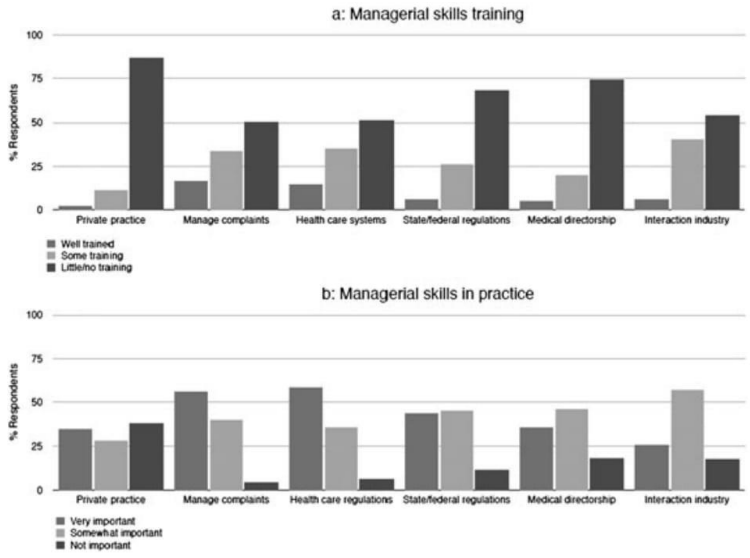

Fig. 3 Reported training adequacy (a) and importance to current practice (b) of managerial skills for Australia and New Zealand nephrologists awarded Fellowship from 2003–2014 ($n = 98$).

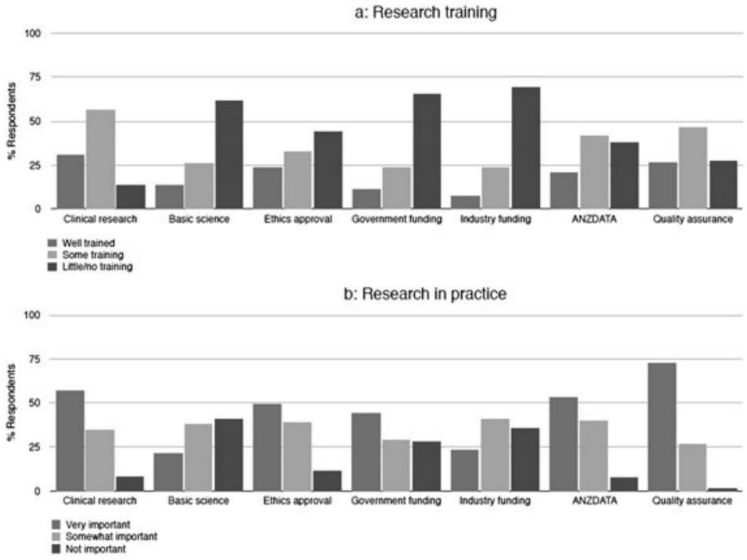

Fig. 4 Reported training adequacy (a) and importance to current practice (b) of research skills for Australia and New Zealand nephrologists awarded Fellowship from 2003–2014 ($n = 98$).

Table 3 Comparison of training adequacy (responses of 'well trained') in end-stage kidney disease, transplant and nephrology skills among Fellows awarded FRACP from 2003–2009 (Group 1) and 2010–2014 (Group 2)

	Group 1 ($n = 53$)	Group 2 ($n = 45$)	*P*
Age (IQR)	43 (40–47)	38 (35–41)	<0.001*
Gender (Male)	40 (69.0%)	26 (55.3%)	0.1
Dialysis			
APD	21 (39.6%)	17 (37.8%)	0.8
CAPD	27 (50.9%)	22 (48.9%)	0.9
In-centre HD	38 (71.7%)	30 (66.7%)	0.8
Home HD	22 (41.5%)	19 (42.2%)	0.9
Haemofiltration	12 (22.6%)	11 (24.4%)	0.5
Transplant			
Recipient assessment	29 (54.7%)	18 (40.0%)	0.1
Donor assessment	20 (37.7%)	14 (31.1%)	0.7
Acute care	41 (77.3%)	35 (77.8%)	0.5
Chronic care	42 (79.2%)	35 (77.8%)	0.8
Nephrology skills			
Native renal biopsy	42 (79.3%)	36 (80.0%)	0.5
Transplant renal biopsy	42 (79.3%)	33 (73.3%)	0.8
Non-tunnelled HD catheter	35 (66.0%)	28 (62.2%)	0.5
PD catheter insertions	12 (22.6%)	17 (37.8%)	0.03*
Plasmapheresis	2 (3.7%)	8 (17.8%)	0.08

*Indicates statistical significance Data expressed as median (IRQ) or number (%). APD, automated peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis; HD, haemodialysis; IQR, interquartile range; PD, peritoneal dialysis.

nephrology areas, suggesting that some new Fellows may be working in non-traditional nephrology fields.

A significant number of nephrology Fellows pursued a higher research degree, mainly for career development or a desire to undertake research. The numbers of ANZ nephrologists who had completed a higher degree (56.2%) was higher than reported by a study from the USA of both 'academic nephrologists' (41.1%) and 'non-academic nephrologists' (16.1%).[16] However, 40.7% who had completed a higher degree are no longer involved in research. This correlates with the proportion of those who undertook a higher degree for career development (43.2%) and may reflect competition for clinical job opportunities immediately post-Fellowship. On the other hand, the prevalence of those undertaking higher degrees may also reflect recent Fellows filling the perceived gap in research knowledge from their training.

Our study has shown that ANZ nephrologists feel there were many areas of the nephrology curriculum for which they received adequate training prior to being awarded FRACP. In particular, in-centre and satellite haemodialysis, the care of transplant patients in both the acute and chronic setting, as well as the use of immunosuppressive agents, were highlighted as areas of adequate training. These areas of patient care were also viewed as having high levels of importance to current practice. Procedural nephrology, such as performance of native and transplant renal biopsies and non-tunnelled haemodialysis catheter placement, were also areas of strength, with perceived significant importance to current practice. These results are similar to research from the USA.[6]

Despite these strengths in ANZ nephrology training, there were some clinical areas that were perceived as having high importance to practice in which many nephrologists felt less adequately trained on completion of Fellowship. Training in home-based dialysis (peritoneal dialysis and

home haemodialysis) was surprisingly less adequate than expected, despite home dialysis modalities being common in ANZ (32% of prevalent dialysis patients in Australia and 36% in New Zealand).[17] Training in conservative or supportive care management of people with ESKD is increasingly recognized as an important area, but was identified as an area for improved training, similar to a USA study.[18,19] Transplant training was adequate for acute and chronic care, but training in assessment of live kidney donors and potential transplant recipients was less adequate. Training in these two areas is critical to ensure patients receive early access to transplantation with the associated survival benefits and cost benefit to the wider community.[20–22]

A majority of respondents reported inadequate training in CRRT and also that this area was less important to their practice. This is consistent with practice in ANZ where CRRT is most commonly supervised by intensive care specialists. Respondents reported high rates of inadequate training for insertion of tunnelled haemodialysis catheters, peritoneal dialysis catheters and interventional haemodialysis access. These areas were also considered of low significance to most nephrologists' current practice. This is consistent with results of a recent ANZ survey of procedures performed by nephrologists. which showed high rates of renal biopsy and non-tunnelled central venous catheter insertion but lower rates of other procedures.[23] Interventional nephrology is a developing field in ANZ and a number of centres have nephrologists who are performing interventional procedures with evidence of good outcomes.[24,25] It would appear that, although not essential for most practitioners, nephrologists who are interested in learning these skills seek them out during training. A USA study also found significant variation of experience in procedures between trainees in different hospitals.[26]

Similar to research from the USA, nephrologists reported inadequate training in research and managerial areas despite being of significant importance to practice and part of the current curriculum.[6,7] Inadequate training was reported universally for managerial skills despite high importance to practice. It may be argued that nephrologists should focus their advanced training on core knowledge and clinical practice and would be able to learn managerial and research skills post-FRACP. Many nephrologists advance their research skills post-Fellowship with a majority undertaking a higher degree in research. It would also be expected that nephrologists improve their management skills post-Fellowship, but it was beyond the scope of this study. Considering the high importance placed on many aspects of management, it would seem that an adequate level of education and experience in these areas during their training would be of significant benefit to trainees and their subsequent practice. This could potentially be achieved by participating in structured course work. In Ireland for example, leadership and communication courses are a compulsory component of the curriculum.[9]

Our study provides a valuable insight into the perceived adequacy of nephrology training by recent nephrology Fellows although there are a number of limitations. Given the nature of the survey, there is a possibility of recall bias by respondents, especially regarding their competency at the time of finishing training and their career choices. Furthermore, responses were subjective as no objective measure is currently available. Population bias also potentially affects the results of this survey. The response rate was 44.1% and may not necessarily be representative of the views and experiences of all recent nephrology Fellows, especially with the low number of respondents who attended medical school in New Zealand. Considering nephrologists are time limited and frequently asked to complete surveys, it is possible our response rate leads to bias. The response rate of a similar USA study was estimated to be 8–10%.[6] This study did not investigate whether, with continuing education, nephrologists now feel competent and well trained after practising as Fellows of the RACP. Furthermore, changes associated with three core clinical years, the increase in trainee numbers, decreased working hours and a plan to change to a competency-based curriculum may impact perceived adequacy of training in the future. A repeat assessment of training adequacy post implementation of the recent change to a 3 year core training programme will be necessary to evaluate the effectiveness of the extended programme, particularly in its ability to address current areas of weakness.

CONCLUSION

A comprehensive advanced training programme is essential to continue producing high-quality nephrologists and provide a high standard of care to patients in ANZ. The adequacy of nephrology training should continue to be evaluated and subsequently evolve as the needs of the profession, trainees, patients and the wider community change over time. At present, on completion of nephrology training in ANZ, most nephrologists obtain their first preference for employment and, a large percentage undertake higher degrees. ANZ nephrology training equips new Fellows with most clinical skills required for practice, but training in management and research needs further attention.

Abbreviations: ANZ; Australia and New Zealand; ANZDATA; Australia and New Zealand Dialysis and Transplant Registry; ANZSN; Australian and New Zealand Society of Nephrology; ATC; Advanced Training Committee; CRRT; Continuous renal replacement therapy; ESKD; End stage kidney disease; FRACP; Fellow of the Royal Australasian College of Physicians; IQR; Interquartile range; RACPRoyal Australasian College of Physicians; SD; Standard deviation; USA; United States of America;

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher's web-site.

Appendix 1: Nephrologist Survey

Nephrologists Survey 2015

Note – the survey was formatted for Survey Monkey™

Demographics

1. Age
2. Gender
   M/F
3. Current Marital status
   Single
   Married / Partner
   Separated / Divorced
4. Where did you complete medical school?
   QLD
   NSW
   Vic
   SA
   WA
   Tas
   ACT
   NT
   New Zealand
   Other country (specify):
5. In what year did you graduate from medical school?
6. In what year were you awarded Fellowship of the RACP?
7. Did you complete any of your physician training (basic or advanced training) in a rural setting?

   Yes / No
8. Are you accredited in another specialty area?
   No
   Yes General Medicine
   other (specify)
9. Do you have a higher degree?
   No – go to question 14
   Commenced but not yet finished higher degree – go to question 13
   PhD
   Masters
   Other (specify)
   Yes
   PhD
   Masters
   Other (specify)
10. Did you complete this higher degree following completion of your FRACP?
    Yes/No
11. Did completion of a higher degree assist in securing your preferred position?

Not applicable – still undertaking higher degree
Yes
No

12. Having completed a higher degree, are you currently active in research (ie grants, supervision of higher degree students)?
    Yes
    No
13. What is the primary reason you chose to undertake a higher degree (if applicable)?
    Not applicable – no higher degree
    Desire to do research
    Career development
    It suited my work/life balance at the time
    It was expected
    No other employment options
    Other (specify)
14. What were your immediate plans post–FRACP as you neared the end of your training?
    Higher degree
    Full time work in a public hospital
    Part-time work in a public hospital
    Full time work in private practice
    Part-time work in private practice
    Mixture of work in public hospitals and private practice
    Unsure
    Other (specify)
15. What did you do immediately post–FRACP?
    Higher degree
    Full time work in a public hospital
    Part-time work in a public hospital
    Full time work in private practice
    Part-time work in private practice
    Mixture of work in public hospitals and private practice
    Other (specify)
16. Please complete regarding your initial main place of work post fellowship
    Setting (University/teaching hospital, other public hospital, private practice, research centre, other (specify))
    Country
    Postcode (Australia only)
    Total hours per week (average)
    Hours/week at this workplace spent doing clinical work (average)
    Hours/week of clinical time at this workplace spent doing nephrology (average)
17. Was your first workplace position/role following FRACP:
    -Your first choice for work?
    -What you expected it to be?
    -An enjoyable experience?
    Comments……..
18. Please provide details for each of your current places of work

    Workplace 1
        Setting (University/teaching hospital, other public hospital, private practice, research centre, other (specify))
        Country
        Postcode (Australia only)
        Total hours per week (average)
        Hours/week at this workplace spent doing clinical work (average)

Hours/week of clinical time at this workplace spent doing nephrology (average)
Workplace 2
(as above, repeated as many times as needed)

19. On average, how many hours do you spend each week involved in:
    Research
    Teaching
    Administration
    Supervising nephrology advanced trainees
20. Would you consider increasing the amount of work you currently do in a rural setting?
    Yes / No
21. What do you think could have been improved/ done differently in your time as an advanced trainee in nephrology?
22. What could be improved/ done differently with the current advanced training in nephrology?

For each area in the next section respondents were asked to:

1. **Rate your training:**
   - little or no training
   - some training but not enough to feel competent
   - well trained, competent
2. **Rate how important is this learning objective to your practice**
   - Not at all important
   - Somewhat important
   - Very important

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End Stage Kidney Disease (ESKD)

1) Conservative care and symptom control in people with ESKD
2) Plan and manage automated peritoneal dialysis
3) Plan and manage continuous ambulatory PD
4) Plan and manage centre/satellite haemodialysis
5) Plan and manage home haemodialysis
6) Haemofiltration and continuous renal replacement therapy

Transplantation

1) Assess potential transplant recipients
2) Assess live kidney donors
3) Prescribe immunosuppressant medications and recognize complications
4) Acute transplant management (first 2 months)
5) Chronic transplant management (after 2 months)

Skills

1) Perform native renal biopsy
2) Perform transplant renal biopsy
3) Insertion of an non-tunneled dialysis catheter
4) Insertion of a tunneled dialysis catheter
5) Insertion of a PD catheter

6) Interventional HD access procedures
7) Interpret a kidney biopsy
8) Prescribe plasmapheresis and plasma exchange

Managerial

1) Running a private practice
2) Managing complaints
3) Knowledge of health care systems
4) State and federal regulations
5) Medical directorship
6) Interaction with industry / pharmaceutical companies

Research

1) Clinical research
2) Basic Science Research
3) Obtaining ethics approval for research
4) Obtaining government research funding
5) Obtaining Industry research funding
6) Obtaining research funding from other sources such as foundations
7) Interpretation of medical literature and use of electronic resources
8) Access and use of ANZDATA
9) Quality assurance

2.4 Telemedicine for outpatient care of kidney transplant and CKD patients

Lambooy S, Krishnasamy R, Pollock A, Hilder G, Gray NA

Kidney Int Rep 2021; 6(5): 1265-1272

DOI: 10.1016/j.ekir.2021.02.016

Journal Impact Factor 6.234 in 2021. 5.7 in 2023. 22 citations and FWCI of 2.09 (27/3/25)

Co-Authorship statement: S Lambooy was a basic physician trainee at the time. He helped with data collection and analysis. R Krishnasamy assisted with statistics. Nurses A Pollock and G Hilder assisted with data collection. As senior author I was responsible for study design, securing grant funding, ethics approvals, patient recruitment, interpretation of data, supervision of S Lambooy, and extensive editing of the manuscript.

Original contribution to literature: Demonstrated feasibility of telemedicine with reduced travel for people with CKD or a kidney transplant, and showed comparable long-term outcomes compared with standard care.

Funding: Sunshine Coast Hospital and Health Service Private Practice Trust Fund, 2014-NG. $22,400

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CLINICAL RESEARCH

Telemedicine for Outpatient Care of Kidney Transplant and CKD Patients

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Introduction: Telehealth videoconferencing (TVC) may improve access in rural areas, but reported uptake and outcomes among kidney transplant recipients (KTRs) and chronic kidney disease (CKD) patients are limited. This study aimed to assess the feasibility, sustainability, and clinical outcomes of TVC for this patient population.

Methods: A total of 64 participants were recruited in this single-center, prospective, 2-year longitudinal, case-control study. Inclusion criteria for the telemedicine group included travel of ≥15 km to the hospital, and the control group was matched for transplant or CKD status, age, and sex. The primary outcome was feasibility (≥50% of consultations for each individual patient in the telemedicine group being conducted by TVC in year 1). Secondary outcomes were sustainability of telemedicine, change in blood pressure and creatinine, hospitalization, and travel distance.

Results: There were 32 participants in both the telemedicine and control arms, with no baseline differences. The majority were male (65.6%) and the mean age was 63.9 years (SD = 12.3 years). TVC uptake in year 1 in the telemedicine arm was 71% (interquartile range [IQR] = 50.0−100.0) but reduced significantly in year 2 (50.0% [IQR = 33.3−71.4], $P < 0.01$). No significant differences in creatinine or blood pressure were observed between groups, including in the KTRs and CKD subgroup analysis. Patient satisfaction remained high for both groups. Compared with travel distance required if TVC was unavailable, travel distance in the TVC group decreased by 48% (16,644 km) in year 1 and by 37.0% (8177 km) in year 2.

Conclusion: TVC was feasible and sustainable, with outcomes comparable to those of standard care. Larger studies, especially among KTRs, are needed to confirm these findings.

Kidney Int Rep (2021) **6,** 1265–1272; https://doi.org/10.1016/j.ekir.2021.02.016
KEYWORDS: chronic kidney disease; kidney; telehealth; telemedicine; transplant

Kidney disease is associated with high morbidity and mortality. Poorer outcomes from kidney disease have been shown among Indigenous and non-Indigenous people living in rural areas or more distant from nephrology services.[1–5] Residents of rural areas are often of low socioeconomic status, which is also associated with poorer outcomes.[6–8]

Nephrology care is critical to improve outcomes; however, disadvantaged groups may not access care or may experience poorer quality of care. Canadian data have shown that people with chronic kidney disease (CKD) in rural areas are less likely to see a nephrologist, and that those with diabetes are less likely to have an HbA1c or urine albumin measured or to receive an angiotensin-converting enzyme inhibitor or a receptor blocker.[5] Hemodialysis patients more distant from a nephrologist are less likely to have seen a nephrologist within 90 days and have poorer Kt/V and suboptimal phosphate control.[9] Aboriginal Australians are less likely to be waitlisted or to undergo kidney transplantation once undergoing dialysis[10] and have poorer transplantation outcomes, especially in rural areas.[3]

Telemedicine (or telehealth), including the modalities of Web-based applications, videoconferencing, and remote monitoring devices, has been proposed to improve healthcare access and outcomes for rural populations with kidney disease.[11] In Australia, telehealth videoconferencing (TVC) between a medical practitioner and patient has become a standard of care, supported by Medicare reimbursement for the provider.[12] However, the uptake of TVC for management of kidney transplant recipients (KTRs) has been

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Received 26 October 2020; revised 17 January 2021; accepted 8 February 2021; published online 26 February 2021

lagging,[13] and reports of outcomes of care are limited.[14,15] Telehealth videoconferencing has been more widely reported among the CKD population, including in observational studies[16–18] and a randomized controlled trial,[19] all suggesting improved patient access and clinical outcomes comparable to those of standard care. A systematic review of telemedicine for blood pressure control in nondialysis CKD found only 3 studies with no difference compared to standard care.[20]

Studies of telemedicine typically report positive or neutral findings, are of relatively short duration,[21] or report patient satisfaction.[22] We aimed to examine the feasibility, sustainability, and clinical outcomes of TVC for chronic care of KTRs and CKD patients in a case-matched observational cohort study.

MATERALS AND METHODS

We performed a case-controlled longitudinal observational cohort study, with each participant of a matched pair having nephrology care by telemedicine or standard care with 2 years' follow-up. Case matching (1:1) was for transplant or CKD status, age, and sex. Inclusion criteria for the telemedicine arm were ≥18 years of age and living at least 15 km from the specialized clinic or in an aged care facility (to comply with Medicare telehealth payment requirements). Exclusion criteria included requiring dialysis, poor compliance (i.e., a history of regular nonattendance at outpatient appointments), cognitive impairment (documented in the medical record), life expectancy <1 year, requirement of an interpreter, nephrologist discretion (i.e., where the nephrologist was of the opinion that face-to-face appointments were essential for patient care), inability to access or use a computer, and inability to measure blood pressure or weight or to obtain pathology results prior to the appointment. The control arm had the same inclusion and exclusion criteria except for the requirement to live >15 km from the specialized clinic.

Participants were recruited opportunistically from a single tertiary hospital outpatient clinic that serviced an area of 10,000 km^2 (3900 square miles). The recruitment target for this pilot study was 30 in each arm, divided between KTRs and nondialysis CKD patients. Recruitment commenced on 15 May 2015 and was completed on 17 May 2016, with the last follow-up on 7 June 2018 All participants were followed for 2 years unless they withdrew from the study, died, started hemodialysis, or were lost to follow-up.

The TVC was delivered with the nephrologist at the tertiary hospital clinic and the patient either in their own home or at the health facility nearest to their residence. The hospital telehealth service assisted staff and patients to establish telehealth capability. Staff used a desktop computer with specific telehealth software and linked to the patient in the virtual waiting room using a dial code. The patient could choose where to receive TVC. If it was conducted to the patient's home, the telehealth service assisted the patient with initial software set-up on their desktop computer, tablet, or smartphone, and a dial-up code was provided prior to each appointment. If the patient preferred, they could attend a telehealth clinic at their nearest healthcare facility, where a nurse measured blood pressure, noted other observations, and facilitated the TVC. The telemedicine group aimed to receive up to 75% of consultations by TVC, with the remainder delivered by standard face-to-face care, whereas the control group received only face-to-face consultations.

The primary outcome of the study was feasibility of telemedicine, defined as at least 50% of consultations for each individual patient in the telemedicine group being conducted by TVC in the first year. This measure was chosen pragmatically, prior to study commencement, as a target that would justify establishing TVC capabilities at patients' homes or local health care facilities. Secondary outcomes were sustainability of telemedicine (defined as percentage consultations for each individual patient in the telemedicine arm being conducted by TVC in year 2); change in blood pressure, serum creatinine, and estimated glomerular filtration rate (eGFR) at 1 and 2 years; hospitalizations; and travel distance.

The study was approved by The Prince Charles Hospital Human Research Ethics Committee (HREC/14/QPCH/250) and local governance. It was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12614001237673). All participants provided written informed consent.

Data Collection

Baseline data for participants in both the telemedicine and control groups were collected at the enrollment visit. This included both demographic (age, sex, race, marital status, first language, education level, family income, occupation, home Internet access, computer at home, home address) as well as health-related data (comorbidities, smoking status, medications, serum creatinine, total cholesterol, blood pressure, height, and weight). Participants were asked "Out of 10, how would you rate your entire experience with all staff and services at the Sunshine Coast Hospital and Health Service Renal Unit?" and scored from 0 to 10 on a visual analogue scale at baseline, month 12, and month 24.

Follow-up data were collected by telephone or in person every 6 months for a total of 2 years from

enrollment. Pathology results were either those taken at the face-to-face appointment or those closest to the time of the telemedicine appointment and the 6-monthly dataset. Pathology was from either the hospital laboratory or a private laboratory as part of the patients' routine medical assessment. Blood pressure for the TVC group was as provided by the participant or as recorded during a face-to-face visit at the relevant time point.

Travel Distance

Travel distance used the patients' home address as collected with baseline data. Travel distance (in kilometers) to each appointment was calculated using Google Maps. For those patients having standard care (or a face-to-face appointment when in the telemedicine group), travel was from home to the tertiary hospital clinic. For those having TVC, travel distance was either 0 km, if staying at home, or was calculated to the nearest health facility that they attended with TVC facilities. Travel distance to the tertiary hospital clinic was used as the comparator for the telemedicine group.

Hospitalization

Overnight hospitalizations were recorded throughout the study for each subject. Hospitalizations were identified by hospital record review and by asking the participants at each 6-month study visit. The hospitalization rate was calculated by dividing the number of days in the hospital by the number of days that each subject was in the study and multiplied by 100 to give a rate per 100 at-risk days.

Data Analysis

Data analyses were performed using STATA SE 16.1 (Statcorp LLC, College Station, TX), and figures were produced with GraphPad Prism version 8.4.2 for Windows, GraphPad Software, La Jolla, CA. Normality plots and histograms were used for evaluating normality of data. For baseline data with non-parametric distribution, Mann–Whitney U test was used to compare telemedicine and standard care groups. For baseline data with normal distribution, t tests were used. Complete data was available for the primary outcome which was assessed using Wilcoxon signed rank test. Other secondary outcomes were analyzed using the Mann–Whitney U test or Wilcoxon signed rank test for unpaired and paired data, respectively. Subgroup analysis for CKD and transplant groups were conducted for feasibility, blood pressure, creatinine, and glomerular filtration rate. A 2-tailed P value of <0.05 was considered significant. Data are expressed as mean ± standard deviation or as median (interquartile range) unless otherwise stated.

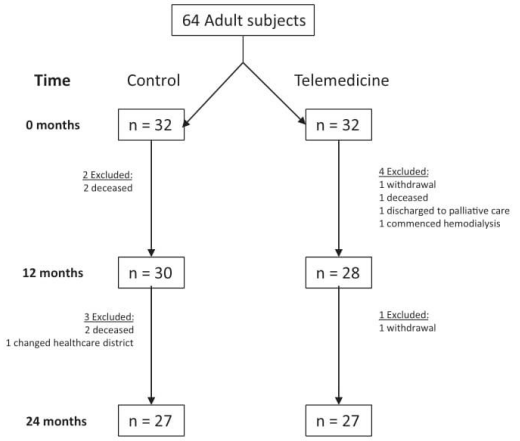

Figure 1. Study flow chart describing subjects excluded from study at 12 and 24 months.

RESULTS

A total of 64 subjects were included, 32 each in both the telemedicine and control arms, evenly divided in each group between KTRs and CKD patients. After 1 year, 28 patients were available for analysis in the telemedicine arm and 30 in the standard care arm (Figure 1). After 2 years, there were 27 participants in each group. Throughout the study, there were 4 deaths and 1 patient lost to follow-up in the control group, and 2 withdrawals of consent and 1 each of death, transfer to palliative care, and commencement of hemodialysis in the telemedicine group.

At baseline, the mean age was 64.4 ± 12.0 years and 63.4 ± 12.7 years ($P = 0.74$) for the control and telemedicine subjects, respectively (Table 1). The majority of subjects were male (65.6%), and there were no significant differences between groups for primary renal disease, comorbidity status, smoking status, medication use, or income. There were also no significant differences between groups in serum creatinine, estimated glomerular filtration rate (eGFR), blood pressure, cholesterol, or satisfaction with care.

Baseline characteristics of KTRs and CKD patients allocated to the telemedicine and control arms were also not statistically different (Supplementary Table S1).

Feasibility

Uptake of TVC for consultations by each participant in the first year among the telemedicine group was 71% (IQR = 50.0–100.0) (Figure 2a), meeting the prespecified definition of feasibility. Telemedicine was sustainable, although patient uptake was lower in year 2 compared with year 1 (50% [IQR = 33.3–71.4] vs. 71% [IQR 50.0–100]; $P < 0.01$), respectively. Both

Table 1. Baseline characteristics of study population

	Control (n = 32)		Telemedicine (n = 32)		*P* value
Age, yr mean (SD)	64.41	12	63.37	12.74	0.74
Female sex, (%)	11	34.40%	11	34.40%	1.00
Transplant, (%)	16	50.00%	16	50.00%	1.00
Caucasian race, (%)	32	100%	32	100%	1.00
Primary renal disease					0.07
Diabetes	9	28.1%	2	6.3%	
Hypertension	2	6.3%	4	12.5%	
Vascular	2	6.3%	5	15.6%	
Glomerulonephritis	6	18.8%	13	40.6%	
Cystic disease	2	6.3%	1	3.1%	
Other	11	34.4%	7	21.9%	
Time since transplantation, yr [IQR]	4.74	[2.39– 9.47]	0.95	[0.57– 5.54]	0.13
Smoking status[a]					0.59
Current/former	17	53.1%	18	56.3%	
Never	15	46.9%	12	37.5%	
Comorbidities					
Diabetes	13	40.6%	10	31.3%	0.43
Peripheral vascular disease	3	9.4%	1	3.1%	0.30
Ischemic heart disease	6	18.8%	4	12.5%	0.49
Medication use					
ACEi or ARB	22	68.8%	22	68.8%	1.00
Loop diuretic	7	21.9%	7	21.9%	1.00
β-Blocker or CCB	16	50.0%	12	37.5%	0.31
Corticosteroid	15	46.9%	18	56.3%	0.45
Azathioprine	1	3.1%	1	3.1%	1.00
Mycophenolate	13	40.6%	16	50.0%	0.45
Tacrolimus or cyclosporin	13	40.6%	13	40.6%	1.00
Sirolimus or everolimus	2	6.3%	2	6.3%	1.00
Household characteristics					
Home computer (%)[b]	27	84.4%	26	81.3%	0.53
Home Internet (%)[b]	28	87.5%	25	78.1%	0.19
Income (AUD)					0.69
< $30k	17	53.1%	12	37.5%	
$30k to $60k	8	25.0%	9	28.1%	
$60k to $100k	3	9.4%	3	9.4%	
> $100k	1	3.1%	2	6.3%	
Declined to answer	3	9.4%	6	18.8%	
Employment status					
Retired	23	71.9%	19	59.4%	0.26
Occupation unknown	2	6.3%	2	6.3%	
Metabolic parameters					
Creatinine, μmol/l [IQR]	155.5	[108.5–215]	129	[94–185]	0.49
eGFR, ml/min per 1.73 m^2 [IQR]	37	[23–58]	50	[26–60.50]	0.46
Systolic BP, mm Hg (SD)	132.4	16.3	134.9	15.2	0.53
Diastolic BP, mm Hg (SD)	75.1	11.3	77.8	8.5	0.29
Cholesterol, mmol/l [IQR]	4.05	[3.5–4.85]	4.75	[3.85–5.5]	0.19
BMI, kg/m^2 [IQR]	28.93	[24.5–35.3]	28.11	[25.3–30.8]	0.65
HbA1c, %[c] [IQR]	7.1	[5.9–8.2]	6.55	[6.1–7.8]	0.78
Satisfaction, Likert scale score 0–10 [IQR]	10	[10–10]	10	[10–10]	0.15

Data are presented as n (%), mean (standard deviation), or median [interquartile range].
ACEi, angiotensin-converting enzyme inhibitor; ARB, angiotensin receptor blocker; AUD, Australian dollars; BMI, body mass index; BP, blood pressure; CCB, calcium channel blocker; eGFR, estimated glomerular filtration rate.
[a]Two absent in telemedicine group.
[b]One absent in control group.
[c]Includes only diabetic patients (control, n = 13; telemedicine, n = 10),

CKD and KTR subgroups had significant reductions in telemedicine uptake in year 2 compared with year 1 (Figure 2b), 57% (IQR = 50.0−80.0) vs. 100% (IQR = 62.5−100.0), $P < 0.05$ and 45.0% (IQR = 0.0−63.0) vs. 61.1% (IQR = 35.4−93.8), $P < 0.05$, respectively. The broad interquartile ranges show significant variability in uptake of TVC at the patient level. Over the 2 years of the study, 177 TVC consultations were conducted,

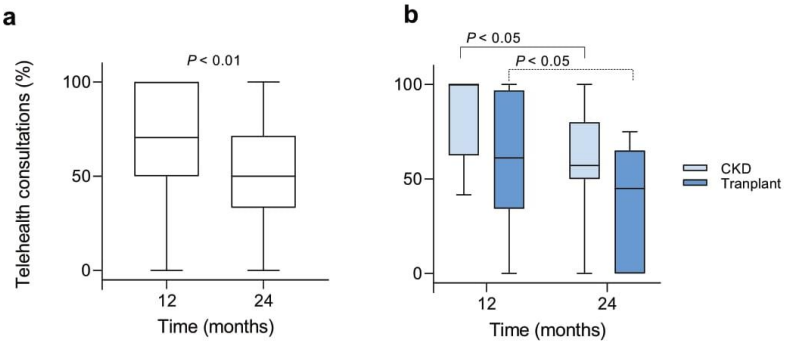

Figure 2. Individual uptake of telemedicine per year. (a) Telemedicine consultations are shown as a percentage of total consultations for each patient at 12 months and 24 months in the telemedicine arm. (b) Subgroup analysis of chronic kidney disease (CKD) patients and kidney transplant recipients. Data expressed as median and interquartile range.

comprising 48.6% of total consultations in the telemedicine arm.

Secondary Outcomes

Change in creatinine, eGFR, and systolic/diastolic blood pressure for each group was expressed as percentage change from baseline at 12 and 24 months (Figure 3). No significant changes were measured at 1 and 2 years compared to baseline for the above parameters in either group, nor were there any differences between the control and telemedicine groups at 1 or 2 years (Supplementary Table S2). There were no graft failures in the transplant recipients in either group. Patient satisfaction with the care provided during the study was high throughout, measured at 10 (IQR = 9−10) and 10 (IQR = 10−10) at baseline for the standard care and telemedicine group, respectively, and 10 (IQR = 10−10) and 10 (10−10) at 2 years. There was no significant change in satisfaction over time in the KTR and CKD subgroup analysis (Supplementary Table S2).

At 24 months, the number of overnight days admitted to hospital per 100 at-risk days remained low in both the control and telemedicine groups 0 (IQR = 0−0.55) vs. 0 (IQR = 0−0.48) ($P > 0.05$), respectively.

Travel distance to the tertiary hospital outpatient clinic in the standard care group was significantly less than the telemedicine group (21.0 km [IQR = 12.6−32.9] vs. 65.4 km [IQR = 31.8−106.7], $P < 0.0001$). To investigate whether TVC had a significant reduction in distance traveled, the theoretical distance (the distance to travel to the outpatient clinic for a face-to-face appointment if telemedicine was unavailable) was calculated and compared to actual distance traveled. Travel distance in the TVC group reduced by 47.9% (16,644 km) in year 1 and 37.0% (8177 km) in year 2 (Figure 4).

DISCUSSION

We conducted a case-matched longitudinal observational cohort study of telemedicine compared with standard care including KTRs and CKD patients, and found that the intervention was feasible at 1 year. Furthermore, uptake of TVC in the telemedicine group remained at 50% of consultations in the second year, although it was lower than in the initial 12 months. Travel distance reduced significantly in the TVC group, and there were no between-group differences during follow-up for 2 years in kidney function, blood pressure, mortality, or hospitalization.

Studies of TVC are often brief and examine feasibility and satisfaction, without continuing follow-up for long enough to assess whether the initial enthusiasm for telemedicine wanes or whether relevant clinical outcomes are comparable. We have shown that feasibility of TVC persists beyond 1 year, albeit with lower uptake. It is possible this decrease in TVC may be due to both patient and clinician factors, including comfort with standard care, concerns with technology, failure to consider TVC as an option, and additional reasons to travel from home to the tertiary hospital area such as shopping, other appointments, or visiting family members. Nevertheless, 50% of consultations were with TVC in the second year of the study and reduced travel distance by 8177 km (37%).

There are limited studies of TVC for KTRs. In the United States, the Department of Veterans Affairs has reported that TVC resulted in reduced travel time for patients and reduced travel costs for both patients and healthcare providers.[14] An Australian group has reported on 263 clinical consultations delivered by TVC, saving significant travel distance for patients with resultant reductions in carbon dioxide emissions.[15] A small randomized controlled trial from Germany

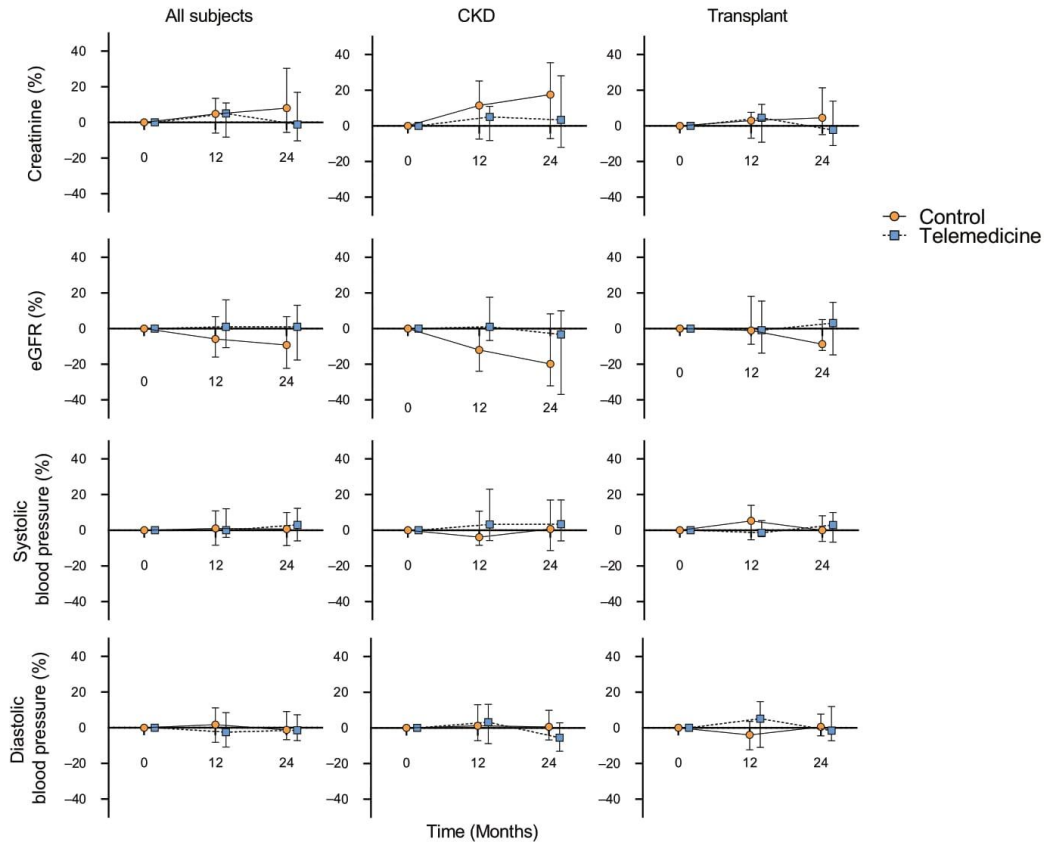

Figure 3. Change (%) in creatinine, estimated glomerular filtration rate (eGFR), and blood pressure over time. Percentage change in secondary outcomes at 12 and 24 months normalized to baseline. Data are expressed as median and interquartile range. CKD, chronic kidney disease.

comparing standard care with standard care plus case management and telemedicine found lower hospitalizations and less medication nonadherence.[23] Our study showing that TVC has clinical outcomes equivalent to those of standard care has expanded on the reported literature for management of KTRs by TVC; however, the results of larger studies[24,25] are needed to confirm our findings.

Our findings among the CKD population are similar to those of previous studies.[16,17] Interestingly, Ladino *et al.* found improved outcomes for blood pressure, although this was among an underserviced population compared with our study population, who were already accessing care.[18]

The experience of patients is important to consider. Overall patient satisfaction with the care provided was very high in both groups. The TVC was comparable to standard care, which may be due to an established relationship with the staff and the opportunity to have face-to-face consultations if desired. The extremely high satisfaction with care in both groups suggests that the question asked did not adequately explore the

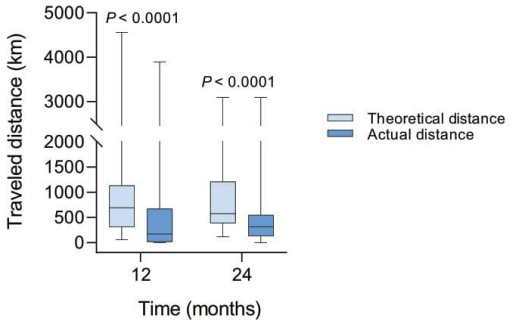

Figure 4. Travel distance in the telemedicine group. Theoretical (if telemedicine was not available) and actual distance traveled annually at 12 and 24 months in the telemedicine group. Data are expressed as median and interquartile range.

impact of TVC on patients. Future work should examine the ease of using the technology, adequacy of video and audio quality, perceived quality of care, and preference for TVC versus travel for face-to-face appointments.

We did not explore why patients may not access TVC when available. A study of transplant recipients from Belgium found that there was limited smartphone ownership but that 72% of patients owned a computer with Internet access. Several patient variables affected the willingness to use interactive health technology, including marital status and previous use of information and communications technology.[26] Patients may also identify the risks and barriers of TVC, such as cost of telehealth equipment, poor Internet access, loss of personal interaction with the multidisciplinary team, or concerns with data breach as reasons not to pursue TVC.[27]

The COVID-19 pandemic highlights another role for telemedicine, whereby patients can receive routine clinical care without attending a hospital clinic with the associated risks of infection.[28] Telemedicine was used in New York to deliver care to KTRs in response to COVID-19.[29] In Australia, COVID-19 prompted an expansion of the criteria for reimbursement for TVC. As a result, routine outpatient appointments were able to be undertaken by TVC as previously, but also by standard telephone call without any restrictions on distance to the treating practitioner.[30] It is likely that the ability to use a telephone will benefit patients with poor or no Internet access and those who are not technology literate, especially elderly and socioeconomically disadvantaged individuals, allowing them to access healthcare safely during a pandemic.

Reimbursement and regulation related to telehealth is central to its uptake and acceptance. In Australia, the Medicare Benefits Schedule details criteria that allow medical practitioners to claim reimbursement for TVC.[30] In the United States, there is a need to show cost-effectiveness or superior outcomes to allow reimbursement.[11] Furthermore, a number of specifications and legislative requirements are listed relevant to dialysis patients, including that only 2 of 3 monthly visits may be conducted via telehealth, and the provider must be registered in the state the patient resides.[27]

This study has several limitations. It was performed at a single Australian center in a Caucasian population, which limits the generalizability of the results. Pathology was not analyzed at a central laboratory, and blood pressure in the TVC group was measured either at the hospital clinic or was measured and reported by the participant at home, who may not have followed the standard protocol. The study is small, and larger studies are needed to confirm these findings, especially in the transplant population, in which important end points must include patient and graft survival, whereas among the CKD population, progression to kidney failure and mortality must be examined. Nevertheless, the study has strengths, including the 2-year follow-up and high retention rate.

In conclusion, in this study, telemedicine delivered as TVC was shown to be feasible and had outcomes similar to those of standard care for both KTRs and CKD patients. The slow uptake of telemedicine among the nephrology community, especially for KTRs, should be an area of attention so as to improve access to specialist care for patients who have difficulty attending clinics.

DISCLOSURE

All the authors declare no competing interests.

ACKNOWLEDGMENTS

This work was funded by the Sunshine Coast Hospital and Health Service Private Practice Trust Fund.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Table S1. Subgroup (CKD and KTRs) baseline characteristics

Table S2. Percentage change in secondary outcomes compared with baseline

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Supplementary Material

STROBE Statement—Checklist of items that should be included in reports of ***case-control studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3,4
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5,6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	6-9
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls	6
		(*b*) For matched studies, give matching criteria and the number of controls per case	6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9
		(*b*) Describe any methods used to examine subgroups and interactions	9
		(*c*) Explain how missing data were addressed	9
		(*d*) If applicable, explain how matching of cases and controls was addressed	6
		(*e*) Describe any sensitivity analyses	9
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9,10
		(b) Give reasons for non-participation at each stage	9,10
		(c) Consider use of a flow diagram	Fig 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of	Table

		interest	1, sup t 1&2
Outcome data	15*	Report numbers in each exposure category, or summary measures of exposure	9,10

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(*b*) Report category boundaries when continuous variables were categorized	Table 1
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10,11, Supp tbl 2
Discussion			
Key results	18	Summarise key results with reference to study objectives	11,12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13,14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

*Give information separately for cases and controls.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.

Supplementary Table 1 – Subgroup (CKD and KTRs) baseline characteristics

	CKD					KTRs				
	Control (n=16)		Telemedicine (n=16)		p-value[y]	Control (n=16)		Telemedicine (n=16)		p-value[z]
Age (years)	68.56	10.732	67.99	12.25	*0.89*	60.26	12.09	58.75	11.84	*0.7241*
Sex (% Female)	6	37.5	6	37.5	*1*	5	31.25	5	31.25	
Race: Caucasian	16	100%	16	100%	*1*	16	100%	16	100%	
Primary Renal Disease					*0.069*					*0.719*
Diabetes	8	50.00%	1	6.25%		1	6.25%	1	6.25%	
Hypertension	1	6.25%	2	12.50%		1	6.25%	2	12.50%	
Vascular	2	12.50%	4	25.00%		0	0.00%	1	6.25%	
Glomerulonephritis	2	12.50%	7	43.75%		4	25.00%	6	37.50%	
Cystic Disease	1	6.25%	0	0.00%		1	6.25%	1	6.25%	
Other	2	12.50%	2	12.50%		9	56.25%	5	31.25%	
Time Since Transplant (years)	n/a	n/a	n/a	n/a		4.74	[2.39; 9.47]	0.95	[.57; 5.54]	*0.128*
Smoking Status[ab]					*0.32*					*0.85*
Current/Former	9	56.25%	11	68.75%		8	50.00%	7	43.75%	
Never	7	43.75%	4	25.00%		8	50.00%	8	50.00%	
Co-morbidities										
Diabetes	10	62.50%	3	18.75%	*0.12*	3	18.75%	7	43.75%	*0.127*
Peripheral Vascular Disease	1	6.25%	0	0.00%	*0.31*	2	12.50%	1	6.25%	*0.544*
Ischemic Heart Disease	3	18.75%	1	6.25%	*0.285*	3	18.75%	3	18.75%	*1*
Medication Use										
ACEi OR ARB	13	81.25%	14	87.50%	*0.626*	9	56.25%	8	50.00%	*0.723*
Loop Diuretic	6	37.50%	5	31.25%	*0.71*	1	6.25%	2	12.50%	*0.544*
Betablocker or CCB	9	56.25%	4	25.00%	*0.072*	7	43.75%	8	50.00%	*0.723*
Corticosteroid	0	0.00%	3	18.75%	*0.069*	15	93.75%	15	93.75%	*1*
Azathioprine	0	0.00%	0	0.00%	*n/a*	1	6.25%	1	6.25%	*1*
Mycophenolate	0	0.00%	2	12.50%	*0.144*	13	81.25%	14	87.50%	*0.626*
Tacrolimus or cyclosporin	0	0.00%	0	0.00%	*n/a*	13	81.25%	13	81.25%	*1*
Sirolimus or everolimus	0	0.00%	0	0.00%	*n/a*	2	12.50%	2	12.50%	*1*
Household Characteristics										
Home Computer[c]	11	68.75%	11	68.75%	*0.779*	16	100.00%	15	93.75%	*0.31*
Home Internet[c]	12	75.00%	10	62.50%	*0.283*	16	100.00%	15	93.75%	*0.31*
Income (AUD)					*0.083*					*0.489*
< $30k	12	75.00%	6	37.50%		5	31.25%	6	37.50%	
$30k - $60k	2	12.50%	7	43.75%		6	37.50%	2	12.50%	
$60k - $100k	0	0.00%	0	0.00%		3	18.75%	3	18.75%	
> $100k	0	0.00%	0	0.00%		1	6.25%	2	12.50%	
Declined to answer	2	12.50%	3	18.75%		1	6.25%	3	18.75%	
Employment Status										

Retired	14	87.50%	12	75.00%	*0.283*	9	56.25%	7	43.75%	*0.464*
Occupation unknown	1	6.25%	1	6.25%		1	6.25%	1	6.25%	
Metabolic Parameters										
Creatinine (µmol/L)	171	[155.5;245]	179.5	[87.5;246.5]	*0.60*	114	[83;161.5]	119.5	[95;150.5]	*0.69*
eGFR (mL/min/1.73m2)	29	[18.5;39.5]	31.5	[19.5;60]	*0.37*	58	[34;77]	51.5	[40.5;66]	*0.60*
Systolic BP (mmHg)	133.1	17.3	136.9	19.4	*0.56*	131.8	15.8	132.9	9.6	*0.81*
Diastolic BP (mmHg)	73.07	8.61	75.9	8.75	*0.37*	77.13	13.5	79.63	8.12	*0.53*
Cholesterol (mmol/L)	3.75	[3.45;6.55]	5.05	[4;5.9]	*0.28*	4.2	[3.65;4.6]	4.4	[3.6;5.35]	*0.61*
Satisfaction (0-10)	10	[9;10]	10	[9;10]	*0.25*	10	[9;10]	10	[10;10]	*0.32*
BMI (kg/m2)	29.22	[24.12;37.70]	28.11	[26.2;31.51]	*0.85*	28.77	[24.57;31.35]	28.03	[24.66;29.97]	*0.68*

Data presented as N (%) or Mean (standard deviation) or Median (interquartile range). CKD = chronic kidney disease; KTRs = kidney transplant recipients; ACEi = Angiotensin converting enzyme inhibitor; ARB = Angiotensin receptor blocker; CCB = calcium channel blocker; eGFR = estimated glomerular filtration rate. a – 1 absent data in telemedicine CKD group; b – 1 absent data in telemedicine KTR group; c – 1 absent data in control CKD group. y - CKD Control vs CKD Telemedicine; z – KTR control vs TKR Telemedicine.

Supplementary Table 2 – Percentage change in secondary outcomes compared with baseline

	All					CKD					KTRs				
	Control (*n=27*)		Telemedicine (*n=27*)		P value[x]	Control (n=14)		Telemedicine (n=11)		p-value[y]	Control (n=13)		Telemedicine (n=16)		p-value[z]
Creatinine	%		%			%		%			%		%		
12 months	4.82	(-5.95-13.51)	5.02	(-8.19-10.97)	*0.57*	11.48	(-5.95-23.70)	5.02	(-8.19-10.97)	*0.32*	2.94	(-4.53-4.82)	4.53	(-8.57-11.36)	*0.66*
24 months	8.00	(-5.52-30.39)	-1.11	(-10.27-16.85)	*0.40*	17.57	(-5.52-33.42)	7.79	(-5.86-50.53)	*0.91*	4.53	(-3.61-12.30)	-2.28	(-10.78-11.39)	*0.33*
eGFR															
12 months	-5.77	(-15.94-4.35)	1.06	(-10.71-16.13)	*0.12*	-11.93	(-22.22--2.44)	1.06	(-6.67-17.65)	*0.071*	-2.94	(-11.86-4.35)	-0.88	(-12.71-14.80)	*0.78*
24 months	-9.17	(-22.22-6.67)	1.00	(-17.65-13.10)	*0.23*	-19.83	(-30.77-6.67)	-3.33	(-36.84-10.00)	*0.70*	-8.70	(-11.11-3.33)	3.09	(-12.41-14.24)	*0.33*
Systolic Blood Pressure															
12 months	1.00	(-8.21-10.83)[a]	0.00	(-3.60-8.20)[b]	*0.81*	-3.91	(-8.21-10.61)[a]	3.29	(-4.29-17.78)[a]	*0.42*	5.30	(-0.78-10.95)	-1.36	(-3.60-5.38)[a]	*0.41*
24 months	0.74	(-8.59-9.93)	3.05	(-5.92-12.31)	*0.51*	0.74	(-10.83-14.89)	3.38	(-5.92-17.04)	*0.44*	0.00	(-5.84-7.20)	2.97	(-6.01-9.46)	*0.79*
Diastolic Blood Pressure															
12 months	1.76	(-8.11-9.21)[a]	-2.44	(-9.76-7.41)[b]	*0.24*	1.19	(-6.15-9.21)[a]	3.23	(-7.81-11.36)[a]	*0.85*	5.13	(-9.88-6.33)	-3.95	(-12.36-3.66)[a]	*0.19*
24 months	-1.19	(-6.74-9.09)	-1.39	(-7.23-7.32)	*0.60*	0.64	(-6.74-9.09)	-5.48	(-13.04-2.90)	*0.27*	-1.54	(-6.74-9.09)	0.56	(-4.02-7.59)	*0.86*
Satisfaction															
12 months	0.00	(0.00-0.00)[c]	0.00	(0.00-0.00)[d]	*0.75*	0.00	(0.00-11.11)[h]	0.00	(0.00-0.00)[g]	*0.47*	0.00	(0.00-0.00)[b]	0.00	(0.00-0.00)[j]	*0.56*
24 months	0.00	(0.00-0.00)[e]	0.00	(0.00-0.00)[d]	*0.17*	0.00	(0.00-11.11)[h]	0.00	(0.00-0.00)[g]	*0.43*	0.00	(0.00-0.00)[j]	0.00	(0.00-0.00)[j]	*0.22*
BMI															
12 months	0.00	(-2.64-2.31)[a]	0.34	(-2.57-3.85)[f]	*0.76*	0.26	(-0.83-1.85)[a]	-0.74	(-5.16-2.28)[a]	*0.54*	-0.29	(-2.90-2.41)	1.39	(-2.08-3.91)[h]	*0.36*
24 months	-0.66	(-4.18-2.00)	-0.57	(-2.15-4.23)	*0.40*	-1.63	(-3.14-2.00)	-0.97	(-4.48-3.90)	*0.74*	0.40	(-4.18-1.79)	0.88	(-1.84-4.41)	*0.46*
Cholesterol															
12 months	-1.56	(-11.43-13.51)	2.41	(-7.48-14.33)[f]	*0.45*	-4.53	(-11.90-13.51)	2.44	(-6.45-16.67)	*0.27*	2.38	(-5.71-12.20)	2.38	(-8.51-13.04)[f]	*0.88*
24 months	-4.76	(-13.95-11.90)	4.88	(-9.43-23.91)[g]	*0.13*	-3.77	(-12.90-3.03)	5.56	(-8.93-12.82)[a]	*0.29*	-5.00	(-13.95-13.51)	4.76	(-9.43-23.91)[f]	*0.24*

Percentage change in secondary outcomes normalised to baseline at 1 and 2 years. Data presented as N (%) or Mean (standard deviation) or Median (interquartile range). a – 1 absent data; b – 2 absent data; c – 7 absent data; d – 10 absent data; e – 11 absent data; f – 3 absent data; g – 4 absent data; h – 5 absent data; I – 6 absent data. x – control vs telemedicine (all subjects); y – CKD Control vs CKD Telemedicine; z – KTR Control vs KTR Telemedicine. Note that due to the small sample size in the subgroup analysis, changes in HbA1c were unable to be tested – however there was no significant difference between Control and Telemedicine groups at year 2 (data not shown).

CHAPTER 3: CKD, SOCIOECONOMIC STATUS AND QUALITY OF CARE

3.1 Dialysis in public and private hospitals in Queensland

Gray NA, Dent H, McDonald SP

Intern Med J 2012; 42(8): 887-893

DOI: 10.1111/j.1445-5994.2012.02795.x

Journal Impact Factor 1.823 in 2012. 1.8 in 2023. 11 citations and FWCI of 0.28 (27/3/25)

Co-Authorship statement: H Dent assisted with statistics. S McDonald provided guidance and senior oversight. I conceptualised and designed the study, analysed and interpreted the data, and wrote the manuscript.

Original contribution to literature: Comparison of private hospital dialysis patient characteristics and outcomes with public hospital patients.

INTERNAL MEDICINE JOURNAL

Dialysis in public and private hospitals in Queensland

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Key words
dialysis, hospital, private, public, Queensland.

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Received 1 December 2011; accepted 25 March 2012.

doi:10.1111/j.1445-5994.2012.02795.x

Abstract

Background: Clinical outcomes for patients treated in public and private hospitals may be different.
Aim: The aim of the study was to compare the characteristics and outcomes of patients receiving dialysis at public and private hospitals in Queensland.
Methods: Incident adult dialysis patients in Queensland registered with the Australia and New Zealand Dialysis and Transplant Registry between 1999 and 2009 were classified by dialysis modality at either a public or private hospital. Outcomes were dialysis patient characteristics and survival.
Results: Three thousand, three hundred and ten patients commenced dialysis in public hospitals, 1939 haemodialysis (HD) and 1371 peritoneal dialysis (PD). Seven hundred and ninety-three patients commenced dialysis in private hospitals, 757 HD and 36 PD. Compared with public HD, private HD patients were older, had more coronary artery disease and less diabetes, and were more likely to live in an urban area. Public HD patients were more likely to be obese and referred late to a nephrologist. Nearly all indigenous patients were managed in public hospitals. Private patients were more likely to have an arteriovenous fistula or graft at first HD ($P < 0.001$) but not after excluding late referrals ($P = 0.09$). Public hospitals provided longer HD sessions and more HD hours per week for all age groups except 75+ years. Compared with public hospital HD, patient survival adjusted for multiple variables was comparable for private hospital HD (hazard ratio 1.20 (95% confidence interval 0.98–1.46, $P = 0.07$)) but worse for public PD (hazard ratio 1.14 (95% confidence interval 1.05–1.24, $P = 0.002$)).
Conclusion: Private HD patients are older and less likely to be diabetic than public patients. Patient survival is worse for public PD than public HD.

Introduction

The Australian Health Care System is broadly divided into a public hospital sector funded by government and a private hospital sector funded by individuals, mainly through health insurance. While there are many similarities between the systems, there are also differences. Comparison of the two systems was recently completed by the Australian Government Productivity Commission.[1]

There have been some publications comparing clinical outcomes for patients treated in public and private hospitals. Rates of obstetric interventions are lower in public hospitals,[2] but perineal injury and newborn outcomes are better in private hospitals.[3] Survival from colorectal cancer is better for patients in the private sector.[4] Public hospital patients are less likely to have coronary angiography or revascularisation following acute myocardial infarction.[5] There are no publications comparing dialysis in public and private hospitals in Australia.

Dialysis is provided in both sectors of the health system and comprises 34.82% of same day admissions in the public sector and 8.29% in the private sector.[1] However, unlike public hospitals that generally provide all modalities of dialysis including home-based therapies, such as home haemodialysis (HHD) and peritoneal dialysis (PD), the private sector mainly provides facility-based haemodialysis (HD). In the past, a small number of patients was funded by the Department of Veteran's Affairs for PD in private hospitals. Funding is different between sectors with public facilities generally having a set budget or some form of activity-based funding, whereas private facilities are reimbursed on a per-treatment basis. The aim of this study was to compare public and private hospital dialysis patient characteristics and survival outcomes.

Funding: None.
Conflict of interest: None.

Methods

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collect data on all patients receiving renal replacement therapy in Australia and New Zealand. This study included all adult patients registered with ANZDATA who commenced dialysis in Queensland between 1 January 1999 and 31 December 2009. Data on the treating hospital and treating nephrologist were used to categorise patients as undergoing dialysis at a public or private hospital. Patients were classified by dialysis modality at day 90 of treatment as hospital or satellite HD (ICHD), HHD, or PD (including continuous ambulatory PD and automated PD).

Patient characteristics at commencement of dialysis among the ICHD and PD groups in the public and private setting were compared. Comparisons were made using the chi-squared or Fisher's exact test, as appropriate, for categorical variables and the median test for continuous, non-normally distributed variables. The frequency of comorbid conditions among these groups was compared using logistic regression, including adjustment for age. Patient survival was compared using Cox regression analysis, including adjustment for age, gender, body mass index, smoking status, late referral, coronary artery disease, diabetes, lung disease, cerebrovascular disease, peripheral vascular disease, primary renal disease, indigenous status and remote area index. Proportional hazards assumptions were checked by Schoenfeld residuals and scaled Schoenfeld residuals examined by formal hypothesis test and graphically. At the end of the study period, patient measures of dialysis effectiveness, and frequency and length of dialysis periods were compared among the ICHD, HHD and PD groups in the public and private setting. All analysis was carried out using Stata 11.0 (StataCorp, College Station, TX, USA). This study has been approved by a human research ethics committee.

Results

Baseline characteristics

During the study period, 3310 patients commenced dialysis in public hospitals and 793 in private hospitals. Treatment at commencement of dialysis occurred at 14 public HD centres, 8 private HD centres, 13 public PD centres and 6 private PD centres. Of the public hospital patients at day 90 of treatment, 1939 were on ICHD, 1371 PD and 0 HHD (no patients were recorded as being established on HHD by day 90 of treatment and are included in the ICHD numbers). Of the private hospital patients at day 90 of treatment, 757 were on ICHD and 36 PD.

Patient characteristics at commencement of dialysis are shown in Table 1. Public patients were younger, less likely to have coronary artery disease or a functioning arteriovenous fistula (AVF)/graft at commencement of HD, but more likely to be of indigenous background, and be a current smoker. Public hospital patients were more likely to have diabetes. Obesity was most prevalent among the public HD group. Estimated glomerular filtration rate (eGFR) was lower at dialysis start in public patients. Patients living in outer regional or remote/very remote regions of Queensland were nearly all treated in public hospitals, reflecting the absence of private dialysis facilities in these areas. The majority of private patients lived in a major city or inner regional area, corresponding to Brisbane or the Gold Coast.

Table 2 shows the primary renal disease for public and private hospital patients. Public patients were more likely to have diabetes and glomerulonephritis but less likely to have a vascular cause for end-stage kidney disease (ESKD).

Table 3 shows characteristics for patients on dialysis and alive at the end of the study period. Haemoglobin, phosphate and calcium phosphate products were not different among groups. Serum calcium was lower in public HD and PD but not HHD compared with private HD. Most patients having ICHD in either system undertook HD thrice weekly or less, whereas public HHD patients undertook more frequent dialysis. Table 4 shows total weekly HD hours by age group at study end. Public hospitals provided longer HD sessions for all age groups, except 75+ years (data not shown), and more HD hours per week for all age groups, except 75+ years. HHD patients mainly had 15 or more hours/week of HD.

Patient survival

There were 1716 deaths during the study period, including 737 public HD patients, 386 private HD, 569 public PD and 24 private PD. Cause of death was different between groups (Table 5), with withdrawal from treatment being most prevalent among the private HD group. Cardiac causes were more common among the PD groups. Compared with public HD, unadjusted survival was worse in private HD with a hazard ratio of 1.57 (95% confidence interval (CI) 1.33–1.85, $P < 0.001$) and private PD with a hazard ratio of 1.58 (95% CI 1.33–1.89, $P < 0.001$) but not significantly different in public PD with hazard ratio 1.14 (95% CI 0.98–1.32, $P = 0.08$)

After adjusting for confounders, compared with public HD, the hazard ratio for death in private HD was 1.20 (95% CI 0.98–1.46, $P = 0.074$), public PD 1.14 (95% CI 1.05–1.24, $P = 0.002$) and private PD 0.96 (95% CI 0.78–

Table 1 Patient characteristics at dialysis start

Characteristic	Public HD	Private HD	Public PD	Private PD	*P*-value
Number	1939	757	1371	36	
Male (%)	59.9	60.6	53.5	66.7	0.001
Age (years) at first dialysis (median ± IQR)	60.2 (48.5–71.4)	74.8 (63.4–80.9)	60.6 (47.1–70.6)	78.0 (67.8–81.0)	<0.001
Indigenous (%)	20.5	0.5	16.6	0	<0.001
BMI (kg/m^2)					
Underweight (<18.5)	3.3%	3.6%	5.7%	0	<0.001
Normal (18.5–24.9)	34.5%	39.6%	37.9%	27.8%	
Overweight (25–29.9)	29.8%	33.6%	31.5%	50.0%	
Obese (30+)	32.4%	23.3%	24.9%	22.2%	
Current smoker (%)	13.9	4.6	13.1	5.6	<0.001
Region (RAI)					
Major city	49.1%	86.0%	53.1%	83.3%	<0.001
Inner regional	24.6%	13.2%	16.1%	11.1%	
Outer regional	22.0%	0.7%	23.7%	5.6%	
Remote/very remote	4.3%	0.1%	7.2%	0	
Chronic lung disease (%)	14.8	15.6	13.4	30.6	0.021
Coronary artery disease (%)	39.9	49.3	34.1	55.6	<0.001
Cerebrovascular disease (%)	13.7	15.2	12.1	22.2	0.089
Peripheral vascular disease (%)	27.2	30.5	22.2	19.4	<0.001
Diabetes (%)	44.8	27.9	38.0	33.3	<0.001
Late referral (%)	29.9	22.3	22.0	16.7	<0.001
eGFR at start mL/min (median ± IQR)	6.8 (5.0–9.2)	8.4 (6.3–11.4)	7.0 (5.2–9.3)	7.3 (5.0–9.9)	<0.001
AVF/AVG at first HD (%)	39.2	49.1	—	—	<0.001
AVF/AVG at first HD – late referral excluded (%)	51.6	56.7	—	—	0.087

AVF, arteriovenous fistula; AVG, arteriovenous graft; BMI, body mass index; eGFR, estimated glomerular filtration rate; HD, haemodialysis; IQR, interquartile range; PD, peritoneal dialysis; RAI, remote area index; —, not applicable to PD.

1.19, $P = 0.73$). Adjusted survival is shown in Figure 1. The power for detecting the observed difference between public HD and private HD was 68%. When looking at HD only, and including vascular access at first HD and HD hours/week in the Cox regression analysis, the hazard ratio for private HD was 1.16 (95% CI 0.94–1.43, $P = 0.18$) compared with public HD.

Discussion

This study has shown that public HD patients have better survival outcomes than public PD patients in Queensland. Private HD patients have very different characteristics to public HD and a trend towards poorer survival.

Why was survival for patients on public PD worse than public HD? Randomised trials comparing HD and PD have lacked statistical power,[6] suffered poor recruitment[7] or been pilot studies to test the feasibility of a large trail.[8] Several observational studies have been published, usually based on large databases. Bloembergen *et al.*[9] looked at the United States Renal Data System and found PD associated with a 19% higher all-cause mortality rate than HD. Our data show a high rate of diabetes in public hospital patients. Survival on PD has been reported to be

Table 2 Primary renal disease in public and private hospitals by dialysis type

Primary renal disease	Public HD	Private HD	Public PD	Private PD	*P*-value
Total	*n* = 1939	*n* = 757	*n* = 1371	*n* = 36	
Glomerulonephritis	20.5%	18.2%	22.8%	8.3%	<0.001
Vascular	12.3%	21.1%	12.3%	27.8%	
Cystic	6.8%	6.6%	7.4%	8.3%	
Reflux	5.1%	3.4%	5.5%	5.6%	
Diabetes	33.1%	17.2%	29.1%	19.4%	
Uncertain	7.8%	12.8%	9.1%	16.7%	
Other	14.3%	20.6%	13.9%	13.9%	

HD, haemodialysis; PD, peritoneal dialysis.

Table 3 Patient characteristics at 31/12/2009 (alive and receiving dialysis)

Characteristic	Public HD	Public HHD	Private HD	Public PD	Private PD	*P*-value
Number	851	154	263	338	3	
Haemoglobin (g/L) (median ± IQR)	115 (106–124)	116 (110–126)	117 (110–123)	114 (103–122)	114	0.109
Ferritin (mcg/L) (median ± IQR)	397 (208–663)	308 (131–569)	420 (174–655)	240 (123–472)	1978	<0.001
Transferrin saturation (%) (median ± IQR)	24 (17–33)	23 (16–29)	27 (21–36)	23 (18–31)	18	<0.001
Calcium (mmol/L) (median ± IQR)	2.23 (2.11–2.35)	2.34 (2.21–2.42)	2.33 (2.21–2.48)	2.24 (2.12–2.36)	1.09	<0.001
Phosphate (mmol/L) (median ± IQR)	1.60 (1.28–2.00)	1.63 (1.27–2.00)	1.58 (1.27–1.90)	1.63 (1.39–1.98)	1.1	0.199
Calcium phosphate product ($mmol^2/L^2$) (median ± IQR)	3.58 (2.84–4.41)	3.80 (2.89–4.60)	3.68 (2.88–4.45)	3.73 (3.02–4.46)	1.20	0.173
URR >70%	69.3%	62.2%	73.2%	—	—	0.153
HD ≤3×/week (%)	97.8	30.5	97.0	—	—	$P < 0.001$

Note: Because of small numbers in private PD, only the median value is recorded. HD, haemodialysis; HHD, home haemodialysis; IQR, interquartile range; PD, peritoneal dialysis; URR, urea reduction ratio; —, not applicable to PD.

worse than HD for patients with diabetes.[10] An analysis of ANZDATA examined survival based on dialysis modality at day 90 of treatment but also with an 'as treated' analysis. The authors found that PD treatment may be advantageous initially but may be associated with higher mortality than HD after 1 year.[11] PD was not separated into continuous ambulatory PD and automated PD for this study, as no differences in outcome have been found between these modalities.[12]

Potential advantages of home dialysis (PD and HHD) for patients include quality of life, flexible dialysis times and control of disease state. For healthcare providers, increasing PD rates has been shown to reduce dialysis costs.[13] A recent change to funding dialysis in Queensland public hospitals introduces a home dialysis target with penalties for not achieving the 50% benchmark. Australia has a high rate of home dialysis by international standards,[14] with more patients being treated with PD than HHD. Efforts to increase home dialysis may lead to limitation of patient choice, increased PD uptake by patients who are better suited to ICHD or leaving patients on PD longer than appropriate, changes that may result in increased adverse PD outcomes. Improved home dialysis support services may facilitate achieving higher PD and HHD uptake. Nephrologists need to be aware of the survival differences shown in

Table 4 HD hours/week by age group (alive and on HD at 31/12/09)

Age group	HD hours/week	Public HD ($n = 851$)	Public HHD ($n = 154$)	Private HD ($n = 263$)	*P*-value
All ages	<12	6.6%	0.7%	20.2%	<0.001
	12–13.4	29.5%	4.6%	50.2%	
	13.5–14.9	18.7%	5.2%	14.8%	
	15+	45.2%	89.6%	14.8%	
Age <55	<12	2.0%	0	27.3%	<0.001
	12–13.4	21.1%	1.1%	45.5%	
	13.5–14.9	14.2%	5.3%	4.6%	
	15+	62.7%	93.7%	22.7%	
Age 55–64	<12	6.2%	0	11.8%	<0.001
	12–13.4	23.9%	7.5%	52.9%	
	13.5–14.9	22.1%	5.0%	17.7%	
	15+	47.8%	87.5%	17.7%	
Age 65–74	<12	8.3%	5.9%	26.3%	<0.001
	12–13.4	36.1%	11.8%	40.8%	
	13.5–14.9	22.2%	5.9%	15.8%	
	15+	33.5%	76.5%	17.1%	
Age 75+	<12	15.6%	0	17.6%	0.538
	12–13.4	49.2%	50.0%	55.7%	
	13.5–14.9	18.0%	0	15.3%	
	15+	17.2%	50.0%	11.5%	

HD, haemodialysis; HHD, home haemodialysis.

Table 5 Cause of death in public and private hospitals by dialysis modality

Cause of death	Public HD	Private HD	Public PD	Private PD	*P*-value
Number	*n* = 737	*n* = 386	*n* = 569	*n* = 24	
Cardiac	34.9%	32.9%	39.5%	41.7%	<0.001
Vascular	8.7%	7.3%	9.1%	8.3%	
Malignancy	6.0%	7.3%	5.5%	0	
Infection	12.2%	6.2%	13.4%	12.5%	
Withdrawal	33.5%	43.5%	26.0%	33.3%	
Other	4.8%	2.9%	6.5%	4.2%	

HD, haemodialysis; PD, peritoneal dialysis.

this study and direct efforts in identifying and rectifying possible causes.

Private HD patients were older than public patients. Private health insurance for hospital treatment covered 40.1–42.6% of the Queensland population between 2000 and 2009 inclusive.[15] Examining private health insurance rates by age reveals that in those over age 45, the lowest private health insurance rate was in the 75+ group, the group most likely to have private HD. Therefore, private insurance status does not explain the age difference between public and private HD. This study has no data on how many patients treated in public hospitals were covered by private health insurance. It is possible that younger patients with private health insurance were diverted to public hospitals for HHD or PD (private health funds do not cover home dialysis therapies).

Diabetes was less common in private HD. This study cannot explain this finding, but it is possible that patients with longstanding chronic disease have been under the care of public hospitals for many years before commencement of dialysis, or may have become financially less well-off and forfeited membership of private health funds. Indigenous patients were underrepresented in private HD, reflecting the poor socioeconomic status of this group and the absence of private HD in regional and remote Queensland. Private HD patients were more likely to die as a result of withdrawal from dialysis than public HD patients. This was associated with patient age, as cause of death and dialysis withdrawal rates in patients aged 75+ were not different among groups.

There was a trend towards poorer survival for private HD compared with public HD. The public hospitals provided more hours of HD per week, except among the 75+ year old group. Dialysis Outcomes and Practice Patterns Study data have shown improved survival for HD of >240 min each treatment, with a 7% lower relative risk of mortality for every 30 min extra session length.[16] However, the Hemodialysis (HEMO) study did not show improved survival with a larger delivered dialysis dose, although the time on dialysis only increased from 190 ± 23 to 219 ± 23 min each session.[17] The reason for the shorter dialysis hours in private hospitals is unknown. Queensland Health, which manages the public hospitals, developed a Collaborative for Health Improvement from 2004 to 2007. This Collaborative allowed benchmarking of clinical key-performance indicators throughout the public hospital dialysis facilities and may have improved standards of care and possibly outcomes. A subanalysis of the HD data alone shows a reduction in the relative risk of private HD compared with public HD when including vascular access at first dialysis and dialysis hours per week in the multivariable model.

Whether the different methods of remuneration in public and private hospitals contribute to treatment differences is unknown. In private hospitals, health funds pay a set price per HD session to the hospital and medical staff are remunerated a fee for service. This structure may impact dialysis session duration, frequency, eGFR at dialysis start or commencing dialysis in patients with a perceived poor prognosis. While medical staff report that financial considerations are not among the main reasons

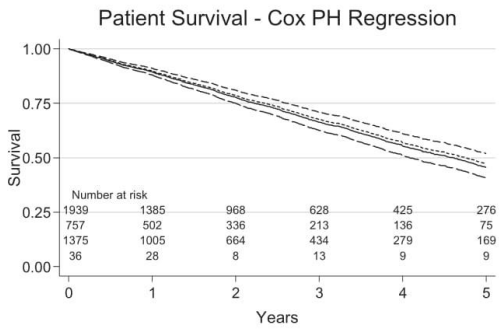

Figure 1 Adjusted patient survival in Queensland public and private hospitals by dialysis modality. Adjusted for age, gender, race, body mass index, smoking status, late referral, primary renal disease, comorbidities and region. Adjustment is to the mean value of all covariates. (– – –) Public HD, (——) private HD, (·····) public PD, (— –) private PD. HD, haemodialysis; PD, peritoneal dialysis.

for directing patients to a dialysis modality, the literature suggests that financial remuneration is the most important non-medical factor to guide modality selection.[18] This may result in patients who see a private physician being offered private HD as the only treatment modality, even if they are suitable for HHD or PD. On the other hand, these patients may choose private HD even if capable of performing home-based therapy to continue care with the same specialist. The Australian Government has attempted to encourage home dialysis by provision of a rebate to nephrologists, for services provided outside usual clinic appointments. The rebate commenced in November 2005, and data suggest large variations in uptake among states.[19] So far, there has been no change in home dialysis rates across Australia.[20]

The private hospitals performed well in a number of areas. The rate of commencement of HD with a functional AVF was higher in private, although the difference was not significant after correcting for late referral of patients. The main modifiable reason for a dialysis patient commencing HD without a functional fistula is failure of timely referral to a vascular surgeon by the treating nephrologist.[21] Perhaps, the structure of clinics in public hospitals impairs timely referral for vascular access creation.

This study has several limitations. This analysis was only performed for dialysis care in Queensland because of variations in practice across Australia. Private health insurance rates in Queensland are below the national average.[15] In Queensland, private HD facilities were easily identifiable, and patients receiving dialysis treatment in private hospitals generally undertake the majority of their care in private facilities. This is not the case elsewhere, and hence, there is uncertainty as to whether the results of this study can be extrapolated to the entire country. Second, ANZDATA does not collect information on individual dialysis prescriptions, the severity of comorbidities, medication usage, socioeconomic status or hospitalisation. Third, we adjusted for many patient characteristics, but it is possible that confounding remained. Fourth, ANZDATA does not record those who died from ESKD but did not undertake dialysis. Finally, mortality is not the sole reason for an individual to select a type of dialysis, and other factors may have been critical in decisions made, such as transport, location, time, quality of life, patient satisfaction, local expertise, funding, health insurance status and geography.

Conclusion

This observational registry analysis shows that treatment with HD in public hospitals in Queensland was associated with better patient survival than public PD. Private HD patient characteristics are different to public hospital patients. The reasons for these differences are unknown. Both systems should collaborate to improve health outcomes for dialysis patients whether treated publicly or privately. Patients should be offered dialysis modality choice regardless of public hospital funding model or health insurance status.

Acknowledgements

The authors gratefully acknowledge the contributions of the Australian and New Zealand nephrology community in providing information for and maintaining the ANZDATA database. The data reported here have been supplied by ANZDATA. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of ANZDATA.

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3.2 Low socio-economic status adversely effects dialysis survival in Australia

Krishnasamy R, Gray NA

Nephrology (Carlton) 2018; 23(5): 453-460

DOI: 10.1111/nep.13053

Journal Impact Factor 1.913 in 2018. 2.4 in 2023. 13 citations and FWCI of 0.98 (27/3/25)

Co-Authorship statement: R Krishnasamy assisted with the statistical analysis and manuscript review. I was responsible for study design, ethics, data interpretation, and writing the manuscript.

Original contribution to literature: Showed poorer dialysis survival among lower SES dialysis recipients in Australia, mainly among the youngest cohort.

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NEPHROLOGY

Nephrology **23** (2018) 453–460

Original Article

Low socio-economic status adversely effects dialysis survival in Australia

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KEY WORDS:
ANZDATA, dialysis, income, kidney, mortality, socio-economic status.

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Accepted for publication 29 March 2017.
Accepted manuscript online 6 April 2017.

doi: 10.1111/nep.13053

SUMMARY AT A GLANCE

The authors concluded that low socio-economic status has an adverse effect on dialysis patient survival despite universal healthcare in Australia by using Australia and New Zealand Dialysis and Transplant Registry who commenced dialysis between 2003 and 2013. This effect is mainly among younger patients where SES may have a greater proportional impact than co-morbidities.

ABSTRACT:

Aim: **Low socio-economic status (SES) is associated with increased incidence of end-stage kidney disease and in the USA, poorer dialysis survival. All Australians have access to a universal healthcare system.**

Methods: **The study included all non-indigenous adult Australians registered with the Australia and New Zealand Dialysis and Transplant Registry who commenced dialysis between 2003 and 2013. SES at dialysis start was classified into quartiles of advantaged through to disadvantaged using Australian Bureau of Statistics socio-economic indexes for areas. The primary outcome was survival assessed using a competing risk regression model with renal transplantation as a competing risk. There was a significant interaction between age and SES, and hence, age-stratified survival analyses were performed.**

Results: **A total 20 810 commenced dialysis during the study period. Mortality for the most advantaged quartile was 102.4/1000 person–years (95% confidence interval (CI) 98.0–106.9) compared with 110.7/1000 person–years (95% CI 105.8–115.7) in the disadvantaged quartile. In adjusted analysis, dialysis survival, compared with quartile 1 (advantaged), was inferior in quartile 3 (sub-hazard ratio 1.10, 95% CI 1.03–1.17) and the disadvantaged quartile (sub-hazard ratio 1.09, 85% CI 1.02–1.16) and was significantly modified by age. This disparity in survival outcome between the different SES quartiles was only observed in younger patients but was attenuated in the older ones following an age-stratified analysis.**

Conclusions: **In Australia, low SES has an adverse effect on dialysis patient survival despite universal healthcare. This effect is mainly among younger patients where SES may have a greater proportional impact than co-morbidities.**

Low socio-economic status (SES) has been associated with an increased incidence of renal replacement therapy in Australia,[1] the UK[2] and the USA.[3] SES also impacts dialysis modality selection with low compared with high SES patients more likely to undertake peritoneal dialysis in Australia,[4] but less likely in the UK[5,6] and USA.[7]

The association between SES and survival on dialysis is mixed with most reports from the USA. A study in the early 1990s among incident dialysis patients found increasing neighbourhood income was associated with reduced mortality.[8] Another study of patients initiating haemodialysis in the late 1990s showed no impact of income on survival.[9] Analysis from the US Renal Data System found low income was associated with 46% increased mortality among young African Americans compared with white dialysis patients. However, this risk was attenuated among patients of higher SES.[10] Another US Renal Data System study reported mortality was associated with low income for all patients as well as racial segregation among African Americans.[11] On the other hand, SES did not impact survival among Caucasians on dialysis in the UK,[6] and a Brazilian study found no effect of family income on mortality for peritoneal dialysis patients.[12]

The Australian health system is different to the USA, with all residents having access to a universal government-funded healthcare scheme. Many Australians also pay for private health insurance, which may improve access for elective

surgery and allow choice of doctor. Provision of dialysis is also different with a much greater uptake of peritoneal dialysis and home haemodialysis. Therefore, the aim of this study was to determine the impact of SES on all-cause mortality among non-indigenous dialysis patients in Australia.

METHODS

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects data on all people receiving renal replacement therapy, as supplied by their treating nephrologist or renal unit. This study included all non-indigenous Australian adults (age $\geq$ 18 years) who commenced haemodialysis or peritoneal dialysis for at least 90 days between 2003 and 2013. Patients were followed up until death or 31 December 2013. Forty-four patients without postcode data at entry were excluded. Indigenous adults (those who self-identify when asked their racial origin) were excluded because the recorded postcode at the commencement of renal replacement therapy may not reflect their usual place of residence.[13]

The Australian Bureau of Statistics (ABS) produces socio-economic indexes for areas based on the 2006 population census. We used the ABS-reported Index of Relative Socio-economic Advantage and Disadvantage to classify postcodes into quartiles from most advantaged to most disadvantaged. This index uses data on 21 measures such as income, occupation, education, car ownership, rent or mortgage payments, single-parent families, home crowding, disability below age 70 years and Internet access to classify postcodes by percentiles (Table S1).[14,15] To allow comparison with other studies and countries, low income includes a stated annual household equalized income between $13 000 and $20 799 (approximately the second and third deciles in 2006) whereas high income would be >$52 000 (approximately the 9th and 10th deciles).[14]

The ABS also produces a remoteness index using the Australian Standard Geographical Classification.[16] Remoteness is determined by the Accessibility/Remoteness Index of Australia based upon physical road distance from a location to the nearest urban centre of five different sizes. We used this to classify each patient's postcode at commencement of dialysis by remoteness as major city, inner regional, outer regional or remote/very remote.

The primary outcome measure was all-cause mortality after initiation of dialysis. Causes of death as reported to ANZDATA were categorized into cardiovascular, infection, malignancy, dialysis withdrawal and miscellaneous/other causes. This research was approved by The Prince Charles Hospital Human Research and Ethics Committee (HREC/15/QPCH/223).

Statistics

Results were expressed as frequencies and percentages for categorical variables and median (interquartile range) for continuous non-normally distributed variables. Baseline characteristics categorized by SES quartiles at commencement of dialysis were compared using chi-squared test for categorical data and Kruskal–Wallis test for continuous non-normally distributed data.

The primary survival analyses were assessed using competing risk regression model using Fine and Gray's proportional sub-hazards models with renal transplantation as a competing risk. Patients were censored at recovery of renal function, loss to follow-up and study end. Covariates with univariate $P < 0.2$ (age, race, body mass index, late referral (being referred to a nephrologist <3 months from start of dialysis), smoking status and co-morbidities (diabetes, chronic lung disease, ischaemic heart disease, peripheral vascular disease and cerebrovascular disease)) and gender were included in the model. Interactions between SES and all covariates were examined using two-tailed Wald test. Significant interaction was identified between age and SES, and hence, age-stratified survival analyses were further performed.

A sensitivity analysis using Cox proportional hazard models censoring for renal transplantation was performed. Proportional hazards assumptions were assessed graphically and by formal tests including Schoenfeld's test.

Data were analysed using STATA (version 13; StataCorp LP, College Station, Tx, USA). *P*-values less than 0.05 were considered statistically significant.

RESULTS

A total of 20 854 non-indigenous adults commenced dialysis for at least 90 days during the study period, of which 44 were excluded because of absent postcode data. Patient characteristics at commencement of dialysis stratified by SES quartile are shown in Table 1. Patient characteristics were significantly different by SES. When the disadvantaged quartile was compared with the advantaged quartile, obesity, peripheral vascular disease, ischaemic heart disease, diabetes, lung disease and smoking were found to be more common. Low SES patients were more likely to undertake peritoneal dialysis as initial modality and be resident outside a major city. There were no differences in the rate of late referral to a nephrologist or commencement of haemodialysis with an arteriovenous fistula or graft. High SES patients had higher rates of transplantation (21.1% advantaged, 20.2% second quartile, 18.5% third quartile and 17.3% disadvantaged; $P < 0.001$).

There were a total of 8313 (40%) deaths over a median patient follow-up of 3.0 (interquartile range 1.4–5.5) years. Overall mortality rate was 108.4/1000 person–years (95% confidence interval (CI) 106.1–110.8). The mortality rate for the most advantaged SES quartile was 102.4/1000 person–years (95% CI 98.1–106.9) compared with 110.7/1000 person–years (95% CI 105.8–115.7) for the disadvantaged quartile. The crude and adjusted association between all-cause

Table 1 Dialysis patient characteristics at commencement by socioeconomic status quartile

	Advantaged Quartile	Second Quartile	Third Quartile	Disadvantaged Quartile	p
Number	5398	5548	5032	4832	
Age quartiles (years)					<0.001
≤ 53(%)	25.2	26.5	25.9	27.0	
54-65(%)	24.2	25.9	26.1	27.0	
66-74(%)	23.8	23.5	24.4	26.2	
≥75 (%)	26.8	24.1	23.6	19.9	
Males (%)	63.4	61.7	63.3	61.4	0.07
Ethnicity					<0.001
Caucasian (%)	83.9	85.0	88.3	83.7	
Asian (%)	11.9	9.2	6.5	9.8	
Maori and Pacific Islander (%)	1.8	3.1	3.2	4.2	
Other (%)	2.2	2.5	2.0	2.2	
Remoteness					<0.001
Major cities (%)	95.3	79.6	58.9	52.9	
Inner regional (%)	3.8	14.8	27.7	29.1	
Outer regional (%)	0.65	4.8	11.9	15.9	
Remote/Very remote (%)	0.22	0.8	1.5	2.2	
BMI at entry (kg/m^2) (%)					<0.001
Underweight (<18.5)	3.9	3.0	3.2	2.6	
Normal (18.5-24.9)	38.0	32.5	32.2	31.5	
Overweight (25.0-30.0)	32.3	34.4	32.4	32.0	
Obese (>30)	25.8	30.1	32.2	34.0	
Primary Renal Disease					<0.001
Diabetes (%)	27.6	31.1	30.8	34.5	
Glomerulonephritis (%)	26.3	24.2	22.0	21.8	
Hypertension/vascular (%)	15.8	15.5	17.0	14.5	
Polycystic kidney disease (%)	7.7	6.1	6.5	6.3	
Reflux nephropathy (%)	2.2	2.7	2.9	2.8	
Analgesic nephropathy (%)	1.8	2.2	2.6	2.9	
Other/unknown (%)	18.7	18.2	18.4	17.4	
Creatinine at entry (umol/L) median (IQR)	610(472-800)	608(469-791)	610(475-802)	620(479-810)	0.03
Peripheral vascular disease (%)	16.8	19.8	19.7	20.4	<0.001
Cerebrovascular disease (%)	11.7	12.9	13.0	12.1	0.1
Ischaemic heart disease (%)	33.6	35.3	36.0	36.2	0.02
Diabetes (%)	37.6	42.0	42.9	46.4	<0.001
Chronic lung disease (%)	11.5	12.7	13.5	14.8	<0.001
Smoking history (%)	48.7	52.8	56.7	56.6	<0.001
History of malignancy (%)	24.0	24.3	25.4	23.7	0.2
Late referral (%)	21.4	22.5	22.8	23.5	0.07
Initial modality PD (%)	28.6	31.0	32.8	34.1	<0.001
AVF/AVG at first HD (%)	44.0	41.2	42.4	42.3	0.08

AVF, arteriovenous fistula; AVG, arteriovenous graft; BMI, body mass index; HD, haemodialysis; IQR, interquartile range; Late referral, referral to a nephrologist <90 days from commencement of dialysis; PD, peritoneal dialysis.

mortality and SES and other variables of interest following the competing risk of renal transplant is reported in Table 2. Compared with the most advantaged quartile, those in quartile 3 (sub-hazard ratio 1.10, 95% CI 1.03–1.17) and the most disadvantaged quartile (sub-hazard ratio 1.09, 95% CI 1.02–1.16) had an increased risk of death, although the sub-hazard ratio was much smaller than co-morbidities and age.

There was a significant interaction between the quartiles of SES and age ($P = 0.02$), so an age-stratified survival analysis was undertaken. Figure 1 shows the cumulative incidence of all-cause mortality by SES and stratified by age. In the youngest age quartile (age < 53 years), compared with the advantaged group, the sub-hazard ratio for death in a competing risk regression for transplant was 1.32 (95% CI 1.07–1.63) in quartile 3 and 1.31 (95% CI 1.06–1.61) for the most disadvantaged group (Table 3). This association was lost in older age groups. In the sensitivity analysis using Cox proportionate hazard model censoring for renal transplant, a similar trend of survival disparities among younger patients from lower SES quartiles compared with the advantaged group was observed but did not reach statistical significance (quartile 3: hazard ratio 1.22, 95% CI

Table 2 Univariable and Multivariable regression analysis for predictors of all-cause mortality after accounting for renal transplant as a competing risk

Variable	Unadjusted SHR (95% CI)	p value	Adjusted SHR (95% CI)	p value
SES				
Advantaged	1.00 (reference)		1.00 (reference)	
Quartile 2	1.05(0.99-1.11)	0.1	1.05(0.99-1.12)	0.1
Quartile 3	1.11(1.05-1.18)	<0.001	1.10(1.03-1.16)	0.003
Disadvantaged	1.08(1.02-1.15)	0.01	1.09(1.02-1.16)	0.007
Age(years)				
Quartile 1 (≤53)	1.00 (reference)		1.00 (reference)	
Quartile 2 (54-64)	2.75(2.52-2.99)	<0.001	2.38(2.19-2.59)	<0.001
Quartile 3 (65-74)	5.54(5.11-6.01)	<0.001	4.31(4.00-4.69)	<0.001
Quartile 4 (≥75)	8.56(7.91-9.27)	<0.001	6.58(6.05-7.17)	<0.001
Male	1.02 (0.97-1.06)	0.5	0.90 (0.86-0.95)	<0.001
Race				
Caucasian	1.00 (reference)		1.00 (reference)	
Asian	0.63(0.58-0.70)	<0.001	0.65(0.59-0.70)	<0.001
Maori and Pacific Islanders	0.66(0.56-0.76)	<0.001	0.94(0.81-1.09)	0.4
Others	0.49(0.39-0.59)	<0.001	0.63(0.51-0.77)	<0.001
BMI(kg/m^2)				
<18.5	1.22(1.08-1.38)	0.002	1.42(1.26-1.61)	<0.001
18.5-24.9	1.00 (reference)		1.00 (reference)	
25.0-30.0	0.95(0.90-1.00)	0.05	0.84(0.79-0.88)	<0.001
>30.0	0.88(0.84-0.93)	<0.001	0.81(0.76-0.86)	<0.001
Late referral	1.31(1.25-1.38)	<0.001	1.36(1.29-1.43)	<0.001
Diabetes	1.69(1.62-1.77)	<0.001	1.45(1.38-1.52)	<0.001
Chronic lung disease	2.05(1.94-2.17)	<0.001	1.34(1.27-1.43)	<0.001
Ischemic heart disease	2.53(2.42-2.64)	<0.001	1.41(1.34-1.48)	<0.001
Peripheral vascular disease	2.28(2.17-2.39)	<0.001	1.36(1.29-1.44)	<0.001
Cerebrovascular disease	2.11(2.00-2.23)	<0.001	1.26(1.22-1.37)	<0.001
Smoking history	1.28(1.22-1.33)	<0.001	1.09(1.04-1.14)	<0.001
Remoteness				
Major cities	1.00 (reference)			
Inner regional	1.03(0.98-1.09)	0.2		
Outer regional	1.05(0.97- 1.14)	0.2		
Remote / Very remote	1.01(0.82-1.24)	0.9		

Interaction between quartiles of SES and age was significant with P = 0.02. BMI, body mass index; CI, confidence interval; SES, socio-economic status; SHR, sub-hazard ratio.

1.00–1.50 (P = 0.05); disadvantaged quartile: hazard ratio 1.22, 95% CI 0.99–1.49 (P = 0.06)) (Table 3).

Figure 2 shows causes of death by SES. Death from cardiovascular disease was most common, followed by withdrawal from dialysis. There was a significant difference for withdrawal from dialysis being less common among the disadvantaged quartile (P = 0.03), but no association existed for the other causes.

DISCUSSION

This study has shown that despite a universal healthcare system, dialysis survival among the most disadvantaged group is poorer than the advantaged group in Australia. Furthermore, this effect is greatest in the youngest age quartile and attenuated in the older population.

Reports of the effect of SES on dialysis outcomes vary. While some studies have shown no significant effect of SES on dialysis outcomes,[6,9,12] others have shown an effect comparable with our study[8,11,17] or an effect for areas with a large African–American population.[10,11] Our study has used SES at an area level determined by 21 different measures by the ABS.[14] This is different to other studies that have relied on income,[8–12,17] residential segregation by race[11,17] or Townsend Index (which incorporates unemployment, non-car ownership, non-home ownership and household overcrowding),[5,6] measures that are not as broad as used in our study and may therefore lead to differences of classification by SES. Individual level SES data were not available for this study, but Australian postcode area level data have been shown to provide a reliable but understated indication of disadvantage.[18] It is noteworthy that while disadvantage was associated with poorer survival in our study, the effect was comparable with current or previous smoking and much smaller than the risk associated with co-morbidities or late referral to nephrology care.

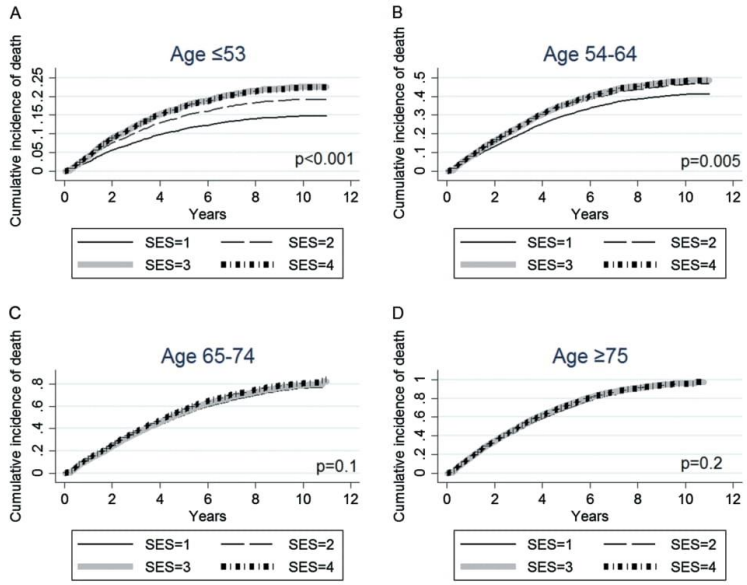


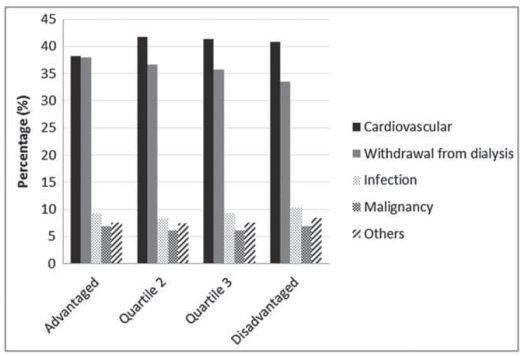
Fig. 1 Cumulative incidence of all-cause mortality according to socio-economic status (SES) and stratified by age.

Table 3 Age-stratified adjusted association between SES and all cause-mortality

	Model 1		Model 2	
	Competing risk regression for transplant SHR (95% CI)		Cox proportional hazard model censored for transplant HR (95% CI)	
Age≤ 53 yrs		p		p
Advantaged	reference		reference	
Quartile 2	1.18(0.96-1.45)	0.1	1.20(0.97-1.47)	0.09
Quartile 3	1.32(1.07-1.63)	0.01	1.22(1.00-1.50)	0.05
Disadvantaged	1.31(1.06-1.61)	0.01	1.22(0.99-1.49)	0.06
Age 54-64 yrs				
Advantaged	reference		reference	
Quartile 2	1.09(0.94-1.25)	0.2	1.10(0.96-1.26)	0.2
Quartile 3	1.17(1.02-1.35)	0.02	1.16(1.01-1.32)	0.04
Disadvantaged	1.08(0.93-1.24)	0.3	1.02(0.89-1.18)	0.7
Age 65-74 yrs				
Advantaged	reference		reference	
Quartile 2	1.02(0.91-1.13)	0.8	1.02(0.91-1.14)	0.7
Quartile 3	1.01(0.90-1.13)	0.9	1.00(0.89-1.11)	0.9
Disadvantaged	1.04(0.93-1.16)	0.5	1.03(0.92-1.15)	0.6
Age ≥ 75 yrs				
Advantaged	reference		reference	
Quartile 2	1.05(0.96-1.16)	0.3	1.05(0.95-1.15)	0.3
Quartile 3	1.09(0.99-1.20)	0.08	1.08(0.98-1.20)	0.1
Disadvantaged	1.10(0.99-1.22)	0.08	1.09(0.99-1.21)	0.09

Models adjusted for gender, race, body mass index, late referral, smoking, diabetes, chronic lung disease, ischaemic heart disease, peripheral vascular disease and cerebrovascular disease. CI, confidence interval; HR, hazard ratio; SHR, sub-hazard ratio.

Care prior to commencement of dialysis has been associated with better outcomes including reduced mortality.[19] Furthermore, care for more than 12 months prior to commencement of dialysis is associated with lower mortality than care for 4–12 months or <4 months.[19] ANZDATA only records if a patient was referred to a nephrologist 'late' (<3 months



Withdrawal from dialysis, P=0.03 for trend.

Fig. 2 Causes of death by socio-economic status.

from dialysis start) or not. Although there was a trend for more late referral among the disadvantaged quartile ($P = 0.07$), we do not know what care was provided more than 3 months from start of dialysis. It is possible that the lower SES group was less likely to receive pre-dialysis care for more than 12 months than the advantaged group. Data from the USA examining pre-dialysis care found the lowest quintile, which was less likely to have attained a high school diploma, and more likely to have no insurance and be African American, although poverty rates were no different.[20] We found no difference among SES quartiles for rate of arteriovenous fistula or graft at first haemodialysis ($P = 0.08$), although lower rates of fistula use at first haemodialysis have been reported among the lowest SES quintile in the USA.[21]

There are many factors associated with dialysis care that may contribute to differences in survival. Quality-of-care indicators such as haemodialysis dose, haemoglobin, calcium, phosphate and parathyroid hormone were not recorded in our study, but were not shown to be different by area level SES in the UK.[5] A second UK study among Caucasian patients found poorer achievement of haemoglobin and phosphate targets at 1 year among disadvantaged patients, but no difference in blood pressure or haemodialysis dose.[6] Peritoneal dialysis complications including peritonitis-associated hospitalization and death have been shown higher in low SES Australians,[22] but a study from Brazil failed to demonstrate an effect of SES on peritoneal dialysis technique or patient survival.[12]

We found the main effect of low SES on survival was among the youngest quartile of dialysis patients (age ≤ 53 years). Low SES has been associated with an increased incidence of renal replacement therapy in those aged <70 years in Australia, but not among older age groups.[1] In the UK, crude dialysis survival decreased with increasing disadvantage for those aged <65 years but not for those 65 years or more.[6] There are several theories on the impact of low SES on health with age, including the divergence–convergence theory, which states that SES impacts health outcomes in middle age and early old age but has little effect in the young and old.[23] As a result of psychosocial stress in middle age, there are greater adverse health outcomes in those disadvantaged by low education and/or income, but with advanced age, general health declines and overrides the effect of disadvantage. It is possible that this effect of SES is seen in the dialysis population at an even earlier age than the general population and could therefore explain our findings.

We hypothesized that access to a universal healthcare system would attenuate any effect of SES on outcomes. The UK has a publicly funded National Health Service, and SES has not been shown to affect dialysis survival there.[6] A recent large study showed increased unemployment is associated with increased cancer deaths, but universal healthcare attenuated this effect.[24] On the other hand, Sweden with a publicly funded health system has significantly higher mortality among diabetic patients with low SES.[25] In Australia, high SES end-stage kidney disease patients have lower rates of peritoneal dialysis,[4] higher rates of pre-emptive and living donor transplantation[26] and better survival post-transplantation.[27] Therefore, access to universal healthcare alone does not appear to remove the effect of SES on outcomes. Other factors associated with low SES such as tobacco use, physical inactivity, poor nutrition, excess weight, psychosocial stress, isolation, financial loss, lifestyle and health literacy[28] are all contributing factors.

Perhaps the most notable difference between the advantaged and disadvantaged SES groups is the difference in living outside a major city, with 47.1% of the disadvantaged group living in regional and rural areas but only 4.7% of the advantaged quartile. In Australia, rates of peritoneal dialysis have been shown higher outside major cities with no difference in peritoneal dialysis survival,[29] although overall dialysis mortality is higher in rural Australia.[30] While the classification of remoteness includes travel to healthcare, it is possible that residual confounding exists. For example, local health services in rural areas may be understaffed, under-resourced or not include the subspecialty care needed for the disadvantaged group that has higher rates of co-morbidity.

Cause of death due to withdrawal from dialysis was less common among the disadvantaged quartile. This may be explained by the group baseline characteristics, in particular, that the group was younger than the advantaged group and may be less accepting of stopping treatment. The disadvantaged group was also more likely to live outside major cities, and this demographic has been shown less likely to withdraw from dialysis.[30] Lastly, there are conflicting reports on access to palliative care services among low SES populations with some reporting no effect[31] and others showing barriers.[32]

Our study has a number of strengths including the near 100% inclusion and follow-up of patients across Australia who commenced dialysis. Furthermore, SES was determined by the ABS based upon 21 measures, compared with often single measures such as income in other studies. There are a number of limitations to this study including SES was classified at an area level based upon postcode at commencement of

dialysis; we have no data on people who chose conservative care and died from kidney disease without commencing dialysis; ANZDATA does not record information on dialysis prescriptions, severity of co-morbidities, compliance, quality of life, hospitalization or medication use, and these, or other unmeasured factors, may cause confounding; and lastly, ANZDATA data quality has not undergone a large audit, although a small study among haemodialysis patients has been reported.[33]

Future research should focus on identifying which factors associated with disadvantage contribute to the disparity in outcomes. Many of these factors are complex and varied, and a large number of interrelated factors likely contribute. Work from the USA among people with chronic kidney disease has reported potentially modifiable factors such as health-related behaviours (smoking, alcohol and physical activity), co-morbid conditions and healthcare access (health insurance and health visits) substantially explain the association between SES and chronic kidney disease.[34] Determining future actions to reduce the gap needs further work.

In conclusion, this study has shown that despite universal healthcare in Australia, low SES is associated with poorer dialysis survival, mainly among younger dialysis patients. Other factors associated with low SES most likely explain the association. Efforts to identify and manage these factors may lead to a reduction in the effect of SES on dialysis outcomes.

ACKNOWLEDGMENTS

The authors gratefully acknowledge the contributions of the Australian and New Zealand nephrology community in providing information for and maintaining the ANZDATA database. The data reported here have been supplied by ANZDATA. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the Australia and New Zealand Dialysis and Transplant Registry.

Funding

No funding received for this project.

CONFLICT OF INTEREST

The results presented here have not been published in whole or in part, except in abstract form. Neither author has any conflicts to declare.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article:

Table S1. Variables included in the Australian Bureau of Statistics Index of Relative Socio-economic Advantage and Disadvantage (14)

Supplementary Table 1: Variables included in the Australian Bureau of Statistics Index of Relative Socio-economic Advantage and Disadvantage (14)

Dimension	**Advantage**	**Disadvantage**
Income	% People with stated annual household equivalised income greater than $52,000 (approx. 9th and 10th deciles)	% People with stated annual household equivalised income between $13,000 and $20,799 (approx. 2nd and 3rd deciles)
Education	% People aged 15 years and over at university or other tertiary institution % People aged 15 years and over with an advanced diploma or diploma qualification	% People aged 15 years and over with no post-school qualifications
Employment		% People (in the labour force) who are unemployed
Occupation	% Employed people classified as Professionals	% Employed people classified as Machinery Operators and Drivers % Employed people classified as Labourers % Employed people classified as Low-Skill Community and Personal Service Workers
Housing	% Occupied private dwellings with four or more bedrooms	% Households paying rent who pay less than $120 per week (excluding $0 per week)

	% Households paying mortgage who pay more than $2,120 per month % Households paying rent who pay more than $290 per week	% Occupied private dwellings requiring one or more extra bedrooms (based on Canadian National Occupancy Standard) % Households renting dwelling from a government or community organisation
Other	% Occupied private dwellings with a broadband Internet connection	% People aged under 70 who need assistance with core activities due to a long-term health condition, disability or old age % Occupied private dwellings with no cars % Occupied private dwellings with no Internet connection % Families that are one parent families with dependent offspring only

3.3 Socioeconomic status and dialysis quality of care

Krishnasamy R, Jegatheesan D, Lawton P, Gray NA

Nephrology (Carlton) 2020; 25(5): 421-428

DOI: 10.1111/nep.13629

Journal Impact Factor 2.506 in 2020. 2.4 in 2023. 5 citations and FWCI of 0.28 (27/3/25)

Co-Authorship statement: R Krishnasamy assisted with the statistical analysis and manuscript review. D Jegatheesan was an advanced physician trainee who assisted with ethics and manuscript review. P Lawton reviewed the analysis and the final manuscript. I was responsible for study design, ethics, data interpretation, supervision, and writing the manuscript.

Original contribution to literature: Showed no significant differences in quality indicators of care among different SES groups in Australia.

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NEPHROLOGY

Nephrology (2019)

Original Article

Socioeconomic status and dialysis quality of care

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KEY WORDS:
ANZDATA, dialysis, disadvantage, quality of care, socioeconomic status.

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Accepted for publication 25 June 2019.
Accepted manuscript online 2 July 2019.

doi: 10.1111/nep.13629

SUMMARY AT A GLANCE

This study was designed to test whether the quality of care delivered to dialysis patients varied by socioeconomic status among 19 486 patients commencing haemodialysis or peritoneal dialysis between 2002 and 2012, as recorded in Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). The conclusion showed socioeconomic status has minimal impact on quality of care. Increased mortality in lower SES groups may be due to pre-dialysis factors and other variables such as health-related behavior, lifestyle and literacy.

ABSTRACT:

Aim: **Lower socioeconomic status (SES) has been associated with increased dialysis mortality. This study aimed to determine if the quality of care (QOC) delivered to dialysis patients varied by SES.**

Methods: **All non-Indigenous adults commencing haemodialysis (HD) or peritoneal dialysis (PD) registered with the Australia and New Zealand Dialysis and Transplant Registry between 2002 and 2012 were included. Each patient's location at dialysis start was classified into SES quartiles of advantaged to disadvantaged. Guidelines were used to determine attainment of adequate QOC at 6–<18 months and 18–<30 months after dialysis start, using logistic regression models. QOC measures included pre-dialysis phosphate, calcium, haemoglobin, transferrin saturation and ferritin. HD-related parameters included single pool Kt/V and percentage with functioning arteriovenous fistula/graft. PD-related parameters included weekly Kt/V and percentage transferring to HD.**

Results: **Of 19 486 commencing dialysis, the median age was 65 years (interquartile range 53–74), 62.2% were male and 85.1% were Caucasian. At 6–<18 months after dialysis start, there were no significant differences by SES in attainment of biochemical targets, PD or HD adequacy. The disadvantaged quartile was less likely to achieve haemoglobin targets (odds ratio 0.88, 0.80–0.96, $P = 0.01$) or have a functioning arteriovenous fistula or graft (odds ratio 0.79, 0.68–0.92, $P = 0.003$) compared with the most advantaged group. Vascular access differences persisted at 18–<30 months.**

Conclusion: **Other than vascular access, area-level SES has minimal impact on QOC attainment among non-Indigenous dialysis patients in Australia. Increased mortality in lower SES groups may be due to pre-dialysis factors and other variables such as health-related behaviours, lifestyle and literacy.**

INTRODUCTION

The association between socioeconomic status (SES) and end-stage kidney disease (ESKD) has been well studied. The incidence of ESKD and renal replacement therapy is higher among disadvantaged populations,[1,2] who are more likely to be treated with peritoneal dialysis (PD) than facility haemodialysis (HD).[3] Furthermore, low SES has been associated with increased mortality in ESKD populations across the United States,[4] Europe[5] and Australia.[6] However, less is known about the association between SES and the quality of care (QOC) received by dialysis patients.

Dialysis-related QOC indicators have been well defined and include dialysis dose, vascular access, anaemia, nutrition, bone mineralization and cardiovascular disease measurements.[7–9] Achievement of these various targets is associated with a reduction in all-cause mortality.[8,10]

The relationship between SES and QOC has been reported in US and UK populations. In the United States, socially deprived patients have lower haemoglobin levels at dialysis commencement.[11] Once commenced on dialysis, African–Americans achieve lower haemoglobin levels and dialysis

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dose than Whites.[12] In the United States, ethnicity and SES are inter-related, leading to uncertainty as to whether SES is the sole reason for QOC differences. Furthermore, the funding of health may include a significant personal contribution, although uninsured patients can access the Medicare ESRD benefit by their fourth in-centre dialysis month. In the United Kingdom, which has a universal health-care system, registry data found no socioeconomic inequity in attainment of clinical standards.[13,14] Differences in access to health care, health-care systems and reporting of QOC may thus account for some of the disparity in dialysis mortality between countries.

The aim of this study was to determine the impact of SES on QOC among non-Indigenous dialysis patients in Australia – where all residents have access to government funded healthcare and some choose to access private hospital care through self-funding extra health insurance. We hypothesized that there would be no difference in the attainment of QOC targets between SES groups in Australia.

MATERIALS AND METHODS

We included all non-Indigenous (those who do not self-identify as Aboriginal and/or Torres Strait Islander) adults (age ≥ 18 years) commencing HD or PD between 2002 and 2012, as recorded in the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). Indigenous Australians were excluded as available Australian area-level measures do not accurately reflect Indigenous SES[15] and research in this population has recently been completed.[16]

Individual patient SES data are not collected by ANZDATA. However, area-level SES for each patient was derived from the Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD), produced by the Australian Bureau of Statistics using population census data including income, education, employment status, occupation, housing, internet access, disability status, car ownership and single parent status.[17] IRSAD scores provided for each Australian postcode (from 2006 census data) enabled classification into quartiles from advantaged to disadvantaged areas.[18] This measure of SES has been widely used previously.[1,3,6]

Quality of care indicators

Biochemical and haematological measures examined were pre-dialysis serum phosphate, calcium, haemoglobin, transferrin saturation and ferritin. PD-related adequacy parameters evaluated were weekly Kt/V, creatinine clearance (L/week/1.73m^2) and percentage transferred to HD (technique failure). HD-specific adequacy was determined by dialysis hours per week, single pool Kt/V, urea reduction ratio and prevalence of functioning arteriovenous fistula/graft (AVF/AVG). Achievement of clinical practice standards was defined using the International Society for Peritoneal Dialysis and Kidney Health Australia Caring for Australasians with Renal Impairment dialysis guidelines available at the time of the patient cohort,[19] or if these were unavailable, KDOQI guidelines[20](Table 1).

ANZDATA records most indicators of QOC on an annual basis at calendar year end. Where dialysis units collect QOC data at more frequent intervals throughout the year, the data set most adjacent to the end of year record date is reported. To ensure people receiving dialysis had been under nephrology supervision for sufficient time to allow implementation of quality care (e.g. to reduce the impact of people who had no or < 3 months nephrology care prior to commencement of dialysis), we chose QOC measures at 6 to <18 months after dialysis commencement for our primary outcome. We also included patient characteristics at commencement of dialysis and QOC indicators 18 to <30 months post dialysis commencement.

This research was approved by The Prince Charles Hospital Human Research and Ethics Committee (HREC/16/QPCH/128).

Statistical analysis

Results were expressed as frequencies and percentages for categorical variables and median (interquartile range) for continuous, non-normally distributed variables. Baseline characteristics categorized by SES quartiles at dialysis commencement were compared using χ^2 test for categorical data

Table 1 Dialysis quality of care indicators

Measure	Target	Guideline (year†)
Phosphate	0.8–1.6 mmol/L	KHA-CARI (2005)
Calcium	2.1–2.4 mmol/L	KHA-CARI (2005)
Haemoglobin	110–120 g/L	KDOQI (2007)
Transferrin saturation	>20%	KDOQI (2006)
Ferritin	>200 ng/mL	KDOQI (2006)
PD technique failure		
PD weekly Kt/V	≥1.6	KHA-CARI (2005)
PD weekly creatinine clearance	≥50 L	KHA-CARI (2005)
HD functioning AVF/AVG		KDOQI (2006)
HD Kt/V	≥1.2	KHA-CARI (2005)
HD URR	>65%	KHA-CARI (2005)
HD weekly dialysis hours	≥4 h/session and thrice weekly	KHA-CARI (2004)

†Guidelines may now be superseded but were in place at the time the study population was undergoing dialysis. AVF, arteriovenous fistula; AVG, arteriovenous graft; HD, haemodialysis; ISPD, International Society of Peritoneal Dialysis; KDOQI, National Kidney Foundation Kidney Disease Outcomes Quality Initiative; KHA-CARI, Kidney Health Australia – Caring for Australasians with Renal Impairment; PD, peritoneal dialysis; URR, urea reduction ratio.

and Kruskal-Wallis test for continuous non-normally distributed data. The primary outcome of attainment of QOC indicators at 6 to <18 months was assessed using multivariable logistic regression with estimation of odds ratio and their 95% confidence interval. The covariates included in the model were age, gender, ethnicity, body mass index, diabetes, chronic lung disease, ischaemic heart disease, cerebrovascular disease, peripheral vascular disease and late referral for dialysis. This analysis was also performed to assess the attainment of QOC indicators at 18 to <30 months after dialysis commencement. Data were analysed using Stata (version 15; StataCorp LP, College Station, TX, USA). *P* values <0.05 were considered statistically significant.

RESULTS

A total of 19 534 non-Indigenous adults commenced dialysis for at least 90 days during the study period, of which 48 were excluded at baseline due to no postcode data or incomplete data collection, leaving 19 486 included in the study. A total 17 448 had QOC data at 6 to <18 months and 14 187 at 18 to <30 months (Fig. 1).

Patient characteristics at commencement of dialysis stratified by SES are shown in Table 2. The cohort had a median age of 65 years (interquartile range 53–74 years), 62.2% were male and 85.1% were Caucasian. Diabetic nephropathy and hypertension/vascular disease were the cause of ESKD in 31.2% and 15.5% of patients respectively. Patients in the disadvantaged quartile were younger and more likely to have diabetes, peripheral vascular disease, smoking history and obesity. PD as initial dialysis modality was more common among the disadvantaged group but rates of late referral (less than 3 months before dialysis start) did not differ by SES.

SES and QOC indicators at 6 to <18 months after dialysis commencement

With the advantaged quartile as the reference group, there were no significant differences in attainment of biochemical targets between the SES quartiles at 6 to <18 months post dialysis commencement (Table 3 and Table SS1). Patients in the disadvantaged quartile were less likely to achieve the haemoglobin target (adjusted odds ratio (OR) 0.88, 95% confidence interval (CI) 0.80–0.96, $P = 0.01$). Among PD patients, there were no differences between SES groups for technique failure or weekly Kt/V; however the disadvantaged quartile was more likely to achieve a creatinine clearance >50 L/week (adjusted OR 1.22, 95% CI 1.01–1.46, $P = 0.04$). Among HD patients, all SES quartiles were significantly less likely to have a functioning AVF/AVG compared with the advantaged quartile, with no between group differences seen for Kt/V, urea reduction ratio or weekly dialysis duration targets. There was no interaction between SES and age, gender, ethnicity, body mass index, diabetes, ischaemic heart disease, cerebrovascular disease, smoking and peripheral vascular disease in predicting functional AVF/AVG.

SES and QOC indicators at 18 to <30 months after dialysis commencement

There were no consistent significant differences in attainment of biochemical, haematological or PD-related

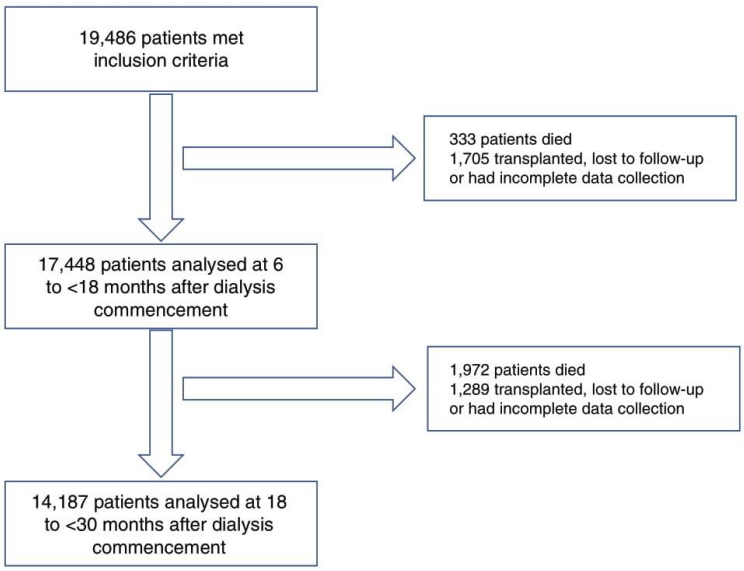

Fig. 1 Patient flow during the study.

Table 2 Patient characteristics according to socioeconomic status

	Advantaged Quartile	Second Quartile	Third Quartile	Disadvantaged Quartile	*P*
Number	4827	4902	4839	4918	
Age quartile (years)					<0.001
≤53 (%)	25.2	28.2	26.4	27.4	
54–65 (%)	25.2	26.4	26.6	27.7	
66–74 (%)	24.9	24.6	26.9	28.2	
≥75 (%)	24.8	20.8	20.2	16.7	
Males (%)	63.0	62.1	61.8	62.5	0.6
IRSAD median (IQR)	1090 (1068–1126)	1013 (1001–1025)	966 (956–975)	910 (892–928)	<0.001
Ethnicity (%)					<0.001
Caucasian	83.4	85.7	87.4	86.9	
Asian	12.6	9.1	7.1	7.9	
Maori and Pacific Islander	1.9	2.8	3.6	3.5	
Other	2.0	2.3	1.8	1.8	
BMI at entry (kg/m^2)					<0.001
<20 (%)	8.6	7.0	7.6	6.1	
20–24.9 (%)	33.3	30.2	28.0	27.3	
25–29.9 (%)	32.8	34.0	33.1	33.1	
>30 (%)	25.3	28.9	31.3	33.1	
Primary renal disease (%)					<0.001
Diabetes	28.3	31.2	31.2	34.3	
Glomerulonephritis	25.8	23.5	23.2	21.9	
Hypertension/vascular	16.2	15.3	15.9	14.7	
Polycystic kidney disease	7.6	6.7	6.6	6.7	
Reflux nephropathy	2.1	2.9	3.2	3.1	
Analgesic nephropathy	2.0	2.5	2.9	3.2	
Other/unknown	18.1	17.8	17.1	16.1	
Creatinine at entry (μmol/L)	613 (473–805)	619 (480–810)	617 (480–804)	630 (490–820)	0.004
Peripheral vascular disease (%)	17.3	19.2	19.8	19.7	0.006
Cerebrovascular disease (%)	11.9	12.8	12.8	11.9	0.3
Ischaemic heart disease (%)	34.5	34.3	36.4	35.9	0.08
Diabetes (%)	37.1	41.0	42.1	45.2	<0.001
Chronic lung disease (%)	11.4	12.3	14.2	13.6	<0.001
Smoking history (%)	48.4	53.1	55.8	57.3	<0.001
History of malignancy (%)	26.7	27.3	27.9	27.2	0.6
Late referral (%)	21.5	22.7	23.6	22.5	0.1
Initial dialysis modality (%)					<0.001
Peritoneal dialysis	28.4	31.9	32.9	34.0	
Home HD	2.7	2.7	2.0	2.2	
Facility HD	69.0	65.4	65.1	63.8	
AVF/AVG at first HD (%)	45.2	42.5	41.9	44.8	<0.001

AVF, arteriovenous fistula; AVG, arteriovenous graft; BMI, body mass index; HD, haemodialysis; IRSAD, Index of Relative Socioeconomic Advantage and Disadvantage.

adequacy targets between SES quartiles at 18 to <30 months post dialysis commencement (Table 3 and Table SS1). HD patients in the third quartile and disadvantaged quartile were less likely to have a functioning AVF/AVG compared with the reference group (third quartile – adjusted OR 0.70, 95% CI 0.59–0.83, $P = 0.001$; disadvantaged quartile – adjusted OR 0.79, 95% CI 0.66–0.94, $P = 0.008$).

DISCUSSION

This is the first study to evaluate socioeconomic differences in clinical practice standards in Australian dialysis patients. After adjustment for patient characteristics, co-morbidities and dialysis modality, we found that in general, overall dialysis QOC does not vary significantly between SES groups. The main consistent difference was a higher prevalence of a functional AVF/AVG among HD patients in the advantaged group.

In a similar study of 14 117 incident dialysis patients in the UK, Udayaraj *et al.*[13] observed no significant association between SES and attainment of haemoglobin, dialysis dose or bone mineral disorder targets. The overall conclusions of their paper parallel the present study findings despite potentially important differences in the UK study, including different ethnic proportions, social deprivation indices and clinical target parameters as well as limited QOC indicators and

Table 3 Association between socioeconomic status and biochemical quality of care indicators at 6 to <18 months and 18 to <30 months after commencement of dialysis

	6 to <18 months (*n* = 17 448) Adjusted OR (95% CI)	*P*	18 to <30 months (*n* = 14 187) Adjusted OR (95% CI)	*P*
Phosphate 0.8–1.6 mmol/L				
Advantaged	Reference		Reference	
Second quartile	1.03 (0.94–1.14)	0.5	1.02 (0.93–1.13)	0.7
Third quartile	0.99 (0.90–1.09)	0.9	0.99 (0.90–1.09)	0.8
Disadvantaged	1.04 (0.95–1.15)	0.3	1.01 (0.91–1.11)	0.9
Calcium 2.1–2.4 mmol/L				
Advantaged	Reference		Reference	
Second quartile	1.01 (0.92–1.11)	0.9	0.99 (0.89–1.09)	0.8
Third quartile	1.01 (0.91–1.11)	0.8	0.94 (0.85–1.04)	0.2
Disadvantaged	1.01 (0.0.91–1.10)	0.9	1.00 (0.91–1.11)	0.9
Haemoglobin 110–120 g/L				
Advantaged	Reference		Reference	
Second quartile	0.96 (0.90–1.06)	0.9	1.00 (0.90–1.10)	0.9
Third quartile	0.92 (0.85–1.02)	0.1	1.01 (0.91–1.12)	0.8
Disadvantaged	0.88 (0.80–0.96)	0.01	0.92 (0.83–1.02)	0.1
Transferrin saturation > 20%				
Advantaged	Reference		Reference	
Second quartile	0.96 (0.87–1.06)	0.5	1.03 (0.93–1.16)	0.51
Third quartile	0.97 (0.88–1.08)	0.6	1.09 (0.98–1.22)	0.1
Disadvantaged	0.97 (0.88–1.08)	0.6	1.01 (0.90–1.13)	0.9
Ferritin > 200 ng/mL				
Advantaged	Reference		Reference	
Second quartile	1.00 (0.91–1.10)	0.9	1.04 (0.93–1.16)	0.4
Third quartile	1.05 (0.95–1.16)	0.3	1.12 (1.00–1.25)	0.05
Disadvantaged	0.95 (0.86–1.05)	0.3	1.04 (0.93–1.16)	0.5
	PD patients (*n* = 5604)		PD patients (*n* = 3854)	
Technique failure				
Advantaged	Reference		Reference	
Second quartile	1.03 (0.79–1.34)	0.8	1.00 (0.82–1.22)	0.9
Third quartile	0.99 (0.76–1.28)	0.9	1.01 (0.82–1.22)	0.9
Disadvantaged	1.11 (0.86–1.43)	0.4	1.01 (0.83–1.23)	0.2
Weekly Kt/V ≥ 1.6				
Advantaged	Reference		Reference	
Second quartile	0.96 (0.81–1.14)	0.7	1.07 (0.88–1.31)	0.5
Third quartile	1.14 (0.96–1.35)	0.1	1.16 (0.95–1.41)	0.1
Disadvantaged	1.08 (0.91–1.28)	0.4	1.12 (0.92–1.37)	0.2
Weekly creatinine clearance ≥ 50 L				
Advantaged	Reference		Reference	
Second quartile	1.04 (0.86–1.25)	0.9	1.13 (0.92–1.42)	0.3
Third quartile	1.09 (0.90–1.31)	0.4	1.12 (0.90–1.40)	0.3
Disadvantaged	1.22 (1.01–1.46)	0.04	1.17 (0.94–1.45)	0.1
	HD patients (*n* = 11 844)		HD patients (*n* = 10 333)	
Functioning AVF/AVG				
Advantaged	Reference		Reference	
Second quartile	0.79 (0.68–0.91)	0.002	0.84 (0.70–1.00)	0.05
Third quartile	0.77 (0.66–0.89)	0.001	0.70 (0.59–0.83)	0.001
Disadvantaged	0.79 (0.68–0.92)	0.003	0.79 (0.66–0.94)	0.008
Kt/V ≥ 1.2				
Advantaged	Reference		Reference	
Second quartile	1.30 (0.90–1.86)	0.2	1.61 (1.06–2.46)	0.03
Third quartile	1.44 (0.98–2.10)	0.06	1.30 (0.86–1.96)	0.2
Disadvantaged	1.53 (1.00–2.36)	0.06	1.14 (0.73–1.78)	0.5
URR≥65				
Advantaged	Reference		Reference	
Second quartile	0.88 (0.73–1.07)	0.2	0.83 (0.65–1.06)	0.1
Third quartile	0.89 (0.73–1.08)	0.2	0.77 (0.61–0.97)	0.03
Disadvantaged	0.96 (0.80–1.16)	0.7	0.82 (0.65–1.05)	0.1
Hours/week (≥4 h × 3 sessions/week)				
Advantaged	Reference		Reference	
Second quartile	0.84 (0.61–1.16)	0.3	0.86 (0.61–1.21)	0.4
Third quartile	0.89 (0.64–1.23)	0.5	0.93 (0.66–1.32)	0.7
Disadvantaged	1.12 (0.79–1.59)	0.5	1.02 (0.71–1.46)	0.9

AVF, arteriovenous fistula; AVG, arteriovenous graft; HD, haemodialysis; PD, peritoneal dialysis; URR, urea reduction ratio.

covariates for adjustment. Furthermore, the Australian system has a much greater uptake of private hospital treatment, although all are covered by a universal system of healthcare.

Commencement of HD with an AVF was less common among low SES populations in the United States when assessed by ZIP code-level median household income.[21] The current study has found the most advantaged quartile is most likely to start dialysis with an AVF/AVG. In Australia, there is a strong association between rates of private health insurance and high SES.[22] Gray *et al.*[23] compared private and public sector dialysis in Queensland (Australia), and found that private HD patients were significantly more likely to have a functioning AVF/AVG at first HD, but not after excluding late referrals to nephrology services. Previous studies have observed commencement with a catheter is most likely if the first nephrologist assessment is less than 12 months from dialysis start[24] or there are fewer pre-dialysis visits,[25] however this information is not collected by ANZDATA. We did not analyse remoteness in this study, although in Australia the most affluent postcodes are mainly located in major cities.[3] It is therefore possible that the disadvantaged group was impacted by geographic location and reduced access to nephrology and vascular surgery services. Equally, there may be differences in wait times for vascular surgical services, potentially favouring those from advantaged areas who are more likely to have private health insurance.[22]

Although the lower rate of AVF/AVG use at first HD has been reported previously among low SES groups, the finding this difference persists at 6 to <18 months and 18 to <30 months post HD commencement is new. Reddan *et al.*[26] found less time since dialysis initiation was associated with higher catheter use in the United States. Furthermore, people in the United States who start dialysis with a catheter and are uninsured, are less likely to have a functional AVF/AVG at the fourth month since dialysis start than those who commence dialysis with a catheter but have Medicare or Medicaid.[27] In Australia with universal health care the poorer AVF/AVG rate among low SES patients persists.

The higher rate of dialysis catheter use among the disadvantaged HD quartile is important because use of HD catheters is associated with increased mortality[28] and hence may be a causative factor for the higher mortality among low SES groups. In addition to the aforementioned impact of rural residence and access to private health care, other possible explanations include differences in the classification and severity of recorded comorbidities. Furthermore, patients in the disadvantaged group had more comorbidity including diabetes, peripheral vascular disease and smoking history, all established risk factors that negatively influence AVF patency.[29]

The association between haemoglobin levels and SES in dialysis populations has been reported previously.[13,14,30] A retrospective study of incident PD patients from China found lower baseline haemoglobin levels in low income individuals, compared with those with medium and high incomes.[30] In a UK Renal Registry study, the least advantaged SES group was 18% less likely to achieve the haemoglobin target than the most advantaged group although this association became non-significant after adjustment for centre effects.[13] In the present study, the disadvantaged quartile achieved the haemoglobin target less frequently than the most advantaged quartile at 6 to <18 months, which became non-significant at 18 to <30 months. We did not analyse erythropoiesis stimulating agent use, which may differ between SES groups, although all patients have access at minimal cost to government subsidized erythropoietin both before and after starting dialysis and iron stores were comparable. Furthermore, the higher rate of dialysis catheters among the HD group may contribute to inflammation which is associated with erythropoietin hypo-responsiveness and anaemia has been associated with a higher rate of prevalent HD catheters in the United States.[26]

Service delivery equity is central to a successful government funded healthcare system. The overall study findings therefore support our initial hypothesis and are reassuring for dialysis patients, caregivers, health professionals and administrators in Australia. A prior study of 20 810 dialysis patients in Australia found low SES to have an adverse effect on patient survival,[6] with similar results observed in studies from United States.[4] The present study suggests that survival differences between SES groups are therefore unlikely due to differences in QOC that are routinely measured on dialysis. Other plausible factors that may have a role include (i) patient-related: health associated literacy and behaviours, cultural beliefs, co-morbidities (beyond those collected in ANZDATA), frailty; (ii) environment-related: rurality and remoteness from health care; (iii) health-care system-related: chronic kidney disease awareness programs and prevention measures, pre-dialysis care, private *versus* public nephrology care.[6,23,31–33] National registries and future clinical studies should consider inclusion of patient-related outcome measures as QOC indicators.

The strengths of this study include its large sample size and inclusion of all centres across Australia. By using the IRSAD score, this study has used a multifactorial assessment of SES compared with others studies that evaluated individual/family income,[4,34] residential segregation by race[4,35] or the Townsend Index.[13,14] The limitations of the study include its retrospective design and uncertain generalizability of results to centres outside Australia. The results may have been confounded by individual centre effects, remoteness, survivor bias, unobserved variable bias and residual confounding. Furthermore, ANZDATA does not collect information on medication use and adherence and has only undergone small audits for data accuracy.[36]

In conclusion, this national registry study of dialysis patients has shown that overall, QOC as measured by ANZDATA does not vary significantly between SES groups in Australia. The reported differences in attainment of haemoglobin targets and maintenance of permanent vascular access require further investigation. Factors other than

those measured in ANZDATA may contribute to the adverse outcomes of disadvantaged people.

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the contributions of the Australian and New Zealand nephrology community in providing information for and maintaining the ANZDATA database. The data reported here have been supplied by ANZDATA. The interpretation and reporting of these data are the responsibility of the authors and should not be seen as an official policy or interpretation of ANZDATA. The results presented in this paper have not been published previously in whole or part, except in abstract form.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher's website:

Table S1 Number (%) of patients achieving quality of care indicators.

Supplementary Table 1: Number (%) of patients achieving quality of care indicators

	6 to <18 months, n (%)	18 to <30 months, n (%)
All patients		
Phosphate (0.8 -1.6mmol/L)	7330 (48)	6608 (49)
Calcium (2.1-2.4mmol/L)	9091 (60)	8085 (60)
Haemoglobin (110-120 g/L)	5165 (30)	4581 (33)
Transferrin saturation >20%	11795 (72)	9672 (73)
Ferritin>200 ng/mL	11887(72)	10068 (75)
PD patients		
Technique failure	720 (13)	1194 (27)
Weekly Kt/V ≥1.6	2521 (49)	1931(52)
Weekly creatinine clearance≥50L	1333 (26)	1012(27)
HD patients		
Functioning AVG/AVF	9904 (84)	9140 (89)
Kt/V≥1.2	1605 (86)	1513 (88)
URR≥65	7720 (88)	7018 (91)

PD = peritoneal dialysis; HD = haemodialysis; AVF = arteriovenous fistula; AVG = arteriovenous graft; URR = urea reduction ratio

3.4 Kidney disease health literacy among new patients referred to a nephrology outpatient clinic

Burke M, Kapojos J, Sammartino C, Gray NA

Intern Med J 2014; 44: 1080-1086

DOI: 10.1111/imj.12519

Journal Impact Factor 1.644 in 2014. 1.8 in 2023. 22 citations and FWCI of 0.68 (27/3/25)

Co-Authorship statement: M Burke was a training registrar who helped with data collection and drafting manuscript. J Kapojos and C Sammartino were training registrars who helped data collection. I was responsible for study conception, design, grant, ethics, data interpretation, supervision, and revision of draft manuscript.

Original contribution to literature: Showed poor knowledge about CKD among people newly referred to a nephrology outpatient clinic.

Funding: Wishlist, Sunshine Coast Health Foundation, 2010-1226. $4500.

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Kidney disease health literacy among new patients referred to a nephrology outpatient clinic

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Key words
chronic kidney disease, health literacy, knowledge, questionnaire, survey.

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Received 24 March 2014; accepted 20 June 2014.

doi:10.1111/imj.12519

Abstract

Background: Knowledge about kidney disease among the general population is poor but has not been assessed in the population selected for referral to nephrology care.
Aim: This study aimed to determine patients' understanding of chronic kidney disease (CKD) when first presenting to a nephrology clinic.
Methods: Newly referred patients to a nephrology clinic were surveyed with open-ended questions about their understanding of CKD causes, symptoms and management.
Results: Two hundred and ten patients were surveyed. Median age was 66.5 years (interquartile range 52–77), 50.5% female and mean body mass index 29.7 ± 6.8 kg/m^2. Prevalence of risk factors for CKD included 31% diabetic, 62% hypertension, 19% family history of CKD and 2% Aboriginal or Torres Strait Islander. CKD stage prevalence was 0 (8%), 1 (24%), 2 (11%), 3 (38.5%), 4 (18%) and 5 (0.5%). Eighty-two per cent were referred by their primary care physician and 29% had seen a nephrologist previously. Kidney Health Australia was mentioned by 2.4%. Sixteen per cent were unsure why they had been referred. CKD causes identified by patients were unsure (40%), alcohol (29%), hypertension (16%) and diabetes (14%). Symptoms identified included asymptomatic (16%), kidney pain (17%) and other (42%). Management suggested by patients was uncertain (51%), dialysis (32%) and anti-hypertensive medication (16%). Eighty-two per cent reported unsatisfactory education from their primary care physician.
Conclusions: New patients referred to a renal outpatient department had poor knowledge about kidney disease. Education of patients should begin in primary care prior to referral. For most patients, education programmes need to be targeted at a simplistic level.

Introduction

Health literacy is a term used to describe the skills required for a person to function effectively in a healthcare environment and to act suitably on health information.[1,2] Important aspects of health literacy include ability to understand health information, engagement in the healthcare process and the removal of barriers from the medical system that prevent patient understanding and involvement.[3]

Poor health literacy has been associated with increased emergency medical care, hospitalisations and mortality in the elderly.[2]

Limited health literacy may affect 23% of people with chronic kidney disease (CKD) and is associated with poorer education, lower income, male gender and non-white race.[4] Referral for renal transplantation is less likely, although there is no difference in the likelihood of being placed on the waiting list.[5] Poorer health literacy has also been associated with missed dialysis sessions, emergency department visits, kidney disease-related hospitalisations[1] and mortality.[4]

Improving health literacy through education is necessary to optimise outcomes in people with CKD. Trials aimed at improving patient knowledge have been linked to better clinical outcomes in people with CKD, including higher rates of pre-dialysis nephrologist care, peritoneal dialysis, pre-emptive transplant wait listing, transplantation[6] and increased time to commencement of renal replacement therapy.[7]

Kidney disease health literacy is poor in the general Australian population.[8] Health literacy has not previously been studied in non-dialysis patients newly referred to a nephrology clinic. We hypothesised that patients newly referred to a nephrology clinic would have received some education about kidney disease from their primary care physician, and therefore, we performed a single-centre study to assess the understanding of kidney disease in this population.

Methods

All adults (age ≥18 years) newly referred by a medical practitioner to a general nephrology outpatient department were invited to participate. Patient recruitment commenced 16 August 2010 and completed 31 October 2011. Exclusion criteria included end-stage kidney disease with a functioning renal transplant or established on dialysis, non-English speaking, cognitive impairment and patients who had previously been seen at the same nephrology clinic within 12 months. Patients who previously had seen a nephrologist elsewhere were included.

The study was a cross-sectional survey administered in a hospital renal outpatient department at the patient's first visit to the clinic and prior to being seen by a nephrologist. The survey was designed following a review of studies assessing patients' understanding of kidney disease and impressions obtained by staff from clinical experience. A panel of nephrologists and nurses reviewed questions and designed the final study questionnaire. A validated health literacy survey such as Rapid Estimate of Adult Literacy in Medicine[9] was not used because no surveys specific to CKD literacy were available. The survey collected demographic data including age, gender, indigenous status (whether the participant self-identifies as being of Aboriginal or Torres Strait Islander descent), marital status, education level and occupation. Personal health data included smoking status and family history of kidney disease. Previous self-reported education or treatment for kidney disease was recorded. Open-ended survey questions examined patient perceived reason for referral, and knowledge of symptoms, causes, treatments and outcomes of kidney disease. Medical staff recorded comorbidities (ischaemic heart disease, peripheral vascular disease, cerebrovascular disease, chronic lung disease and diabetes mellitus) as present or absent, reason for referral, proteinuria (and/or albuminuria), serum creatinine and CKD stage from the medical records. Hypertension was defined as being prescribed antihypertensive medication or having a systolic blood pressure ≥140 mmHg and/or diastolic blood pressure ≥90 mmHg. The survey was administered by nursing staff who had been educated about the project and how to administer the survey, strictly adhering to asking open-ended questions (participants were not prompted if they did not have an answer to a question). For all open-ended questions, participants could provide a single or multiple answers.

Creatinine was recorded as the most recent result prior to clinic attendance and was measured by several different laboratories. The use of isotope dilution mass spectrometry in Australian laboratories reduces interlaboratory variation.[10] At the time of the study, estimated glomerular filtration rate (eGFR) was measured and reported using the Modification of Diet in Renal Disease study equation.[10] The eGFR was used to allocate participants a CKD stage based on the National Kidney Foundation criteria.[11]

A range of methods was used to assess proteinuria in the study population reflecting the heterogeneous approach to the diagnosis of proteinuria at the time. Proteinuria was variably assessed including spot urine

Funding: Wishlist, Sunshine Coast Health Foundation and Sunshine Coast Hospital and Health Service.
Conflict of interest: None.

albumin-to-creatinine ratio (UACR), spot urine protein-to-creatinine ratio (UPCR) and timed (24-h) urine protein collections. Proteinuria or albuminuria was recorded as the most recent result available prior to the clinic visit or at the time of the appointment. Proteinuria was defined as being present if UPCR was more than 50 g/mol, or UACR was more than 25 mg/mmol for men and 35 mg/mmol for women, or timed urine protein collections reported proteinuria >300 mg/day.

Ethical approval to conduct the study was obtained from the Prince Charles Hospital Human Research and Ethics Committee and all participants gave signed informed consent.

Statistical methods

Descriptive statistics were calculated as median and interquartile range (IQR) for continuous variables, or frequency (%) for categorical variables. Results from open-ended questions could include multiple responses from each participant and were therefore presented as graphs of the most frequent responses. Pre-specified analyses of subgroup responses to causes of CKD included diabetic versus non-diabetic patients, age groups by quartiles and those who had seen a nephrologist previously. All analyses were conducted with Stata Version 12 (Stata Corporation, College Station, TX, USA).

Results

Two hundred and ten of 276 eligible patients (76% response rate) were recruited during the study period. Time constraint was the most common reason for not participating in the trial. No participants who commenced the questionnaire withdrew prior to its completion. Patients were referred to the renal outpatient department from primary care physicians (81.9%), specialist physicians (5.2%), other medical specialists (6.7%) or from hospital doctors (6.2%). Overall, 78.5% of people referred to the clinic met the Kidney Check Australia Taskforce guidelines for referral to a nephrologist.[12]

Baseline characteristics are shown in Table 1. The study population was as expected in a general nephrology clinic in this region. Median age was 66.5 years (IQR 52–77), 49.5% male, but only 2% were indigenous. CKD was mild to moderate with median serum creatinine of 115 μmol/L (IQR 82–155). Participant CKD stage was 7.6% (stage 0), 24.3% (stage 1), 11.4% (stage 2), 38.6% (stage 3), 17.6% (stage 4) and 0.5% (stage 5).

One hundred and seventy-two of the 210 patients (81.9%) had an assessment of urinary protein, which was measured by one of three different techniques. Of the 84 participants who had a UACR measured, 54.8% had no albuminuria, 20.2% microalbuminuria and 25% macroalbuminuria. Of the 52 participants who had a UPCR measured, this was <50 g/mol for 67.3% and >50 g/mol for 32.7%. Thirty-six participants had a 24-h urine protein collection and this was <300 mg/24 h for 52.8% and >300 mg/24 h for 47.2%. Overall, 26% had significant proteinuria or albuminuria.

Table 1 Baseline participant characteristics

Characteristic	
Age (years) – median (IQR)	65.5 (52–77)
Male	49.5%
Level of Education	
Primary school	17.6%
Secondary school	52.9%
Tertiary	23.8%
Other	5.7%
Occupation	
Age pension	44.8%
Self-funded retiree	7.1%
Tradesperson	3.3%
Professional	5.7%
Student	0.5%
Unemployed	5.2%
Invalid/carer pensioner	9.5%
Other	23.9%
Aboriginal or Torres Strait Islander	2.0%
Healthcare worker	4.3%
Married/partner	60%
Diabetes	31.4%
Body mass index (kg/m^2)	
Underweight (<18.5)	4.5%
Normal (18.5–24.9)	20.5%
Overweight (25.0–29.9)	34%
Obese (30+)	41%
Hypertension	62.4%
Ischaemic heart disease	19.6%
Peripheral vascular disease	8.6%
Chronic lung disease	13.4%
Cerebrovascular disease	5.7%
Smoker	15.9% (Current)
	30.8% (Former)
Family history of kidney disease	18.6%

IQR, interquartile range.

28.7% of patients had previously seen a nephrologist and 2% had seen a CKD nurse educator. Of those who had previously seen a nephrologist, 7.3% had seen a nephrologist in the past 12 months. 11.1% reported reading paper education material about kidney disease, and 14.8% had conducted an internet search. Only 2.4% of patients were aware of the consumer support group, Kidney Health Australia (or its previous name, the Australian Kidney Foundation).

Figure 1 shows bar graphs of the most common responses provided for the questionnaire. Figure 1A shows responses to the question 'Did your local doctor or

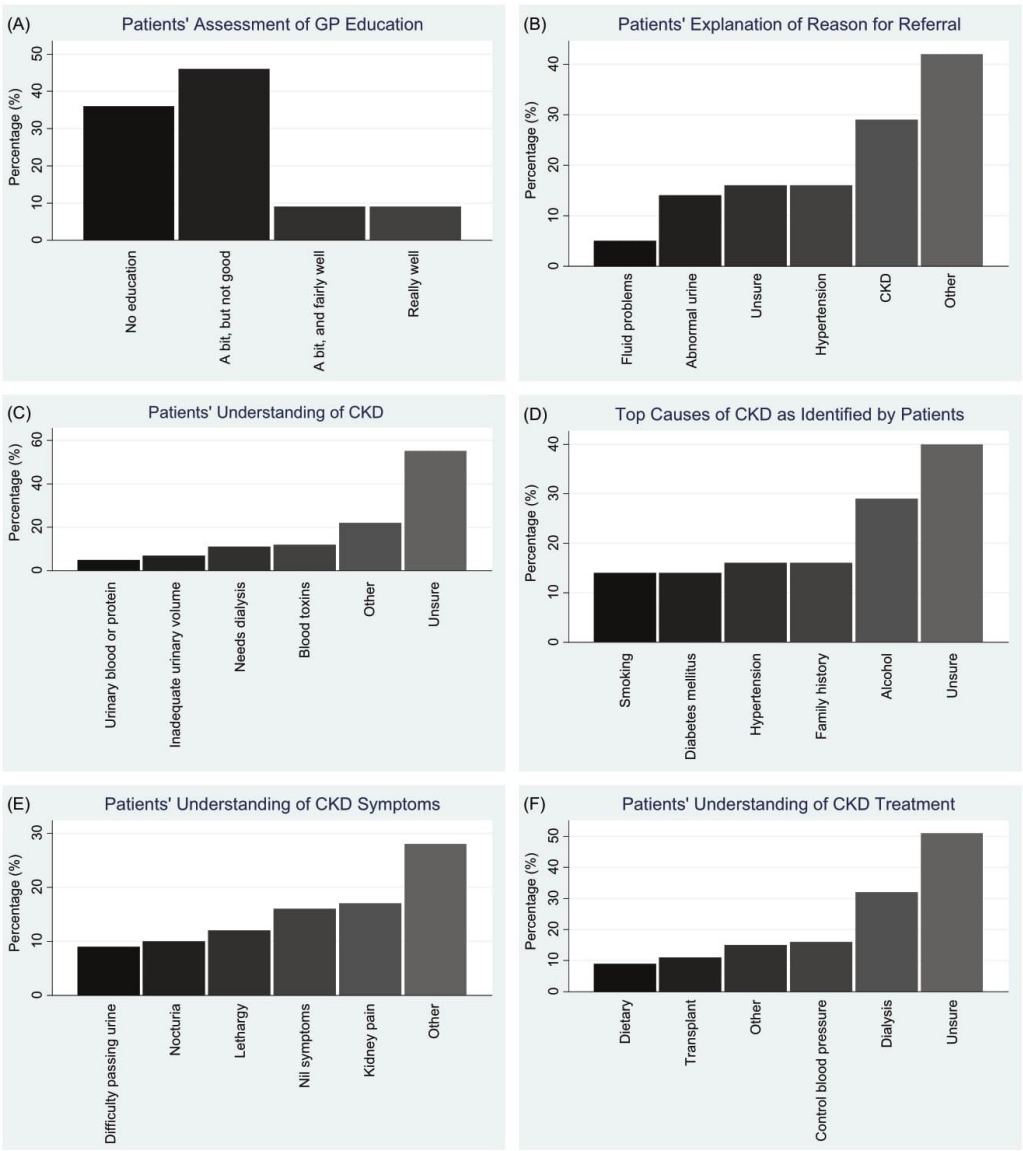

Figure 1 Patient responses to open-ended questions about prior education, referral reason and CKD causes, symptoms and treatment.

general practitioner (GP) explain your kidney problem before sending you to this clinic?' 35.8% reported no education and 46.2% a little, but not adequate. However, 18% found education prior to referral to be good. Figure 1B shows that 16% of participants responded as unsure when asked 'What do you understand to be the reason you have been referred to this clinic?' and 29% responded kidney disease. Less common responses were specific to renal disease and included hypertension, abnormal urine and fluid problems. Figure 1C shows most were unsure when asked 'What does it mean if you have chronic kidney disease?' Unsure and alcohol were

the most common responses to the question 'What sort of things do you think may lead to a person developing kidney disease?' (Fig. 1D). When age was divided into quartiles, younger people were more likely to identify alcohol as a risk factor for CKD ($P \leq 0.001$). Differences in patients' age were not associated with recognising diabetes mellitus as a cause for CKD ($P = 0.47$). Those patients who had previously been reviewed by a nephrologist were not more likely to consider alcohol ($P = 0.29$) or diabetes mellitus ($P = 0.52$) as risk factor for CKD. Perhaps not surprisingly diabetic patients were more likely to report diabetes mellitus as a cause for CKD ($P < 0.001$). Patients reporting alcohol ($P = 0.054$) or diabetes mellitus ($P = 0.19$) as a risk factor for CKD were not dependent on stage of CKD (stages 0–3 vs 4–5). Figure 1E shows responses to 'What symptoms might you have if you had chronic kidney disease?' The response 'other' included shortness of breath, kidney stones, itch and taste disturbance. Lastly, Figure 1F shows responses to the question 'How do we treat chronic kidney disease?' Most patients were unsure or identified renal replacement therapy (dialysis or transplantation).

Discussion

This study has shown that among newly referred patients to a general nephrology outpatient clinic, most receive limited or no education from their primary care physician. Many people are uncertain of the reason for referral and most do not know what CKD is, what causes it or how it is managed. Misunderstanding and misconceptions about CKD are common.

The finding of poor education by primary care providers prior to first nephrology clinic attendance is unsurprising. CKD is common,[8] but its recognition and management in primary care, where multiple competing health issues exist, could be improved. An Italian study examining people with hypertension managed in primary care found that 23% had CKD but this was only diagnosed by the primary care physician in 3.9% of cases.[13] In Australia, CKD in general practice has been shown to be under-recognised and under-treated.[14,15] Furthermore, discussions with patients about CKD in the primary care setting are rare and if they do occur, the GP may use technical terms that hamper education. These discussions occur more frequently with more educated patients, longer consultations or when diabetes is discussed.[16] With the large burden of CKD in the community, it is not possible (or necessary) for all patients to attend a nephrology clinic and it is therefore essential that education about CKD occurs in the primary care setting. Efforts such as the Kidney Check Australia Taskforce[12] and Kidney Health Australia's guidelines for CKD management in general practice[17] will hopefully increase GP awareness and knowledge about CKD. This should translate into improved patient outcomes and knowledge. For example, when a GP diagnoses CKD in a patient with hypertension, the doctor manages the blood pressure better than if CKD is not diagnosed.[13]

The poor kidney disease literacy noted in our study is unlikely to be solely due to inadequate education by the primary care physician. Knowledge among the Australian Diabetes, Obesity and Lifestyle study population,[8] a sample of adults across Australia both with and without CKD, found poor levels of knowledge about CKD in the general community. This poor kidney disease health literacy is not unique to Australia. In America, awareness of CKD among people with an eGFR <60 mL/min per 1.73 m^2 was only 10% for people with two to four markers of CKD and 16% for people with ≥5 markers.[18] Another American study reported only 9% of those with albuminuria or eGFR <60 mL/min per 1.73 m^2 were aware they had kidney disease.[19]

Patient-reported awareness in our study of the peak consumer group, Kidney Health Australia, was poor. This may reflect the low profile of kidney disease in the Australian health system. Kidney disease is not one of the nine national health priority areas of Australian Governments,[20] but does constitute one of the elements of the National Service Improvement Framework for heart, stroke and vascular disease.[21]

While our study is the first to examine knowledge among patients newly referred to a nephrology clinic, the problem of poor kidney disease health literacy extends to those already known to renal units. Observational data from North America has shown that only half of patients with CKD stage 3–5 and seen at least four times in the previous year by a nephrologist knew of haemodialysis, peritoneal dialysis or renal transplantation.[22] Furthermore, one third reported limited or no understanding of CKD. Even among patients established on dialysis, knowledge of phosphate and phosphate binder use is poor.[23] In our study, despite 28% of participants having seen a nephrologist previously, overall knowledge was generally poor.

There are reports of interventions to improve health literacy successfully among patients with kidney disease. A systematic review has shown efforts to improve diet and fluid concordance among dialysis patients with multicomponent interventions can be successful.[24] In Canada, one-on-one pre-dialysis education, provision of a booklet and regular telephone follow up was associated with increased time until commencement of renal replacement therapy.[7] Follow up of this group showed

overall longer survival and longer survival after commencement of dialysis.[25] Participation in the National Kidney Foundation Kidney Early Evaluation Program (KEEP) resulted in higher rates of pre-dialysis nephrologist care, peritoneal dialysis, pre-emptive transplant wait listing and transplantation but not permanent vascular access. Recently, a physician-delivered education tool has made patients more aware they have CKD, their stage of CKD and awareness of kidney function.[1] Knowledge may be further assisted by novel approaches such as a Medicare education benefit in the United States for patients with CKD stage 4.[26]

There are several limitations to our study that impact the generalisability of the results. Our data are from a single-centre and health literacy and primary care physician education practices along with awareness of renal disease support organisations reported in this study may not reflect those in other regions. The study relied on patient recall of previous nephrologist consultation or CKD education. Our population included few indigenous patients. Poor CKD health literacy has been shown among the Australian Indigenous population[27] and hence areas with larger indigenous populations may face a greater challenge with kidney disease health literacy. Non-English speakers were excluded and our population did not have many non-white participants, groups that have been found to have poorer health literacy in other studies.[28–31] Lastly, we did not use a validated scoring system for CKD health literacy but did focus on patient identification of alcohol and diabetes mellitus as risk factors for CKD because of a previous study in a survey of kidney disease knowledge in an Australian population.[32] There are also strengths in our study, including the high response rate and use of open-ended questions without prompting.

Conclusion

The present study has shown that despite the known benefits of improved health literacy, CKD knowledge is poor among patients newly referred to a nephrology clinic and an opportunity to educate patients in the primary care setting is being missed. Ongoing efforts to improve primary care providers' recognition and knowledge of CKD will hopefully translate into improved efforts to educate patients about their illness and better outcomes. Nephrologists need to be aware that newly referred patients are likely to have a poor understanding of kidney disease and should tailor their consultation appropriately.

Acknowledgements

The authors thank Wishlist, Sunshine Coast Health Foundation and Sunshine Coast Hospital and Health Service for their financial support for this work.

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3.5 Patient kidney disease knowledge remains inadequate with standard nephrology outpatient care

Gray NA, Kapojos JJ, Burke MT, Sammartino C, Clark CJ.

Clin Kidney J 2016; 9(1): 113-118

DOI: 10.1093/ckj/sfv108

Journal Impact Factor 2.975 in 2018. 3.9 in 2023. 23 citations and FWCI of 1.08 (27/3/25)

Co-Authorship statement: J Kapojos, M Burke, C Sammartino were training registrars who helped with data collection. C Clark assisted data interpretation. I was responsible for study conception, design, grant, ethics, data interpretation, supervision, and drafting of manuscript.

Original contribution to literature: In a single centre demonstrated that standard nephrology clinic care is insufficient to improve patients' knowledge of CKD.

Funding: Wishlist, Sunshine Coast Health Foundation, 2011-02. $5000.

Clinical Kidney Journal

ckj OXFORD

Leading European Nephrology

Clinical Kidney Journal, 2016, vol. 9, no. 1, 113–118

doi: 10.1093/ckj/sfv108
Advance Access Publication Date: 22 October 2015
Original Article

ORIGINAL ARTICLE

Patient kidney disease knowledge remains inadequate with standard nephrology outpatient care

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Abstract

Background: Chronic kidney disease (CKD) knowledge among patients newly referred to a nephrology clinic is limited. This study aimed to determine if CKD knowledge 1 year after initial consultation in a nephrology clinic improves with standard care.

Methods: Patients newly referred to a nephrology outpatient clinic received standard care from nephrologists, and had access to educational pamphlets, relevant internet sites and patient support groups. Those with estimated glomerular filtration rate <20 mL/min/1.73 m^2 received individual education from a multi-disciplinary team. Knowledge was assessed by questionnaire at first visit and after 12 months.

Results: Of 210 patients at baseline, follow-up data were available at 12.7 (±1.7) months for 95. Median age was 70 [interquartile range (IQR) 60–76] years and 54% were male. Baseline median creatinine of the follow-up cohort was 137 (IQR 99–179) µmol/L. Eighty per cent had seen a nephrologist at least three times, 8% saw a CKD nurse, 50% reported collecting pamphlets and 16% reported searching the internet. At 12 months, fewer patients reported being uncertain why they had been referred (5 versus 20%, P = 0.002) and fewer reported being unsure of the meaning of CKD (37 versus 57%, P = 0.005). Unknown (44%) and alcohol (23%) remained the most common causes of CKD identified. Fewer patients responded 'unsure' regarding the treatment of CKD (38 versus 57%, P = 0.004).

Conclusions: After a year of standard care at nephrology outpatient clinics there were some minor improvements in patient knowledge; however, patient understanding of CKD remained poor.

Key words: chronic kidney disease, education, kidney, knowledge, survey

Introduction

Health literacy describes an individual's ability to understand health information and engage in the healthcare process, and allows removal of barriers that otherwise prevent patient involvement [1]. Low health literacy among the general population is associated with poorer health outcomes and poorer use of health care services [2].

Received: June 14, 2015. **Accepted:** October 1, 2015

An estimated 23% of patients with chronic kidney disease (CKD) have limited health literacy [3]. In the Australian general population, awareness of risk factors of CKD among those with CKD was no greater than those without [4]. Our recent study has found poor knowledge and understanding of kidney disease in newly referred patients to a renal outpatient department [5]. Limited health literacy among people with kidney disease has been associated with lower socio-economic status, worse health outcomes [3], increased risk of missed dialysis sessions, hospitalization [6] and mortality among haemodialysis patients [7], and reduced likelihood of referral for transplantation [7].

Educational interventions are integral to chronic disease management. Most interventions in kidney disease have targeted diet and/or fluid management in dialysis patients using a multi-component education programme [8]. When compared with usual care, a 20-year follow-up study of a predialysis psychoeducational intervention showed increased survival of 2.25 years and an additional 8 months before commencement of dialysis [9]. Furthermore, formal patient education through participation in the National Kidney Foundation Kidney Early Evaluation Program (KEEP) was associated with higher pre-end stage kidney disease nephrologist care, peritoneal dialysis, preemptive transplant wait listing and transplantation [10].

CKD is very common and there is little published data examining the impact of educational interventions aimed at the early-stage CKD population [8]. Therefore, we assessed knowledge and understanding of kidney disease among patients 1 year after their initial consultation in a nephrology outpatient clinic to assess changes with standard care.

Materials and methods

This study is a longitudinal survey of kidney disease knowledge in adults (age ≥18 years) who were referred to a single nephrology outpatient clinic between 16 August 2010 and 31 October 2011. Selection methods, including inclusion and exclusion criteria, and baseline data have been published elsewhere [5]. In brief, baseline demographic data included age, gender, level of education, occupation and marital status. Other baseline data included referral source, body mass index, comorbidities, serum creatinine, estimated glomerular filtration rate (eGFR) and CKD stage. Prior to the first nephrology outpatient attendance, patients were asked open-ended questions to determine their perceived reason for referral; and understanding, causes, symptoms and treatment of CKD. Twelve months after the initial survey, subjects who were still actively attending the same nephrology clinic were approached to repeat the survey with the same open-ended questions. Written informed consent was obtained from all participants and the study was approved by the Prince Charles Hospital Human Research and Ethics Committee.

Education intervention

Patients received non-standardized explanation of their kidney disease from nephrologists during their outpatient visits as part of routine care. This was provided at the initial visit (typically a 45 min consultation) and then at subsequent visits (15–20 min consultations) as deemed necessary by the nephrologist. Education included some or all of the following: verbal explanation of causes, symptoms and treatment of CKD; verbal explanation of the individual patient's cause for CKD or reason for referral to clinic; provision of written material; direction to internet sites; direction to pamphlets; and referral to allied health staff or a CKD nurse educator as deemed necessary. The information provided by nephrologists was directed at the individual needs of each patient. Non-medical staff were unaware of what information was provided to each patient.

At each visit, patients had access to additional education material in the waiting room including posters and take-home pamphlets. Included within the pamphlets were the contact details of consumer support groups, Kidney Health Australia as well as the Kidney Support Network. Collection of pamphlets was at the discretion of each patient.

Patients with an eGFR <20 mL/min/1.73 m^2 were all reviewed by a CKD nurse educator for one-on-one education during a single session followed by further education sessions with social work, dietetics and pharmacy as needed. Follow-up contact with the CKD nurse was arranged after the initial education sessions to clarify any questions.

Data collection at follow-up

Data were only collected for patients who continued to attend the nephrology clinic 12 months after their initial consultation. The survey was conducted prior to a clinic appointment, or if no clinic appointment was scheduled at the 12 month time-point, patients were contacted by telephone. If a patient was unable to be contacted after three telephone calls, they were recorded as un-contactable.

Patients self-reported details of collection of educational pamphlets, searching relevant internet sites and awareness of patient support groups. The numbers of visits to a nephrologist and/or CKD nurse educator during the study period were recorded from hospital databases.

Patients were re-surveyed with the same open-ended questions (Table 1) used in the initial questionnaire with no prompting for each question. The survey was delivered by renal nursing staff that had been trained for this project and had administered the baseline questionnaire. The nursing staff were blinded to the patients' diagnosis, any information provided by each nephrologist during consultations, as well as details of any pamphlets patients had collected or CKD nurse education sessions attended.

Patients could provide multiple responses to each question, all of which were recorded. Data were summarized and tabulated as recurring themes. For example, responses of 'not drinking enough water' and 'not drinking enough' to the question 'What sort of things do you think may lead to a person developing kidney disease?' were grouped as 'inadequate fluid intake'. The coding was performed by the investigators. The responses provided by each individual patient were not compared with that person's reason for referral, underlying cause of kidney disease or treatment plans.

Statistical analysis

For the demographic data, descriptive statistics were calculated as median and interquartile range (IQR) for continuous variables,

Table 1. Open-ended questions asked at baseline and 12-month follow-up

- What do you understand to be the reason you attend this clinic?
- What does it mean if you have chronic kidney disease?
- What sort of things do you think may lead to a person developing kidney disease?
- What symptoms might you have if you had chronic kidney disease?
- How do we treat chronic kidney disease?

or frequency (%) for categorical variables and analysed with chi squared tests for categorical values and unpaired *t*-tests for continuous variables.

Answers to open-ended questions could include multiple responses from each participant. Graphs of the most frequent responses are presented, with the percentage of patients using those responses compared between baseline and 12-month data and analysed using a paired *t*-test. Because alcohol was incorrectly but frequently identified in our baseline results as a cause for CKD, pre-specified analyses about perception of alcohol or diabetes as a cause for CKD were undertaken for those who self-reported collecting pamphlets and those who saw a nephrologist ≥5 times versus <5 times. Furthermore, a pre-specified analysis of those with diabetes as a comorbidity who nominated diabetes as a cause for CKD was undertaken and analysed by paired *t*-test. All analyses were conducted with Graph Pad Prism version 6 software.

Results

Of 210 patients surveyed at baseline, 125 (59.5%) were still actively under the care of the clinic after 12 months, 77 (36.7%) had been discharged and 8 (3.8%) had died. Of the 125 patients who met the inclusion criteria, 95 were included in the current analysis (representing 45.2% of baseline numbers and 76% of those still under care of the clinic); 19 (15.2%) were unable to be contacted to complete the 12-month survey, 7 (5.6%) declined to participate and 4 (3.2%) completed surveys which were misplaced. Mean (standard deviation) time to follow-up was 12.7 (1.7) months.

Baseline characteristics (month 0) of the original group at first visit to the nephrology clinic ($n = 210$) and the follow-up cohort ($n = 95$) are shown in Table 2. The follow-up group was generally similar to the baseline group with a median age of 70 years (IQR 60–76) and 54% age pensioners. The only significant difference between the baseline and follow-up groups was CKD stage, although there was no difference in serum creatinine [115 µmol/L (81–155) versus 137 µmol/L (99–179), P = 0.06]. Only 6% of the follow-up group had an eGFR <20 mL/min/1.73 m^2. The median number of attendances with a nephrologist over the 12 months was 4 (IQR 3–6). Fifty-one per cent reported collecting pamphlets, 15.8% searched the internet for information on kidney disease and 8.4% saw a CKD nurse educator. Only 3.2% reported knowledge of Kidney Health Australia and 1.1% of the Kidney Support Network.

Figure 1 shows responses to the open-ended questions about kidney disease for the cohort of 95 that had both initial and 12-month responses available for analysis. Although there were improvements noted in some areas of knowledge, the results of follow-up data remained disappointing. Figure 1A shows a reduction in people responding 'unsure' as to the reason for referral (20% at baseline compared with 5% at follow-up, P = 0.002). The most common response among those who responded 'other' reason for referral was because of a recommendation by their general practitioner. Figure 1B shows responses to the question regarding patients' understanding of CKD. Although the percentage responding 'unsure' had reduced from 57 to 37% (P = 0.005), it remained the most common response. The next most common response was 'other', and among this group the most frequent answers were '(slow) death' or 'bad news'. The most common perceived causes of CKD listed in the follow-up data were similar to the initial data (Figure 1C). Disappointingly, the most common causes identified remained 'unknown' and 'alcohol'. The follow-up of participants' understanding of CKD management (Figure 1D) showed fewer patients' responding 'unsure' at follow-up (57% at baseline, 38% at follow-up, P = 0.004), although it remained the most common response. In general, the most frequent responses for the management of CKD in follow-up data were comparable to initial data.

Table 2. Baseline characteristics of initial and 12 month follow-up groups

Characteristic	Initial survey ($n = 210$)	12-month follow-up survey ($n = 95$)	P-value
Age in years (median, IQR)	65.5 (52–77)	70 (60–76)	0.16
Male gender	104 (49.5%)	51 (53.7%)	0.76
Level of education			0.82
Primary school	37 (17.6%)	20 (21.1%)	
Secondary school	111 (52.9%)	48 (50.5%)	
Tertiary education	50 (23.8%)	21 (22.1%)	
Other	12 (5.7%)	6 (6.3%)	
Occupation			0.55
Age pension	94 (44.8%)	51 (53.7%)	
Self-funded retiree	15 (7.1%)	8 (8.4%)	
Tradesperson	7 (3.3%)	2 (2.1%)	
Professional	12 (5.7%)	3 (3.2%)	
Student	1 (0.5%)	0 (0%)	
Unemployed	11 (5.2%)	2 (2.1%)	
Invalid/carer pensioner	20 (9.5%)	9 (9.5%)	
Other	50 (23.9%)	20 (21%)	
Aboriginal or Torres Strait Islander	4 (1.9%)	2 (2.1%)	0.89
Healthcare worker	9 (4.3%)	3 (3.2%)	0.58
Married/partner	127 (60%)	51 (53.7%)	0.21
Comorbidities			
Diabetes	66 (31.4%)	36 (37.9%)	0.17
Hypertension	131 (62.4%)	63 (66.3%)	0.43
Ischaemic heart disease	41 (19.5%)	25 (26.3%)	0.09
Peripheral vascular disease	18 (8.6%)	7 (7.4%)	0.67
Chronic lung disease	28 (13.3%)	17 (17.9%)	0.20
Cerebrovascular disease	12 (5.7%)	5 (5.3%)	0.85
Smoker (current)	34 (16.2%)	17 (17.9%)	0.65
Smoker (former)	64 (30.5%)	29 (30.5%)	1.0
Body mass index (kg/m^2)			0.87
Underweight (<18.5)	5 (2.5%)	3 (3.2%)	
Normal (18.5–24.9)	45 (22.5%)	22 (23.2%)	
Overweight (25.0–29.9)	68 (34%)	29 (30.5%)	
Obese (>30)	82 (41%)	38 (41%)	
Family history of kidney disease	37 (17.6%)	14 (14.7%)	0.46
CKD stage			0.04
CKD stage 5 (eGFR <15)	1 (0.5%)	0 (0%)	
CKD stage 4 (eGFR 15–30)	44 (21%)	29 (30.5%)	
CKD stage 3 (eGFR 30.1–60)	89 (42.4%)	44 (46.3%)	
CKD stage 1 & 2 (eGFR >60)	74 (35.2%)	22 (23.2%)	
Creatinine, µmol/L (median, IQR)	115 (81–155)	137 (99–179)	0.06

Participants were asked what symptoms they associate with CKD. The vast majority of responses were categorized as 'other' which included 'do not know'. The frequency of symptoms mentioned such as lethargy, reduced urine output or kidney pain was <10%.

A subgroup analysis showed no difference in the numbers who identified 'alcohol' or 'diabetes' as causes for CKD among participants who reported collecting education pamphlets ($n = 48$) compared with those who did not ($n = 47$) (Figure 2). There was also no difference among those who saw a nephrologist ≥5 times ($n = 44$) compared with those with <5 visits ($n = 51$) who identified 'alcohol' as a cause, and a worse outcome at

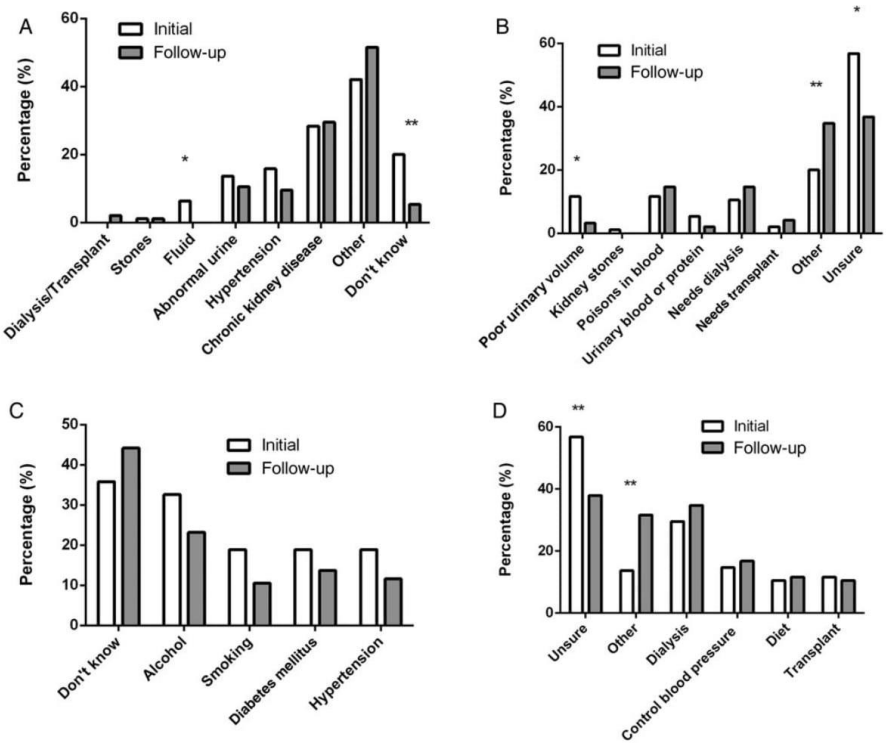

Fig. 1. Patient responses to open-ended questions about kidney disease after attending routine clinic care for 12 months. Data presented as initial ($n = 95$) and follow-up ($n = 95$) response rates as a percentage. *$P < 0.05$, **$P < 0.01$. (**A**) Patient self-reported explanation of reason for initial referral to the nephrology clinic. (**B**) Patient self-reported explanation of their understanding of chronic kidney disease. (**C**) Patient self-reported explanation of causes of chronic kidney disease. (**D**) Patient self-reported explanation of treatment for chronic kidney disease.

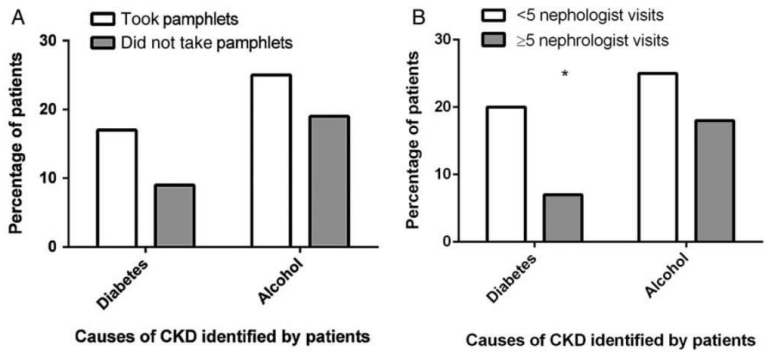

Fig. 2. Frequency of diabetes and alcohol being identified as causes for CKD at follow-up ($n = 95$) and association with uptake of pamphlet education or more frequent nephrologist visits. *$P = 0.01$

follow-up for those identifying diabetes ($P = 0.01$) (Figure 2). There was no difference in the number of patients with diabetes ($n = 36$) who nominated diabetes as a cause for CKD at baseline ($n = 12$) and follow-up ($n = 10$).

Discussion

Despite attending a nephrology outpatient clinic for 12 months with several nephrologist visits and easy access to education materials at the clinic, patient knowledge about kidney disease

remained limited with only small changes compared with baseline results.

Although 80% of our respondents visited nephrologists at least three times, their kidney disease knowledge and understanding remained inadequate. These results are supported by a study of patients with CKD stage 3–5, where although perceived knowledge improved with the frequency of nephrology visits, only half of patients who had seen a nephrologist at least four times reported knowledge of haemodialysis, peritoneal dialysis or transplantation [11]. The reasons for inadequate education by nephrologists are uncertain but may include time constraints. Recognizing the inadequate education delivered by nephrologists has led to the development of a physician-delivered education intervention whereby a one-page educational worksheet reviewed with the patient was associated with higher patient kidney disease knowledge [12].

The clinic area had a large display of kidney disease pamphlets with information on diet, medications, disease management and support groups. Although this information was readily available, only 50.5% collected pamphlets to read. Given that the information was free we thought the uptake of this information may have been higher. It is possible that participants under-reported the collection of pamphlets when surveyed at 12 months. However, it seems likely that many did not collect pamphlets at all. In an Australian study on CKD mineral and bone disorder, only 18% of patients received information about phosphate from written material [13].

The information gained by those who did collect pamphlets seems inadequate. We were unable to show a difference in knowledge when comparing participants who had and had not collected information material. Furthermore, participants' awareness of community support groups was poor, suggesting that although pamphlets were available detailing these groups, participants did not read or comprehend the information. The Department of Education has reported that half of the adult population of the USA has difficulty using commonly available print materials to accomplish everyday tasks. More than 1000 studies conducted since the 1960s indicate that health materials for the public and patients are generally written at levels of complexity beyond the reading skills of high-school graduates [14].

People with CKD often suffer multiple medical problems, many of which cause greater morbidity than CKD. It is possible that people prioritize their medical conditions. Diabetic patients with multiple comorbidities ranked diabetes and hypertension among their top three important concerns, but none of the patients reported renal disease when asked of 'other health concern(s)'. Patients were likely to focus on symptomatic conditions such as pain, depression and breathing problems [15]. Our population, in general, had mild CKD and hence they may not see kidney disease as a major issue.

A multi-disciplinary team (MDT) may be a better model to improve patient knowledge. A randomized controlled trial in patients with progressive CKD has shown that additional educational and social worker interventions improved discussion and active pursuit of living donor kidney transplantation compared with usual care [16]. A systematic review of 22 randomized trials involving multi-component structured educational and psychological care with usual care revealed significant improvement of at least one of the outcomes (diet and/or fluid) in a majority of pre-dialysis and dialysis studies [8]. MDT care has been associated with a lower mean annual decline in eGFR compared with usual nephrology care in CKD stage 3 [17]. In the adult population, MDT care has been shown to be cost effective for patients with CKD stage 3 and 4 mainly due to reduced hospitalizations [18]. Furthermore, MDT care has been shown to reduce costs in the first 6 months after commencement of haemodialysis [19].

Repetitive education may be effective in maintaining knowledge. In early-stage CKD, an educational intervention covering management of CKD increased knowledge at 6 months but it had fallen again by 12 months [20]. Pre-dialysis education increased time to dialysis in Canada, but required a one-on-one interactive educational session, booklet and importantly a phone call every 3 weeks [21]. This was far more intense than provided by standard care in our model. In transplant patients, an intervention consisting of five one-to-one sessions had both short- and long-term (6 months post-transplant) benefits [22].

Education programmes and participation in a voluntary community kidney disease programme were associated with improved outcomes in end-stage kidney disease adults who participated in the National Kidney Foundation Kidney Early Evaluation Program [10]. In the USA, this finding is particularly important for those with CKD stage 4 who are eligible for the Medicare education intervention [23] consisting of up to six education sessions. In Australia, there is no funding for CKD education and for this reason an eGFR cut-off for nurse-provided education in our unit is <20 mL/min/1.73 m^2 due to financial constraints.

There are a number of limitations to our study. The survey questions were not validated prior to the study. Following commencement of our study, a kidney-specific knowledge questionnaire has been validated, the Kidney Knowledge Survey [24]. However, this survey has some limitations including only being validated in a predominantly white and educated population, and there is a need to develop CKD stage-specific knowledge surveys [25]. Secondly, due to our limited resources, only those with advanced CKD (8.4%) received more individualized education by a CKD nurse and MDT. Thirdly, our study population does not reflect the multicultural population in other areas in Australia by excluding non-English speakers, and only 2% were indigenous. Lastly, we relied on patient recall for determining collection of pamphlets and searching the internet.

In summary, our study has shown that after a year of attending a single nephrology outpatient clinic, standard care and access to pamphlets are insufficient for improving kidney disease knowledge. A more structured, individualized and repetitive education programme delivered by a multi-disciplinary team may be more effective and hopefully lead to better health outcomes. The cost-effectiveness of this educational intervention remains to be proven.

Acknowledgements

The authors thank Wishlist, Sunshine Coast Health Foundation for financial support.

Conflict of interest statement

The authors have no competing interests. These results have not been published previously in whole or in part, except in abstract form.

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CHAPTER 4: CAREGIVERS OF PEOPLE WITH CKD

4.1 Burden of care and quality of life among caregivers for adults receiving maintenance dialysis: A systematic review

Gilbertson EL, Krishnasamy R, Foote C, Kennard AL, Jardine MJ, Gray NA

Am J Kidney Dis 2019; 73(3): 332-343

DOI: 10.1053/j.ajkd.2018.09.006

Journal Impact Factor 6.618 in 2019. 9.4 in 2023. 103 citations and FWCI of 6.75 (27/3/25)

Co-Authorship statement: E Gilbertson was an advanced physician trainee at the time. She helped as one of the reviewers for the papers included in the systematic review and wrote the first draft of the manuscript. R Krishnasamy assisted with statistics. C Foote and A Kennard assisted with some data collection and review of the manuscript. M Jardine provided senior advice. As senior author I was responsible for study design and methodology, review of all search results including titles and abstracts and then full text manuscripts for the systematic review, interpretation of data, supervision of E Gilbertson, and extensive editing/reworking of the manuscript.

Original contribution to literature: Large systematic review of caregiver burden and quality of life in dialysis, identifying multiple future areas of need for research.

Burden of Care and Quality of Life Among Caregivers for Adults Receiving Maintenance Dialysis: A Systematic Review

Elise L. Gilbertson, Rathika Krishnasamy, Celine Foote, Alice L. Kennard, Meg J. Jardine, and Nicholas A. Gray

Rationale & Objective: Dialysis is a burdensome and complex treatment for which many recipients require support from caregivers. The impact of caring for people dependent on dialysis on the quality of life of the caregivers has been incompletely characterized.

Study Design: Systematic review of quantitative studies of quality of life and burden to caregivers.

Setting & Study Population: Caregivers of adults receiving maintenance dialysis.

Selection Criteria for Studies: The Cochrane Library, Embase, PsycINFO, CINAHL, PubMed, and MEDLINE were systematically searched from inception until December 2016 for quantitative studies of caregivers. Pediatric and non–English language studies were excluded. Study quality was assessed using a modified Newcastle-Ottawa scale.

Data Extraction: 2 independent reviewers selected studies and extracted data using a prespecified extraction instrument.

Analytical Approach: Descriptive reports of demographics, measurement scales, and outcomes. Quantitative meta-analysis using random effects when possible.

Results: 61 studies were identified that included 5,367 caregivers from 21 countries and assessed the impact on caregivers using 70 different scales. Most (85%) studies were cross-sectional. The largest identified group of caregivers was female spouses who cared for recipients of facility-based hemodialysis (72.3%) or peritoneal dialysis (20.6%). Caregiver quality of life was poorer than in the general population, mostly comparable with caregivers of people with other chronic diseases, and often better than experienced by the dialysis patients cared for. Caregiver quality of life was comparable across dialysis modalities.

Limitations: Heterogeneity in study design and outcome measures made comparisons between studies difficult and precluded quantitative meta-analysis. Study quality was generally poor.

Conclusions: Quality of life of caregivers of dialysis recipients is poorer than in the general population and comparable to that of caregivers of individuals with other chronic diseases. The impact of caring for recipients of home hemodialysis or changes in the impact of caring over time have not been well studied. Further research is needed to optimally inform dialysis programs how to educate and support caregivers.

Complete author and article information provided before references.

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Am J Kidney Dis. 73(3): 332-343. Published online November 16, 2018.

doi: 10.1053/j.ajkd.2018.09.006

Caregivers and partners play an integral role in the management of many chronic diseases.[1-5] In the United States, there are an estimated 14.7 million family and unpaid caregivers for people living in the community with disabilities and an estimated 78% of caregivers incur out-of-pocket expenses averaging US $6,954 annually.[6]

Dialysis for the management of kidney failure represents perhaps one of the more burdensome ongoing medical interventions, encompassing mental, physical, financial, and social demands. The adverse impact of kidney failure on patient quality of life (QoL) is widely acknowledged.[7-11] The potential impact of caring for people with kidney failure treated by dialysis on the QoL of the caregivers is less often discussed.

The prevalence of dialysis dependence is increasing, with the greatest growth among the elderly, who typically have increased comorbid conditions and potentially greater care needs.[12-16] The older age among dialysis recipients is often associated with advancing age among caregivers, who are often lifetime partners.[17,18] Although most dialysis therapy is administered in facilities by professional health staff, a substantial minority of recipients undertake dialysis therapy at home. There is some evidence that home dialysis therapy, either as peritoneal dialysis (PD) or home hemodialysis (HD), is associated with improved QoL for recipients.[19,20] However, improved health outcomes for recipients and lower costs for providers may risk medicalizing the home and imposing increased responsibility on caregivers.[19,20]

Our primary aim was to systematically review studies that quantitatively evaluated caregiver QoL and burden of caregiving for adult dialysis recipients. Secondary aims included demographic profiling of caregivers, details of measurement scales used by investigators, and comparing QoL of caregivers of dialysis recipients with other caregivers, the general population, and the dialysis recipients themselves. Last, we compared QoL of caregivers of people undergoing different dialysis modalities.

Methods

Search Strategy and Inclusion Criteria

A prespecified search strategy (Item S1) was used to identify studies published before January 1, 2017, that

reported the burden or QoL of caregivers of dialysis (facility HD, home HD, or PD) patients. Electronic databases including The Cochrane Library, Embase, PsycINFO, CINAHL, PubMed, and MEDLINE were systematically searched with an English language restriction. Unpublished studies were identified, when possible, by abstracts of conference proceedings, as well as reference lists of relevant studies and review articles.

Two investigators independently evaluated the title and abstract of each study identified from the search for potential inclusion. Any citations without electronically available abstracts were discarded unless the title was convincing of the study's relevance. When there was disagreement between the 2 reviewers, a third investigator adjudicated. A second round of title and abstract review was undertaken to select only quantitative studies involving caregivers of adult patients.

Inclusion criteria limited the systematic review to original investigations, with review articles and commentaries excluded. Other excluded studies used qualitative measures to assess QoL. Studies with >50% of participants being caregivers for non–dialysis-dependent patients (patients with earlier stages of chronic kidney disease, kidney transplant recipients, or patients with other chronic diseases) were also excluded. Caregivers of pediatric dialysis patients were excluded because the issues for children were considered unique.

Full-text articles of each manuscript considered for inclusion based on title and abstract were reviewed independently by 2 investigators. If there was disagreement about whether a study should be included, a third reviewer adjudicated.

Data Extraction and Trial Quality Assessment

A prespecified data extraction instrument was used to collect data from identified studies. Data extraction was completed independently by 2 reviewers with disagreements resolved by consensus. When more than 1 publication of one study existed, reports were grouped together to include the most complete data.

Specific data collected included study design, country, recruitment era, sample size, and dialysis modality. Caregiver data collected included age, sex, relationship to patient, time spent caregiving, education level, and employment status. The scales used to measure various aspects of QoL and/or burden were documented. Comparator groups or any interventions used were noted.

Study quality and risk of bias were assessed using the Newcastle-Ottawa scale,[21] which has been validated for use in both case-control and cohort studies.[22,23] Two authors independently assessed each study for risk of bias using a modified scale including sample representativeness; sample size; comparability with nonrespondents; ascertainment of QoL, burden, or depression; and quality of descriptive statistics reporting (Item S2). Studies were judged low (≥3 points) or high (<3 points) risk of bias.

Continuous data were analyzed using mean differences and their 95% confidence intervals, and dichotomous data were expressed as relative risk and 95% confidence interval. When possible, meta-analysis using a random-effects model was planned using the DerSimonian-Laird approach with sensitivity analysis using the method of residual maximum likelihood. All statistical analyses were conducted using Review Manager (RevMan), version 5.3 Copenhagen (The Nordic Cochrane Centre, The Cochrane Collaboration, 2014) and R, version 3.5.1. $P < 0.05$ was considered to be significant.

Results

Literature Search and Study Characteristics

The search strategy yielded 1,072 articles, of which 86 underwent full-text review (Fig 1). Another 25 were excluded, leaving 61 papers meeting the inclusion/exclusion criteria (Tables 1 and S1). There were 17 studies published before 2000[24-40] and 44 from 2000 to December 2016.[17,41-83]

Fifty-two studies were cross-sectional and 9 studies reporting 897 caregivers were longitudinal.[39,40,49,59,67,68,70,74,76] Eight longitudinal studies were prospective cohort studies, with follow-up ranging from 3 months to 2 years.[40,49,59,67,68,70,74,76] The remaining longitudinal study reported 60 caregivers included in a quasi-randomized controlled trial design.[39] One of the cohort studies collected data pre- and posttransplantation for 67 caregivers.[68] Four studies reporting 221 caregivers collected data before and after an intervention for caregivers and/or patients.[39,59,70,80]

The modified Newcastle-Ottawa Scale revealed that 85% of studies were at high risk of bias (Table S2). Only 3 studies enrolled more than 200 participants,[41,57,67] whereas 2 studies had more than 200 participants but included data previously reported.[43,76] There were frequent methodological flaws in sample representativeness, comparability between respondents and nonrespondents, and poor-quality descriptive statistics. Twenty-seven studies used infrequently used measurement scales, as defined in Item S2.

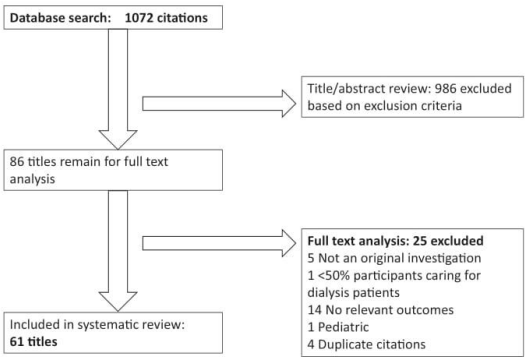

Figure 1. Literature search.

Table 1. Characteristics of Included Studies

Study	Country	Design	N	Caregiver		Employed	Dialysis Modality		
				Female	Age[a]		FHD	HHD	PD
Blogg[24] (1999)	AU	CS	61	68.9%	NA	36.67%	0%	100%	0%
Piira[58] (2002)	AU	CS	38	52.6%	HHD: 51.11 ± 8.77; PD: 54.55 ± 17.17	NA	0%	39.5%	60.5%
Belasco[44] (2002)	BR	CS	100	84%	46.4 ± 1.6	34%	100%	0%	0%
Belasco[43] (2006)	BR	CS	124	80.1%	FHD: 57.5 ± 16; PD: 52.1 ± 14.1	32.34%	80.1%	0%	19.9%
Rideout[29] (1990)	CA	CS	40	65%	51[b]	NA	25%	0%	75%
Rioux[61] (2012)	CA	CS	32	66%	51 ± 11	NA	0%	100%[c]	0%
Srivastava[35] (1988)	CA	CS	30	76.7%	55.4 (28-75)	NA	0%	0%	100%
Starzomski[68] (2000)	CA	CS, LC	67	68.7%	NA	NA	65.7%	0%	34.3%
Suri[76] (2014)	CA, US	LC	188	NA	NA	NA	68.4%	31.6%	0%
Jiang[78] (2015)	CN	CS	38	52.6%	55.8 ± 12.9	60.5%	100%	0%	0%
Morelon[57] (2005)	FR	CS	988	72%	60.8[b]	78.6	100%	0%	0%
Antonaki[77] (2016)	GR	CS	133	55.6%	NA	NA	100%	0%	0%
Khaira[53] (2012)	IN	CS	49	65.3%	41.9 ± 12.5	NA	100%	0%	0%
Rai[60] (2011)	IN	CS	69	NA	NA	NA	100%	0%	0%
Rahim[59] (2009)	IR	LC	36	50%	NA	55.6%	100%	0%	0%
Hener[39] (1996)	IL	RCT	60	66.7%	51.1 ± 10.7	NA	0%	0%	100%
Soskolne[32] (1984)	IL	CS	120	62.5%	48[b]	NA	100%	0%	0%
Soskolne[33] (1987)	IL	CS	63	79.4%	HHD: 50.2 ± 10.1; PD: 54.5 ± 10.7	NA	0%	46%	54%
Soskolne[34] (1989)	IL	CS	68	76.5%	♀: 53 ± 11.6; ♂: 58.5 ± 11.4	NA	100%	0%	0%
Ferrario[50] (2002)	IT	CS	50	80%	54.16 ± 13.22	26%	100%	0%	0%
Matsuu[56] (2001)	JP	CS	43	88%	25%, 42%, & 33% are age 50-59, 60-69, & ≥70	NA	100%	0%	0%
Shimoyama[65] (2003)	JP	CS	34	61.7%	Primary group (n = 22): 50.7 ± 11.7; respite group (n = 12): 38.5 ± 19.2	67.63%	0%	0%	100%
Washio[72] (2012)	JP	CS	108	76.9%	Heavy burden group (n = 48): 64 ± 12; light burden group (n = 60): 61.7 ± 12.5	29.5%	100%	0%	0%
Parlevliet[75] (2012)	NL	CS	50	NA	NA	NA	76.6	0	23.4
Anees[42] (2011)	PK	CS	50	NA	59.46 ± 12.56	NA	100%	0%	0%
Saeed[71] (2012)	PK	CS	180	43.3%	48 (19-76)	39.44	100%	0%	0%
Klak[54] (2008)	PL	CS	30	80%	65 ± 11.21	NA	83.3	0	16.7
Al Wakeel[83] (2016)	SA	CS	105	FHD: 70%; PD: 78.2%	FHD: 40.6 ± 11; PD: 37.5 ± 9.1	35.24	47.6	0	52.4
Griva[82] (2016)	SG	CS	111	72.9%	45.13 ± 14.01	61.1	0%	0%	100%
Kang[74] (2014)	SG	LC	CS: 86; LC: 44	NA	NA	NA	0%	0%	100%
Yu[80] (2016)	SG	Case series	3	NA	NA	NA	0%	0%	100%
Alvarez-Ude[41] (2004)	ES	CS	221	76.8%	56.5 ± 14.9	33.8	68.8	0	31.2
Lindqvist[55] (2000)	SE	CS	35	57.1%	FHD: 60.8 ± 15.1; PD: 62.7 ± 9.9	NA	57.1	0	42.9
Asti[17] (2006)	TR	CS	65	81.5%	43.9 ± 8.52	NA	0%	0%	100%
Avsar[69] (2013)	TR	CS	60	45%	♂: 47.39 ± 15.9; ♀: 36.74 ± 13.6	NA	0%	0%	100%
Avsar[79] (2015)	TR	CS	68	58.8%	43.1 ± 8.5	NA	100%	0%	0%

(Continued)

Table 1 (Cont'd). Characteristics of Included Studies

Study	Country	Design	N	Caregiver		Employed	Dialysis Modality		
				Female	Age[a]		FHD	HHD	PD
Cantekin[81] (2016)	TR	CS	114	FHD: 31%; PD 34%	FHD: 38.24 ± 12.3; PD: 36.64 ± 15.08	NA	47.4%	0%	52.6
Celik[46] (2012)	TR	CS	142	62%	46.1 ± 10.9	NA	100%	0%	0%
Mollaoglu[70] (2013)	TR	LC	122	80.3%	52.4 ± 8.9	9.84%	0%	27.9	72.1
Sezer[64] (2003)	TR	CS	60	46.7%	FHD: 50.9 ± 12.1; PD: 47.1 ± 12.5	NA	55%	0%	45%
Sezer[73] (2013)	TR	CS	40	NA	NA	NA	100%	0%	0%
Yilmaz[66] (2009)	TR	CS	45	68.9%	45.2 ± 10.3	31.1%	100%	0%	0%
Daly[38] (1970)	UK	CS	15	NA	NA	NA	0%	100%[c]	0%
Fan[49] (2008)	UK	LC	36	NA	NA	NA	0%	0%	100%
Brackney[37] (1979)	US	CS	12	100%	NA	NA	0%	100%	0%
Byers[45] (2011)	US	CS	75	100%	NA	NA	100%	0%	0%
Courts[47] (2000)	US	CS	14	92.9%	47 [21]	NA	0%	100%	0%
Daneker[48] (2001)	US	CS	55	76.4%	51.9 ± 13.3	56.4%	100%	0%	0%
Dunn[25] (1994)	US	CS	38	NA	58.4 ± 14.5	NA	0%	0%	100%
Finkelstein[26] (1976)	US	CS	17	58.8%	46 [17.5]	88.2%	58.8%	41.2%	0%
Harris[52] (2000)	US	CS	78	74.2%	Younger group (n = 56): 39.7 ± 9.78; older group (n = 22): 64.45 ± 7.23	70.23%	NA	NA	NA
Harris[51] (2003)	US	CS	120	75.8%	52.2 ± 15.9	51.7%	94.2%	0%	5.8%
Lowry[40] (1984)	US	LC	29	72.4%	48 ± 13	62.07%	0%	100%	0%
Page[27] (1991)	US	CS	37	NA	42.18[b]	35%	NA	NA	NA
Peterson[28] (1985)	US	CS	19	100%	49.6[b]	57.9%	100%	0%	0%
Pruchno[67] (2009)	US	LC	315	73%	67.9 ± 9	NA	100%	0%	0%
Schneider[62] (2002)	US	CS	45	100%	62 ± 13.8	NA	100%	0%	0%
Schneider[63] (2004)	US	CS	80	81.2%	62.6 ± 15.3	NA	100%	0%	0%
Schoeneman[30] (1983)	US	CS	56	100%	52.2 ± 10.6	NA	100%	0%	0%
Simone[31] (1986)	US	CS	15	NA	31.5 ± 6.4	NA	NA	NA	NA
Wicks[36] (1997)	US	CS	76	63.2%	46.7 ± 11.4	67%	76.3%	2.6%	21.1%

Abbreviations: AU, Australia; BR, Brazil; CA, Canada; CN, China; CS, cross-sectional; ES, Spain; FHD, facility-based hemodialysis; FR, France; GR, Greece; HHD, home hemodialysis; IL, Israel; IN, India; IR, Iran; IT, Italy; JP, Japan; LC, longitudinal cohort; NA, not available; NL, Netherlands; PD, peritoneal dialysis; PK, Pakistan; PL, Poland; RCT, randomized controlled trial; SA, Saudi Arabia; SD, standard deviation; SE, Sweden; SG, Singapore; TR, Turkey; UK, United Kingdom; US, United States.
[a]Values given as mean ± SD, median [interquartile range], or mean (range).
[b]Mean (no SD available).
[c]Nocturnal HD.

Study Settings

The 61 studies included 5,367 caregivers from 21 countries (Fig 2), most commonly the United States (22% of caregivers, 17 studies) and a single French study (18.4% of caregivers).[57] Thirty-three studies included multiple centers, and only 1 study was multinational in design.[76]

Caregiver Definition

Few studies provided a definition of a caregiver. When reported, definitions were not comparable and included "the person mainly responsible for looking after the patient during the course of the disease and most closely involved in caring for the patient" as identified by the patient,[44(p806)] "family member caregiver,"[46(p519)] "dialysis partner,"[47(p179)] the "person who principally cared for the patient outside the hospital, regardless of family relationship,"[64(p333)] "the person they could depend on to assist them if they could no longer care for themselves" as identified by the patient,[52(p386)] "a key member of the care-providing team who is expected to be an ever-present source of psychological as well as material support,"[57(p1670)] "dialysis helper,"[28(p16)] and an individual who played "a significant role in the dialysis process and in caring for the patient."[58(p314)]

Caregiver Demographics

Table 1 summarizes clinical and demographic characteristics in all 61 studies. Study sample size ranged from 3 to 988 caregivers. The mean age of caregivers ranged from 31.5 to 67.9 years. When reported, the majority of caregivers were female (70.8%; range, 31%-100%). Education level was reported in 26 studies with 1,766 participants,

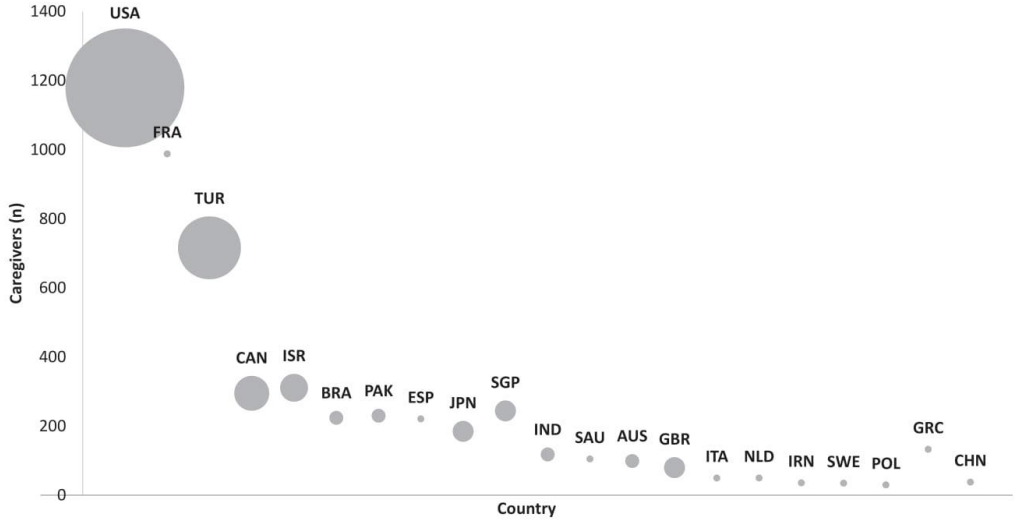

Figure 2. Number of caregivers and studies according to countries (size of bubble in graph represents number of studies). Abbreviations: AUS, Australia; BRA, Brazil; CAN, Canada; CHN, China; ESP, Spain; FRA, France; GBR, Great Britain; GRC, Greece; IND, India; IRN, Iran; ISR, Israel; ITA, Italy; JPN, Japan; NLD, Netherlands; PAK, Pakistan; POL, Poland; SAU, Saudi Arabia; SGP, Singapore; SWE, Sweden; TUR, Turkey; USA, United States of America.

with 15.6% (range, 11.1%-63.1%) reaching tertiary-level education and 12.6% (range, 1.4%-50.8%) illiterate. Employment status was reported in 23 studies with 2,754 participants, with 34.5% (range, 9.8%-88.3%) employed in an occupation outside of their caregiving role. Only 7 studies (13.9% of total participants) reported the mean hours of caregiving, which ranged from 26 to 69 hours per week.

Dialysis Modality

Fifty-seven studies reported dialysis modality in 5,166 (96.3%) patients. Of these, 3,734 (72.3%) were managed with facility HD; 1,066 (20.6%), with PD; and 366 (7.1%), with home HD. Table 2 shows caregivers' age, sex, and relationship to patient by dialysis modality.

Measurement Scales

A total of 70 different quantitative measurement scales were used to assess QoL and caregiver burden (Table S3). The most frequently used scales were the Zarit Burden Interview (ZBI; 1,316 caregivers in 13 studies), the Medical Outcomes Study 36-Item Short Form Survey (SF-36; 835 caregivers in 8 studies), the Center for Epidemiologic Studies Depression Scale (CES-D; 781 caregivers in 7 studies), and the Beck Depression Inventory (BDI; 606 caregivers in 9 studies). Figure 3 shows numbers of caregivers assessed using the most commonly used measurement scales.

The 70 measurement scales used in the studies can be categorized into outcome domains (Table S4). The most frequently studied domain was mental health, including depression, anxiety, and psychological distress.

QoL/Burden Data

When compared with population norms for the SF-36 and accepted thresholds for the ZBI, CES-D, and BDI, caregivers generally experience significant burden and have poorer QoL, but rates of depression are not elevated

Table 2. Demographic Data for Caregivers and Patients According to Dialysis Modality

Demographic Characteristic	Facility-Based Hemodialysis	Home Hemodialysis	Peritoneal Dialysis
Range of mean patient age, y	43.7-74.2 (n = 1,859)	47.1-52.5 (n = 146)	44.7-72.1 (n = 463)
Range of mean caregiver age, y	38.2-67.9 (n = 2,891)	47.3-55.0 (n = 224)	36.6-62.7 (n = 721)
Female sex of caregiver	71.4%; range, 43.3%-100% (n = 3,147)	72.3%; range, 26.7%-100% (n = 155)	66.1%; range, 45.0%-81.5% (n = 649)
Spousal patient-caregiver relationship	90.4%; range, 49%-100% (n = 2,425)	92.8%; range, 60%-100% (n = 222)	77.1%; range, 31.5%-100% (n = 580)

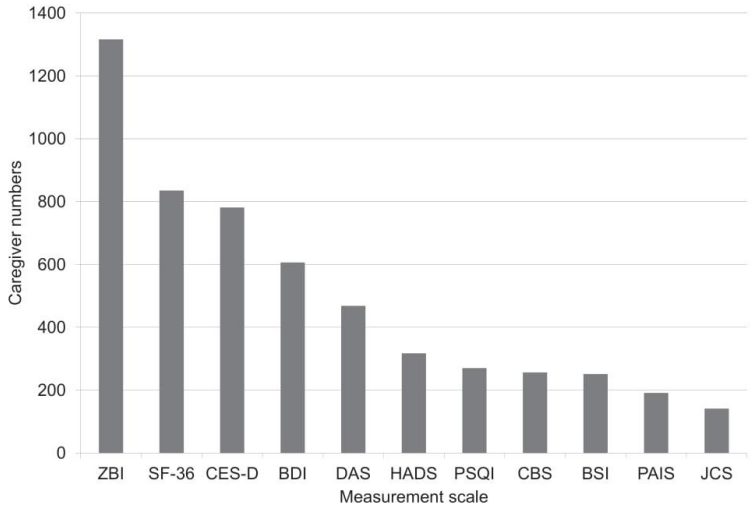

Figure 3. Caregiver numbers assessed by measurement scales in 3 or more studies and 100 or more caregivers. Abbreviations: BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; CBS, Caregiver Burden Scale; CES-D, Center for Epidemiologic Studies Depression Scale; DAS, Dyadic Adjustment Scale; HADS, Hospital Anxiety and Depression Scale; JCS, Jaloweic Coping Scale; PAIS, Psychosocial Adjustment to Illness Scale; PSQI, Pittsburgh Sleep Quality Index; SF-36, Medical Outcomes Study 36-Item Short Form Study; ZBI, Zarit Burden Interview.

(Fig 4). However, studies that reported only categorical results (not included in Fig 4) found depression rates of 34.7% to 55% among caregivers.[45,52,56,64] Less frequently used scales reported significant impairment of QoL.[55,57,74] Dyadic adjustment scale scores[25,48,53,67] were consistent with poor marital adjustment, although there were no data for divorce rates. One study reported higher rates of marital dissatisfaction and distress among caregivers than in a control population.[31] Pittsburgh Sleep Quality Index scores[46,69] reflected poor sleep.

Longitudinal studies had varied outcomes, with one showing no change in QoL over time[49] while others showed a decline in psychosocial adjustment,[39] increasing burden,[74,76] poorer marital adjustment,[67] and worsening QoL.[74]

Caregivers' QoL Compared With a Control Group or General Population

Thirteen studies compared caregiver results with a control group or general population norms. Three of the studies used the SF-36 and showed poorer QoL in caregivers when compared with a control group or the country norm.[55,62,65] The remaining studies used various measurement scales yielding results of either similar or poorer QoL,[74] similar or higher rates of depression,[26,56,64] greater anxiety,[50] poorer adjustment,[31,39,78] and higher rates of stress[32,39,68,78] in caregivers compared with either a control group or the broader community norm.

Caregiver Compared With Dialysis Patient QoL

Twenty-five studies compared caregiver QoL with that of dialysis patients. Figure 5 shows forest plots (using the DerSimonian-Laird approach) comparing caregivers with the dialysis patients they care for as measured with the BDI and SF-36 physical and mental component score. Comparable results were found in the sensitivity analysis using the method of residual maximum likelihood. Nine studies suggested that caregivers were less depressed and had better QoL than the dialysis patients.[17,43,44,46,48,49,53,61,71] The remaining studies used various measurement scales showing either similar or better QoL or less depression in caregivers compared with patients.[25-27,29,34,38,40,42,47,50,65-68,73,78] A single study reported sleep duration and quality as inferior to that of patients in a group of 142 caregivers of facility HD patients.[46]

Impact of Dialysis Modality on Caregivers

Seventeen studies reported data for caregivers of patients from more than 1 dialysis modality,[26,29,33,36,41,43,51,54,55,58,64,68,70,75,76,81,83] of which most only reported combined results, making comparison impossible.[26,29,36,51,54,55,58,68,70,75] Two studies reported on the ZBI and found no difference in caregiver burden between HD or PD. The SF-36 was reported by 2 studies,[41,43] with no difference found between HD and PD caregivers for physical component score. The mental component score was worse for PD caregivers in the smaller study,[43] but comparable in the larger study.[41] A small study from Turkey reported greater somatization and

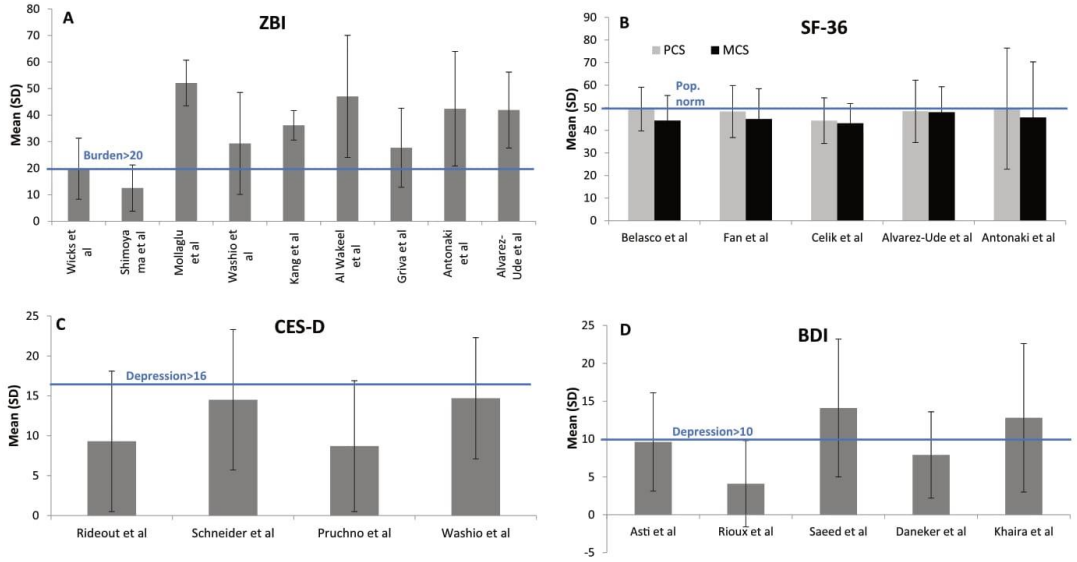

Figure 4. Burden, quality of life, and depression in caregivers of dialysis patients compared with population norm or threshold using the: (A) Zarit Burden Interview (ZBI), (B) Medical Outcomes Study 36-Item Short Form Survey (SF-36), (C) Center for Epidemiologic Studies Depression Scale (CES-D), and (D) Beck Depression Inventory (BDI).

depression among caregivers of facility HD compared with PD patients.[64] The burden on caregivers of assisted PD patients compared with self-care PD patients in Singapore has been reported as equivalent.[82]

The Frequent Hemodialysis Network (FHN) Study showed no difference for caregivers of frequent in-center HD patients, but a nominally increased burden for caregivers of home nocturnal HD when compared with caregivers of standard facility HD patients, although this difference was not statistically significant.[76] However, a study of caregivers of nocturnal home HD patients reported a low BDI score of 4.1 ± 5.7 (75% of caregivers had no depression), but there was no comparator group.[61]

Dialysis Caregivers Compared With Other Caregivers

Seven studies compared QoL of dialysis caregivers with that of other caregivers.[36,55-57,69,75,79] Four studies showed poorer outcomes for dialysis caregivers compared with caregivers of renal transplant recipients.[55,57,69,79] However, transplant recipient caregivers were younger than dialysis caregivers[55] or the patients cared for were not described,[69,79] leading to probable bias. A large French study reported better QoL for caregivers of transplant recipients compared with caregivers of dialysis patients awaiting transplantation.[57] One study showed no difference in 76 dialysis caregivers' QoL compared with caregivers of non–dialysis-dependent patients with chronic kidney disease, although the authors suggested possible sampling bias.[36] Other studies showed no difference in rates of depression in dialysis caregivers compared with caregivers of the frail elderly,[56] but increased burden compared with caregivers of oncology patients.[75]

Discussion

This systematic review has found that caregiver QoL and burden is worse than in the general population and comparable to caregivers of patients with other chronic diseases. Depression is less common than among the cared for dialysis patients and comparable or slightly greater than for the general population. Furthermore, the impact on caregiving for facility HD patients is similar to that of PD patients. QoL is better for caregivers of transplant recipients than dialysis patients.

Despite the breadth of research to date investigating the QoL and burden of dialysis caregivers, a systematic review of the literature is difficult due to the heterogeneity of studies. We found a total of 70 quantitative measurement scales used to assess caregivers across 61 studies, suggesting no consensus among researchers regarding which scales are ideal. Some scales were adapted to suit the study setting or sample, potentially affecting their validity.[44,46,70] Furthermore, caregivers have been studied from various countries and cultures, and it is possible that some scales were not validated in these populations. Numerous studies used multiple scales to measure impact on caregivers, further suggesting a lack of consensus regarding the ideal scales to use. Although the most commonly used scales were the SF-

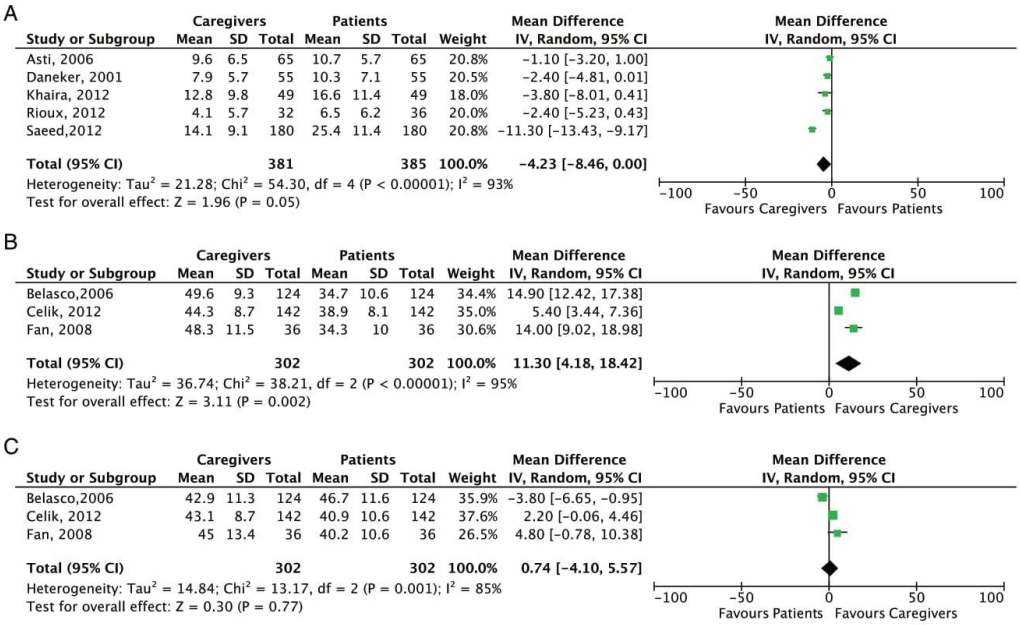

Figure 5. Forest plot comparison of depression and quality of life between caregivers of dialysis patients versus dialysis patients using the: (A) Beck Depression Inventory, (B) Medical Outcomes Study 36-Item Short Form Survey physical component score, and (C) Medical Outcomes Study 36-Item Short Form Survey mental component score. Abbreviations: CI, confidence interval; SD, standard deviation.

36, ZBI, CES-D, and BDI, recommending a preferred measurement scale is difficult. A preferred scale would be simple, brief, and validated across countries and languages and allow comparison with other caregiver and general populations. It is also important that it detects some of the unique issues of caregivers of patients on different dialysis modalities. We suggest a role for qualitative studies and an approach such as used by the SONG (Standardized Outcomes in Nephrology) HD initiative[84] to determine and possibly develop the best scales.

Overall, this review suggests that QoL of caregivers of dialysis patients may not be as poor as some qualitative research suggests.[85-87] However, the scales used may not assess QoL, human emotion, mental state, and relationships, as well as qualitative research. Furthermore, the included studies often do not report the severity of illness of the dialysis patients and the associated caregiving demands.

QoL of dialysis patients undertaking home HD and PD has been reported to be comparable or better[19,20] than for patients undertaking facility HD.[88] This review has found that the burden and QoL of caregivers is comparable between HD and PD. This finding may be confounded by self-selection of people undertaking home dialysis who tend to be younger and may need less caregiver support. Furthermore, the number of caregivers of home HD patients studied is relatively small. Further work is needed to adjust for differences in patient profiles of home dialysis therapies (especially home HD) and facility HD and the assistance they require from caregivers to allow valid comparison.

Secondary outcome data of this systematic review served to build the profile of a dialysis caregiver. This group is dominated by female spouses of often older male patients. Although female sex and younger age are thought to be risk factors for higher levels of burden, the spousal relationship may be protective.[70] A lower education level is also protective, but a significant rate of illiteracy in this systematic review was surprising given the importance and complexity of the caregiving role in maintenance dialysis. When reported, one-third of caregivers were employed, but results from included studies did not allow for comparison of QoL between employed and unemployed caregivers. One study suggests that employment outside the caregiving role may be protective against depression.[71] Caregivers with more health problems have been reported to experience greater burden.[70]

Few studies trialled an intervention to reduce caregiver burden or improve QoL. A previous systematic review found just 3 studies, which all showed that an education intervention led to improved knowledge of caregivers, but no other outcomes were measured.[89] Among studies in this systematic review, an education program reduced burden,[70] a continuous care model improved perceived QoL,[59] and

supportive and cognitive behavioral therapy aided maintenance of psychosocial adjustment over time.[39] These studies are small and require replication, and further work is needed, perhaps by qualitative interviews, to identify which supports are needed and have the greatest impact.

This systematic review has a number of limitations. Despite using quantitative measures of QoL, many studies only reported data graphically or categorically, which limited our ability to examine the data further. Studies did not report data to allow assessment of the caregiver role and the impact of caregiver age, marital and employment status, or dialysis vintage on caregiver burden and QoL. Overall study quality was generally poor and there is a high likelihood of recruitment or participation bias. Refusal to participate by the most affected patients is an inherent problem with studies that may include those with depression, anxiety, distress, or significant burden.[29] The limitation to English publications may reduce data available from some cultures or ethnic backgrounds that will not have been included. Caregivers of pediatric dialysis recipients were excluded from this analysis and our findings may not be applicable to this population.

Relatively few studies in this systematic review were longitudinal in nature or trialled an intervention. These issues must be addressed in future research. Does the caregiver's QoL reflect the severity of illness and QoL of the dialysis patient or the duration and demands of caregiving? There is also a relative paucity of data surrounding home HD caregivers in comparison to facility HD. Another important area lacking data is the effect of increasing HD frequency or extending HD hours, including at night. Patients enrolled in the FHN trials perceived caregiver burden to be high, but the caregivers themselves did not participate in the study.[90] The enthusiasm for home HD among some nephrologists, as well as opportunities for novel regimens, highlights a need to explore the impact on caregivers.

In conclusion, caregivers have an important role in the management of people undergoing dialysis. This review demonstrates that caregiver QoL is adversely affected compared with the general population and comparable to other chronic disease caregivers. Suggestions that home-based therapies strain the caregiver psychosocial well-being[44] are not supported by this systematic review, although further work is needed with better longitudinal and case-matched studies. Consensus on the best scales to measure QoL and burden will also assist interpretation of results and reproducibility of data. Last, studying and implementing interventions to assist caregivers and improve their QoL will hopefully enable them to persist in their role and support the dialysis recipient in the long term.

Supplementary Material

Item S1: Search strategy.

Item S2: Modified Newcastle-Ottawa risk of bias scoring guide for caregivers of dialysis patients.

Table S1: Measurement scales and results of included studies.

Table S2: Risk of bias assessment for included studies using Newcastle-Ottawa scale.

Table S3: Measurement scales–frequency of use.

Table S4: Summary of outcome domains by number of measurement scales.

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Support: No financial support for this research was received.

Financial Disclosure: The authors declare that they have no relevant financial interests.

Peer Review: Received April 10, 2018. Evaluated by 2 external peer reviewers, with direct editorial input from a Statistics/Methods Editor, an Associate Editor, and the Editor-in-Chief. Accepted in revised form September 16, 2018.

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Item S1: Search strategy

The Cochrane Library (1993 to 31 December 2016)

carer OR caregiver OR partner OR spouse [Title, abstract, keywords]

AND

dialysis OR haemodialysis OR hemodialysis OR peritoneal dialysis OR home hemodialysis OR home haemodialysis [Title, abstract, keywords]

Limit to English language

EMBASE (1974 to 31 December 2016)

carer OR caregiver OR partner OR spouse [Title, abstract, keywords]

AND

dialysis OR haemodialysis OR hemodialysis OR peritoneal dialysis OR home hemodialysis OR home haemodialysis [Title, abstract, keywords]

Limit to English language

PsycINFO (1806 to 31 December 2016)

carer OR caregiver OR partner OR spouse [Title, abstract, keywords]

AND

dialysis OR haemodialysis OR hemodialysis OR peritoneal dialysis OR home hemodialysis OR home haemodialysis [Title, abstract, keywords]

Limit to English language

CINAHL (1937 to 31 December 2016)

carer OR caregiver OR partner OR spouse [Title, abstract, keywords]

AND

dialysis OR haemodialysis OR hemodialysis OR peritoneal dialysis OR home hemodialysis OR home haemodialysis [Title, abstract, keywords]

Limit to English language

PubMed (1966 to 31 December 2016)

carer OR caregiver OR partner OR spouse [Title, abstract, keywords]

AND

dialysis OR haemodialysis OR hemodialysis OR peritoneal dialysis OR home hemodialysis OR home haemodialysis [Title, abstract, keywords]

Limit to English language

MEDLINE (1946 to 31 December 2016)

carer OR caregiver OR partner OR spouse [Title, abstract, keywords]

AND

dialysis OR haemodialysis OR hemodialysis OR peritoneal dialysis OR home hemodialysis OR home haemodialysis [Title, abstract, keywords]

Limit to English language

Item S2: Modified Newcastle-Ottawa risk of bias scoring guide for Caregivers of Dialysis Patients

Sample representativeness

1 point: Population contained multiple caregivers of ≥2 dialysis modalities at ≥2 sites.

0 points: Population contained either a single dialysis modality, single site, or both.

Sample size

1 point: Sample size was ≥200 participants.

0 points: Sample size was <200 participants.

Non-respondents

1 point: Comparability between respondent and non-respondent characteristics

was established with a satisfactory response rate.

0 points: The comparability between respondents and non-respondents was

unsatisfactory, the response rate was unsatisfactory, or there was no description of

the response rate or the characteristics of the responders or non-responders.

Ascertainment of quality of life, burden, or depression

1 point: The study employed a commonly used validated measurement tool (Beck Depression Inventory, Centre for Epidemiologic Studies Depression Scale, Hospital Anxiety and Depression Scale, Medical Outcomes Study 36 Item Short Form Survey, Zarit Burden Interview, Spielberger State-Trait Inventory, 12 Item Short Form Health Survey, Perceived Social Support, Pittsburgh Sleep Quality Index, Fatigue Severity Scale)

0 points: The study employed an infrequently used or non-validated measurement tool.

Quality of descriptive statistics reporting

1 point: The study reported descriptive statistics to describe the population (age, gender, caregiver relationship to dialysis patient) with proper measures of dispersion (mean, standard deviation).

0 points: The study did not report descriptive statistics, incompletely reported descriptive statistics, or did not report measures of dispersion.

Scoring: The individual components listed above are summed to generate a total modified Newcastle-Ottawa risk of bias score for each study.

Table S1: Measurement scales and results of included studies

First author, year of publication (reference)	Measurement scale	Results	Conclusions/Significance
Alvarez-Ude, F. 2004 [1]	Medical Outcomes Study 36 Item Short Form Survey	PCS 48.4 ± 13.8 MCS 48.0 ± 11.3	Authors report caregiver quality of life as slightly below population norm although statistical analysis not performed No significant difference in caregiver quality of life between dialysis modalities
	Zarit Burden Interview	41.9 ± 14.3	Moderate caregiver burden in 32.6% and severe in 7.3% No significant difference in caregiver burden between dialysis modalities
	Duke-UNC Functional Social Support Questionnaire	42.4 ± 8.0	Low social support in 12.2% of caregivers No significant difference in caregiver support between dialysis modalities
Anees, M. 2011 [2]	World Health Organisation Quality of Life Questionnaire	Physical health 14.96±3.04 Psychological health 14.08±2.85 Social relationship 14.64±3.74 Environment 12.76±2.93	Caregiver quality of life greater than HD patients in physical health, psychological health and social relationship domains No difference in environment domain
Asti, T. 2006 [3]	University of California Los Angeles Loneliness Scale	28.3±14.96	93.8% had low levels of loneliness Loneliness levels lower than PD patients
	Beck Depression Index	9.61±6.49	86.1% had no clinically significant depression
	Perceived Social Support	Family 17.95±2.97 Friends 14.23±3.46	High perceived social support from family and friends
Belasco, A. 2006 [4]	Medical Outcomes Study 36 Item Short Form Survey[a]	Elderly HD PCS 49.6±9.1 Elderly HD MCS 45.7±11.1 PD PCS 49.6±9.7 PD MCS 37±12	MCS significantly lower for PD caregivers compared with HD caregivers and the general population Caregivers had higher PCS than elderly HD and PD patients Caregivers had equivalent MCS to elderly HD patients but lower MCS than PD patients

	Caregiver Burden Scale	Elderly HD 2.06±0.47 PD 2.05±0.59	Greater caregiver burden compared with other studies of caregivers (stroke, rheumatoid arthritis) No difference between HD and PD caregivers
	Cognitive Index of Depression	HD 67.2% nil, 29.5% mild, 3.3% moderate depression PD 70% nil, 25% mild, 2.5% moderate, 2.5% severe depression	Nearly one-third of caregivers report depression No difference between HD and PD caregivers
Belasco, A. 2002 [5]	Medical Outcomes Study 36 Item Short Form Survey	Functional capacity 83.9 ± 2.0 Physical aspect 66.3 ± 4.1 Pain 75.1 ± 2.6 General health 69.5 ± 2.2 Vitality 66.6 ± 1.7 Social aspect 80.2 ± 2.6 Emotional aspect 75.3 ± 3.9 Mental Health 64.4 ± 1.8	Greatest impairment in mental health, vitality and physical aspect domains Scores in mental health, emotional and physical aspect domains lower than general USA population
	Caregiver Burden Scale	2.07±0.05	Greater caregiver burden compared with other studies of caregivers (stroke, rheumatoid arthritis) Greater burden in female caregivers compared with male Lower caregiver quality of life correlated with increased burden
Blogg, A. 1999 [6]	28-Item General Health Questionnaire	49.14±12.06	Low to moderate caregiver distress, greater in younger caregivers
	Relatives' Stress Scale	21.1±10.95	Low to moderate caregiver burden
Byers, 2011 [7]	Center for Epidemiological Studies Depression Scale	Median 12 65.3% nil, 14.7% mild, 14.7% moderate, 4% severe depression	35% of caregivers had a degree of depression Consistent with caregivers of elderly
Celik, G. 2012 [8]	Pittsburgh Sleep Quality Index	11.9±3.0	88% poor sleepers Caregiver sleep quality poorer than dialysis patients
	Medical Outcomes Study 36 Item Short Form Survey	MCS 43.1±8.7 PCS 44.3±10.1	Caregiver quality of life better than HD patients
	Hospital Anxiety and	Depression 7.2±4.7	43.3% of caregivers depressed

	Depression Scale	Anxiety 7.8±4.4	No difference between caregivers and HD patients overall scores
Courts, N. 2000 [9]	Clinical Anxiety Scale	Mean 9 (range 2-19)	No clinically significant anxiety
	Generalised Contentment Scale	Mean 20.3 (range 6-29)	No clinically significant depression
	Spielberger State-Trait Inventory	State mean 31.8 (range 20-52) Trait mean 33.8 (range 20-52)	Low levels of anxiety
Daneker, B. 2001 [10]	Beck Depression Index	7.9±5.7	8.9% of caregivers reached criteria for severe depression Lower scores than dialysis patients
	Dyadic Adjustment Scale	35.6±7.0	Poor marital adjustment
	Multidimensional Scale of Perceived Social Support	60.9±16.3	Low to adequate perceived social support
Dunn, S. 1994 [11]	Quality of Life Index	21.99±3.65	Moderate quality of life Quality of life comparable to PD patients except poorer family domain
	Dyadic Adjustment Scale	38% below average, 34% average, 28% above average	At least 62% have reasonable marital adjustment
	Jalowiec Coping Scale	Problem-oriented 62.5±14.6 Affective-oriented 45.6±9.59	PD caregivers used more problem-oriented than affective-oriented coping strategies
Fan, S. 2008 [12]	Medical Outcomes Study 36 Item Short Form Survey	PCS 48.3±11.5 MCS 45.0±13.4	Caregiver quality of life greater than patients in all domains, especially physical PCS and MCS did not change over 12 months follow up
Ferrario, S. 2002 [13]	Spielberger State-Trait Inventory	State 41.16±11.05 Trait 41.16±9.15	Low to moderate anxiety No difference compared with the general population
	Depression Questionnaire	5.28±3.85	Low risk of depression, lower than the general population
	Satisfaction with Life Scale	Numerical data not Reported	

	Family Strain Questionnaire	Numerical data not reported	
Finkelstein, F. 1976 [14]	Kupfer-Detre System Form 1	Depression cluster 4.3±0.7 Organic cluster 2.9±0.6	Rates of caregiver depression and organic brain dysfunction lower than dialysis patients
Harris, T. 2003 [15]	Center for Epidemiological Studies Depression Scale	Median 12 (IQR 4-21) 60.2% nil, 15% mild, 15.8% moderate, 9% severe depression	39.8% of caregivers experience depression
	Measurement of Burden Scale	Objective 29.61±5.52 Subjective median 23 (IQR 18-29)	Low subjective burden but moderate objective burden
Harris, T. 2000 [16]	Zarit Burden Interview	68% little to none, 28% mild to moderate, 8% moderate to severe, nil severe burden	Most caregivers suffer mild or no burden
Khaira, A. 2012 [17]	Beck Depression Index	12.8±9.8	42.8% depressed
	Revised Dyadic Adjustment Scale	25.3±16.2	24.4% suffering marital distress
	Quality of Life (single question, Likert 1-5)	2.8±1.2	
Klak, R. 2008 [18]	28-Item General Health Questionnaire	Mean 5 (no SD) 87% scored >2	High levels of psychological distress
	Questionnaire of Caregiver's Burden	Mean 20 (no SD)	High caregiver burden
Lindqvist, R. 2000 [19]	Swedish Health-Related Quality of Life Survey	Summary numerical data not reported	Quality of life poorer than caregivers of transplant patients and than the general population No significant difference between HD and PD caregivers
	Jalowiec Coping Scale	Only sub-scale data reported	Optimism the most widely used coping strategy
Matsuu, K. 2001 [20]	Center for Epidemiological Studies Depression Scale	40% depressed	Rates of depression similar to caregivers of frail elderly
Morelon, E. 2005 [21]	Quality of Life (single question, 1-10)	Graphical format only	Quality of life poorer than caregivers of transplant patients
Page, S. 1991 [22]	Family Environment Scale	Data presented for 10 sub-scales separated by home	Family environment not significantly different between home and hospital-based therapy caregivers

		or hospital-based dialysis	
	Marital Attitudes Evaluation Scale	Data presented for 10 sub-scales separated by home or hospital-based dialysis	Home-based therapy caregivers report greater marital satisfaction than hospital-based caregivers
Peterson, K. 1985 [23]	Sickness Impact Profile	Not clearly reported (only % change within each subscale) 61.1% change in social interaction scale	Commencement of home therapy most significantly impacted social interaction, recreational pastimes and sexual activity
Piira, T. 2002 [24]	Locus of Control Behaviour Scale Jalowiec Coping Scale Depression Anxiety and Stress Scale	Not reported	Negative affect of caregivers predicted by patient disability and caregiver coping mechanisms such as emotion-focused No significant difference between caregivers of home HD patients compared with caregivers of PD patients
Rahim, A. 2009 [25]	Perceived Quality of Life Questionnaire	Pre-intervention 54.9±23.4 Post-intervention 64.8±21.9	Applying a continuous care model improved perceived quality of life.
Rai, M. 2011 [26]	Beck Depression Index	32% scored >10	Approximately 32% of caregivers experience depression.
Rideout, E. 1990 [27]	Center for Epidemiological Studies Depression Scale Impact on Family Scale Perceived Social Support	9.3 ± 8.8 15.1 ± 6.1 101.1 ± 16.6	Rates of caregiver depression (20%) similar to dialysis patients and general population Good support of caregivers by patients
Rioux, J. 2012 [28]	12 Item Short Form Health Survey Beck Depression Index Caregiver Burden Scale	PCS 49.4±10.2 MCS 46.1±11.6 4.1±5.7 Global burden 1.7 ±0.5	Caregivers had higher PCS but similar MCS to dialysis patients 25% of caregivers report depression Low levels of global burden
Schneider, R. 2002 [29]	Medical Outcomes Study 36 Item Short Form Survey	Functional capacity 68.22 ± 40.02 Physical aspect 63.67 ± 18.09 Pain 26.2 ± 7.98 General health 53.62 ±	Quality of life poorer than general population

		10.76 Vitality 63.22 ± 11.83 Social aspect 53.33 ± 8.17 Emotional aspect 69.78 ± 39.87 Mental Health 61.96 ± 7.98	
	Multidimensional Fatigue Inventory	General fatigue 11.86±3.67	
Schneider, R. 2004 [30]	Fatigue Severity Scale 12 Item Short Form Health Survey Center for Epidemiological Studies Depression Scale	27.41±13.71 PCS 46.42±10.88 MCS 47.77±11.19 14.46±8.75	Fatigue burden on caregivers Quality of life poorer than general population Little to no depression
Schoeneman, S. 1983 [31]	Multidimensional health locus of control scale Spielberger State-Trait Inventory Beck Depression Index	Not reported	Higher anxiety/depression in caregivers with external locus of control
Sezer, M. 2003 [32]	Brief Symptom Inventory Brief Disability Questionnaire Social Disability Schedule	HD 0.64±0.53 PD 0.53±0.34 Not reported Not reported	Greater somatisation and depression in caregivers of facility-based HD patients compared with both caregivers of PD patients and non-caregiver controls Physical disability of caregivers not different for HD and PD patients Social disability of caregivers not different for HD and PD patients
Shimoyama, S. 2003 [33]	Medical Outcomes Study 36 Item Short Form Survey	Physical Functioning 90.9 Role Physical 90.9 Pain 72.1 General health 61.5 Vitality 61.0 Social functioning 87.5 Emotional functioning 87.9 Mental Health 68.7	Quality of life better than PD patients for physical functioning, role physical, general health, social functioning, emotional functioning and overall poorer than general population

	Zarit Burden Interview	10.2 ± 8.7	Little to no burden
Simone, S. 1986 [34]	Locke-Wallace Marital Adjustment Scale Spouse Observation Checklist Area of Change Questionnaire Marital Satisfaction Inventory	Multiple subscale results reported, no summary scores	Increased incidence of marital dissatisfaction and distress than control population
Soskolne, V. 1984 [35]	Langer 22-Item Scale	Oriental origin 6.7±4.2 Western origin 4.7±3.1	No statistically significant difference between ethnic groups or compared to control groups
Soskolne, V. 1987 [36]	Brief Symptom Inventory Psychosocial Adjustment to Illness Scale	Not reported Home HD 26.9±17.78 Hospital HD (group 1) 34.9±19.29 PD 30.3±17.18 Hospital HD (group 2) 36.7± 21.83	No evidence of increased stress for spouses of patients on home dialysis compared with hospital dialysis
Soskolne, V. 1989 [37]	Brief Symptom Inventory Psychosocial Adjustment to Illness Scale	Graphical format only Graphical format only	Less psychological distress in spouses than dialysis patients Poorer adjustment of female spouses compared to patients No difference with male spouses and patients
Srivastava, R. 1988 [38]	Modified Jalowiec Coping Scale Visual analogue scale	Not reported 60% reported >80/100 for coping well	Spouses of peritoneal dialysis patients perceive themselves to be coping well
Wicks, M. 1997 [39]	Quality of Life (single question, Likert 1-5) Zarit Burden Interview	23% excellent, 57% good, 17% adequate, 1% poor, 1% very poor 19.84±11.5	97% of caregivers report adequate, good or excellent quality of life 60% little to no burden, 35% mild to moderate, 5% moderate to severe

Yilmaz, A. 2009 [40]	Hamilton Depression Rating Scale Hamilton Anxiety Rating Scale Arizona Sexual Experience Scale	4.98±5.62 6.29±6.38 14.04±6.00	Low rates of depression, and less than dialysis patients Low rates of anxiety, and less than dialysis patients Low rates of sexual dysfunction, and less than dialysis patients
Brackney, B. 1979 [41]	Locke-Wallace Marital Adjustment Scale	Numerical result not reported	Caregiver marital satisfaction positively correlated with physical health and emotional adjustment of patient
Daly, R. 1970 [42]	Sleep (hours per night)	Weekly total: mean 53.6 ± 5.5 hours	Less sleep than dialysis patients on non-dialysis nights
Hener, T. 1996 [43]	Brief Symptom Inventory Millon Behavioural Health Inventory Psychosocial Adjustment to Illness Scale Beck Depression Index Perceived Self-Control and Self-Efficacy Lavic Sleep Scale Family Environment Scale Dyadic Adjustment Scale	Results of multiple subscales combined	Psychosocial adjustment of a control group of caregivers deteriorated over time Supportive and cognitive-behavioural interventions aided maintenance or slight improvement in psychosocial adjustment over time
Lowry, M. 1984 [44]	No validated scale (symptom frequency only)	38% depressed mood, 38% sleep disturbance, 45% reduced concentration, 10% suicidal thoughts	Approximately one-third of caregivers reported depressive symptoms, anxiety and irritability but most did not meet criteria for a diagnosis of depression
Pruchno, R. 2009 [45]	Dyadic Adjustment Scale	Baseline 37±4.9 2-year follow-up 36.3±5.7	Poor marital adjustment with deterioration over time

	Center for Epidemiological Studies Depression Scale	Baseline 8.7±8.2 2-year follow-up 9.7±8.2	No significant depression Depressive symptoms associated with own marital satisfaction
Starzomski, R. 2000 [46]	Family Inventory of Life Events and Changes Family Inventory of Resources and Management Feetham Family Functioning Survey	277.6±269 123.1±23.9 Absolute satisfaction score 7.4±6.5	Lower absolute satisfaction scores than dialysis patients, but not reaching statistical significance[b] Greater stress than general population
Avsar, U. 2013 [47]	Pittsburgh Sleep Quality Index Hospital Anxiety and Depression Scale Zarit Burden Interview	Poor sleep quality 38.3% Depression 38.3% Anxiety 31% 31.6% low, 50% moderate, 18.3% severe caregiver burden	Greater anxiety and depression, poorer sleep quality, and greater burden than caregivers of transplant patients
Mollaoglu, M. 2013 [48]	Zarit Burden Interview	52.1 ± 8.6	Moderate caregiver burden Burden greater in females, singles, young, and those with health problems Burden reduced by an education program
Saeed, Z. 2012 [49]	Beck Depression Index	14.1±9.1	33.4% were moderately or severely depressed Depression less severe than dialysis patients
Washio, M. 2012 [50]	Zarit Burden Interview Center for Epidemiological Studies Depression Scale	29.3±19.2 Heavily-burdened group 19±9.5 Lightly-burdened group 11.2±5.6	Mild to moderate caregiver burden Mild caregiver distress
Sezer, S. 2013 [51]	Beck Depression Index	55% depressed	Rates of caregiver depression correlated with patient depression
Kang, A. 2014 [52]	World Health Organisation Quality of Life Questionnaire Zarit Burden Interview Lay Care-Giving for Adults	Baseline 17.05±3.86 1-year follow-up 15.18±2.88 Baseline 36±5.55 1-year follow-up 41.39±5.44 Numerical results not	Poorer quality of life compared with general population, declining over one year Moderate caregiver burden, increasing over one year

	Receiving Dialysis Hospital Anxiety and Depression Scale	reported No baseline data 1-year follow-up: Anxiety 5.13±1.53 1-year follow-up: Depression 6.55±2.55	
Parlevliet, J. 2012 [53]	Systematic Comprehensive Geriatric Assessment	84.4% overburdened	Higher burden than caregivers of oncology patients
Suri, R. 2014 [54]	Cousineau Perceived Burden Scale	Facility HD baseline conventional 37.7±23, daily 37.1±27.6 Facility HD 4-month follow-up conventional 35±22.7, daily 32.9±25.1 Facility HD 12-month follow-up conventional 31.2±21.9, daily 30.1+/22.9 Home HD baseline conventional 32.9±18.3, daily nocturnal 32±19.7 Home HD 4-month follow-up conventional 32±16.9, daily nocturnal 41.1±18.5 Home HD 12-month follow-up conventional 26.9±15.3, daily nocturnal 33.9±22	A trend to increased caregiver burden (as perceived by patients) over time for the nocturnal HD group, with no change over time for the other groups
Antonaki, E. 2016 [55]	Zarit Burden Interview Medical Outcomes Study 36 Item Short Form Survey	42.4±21.6 Males PCS 51.4±27.1, MCS 48.6±25.3 Females PCS 48.1±27, MCS 43.4±24.3	Moderate to severe caregiver burden
Jiang, H. 2015 [56]	Family Adaptability and Cohesion Evaluation Scales	34.21% inflexible family	Reduced flexibility in family adaptability compared with control group

	Evaluating & Nurturing Relationship Issues, Communication & Happiness	Stress reaction 59.02 ± 22.76 Instrumental support 10.20 ± 3.09	Higher levels of stress reactions compared with control group
Avsar, U. 2015 [57]	Pittsburgh Sleep Quality Index Hospital Anxiety and Depression Scale Zarit Burden Interview	Poor sleep quality 36.8% Anxiety 29.4% Depression 42.6% 45.6% low, 39.7% moderate, 14.7% severe burden	Greater anxiety and depression, poorer sleep quality, and greater burden than caregivers of transplant patients
Yu, Z. 2016 [58]	12 Item Short Form Health Survey Hospital Anxiety and Depression Scale (depression sub-scale) Zarit Burden Interview Short Form 12	Data in graphical format and only 3 caregivers included	Too small to draw conclusions
Cantekin, I. 2016 [59]	Zarit Burden Interview	HD 13% low, 53.7% intermediate, 33.3% high burden PD 35% low, 48.3% intermediate, 16.7% high burden	PD caregivers had lower levels of burden than HD caregivers
Griva, K. 2016 [60]	Zarit Burden Interview Lay Care-Giving for Adults Receiving Dialysis	27.73+/-14.86 (assisted PD) 27.13 ± 14.85 (self-care PD) Think 3.88+/-0.68 (assisted PD) and 3.82 ± 0.96 (self-care PD) Task 3.64+/-0.71 (assisted PD) and 3.22 ± 0.91 (self-care PD)	Mild to moderate caregiver burden Caregivers of assisted PD patients did not experience higher burden than family members of self-care PD patients Assisted PD caregivers reported higher overall Task scores (concrete and observable tasks related to caregiving)

Al Wakeel, J. 2016 [61]	Zarit Burden Interview	HD 43.3±21.7 PD 49.9±24.5	Moderate to severe caregiver burden, no difference between HD and PD

[a]MCS and PCS data for caregivers of non-elderly HD patients not included in this review as data for those caregivers are included in domain scores

Table S2: Risk of bias assessment for included studies using Newcastle-Ottawa scale

Author, year, Study number	Representativeness	Sample size (≥200)	Non-respondents	Ascertainment of quality of life, burden or depression	Descriptive statistics	Total
Alvarez-Ude, F 2004 (41)	1	1	0	1	1	4
Anees, M. 2011 (42)	0	0	0	0	0	0
Asti, T. 2006 (17)	0	0	1	1	0	2
Belasco, A. 2006 (43)	1	1*	0	1	1	4
Belasco, A. 2002 (44)	0	0	0	1	1	2
Blogg, A. 1999 (24)	0	0	1	0	0	1
Byers, D. 2011 (45)	0	0	0	1	0	1
Celik, G. 2012 (46)	0	0	0	1	0	1
Courts, N. 2000 (47)	0	0	0	1	1	2
Daneker, B. 2001 (48)	0	0	1	1	1	3
Dunn, S. 1994 (25)	0	0	0	0	1	1
Fan, S. 2008 (49)	0	0	0	1	1	2
Ferrario, S. 2002 (50)	0	0	0	1	1	2
Finkelstein, F. 1976 (26)	1	0	0	0	1	2
Harris, T. 2003 (51)	1	0	0	1	1	3
Harris, T. 2000 (52)	0	0	0	1	1	2
Khaira, A. 2012 (53)	0	0	0	1	1	2
Klak, R. 2008 (54)	0	0	0	0	1	1
Lindqvist, R. 2000 (55)	1	0	0	0	1	2
Matsuu, K. 2001 (56)	0	0	0	1	0	1

Morelon, E. 2005 (57)	0	1	0	0	0	1
Page, S. 1991 (27)	0	0	0	0	0	0
Peterson, K. 1985 (28)	0	0	0	0	0	0
Piira, T. 2002 (58)	0	0	0	0	1	1
Rahim, A. 2009 (59)	0	0	0	0	0	0
Rai, M. 2011 (60)	0	0	0	1	0	1
Rideout, E. 1990 (29)	0	0	0	1	0	1
Rioux, J. 2012 (61)	0	0	0	1	1	2
Schneider, R. 2002 (62)	0	0	0	1	1	2
Schneider, R. 2004 (63)	0	0	0	1	1	2
Schoeneman, S. 1983 (30)	1	0	0	1	1	3
Sezer, M. 2003 (64)	0	0	0	1	1	2
Shimoyama, S. 2003 (65)	0	0	0	1	1	2
Simone, S. 1986 (31)	0	0	0	0	0	0
Soskolne, V. 1984 (32)	0	0	1	0	0	1
Soskolne, V. 1987 (33)	1	0	1	0	1	3
Soskolne, V. 1989 (34)	0	0	0	0	1	1
Srivastava, R. 1988 (35)	0	0	0	0	1	1
Wicks, M. 1997 (36)	1	0	0	1	1	2
Yilmaz, A. 2009 (66)	0	0	0	0	1	1
Brackney, B 1979	0	0	0	0	0	0

(37)						
Daly, R. 1970 (38)	1	0	0	0	0	1
Hener, T. 1996 (39)	0	0	0	1	1	2
Lowry, M. 1984 (40)	0	0	0	0	1	1
Prunchno, R. 2009 (67)	0	1	1	1	1	4
Starzomski, R. 2000 (68)	1	0	0	0	0	1
Avsar, U. 2013 (69)	0	0	0	1	0	1
Mollaoglu, M. 2013 (70)	1	0	0	1	1	3
Saeed, Z. 2012 (71)	0	0	0	1	0	1
Washio, M. 2012 (72)	0	0	0	1	1	2
Sezer, S. 2013 (73)	0	0	0	1	0	1
Kang, A. 2014 (74)	0	0	0	1	0	1
Parlevliet, J 2012 (75)	1	0	0	0	0	1
Suri, R. 2014 (76)	1	1*	1	0	0	3
Antonaki, E. 2016 (77)	0	0	0	1	0	1
Jiang, H. 2015 (78)	0	0	0	1	1	2
Avsar, U. 2015 (79)	0	0	0	1	0	1
Yu, Z. 2016 (80)	0	0	0	1	0	1
Cantekin, I. 2016 (81)	0	0	0	1	0	1
Griva, K. 2016 (82)	0	0	0	1	1	2
Al Wakeel, J. 2016 (83)	0	0	0	1	1	2

* Although including >200 participants, these studies included participant data reported elsewhere and total included in the systematic review was <200 from each of these studies

Table S3: Measurement scales - frequency of use

Scale	Number of studies	Caregiver numbers (% of total)	Scale	Number of studies	Caregiver numbers (% of total)
Zarit Burden Interview	13	1316 (24.5)	Millon Behavioural Health Inventory	1	60 (1.1)
Beck Depression Inventory	9	606 (11.3)	Perceived Self-Control and Self-Efficacy	1	60 (1.1)
Centre for Epidemiologic Studies Depression Scale	7	781 (14.6)	Social Disability Schedule	1	60 (1.1)
Medical Outcomes Study 36 Item Short Form Survey	8	835 (15.6)	Multidimensional Health Locus of Control Scale	1	56 (1)
Hospital Anxiety and Depression Scale	5	317 (5.9)	Multidimensional Scale of Perceived Social Support	1	55 (1)
Dyadic Adjustment Scale	4	468 (8.7)	Depression Questionnaire	1	50 (0.9)
Brief Symptom Inventory	4	251 (4.8)	Family Strain Questionnaire	1	50 (0.9)
Jalowiec Coping Scale	4	141 (2.6)	Satisfaction with Life Scale	1	50 (0.9)
Pittsburgh Sleep Quality Index	3	270 (5)	Systematic Comprehensive Geriatric Assessment	1	50 (0.9)
Caregiver Burden Scale	3	256 (4.8)	Revised Dyadic Adjustment Scale	1	49 (0.9)
Psychosocial Adjustment to Illness Scale	3	191 (3.6)	Arizona Sexual Experience Scale	1	45 (0.8)
Spielberger State-Trait Inventory	3	90 (1.7)	Hamilton Anxiety Rating Scale	1	45 (0.8)
WHO Quality of Life questionnaire	2	136 (2.5)	Hamilton Depression Rating Scale	1	45 (0.8)
Quality of life (single question rated 1-5)	2	125 (2.3)	Multidimensional Fatigue Inventory	1	45 (0.8)
12 Item Short Form Health Survey	2	112 (2.1)	Impact on Family Scale	1	40 (0.7)
Perceived Social Support	2	105 (2)	Depression Anxiety and Stress Scale	1	38 (0.7)
Family Environment Scale	2	97 (1.8)	Evaluating & Nurturing Relationship Issues, Communication & Happiness	1	38 (0.7)
Sickness Impact Profile	2	57 (1.1)	Family Adaptability and Cohesion Evaluation Scales	1	38 (0.7)
Locke-Wallace	2	27 (0.5)	Locus of Control	1	38 (0.7)

Marital Adjustment Scale			Behaviour Scale		
Quality of life (single question rated 0-10)	1	988 (18.4)	Quality of Life Index	1	38 (0.7)
Cousineau Perceived Burden Scale	1	253 (4.7)	Marital Attitudes Evaluation Scale	1	37 (0.7)
Duke-UNC Functional Social Support Questionnaire	1	221 (4.1)	Perceived Quality of Life Questionnaire	1	36 (0.7)
Cognitive Index of Depression	1	124 (2.3)	Swedish Health-Related Quality of Life Survey	1	35 (0.7)
Langer 22-item Scale	1	120 (2.2)	General Health Questionnaire (12-item)	1	30 (0.6)
Measurement of Burden Scale	1	120 (2.2)	Modified Jaloweic Coping Scale	1	30 (0.6)
Lay Care-Giving for Adults Receiving Dialysis	1	86 (1.6)	Questionnaire of Caregiver's Burden	1	30 (0.6)
Fatigue Severity Scale	1	80 (1.5)	Visual Analogue Scale	1	30 (0.6)
Family Inventory of Life Events and Changes	1	67 (1.2)	Kupfer-Detre System Form 1	1	17 (0.3)
Family Inventory of Resources and Management	1	67 (1.2)	Areas of Change Questionnaire	1	15 (0.3)
Feetham Family Functioning Survey	1	67 (1.2)	Marital Satisfaction Inventory	1	15 (0.3)
UCLA Loneliness Scale	1	65 (1.2)	Sleep (reported hours/night)	1	15 (0.3)
General Health Questionnaire (28-item)	1	61 (1.1)	Spouse Observation Checklist	1	15 (0.3)
Relatives' Stress Scale	1	61 (1.1)	Clinical Anxiety Scale	1	14 (0.3)
Brief Disability Questionnaire	1	60 (1.1)	Generalized Contentment Scale	1	14 (0.3)

Table S4: Summary of outcome domains by number of measurement scales

Domains	Number of scales	Caregiver numbers (% of total)*
Mental health	15	2395 (44.6)
Marital/family relationship	15	1151 (21.4)
Caregiver burden	9	2266 (42.2)
Quality of life	9	2213 (41.2)
Functional status	7	485 (9.0)
Coping skills	5	260 (4.8)
Social support/loneliness	4	404 (7.5)
Sleep	3	277 (5.2)
Fatigue	2	365 (6.8)
Sexual dysfunction	1	45 (0.8)

*numbers >100% due to studies using multiple scales

4.2 Experiences of caregivers of patients with conservatively managed kidney failure: A mixed methods systematic review

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Can J Kidney Health Dis 2022; 9: 1-11

DOI: 10.1177/20543581221089080

Journal Impact Factor 1.77 in 2022. 1.50 in 2023. 8 citations and FWCI of 1.25 (27/3/25)

Co-Authorship statement: A Walavalkar was an advanced physician trainee at the time. She was one of the reviewers for all manuscripts included in the systematic review and drafted the first version of the paper. A Craswell is a nurse researcher experienced in qualitative studies and assisted with supervision. I developed study concept and design, was one of the reviewers of the search titles and abstracts and subsequently full text manuscripts for the systematic review, interpreted the data, provided senior oversight, and edited the final paper.

Original contribution to research: Systematic review synthesizing the impacts of caregiving for people choosing CKM.

Canadian Society of Nephrology/ Société canadienne de néphrologie CSN/SCN
CANADIAN JOURNAL OF KIDNEY HEALTH AND DISEASE Journal canadien de la santé et de la maladie rénale

Original Clinical Research Mixed Method

Canadian Journal of Kidney Health and Disease
Volume 9: 1–11

DOI: 10.1177/20543581221089080
journals.sagepub.com/home/cjk
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Experiences of Caregivers of Patients With Conservatively Managed Kidney Failure: A Mixed Methods Systematic Review

Anisha Walavalkar[1], Alison Craswell[2,3], and Nicholas A. Gray[1,2,3]

Abstract

Background: Older people with kidney failure often choose conservative kidney care. The experiences and quality of life (QOL) of caregivers who support them are incompletely characterized.

Objective: To determine the burden, QOL, and understand experiences of caregivers supporting patients managed conservatively.

Design: Systematic review of quantitative and qualitative studies.

Sources of information: PubMed, Embase, PsycINFO, CINAHL, and MEDLINE electronic databases were systematically searched for quantitative and qualitative studies published between January 2000 and July 2020.

Subjects: Caregivers of adults with kidney failure (estimated glomerular filtration rate $<$ 15 mL/min/1.73 m^2) managed conservatively.

Methods: Data were extracted by 2 independent reviewers using a prespecified extraction tool. Study quality was assessed using the Critical Appraisal Skills Program (CASP) tool.

Measurements: Descriptive reports of demographics, measurement scales, and outcomes. Thematic synthesis of qualitative data.

Results: Six studies met inclusion criteria, including 3 quantitative and 3 descriptive qualitative studies. Caregivers of patients receiving conservative kidney management (CKM) experienced significant caregiver burden and similar impacts to their QOL as those caring for patients receiving dialysis. Thematic synthesis revealed 5 themes: Understanding the concept of CKM, Need for involvement in the decision for CKM, Identifying available supports, Uncertainty about the future and negotiating deteriorations and dying, and Burden of care impacting on QOL.

Limitations: Low numbers of included studies, data collection and recruitment biases in qualitative studies and small caregiver numbers in quantitative studies, limit transferability of findings. Heterogeneity in study design and outcome measures precluded meta-analysis.

Conclusions: Caregivers of patients with conservatively managed kidney failure suffer significant burden and experience QOL comparable with those caring for patients on dialysis. Limited understanding and involvement in conservative management decision making, and a fear of deterioration and dying, result in anxiety in caregivers. Further research into the experiences of caregivers will help support both caregivers and the patients who choose conservative management.

Registration: PROSPERO registration number CRD42021209811.

Abrégé

Contexte: Les personnes âgées atteintes d'insuffisance rénale optent souvent pour des soins rénaux conservateurs, mais on en sait peu sur l'expérience et la qualité de vie (QV) de leurs soignants.

Objectif: Mieux comprendre l'expérience des soignants de patients pris en charge de façon conservatrice, particulièrement en ce qui concerne la qualité de vie et le fardeau de l'aidant.

Type d'étude: Revue systématique d'études quantitatives et qualitatives.

Sources: PubMed, Embase, PsycINFO, CINAHL et MEDLINE ont fait l'objet d'une recherche systématique afin de répertorier les études quantitatives et qualitatives publiées entre janvier 2000 et juillet 2020.

Sujets: Les soignants d'adultes atteints d'insuffisance rénale (DGFe$<$15 mL/min/1,73 m^2) et pris en charge de façon conservative.

Méthodologie: Deux réviseurs indépendants ont procédé à l'extraction des données d'intérêt à l'aide d'un outil préétabli. La qualité des études a été évaluée à l'aide de l'outil du Programme de développement des compétences en évaluation critique (CASP — *Critical Appraisal Skills Program*).
Mesures: Les rapports descriptifs sur les données démographiques, les échelles de mesure et les résultats. Synthèse thématique des données qualitatives.
Résultats: Six études répondaient aux critères d'inclusion, soit trois études quantitatives et trois études qualitatives descriptives. Les soignants de patients recevant des soins rénaux conservateurs (SRC) rapportaient un important fardeau de l'aidant et des effets sur leur QV similaires à ceux rapportés par les personnes qui s'occupent de patients sous dialyse. La synthèse thématique a révélé cinq thèmes: 1) la compréhension du concept de SRC; 2) le besoin de participer à la décision d'opter pour des SRC; 3) l'identification des ressources de soutien disponibles; 4) l'incertitude quant à l'avenir et à la façon de composer avec la dégradation de l'état de santé et le décès; et 5) l'incidence du fardeau de l'aidant sur la qualité de vie.
Limites: La transférabilité des résultats est limitée par le faible nombre d'études incluses, ainsi que par la méthode de collecte de données et les biais de recrutement dans les études qualitatives, et par le faible nombre de soignants dans les études quantitatives. L'hétérogénéité dans la conception de l'étude et les mesures des résultats a empêché une méta-analyse.
Conclusion: Les soignants de patients atteints d'insuffisance rénale et pris en charge de façon conservatrice rapportent un important fardeau de l'aidant et une QV comparable à celle des soignants de patients sous dialyse. Le fait de ne pas bien comprendre le concept de SRC, d'avoir une participation limitée dans la prise de décisions, ainsi qu'une crainte liée à la détérioration de la santé et au décès, entraîne de l'anxiété chez les soignants. Des recherches plus approfondies sur l'expérience des soignants contribueront à mieux soutenir les patients qui optent pour une prise en charge conservatrice et leurs soignants.
Enregistrement de l'essai: Numéro d'enregistrement PROSPERO CRD42021209811.

Keywords
kidney failure, chronic, conservative treatment, caregivers, caregiver burden, quality of life

Received November 15, 2021. Accepted for publication February 7, 2022.

Introduction

Chronic kidney disease (CKD) is a progressive and irreversible decline in kidney function and its prevalence increases with advancing age. Treatment options for kidney failure include kidney replacement therapy (KRT), which includes dialysis and kidney transplantation, and conservative kidney management (CKM). CKM involves a broad range of interventions designed to manage the symptoms and complications arising from advancing CKD, but without the use of KRT. In the past 20 years, interest in CKM has increased due to awareness of the burden faced by older people receiving dialysis, the poor survival of patients having dialysis, and knowledge that conservatively managed patients retain a similar quality of life (QOL) compared with patients on dialysis.[1-3] Consequently, research from Canada and Australia demonstrates that approximately half of all older patients with a diagnosis of kidney failure choose CKM as compared with those who pursue dialysis or transplantation.[4,5]

Advanced CKD and associated comorbid conditions may result in cognitive and functional impairments that restrict the capacity of the patient to care for themselves. As a result, many patients rely on a caregiver, usually unpaid, to assist with activities and instrumental activities of daily living.[6,7] Caregiver burden, characterized by the physical, psychological, and financial consequences of caring for an individual with a medical condition, is well described among those caring for patients on dialysis.[8] Furthermore, caregiver QOL is adversely impacted by caring for someone undergoing dialysis.[8] However, QOL, burden, and experiences for caregivers of someone with kidney failure choosing CKM is less well described, despite increasing rates of kidney failure in the older population and the growing importance of CKM. Therefore, the primary aim of this mixed methods systematic review was to define the QOL and caregiver burden among caregivers of adults with kidney failure managed conservatively and to synthesize qualitative data to further understand the caregiver experience.

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Methods

This article reporting our mixed methods systematic review was prepared in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guideline and prospectively registered with PROSPERO (CRD42021209811).

Search Strategy and Inclusion Criteria

PubMed, Embase (Elsevier), PsycINFO, CINAHL, and MEDLINE (Ovid) electronic databases were searched using a prespecified search strategy which was developed and refined with support from a librarian with skills in systematic reviews (Table S1). The search was limited to English language studies published between January 1, 2000, and July 31, 2020, reflecting the increased focus on CKM in the last few decades. Inclusion and exclusion criteria are shown in Table S2. Inclusion criteria were original investigations, either observational or interventional, that used objective tools to assess caregiver QOL and burden, or studies using qualitative methods to describe the experiences of caregivers of adult patients with kidney failure (estimated glomerular filtration rate of $<$15 mL/min/1.73 m^2) managed conservatively or CKD G5C. Studies including only caregivers of patients already undertaking or planning on undertaking KRT, patients with an undefined treatment choice for kidney failure or patients withdrawing from dialysis, were excluded. Similarly, studies including caregivers of people with other medical conditions where it was impossible to extract data for caregivers of people with CKD, and studies examining caregivers of patients where kidney failure was not the dominant life limiting problem, were excluded. Reference lists of relevant studies were reviewed for further studies that met the inclusion criteria.

Two authors (A.W. and N.G.) evaluated the title and abstract of each study for inclusion using the record management software Covidence.[9] Conflict between the two reviewers was resolved through consensus. Full text articles of each manuscript considered for inclusion based on title and abstract were reviewed independently by 2 authors (A.W. and N.G.), with disagreement resolved through consensus.

Data Extraction and Trial Quality Assessment

Data were extracted using a prespecified data extraction tool, by 2 independent reviewers (A.W. and N.G.) with disagreements resolved by consensus. Data collected included study design, country, sample size, and caregiver age, sex and relationship to patient. Study quality was assessed using the Critical Appraisal Skills Program (CASP) tool[10] for qualitative, cohort, case control, and randomized controlled trials (RCT) with a modified CASP tool used for cross-sectional studies.

For quantitative studies, results of measures of QOL and burden were recorded. Meta-analysis was not possible due to different scoring scales in each study. Extracted data from qualitative studies were analyzed through a process of thematic synthesis, described by Thomas and Harden (2008),[11] with initial analysis performed by 2 researchers (A.W. and N.G.) and confirmed by a third author (A.C.). Text, statements, and quotations from caregivers and individual themes and subthemes were extracted from the results and discussion sections of included studies and were coded to develop descriptive themes in a level 2 qualitative synthesis. Level 3 synthesis of qualitative themes then followed, transforming the qualitative evidence to move beyond the individual findings of the included studies. These higher order themes were verified with the source data by all authors with analysis of conflicting evidence before drawing conclusions. These results were integrated (where possible) with the results from the quantitative analyses, to support and provide context for, and deeper understanding of the findings, following Sandelowski et al's (2006)[12] segregated approach to mixed methods systematic review.

Results

Literature Search and Study Characteristics

The search strategy identified 181 articles, and after title and abstract review 18 met inclusion criteria and underwent full text review. Six were included in the final analysis (Figure 1). There were 3 quantitative studies including 1 RCT, 1 cohort study, and 1 cross-sectional study (Table 1). Three descriptive qualitative studies were included. Of the included studies, 2 were from the United Kingdom, 1 each from Australia, Hong Kong, and Italy, and 1 was a multicenter study from the United Kingdom and Australia.[13-18]

The mean patient age in the included studies ranged from 81.5 to 84 (Table 1) and, when reported, the majority of caregivers were female (ranging from 58% to 76% of all caregivers). The mean age of caregivers ranged from 50.7 to 69 years. Generally, studies with an older mean caregiver age had a larger percentage of spouse or sibling caregivers as compared with those with a younger mean caregiver age, where children formed a greater proportion (Table 1).

Risk of Bias and Study Quality

The qualitative studies had well documented aims, methodology, design, data analysis, and consideration of ethical issues. However, data collection in the studies by Hoffman et al[17] and Noble et al[18] were performed by clinicians who may have been involved in patient care and in the presence of the patient in Low et al,[16] hence findings may have been impacted. The recruitment method in the study by Noble et al[18] included a convenience sample of caregivers but had limited details of people who chose not to participate and similarly, the study by Hoffman et al[17] had a high noninclusion rate, which was not detailed.

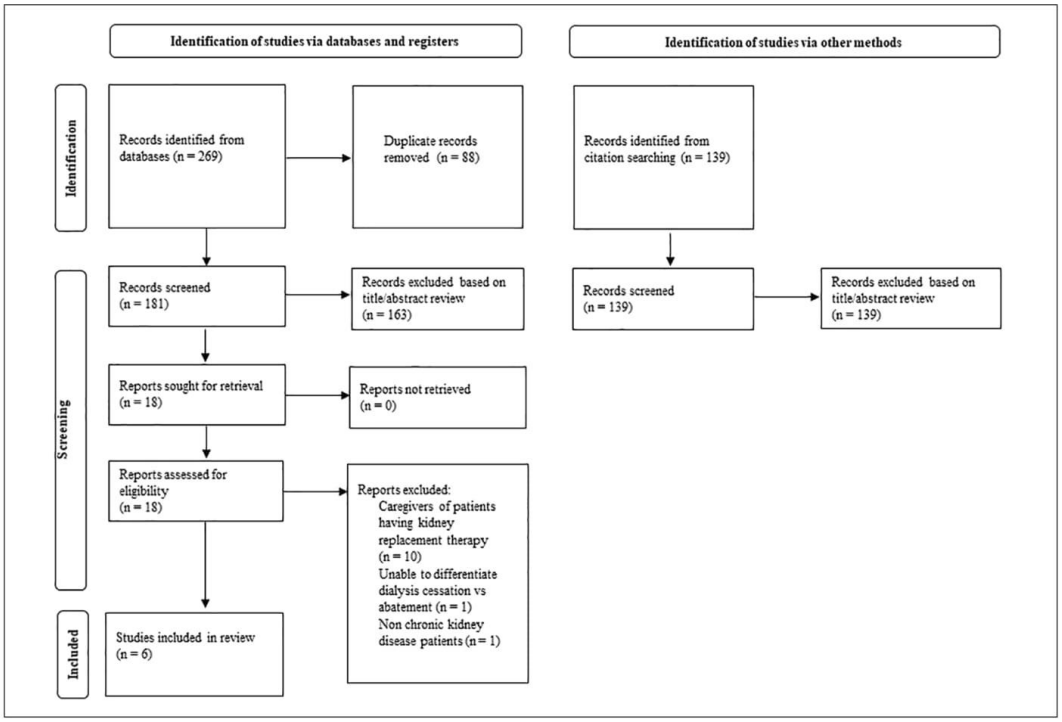

Figure 1. Literature search.

With regard to the quantitative studies, the methods of recruitment of subjects in Shah et al[15] were not clearly specified. There was limited discussion and reporting of caregiver specific potential confounding factors in the cohort study by De Biase et al,[14] and the single RCT by Chan et al[13] had limited reporting of cost-effectiveness data and harms of the intervention. All the quantitative studies had small sample sizes ranging from 11 to 37, resulting in large confidence intervals with reported results. The single-center design and limited geographic region of the studies necessitates caution in applying the findings to other populations.

Quantitative Study Findings

Quality of life. QOL was assessed by 2 quantitative studies (Table 2); the cohort study by Shah et al[15] compared the caregivers of conservatively managed patients, with those on dialysis and found no significant difference in health-related QOL as assessed by the Short Form 6-Dimensions (SF-6D). Caregiver-related QOL as measured by the Carer Experience Scale (CES) score was lower for caregivers of patients on dialysis. Significantly lower mean CES scores were also noted for caregivers residing in the United Kingdom rather than Australia, and for spouse/partner caregivers compared with children of patients. Similar results were noted by the cohort study by De Biase et al[14] who compared caregivers of conservatively managed patients with caregivers of patients on dialysis, finding that caring for conservatively managed patients was associated with a negative impact on caregiver QOL (as measured by the 36-Item Short Form Survey [SF-36]), especially in domains of "physical role," "vitality," and "emotional role" compared with age matched norms (Table 2). Results were similar for caregivers of patients on hemodialysis except for better scores in the "physical functioning" domain which may be explained by a younger mean age in that group.

Caregiver burden. Burden was measured by De Biase et al,[14] where the Caregiver Burden Inventory (CBI) showed high scores for objective burden in both caregivers of patients on dialysis and those managed conservatively. The study by Chan et al,[13] which examined the effects of a comprehensive psychosocial support program with caregivers of conservatively managed patients demonstrated a baseline Zarit Burden Index (ZBI) score was 28.3 $\pm$ 10.7 in the control group and 32.8 $\pm$ 12.2 in the intervention group (ZBI $>$17 consistent with high levels of burden).[19]

Table 1. Characteristics of Included Studies.

Study	Country	Design	Purpose	N	Patient age	Caregiver age	Female	Relationship
Chan et al[13]	HK	RCT	Investigate the effectiveness of enhanced psychosocial support in reducing caregiver burden in patients with chronic kidney failure opting for conservative management	29	81.6 ± 14.2 (mean)	59.8 ± 14.2 (mean)	76%	SP: 52%; SB: 45%; FM: 4%
De Biase et al[14]	IT	CO	Report on the clinical results, disease progression, burden of care, and QOL of patients and caregivers on prolonged conservative treatment	11	81.5 (mean) 81 (median) 75-88 (range)	50.7 (mean)	NA	NA
Shah et al[15]	AU, UK	CS	To assess and compare the heath-related QOL and care-related QOL among informal caregivers of older people with end-stage kidney disease, managed with dialysis or comprehensive conservative care	37	NA	76 (median) 68-82 (range)	70%	SP: 63%; CH: 28%; FM: 9%
Low et al[16]	UK	DS	To show how the discourses around aging and old age play an implicit role in shaping the experiences of close persons caring for someone on conservative management	26	83.7 (mean) 61-96 (range)	63 (mean) 38-91 (range)	58%	SP: 30%; CH: 53.8%; FM: 7.6%
Hoffman et al[17]	AU	DS	To gain a greater understanding of the experiences of conservatively managed patients and their carers/families	11	84 (mean) 77-91 (range)	69 (mean) 42-89 (range)	64%	SP: 55%; CH:45%
Noble et al[18]	UK	DS	Explore the impact of being a family carer to patients with stage 5 chronic kidney disease managed without dialysis	19	NA	20-30: 3 30-40: 1 40-50: 3 50-60: 6 60-70: 1 >70: 5	68%	SP: 21%; CH: 68%

Note. RCT = randomized control trial; SP = spouse; SB = sibling; FM = family (other); CO = cohort study; NA = not available; CH = child or child-in-law; CS = cross-sectional study; DS = descriptive.

Table 2. Results From Quantitative Studies.

Study	Intervention/comparison	Mean score (control)	Mean score (comparator)	Conclusion
Chan et al[13]	Comprehensive psychosocial intervention	Baseline ZBI = 28.3 ± 10.7 HADS anxiety = 9.1 ± 2.3 HADS depression = 6.4 ± 2.9 1 month ZBI = 31.6 ± 9.5 HADS anxiety = 10.1 ± 2.2 HADS depression = 5.9 ± 3.2 3 month ZBI = 33.4 ± 7.2 HADS anxiety = 11.0 ± 3.1 HADS depression = 6.7 ± 3.6 6 month ZBI = 31.6 ± 7.2 HADS anxiety = 10.6 ± 1.8 HADS depression = 7.4 ± 3.0	Baseline ZBI = 32.8 ± 12.2 HADS anxiety = 9.9 ± 3.3 HADS depression = 5.4 ± 4.5 1 month ZBI = 22.0 ± 5.3 HADS anxiety = 7.1 ± 3.2 HADS depression = 4.4 ± 3.1 3 month ZBI = 21.3 ± 6.6 HADS anxiety = 6.5 ± 4.5 HADS depression = 3.8 ± 3.1 6 month ZBI = 24.3 ± 6.3 HADS anxiety = 8.5 ± 1.9 HADS depression = 4.5 ± 1.9	Enhanced psychosocial support led to an early and significant reduction in caregiver burden, as evidenced by lower ZBI and HADS anxiety scores at 1 and 3 months with insignificant reductions at 6 months.
Study		Mean score (conservative care)	Mean score (dialysis)	Conclusion
De Biase et al[14]		BDI identified 1 case of depression among caregivers STAI-Y 1-2 did not identify evidence of anxiety CBI showed high score for objective burden SF36: Physical functioning = 77 (vs age matched 88.69 ± 14.93) Role physical = 60 (vs 81.71 ± 30.27) Bodily pain = 72.8 (vs 75.26 ± 24.07) General health = 68.6 (vs 66.45 ± 17.49) Vitality = 52 (vs 63.36 ± 18.19) Social functioning = 72.2 (vs 78.37 ± 20.38) Role emotional = 46.4 (vs 79.2 ± 33.58) Mental health = 68 (vs 67.76 ± 18.18)	BDI identified 1 case of depression among caregivers STAI-Y 1-2 did not identify evidence of anxiety CBI showed high score for objective burden SF36: Physical functioning = 51.25 (vs age matched 67.28 ± 26.00) Role physical = 75 (vs 60.00 ± 40.43) Bodily pain = 72.75 (vs 62.81 ± 29.05) General health = 62 (vs 51.63 ± 21.54) Vitality = 55 (vs 55.01 ± 21.09) Social functioning=68.5 (vs 72.86 ± 24.86) Role emotional = 58.25 (vs 70.45 ± 36.82) Mental health = 65 (vs 60.44 ± 21.04)	Caregiving for conservatively managed patients was associated with a negative effect on QOL especially in physical role, vitality, and emotional role scales—similar to HD patients but scoring better in physical functioning (possibly explained by a younger mean age). No evidence of significant impact of conservative care on depression or anxiety.
Shah et al[15]		CES = 80.91 (SD = 15.20) SF-6D Mean utility = 0.77 (SD = 0.12)	CES = 64.39 (SD 16.75) Mean utility = 0.70 (SD = 0.13)	No significant difference in health-related QOL as assessed by the SF-6D between caregivers of dialysis and conservatively managed patients. Care-related QOL as measured by the CES score was lower for caregivers of patients on dialysis. Significantly lower mean CES scores were also noted for caregivers residing in the United Kingdom and for spouse/partner compared with children of care recipients.

Note. ZBI = Zarit Burden Interview; HADS = Hospital Anxiety and Depression Scale; BDI = Beck Depression Inventory; STAI-Y 1-2 = State Trait Anxiety Inventory; SF36 = Short-Form 36 Health Survey Questionnaire; CBI = Caregiver Burden Inventory; QOL = quality of life; HD = hemodialysis; CES = Carer Experience Scale; MQOL = McGill Quality of Life; SF-6D = Short-Form 6-Dimension.

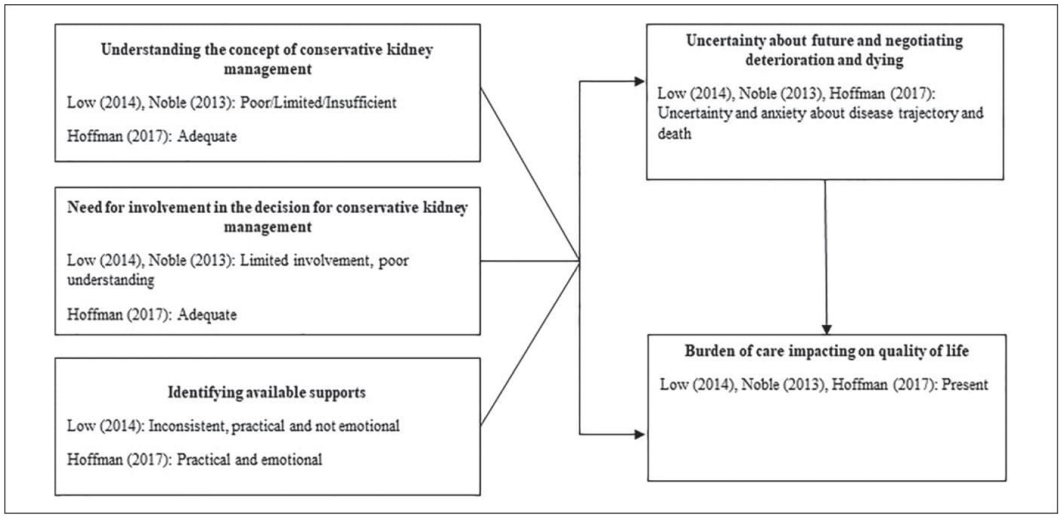

Figure 2. Thematic synthesis of qualitative studies.

Depression and anxiety. De Biase et al[14] compared caregivers of conservatively managed patients with caregivers of patients on dialysis, finding no difference in the number of cases of depression or anxiety, as measured by the Beck Depression Inventory (BDI) and the State Trait Anxiety Inventory (STAI-Y 1 and 2), respectively. The study by Chan et al[13] also reported caregiver anxiety and depression; the Baseline Hospital Anxiety and Depression Scale (HADS) anxiety score was 9.1 ± 2.3 and 9.9 ± 3.3 and HADS depression score was 6.4 ± 2.9 and 5.4 ± 4.5 in the control and intervention groups respectively (HADS score 0-7 normal, 8-10 borderline abnormal, 11-21 abnormal).[20] The enhanced psychosocial intervention led to a lower ZBI and HADS anxiety scores at 1 and 3 months but with insignificant reductions at 6 months (Table 2).

Qualitative Study Findings

The qualitative studies included 3 descriptive studies investigating the experiences of caregivers for conservatively managed patients, recruited from renal supportive care clinics in 2 studies,[17,18] and in general tertiary renal centers.[16] Recruitment was in the United Kingdom[16,18] and Australia.[17] Data were collected using semi-structured[17,18] and narrative interview[16] techniques.

Thematic synthesis of the qualitative studies revealed 5 themes: (1) Understanding the concept of CKM, (2) Need for involvement in the decision for CKM, (3) Identifying available supports, (4) Uncertainty about the future and negotiating deterioration and dying, and (5) Burden of care impacting on QOL (Figure 2, Table S4).

Understanding the concept of CKM. The concept of CKM was difficult for caregivers to understand. Caregivers reported confusion regarding CKD, the treatment options available, and the reasons to not commence dialysis. Low et al[16] described a limited understanding by caregivers about what CKM involved; a possible factor being the absence of a definite change in duties as a caregiver with the transition to a conservative approach. Caregivers were appreciative of good communication between kidney clinics and primary care, particularly in light of conflicting advice from different medical specialties involved in the patients' care.[16,17]

Need for involvement in the decision for CKM. Some caregivers reported a lack of involvement in the decision to choose not to undertake dialysis, a lack of understanding behind the reasoning for a conservative approach and subsequently, difficulties with coming to terms with the person's decision to not have dialysis.[16,18] Other caregivers felt well informed in this regard.[17] Reasons for acceptance of the decision for CKM were similar across all studies, with convenience (in terms of time commitment and travel for dialysis), noninvasive nature of care, lack of perceived benefits from dialysis, and impact on patient's QOL influencing caregiver acceptance.[16,17]

Identifying available supports. Caregivers were appreciative of medical and emotional support provided by kidney clinics and good communication with primary care.[17] Some caregivers described a need for more emotional support, particularly with end of life issues and were confused about the role and remit of social service departments.[16] While the study by Noble et al[18] did not report directly on support service utilization, older participants in the study reported a reliance on

wider family and social networks to support patients in their activities of daily living and accessing health care.

Uncertainty about the future and negotiating deterioration and dying. Caregivers reported specific anxiety about the process of deterioration and dying, concerns about managing the practicalities of death itself, particularly managing death at home. This was compounded by the uncertainty of the timing.[16-18] Caregivers reported coping strategies including living in the present and discounting the future, but this also manifested as a reluctance to discuss the issue with patients and manage differences of opinion.[16,18] Uncertainty of disease trajectory and prolonged decline resulted in a sense of frustration and disappointment with associated guilt about this disappointment, which contributed to relationship problems in younger caregivers.[18] Caregivers were appreciative of these topics being broached by renal teams and of any practical and emotional support available.[16]

Burden of care impacting on QOL. There was an apparent difference in the caregiving duties of younger caregivers (usually children), with greater participation in comprehensive caregiving and performance as intermediaries between older patients and professional services.[16] Younger caregivers experienced difficulties balancing their own lives with caregiving whereas older caregivers reported difficulties managing their own health in addition to that of the patient.[17] Caregivers reported a sense of responsibility to provide a level of care that permitted the patient to remain at home and subsequently, caregiver burnout was found to be associated with patient admission to residential aged care facilities.[16,18] Caregivers across all studies reported a sense of worry about the trajectory of deterioration and specifically of unexpected death.[16-18] At the same time, caregivers found themselves vulnerable when patients were medically ill, specifically when deciding what constituted an urgent problem requiring medical attention, given the decision to minimize medical intervention.[16]

Discussion

This systematic review found caregivers of patients having CKM experience significant burden, and suggests that they suffer depression, anxiety, and negative impacts on QOL comparable to caregivers of patients having dialysis. These findings are complemented by our thematic synthesis that demonstrates that there are several unique factors that shape the experience of these caregivers, including the age and relationship of caregivers, the degree of involvement in, and understanding of the decision for CKM and the fear and uncertainty about the trajectory of kidney disease. Caregivers also experience personal and physical impacts as a consequence of their caregiving duties, express a need to be supported by health care providers, and demonstrate significant anxiety with regard to deterioration and dying of the person in their care.

Our analysis revealed a distinct divergence in the experiences of caregivers of conservatively managed patients. Caregivers in 2 studies reported a lack of involvement in the decision to not undertake dialysis. This was reflected in confusion about CKM as a concept and consequent difficulty in coming to terms with the patient's decision not to undergo dialysis.[16,18] In contrast, Hoffman et al reported caregivers were well informed and comfortable with the decision to not undergo dialysis.[17] The difference in experience could potentially reflect the support caregivers received under the dedicated renal supportive care program reported in that study.[17] However, the study by Hoffman et al[17] was at a single center, with a high noninclusion rate, potentially reflecting bias in data collection. In addition, their means of data collection, which included interviews performed by a senior nurse from the service, may have resulted in a positive bias to the reported experiences.[17] The renal supportive and palliative care position statement by Crail et al[21] recommends the involvement of caregivers in the process of decision making. Findings from our analysis support this and suggest a need to address caregiver anxieties and concerns at the time.

Caregiver concern about supporting a deteriorating patient was a recurrent theme. Caregivers reported a lack of understanding of services which, together with a sense of responsibility to provide care at home, resulted in anxiety and ultimately, patient institutionalization in situations of crisis. Specific concerns included managing the practicalities of death—an issue compounded by the uncertainty of the timing, frustration, and/or guilt with regard to the prolonged disease trajectory, and a reluctance to verbalize their concerns. Similarly, Harrison et al reported the top 10 quality indicators of CKM for patients and caregivers included ensuring a peaceful death for the patient, availability of a key contact person in the CKM program, access to clinic staff during and after hours, and referrals for home care services.[22] Providing support to these caregivers, therefore, would require a comprehensive, multifaceted approach with a focus on emotional support in addition to practical support. This is supported by the RCT by Chan et al,[13] where a comprehensive intervention comprising support with advanced care planning, psychological support, and counseling, respite care, and community support resulted in a significant reduction in burden of care and anxiety measures in caregivers. Shah et al[15] also noted lower scores in the care-related QOL domains of "assistance from organizations and government," reflecting low levels of uptake in existing services among caregivers or a need for further services.

Caregiver QOL, depression, and anxiety were generally comparable for caregivers of patients managed conservatively or with dialysis. Di Biase et al[14] reported a difference in physical functioning, attributed to a difference in caregiver age between the two groups in that study. Univariate analyses

in data collected from Shah et al showed significantly lower CES (Caregiver QOL) scores in caregiver partners compared with children of care recipients.[15] This is supported by qualitative studies with an apparent difference in the experiences of younger and elderly caregivers. Younger caregivers (predominantly children of the patient) experience difficulty balancing their own lives as compared with older caregivers who struggle managing their own health and consequently relying on wider supports.[16,17] Overall, the impact of caring for a patient with kidney failure is driven more by the advanced disease and process of aging, rather than the benefits or burdens of supporting a patient on dialysis compared with CKM.

Caring for a person with kidney failure has similarities to caregiver experiences of other diseases. Uncertainty, difficulty negotiating the process of deterioration and dying, and the need for continuity of care and emotional support around end of life have been reported in advanced liver disease,[23] severe chronic obstructive pulmonary disease (COPD),[24] and advanced heart failure.[25] Similarly reduced QOL and high burden of care have been reported in caregivers of patients with advanced heart failure, COPD, cancer,[26-28] and CKD on dialysis.[8,29] Evidence around supporting caregivers in end-of-life roles, through palliative and supportive services, has historically focused on patients with cancer. However, the care needs of noncancer advanced illnesses such as CKD at the time of referral to a palliative service can exceed those with cancer.[30] While this reflects a bias in referring patients with noncancer diseases to palliative and supportive care services, it also manifests due to the ambiguity in defining a transition point to supportive care in diseases that have a less predictable and slower course. The decision to not undertake dialysis could be a trigger point to introduce patients and caregivers to palliative and supportive services. Given the similar experiences of caregivers of patients with CKD to other chronic diseases, established models of care that integrate primary and specialist care with palliative care in other diseases, may help guide the creation of renal supportive care services in areas where the practice is not yet established.

Gaps in the Literature

As the move to personalized medicine and shared decision making is emerging and the limited use of RCTs in this field (mainly to trial interventions to impact experiences), a predominance of cohort and qualitative studies are to be expected and consistent with our results.

There was limited information in the available studies with regard to positive aspects of providing care to patients undergoing CKM, an understanding of which could form a vital part of decision making with regard to pursuing CKM. While our review describes some of the influence of factors such as age (of the caregiver) and relationship with the patient, there is a need for further research into education, employment, and the impact of the health and comorbidities of patients on the negative aspects of caregiving. We identified only 1 study trialing an intervention related to caregiver burden; this needs to be expanded further with more research into the cost-effectiveness of these interventions.

Strengths and Limitations

This study had several strengths, including the use of a comprehensive search strategy across multiple databases, and the use of a mixed methods review such that thematic synthesis of qualitative data provided understanding of the quantitative findings. To the best of our knowledge, this is the first systematic review focusing on the experiences of caregivers supporting patients receiving CKM.

Our review had several limitations. While we tried multiple search strategies, research in this field is limited with only 6 studies meeting our inclusion criteria. Studies were of moderate quality, with small caregiver numbers, from mainly single centers in developed countries. Consequently, the findings are not transferable to caregivers in different settings where cultural and socioeconomic factors might influence the caregiver experience. It is also likely that these studies are from sites with a focus on CKM and caregivers, and hence the experience of caregivers in other sites without that focus is likely to vary. The included qualitative studies had significant biases in recruitment of subjects and collection of data, and in the quantitative studies, key data including patient and caregiver age, comorbidities, education, and employment status were poorly reported. Study heterogeneity precluded meta-analysis.

Conclusion

Caregivers of patients with conservatively managed kidney failure experience similar impacts on QOL and burden as caregivers of patients undergoing dialysis. However, understanding and involvement of caregivers in the patient's decision-making process leading to conservative management are lacking. This, together with the prospect of deterioration and dying, leads to fear, uncertainty, and anxiety for the caregiver. This burden of care is increasingly relevant in the setting of an aging population and as more patients opt for CKM. The role played by caregivers is a vital one and further research into their experiences, particularly focused on diverse populations, and into interventions that improve caregiver burden, is a critical part of supporting people with kidney failure choosing CKM.

Ethics Approval and Consent to Participate

Ethics approval not applicable to this study type.

Consent for Publication

All authors consent to publication of this study.

Availability of Data and Materials

Data available on request.

Author Contributions

Research idea and study design: N.G.; data acquisition: A.W., N.G., and A.C.; data analysis/interpretation: A.W., N.G., and A.C.; supervision or mentorship: N.G. and A.C.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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Supplemental Material

Supplemental material for this article is available online.

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Table S1: Search Strategy

Pubmed	
1	"Kidney Failure, Chronic"[Mesh] OR "Renal Insufficiency, Chronic"[Mesh]
2	"chronic kidney"[Title/Abstract] OR "chronic renal"[Title/Abstract] OR "end stage renal"[Title/Abstract] OR "end stage kidney"[Title/Abstract] OR "CKD"[Title/Abstract]
3	1 OR 2
4	"Caregivers"[Mesh] OR "Spouses"[Mesh]
5	("carer*"[Title/Abstract] OR "caregiver*"[Title/Abstract] OR "spouse"[Title/Abstract] OR "partner"[Title/Abstract])
6	4 OR 5
7	“Quality of life”[Mesh]
8	“Quality of life"[Title/Abstract] OR “QOL"[Title/Abstract] OR “HRQOL"[Title/Abstract] OR “health related quality of life"[Title/Abstract] OR “burden"[Title/Abstract] OR “interview” [Title/Abstract] OR “experience*” [Title/Abstract]
9	7 OR 8
10	“Palliative Care”[Mesh] OR “Conservative Treatment”[Mesh]
11	“Supportive"[Title/Abstract] OR “Conservative"[Title/Abstract] OR “Palliative"[Title/Abstract] OR “not for dialysis"[Title/Abstract] OR “non dialy*"[Title/Abstract] OR “without dialysis”[Title/Abstract]
12	10 OR 11
13	3 AND 6 AND 9 AND 12
14	13 Filters: English, Adult:19+ years, from 2000-2020

Embase (Elsevier)	
1	'chronic kidney failure'/exp OR 'chronic kidney failure' OR 'end stage renal disease'/exp
2	'chronic kidney':ti,ab,kw OR 'chronic renal':ti,ab,kw OR 'end stage renal':ti,ab,kw OR 'end stage kidney':ti,ab,kw OR 'ckd':ti,ab,kw
3	1 OR 2
4	'caregiver'/exp OR caregiver OR 'spouse'/exp OR spouse
5	‘carer*':ti,ab,kw OR 'caregiver*':ti,ab,kw OR 'spouse':ti,ab,kw OR 'partner':ti,ab,kw
6	4 OR 5
7	‘quality of life’/exp OR ‘burden’/exp
8	‘quality of life’:ti,ab,kw OR ‘QOL’:ti,ab,kw OR ‘HRQOL’:ti,ab,kw OR ‘health related QOL’:ti,ab,kw OR ‘burden’:ti,ab,kw OR ‘interview’:ti,ab,kw OR ‘experience*’:ti,ab,kw
9	7 OR 8
10	‘Conservative treatment’/exp OR ‘Palliative therapy’/exp
11	‘Supportive’:ti,ab,kw OR ‘Conservative’:ti,ab,kw OR ‘Palliative’:ti,ab,kw OR ‘not for dialysis’:ti,ab,kw OR ‘non dialy*’:ti,ab,kw OR ‘without dialysis’:ti,ab,kw
12	10 OR 11
13	3 AND 6 AND 9 AND 12
14	13 AND [english]/lim AND ([adult]/lim OR [aged]/lim AND [2000-2020]/py
Psycinfo	
1	DE "Kidney Diseases"
2	AB "chronic kidney" OR "chronic renal" OR "end stage renal" OR "end stage kidney" OR "CKD"

3	1 OR 2
4	DE "caregivers" OR DE "spouses" OR DE "partners"
5	AB "carer*" OR "caregiver*" OR "spouse" OR "partner"
6	4 OR 5
7	DE “Quality of Life” OR DE “Health Related Quality of Life” OR DE "Caregiver Burden"
8	AB “quality of life” OR “QOL” OR “HRQOL” OR “health related QOL” OR “burden” OR “interview” OR “experience*”
9	7 OR 8
10	DE “Palliative Care”
11	AB “Supportive” OR “Conservative” OR “Palliative” OR “not for dialysis” OR “non dialy*” OR “without dialysis”
12	10 OR 11
13	3 AND 6 AND 9 AND 12
14	7 Filters: adulthood (18 yrs & older), English, Publication year 2000-2020
CINAHL	
1	MH "Kidney Diseases+" OR MH "Renal Insufficiency, Chronic+" OR (MH "Kidney Failure, Chronic+")
2	(AB "chronic kidney" OR "chronic renal" OR "end stage renal" OR "end stage kidney" OR "CKD")
3	1 OR 2
4	(MH "spouses+") OR (MH "caregivers+")
5	(AB "carer*" OR "caregiver*" OR "spouse" OR "partner")
6	4 OR 5

7	MH “Quality of Life+” OR MH “Caregiver Burden+”
8	(AB “quality of life” OR “QOL” OR “HRQOL” OR “health related QOL” OR “burden” OR “interview” OR “experience*”)
9	7 OR 8
10	MH “Palliative Care+”
11	(AB “Supportive” OR “Conservative” OR “Palliative” OR “not for dialysis” OR “non dialy*” OR “without dialysis”)
12	10 OR 11
13	3 AND 6 AND 9 AND 12
14	13 Filters: all adult, English, Publication year 2000-2020
1	MH "Kidney Diseases+" OR MH "Kidney Failure, Chronic+" OR (MH "Renal Insufficiency, Chronic+")
2	(AB "chronic kidney" OR "chronic renal" OR "end stage renal" OR "end stage kidney" OR "CKD")
3	1 OR 2
4	(MH "Spouses+") OR (MH "Caregivers+")
5	(AB "carer*" OR "caregiver*" OR "spouse" OR "partner")
6	4 OR 5
7	MH “Quality of Life+”
8	(AB “quality of life” OR “QOL” OR “HRQOL” OR “health related QOL” OR “burden” OR “interview” OR “experience*”)
9	7 OR 8
10	(MH “Palliative Care+”) OR (MH “Conservative Treatment+”

11	(AB “Supportive” OR “Conservative” OR “Palliative” OR “not for dialysis” OR “non dialy*” OR “without dialysis”)
12	10 OR 11
13	3 AND 6 AND 9 AND 12
14	13 Filters: all adult, English, Publication year 2000-2020
MEDLINE (Ovid)	
1	exp Kidney Diseases/ or exp Kidney Failure, Chronic/ or exp Renal Insufficiency, Chronic/
2	("chronic kidney" or "chronic renal" or "end stage renal" or "end stage kidney" or "CKD").ab,ti.
3	1 OR 2
4	exp Caregivers/ or exp Spouses/
5	("carer*" or "caregiver*" or "spouse" or "partner").ab,ti.
6	4 OR 5
7	exp Quality of Life/
8	("quality of life" or "QOL" or "HRQOL" or "health related QOL" or "burden" or "interview" or "experience*").ab,ti.
9	7 OR 8
10	exp Conservative Treatment/ or exp Palliative care/
11	("supportive" or "conservative" or "palliative" or "non dialy*" or "not for dialysis" or "without dialysis").ab,ti.
12	10 OR 11
13	3 AND 6 AND 9 AND 12
14	limit 7 to (yr=”2000 -Current” and English and "all adult (19 plus years)")

Table S2: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Studies published between January 1, 2000 and June 30, 2020 (inclusive), no geographical restriction	Non-English language studies
Original investigations	Abstracts, Review articles, Study protocols, Letters, Editorials
Studies including caregivers of people with kidney failure (estimated glomerular filtration rate <15 ml/min) with a confirmed decision to not undergo kidney replacement therapies (KRT) or CKD G5C.	Studies only including caregivers of patients already undertaking, or planning on undertaking, active KRT; or patients with an undefined treatment choice for kidney failure; or patients withdrawing from dialysis Studies which include caregivers of people with medical conditions other than chronic kidney disease, where it is impossible to extract individual data for caregivers of people with CKD choosing not to undertake KRT Studies examining caregivers of patients where kidney failure is not the dominant life limiting medical problem.

Observational or interventional studies that use objective tools to assess the quality of life, caregiver burden and prevalence of psychological comorbidities Observational studies using qualitative tools to describe the experiences of caregivers	Studies that do not describe caregiver outcomes
Studies including patients and caregivers aged 18 or older	Studies focusing on caregivers of people aged <18 years

Table S3a: Quality appraisal of quantitative studies

Study	CASP Criteria											
	Focused research question	Appropriate randomization	Loss to follow up	Blinding	Baseline similarity	Equal treatment of study groups	Comprehensive effect reporting	Precision reporting	Cost-effectiveness analysis	Generalizability of results	Value of intervention	
Chan (2016)[13]	Yes	Yes	Yes	No/ Can't tell	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	
	• Single center in Hong Kong, with a small number of participants. • Application of results difficult due to inability to generalize findings and lack of a cost-effectiveness analysis											

	Focused research question	Appropriate recruitment	Appropriate exposure	Appropriate outcome measurement	Identification of confounding factors	Completeness/ Length of follow up	Reporting of results	Preciseness of results	Reliability of results	Generalizability of results	Fit with available evidence	Implications for practice
De Biase (2008)[14]	Yes	Yes	Yes	Yes	No	Yes/ Can't tell	Poor	No	No	No	Can't tell	Can't tell
	• Limited data on caregivers, hence, several potential confounders (comorbidities of patients and caregivers, socio-economic differences, time spent caregiving, etc.) have not been identified or addressed • Small numbers of caregivers • Lack of generalizability of results • Imprecise results with large confidence intervals (when reported).											
Shah (2020)[15]	Yes	Can't tell	Yes	Yes	Yes	Yes/ Can't tell	Good	No	Can't tell	Yes	Can't tell	Can't tell

	• Method of recruitment of subjects not specified • Limited study participants and reduced precision

Table S3b: Quality appraisal of qualitative studies

Study	CASP Criteria									
	Statement of aims	Appropriate Methodology	Appropriate design	Recruitment	Data collection	Reflexivity	Ethical issues	Data analysis	Statement of findings	Valuable
Low (2014)[16]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
	This research identified a new area (the role of the discourses of ageing in the provision of care to conservatively managed renal patients) – allowing the relation of the care provided to those with chronic kidney disease managed conservatively to that provided to the elderly in general									
Hoffman (2017)[17]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Moderate
	• High non-inclusion rate									
	• Suggestion of bias with results being very positive of care provided by the clinic (possible reflection of the means of data collection). • Single center and hence not transferable									
Noble (2013)[18]	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Moderate
	• A convenience sample of carers managed in renal supportive unit were approached - unclear why people chose to not take part. • Participants were recruited by individuals independent of research team but not clear if they were directly involved in patient care. • The senior Clinical Nurse Specialist responsible for the study and data collection was the manager of renal supportive and palliative care service. While this relationship was acknowledged, the actual/potential impact was not explicitly mentioned.									

Table S4: Themes identified from each study

Study	Themes	Subthemes
Low (2014)[16]	Awareness of the onset of CKD	• The absence of a change in the duties of caregiving with a transition to conservative care (with the awareness of CKD G5C being a slow deteriorating akin to ageing) • An increased sense of responsibility to provide a level of care to allow the patient to remain at home • The role of younger caregivers as intermediaries between patients and professional services and their greater engagement in comprehensive caregiving as opposed to older caregivers who had an increased reliance on external support • The anxiety faced by carers about ability to manage patients at home (versus institutionalization) in the future and uncertainty about resource availability
	Conservative kidney management	• Difficulty accepting/coming to terms with the decision or not agreeing with the patient's decision to not have dialysis • Acceptance of CKM by virtue of it being non-invasive, a continuation of current cares, a more convenient way to manage CKD G5C and a perceived lack of benefit of dialysis • Lack of involvement in the decision-making process

		• Limited understanding of the nature of conservative kidney management and a need for further information
	Discourses of ageing in relation to health on social care	• Vulnerability at times of crisis and uncertainty about what constituted an urgent problem (given the stage of minimal medical intervention) • Problems with role and remit of social services departments • Appreciation of the continuity of care but concern about conflicting advice from different specialties (with regards to medical comorbidities) • Appreciation of renal teams broaching the topic of palliative care
	Negotiating the discourses of ageing and death	• Anxiety and confusion surrounding the decline in kidney function and timing of death • Tendency to live in the present and discount the future (to manage feelings of uncertainty) • Fear and anxiety about supporting patients at home at the time of death and a reluctance to discuss the issue and tackle differences of opinion with patients • Available support for end-of-life arrangements with health care teams mainly being practical and not emotional

Hoffman (2017)[17]	Awareness of what is going on	• Well informed and understanding of why dialysis was not the best option
	Informed decision making	• Comfortable with decision to not undergo dialysis to avoid burden on family and maintain QOL
	Feeling supported	• Support of kidney clinic for practical issues and for medical and emotional support/advice • Appreciative of good communication between kidney clinic and primary care
	Waiting	• Uncertainty about time until end of life • Need to feel prepared to manage the practicalities of end-of-life care
	Adjusting to role of a carer	• Difficulty with watching decline of patient • Difficulty with managing their own health together with patient with older partners relying more on wider supports • Stress managing their own lives together with needs of patient (especially when carers were children and/or when living with patient)
Noble (2013)[18]	Caregiver's plight - Making sense of the	• Confusion/lack of understanding about CKD and treatment options, reasons for not commencing dialysis • Anxiety about approaching death and managing concerns, fears and expectations

	disease and potential deterioration	• Worry about rapid and unexpected deterioration • Worry, concern and dread about current situation
	Having to care "indefinitely"	• Risk of relationship problems as patient may live well past expected (especially for child carers) • Uncertainty of prognosis leading to frustration and disappointment • Feelings of guilt about disappointment with prolonged end stage • Carer burnout and admission to RACF • Difficulty managing uncertainty and worry about the trajectory of deterioration and possibility of sudden death
	Avoiding talk of death	• Difficulty with verbalizing issues and difficulty broaching topic • Advanced age as much a factor in end of life as kidney disease

Abbreviations: CKD, Chronic kidney disease; CKD G5C , Kidney failure (estimated glomerular filtration rate of <15 ml/min/1.73m2) managed conservatively; CKM, Conservative kidney management; RACF, Residential aged care facility

4.3 Quality of life in caregivers compared with dialysis recipients: The Co-ACTIVE sub-study of the ACTIVE Dialysis trial

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Nephrology (Carlton) 2019; 24(10): 1056-1063

DOI: 10.1111/nep.13530

Journal Impact Factor 1.749 in 2019. 2.4 in 2023. 11 citations and FWCI of 1.09 (27/3/25)

Co-Authorship statement: This work was a sub-study of the larger randomised controlled trial, ACTIVE Dialysis. I developed study concept, design, and ethics. I obtained grant funds, interpreted the data, and drafted the manuscript. M Jardine provided senior guidance and was lead of the ACTIVE Dialysis study. All other authors were on the ACTIVE Dialysis steering committee and reviewed the final manuscript.

Original contribution to literature: Report of caregiver of dialysis patient QOL in China.

Funding: Sunshine Coast Hospital and Health Service Private Practice Trust Fund, 2013-NG. $20,000.

NEPHROLOGY

Nephrology (2019)

Original Article

Quality of life in caregivers compared with dialysis recipients: The Co-ACTIVE sub-study of the ACTIVE dialysis trial

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KEY WORDS:
caregiver, A clinical trial of intensive dialysis, extended dialysis, haemodialysis, quality of life.

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Accepted for publication 10 November 2018.

doi: 10.1111/nep.13530

SUMMARY AT A GLANCE

The authors compared quality of life (QOL) of caregivers of dialysis patients *versus* that of the patients themselves and found that the former had higher physical and equivalent mental QOL but poorer personal well-being than the Chinese population norm.

ABSTRACT:

Aim: **To compare quality of life (QOL) of caregivers of dialysis patients with the cared for patients and population norms.**

Methods: **The ACTIVE Dialysis study randomized participants to extended (median 24 h/week) or standard (median 12 h/week) haemodialysis hours for 12 months. A subgroup of participants and their nominated caregivers completed QOL questionnaires including the EuroQOL-5 Dimension-3 Level (EQ5D-3 L), short form-36 (SF-36, also allowing estimation of the SF-6D), as well as a bespoke questionnaire and the personal wellbeing index (PWI). Caregiver QOL was compared with dialysis patient QOL and predictors of caregiver QOL were determined using multivariable regression.**

Results: **There were 54 patients and caregiver pairs, predominantly from China. Caregivers mean (SD) age was 53.4 (11.3) years, 60% were female, 71% cared for their spouse/partner, and 36% were educated to university level. Caregivers had better physical but similar mental QOL compared with dialysis patients (mean SF-36 physical component summary: 46.9 ± 8.7 *vs* 40.4 ± 10.2, $P < 0.001$; mental component summary: 47.8 ± 9.7 *vs* 49.6 ± 12.0, $P = 0.84$). Health utility measured with EQ5D-3 L was not significantly different between caregivers and dialysis patients (mean 0.869 ± 0.185 *vs* 0.798 ± 0.227, $P = 0.083$). Caregiver PWI was 43.7 ± 15.5, significantly lower than the Chinese population norm (68.2 ± 14.2, $P < 0.001$). Higher physical and mental QOL among caregivers was predicted by university education but not age, gender or daily hours caring.**

Conclusion: **Caregivers have higher physical and equivalent mental QOL to dialysis patients but poorer personal well-being than the Chinese population. University education predicts better QOL and may be a surrogate for socioeconomic or other factors. (NCT00649298).**

In the United States, there are an estimated 14.7 million family and unpaid caregivers assisting 7.7 million community-dwelling people with disabilities.[1] In Australia, an estimated 1 in 8 of the population (2.86 million people) provide informal care for an average of 13 h each week, and if replaced with formal caregivers would cost the equivalent of 3.8% of gross domestic product.[2]Caregiving also has significant financial impact on the caregiver. In the United States, 78% of caregivers incur out-of-pocket expenses averaging US$6954 annually.[3] This burden falls disproportionately on the poor,

people in rural areas, and ethnic minorities. Work-related stress is also common for employed caregivers.[3]

End-stage kidney disease (ESKD) is associated with poor health outcomes with dialysis mortality rates of 10–15% per annum.[4] Incidence rates are highest in the elderly population[5] who generally have the most comorbidity.[6] The complexities of dialysis and multiple comorbidities mean caregivers may be essential for many people with ESKD. However, caregiving for someone needing dialysis may place a significant burden on the caregiver[7–9] and has been associated with poor marital adjustment,[10,11] depression,[12–14] poor sleep,[15] and lower quality of life than the general population.[7,16,17]

Most studies of quality of life of caregivers of dialysis recipients are cross-sectional. No quantitative studies of caregiver quality of life (QOL) have been reported from China, although a small qualitative study from Hong Kong[18] reported exhaustion, declining health and social withdrawal among caregivers.

The multi-centre ACTIVE Dialysis study[19] recruited patients to a trial of standard or extended hour dialysis from home and institution-based dialysis settings. The Co-ACTIVE study aimed to improve our understanding of the characteristics, responsibilities and QOL of caregivers of the ACTIVE Dialysis participants. We aimed to compare caregivers' QOL with that of the ACTIVE Dialysis participants they cared for, as well as with societal norms. As most caregivers recruited to Co-ACTIVE were from mainland China, this represents the first report of quality of life among this group.

METHODS

Co-ACTIVE was a prospective observational cohort study examining the QOL and burden of care for primary caregivers of participants in the multicentre randomized ACTIVE Dialysis trial. The design and results of the ACTIVE Dialysis study have been described elsewhere.[19,20] Briefly, participants were randomized to either standard (≤18 h/week) or extended (≥24 h/week) haemodialysis delivered a minimum three times per week. QOL was measured every 3 months for the 12 months duration of the study. The Co-ACTIVE sub-study was conceived and instigated after the main ACTIVE study had commenced recruitment, meaning that only a subgroup of sites and participants were eligible to participate.

Study population

ACTIVE Dialysis study participants were approached to participate in Co-ACTIVE and to nominate their primary caregiver. The nominated caregiver was then approached and consented to participate in Co-ACTIVE. Caregivers unable to self-complete the questionnaires were ineligible.

Caregivers completed questionnaires at the same time as the ACTIVE Dialysis patients they cared for (baseline and follow-up). Here, we report baseline results for caregivers and ACTIVE Dialysis participants who completed the baseline questionnaire before the ACTIVE study intervention began.

Data collection

A purpose-designed caregiver questionnaire (Supporting Information, Appendix S1) was developed for the study by an expert panel. The questionnaire included demographic data, details of the caregiver's relationship with the dialysis patient, time demands of caring, caregiver health, caregiver responsibilities and support. Questions about the impact of caring on the caregiver were derived from the CODIT study[21] and answered on a Likert scale. These questions included psychological and social effects, financial and employment impacts, overall satisfaction with caregiving and need for caregiver support services. The questionnaire included a number of measures of QOL. Overall QOL was measured using the Personal Well-being Index[22] (PWI) and generic health-related QOL by the Short-Form 36 version 1 (SF-36). Health utility was measured using EuroQol-5D-3 Level (EQ5D-3 L) with preference weights from the general United Kingdom population (to ensure consistency with preference weights used in the primary ACTIVE Dialysis analysis)[23] and, from the SF-6D, calculated from the responses to the SF-36. Preference weights for SF-6D were from the general Hong Kong population[24] because this best reflected the Chinese population included in Co-ACTIVE; no preference weights were available for the Chinese mainland, and the main ACTIVE Dialysis Study did not measure SF-6D. Validated translations of the EQ5D-3 L, SF-36 and PWI were used for non-English speaking participants and demographic and impact of caregiving components of the questionnaire were translated by local staff. Questionnaires were self-administered and data stored on a de-identified secure database.

Ethics

Both dialysis patients and their caregivers provided informed consent to participate in Co-ACTIVE. The study was approved by the Metro South Hospital and Health Service Human Research and Ethics Committee, Queensland, Australia (HREC/12/QPAH/267). Each centre obtained additional approvals as required by local practice.

Statistics

Descriptive statistics were reported as mean ± standard deviation or median (interquartile range) as appropriate for continuous variables, or frequency (percent) for categorical variables. In accordance with usual practice, QOL scores were reported as mean ± standard deviation irrespective of distribution and were compared by Student's *t*-test.

Comparisons for equality between groups of dialysis patients were made using one-way ANOVA (for normally distributed variables and QOL scores), Kruskal–Wallis test (for non-normally distributed variables) and, for categorical variables, χ^2 test or exact logistic regression (if any group contained fewer than five observations). General population values of SF-36 and SF-6D were derived from a sample of 2410 Hong Kong residents[25] and EQ5D-3 L from a sample of 1747 Hangzhou residents.[26] Predictors of higher or lower caregiver QOL were determined using multivariable linear regression with age ≤ 56 years, gender, education level (school or below), and daily hours (<7) of caregiving included in the model. An exploratory prediction model also included dialysis patient QOL. Statistical analysis was performed using SAS 7.15 (SAS Institute Inc., USA) and Stata 15.1 (StataCorp, USA).

RESULTS

There were 54 caregivers recruited after nomination by the ACTIVE Dialysis participant. Most caregivers were of Asian ethnicity reflecting that recruitment to the ACTIVE study at this time was predominantly from China (Table 1). Mean age was 53.4 ± 11.3 years, 96% were married or lived with a partner, most were schooled to secondary school level or beyond, and 25% were in paid employment. The caregivers most often cared for their spouse/partner or child who usually lived in the same residence. Caregivers reported poor access to support services and 21% had been admitted to hospital in the preceding year. Fifty-four percent (29/54) of respondents had been a caregiver for more than 2 years (Fig. 1a) and 55% (30/54) spent at least 3 h per day in the caregiver role (Fig. 1b).

Table 2 shows the baseline characteristics of dialysis patients in the Co-ACTIVE study, as well as the characteristics of Chinese non-Co-ACTIVE participants and non-Chinese non-Co-ACTIVE participants. In general, participants in Co-ACTIVE were similar to the Chinese dialysis patients who were not included, but different to the non-Chinese non-Co-ACTIVE dialysis patients (from Australia, New Zealand, and Canada).

The most commonly reported caregiver activities were attendance at medical appointments and the provision of psychological support for the dialysis patient (Table 3). Most caregivers did not believe their health impacted their ability to provide care. In general, caregivers wanted improved access to a range of support services, such as respite, community care, counselling and education and training. The impact of caregiving on the caregivers was mainly neutral for social activities, sleep, relationships, employment and finances (Table 4). Most were satisfied with their role as a caregiver.

Mean EQ5D-3 L health utility for caregivers was higher than for dialysis patients, but lower than the general Chinese population mean, although neither difference reached statistical significance (0.869 ± 0.185 *vs* 0.798 ± 0.227, $P = 0.083$; and 0.869 ± 0.185 *vs* 0.920 ± 0.17, $P = 0.059$) (Fig. 2a, Tables 1 and 2).[26] Mean SF-6D health utility did not differ significantly between caregivers and patients (0.713 ± 0.138 *vs* 0.682 ± 0.153; $P = 0.292$). Both groups had SF-6D health utility significantly below the general Chinese population mean of 0.787[25] ($P < 0.001$ for both comparisons). Physical composite score (PCS) was higher for caregivers than for dialysis patients (46.9 ± 8.7 *vs* 40.4 ± 10.2, $P = 0.002$), but there was no difference in mental composite score (MCS) (47.8 ± 9.7 *vs* 49.6 ± 12.0, $P = 0.44$). Both the mean PCS and MCS for caregivers were below the means (48.8 and 50.9, respectively[25]) for the general Hong Kong Chinese population, although this was only significant for MCS ($P = 0.232$ and $P = 0.044$, respectively) (Fig. 2b). The caregiver Personal Well-being Index was lower than that of the general Chinese population aged 51–55 (43.7 ± 15.5 *vs* 68.2 ± 14.2[22] ($P < 0.001$) (Fig. 2c).

In multivariate analysis, university education predicted higher caregiver MCS (10.3 (95%CI: 4.2–16.3), $P < 0.001$) and PCS (7.5 (95%CI: 1.7–13.2), $P = 0.011$) (Table 5). Caregiver health utility was higher in those with university education when measured with SF-6D (0.143 (95%CI: 0.061–0.225), $P = 0.001$) but not with EQ5D. Age, gender and daily hours caregiving were not predictors of QOL or health utility. Dialysis patient QOL did not predict caregiver MCS or PCS (P = NS).

DISCUSSION

Caregivers had better physical QOL and equivalent mental QOL to ACTIVE Dialysis participants, but poorer mental QOL and personal well-being than the general Chinese population. University education predicted better caregiver QOL. Caregivers are unlikely to be in paid employment and often remain in the caregiver role for years. The role requires provision of psychological support and attendance at medical appointments and dialysis. Caregivers want better access to respite, education, training and caregiver supports.

Our caregiver QOL results are broadly consistent with previous studies. Some, like us, have found that caregivers have a better PCS but not MCS than the dialysis patient[16,27] while others have reported better caregiver QOL in all domains.[15,17] Our finding that caregiver QOL is poorer than the general population is supported by studies from Spain, USA, Japan and the United Kingdom.[7,9,16,27]

The Co-ACTIVE results provide an insight into the under-reported area of caregivers of dialysis patients in China. The only other report of the home experience of caregivers is from Hong Kong where 30 caregivers of home dialysis patients were interviewed and reported concerns with financial strain, exhaustion, worsening health since commencing caregiving and social withdrawal.[18] Similar to our study, caregivers spent 3 h every day in the role and assisted with shopping, transport, household chores and mobility.[18]

Table 1 Caregiver characteristics

Characteristic	
Number	54
Age (mean ± SD) years (*n* = 50)	53.4 ± 11.3
Gender (*n* = 50)	
Female	60%
Male	40%
Marital status (*n* = 50)	
Married/de facto	96%
Separated/divorced	2%
Single	2%
Ethnicity (*n* = 50)	
Asian	96%
Other	4%
Education (*n* = 50)	
University	36%
Secondary school	54%
Primary school	10%
Occupation (*n* = 52)	
Age pension/retired	38.4%
Paid employment	25.0%
Homemaker	17.3%
Carer's pensioner	9.6%
Other	9.6%
Person cared for (*n* = 51)	
Spouse/partner	70.6%
Son/daughter	11.8%
Sibling	3.9%
Parent	2.0%
Other	11.8%
Provides care for people other than the dialysis patient (*n* = 50)	
Yes	26%
No	74%
Residence of the dialysis patient (*n* = 52)	
With the caregiver	90.3%
Other	9.7%
Caregiver visits to a doctor in the previous year (*n* = 52)	
Nil	42.3%
1–5	42.3%
>5	15.4%
Caregiver medications each day (*n* = 52)	
Nil	40.4%
1–4	44.2%
>4	15.4%
Caregiver hospital admissions in previous year (*n* = 52)	
Nil	78.8%
1	13.5%
2–5	5.8%
>5	1.9%
Caregiver support	
Caregiver has access to respite care (*n* = 48)	10.4%
Caregiver has access to community care services (*n* = 48)	14.6%
Caregiver has access to counselling (*n* = 47)	8.5%
Caregiver has access to caregiver education (*n* = 48)	16.7%
Caregiver responsibilities	
Assists with showering/toileting (*n* = 36)	22.2%
Assists with mobility (*n* = 53)	92.5%
Assists with household chores (*n* = 36)	97.2%
Assists with medications (*n* = 35)	28.6%
Assists with shopping/banking (*n* = 36)	52.8%
Assists with transport (*n* = 34)	58.9%
Caregiver quality of life	
EQ5D-3 L (mean ± SD) (*n* = 50)	0.869 ± 0.185
SF-36 physical component summary (mean ± SD) (*n* = 43)	46.9 ± 8.7
SF-36 mental component summary (mean ± SD) (*n* = 43)	47.8 ± 9.7
SF-6D (mean ± SD) (*n* = 49)	0.713 ± 0.138
Personal Well-being Index (mean ± SD) (*n* = 51)	43.7 ± 15.5

SD = standard deviation.

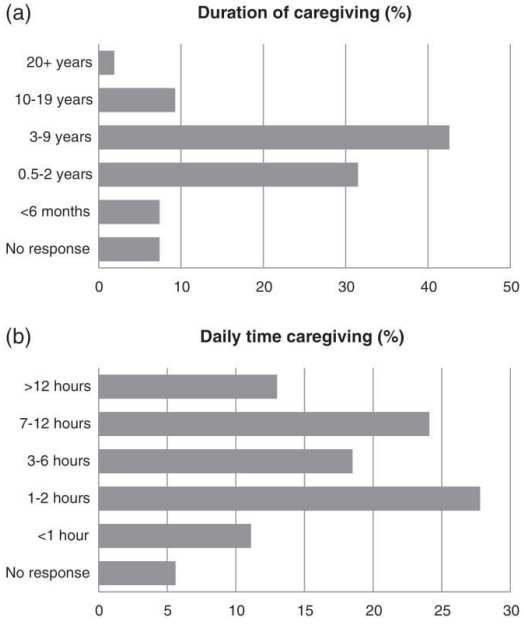

Fig. 1 Duration (a) and daily time (b) spent caregiving.

However, caregivers in Co-ACTIVE also provided psychological support, attended medical appointments and a portion had some role with haemodialysis itself. Furthermore, 37% of caregivers in Co-ACTIVE provided at least 7 h care each day.

Surprisingly, most caregivers of dialysis patients in our study were their spouses rather than children. This is

Table 2 Baseline characteristics of haemodialysis patients in Co-ACTIVE and non-Co-ACTIVE participants by region

Variable	Co-ACTIVE participants	Chinese non-Co-ACTIVE participants	Non-Chinese non-Co-ACTIVE participants	*P*-value for between groups difference
Number	54	72	74	
Age (years) (mean ± SD)	49.5 ± 13.2	50.4 ± 11.3	53.3 ± 11.7	0.15
Female	33.3%	23.6%	35.1%	0.28
Body mass index (kg/m^2) (median (IQR))	23.1 (20.4–24.8)	23.8 (21.5–25.9)	29.0 (25.2–34.6)	<0.001
Dialysis for ≤6 months at enrolment	11.1%	9.7%	35.1%	<0.001
Ischaemic heart disease	14.8%	22.2%	16.2%	0.50
Cerebrovascular disease	9.3%	6.9%	6.8%	0.85
Peripheral vascular disease	5.6%	4.2%	10.8%	0.281
Diabetes	37.0%	26.4%	46.9%	0.049
Weekly dialysis hours (median (IQR))	12.0 (12.0–12.0)	12.0 (12.0–12.0)	16.0 (15.0–18.0)	<0.001
Dialysis sessions/week (median (IQR))	3.0 (3.0–3.0)	3.0 (3.0–3.0)	3.0 (3.0–4.0)	<0.001
Intended for home haemodialysis	1.9%	0%	67.6%	<0.001
Quality of life score				
EQ5D-3 L (mean ± SD)	0.798 ± 0.227	0.784 ± 0.249	0.755 ± 0.240	0.57
SF-36 physical component summary (mean ± SD)	40.4 ± 10.2	38.3 ± 9.1	40.6 ± 9.7	0.32
SF-36 mental component summary (mean ± SD)	49.6 ± 12.0	47.5 ± 10.0	50.5 ± 10.5	0.24
SF-6D (mean ± SD)	0.682 ± 0.153	0.633 ± 0.126	0.681 ± 0.140	0.07

IQR, interquartile range; SD,standard deviation; SF-36, short form-36 .

different to the profile of Chinese caregivers of older adults who were more likely to be children or children-in-law than a spouse.[28,29] However, in these studies, the recipients of care were at least 10 years older than the dialysis cohort in our study. Future work could examine the caregiver profile of older dialysis patients in China. Of note, the QOL of caregivers of the elderly in China is lower than population norms, similar to our findings.[29]

Historically, filial piety as described by Confucius has been viewed as the most important virtue of Chinese culture.[30] Children are expected to revere their parents and take care of them in illness. However, the rapid expansion of China's cities, economic growth, population movement to large cities and the One Child Policy from 1980 to 2015 has made caring for parents difficult.[30] The results of CO-ACTIVE are therefore important to define the current caregiver profile in China and aid health officials to plan for the future needs of caregivers of dialysis patients. China is not alone in dealing with the challenges of a changing society, with forecasts in Australia pointing to insufficient future caregivers due to population ageing, increased female workforce participation, changes in intergenerational attitudes and growing duration and complexity of caregiving.[2]

We found that university education predicted better caregiver QOL. This has also been reported among Chinese caregivers of non-dialysis older adults.[29] Other predictors of poorer caregiver QOL among Chinese caregivers of the elderly include higher subjective caregiver burden, lower income, spousal caregivers and multiple chronic illnesses and higher dependency among the cared for elderly.[29]

Table 3 The caregiver's role and supports

	Median (interquartile range)
Caregiver is present for dialysis	5.0 (3.0–10.0)
Caregiver assists with dialysis procedure	5.0 (2.0–10.0)
Caregiver attends doctor appointments with the dialysis patient	9.0 (5.0–10.0)
Caregiver provides psychological support	10.0 (8.0–10.0)
Caregiver health affects ability to care	2.0 (0.0–5.0)
Caregiver's importance in the care of the dialysis patient	5.0 (5.0–10.0)
Caregiver was provided with information about caring	8.0 (5.0–10.0)
Caregiver needs better access to respite	8.0 (5.0–10.0)
Caregiver needs better access to community care services	8.0 (5.0–10.0)
Caregiver needs better access to carer counselling	8.0 (5.0–10.0)
Caregiver needs better access to carer education/ training	8.0 (5.0–10.0)

Caregiver's answered on a visual analogue scale from 0 to 10 where 0 is never/strongly disagree, 5 is neutral, and 10 is always/strongly agree. Response rate was >94%.

Table 4 Impact of caregiving on the caregiver

	Median (interquartile range)
Impact on caregiver's daily life	5.0 (4.0–6.0)
Impact on caregiver's relationship with the dialysis patient	5.0 (5.0–6.0)
Impact on outlook in life	5.0 (5.0–6.0)
Impact on social life	5.0 (4.0–6.0)
Impact on finances	5.0 (3.0–6.5)
Impact on hobbies	5.0 (1.0–5.0)
Impact on sleep	5.0 (5.0–7.5)
Satisfaction as a caregiver	7.0 (5.0–10.0)

Caregiver's rated the impact of caregiving on a visual analogue scale from 0 to 10 where 0 is a major negative effect, 5 is neutral, and 10 is a major positive effect. Response rate was >96%.

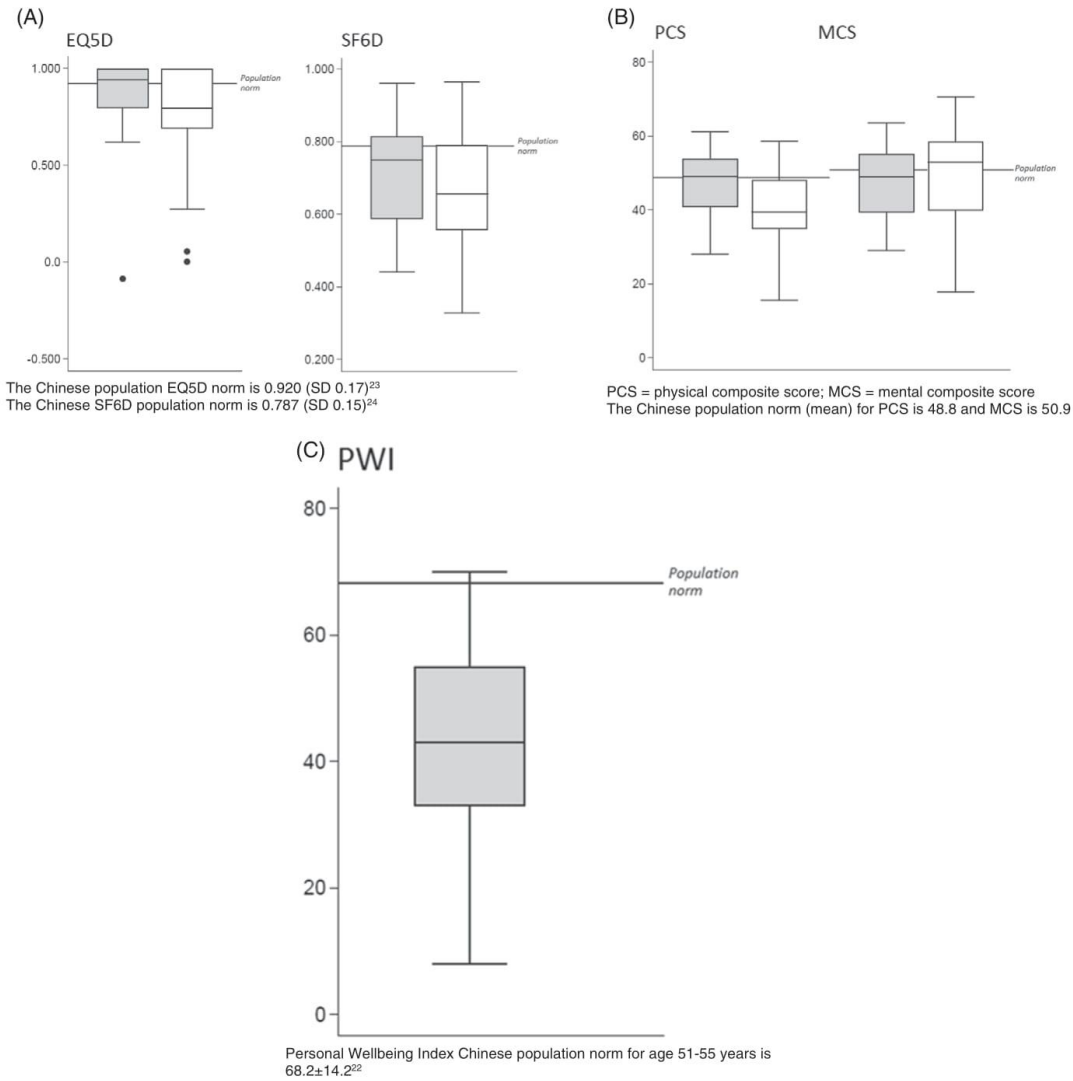

Fig. 2 Caregivers, patients (where measured), and population norm health utility, quality of life, and personal well-being. (a) Health utility measured with EQ5D and SF6D. (b) Health-related quality of life. (c) Caregiver personal well-being index. (▥) caregivers, (□) patients

Another Chinese study found caregiver age had the greatest impact on PCS and caregiver social lives had the greatest impact on MCS.[28] Previous studies have shown a higher depression score with lower caregiver income,[31] a direct relationship between dialysis patient and caregiver depression score,[10,31] younger caregiver age associated with poorer physical QOL, and less social support predicted worse mental QOL.[7]

Caregivers wanted better access to support services, such as respite, community care services, counselling and education. The need for services and access to patient support groups was also reported by caregivers of dialysis patients in Hong Kong.[18] Despite identifying the needs of caregivers of dialysis patients, few studies examining the outcome of interventions have been published. A systematic review published in 2008 found just three studies which all assessed

Table 5 Predictors of caregiver quality of life

Parameter		EQ5D-3 L		Mental composite score		Physical composite score		SF6D	
Reference group	Comparator group	Estimate (95%CI)	*P* value	Estimate (95%CI)	*P* value	Estimate (95%CI)	*P* value	Estimate (95%CI)	*P* value
Intercept	–	0.894 (0.775, 1.013)	<0.001	44.8 (39.2, 50.4)	<0.001	45. 0 (39.6, 50.4)	<0.001	0.691 (0.618, 0.764)	<0.001
Age ≤ 56 years	Age > 56 years	0.019 (−0.094, 0.132)	0.74	−2.6 (−8.0, 2.7)	0.34	0.9 (−4.2, 6.0)	0.72	−0.061 (−0.135, 0.014)	0.108
Female gender	Male gender	−0.059 (−0.173, 0.055)	0.30	−0.5 (−5.9, 5.0)	0.87	−2.6 (−7.8, 2.6)	0.32	−0.012 (−0.088, 0.064)	0.743
School level education	University/further education	0.074 (−0.052, 0.200)	0.24	10.3 (4.2, 16.3)	<0.001	7.5 (1.7, 13.2)	0.01	0.143 (0.061, 0.225)	0.001
Daily care <7 h	Daily care ≥7 h	−0.060 (−0.182, 0.062)	0.33	3.5 (−2.3, 9.2)	0.24	−0.4 (−5.9, 5.1)	0.90	0.020 (−0.059, 0.099)	0.606

CI, confidence interval.

the effect of educational material and found it improved caregivers knowledge.[32] More recently, a day care programme has been shown to improve caregiver mental QOL and reduce burden[33] and enhanced psychosocial support reduced caregiver burden and anxiety.[34] Finally, it is important to ensure caregivers access support services provided, with a study of caregivers of elderly people in the United States finding just one quarter use available support services.[1] Whether greater provision and uptake of interventions assisting caregivers will improve outcomes is a worthwhile area of research.

Our study results are primarily applicable to caregivers resident in China. The dialysis patients cared for in this study were generally younger and with less comorbidity than is typical in Europe, the United States or Australia. Furthermore, there were no caregivers of people receiving home haemodialysis or peritoneal dialysis. Our study, like many of caregivers, is limited by its relatively small size. Nevertheless, we used validated instruments and had details of the cared for patients.

In conclusion, we have shown that caregivers of predominantly Chinese haemodialysis patients have better physical QOL but comparable mental QOL to the dialysis patients they care for, but poorer mental QOL and personal well-being than the general population. Future work should explore the impact of home dialysis therapies and socioeconomic status on caregivers and develop and trial interventions that are designed to improve caregiver QOL and prevent exhaustion.

ACKNOWLEDGEMENTS

We would like to thank all participants of both the ACTIVE Dialysis study and Co-ACTIVE. We also thank all investigators and study personnel without whom this work would not have been successful. Funding was received from the Private Practice Trust Fund, Sunshine Coast Hospital and Health Service. BS is supported by an Australian Government Research Training Program Scholarship via the University of Sydney. MeJ is funded by a Medical Research Future Fund Career Development Fellowship.

DISCLOSURE

We have no conflict of interest to report.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher's website:

Appendix S1. CO-ACTIVE: carers of the ACTIVE dialysis study participants baseline survey

CO-ACTIVE: Carers of the ACTIVE Dialysis Study Participants

Baseline Survey

Section A

1. How old are you? (years): ☐☐

2. Gender:
   - ☐ Male
   - ☐ Female

3. What is your marital status?
   - ☐ Married / defacto
   - ☐ Single
   - ☐ Separated / divorced
   - ☐ Widowed

4. What is your racial origin?
   - ☐ Caucasian
   - ☐ Aboriginal or Torres Strait Islander
   - ☐ Maori/Pacific Islander
   - ☐ Asian
   - ☐ Indian
   - ☐ Other (specify)_____

5. What is the highest education level you have achieved?
   - ☐ Primary school
   - ☐ Secondary school
   - ☐ Qualified in a Trade
   - ☐ University / TAFE

6. What is your current occupation?
   - ☐ Paid Employment
     (If yes, hrs/week ☐☐ and what is your job?_____)
   - ☐ Carer's Pensioner
   - ☐ Disability Pensioner
   - ☐ Aged Pensioner/Retired
   - ☐ Homemaker
   - ☐ Student
   - ☐ Unemployed/Receiving Unemployment Benefit

☐ Other _____

7. Who do you care for?
   ☐ Husband / wife / partner
   ☐ Mother / father
   ☐ Mother-in-law / father-in-law
   ☐ Son / daughter
   ☐ Brother / sister
   ☐ Friend
   ☐ Other (specify)_____

8. How long have you been this person's carer?
   ☐ Less than 6 months
   ☐ 6 months – 2 years
   ☐ 3-9 years
   ☐ 10-19 years
   ☐ More than 20 years

9. Are you a carer for any other people?
   ☐ Yes (How many?_____)
   ☐ No

10. Where does the person you care for live?
    ☐ With you
    ☐ Alone
    ☐ Another household
    ☐ Residential aged care facility
    ☐ Supported accommodation
    ☐ Other (specify_____)

11. How many hours each day do you have immediate caregiving responsibilities?
    ☐ Less than 1
    ☐ 1-2
    ☐ 3-6
    ☐ 7-12
    ☐ More than 12

12. How many visits to a doctor have you made for your own health in the last year?
    ☐ 0
    ☐ 1-5
    ☐ More than 5

13. How many different types of medications do you take each day?
    - ☐ 0
    - ☐ 1-4
    - ☐ More than 4

14. How many times have you been admitted to hospital for at least one night in the last 12 months?
    - ☐ 0
    - ☐ 1
    - ☐ 2-5
    - ☐ More than 5

15. Do you have access to the following?
    Respite
    - ☐ Yes
    - ☐ No

    Community care services
    - ☐ Yes
    - ☐ No

    Carer counseling
    - ☐ Yes
    - ☐ No

    Carer education and training
    - ☐ Yes
    - ☐ No

16. If the person you care for has dialysis at home, where do they have dialysis?
    - ☐ In the bedroom where I sleep, with dialysis during the night
    - ☐ In the bedroom where I sleep, with dialysis not during the night
    - ☐ In another bedroom
    - ☐ In the living area
    - ☐ Other (please specify) _____
    - ☐ Not applicable – go to question 18

17. If the person you care for has dialysis at home, please rate the effect of having the equipment and supplies in the house on your space and lifestyle on a scale from 0 to 10

No impact Major impact

0 1 2 3 4 5(neutral) 6 7 8 9 10

18. Does the person you care for require your assistance with activities other than dialysis?

☐ No

☐ Yes - If yes, Please choose which activity you assist the person with (more than one may apply)

a. showering/toileting

☐ Yes

☐ No

b. mobility/getting around

☐ Yes

☐ No

c. household chores (cooking/cleaning/laundry)

☐ Yes

☐ No

d. medications

☐ Yes

☐ No

e. shopping/banking

☐ Yes

☐

f. transport

☐ Yes

☐ No

19. Have you made significant lifestyle changes as a result of your responsibilities as a carer?

☐ No – go to section B

☐ Yes – go to question 20

20. If you have made significant changes have you had to:

Move to a different town/city

☐ Yes

☐ No

Move house

☐ Yes

☐ No

Section B

The following questions should all be answered on a scale from 0 to 10

1. How necessary do you see yourself in the care of the person you help?

Not necessary Essential

_____

0 1 2 3 4 5(neutral) 6 7 8 9 10

2. What impact does the illness of the person you care for, and the care you provide, have on your own daily life from a practical point of view? (eg time for your own activities, trips away, etc.)

Major negative impact Major Positive impact

_____

0 1 2 3 4 5(neutral) 6 7 8 9 10

3. How does the illness of the person you care for, and the care you provide, impact on the relationship you have with him or her?

Major negative impact Major Positive impact

_____

0 1 2 3 4 5(neutral) 6 7 8 9 10

4. What impact does the illness of the person you care for, and the care you provide, have on your current outlook on life?

Major negative impact Major Positive impact

_____

0 1 2 3 4 5(neutral) 6 7 8 9 10

5. What impact does the illness of the person you care for, and the care you provide, have on your social life (eg contact with extended family and friends)?

Major negative impact Major Positive impact

0 1 2 3 4 5(neutral) 6 7 8 9 10

6. What financial impact does the illness of the person you care for, and the care you provide, have on you?

Major negative impact Major Positive impact

0 1 2 3 4 5(neutral) 6 7 8 9 10

7. I am **present** for dialysis

Never Always

0 1 2 3 4 5(neutral) 6 7 8 9 10

8. I **actively assist** in the dialysis procedure

Never Always

0 1 2 3 4 5(neutral) 6 7 8 9 10

9. I attend clinic/doctor appointments with the person I care for

Never Always

0 1 2 3 4 5(neutral) 6 7 8 9 10

10. I provide psychological support

Strong disagree Strong agree

0 1 2 3 4 5(neutral) 6 7 8 9 10

11. I have been given enough information about dialysis and being a carer

Strong disagree Strong agree

0 1 2 3 4 5(neutral) 6 7 8 9 10

12. Does your health affect your ability to be a carer?

Never Always

0 1 2 3 4 5(neutral) 6 7 8 9 10

13. How satisfied and fulfilled are you in your role as carer?

Very dissatisfied Very satisfied

0 1 2 3 4 5(neutral) 6 7 8 9 10

14. I need better access to respite

Strong disagree Strong agree

0 1 2 3 4 5(neutral) 6 7 8 9 10

15. I need better access to community care services

Strong disagree Strong agree

0 1 2 3 4 5(neutral) 6 7 8 9 10

16. I need better access to carer counseling

Strong disagree Strong agree

0 1 2 3 4 5(neutral) 6 7 8 9 10

17. I need better access to carer education and training

Strong disagree Strong agree

0 1 2 3 4 5(neutral) 6 7 8 9 10

18. Being a carer has affected my employment (or tick here if not currently employed…….)

Increased work hours Decreased work hours

0 1 2 3 4 5(neutral) 6 7 8 9 10

19. Being a carer has affected my time for hobbies

No time Increased time

0 1 2 3 4 5(neutral) 6 7 8 9 10

20. Being a carer has affected my sleep

Poorer sleep Better sleep

0 1 2 3 4 5(neutral) 6 7 8 9 10

Please outline any additional points or clarifications you wish to make.

Section C

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

1. Mobility

☐ I have no problems in walking about

☐ I have some problems in walking about

☐ I am confined to bed

2. Self-Care

☐ I have no problems with self-care

☐ I have some problems washing or dressing myself

☐ I am unable to wash or dress myself

3. Usual Activities (e.g., work, study, housework, family, or leisure activities)

☐ I have no problems with performing my usual activities

☐ I have some problems with performing my usual activities

☐ I am unable to perform my usual activities

4. Pain/Discomfort

☐ I have no pain or discomfort

☐ I have moderate pain or discomfort

☐ I have extreme pain or discomfort

5. Anxiety/Depression

☐ I am not anxious or depressed

☐ I am moderately anxious or depressed

☐ I am extremely anxious or depressed

Section D

Quality of Life

1. In general, would you say your health is:
   - ☐ Excellent
   - ☐ Very good
   - ☐ Good
   - ☐ Fair
   - ☐ Poor

2. Compared to one year ago, how would rate your health in general now?
   - ☐ Much better now than one year ago.
   - ☐ Somewhat better now than one year ago.
   - ☐ About the same as one year ago.
   - ☐ Somewhat worse now than one year ago.
   - ☐ Much worse now than one year ago.

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
Lifting or carrying groceries	☐	☐	☐

Climbing several flights of stairs	☐	☐	☐
Climbing one flight of stairs	☐	☐	☐
Bending, kneeling or stooping	☐	☐	☐
Walking more than one kilometre	☐	☐	☐
Walking half a kilometre	☐	☐	☐
Walking 100 metres	☐	☐	☐
Bathing or dressing yourself	☐	☐	☐

4. During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
Cut down the amount of time you spent on work or other activities	☐	☐
Accomplished less than you would like	☐	☐
Were limited in the kind of work or other activities	☐	☐
Had difficultly performing the work or other activities (for example, it took extra effort)	☐	☐

5. During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No

Cut down the amount of time you spent on work or other activities	☐	☐
Accomplished less than you would like	☐	☐
Didn't do work or other activities as carefully as usual	☐	☐

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

- ☐ Not at all.
- ☐ Slightly.
- ☐ Moderately.
- ☐ Quite a bit.
- ☐ Extremely.

7. How much bodily pain have you had during the past 4 weeks?

- ☐ None.
- ☐ Very mild.
- ☐ Mild.
- ☐ Moderate.
- ☐ Severe.
- ☐ Very severe.

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all.
- ☐ A little bit.
- ☐ Moderately.
- ☐ Quite a bit.
- ☐ Extremely.

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	☐	☐	☐	☐	☐	☐
Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
Have you felt down?	☐	☐	☐	☐	☐	☐
Did you feel worn out?	☐	☐	☐	☐	☐	☐
Have you been a happy person?	☐	☐	☐	☐	☐	☐
Did you feel tired?	☐	☐	☐	☐	☐	☐

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?

☐ All of the time.
☐ Most of the time.
☐ Some of the time.
☐ A little of the time.
☐ None of the time.

11. Please choose the answer that best describes how true or false each of the following statements is for you.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people.	☐	☐	☐	☐	☐
I am as healthy as anybody I know.	☐	☐	☐	☐	☐
I expect my health to get worse.	☐	☐	☐	☐	☐
My health is excellent.	☐	☐	☐	☐	☐

Section E

Thinking about your life and personal circumstances, please circle the number that best represents how satisfied you feel with your life. (0 is completely dissatisfied, 5 is neutral and 10 is completely satisfied.)

How satisfied are you with ….

1. your life as a whole?

0 1 2 3 4 5(neutral) 6 7 8 9 10

2. your standard of living?

0 1 2 3 4 5(neutral) 6 7 8 9 10

3. your health?

0 1 2 3 4 5(neutral) 6 7 8 9 10

4. what you are currently achieving in life?

0 1 2 3 4 5(neutral) 6 7 8 9 10

5. your personal relationships?

0 1 2 3 4 5(neutral) 6 7 8 9 10

6. how safe you feel?

0 1 2 3 4 5(neutral) 6 7 8 9 10

7. feeling part of your community?

0 1 2 3 4 5(neutral) 6 7 8 9 10

8. your future security?

0 1 2 3 4 5(neutral) 6 7 8 9 10

4.4 Quality of life in caregivers of people randomized to standard- versus extended-hours haemodialysis

Nataatmadja M, Krishnasamy R, Zuo L, Hong D, Smyth B, Jun M, De Zoysa J, Howard K, Wang J, Lu C, Liu Z, Chan CT, Cass A, Perkovic V, Jardine M, Gray NA

Kidney Int Rep 2021; 6: 1058-1065

DOI: 10.1016/j.ekir.2021.01.020

Journal Impact Factor 6.234 in 2021. 5.7 in 2023. 5 citations and FWCI of 0.52 (27/3/25)

Co-Authorship statement: This work was a sub-study of the larger randomised controlled trial, ACTIVE Dialysis. M Nataatmadja was a junior nephrologist who drafted the manuscript. I developed study concept, design, ethics, and grant funds. I interpreted the data, edited the manuscript and provided supervision. M Jardine provided senior guidance and was lead of the ACTIVE Dialysis study. All other authors were on the ACTIVE Dialysis steering committee and reviewed the final manuscript.

Original contribution to literature: Report of caregiver QOL of patients randomised to standard or extended hours dialysis showing a possible adverse impact of extended hours haemodialysis.

Funding: Sunshine Coast Hospital and Health Service Private Practice Trust Fund, 2013-NG. $20,000.

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CLINICAL RESEARCH

Quality of Life in Caregivers of Patients Randomized to Standard- Versus Extended-Hours Hemodialysis

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Introduction: Caregivers are essential for the health, safety, and independence of many patients and incur financial and personal cost in this role, including increased burden and lower quality of life (QOL) compared to the general population. Extended-hours hemodialysis may be the preference of some patients, but little is known about its effects on caregivers.

Methods: Forty caregivers of participants of the ACTIVE Dialysis trial, who were randomized to 12 months extended (median 24 hours/wk) or standard (12 hours/wk) hemodialysis, were included. Utility-based QOL was measured by EuroQOL–5 Dimension–3 Level (EQ-5D-3L) and Short Form–6 Dimensions (SF-6D) and health-related QOL (HRQOL) was measured by the 36-Item Short Form Health Survey (SF-36) physical component summary (PCS) and mental component summary (MCS) and the Personal Wellbeing Index (PWI) at enrolment and then every 3 months until the end of the study.

Results: At baseline, utility-based QOL and HRQOL were similar in both groups. At follow-up, caregivers of people randomized to extended-hours dialysis experienced a greater decrease in utility-based QOL measured by EQ-5D-3L compared with caregivers of people randomized to standard hours (–0.18±0.30 vs. –0.02±0.16, $P = 0.04$). There were no differences between extended- and standard-hours groups in mean change in SF-6D (0.03±0.12 vs. –0.04±0.1, $P = 0.8$), PCS (–1.2±9.8 vs. –5.6±9.8, $P = 0.2$), MCS (–4.1±11.2 vs. –0.5±7.1, $P = 0.4$), and PWI (2.3±17.6 vs. 0.00±20.4, $P = 0.9$).

Conclusion: Poorer utility-based QOL, as measured by the EQ-5D-3L, was observed in caregivers of patients receiving extended-hours hemodialysis in this small study. Though the findings are exploratory, the possibility that mode of dialysis delivery negatively impacts on caregivers supports the prioritization of research on burden and impact of service delivery in this population.

Kidney Int Rep (2021) **6,** 1058–1065; https://doi.org/10.1016/j.ekir.2021.01.020
KEYWORDS: caregiver; Co-ACTIVE; extended dialysis; hemodialysis; quality of life

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Received 22 September 2020; revised 4 January 2021; accepted 11 January 2021; published online 1 February 2021

Caregivers play an important role in supporting the independence of people receiving dialysis, including through assistance with activities of daily living (ADL) such as personal hygiene, dressing, and feeding, and instrumental ADL such as shopping, housework, and

meal preparation. Caregivers of people receiving hemodialysis may also be responsible for tasks such as transport to and from dialysis, preparation of meals appropriate for people with kidney disease, and medical/nursing tasks such as setup and assisting with dialysis treatment in patients performing home dialysis.[1–3] Caregivers of patients receiving dialysis treatment experience significantly increased burden and reduced QOL compared with the general population.[4,5] Marital adjustment and sleep quality may be adversely affected.[6–9] In addition, caregivers incur significant financial burden equivalent to an average of US$6954 per year lost or foregone in the United States, through loss of work and out-of-pocket expenses related to caregiving.[10] Yet, caregivers are essential to health systems, as the estimated cost of replacing informal caregivers with paid services in Australia is $60.3 billion per year, approximately 60% of the health and social work industry.[11] Unfortunately, there are limited high-quality studies evaluating QOL, or interventions to improve QOL, in caregivers of dialysis patients.[12,13]

Standard hemodialysis regimens typically involve thrice-weekly sessions of 4 to 5 hours duration. More intensive hemodialysis regimens, which may involve increased duration or frequency, have been associated with improved biochemical parameters and reduced medication burden for patients.[14–17] Despite a lack of proven benefit in terms of either QOL or survival,[14,18] some patients may prefer extended-hours hemodialysis as a lifestyle choice or for biochemical or medication benefits. However, little is known about how more intensive dialysis regimens affect caregivers.[19] It is possible that such regimens may result in greater reductions in caregiver QOL, because of increased demands on time, need for physical assistance, and other responsibilities for caregivers. Conversely, more intensive dialysis regimens could result in improvements in caregiver QOL, by improving the health of the patients for whom they care.

The ACTIVE trial (A Clinical Trial of Intensive Dialysis) was an international, multicenter trial in which QOL, cardiovascular effects, laboratory outcomes, medication usage, and safety were assessed in patients who were randomized to receive either extended-hours (≥24 hours/wk) or standard-hours (≤18 hours/wk) hemodialysis.[14,20] Our study, Caregivers of ACTIVE (Co-ACTIVE), was a longitudinal cohort substudy of the ACTIVE trial, where we sought to investigate the effects of hemodialysis on caregivers' QOL.

METHODS

Study Design

Co-ACTIVE was a prospective, observational study that examined QOL and burden in caregivers of patients enrolled in the ACTIVE study. The design and results of the ACTIVE study have been previously described in detail.[14] Briefly, ACTIVE was an international, multicenter, randomized controlled trial where adult patients receiving maintenance hemodialysis received either standard- (≤18 hours/wk) or extended-hours (≥24 hours/wk) hemodialysis. Co-ACTIVE was conducted in parallel with ACTIVE study, and caregiver data were collected at the same time points as patient data for the ACTIVE study (enrolment and then every 3 months until study end at month 12).

The study was approved by the Metro South Hospital and Health Service Human Research and Ethics Committee, Queensland, Australia (HREC/12/QPAH/267). Each center obtained additional approvals as required by local practice. Written informed consent was obtained from all participants.

Study Participants

Patients enrolled in the ACTIVE study were invited to nominate their primary caregiver to participate in Co-ACTIVE. As Co-ACTIVE was initiated after recruitment for ACTIVE had already begun, not all sites and participants were eligible. Caregivers were not blinded to patient treatment arm allocation (standard vs. extended hours).

Demographic data, including age, sex, marital status, and ethnicity were collected at baseline by written questionnaire. Caregivers also completed a purpose-designed Co-ACTIVE study questionnaire that included caregiver relationship to the patient, duration of being a caregiver, caregiver role and responsibilities, and impacts of caregiving (Supplementary Material S1).[5] This study questionnaire was translated by local staff for participants from non–English speaking backgrounds.

Outcome Measures

Caregiver utility-based QOL was measured with the EQ-5D-3L and SF-6D, and HRQOL was measured with the SF-36 PCS and MCS and the PWI. Health utility aims to assign a single value (on a 0–1, dead to full health, scale) and may be useful for economic evaluation[21]; however, HRQOL measures may provide a more nuanced, multidimensional coverage of QOL assessment, and thus both were used in this study. Validated translations of these instruments were used for participants who were from non–English speaking backgrounds. Patients who could not read or complete their questionnaires were excluded from study participation. The instruments were completed by caregivers at study entry and then at 3-month intervals for 12 months (the same time points as the dialysis recipients). For the EQ-5D-3L, UK population preference weighting was used

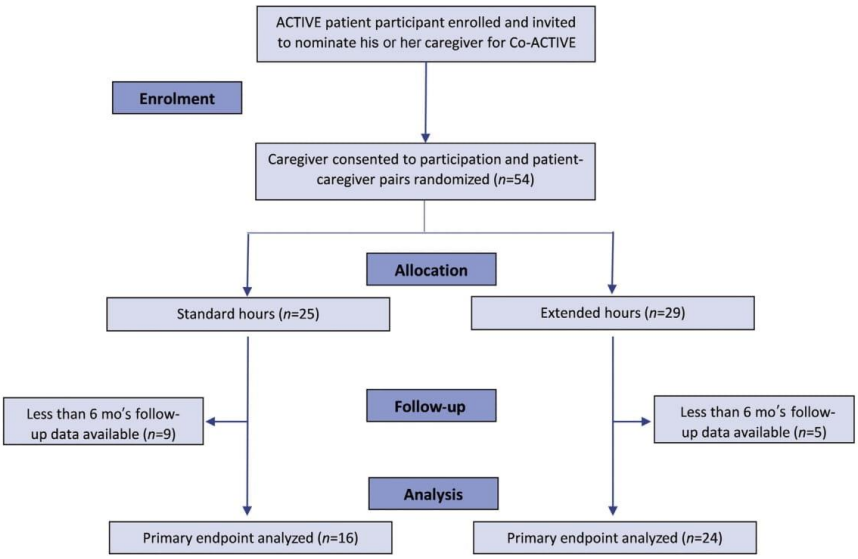

Figure 1. Participant flow through the study.

to maintain consistency with the ACTIVE study.[14] As the majority of caregivers were from China, SF-6D preference weights from a Hong Kong population were used (preference weights from a mainland Chinese population were unavailable).[22]

The primary outcome was the difference in change in EQ-5D-3L from baseline to last available follow-up measurement between standard- and extended-hours dialysis caregivers. Caregivers who did not have at least 6 months of follow-up data were excluded from the final analysis as per the prespecified Statistical Analysis Plan to ensure sufficient time for the intervention to produce effects on HRQOL. Secondary outcomes included the change in caregiver SF-6D, SF-36 PCS and MCS, and PWI from baseline to follow-up in standard- and extended-hours groups. Change in QOL measures of caregivers were compared to those of patients (ACTIVE trial participants) as an exploratory outcome.

Statistical Analysis

Descriptive statistics were reported as mean ± standard deviation, or median (interquartile range) as appropriate. Comparative analysis of continuous data was performed using *t*-test or Kruskal-Wallis for parametric and nonparametric data, respectively. Comparisons of categorical data were performed with χ^2 test. For participants who had missing 12-month HRQOL data, the last-observation carried forward method was used. Analyses were performed on intention-to-treat basis. Statistical analyses were performed using Stata, version 15.0 (StataCorp, College Station, TX).

RESULTS

Baseline Characteristics

Forty caregivers participated in the Co-ACTIVE study and were eligible for inclusion in the analysis (Figure 1). Most caregivers were female, cared for a spouse or partner, and lived at the same residence (Table 1). Standard- and extended-hours groups were not significantly different in terms of age (54.6 ± 10.3 vs. 53.4 ± 13.0 years, $P = 0.9$) or sex (female 71.4% vs. 59.1%, $P = 0.4$). The majority of caregivers were Asian, because recruitment for the ACTIVE study was occurring predominantly in China at the time. As such, all participants were receiving hemodialysis within a facility, as is usual practice in mainland China,[23,24] and so continued with a thrice-weekly schedule. Most caregivers had attained at least high school–level education, and approximately one-third had attained postsecondary education. More than half had been a caregiver for more than 2 years.

Most caregivers were required to assist with at least 1 instrumental ADL such as household chores, shopping, transport, and medications. A smaller proportion were required to assist with basic ADLs such as showering and mobility. More than one-third of caregivers spent 3 or more hours per day performing caregiving duties. At baseline (prior to randomization of dialysis recipients to standard- or extended-hours

Table 1. Baseline characteristics of caregivers

Characteristic	Standard hours (n = 16)	Extended hours (n = 24)
Age, yr, mean (SD)	54.6 (10.3)	53.4 (13.0)
Sex, %		
Female	71.4	59.1
Marital status, %		
Married/*de facto*	92.9	100
Single	7.1	—
Divorced/separated	—	—
Widowed	—	—
Ethnicity, %		
Asian	92.9	95.5
Caucasian	7.1	—
Other	—	4.5
Education, %		
Primary school	7.1	13.6
High school	64.3	45.5
University/TAFE	28.6	40.9
Occupation, %		
Paid employment	40	21.7
Pension (aged/carer's/retired)	40	56.5
Homemaker	13.3	17.4
Unemployed	—	4.4
Other	6.7	—
Person cared for, %		
Spouse/partner	78.6	60.9
Parent	—	4.4
Child	7.1	17.3
Sibling	7.1	—
Friend	—	4.4
Other	7.2	13.0
Duration of being a caregiver, %		
<6 mo	7.1	9.1
6 mo–2 yr	28.6	27.3
3–9 yr	57.1	54.5
10–19 yr	7.2	9.1
Residence of the dialysis patient, %		
With caregiver	87.5	86.4
Alone	—	—
Another household	6.25	13.6
Other	6.25	—
Daily time spent caring, %		
<1 h	13.3	13.1
1–2 h	33.4	29.0
3–6 h	13.3	15.8
7–12 h	33.4	29.0
>12 h	6.6	13.1
Caregiver responsibilities, %		
Assists with showering/toileting	14.3	17.7
Assists with mobility	14.3	17.7
Assists with household chores	100	94
Assists with medications	42.9	23.5
Assists with shopping/banking	42.9	58.8
Assists with transport	42.9	50
Caregiver utility-based QOL/HRQOL, mean ± SD		
EQ-5D-3L	0.920 ± 0.12	0.911 ± 0.12
SF-6D	0.74 ± 0.1	0.71 ± 0.1
SF-36 PCS	50.0 ± 7.3	47.9 ± 8.5
SF-36 MCS	50.4 ± 10.0	48.3 ± 8.8
PWI	63.8 ± 21.1	62.5 ± 23.8

EQ-5D-3L, EuroQoL–5 Dimension–3 Level; MCS, Mental Component Summary; PCS, Physical Component Summary; PWI, Personal Wellbeing Index; SF-6D, Short Form–6 Dimensions; SF-36, 36-Item Short Form Health Survey; TAFE, technical and further education.
Some respondents did not answer all questions.

(Continued on following page)

hemodialysis), there were no significant differences in EQ-5D-3L (0.920±0.12 vs. 0.911±0.12, $P = 0.8$), SF-6D (0.74±0.1 vs. 0.71±0.1, $P = 0.4$), SF-36 PCS (50.0±7.3 vs. 47.9±8.5, $P = 0.4$), SF-36 MCS (50.4±10.0 vs. 48.3±8.8, $P = 0.4$), or PWI (63.8±21.1 vs. 62.5±23.8, $P = 0.8$) scores.

Utility-Based QOL and Health-Related QOL

At study conclusion, EQ-5D-3L was lower than baseline in both caregiver groups, but the mean reduction in QOL was significantly greater in caregivers of patients receiving extended-hours hemodialysis, compared with caregivers of patients receiving standard-hours hemodialysis (–0.18±0.30 vs. –0.02±0.16, $P = 0.04$) (Table 2, Figure 2a).

There was no significant difference between standard- and extended-hours groups in mean change in utility-based QOL as measured by SF-6D (–0.04±0.1 vs. 0.03±0.12, $P = 0.8$) (Figure 2b). Change in HRQOL was similar between groups when measured by SF-36 PCS (–5.6±9.8 vs. –1.2±9.8, $P = 0.2$), SF-36 MCS (–0.5±7.1 vs. –4.1±11.2, $P = 0.4$), and PWI (0.00±20.4 vs. –2.3±17.6, $P = 0.9$) (Figure 2c–e).

When baseline patient and caregiver scores were compared to one another, mean SF-36 PCS was significantly lower in patients than caregivers, in both the standard- (39.81±7.24 vs. 50.0±7.3, $P < 0.01$) and extended-hours groups (40.58±12.2 vs. 47.9±8.5, $P = 0.04$) (Table 3). However, there were no significant differences between patients and caregivers in the change in any measure, in either the standard- or extended-hours groups.

DISCUSSION

Caregivers of patients receiving hemodialysis in our study were required to spend substantial time each day performing caregiving tasks. Most had been in their caregiving role for years, and most commonly cared for a partner with whom they lived. A significantly greater decrease of –0.18 in EQ-5D-3L was observed in caregivers of patients receiving extended-hours hemodialysis. Although the minimum clinically important difference (MCID) has been reported at approximately this value,[25] albeit with some uncertainty, a decrease of 0.18 on a utility scale of 0 to 1 (dead to full health)

Table 2. Changes in utility-based QOL and HRQOL scores of caregivers

Utility-based QOL/ HRQOL measure	Standard hours, mean change (SD)	Extended hours, mean change (SD)	*P* value
EQ-5D-3L	−0.02 (0.16)	−0.18 (0.30)	0.04
SF-6D	−0.04 (0.1)	0.03 (0.12)	0.8
SF36 PCS	−5.6 (9.8)	−1.2 (9.8)	0.2
SF-36 MCS	−0.5 (7.1)	−4.1 (11.2)	0.4
PWI	0.00 (20.4)	2.3 (17.6)	0.9

EQ-5D-3L, EuroQoL–5 Dimension–3 Level; MCS, Mental Component Summary; PCS, Physical Component Summary; PWI, Personal Wellbeing Index; SF-6D, Short Form–6 Dimensions; SF-36, 36-Item Short Form Health Survey.

represents a substantial reduction in QOL. For context, a systematic review by Wyld and colleagues reported a utility-based QOL value for having a kidney transplant of 0.82, that is, a decrement from full health of 0.18.[26] This suggests that caregivers of patients receiving extended-hours hemodialysis in Co-ACTIVE experienced a decrement in utility-based QOL of a similar magnitude to them having a kidney transplant themselves. Moreover, similar utility values have also been observed in caregivers of patients with dementia or cancer receiving chemotherapy.[27,28] It should be noted that there were no significant between-group differences detected in utility-based QOL as measured by SF-6D, or in HRQOL as measured by SF-36 PCS or MCS, or PWI, although these instruments measure different domains and dimensions of QOL; thus, some variation between results would be anticipated. As a result, the true magnitude and clinical significance of the effects of extended-hours dialysis on caregiver QOL remains somewhat unclear.

There are few previous randomized trials evaluating the effect of hemodialysis on caregivers. The Frequent Hemodialysis Network (FHN) Nocturnal trial found a trend to higher perceived caregiver burden, as measured by the Cousineau scale of perceived burden, in patients randomized to receive daily home nocturnal dialysis compared with conventional dialysis in-center or at home.[29–31] However, there was no difference in perceived caregiver burden between those randomized to receive daily facility hemodialysis compared with conventional facility dialysis in the FHN Daily Trial.[31,32] It is important to note, however, that the FHN trials did not directly measure caregiver burden but instead assessed the patient's perception of his or her caregiver's burden.

It is possible that extended-hours hemodialysis may adversely affect caregiver QOL through increased time, transport, and other demands. Our participant population included only facility dialysis patients and thus both standard- and extended-hours participants continued with a thrice-weekly dialysis schedule. Thus, as previously suggested, dialysis being performed by paid health care workers may have potentially helped to lessen any increased burden of extended-hours dialysis.[31,32] In our study, it did not appear that improvements in patient health with extended-hours dialysis would have mitigated increased caregiver burden, as the results of the larger ACTIVE trial did not show any significant improvements in patient QOL, blood pressure, or cardiac parameters with this treatment.[14,33] In addition, we did not identify any significant differences between patients and caregivers in change in any HRQOL or utility-based QOL measure.

Strengths of our study include its design as part of an international, randomized controlled trial and its use of validated HRQOL and utility-based QOL measures. The EQ-5D-3L was selected as the primary outcome measure owing to its more widespread use and to be consistent with the main ACTIVE study. However, we used multiple health utility and HRQOL measures, as there is no single accepted and validated tool for evaluating QOL in the caregiver population. In fact, a previous systematic review and meta-analysis identified the use of 70 different quantitative measures of QOL and burden in studies of caregivers of dialysis recipients.[12] Moreover, although some domains of QOL are shared between different measures, they do differ in the view provided of the underlying concepts. To our knowledge, our study is the first to examine several direct measures of caregiver QOL with extended versus standard hemodialysis treatment. However, our study has limitations, including small sample size and relatively short follow-up. Selection bias may have been present regarding the characteristics of those who agreed to participate in the study. It is not clear how generalizable the results of our study are, as country-specific social and cultural factors may influence caregiver perception of responsibilities and QOL, and the majority of participants were from China. Finally, the patients in the Co-ACTIVE cohort were all receiving facility hemodialysis, so the results may not be applicable to those patients performing home hemodialysis.

In conclusion, the Co-ACTIVE study demonstrated a statistically greater decrease in utility-based QOL measured by EQ-5D-3L in caregivers of patients randomized to receive extended-hours hemodialysis compared with those receiving standard-hours. Given the limited sample size, and as no significant difference was found in change in SF-6D, SF-36 MCS or PCS, or PWI, the results should be regarded as exploratory. However, it is not unreasonable to suggest that different ways of delivering dialysis for people with end-stage kidney disease may impact on the QOL of

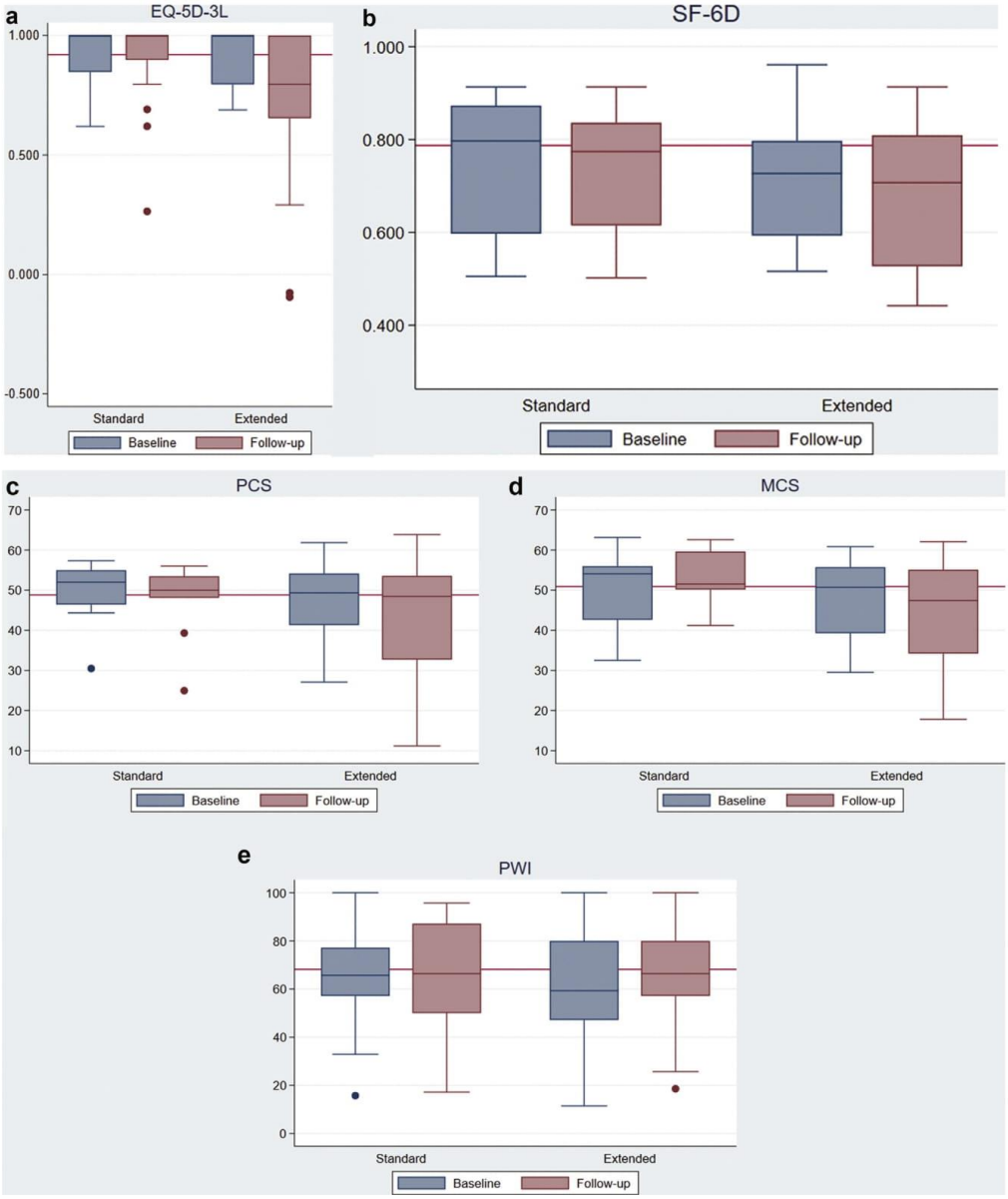

Figure 2. Scores in caregivers of patients randomized to standard- and extended-hours hemodialysis: (a) EQ-5D-3L (Chinese general population norm = 0.920, SD 0.17)[34]; (b) SF-6D (Chinese general population norm = 0.787, SD 0.15)[22]; (c) SF-36 PCS (Chinese general population norm = 48.8)[35]; (d) SF-36 MCS (Chinese general population norm = 50.9)[35]; (e) PWI (Chinese general population norm for age 51–55 years = 68.2, SD 14.2).[36] EQ-5D-3L, EuroQoL–5 Dimension–3 Level; MCS, Mental Component Summary; PCS, Physical Component Summary; PWI, Personal Wellbeing Index; SF-6D, Short Form–6 Dimensions; SF-36, 36-Item Short Form Health Survey.

their caregivers. The findings of our study support prioritization of research, including qualitative studies, to better understand the burden and impact of dialysis service delivery on caregivers, and assist in directing health care funding and provision of financial and social support for these important health care providers.

Table 3. Utility-based QOL and HRQOL in patients and caregivers randomized to standard and extended hours

	Standard hours			Extended hours		
	Patients, mean (SD)	Carers, mean (SD)	*P* value	Patients, mean (SD)	Carers, mean (SD)	*P* value
EQ-5D-3L						
Baseline	0.772 (0.255)	0.920 (0.12)		0.80 (0.25)	0.911 (0.12)	
Follow-up	0.78 (0.2)	0.9 (0.21)		0.76 (0.31)	0.71 (0.32)	
Change from baseline to follow-up	0.005 (0.27)	−0.02 (0.16)	0.9	−0.04 (0.16)	−0.18 (0.30)	0.06
SF-36 PCS						
Baseline	39.81 (7.24)	50.0 (7.3)		40.58 (12.2)	47.9 (8.5)	
Follow-up	40.25 (9.22)	47.13 (8.49)		41.0 (12.05)	45.02 (12.97)	
Change from baseline to follow-up	0.21 (6.5)	−5.34 (8.77)	0.2	−0.66 (8.41)	−1.06 (9.28)	0.6
SF-36 MCS						
Baseline	49.83 (10.98)	50.4 (10.0)		50.1 (10.95)	48.3 (8.8)	
Follow-up	47.02 (13.39)	51.42 (8.17)		49.96 (12.29)	44.74 (12.41)	
Change from baseline to follow-up	0.5 (9.35)	−2.21 (8.68)	0.6	−0.57 (8.25)	−4.21 (11.63)	0.3
SF6D						
Baseline	0.67 (0.14)	0.74 (0.1)		0.7 (0.16)	0.71 (0.1)	
Follow-up	0.65 (0.18)	0.73 (0.14)		0.69 (0.17)	0.68 (0.16)	
Change from baseline to follow-up	0.0003 (0.12)	−0.037 (0.096)	0.6	−0.02 (0.12)	−0.03 (0.12)	0.8

EQ-5D-3L, EuroQoL–5 Dimension–3 Level; MCS, Mental Component Summary; PCS, Physical Component Summary; SF-6D, Short Form–6 Dimensions; SF-36, 36-Item Short Form Health Survey.

DISCLOSURE

MN has received travel support from Amgen. RK is supported by QLD Advancing Clinical Research Fellowship; has received consultancy fees, speaker's honoraria, and travel sponsorship from Baxter Healthcare and travel sponsorship from Amgen. BS is supported by an Australian Government Research Training Program Scholarship through the University of Sydney and has received sponsored travel from Roche International and Vimedimex Binh Duong. MiJ is supported by a Scientia Fellowship from University of New South Wales–Sydney and reports receiving unrestricted grant support from VentureWise (a wholly owned commercial subsidiary of NPS MedicineWise) to conduct a commissioned project funded by AstraZeneca, outside the submitted work. CTC has consulted for Medtronic, Baxter, and Quanta from enrolment to present. VP has served on advisory boards or given scientific presentations for AbbVie, Boehringer Ingelheim, GlaxoSmithKline, Janssen, Pfizer, Astellas, AstraZeneca, Bayer, Baxter, Bristol-Myers Squibb, Chinook, Durect, Eli Lilly, Gilead, Merck, Mitsubishi Tanabe, Mundipharma, Novartis, Novo Nordisk, Pharmalink, Relypsa, Retrophin, Roche, Sanofi, Servier, and Vitae; and is serving/served on steering committees for trials funded by AbbVie, Astra Zeneca, Bayer, Boehringer Ingelheim, Chinook, Eli Lilly, Gilead, GlaxoSmithKline, Janssen, Novartis, Novo Nordisk, and Retrophin. MeJ is supported by a Medical Research Future Fund Next Generation Clinical Researchers Program Career Development Fellowship; is responsible for research projects that have received unrestricted funding from Gambro, Baxter, CSL, Amgen, Eli Lilly, and MSD; has served on advisory boards sponsored by Akebia, Astra Zeneca, Baxter, Boehringer Ingelheim, Merck, and Vifor; serves on steering committees for trials sponsored by Janssen and CSL; and spoken at scientific meetings sponsored by Janssen, Amgen, Roche, and Vifor, with any consultancy, honoraria, or travel support paid to her institution. NG has received speaker's honoraria from Baxter Healthcare and Astra Zeneca. All other authors declare that they have no relevant disclosures.

ACKNOWLEDGMENTS

Funding for Co-ACTIVE provided through grants from the Private Practice Trust Fund of the Sunshine Coast Hospital and Health Service. The ACTIVE Dialysis trial was supported by a National Health and Medical Research Council (NHMRC) of Australia project grant (571045) and a Baxter Clinical Evidence Council Investigator Initiated research grant (2012), with additional support from an unrestricted grant from Baxter International Inc., with funding for the vanguard phase from an NHMRC program grant (358395). The funders had no role in study design; collection, analysis, and interpretation of data; writing the report; and the decision to submit the report for publication. We are grateful to the investigators and study personnel, and especially the participants, involved in both ACTIVE and Co-ACTIVE, whose contributions have made this research possible.

AUTHOR CONTRIBUTIONS

Study inception and design: NG, KH, LZ, JdZ, AC, VP, MeJ. Data collection: LZ, DH, MiJ, BS, JW, CL, ZL. Data analysis and interpretation: MN, RK, NG, BS, KH, MeJ. Manuscript preparation: MN, NG, RK. Revision and approval of final manuscript: all authors

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Supplementary References.

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CHAPTER 5: CONCLUSIONS AND FUTURE DIRECTIONS

5.1 Summary and Impact

Understanding the causes and impacts of health inequities, applying proven support interventions, identifying and testing new interventions, and monitoring progress are vital in allowing individuals to achieve their best possible health. There are many groups in society that experience inequity and this thesis has focussed on the impact of CKD on people living in rural areas, socioeconomically disadvantaged, and their caregivers. The work has resulted in many original contributions to the literature, some of which have been incorporated into guidelines (252-255), and most importantly prompted the reinvigoration of QIs and a quality care focus in the Australian and New Zealand nephrology community.

Rural residence has been associated with poorer healthcare access and outcomes in many countries. My work has built on this literature by detailing the impact for people in rural Australia undertaking KRT, finding a lower incidence of KRT outside urban areas, poorer dialysis but comparable transplant recipient survival, and comparable peritoneal dialysis outcomes. Many of the issues faced by people with CKD in rural areas are shared with other chronic diseases and solutions aimed at rural health in general are likely to have a positive impact on people with CKD. Telemedicine for patient consultation may help reduce access to care barriers in rural areas. Although uptake was increasing through Australia when I undertook my study, there remained anxiety about safety and efficacy especially in the kidney transplant recipient population. Although a single centre study, my work demonstrating that telemedicine was not just feasible but over 2 years follow-up was associated with equivalent clinical outcomes has added some reassurance for patients and health practitioners alike.

The work on SES and CKD expanded the literature by demonstrating poorer dialysis survival among people living in lower SES postcodes, particularly among those aged <65 years. The work was extended to demonstrate there was not a difference by SES in quality of delivered dialysis care, suggesting alternate explanations. Importantly, the rural and socioeconomic work has generated understanding and interest in this area by researchers, and nowadays both area of residence and SES are commonly included in reports and analyses using ANZDATA. The challenges for access and care for these groups have been recognised by my work and others, leading to closer scrutiny of equity of access, care and outcomes for all people.

The most significant and lasting outcome of this work has been the reinvigoration of quality care and QIs in the ANZSN community. ANZDATA had been reporting 2 measures of quality of care for some years and as Chairperson of the Key Performance Indicator Workgroup of ANZSN, I was able to lead the development of new QIs. In my role as Chairperson of the ANZDATA Advisory Committee and member of ANZDATA Executive, I have been able to help implement a suite of QIs

which are now reported by ANZDATA annually on locked data and semi-annually on real-time data. These datasets have been more widely distributed than before, extending beyond heads of renal units, to Health Service Chief Executives, state Departments of Health, and publication on the ANZDATA website.

The governance structure for the ANZDATA QIs required the establishment of an ANZSN Quality Indicators sub-committee. This sub-committee is now driving quality care workshops, conferences, and presentations in Australia and New Zealand. More recently, this group has engaged with the Renal Society of Australasia, whose membership is mainly renal nurses, creating a collaboration based around quality care.

The published work on caregivers of people with CKD comprehensively reviewed the literature for caregivers of people undertaking dialysis and those choosing CKM, clearly distilling the data. Burden and QOL of caregivers were similar whether the care-recipient was having dialysis or CKM, not different by dialysis modality, and comparable to caregivers of people with other chronic diseases. Caregivers of people choosing CKM reported need for involvement in decisions, identifying supports, burden of care, and uncertainty about the future and the dying process as their concerns. This work was taken further by the first report of the QOL and personal wellbeing of caregivers of dialysis patients in China. The baseline data found higher physical but equivalent mental component QOL in caregivers compared with dialysis recipients, and poorer personal well-being than the general Chinese population. The follow-up data was the first exploratory analysis of the impact of extended versus standard hour haemodialysis on caregivers, suggesting a possible adverse impact of longer hour dialysis.

5.2 Future Directions

It is important to monitor progress in reducing the poorer outcomes for KRT in rural areas, and this is currently underway for peritoneal dialysis and should be reported later this year. My work has also been the starting point for other researchers in the field with their contributions including financial impacts, access issues, a proposed patient navigator programme, and rural caregivers' experiences (61, 256-261).

My involvement in QIs, which started with my original work with SES in KRT, continues to expand. This is my main future priority. After completion of a national implementation trial to see if a suite of measures could reduce catheter related bacteraemia among haemodialysis patients (262, 263), the Australia and New Zealand nephrology community made calls for a blood stream infection QI. In collaboration with the ANZSN Quality Improvement sub-committee, ANZDATA has started data collection to allow reporting of infections related to dialysis vascular access from 1 January 2025. Data will be reported semi-annually in real-time and annually on locked data, for the first-time allowing monitoring and benchmarking. There remains a large body of work to undertake in the QI

space. For example, work is underway to report clinicians' interpretation of QI reports and consumer prioritisation of QIs.

While most of the work with QIs has been using ANZDATA, an opportunity in future will be the use of electronic medical records (EMRs). EMRs can be used to improve quality with "nudges" or "prompts" (264), and for extracting data to measure a specific quality of care parameter. EMRs offer opportunities including rapid, efficient, and timely data extraction compared with manual chart audits (265). They could report on more granular data than registries, for example dialysis specific measures including missed dialysis sessions and interdialytic weight gain. EMRs may also enable reporting new patient cohorts such as those choosing CKM (who are currently not captured in ANZDATA). There are of course challenges such as different EMR systems across hospitals and jurisdictions, and data quality. Exploring the feasibility of using EMRs in the Australian and New Zealand context is an important next step. Promisingly, a systematic review has found EMRs to report QIs are feasible and successful (265) and a single centre Canadian experience was very positive (266).

In the field of caregivers of people with CKD, I have developed and commenced the Caregivers of The InfirM ElderLY trial (Co-TIMELY). This study forms one component of the Elderly Advanced CKD Programme (240) which includes people with kidney failure (eGFR <15ml/min/1.73m^2) aged 75+ years (intending either dialysis or CKM). The study will report caregiver QOL at the same timepoints as patient QOL. There is also an interview component, including an opportunity for caregivers to be interviewed after the death of the care-recipient, aiming to provide important insights into end-of-life support.

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