Longitudinal associations between socioeconomic position and overall health of children with chronic kidney disease & their carers

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Ethics: This study was approved by the Human Research Ethics Committees (HRECs) of all participating centres (The Children's Hospital at Westmead and Sydney Children's Hospital (HREC/12/SCHN/159), Lady Cilento Children's Hospital (HREC/12/QCRH/113), The Royal Children's Hospital (Royal Children's Hospital Human Research Ethics Committee: 33229) and Starship Children's Hospital (New Zealand Health

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Abstract

Background: Disadvantaged socioeconomic position (SEP) is an important predictor of poor health in children with chronic kidney disease (CKD). The time-course over which SEP influences the health of children with CKD and their carers is unknown.

Methods: This prospective longitudinal study included 377 children, aged 6-18 years with CKD (stages I-V, dialysis, and transplant), and their primary carers. Mixed effects ordinal regression was performed to assess the association between SEP and carer-rated child health and carer self-rated health over 4 years' follow-up.

Results: Adjusted for CKD stage, higher family household income (adjusted odds ratio (OR) (95% CI) 3.3, 1.8-6.0), employed status of primary carers (1.7, 0.9-3.0), higher carer perceived financial status (2.6, 1.4-4.8) and carer home ownership (2.2, 1.2-4.0), were associated with better carer rated child health. Household income also had a differential effect on carer's self-rated health over time (p=0.005). The predicted probabilities for carer's overall health being 'very good' among lower income groups at 0, 2 and 4 years were 0.43 (0.28-0.60), 0.34 (0.20-0.51), and 0.25 (0.12-0.44), respectively, and 0.81 (0.69-0.88), 0.84 (0.74-0.91), and 0.88 (0.76-0.94) for carers within the higher income group.

Conclusions: Carers and their children with CKD in higher SEP report better overall child and carer health compared with those in lower SEP. Carers of children with CKD in low-income households had poorer self-rated health compared with carers in higher income households at baseline, and this worsened over time. These cumulative effects may contribute to health inequities between higher and lower SEP groups over time.

Introduction

Chronic kidney disease (CKD) in children is a serious and debilitating illness, with the mortality rate for children with kidney failure receiving dialysis being 30 to 150 times higher than the general childhood population [1]. Alongside poorer survival, children with CKD suffer from reduced health-related quality of life, as well as long-term adverse sequelae on growth and development [2]. Apart from the known biological factors that predict poor health in children with CKD, socioeconomic position (SEP) is a major determinant of health [3]. Findings from recent a cross-sectional study suggest that lower SEP is associated with poorer carer-rated health of children, with children from lower SEP backgrounds being approximately 2.5-3.5 times as likely to report only fair or poor health compared with those from higher SEP groups [4]. The effects of low SEP were also found to vary by CKD stage, where lower SEP was independently associated with poor parent-rated health for children with CKD stages I-V, but not amongst children on dialysis or with kidney transplants. The health disadvantage experienced by children of lower SEP backgrounds is further perpetuated by the significant economic stress on carers, manifested as increased health care costs, disruption to work, travel expenses, and out-of-pocket payments, as the disease progresses over time [5].

Financial hardship may contribute to stress, anxiety, uncertainty, and will likely influence the overall well-being of all individuals within families. Prior research has focussed largely on the impact of socioeconomic disadvantage on the health of children with CKD [3], but few studies have assessed how socioeconomic factors influence the overall well-being of carers of children with CKD. A single study has shown that socioeconomic disadvantage is a predictor of poor health in carers of children with CKD, with lower income status being associated with higher levels of carer stress, depression, and anxiety [6]. However, the effect of socioeconomic disadvantage is likely to be cumulative throughout the life course, resulting from the differential exposures to potential mediating factors such as stress, poorer diets, reduced exercise, impaired sleep, poorer housing and other material conditions. These cumulative effects may exacerbate of health inequities between higher and lower SEP groups over time.

In this study, we aimed to assess the longitudinal association between socioeconomic position and the carer's rated health of the child with CKD, and the carers' self-rated health. By improving our understanding of the

socioeconomic factors that may be associated with poorer children's and carer's overall health, we can develop policies to better support the families of children living with CKD.

Materials and methods

Study design and population

The Kids with CKD (KCAD) study is a prospective longitudinal observational study that aims to provide qualitative and quantitative insights into the socioeconomic determinants of health in pediatric CKD. Children aged 6-18 years with CKD (stages I–V, dialysis, and transplanted patients) were enrolled from January 2012 until September 2016. The KCAD study design and methods have been described in detail previously [7].

Study exposures

The key exposure was composite SEP quartile at baseline, which was described previously using this study cohort [4]. Other study exposures included individual components of the composite SEP index – carer educational attainment, household weekly income, carer employment status, home ownership and carer perceived financial status (each analysed in separate models). All socioeconomic data were based on carer self-report.

Study covariates

Child-related covariates for this study included age at study entry, gender, ethnicity, private health insurance status, and CKD stage (stages I-V not requiring kidney replacement therapy, dialysis, or transplant group). Carer-related covariates included relationship to the child, marital status, total family size, carer's age and partner's age. Covariates were collected at baseline through questionnaires given to carers, and selected as potential confounders for the relationship between SEP and carer/child health.

Study outcomes and follow-up

The primary outcome was the carer-rated child health score, and the secondary outcome was carer self-rated health (SRH) score. Carer-related child health is a widely used and previously validated measure of overall

child health in surveys [8, 9]. For the carer-rated child health score, an ordinal 5-point Likert scale was used, where carers were asked the following question: 'In general, would you say your child's health is: (1) poor, (2) fair, (3) good, (4) very good, or (5) excellent?'. For the carer self-rated health score, carers were asked to rate their own health on the 5-point Likert scale. For both outcomes, overall 'health' referred to both physical and psychosocial aspects of health. The five-point Likert scale for health status is a validated, subjective tool that has been used to measure the overall health and to predict mortality in adults and has been used as a measure of overall health status in population surveys [10-12]. Child health scores ranged from 1 to 5 using the original scale, and carer health scores were re-categorised into a 4-level ordinal outcome by combining scores '(1) poor' and '(2) fair', given small sample sizes for these categories. After recruitment at the start of the study, outcome data was collected again at two- and four-years' follow-up.

Statistical analyses

Baseline characteristics were reported by CKD group, with continuous variables compared using the ANOVA test, and categorical variables compared using chi-squared test (or Fisher's exact test if cell counts less than 10). A mixed effects ordinal regression was fitted using the cumulative logit link function. Follow-up time in years since study entry was assessed as a continuous linear effect. Time and SEP were included as fixed effects. A model with a random intercept (for subject identification (ID)) and random slope (for time) was compared against a random intercept model only. Based on the Akaike information criterion (AIC) statistic and nested log likelihood ratio test, the final models retained the random intercept only for patient ID.

For both outcomes of carer-rated child health and carer self-rated health, additional fixed effects included child CKD group status (time-varying; CKD stages I-V not requiring kidney replacement therapy, dialysis or transplant group) and baseline potential covariates of child gender, age, ethnicity, private health insurance status, as well as carer age, marital status, and family size. These covariates were chosen given they are potential confounders of the relationship between SEP and overall health. The six baseline key exposures (composite SEP quartile, educational attainment, weekly household income, employment status, perceived financial status and home ownership) were analysed in separate multivariable models given the high

correlation and risk of multicollinearity. An interaction was assessed between SEP and follow-up time for each multivariable model.

Univariable analyses were performed to identify variables with p-values less than 0.20 for inclusion in the multivariable model. Final covariate selection was guided by manual backwards elimination procedure using AIC and nested log likelihood ratio tests at the 5% significance level. The following terms were retained regardless of statistical significance: CKD group, time and the key SEP exposure for that model. All models presented have satisfied the proportional odds assumption. Overall, measures of effect were presented as adjusted odds ratios (ORs) with 95% confidence intervals (CIs). Analyses were undertaken using R software version 4.0.3 (package 'ordinal') and SAS software (package 'proc glimmix').

Results

Baseline characteristics of children and carers (Table 1)

Of the total 528 patients invited to participate in the KCAD study, 377 were enrolled (Figure 1), and 375 had a child health score recorded at baseline. Of these 375 participants, 199 (53%) were in CKD stages I-V not requiring kidney replacement therapy, 42 (11%) were in the dialysis group, and 134 (36%) were in the transplant group. At least half of patients in all three groups were male and of White ethnicity. The average age of patients was 12 +/- 3.6 years for the CKD stages I-V group, 13 +/- 3.7 years for the dialysis group, and 12 +/- 4.0 years for the transplant group. Supplemental figures S1-3 summarize transitions for patients between CKD stages I-V, dialysis, and transplant status by baseline CKD group over the four-year follow up period. Most carers in all three CKD groups were mothers. The average age of carers was 43 +/- 13 years, 37 +/- 16 years and 42 +/- 14 years for the CKD stages I-V, dialysis, and transplant groups, respectively. The dialysis group had a higher proportion of patients within the lowest SEP quartile (41%, versus 21% for CKD stages I-V, and 20% for transplant groups).

Longitudinal analysis

Of the 375 patients, 342 were included in further analysis based on complete data for outcome and key exposure of SEP quartile. Of these 342, 208 (61%) completed 2-year follow up and 122 (36%) completed 4-

year follow up (Figure 1). Compared with those with complete follow up, carers of those who did not complete the 4-year follow-up were less likely to be married or de facto (88% vs 76%; p=0.01), perceive their financial status as comfortable or better (54% vs 41%; p=0.03) and own a home (75% vs 64%; p=0.05) (Table S1). They did not significantly differ on SEP quartile (p=0.35), carer educational attainment (p=0.41), household income (p=0.81), or carer employment status (p=0.75).

Carer-rated child health

Table 2 shows the results of the separate multivariable models that assessed the relationship between the six different SEP indicators and carer-rated health of the child. The interaction term between follow-up time and SEP covariate is presented for all models in order to assess for differing effects by SEP subgroup over follow up period. Compared with families of the lowest SEP (SEP quartile 1), the adjusted OR for carer-rated child health was 3.9 (95% CI 1.7–9.1) for families with the highest SEP quartile. Compared with families of lower SEP, higher household income (adjusted OR 3.3, 95% CI 1.8-6.0), higher carer perceived financial status (adjusted OR 2.6, 95% CI 1.4-4.8) and carer home ownership (adjusted OR 2.2, 95% CI 1.2-4.0) were associated with better carer-rated child health. Carer education level was not associated with carer-rated child health scores (adjusted OR 0.9, 95% CI 0.5-1.5, p=0.61. Employment status was also not associated with improved carer-rated child health (adjusted OR 1.7, 95% CI 0.9–3.1, p = 0.09). Across the different multivariable models, there was no significant association between other SEP indicators and time. Furthermore, there was no differential effect found for different SEP subgroups over time, with p>0.05 for interaction with time for each of the SEP exposures.

Carer self-rated health

Table 3 shows the results of the separate multivariable models that assessed the relationship between the six different SEP indicators and self-rated carer health. Being in a higher SEP quartile was associated with higher carer self-rated health compared with SEP quartile 1 (p<0.001). Compared with carers of lower SEP, the adjusted OR (95%CI) for the overall health of the carer was 16.9 (6.5–44.0) among those with the highest SEP. Furthermore, household income had differential effects on the carer's self-rated health over time (p=0.005). The predicted probability (95% CI) of carers with lower household incomes reporting their

overall health as 'very good' was estimated at 0 years (0.4, 0.3-0.6), 2 years (0.3, 0.2-0.5), and 4 years (0.3, 0.1-0.4) respectively. For carers with higher household incomes, the predicted probability (95% CI) of reporting their overall health as 'very good' was estimated at 0 years (0.8, 0.7-0.9), 2 years (0.8, 0.7-0.9), and 4 years (0.9, 0.8-0.9), respectively (Figure 2). Higher carer educational attainment (adjusted OR 2.0, 95% CI 1.0- 3.9), carer employment (adjusted OR 3.2, 95% CI 1.6- 6.3), higher carer perceived financial status (adjusted OR 8.9, 95% CI 4.6- 17.5), and home ownership (adjusted OR 2.7, 95% CI 1.3- 5.6) were associated with better carer self-rated health. However, there was no significant association between other SEP indicators and time.

Discussion

Our longitudinal multicentre study showed that, compared with children from families of the lowest SEP, children from families of the highest SEP quartile were around 4-times as likely to have better carer-rated overall health. This differential effect was seen across multiple domains of SEP indicators, with better carer rated child health associated with higher family household income (adjusted OR (95% CI) 3.3, 1.8-6.0), employed status of primary carers (1.7, 0.9-3.0), higher carer perceived financial status (2.6, 1.4-4.8) and carer home ownership (2.2, 1.2-4.0). These health inequities persisted across follow-up, suggesting that socioeconomic disadvantage has a sustained effect on the child's overall health over time. There were also considerable socioeconomic differences in the carer's health across multiple domains of SEP.

In terms of carer health, compared with carers of the lowest SEP quartile, carers of children with CKD from the highest SEP quartile were more likely to report better overall health than carers of lower SEP backgrounds. For most indicators, the effects of socioeconomic disadvantage on the carer's health remained unchanged over time. In contrast, we found that exposure to low family income may have a differing effect over time on overall health of the carers. The predicted probability of very good carer health in the low-income group declined from 0.4 at baseline to 0.2 over the four-year follow-up period, whereas carers in the high-income group maintained high self-rated health status with predicted probabilities of approximately 0.8-0.9. These interactive effects with time were not observed with the other SEP indicators.

SEP is a complex and multidimensional construct. Income is a frequently used indicator of SEP because measures the direct access to resources for an individual and at the household level. Despite universal healthcare in Australia and New Zealand, lower income households may still experience reduced access to appropriate healthcare for both the child with CKD and their carers. Even in the context of universal healthcare, families may have out of pocket costs such as co-payments for specialists, general practitioners appointments, and medications, and indirect healthcare costs associated with travel and accommodation for medical appointments (especially for rural/remote families) [13]. Poor health of the child with CKD also places a significant financial burden on the family, as one parent may need to withdraw from work to provide care, or families may need to set aside and draw on savings to cover the additional costs of medical care [14]. Over time, the potential bidirectional relationships between socioeconomic disadvantage and poor health may result in accumulating disadvantage [15-17]. Such profound economic and financial insecurity and the cumulative physical, psychosocial and behavioural effects of socioeconomic disadvantage may contribute to the worsening predicted self-rated carer's health over time for carers in the low-income group. Future studies should examine the time-varying SEP measures to further tease out the potential impacts of variations in the timing, duration and sequencing of low income on carer and child health [18].

Educational attainment is an important social determinant of health, with better education being associated with improved health literacy, increased employment opportunities and better psychological resilience to buffer the effects of stress on health [19]. In this current study, we found that educational attainment of the carers was associated with better carer's health, but not with the health of the child. In contrast, a systematic review of 22 observational studies in children with chronic diseases (CKD, type 2 diabetes, asthma and epilepsy) found that maternal educational attainment was an important predictor for child health related quality of life [3]. A longitudinal analysis in Nicaragua reported that low parent educational attainment was associated with a 2-fold increased risk of death among children with CKD [20]. This observed association was also reported in children with CKD in high income countries [21]. Overall, the level of education in this study cohort may have been too high to detect a strong association of education with health [20, 21]. It is also possible that the effects of tertiary education of the carers may have been dampened by the chronicity of the disease, or that education may be a less sensitive SEP indicator in our study cohort.

This study highlights some potential individual-level and population-level strategies to reduce the health inequities experienced by children with CKD and their carers associated with lower SEP. Interventions for carers could include scheduling appointment times outside of carer work hours or promoting eHealth tele-appointments and educational sessions (which have become more readily available since the COVID pandemic [22]), in order to reduce the burden on carers' professional commitments. Other strategies to promote job retention for carers may include advocacy to mandate secured paid leave and gradated return-to-work schemes (especially for parent transplant donors). Provision of patient liaison officers and social workers to assist families in navigating government financial support schemes and other sources of support is also critical (e.g., for income support payments, transport support schemes, etc) [23]. Information delivery for this can be aided through developing information packs (in multiple languages) specific to the hospital or local area, and through linking new carers to local carer support groups early on [14]. Furthermore, the socioeconomic impacts of caring for a child with CKD can be disproportionately placed on mothers (who tend to be primary carers). This burden can be alleviated by sharing the burden of carer training amongst both parents (e.g., home dialysis provision training, urinary catheter management, nutrition, and medication administration). More broadly, carers under greater socioeconomic stress can also be at higher risk of sacrificing their own health and missing their own health appointments, thus clinicians play an important role in ensuring carers are linked in with general practitioners and up to date with national screening programs. On a broader population level, there is a need for further research concentrating on addressing the upstream social determinants of health, and directly targeting factors such as financial hardship, employment, and housing. Given the evidence of widening gaps in carer's health across income, along with large inequities in child health by income, policies to reduce out of pocket costs and financial hardship are likely to be of importance.

Our study has several strengths. This is the largest multi-centre study to date, that has examined the longitudinal association between socioeconomic disadvantage and the health of children across all stages of CKD and their carers using multiple individual SEP indicators over time. Our focus on carer-reported outcomes allowed us to capture a more holistic assessment of overall child and carer health beyond solely physical wellbeing. Carers asked to consider both physical and psychosocial aspects of health when denoting an overall health score. Other strengths included consideration of multiple domains of SEP given the

multidimensional nature of the construct. We were able to capture the variation in the effects of SEP across disease stages, and the key confounders that were considered in multivariable models. Furthermore, our study also explored the influence of socioeconomic disadvantage on the carer's health over time, with consideration of wellbeing across the broader family unit being a unique and important aspect of our study.

Our study has several potential limitations. Given the observational nature of the study, there were likely undefined individual and community-level confounders and hence residual confounding. Moreover, most primary carers in the study cohort were mothers, highlighting a need for additional research to further explore the impact of paternal health for caring a child with CKD. Future studies involving families with children under six years of age could also provide valuable insights into the stress and quality of life for caregivers of younger children living with CKD. Similar to other longitudinal cohort analyses, this study had a high attrition rate, particularly at the 4-year follow-up, with the potential of differential loss to follow up over time, and a small sample size in the dialysis cohort. It is well-known that SEP is a dynamic construct. In this study, accurate assessment of the SEP was performed at baseline, but repeated SEP evaluations were incomplete over the 4-year follow-up. Further research is needed to establish the time-varying effects of SEP and the bidirectional relationships between SEP and health over time. Selection bias may also exist due to exclusion of non-English speaking participants. Furthermore, given the differences in health infrastructure globally, these results may not be generalisable to other countries with different health systems and welfare support.

In conclusion, carers, and their children with CKD in lower socioeconomic groups are at greater risk of experiencing poor carer-rated child health and carer self-rated health compared with children and carers of higher socioeconomic groups. The inequities in health for the carers also worsened over time. Our study findings have confirmed that the financial, physical and mental wellbeing of the carers have a direct influence on the health of children with CKD. Therefore, these data may provide guidance for the co-design of novel interventions, with patients and carers, to reduce the health disparities experienced by lower SEP families of children living with CKD. Such targeted interventions should consider a holistic approach that focuses not only on the child affected by CKD, but also on the overall wellbeing of the family.

Disclosures

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Tables

Table 1. Cohort baseline characteristics (n = 375), stratified by CKD group

		CKD stages I-V not requiring kidney replacement therapy (n=199)	Dialysis (n=42)	Transplant (n=134)
Child characteristics				
Age in years (mean (SD))		12 (3.6)	13 (3.7)	12 (4.0)
Male (%)		133 (66.8)	21 (50.0)	78 (58.2)
Ethnicity (%)	White	108 (54.3)	24 (57.1)	88 (65.7)
	Other	88 (44.2)	17 (40.5)	44 (32.8)
	Missing	3 (1.5)	1 (2.4)	2 (1.5)
Private health insurance present (%)		78 (39.2)	7 (16.7)	50 (37.3)
Carer characteristics				
Relationship (%)	Mother	164 (82.4)	32 (76.2)	113 (84.3)
	Father	29 (14.6)	9 (21.4)	17 (12.7)

	Other	6 (3.0)	1 (2.4)	3 (2.2)
	Missing	0 (0.0)	0 (0.0)	1 (0.7)
Marital status (%)	Single or other	34 (17.1)	12 (28.6)	31 (23.1)
	Married/defacto	165 (82.9)	29 (69.0)	101 (75.4)
	Missing	0 (0.0)	1 (2.4)	2 (1.5)
Age in years (mean (SD))		43 (13.3)	37 (16.4)	42 (14.3)
Partner age in years (mean (SD))		39 (11.5)	38 (13.8)	39 (12.5)
Family size (%)	2-3 persons	35 (17.6)	11 (26.2)	26 (19.4)
	4-5 persons	136 (68.3)	22 (52.4)	85 (63.4)
	6 persons or more	28 (14.1)	9 (21.4)	22 (16.4)
	Missing	0 (0.0)	0 (0.0)	1 (0.7)
Composite SEP index score quartile (%)	Quartile 1 (lowest)	42 (21.1)	17 (40.5)	27 (20.1)
	Quartile 2	47 (23.6)	10 (23.8)	36 (26.9)
	Quartile 3	50 (25.1)	7 (16.7)	32 (23.9)
	Quartile 4 (highest)	51 (25.6)	4 (9.5)	30 (22.4)
	Missing	9 (4.5)	4 (9.5)	9 (6.7)

Educational attainment (%)	Primary school/secondary school/trade certificate	76 (38.2)	24 (57.1)	59 (44.0)
	Bachelor's degree or higher/other certificate or diploma/other education	123 (61.8)	18 (42.9)	74 (55.2)
	Missing	0 (0.0)	0 (0.0)	1 (0.7)
Household income (%)	<= 1250 AUD/week	88 (44.2)	26 (61.9)	69 (51.5)
	>$1250 AUD/week	103 (51.8)	12 (28.6)	57 (42.5)
	Missing	8 (4.0)	4 (9.5)	8 (6.0)
Employment status (%)	Not currently working	79 (39.7)	25 (59.5)	51 (38.1)
.	Working full time/part time	120 (60.3)	17 (40.5)	82 (61.2)
	Missing	0 (0.0)	0 (0.0)	1 (0.7)
Perceived financial status (%)	Very poor-just getting along	100 (50.3)	31 (73.8)	72 (53.7)
	Reasonably comfortable-prosperous	99 (49.7)	10 (23.8)	61 (45.5)
	Missing	0 (0.0)	1 (2.4)	1 (0.7)
Home ownership (%)	Renting/other	69 (34.7)	16 (38.1)	32 (23.9)

	Owned outright/with mortgage	129 (64.8)	25 (59.5)	100 (74.6)
	Missing	1 (0.5)	1 (2.4)	2 (1.5)
Study factors				
State/country (%)	New South Wales, Australia	142 (71.4)	15 (35.7)	73 (54.5)
	Victoria, Australia	22 (11.1)	14 (33.3)	30 (22.4)
	New Zealand	30 (15.1)	4 (9.5)	17 (12.7)
	Queensland, Australia	5 (2.5)	9 (21.4)	14 (10.4)

CKD, chronic kidney disease, SEP, socioeconomic position

Table 2. Summary of multivariable models for primary outcome of carer-rated child health score across socioeconomic exposures*

Models	Exposure		Adj OR	95% CI	p	Overall p
1A (model with main effects only)[a]	SEP quartile	Quartile 1 (lowest)	Ref	.	.	<0.001
		Quartile 2	0.7	0.3 – 1.6	0.45	
		Quartile 3	1.8	0.8 – 4.2	0.14	
		Quartile 4 (highest)	3.9	1.7 – 9.1	0.001	
	Time	in years	1.0	0.9 – 1.1	.	0.72
1B (model with interaction term)[a]	Time*SEP quartile	Year*Quartile 2	0.9	0.6 – 1.2	0.38	0.54
		Year*Quartile 3	0.8	0.6 – 1.1	0.18	
		Year*Quartile 4	0.9	0.7 – 1.3	0.71	
2A (model with main effects only)[b]	Educational attainment	Primary school/secondary school/trade certificate	Ref	.	.	0.61
		Bachelor's degree or higher/ other certificate or diploma/other education	0.9	0.5 – 1.5	.	
	Time	In years	1.0	0.9 – 1.1	.	0.64
2B (model with interaction term)[b]	Time*Educational attainment	Year* Bachelor's degree or higher/ other certificate or diploma/other education	1.0	0.8 – 1.3	.	0.77
3A (model with main effects only)[c]	Household income	<= 1250 AUD/week	Ref	.	.	<0.001
		>$1250 AUD/week	3.3	1.8 – 6.0	.	
	Time	in years	1.0	0.9 – 1.1	.	0.73
3B (model with interaction term)[c]	Time*Household income	Year*>$1250 AUD/week	1.1	0.9 – 1.2	.	0.58
4A (model with main effects only)[d]	Employment status	Not currently working	Ref	.	.	0.09
		Working full time/part time	1.7	0.9 – 3.1	.	
	Time	in years	1.0	0.9 – 3.1	.	0.65
4B (model with interaction term)[d]	Time*Employment status	Year*Working full time/part time	1.0	0.8 – 1.2	.	0.87
5A (model with main effects only)[e]	Perceived financial status	Very poor-just getting along	Ref	.	.	0.001

		Reasonably comfortable-prosperous	2.6	1.4 – 4.8	.	
	Time	in years	1.0	0.9 – 1.1	.	0.64
5B (model with interaction term)[e]	Time*Perceived financial status	Year*Reasonably comfortable-prosperous	0.9	0.7 – 1.1	.	0.15
6A (model with main effects only)[f]	Home ownership	Renting/other	Ref	.	.	0.01
		Owned outright/with mortgage	2.2	1.2 – 4.0	.	.
	Time	in years	1.0	0.9 – 1.1	.	0.77
6B (model with interaction term)[f]	Time*Home ownership	Year*Owned outright/with mortgage	1.0	0.8 – 1.3	.	0.89

*Higher health scores indicating better health
[a] OR's also adjusted for CKD group
[b] OR's also adjusted for ethnicity, carer marital status, CKD group
[c] OR's also adjusted for CKD group
[d] OR's also adjusted for ethnicity, carer marital status, CKD group
[e] OR's also adjusted for ethnicity, CKD group
[f] OR's also adjusted for ethnicity, CKD group

Table 3. Summary of multivariable models for secondary outcome of carer self-rated health score across socioeconomic exposures*

Models	Exposure		Adj OR	95% CI	p	Overall p
1A (model with main effects only)[a]	SEP quartile	Quartile 1 (lowest)	Ref	.	.	<0.001
		Quartile 2	1.8	0.8 – 4.2	0.18	
		Quartile 3	8.0	3.2 – 19.6	<0.001	
		Quartile 4 (highest)	16.9	6.5 – 44.0	<0.001	
	Time	in years	1.0	0.9 – 1.1	.	0.52
1B (model with interaction term)[a]	Time*SEP quartile	Year*Quartile 2	1.1	0.8 – 1.5	0.77	0.32
		Year*Quartile 3	1.2	0.8 – 1.7	0.31	
		Year*Quartile 4	1.5	1.1 – 2.1	0.02	
2A (model with main effects only)[b]	Educational attainment	Primary school/secondary school/trade certificate	Ref	.	.	0.04
		Bachelor's degree or higher/other certificate or diploma/other education	2.0	1.0 – 3.9	.	
	Time	in years	1.0	0.9 – 1.1	.	0.49
2B (model with interaction term)[b]	Time*Educational attainment	Year* Bachelor's degree or higher/ other certificate or diploma/other education	1.2	0.9	1.50	0.18
3A (model with main effects only)[c]	Household income	<= 1250 AUD/week	Ref	.	.	<0.001
		>$1250 AUD/week	7.7	4.0 – 15.1	.	
	Time	in years	1.0	0.9 – 1.1	.	0.56
3B (model with interaction term)[c]	Household income	<= 1250 AUD/week	Ref	.	.	<0.001
		>$1250 AUD/week	5.5	2.7 – 11.2		
	Time	in years	0.8	0.7 – 1.0		0.02
	Time*Household income	Year*>$1250 AUD/week	1.4	1.1 – 1.8	.	0.005
4A (model with main effects only)[d]	Employment status	Not currently working	Ref	.	.	0.001
		Working full time/part time	3.2	1.6 – 6.3	.	
	Time	in years	1.0	0.9 – 1.1	.	0.57
4B (model with interaction term)[d]	Time*Employment status	Year*Working full time/part time	1.0	0.8 – 1.3	.	0.75

5A (model with main effects only)[e]	Perceived financial status	Very poor-just getting along	Ref	.	.	<0.001
		Reasonably comfortable-prosperous	8.9	4.6 – 17.5	.	
	Time	in years	1.0	0.8 – 1.1	.	0.40
5B (model with interaction term)[e]	Time*Perceived financial status	Year*Reasonably comfortable-prosperous	1.2	0.9 – 1.5	.	0.14
6A (model with main effects only)[f]	Home ownership	Renting/other	Ref	.	.	0.006
		Owned outright/with mortgage	2.7	1.3 – 5.6		
	Time	in years	1.0	0.9 – 1.1	.	0.53
6B (model with interaction term)[f]	Time*Home ownership	Year*Owned outright/with mortgage	1.2	0.9 – 1.5	.	0.30

*Higher health scores indicating better health
[a] OR's also adjusted for CKD group, ethnicity
[b] OR's also adjusted for CKD group, ethnicity, child gender, private health insurance
[c] OR's also adjusted for CKD group, ethnicity
[d] OR's also adjusted for CKD group, ethnicity, child gender, family size
[e] OR's also adjusted for CKD group, ethnicity
[f] OR's also adjusted for CKD group, ethnicity, child gender

Figure 1. Participant flow diagram

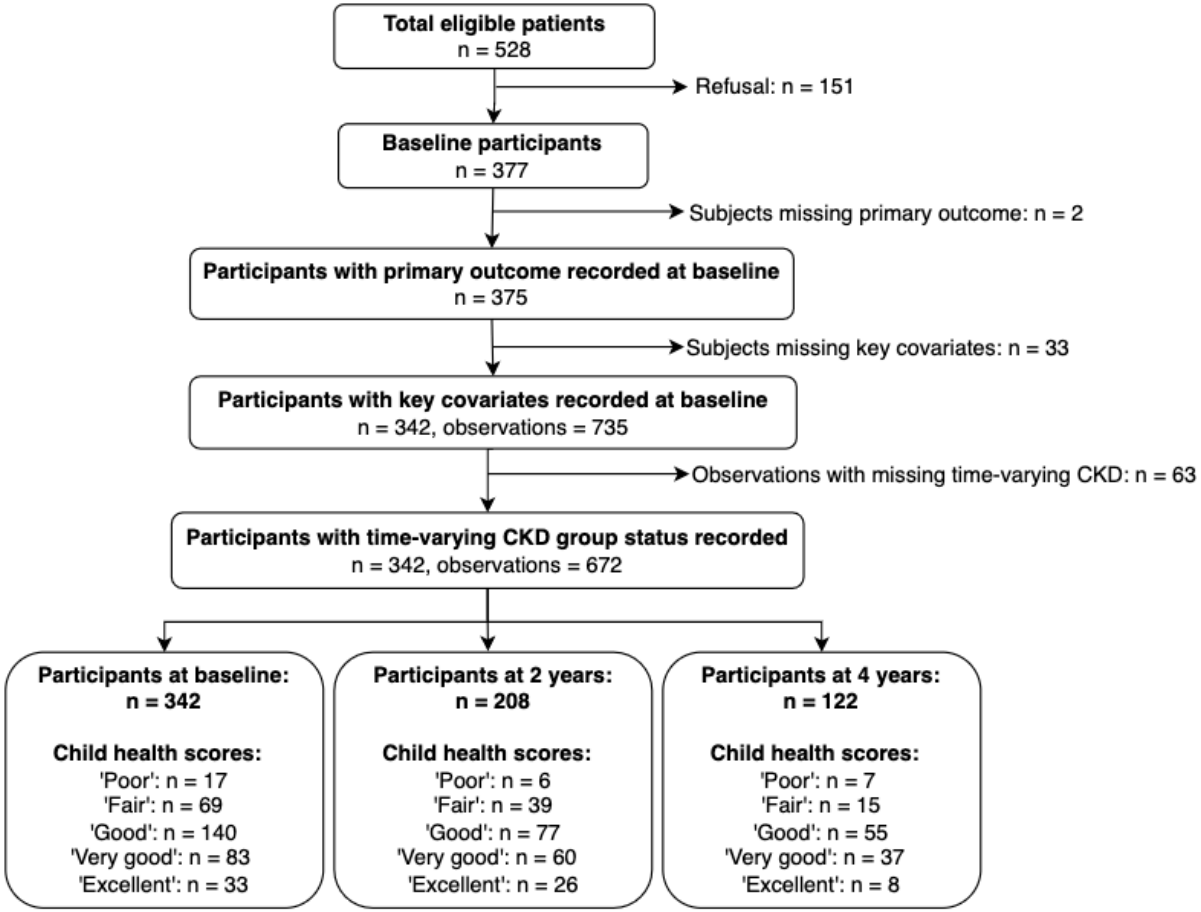
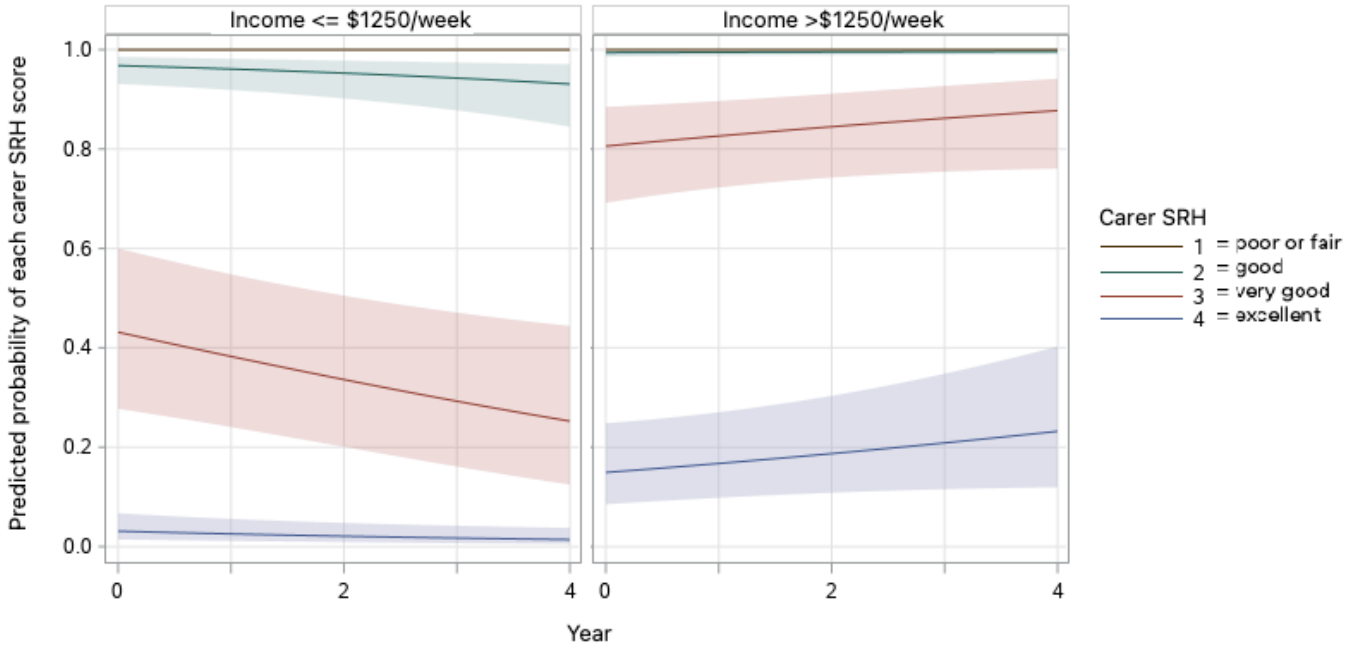


Figure 2. Interactions plot for carer income and time, for secondary outcome of carer self-rated health score*



*Fit computed at CKD group = 'CKD stages I-V not requiring kidney replacement therapy', and ethnicity = 'White'. Bands representing 95% CI.

SUPPLEMENTAL MATERIAL

Table S1. Cohort baseline characteristics stratified by loss to follow up at four years

	Missing at 4-year follow up (n=220)	Not missing at 4-year follow up (n=122)	p
Patient characteristics			
Female (%)	86 (39.1)	42 (34.4)	0.46
Age in years (mean (SD))	12.35 (3.7)	11.65 (3.8)	0.10
Non-White ethnicity (%)	95 (43.2)	41 (33.6)	0.11
Private health insurance present (%)	72 (32.7)	52 (42.6)	0.09
Carer characteristics			
Relationship (%)			0.13
Mother	188 (85.5)	98 (80.3)	
Father	25 (11.4)	23 (18.9)	
Aunt/uncle/sibling/other	7 (3.2)	1 (0.8)	
Marital status of married or defacto (%)	166 (75.5)	107 (87.7)	0.01
Family size (%)			0.34
2-3 persons	42 (19.1)	23 (18.9)	
4-5 persons	140 (63.6)	85 (69.7)	

6 persons or more	38 (17.3)	14 (11.5)	
Age in years (mean (SD))	40.69 (14.6)	43.25 (12.4)	0.10
Partner age in years (mean (SD))	38.29 (12.4)	39.61 (1.0)	0.33
Composite SEP index score quartile (%)			0.35
1 (lowest SES)	58 (26.4)	26 (21.3)	
2	55 (25.0)	34 (27.9)	
3	59 (26.8)	27 (22.1)	
4 (highest SES)	48 (21.8)	35 (28.7)	
Educational attainment of Bachelor's degree or higher/other certificate or diploma/other education (%)	122 (55.5)	74 (60.7)	0.41
Household income > $1250 AUD/week (%)	109 (49.5)	58 (47.5)	0.81
Employment status of working full time/part time (%)	130 (59.1)	75 (61.5)	0.75
Perceived financial status of reasonably comfortable-prosperous (%)	90 (40.9)	66 (54.1)	0.03
Home ownership of owned outright/with mortgage (%)	140 (63.6)	91 (74.6)	0.05

Table S2. Univariable analyses for primary outcome of carer-rated child health score

Predictors		Adjusted OR	95	%	CI	P	Overall P
Child gender	Male	Ref					
	Female	1.0	0.6	-	1.8	0.94	
Child age	in years	1	0.9	-	1.1	0.42	
Child ethnicity	White	Ref					
	Other	0.5	0.3	-	0.8	0.01	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref					<0.001
	Dialysis	0.2	0.1	-	0.5	<0.001	
	Transplant	1.9	1.1	-	3.4	0.2	
Child private health insurance	Absent	Ref					
	Present	1.1	0.6	-	2.1	0.65	
Carer marital status	Single or other	Ref					
	Married/defacto	2.2	1.1	-	4.5	0.03	
Family size	2-3 persons	Ref					
	4-5 persons	1.4	0.7	-	2.9	0.39	
	6 or more persons	1.3	0.5	-	3.3	0.66	

Carer age	in years	1	1.0	-	1.0	0.89
SEP quartile	Quartile 1 (lowest)	Ref				
	Quartile 2	0.8	0.4	-	1.8	0.6
	Quartile 3	2.1	1.0	-	4.7	0.06
	Quartile 4 (highest)	4.5	2.0	0	10.2	<0.001
Educational attainment	Primary school/secondary school/trade certificate	Ref				
	Bachelor's degree or higher/other certificate or diploma/other education	1.1	0.6	-	1.9	0.86
Household income	<= 1250 AUD/week	Ref				
	>$1250 AUD/week	3.4	1.9	-	6.0	<0.001
Employment status	Not currently working	Ref				
	Working full time/part time	2.3	1.3	-	4.1	0.01
Perceived financial status	Very poor-just getting along	Ref				
	Reasonably comfortable-prosperous	3.0	1.7	-	5.3	<0.001
Home ownership	Renting/other	Ref				
	Owned outright/with mortgage	2.6	1.4	-	4.8	<0.001
Time	in years	1.1	0.9	-	1.2	0.41

Table S3. Final mixed effects multivariable model including 'SEP quartile' for primary outcome of carer-rated child health score

Predictors		Adjusted OR	95% CI	p	Overall p
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref			<0.001
	Dialysis	0.3	0.1 – 0.6	0.001	
	Transplant	2.1	1.2 – 3.6	0.01	
Time	in years	1.0	0.9 – 1.1	0.72	
SEP quartile	Quartile 1 (lowest)	Ref			<0.001
	Quartile 2	0.7	0.3 – 1.6	0.45	
	Quartile 3	1.8	0.8 – 4.2	0.14	
	Quartile 4 (highest)	3.9	1.7 – 9.1	0.001	

Table S4. Final mixed effects multivariable model including 'carer education' for primary outcome of carer-rated child health score

Predictors		Adjusted OR	95% CI	p	Overall p
Child ethnicity	White	Ref			
	Other	0.5	0.3 – 0.9	0.01	
Carer marital status	Single or other	Ref			

	Married/defacto	2.5	1.2 – 5.2	0.01	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref	.	.	<0.001
	Dialysis	0.2	0.1 – 0.5	<0.001	
	Transplant	1.9	1.1 – 3.3	0.03	
Time	in years	1.0	0.9 – 1.1	0.64	
Carer educational attainment	Primary school/secondary school/trade certificate	Ref			
	Bachelor's degree or higher/other certificate or diploma/other education	0.9	0.5 – 1.5	0.61	

Table S5. Final mixed effects multivariable model including 'carer income' for primary outcome of carer-rated child health score

Predictors		Adjusted OR	95% CI	p	Overall p
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref			<0.001
	Dialysis	0.3	0.1 – 0.6	0.001	
	Transplant	2.2	1.2 – 3.9	0.01	

Time	in years	0.1	0.9 – 1.1	0.73
Household income	<= 1250 AUD/week	Ref		
	>$1250 AUD/week	3.3	1.8 – 6.0	<0.001

Table S6. Final mixed effects multivariable model including 'carer employment' for primary outcome carer-rated child health score

Predictors		Adjusted OR	95% CI	p	Overall p
Child ethnicity	White	Ref			
	Other	0.5	0.3 – 0.1	0.04	
Carer relationship status	Single or other	Ref			
	Married/defacto	2.3	1.1 – 4.8	0.03	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref			<0.001
	Dialysis	0.2	0.1 – 0.5	<0.001	
	Transplant	1.9	1.1 – 3.4	0.03	
Time	in years	1.0	0.9 – 1.1	0.65	
Employment status	Not currently working	Ref			

	Working full time/part time	1.7	0.9 – 3.1	0.09	

Table S7. Final mixed effects multivariable model including 'perceived financial status' for primary outcome of carer-rated child health score

Predictors		Adjusted OR	95% CI	p	Overall p
Child ethnicity	White	Ref			
	Other	0.6	0.3 – 1.0	0.04	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref			<0.001
	Dialysis	0.2	0.1 – 0.6	0.001	
	Transplant	2.0	1.1 – 3.6	0.03	
Time	in years	1.0	0.9 – 1.1	0.64	
Perceived financial status	Very poor-just getting along	Ref			
	Reasonably comfortable-prosperous	2.6	1.4 – 4.8	0.001	

Table S8. Final mixed effects multivariable model including 'home ownership' for primary outcome of carer-rated child health score

Predictors		Adjusted OR	95% CI	p	Overall p
Child ethnicity	White	Ref			
	Other	0.6	0.3 – 1.0	0.05	

Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref			<0.001
	Dialysis	0.2	0.1 – 0.5	<0.001	
	Transplant	1.7	1.0 – 3.0	0.08	
Time	in years	1.0	0.9 – 1.1	0.77	
Home ownership	Renting/other	Ref			
	Owned outright/with mortgage	2.2	1.2 – 4.0	0.01	

Table S9. Univariable analyses for secondary outcome of carer self-rated health score

Predictors		Unadjusted OR	95% CI	p	Overall p
Child gender	Male	Ref			
	Female	0.4	0.2 - 0.7	0.004	
Child age	in years	1.0	0.9 - 1.1	0.65	
Child ethnicity	White	Ref			
	Other	0.2	0.1 - 0.4	<0.001	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref			0.17

	Dialysis	0.4	0.2	-	1.0	0.06	
	Transplant	0.8	0.4	-	1.4	0.42	
Child private health insurance	Absent	Ref					
	Present	3.3	1.6	-	6.6	0.001	
Carer relationship status	Single or other	Ref					
	Married/defacto	2.1	0.9	-	5.0	0.09	
Family size	2-3 persons	Ref					0.03
	4-5 persons	3.0	1.2	-	7.2	0.02	
	6 or more persons	1.3	0.4	-	4.0	0.69	
Carer age	in years	1.0	1.0	-	1.0	0.58	.
SEP quartile	Quartile 1 (lowest)	Ref					<0.001
	Quartile 2	2.1	0.9	-	4.9	0.10	
	Quartile 3	10.6	4.3	-	26.3	<0.001	
	Quartile 4 (highest)	25.7	9.9	-	66.7	<0.001	
Educational attainment	Primary school/secondary school/trade certificate	Ref					

	Bachelor's degree or higher/other certificate or diploma/other education	2.50	1.26	-	4.97	0.009	
Household income	<= 1250 AUD/week	Ref					
	>$1250 AUD/week	10.6	5.4	-	20.6	<0.001	
Employment status	Not currently working	Ref					
	Working full time/part time	4.9	2.4	-	9.7	<0.001	
Perceived financial status	Very poor-just getting along	Ref					
	Reasonably comfortable-prosperous	10.7	5.4	-	21.2	<0.001	
Home ownership	Renting/other	Ref					
	Owned outright/with mortgage	3.3	1.6	-	6.9	0.002	
Time	in years	1.0	0.9	-	1.1	0.56	

Table S10. Final mixed effects multivariable model including 'SEP quartile' for secondary outcome of carer self-rated health score

Predictors	Adjusted OR	95% CI	p	Overall p

Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref					0.52
	Dialysis	0.6	0.3	-	1.4	0.25	
	Transplant	0.8	0.5	-	1.5	0.55	
Time	in years	1.0	0.9	-	1.1	0.52	
Child ethnicity	White	Ref					
	Other	0.3	0.2	-	0.6	<0.001	.
SEP quartile	Quartile 1 (lowest)	Ref					<0.001
	Quartile 2	1.8	0.8	-	4.2	0.18	
	Quartile 3	8.0	3.2	-	19.6	<0.001	
	Quartile 4 (highest)	16.9	6.5	-	44.0	<0.001	

Table S11. Final mixed effects multivariable model including 'carer education' for secondary outcome of carer self-rated health score

Predictors		Adjusted OR	95% CI			p	Overall p
Time	in years	1.0	0.9	-	1.1		0.49
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref					0.36
	Dialysis	0.5	0.2	-	1.3	0.15	
	Transplant	0.8	0.5	-	1.5	0.56	
Child ethnicity	White	Ref					
	Other	0.3	0.1	-	0.5	<0.001	
Child gender	Male	Ref					
	Female	0.4	0.2	-	0.9	0.02	
Child private health insurance	Absent	Ref					
	Present	2.1	1.1	-	4.2	0.03	
Educational attainment	Primary school/secondary school/trade certificate	Ref					
	Bachelor's degree or higher/other certificate or diploma/other education	2.0	1.1	-	3.9	0.04	

Table S12. Final mixed effects multivariable model (main effects only) including 'carer income' for secondary outcome of carer self-rated health score

Predictors		Adjusted OR	95% CI			p	Overall p
Time	in years	1.0	0.9	-	1.1	0.56	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref					0.46
	Dialysis	0.6	0.2	-	1.4	0.21	
	Transplant	0.9	0.5	-	1.6	0.67	
Child ethnicity	White	Ref					
	Other	0.3	0.2	-	0.6	<0.001	
Household income	<= 1250 AUD/week	Ref					
	>$1250 AUD/week	7.7	4.0	-	15.1	<0.001	

Table S13. Final mixed effects multivariable model (with interaction term) including 'carer income' for secondary outcome of carer self-rated health score

Predictors		Adjusted OR	95% CI	p	Overall p
Time	in years	0.8	0.7 - 1.0	0.02	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref			0.44
	Dialysis	0.6	0.2 - 1.4	0.20	
	Transplant	0.9	0.5 - 1.6	0.63	
Child ethnicity	White	Ref			
	Other	0.3	0.2 - 0.6	<0.001	
Household income	<= 1250 AUD/week	Ref			
	>$1250 AUD/week	5.5	2.7 - 11.2	<0.001	
Time*Household income	Year*>$1250 AUD/week	1.4	1.1 - 1.8	0.005	

Table S14. Final mixed effects multivariable model including 'carer employment' for secondary outcome of carer self-rated health score

Predictors		Adjusted OR	95% CI			P	Overall p
Time	in years	0.1	0.9	-	1.1	0.57	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref					0.27
	Dialysis	0.5	0.2	-	1.2	0.11	
	Transplant	0.8	0.4	-	1.4	0.36	
Child ethnicity	White	Ref					
	Other	0.2	0.1	-	0.5	<0.001	
Family size	2-3 persons	Ref					0.03
	4-5 persons	3.0	1.3	-	6.8	0.01	
	6 or more persons	2.1	0.7	-	6.3	0.19	
Employment status	Not currently working	Ref					
	Working full time/part time	3.2	1.6	-	6.3	0.001	

Table S15. Final mixed effects multivariable model including 'perceived financial status' secondary outcome of carer self-rated health score

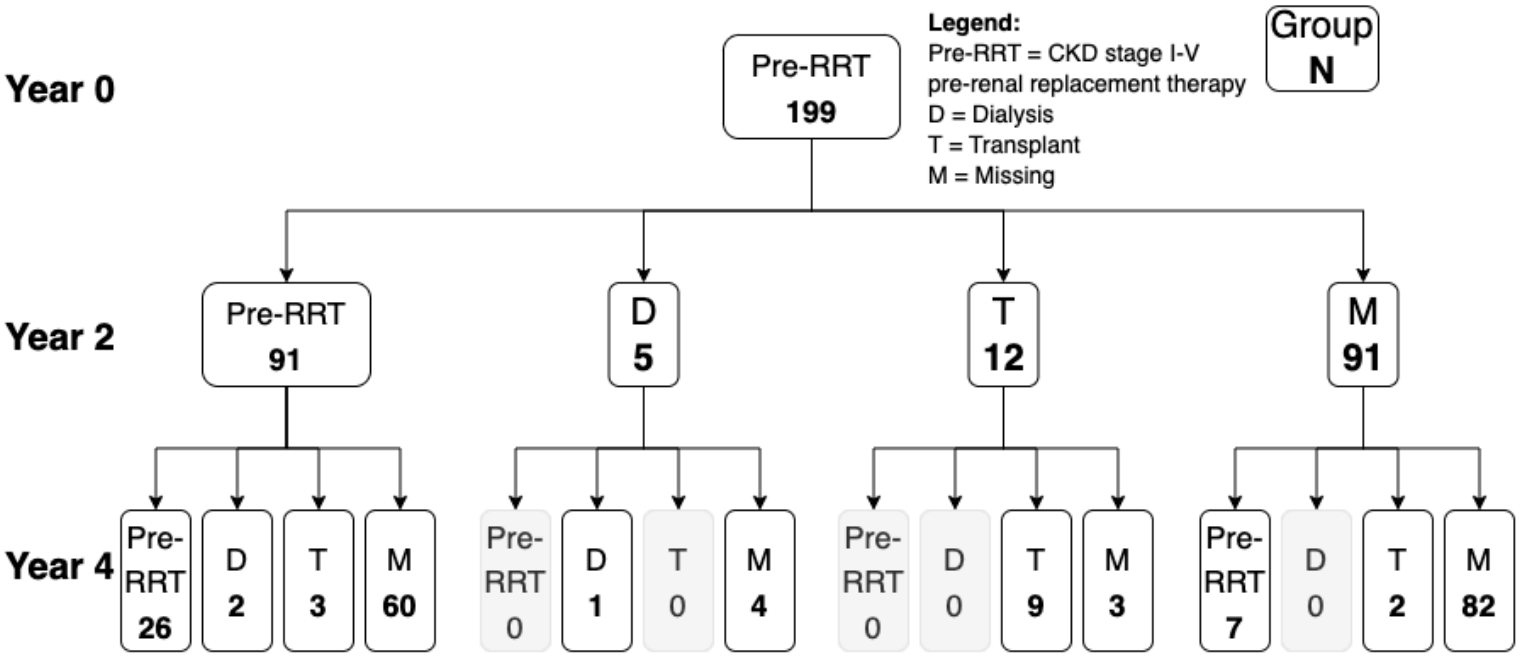
Predictors		Adjusted OR	95% CI			P	Overall P
Time	in years	1.0	0.8	-	1.1	0.40	
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref					0.47
	Dialysis	0.6	0.3	-	1.4	0.22	
	Transplant	0.8	0.5	-	1.5	0.52	
Child ethnicity	White	Ref					
	Other	0.2	0.1	-	0.4	<0.001	
Perceived financial status	Very poor-just getting along	Ref					
	Reasonably comfortable-prosperous	8.9	4.6	-	17.5	<0.001	

Table S16. Final mixed effects multivariable model including 'home ownership' for secondary outcome of carer self-rated health score

Predictors		Adjusted OR	95% CI			p	Overall p
Child CKD group	CKD stages I-V not requiring kidney replacement therapy	Ref				.	0.17
	Dialysis	0.4	0.2	-	1.1	0.07	

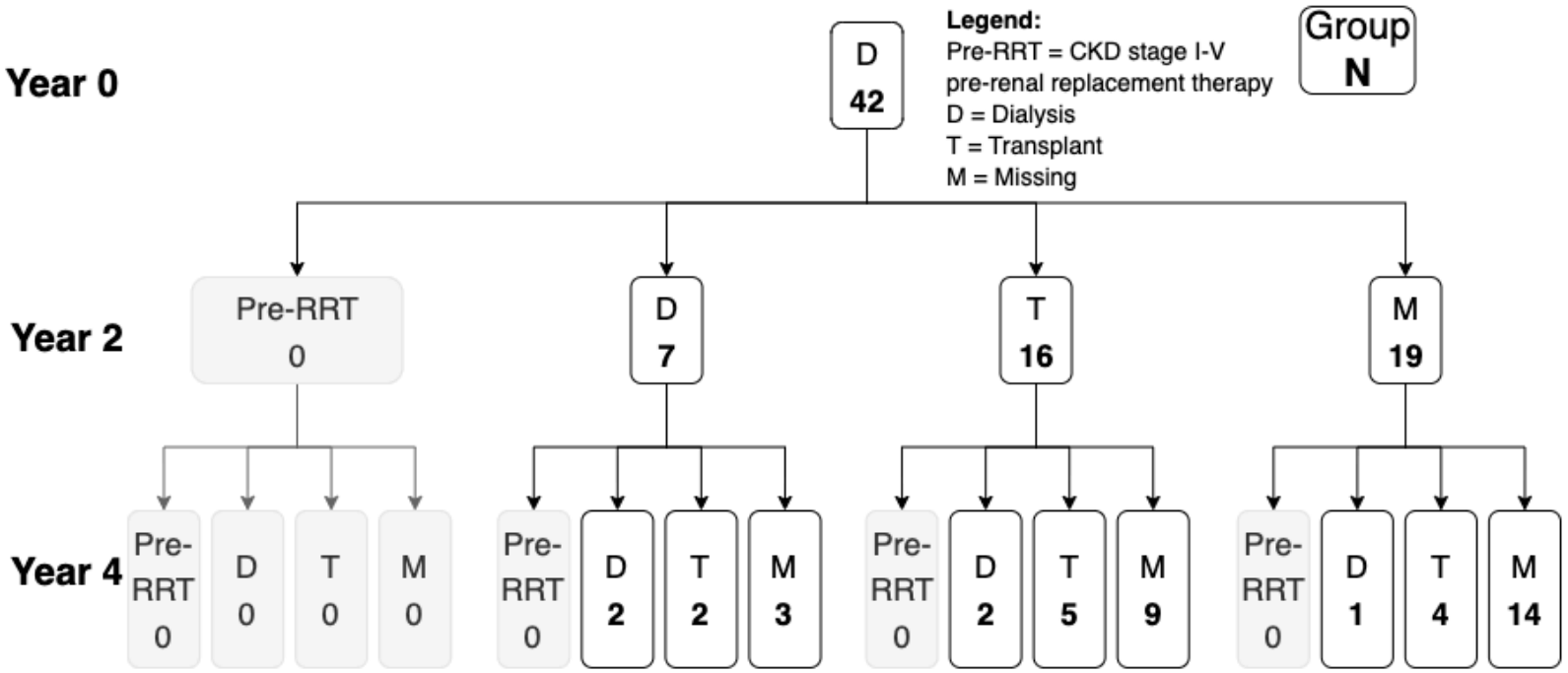
	Transplant	0.7	0.4	-	1.3	0.29
Time	in years	1.0	0.9	-	1.1	0.53
Child ethnicity	White	Ref				
	Other	0.2	0.1	-	0.5	<0.001
Child gender	Male	Ref				
	Female	0.5	0.2	-	0.9	0.02
Home ownership	Renting/other	Ref				
	Owned outright/with mortgage	2.7	1.3	-	5.6	0.006

Figure S1. CKD group over time, for patients in baseline 'CKD stages I-V not requiring kidney replacement therapy' group*



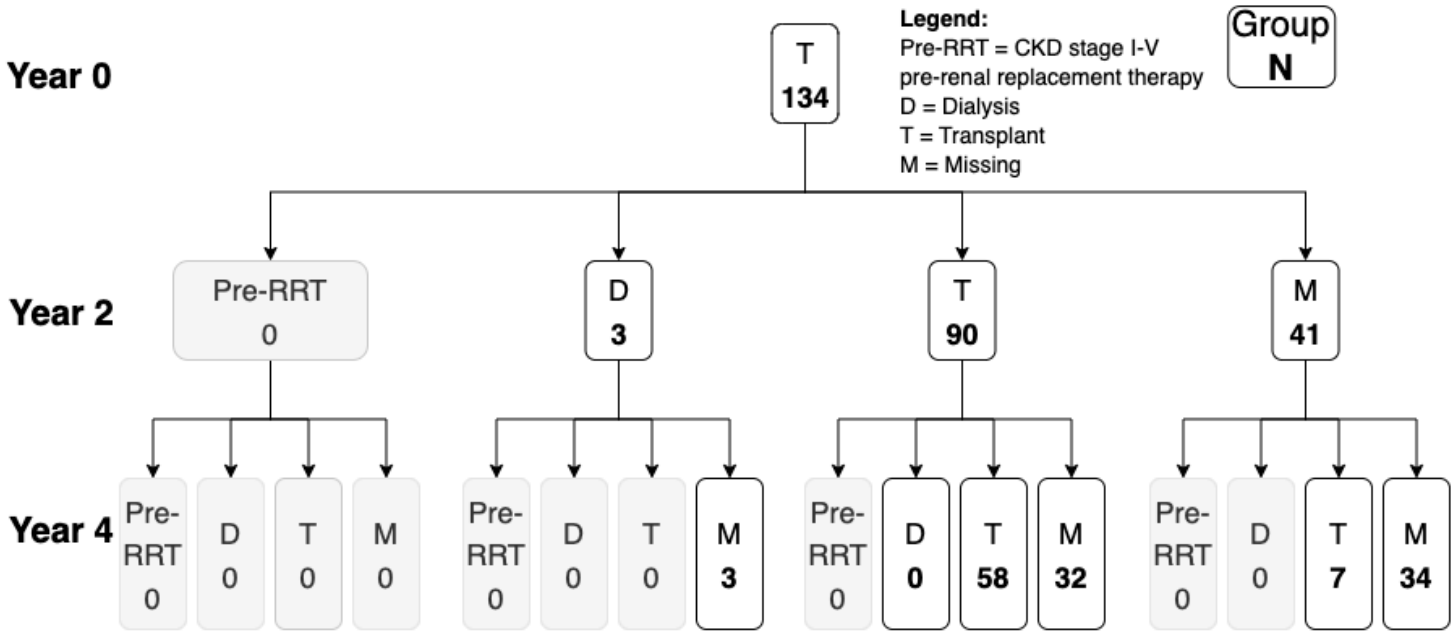
*transitions between transplant-to-transplant groups were with the same allograft

Figure S2. CKD group over time, for patients in baseline 'dialysis' group*



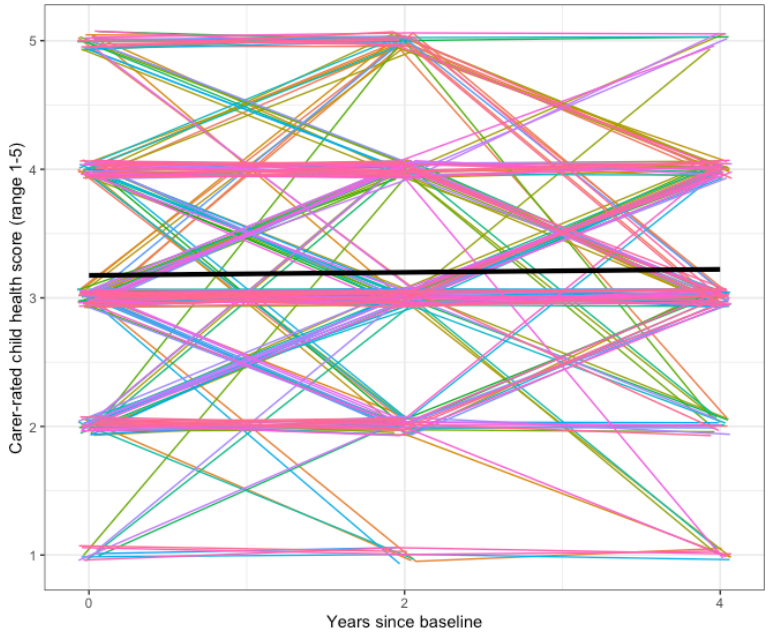
*transitions between transplant-to-transplant groups were with the same allograft

Figure S3. CKD group over time, for patients in baseline 'transplant' group*



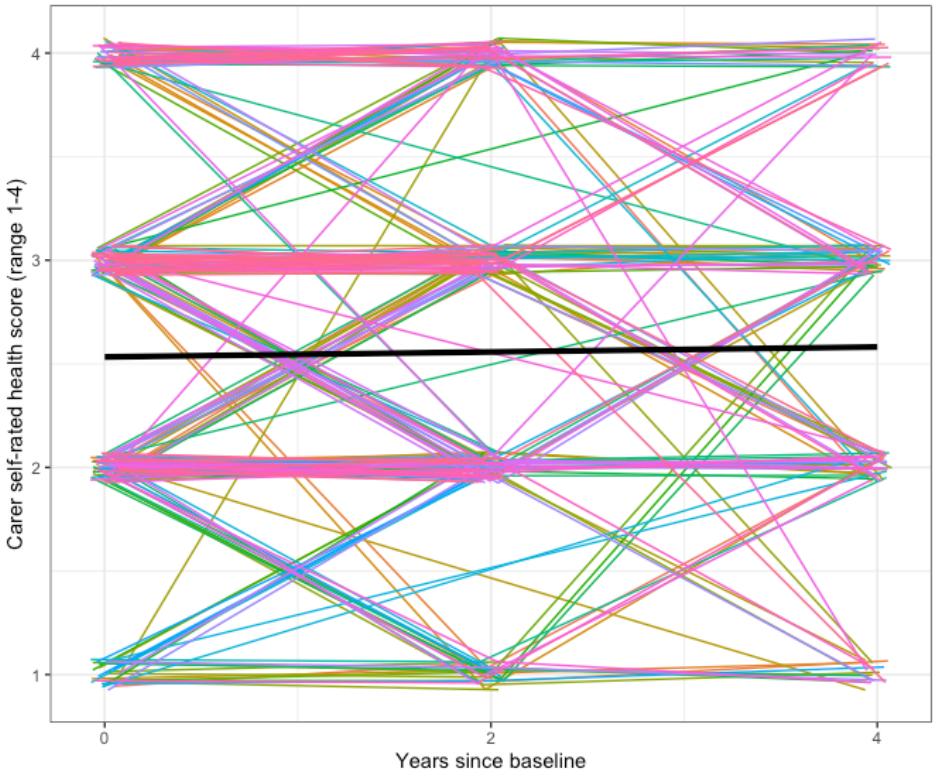
*transitions between transplant-to-transplant groups were with the same allograft

Figure S4. Jitter line plot of carer-rated child health scores over time*



*Different colours for individual participants, with the black line representing the average linear trend.

Figure S5. Jitter line plot of carer self-rated health score over time*



*Different colours for individual participants, with the black line representing the average linear trend.