Article:
Abbott, Jasmin, Fraser, Lorna Katharine and Jarvis, Stuart William (2024) Inequalities in emergency care use across transition from paediatric to adult care:a retrospective cohort study of young people with chronic kidney disease in England. European journal of pediatrics. ISSN: 1432-1076

https://doi.org/10.1007/s00431-024-05561-z

Inequalities in emergency care use across transition from paediatric to adult care: a retrospective cohort study of young people with chronic kidney disease in England

Title: Inequalities in emergency care use across transition from paediatric to adult care: A retrospective cohort study of young people with chronic kidney disease in England

Short title: Emergency care use by young people with chronic kidney disease: A national retrospective cohort study

Number of words: 3398

Number of figures: 3

Number of tables: 3

Keywords: Transition, Chronic Kidney Disease, Health Inequalities, Population Study

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J.A. conceptualised the study with supervision from S.J. and L.F. Study design was completed by J.A., with substantial contributions and revisions from S.J. and L.F. S.J. acquired the data for use in this study. J.A. completed the data analysis, interpretation of the data and drafting the work, with supervision and guidance from S.J. throughout. All authors had substantial contributions to the revision of the work's intellectual content and approved the final manuscript.

All authors meet the following criteria:

1. Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
2. Drafting the work or revising it critically for important intellectual content; AND
3. Final approval of the version to be published; AND
4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

Competing Interests: The authors declare no conflict of interests related to this article.

Supplementary documents: 1 document included (title: onlineresources.pdf)

Abbreviations

A&E	Accident and Emergency
APC	Admitted Patient Care
BIC	Bayesian Information Criteria
CKD	Chronic Kidney Disease
CYP	Children and Young People
HES	Hospital Episode Statistics
ICD	International Classification of Diseases
IMD	Index of Multiple Deprivation
IR	Incidence Rate
IRR	Incidence Rate Ratio
RE	Random Effects

Abstract

Purpose: Transition of young people with chronic kidney disease (CKD) from paediatric to adult healthcare has been associated with poor outcomes, but few population-level studies examine trends in sub-groups. We aimed to assess sociodemographic inequalities in changes in unplanned secondary care utilisation occurring across transfer to adult care for people with CKD in England.

Methods: A cohort was constructed from routine healthcare administrative data in England of young people with childhood-diagnosed CKD who transitioned to adult care. The primary outcome was the number of emergency inpatient admissions and accident and emergency department (A&E) attendances per person year, compared before and after transfer. Injury-related and maternity-admissions were excluded. Outcomes were compared via sociodemographic data using negative binomial regression with random effects.

Results: The cohort included 4,505 individuals. Controlling for age, birth-year, age at transfer, region and socio-demographic factors, transfer was associated with a significant decrease in emergency admissions (IRR 0.75, 95% CI 0.64-0.88) and no significant change in A&E attendances (IRR 1.10, 95% CI 0.95-1.27). Female sex was associated with static admissions and increased A&E attendances with transfer**,** with higher admissions and A&E attendances compared to males pre-transfer. Non-white ethnicities and higher deprivation were associated with higher unplanned secondary care use.

Conclusions: Sociodemographic inequalities in emergency secondary care usage were evident in this cohort across the transition period, independent of age, with some variation between admissions and A&E use, and evidence of effect modification by transfer. Such inequalities likely have multifactorial origin, but importantly, could represent differential meetings of care needs.

Author's Summary

What is known:

- In chronic kidney disease (CKD), transfer from paediatric to adult healthcare is associated with declining health outcomes.
- Known differences in CKD outcomes by sociodemographic factors have limited prior exploration in the context of transfer.

What is new:

- Population-level data was used to examine the impacts of transfer and sociodemographic factors on unplanned secondary care utilisation in CKD.
- Healthcare utilisation trends may not reflect known CKD pathophysiology and there may be unexplored sociodemographic inequalities in the experiences of young people across transfer.

Introduction

Improvements in medical treatments have resulted in more children and young people (CYP) with chronic kidney disease (CKD) living into adulthood. This means that transition, defined "…as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered[sic] to adult-oriented health-care systems" [1], is a key component of their healthcare.

Several studies have evidenced an association between transition and poor outcomes, and evaluated transition interventions [2-6]. However, most studies have smaller sample sizes, which may have limited representativeness of broader childhood CKD populations and cannot delineate outcomes in different sociodemographic groups [7]. Knowing if different outcomes occur by sociodemographic factors may enable targeted interventions.

In this study, we explore how population-level data of CYP with CKD may be used to examine outcomes by different sociodemographic groups across transition. Specifically, we aim to determine whether there are sociodemographic inequalities in changes in unplanned secondary care use associated with transfer (defined as the moment of movement to adult secondary care services) for CYP with CKD, using national population data in England. Our methodology builds on previous studies examining this outcome in other chronic conditions [8, 9], with the assumption that higher rates of emergency care use may indicate poor disease control or other unmet care needs and are indicative of higher costs and disruption to CYP's lives.

Materials and Methods

Study design/setting

A retrospective cohort study using routinely collected national hospital data in England, UK.

Data sources

Pseudonymised Hospital Episode Statistics (HES) records in the admitted patient care (APC, 2006/07-2018/19), accident and emergency (A&E, 2007/08-2018/19) and outpatient (2006/07-2018/19) datasets [9, 10].

Eligibility criteria

Participants were those in the APC or outpatient datasets who met the following criteria:

- Aged 12 to 23 years at any point in the financial years 2006/07 to 2018/2019.
- Had a diagnostic code (ICD-10 [11]) for CKD recorded < 18 years of age.
- Had outpatient records present age ≤ 16 and ≥19, and utilised both paediatric outpatient services (of any type) and adult outpatient nephrology, general medical or adult transplant services (as defined by codes used in Jarvis et. al. (2022) [9]).
- Could be estimated to transfer from paediatric to adult outpatient services ≥ 12 years.

There is no consensus for ICD-10 codes for childhood CKD, so codes used were those present in lists from both Hardelid et al. (2013) (codes of chronic childhood conditions) and Shi et al. (2021) (codes identified based on theoretical descriptors of CKD) [12, 13]. Three additional codes were used to identify dialysis or kidney transplant (online resource, supplementary table 1).

Using method previously developed by Jarvis et al. (2021), transfer was estimated by identifying the age and financial year of transfer from the date of the last paediatric appointment [14]. Individuals who did not have an identifiable transfer or had an estimated transfer age before 12 years were excluded. These individuals were assumed unlikely exposed to transfer from paediatric to adult secondary care services (and more likely indicative of acute care episodes, CYP discharged to primary care or CYP who died or moved out of England before transition).

Determination of demographics

Sex, ethnicity, and year of birth were selected from APC and outpatient datasets based on the modal response, unless missing. Age, index of multiple deprivation (IMD) decile, rural/urban index and region were selected as the first recorded non-missing response for each financial year.

Determination of outcomes

The primary outcomes were a) the number of emergency hospital admissions and b) unplanned attendances to A&E departments in England per person per year. Effort was made to exclude causes of admissions and attendances that were likely unrelated to or that would confound the effect of transfer on healthcare utilisation. These were 1) injuries caused by accidents or assaults, as these are unlikely related to CKD management and may relate more to age-related risk-taking behaviour [9]; 2) maternity-related admissions as these are strongly correlated with age and could confound the relationship of interest (A previous study demonstrated that including these admissions created a significant difference in model outputs [8]).

For APC data, records for individuals in the cohort were selected which were:

- The only or first in a series of episodes (i.e., only one record per admission selected), in any financial year.
- Coded as an emergency admission.
- Non-maternity and non-neonatal type admissions.
- Admissions of all causes, except unintentional injuries (online resources, supplementary table 2).

For A&E data, records for individuals in the cohort were selected which were:

- Coded as an unplanned first or follow-up attendance to an A&E department.
- Attendances not due to assault, road-traffic accident or other unintentional injury as identified by the diagnosis code (online resources, supplementary table 3).

For both APC and A&E datasets, duplicates were defined as any records occurring for the same person on the same day and in such a case only one of these records was included. At each stage there was assessment for outliers and erroneous entries: attendances per person per year more than a plausible upper limit of fifty would be excluded.

For each person in each financial year, the number of eligible records in each of the APC and A&E datasets were summed to give the number of emergency admissions or emergency department attendances per year.

Finally, using the estimated age and year of transfer for each individual, records that were outside the range of four years before and four years after the estimated transfer year were excluded from analysis. A limit of four years was chosen to include sufficient data to reflect average emergency care pre- and post-transfer, while reducing data capture on emergency care unrelated to the transfer event [9].

Statistical methods

Detailed descriptive statistics of cohort characteristics and the number of unplanned secondary care uses of each type per year, person and person-year were calculated.

Negative binomial regression with random effects (RE), with the outcome of the number of emergency secondary care uses (admissions or A&E attendances respectively) per person per year, was used to calculate incidence rate ratios (IRR). Negative binomial models with RE were preferred to Poisson regression with RE as they produced better fit of the data. Model coefficients were considered statistically significant if they met the threshold $p < 0.05$. Socio-demographic factors were included in the model, alongside their interactions with transfer. Sex, ethnicity and socioeconomic deprivation (Index of Multiple Deprivation (IMD), itself a composite of multiple socioeconomic indicators) were included as there have been previously documented differences in paediatric or adult CKD outcomes according to these factors. The rural-urban index was included based on our hypothesis that the geographical structure of paediatric vs adult CKD care could impact outcomes across transition. For the categories of ethnicity, IMD and rural-urban index, sub-groups recorded in HES datasets were combined into logical larger sub-groups due to small numbers in some groups that would limit statistical analysis. Potential confounding factors of age, birth year and age at transfer were included in the model if there was a suggested relationship based on visual inspection after graphing against the outcome or if they improved the fit of the model based on the Bayesian

Information Criteria (BIC) (reduced by >3 points) [15]. Region was also included in the model to ensure differences were not accounted for by regional variations. Missing data were handled using complete case analysis – we considered this approach suitable for this study given the low level of missing demographic data in HES datasets and the impracticality of imputation with the data available. All modelling was completed using Stata 17 [16].

Sensitivity analyses explored several models including alternative methods to estimate transfer (online resource, supplementary appendix I).

Results

The final cohort included 4,505 individuals (Figure 1), with characteristics, including missing data, described in Table 1. The source data contained many individuals who were either too young or too old to have undergone transition during the study period, as indicated by the large decrease in sample size on selecting those with outpatient records at relevant ages. Mode estimated transfer age was 18 years (online resource, supplementary appendix D).

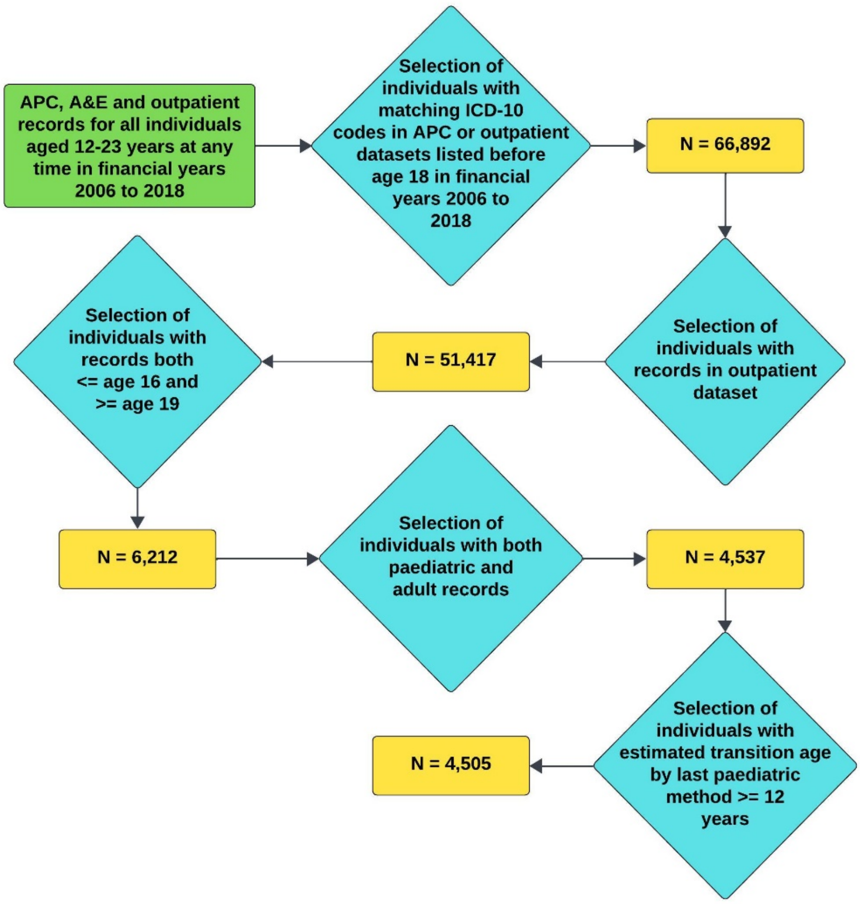

Fig. 1 *Flowchart of cohort definition. Diamond boxes represent selection of records based on eligibility criteria definitions. N = number of individuals in sample. The figure shows an initial cohort selection of 66,892 individuals meeting the criteria for ICD-10 codes, decreasing to the final cohort size of 4,505 through the subsequent steps. Fig. 1 produced using Lucidchart (Lucid Software Inc., 2008).*

Of 4,505 in the cohort, 3,511 individuals had emergency admission records meeting the criteria, equalling 10,338 emergency admissions in the four years before transfer and 8,040 in the four years after. 3,556 individuals had A&E records meeting the criteria, equalling 11,002 unplanned A&E attendances in the four years before transfer and 8,861 in the four years after (online resource, supplementary appendix G).

Mean emergency admissions per person per year before and after transfer were 0.63 (SD = 1.49) and 0.55 (SD = 1.42) respectively (range 0-35).

Mean unplanned A&E attendances per person per year before and after transfer were 0.57 (SD = 1.36) and 0.75 (SD = 1.78) respectively (range 0-41).

Mean admissions and attendances per person-year, stratified by sex and transition status are displayed in figure 2. It should be noted that pre-transfer values post-19 years and post-transfer values pre-16 years are likely to be skewed by few individuals who transfer outside of this age range (see online resources for stratification by other factors).

The incidence rate ratios (IRR) for emergency admissions and A&E attendances four years before and four years after estimated transfer age are reported in Tables 2 and 3 respectively. For both models, adjustments were made for socio-demographic factors of interest as well as birth-year, age, and age at transfer as these demonstrated improvement in the BIC.

To estimate any overall change in the rate of emergency secondary care usage across transition between subgroups, adjusted IRR estimates were calculated from these models: the outputs of these are displayed in figure 3.

Sensitivity analyses found few significant differences in model outputs, discussed in the online resources (appendix I).

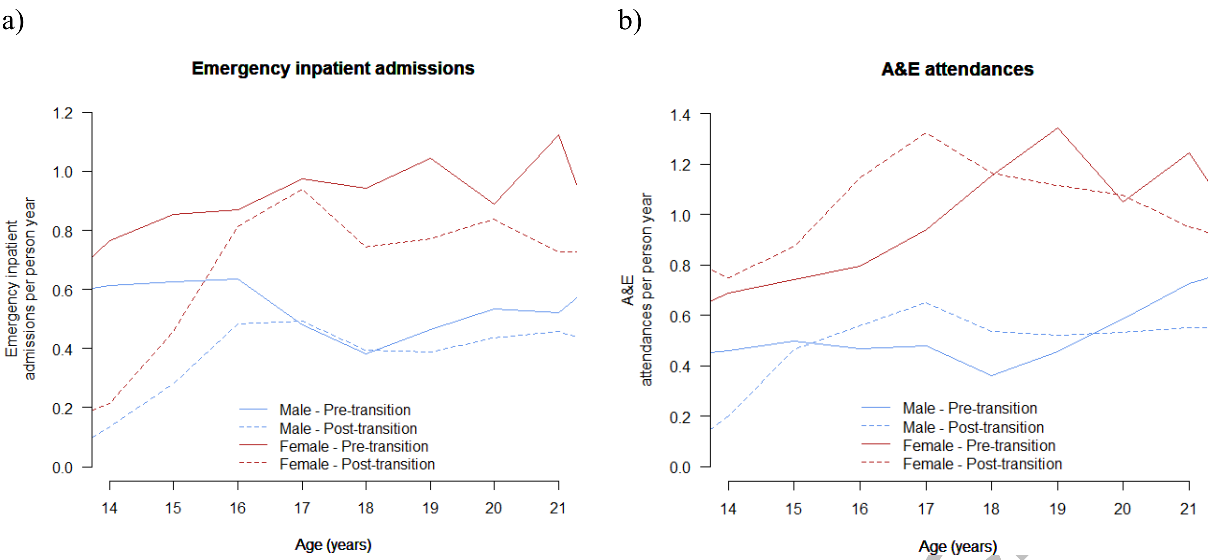
a)
Emergency inpatient admissions
Emergency inpatient admissions per person year
1.2
1.0
0.8
0.6
0.4
0.2
0.0
Male - Pre-transition
Male - Post-transition
Female - Pre-transition
Female - Post-transition
14
15
16
17
18
19
20
21
Age (years)
b)
A&E attendances
A&E attendances per person year
1.4
1.2
1.0
0.8
0.6
0.4
0.2
0.0
Male - Pre-transition
Male - Post-transition
Female - Pre-transition
Female - Post-transition
14
15
16
17
18
19
20
21
Age (years)

Fig. 2 a) *Emergency inpatient admissions by age per person per year, stratified by transition status and sex. Emergency inpatient admissions in this cohort are higher in females than in males across ages 14 to 21 (around 0.7-1.0 admissions per person year in females and 0.4-0.6 in males). In both males and females, the line of the rate of emergency admissions pre-transfer to adult care lies pre-dominantly above the line for the rate after transfer.*
b) *Unplanned A&E attendances by age per person per year, stratified by transition status and sex. Unplanned A&E attendances in this cohort are higher in females than in males across ages 14 to 21 (around 1.0-1.2 per person year in females and around 0.4-0.6 in males). In females, the line of the rate of A&E attendances pre-transfer lies below the line for the rate after transfer up to age 18, where it then overlaps. In males, the pre-transfer line lies below the post-transfer between ages 15 and 20.*
For both figures 2a and 2b, pre-transition indicates the individual has not yet transferred to adult care, whereas post-transition indicates the individual has been transferred. Graphics for figures 2a and 2b produced using R Studio [17].

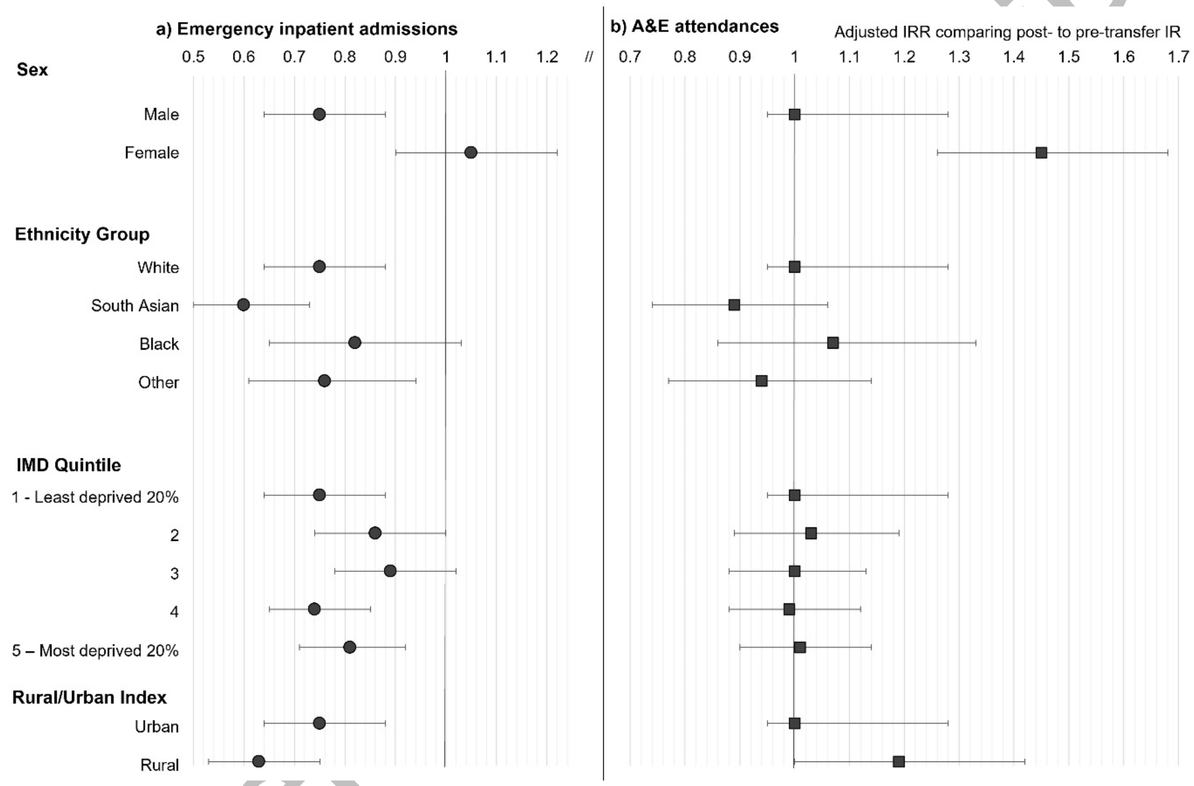

Fig. 2 *Adjusted incidence rate ratios (IRR) per person-year comparing post-transfer to pre-transfer values within sociodemographic groups (sex, ethnicity, Index of Multiple Deprivation (IMD) quintile and rural/urban index on the y-axis) for a) emergency inpatient admissions and b) unplanned A&E attendances. The circle or square represents the point estimate for each co-variate comparing the difference in the incidence rate (IR) after transfer to adult care compared with before transfer to adult care within that covariate group, with the whiskers representing the confidence interval for this estimate. Estimates are calculated from the negative binomial regression models generated in Stata 17 [16], as described in Table 2 (for figure 3a) and Table 3 for (figure 3b). Fig. 3 produced using Microsoft Excel (Microsoft Corporation, 2018).*

Discussion

Key results

Controlling for socio-demographic factors and potential confounders such as age, transfer to adult care was associated with a statistically significant decrease in the rate of emergency secondary care admissions (IRR 0.75, 95% CI 0.64-0.88) but no significant change in the rate of attendances to A&E (IRR 1.10, 95% CI 0.95-1.17) compared to pre-transfer for this population in this model. There are significant differences in the overall rates of emergency care by socio-demographic factors (Tables 2 and 3), with female sex, South Asian and Black ethnicity groups and higher index of deprivation (IMD) all associated with higher usage.

There is evidence of effect modification by transfer to adult care on the rates of emergency care use for some sociodemographic factors: by sex, ethnicity and rural-urban index, but not IMD. However, figure 3 suggests the magnitude of effect modification may not be large enough between most sub-groups to result in tangible differences in the change in rate of care use across transition.

The biggest difference found across both models is by sex. Controlling for co-variates, female sex is associated with significantly greater rates of unplanned secondary care use compared to male sex, which is then further increased by transfer to adult care: whereas male sex demonstrates a decrease in emergency care admissions and no change in A&E attendances with transfer, female sex is associated with no change in emergency admissions and a significant increase in A&E usage.

Interpretation of findings

For CYP with CKD in this cohort, there are inequalities between different sociodemographic groups in two types of emergency care use across the transition period, which may widen between males and females following transfer to adult care and remain stable or possibly decrease for other groups.

Multiple explanations for a change in rate of emergency care use with transfer to adult care are plausible. Decreasing emergency admissions with transfer could be due to appropriate transfer of

CYP with stabilised CKD or improvements in disease control with transfer. That A&E attendances do not fall correspondingly suggests more attendances do not meet the threshold for admission after transfer. This could be due to care needs not being met by other service provision, changes to risk-taking behaviour in this age group or different thresholds for admission between paediatric and adult care [18] (UK paediatric inpatient services often use an 'open access' model which may bypass A&E attendance for some children). Samuel et. al.'s (2014) study noted an overall increase in avoidable hospitalizations of young people with end-stage kidney disease (ESKD) after transfer to adult care in the context of overall decreased hospitalizations [18]: this could indicate a trend not explored here.

Although there is limited evidence on the specific relationship between sociodemographic factors and emergency care use for young people with CKD, differences in outcomes by sex, ethnic group, and deprivation in this age group, mostly in studies conducted in U.S. populations, are well-documented and have proposed social, structural, and biological determinants [19–22]. Male sex has been previously associated with faster rates of progression in certain types of CKD, indicating alternative factors may increase emergency care use among females in this cohort [23]. However, studies in adults highlight poorly understood pathophysiological differences by sex in CKD which could have worse impact on females and highlight that females may be underrepresented in the dialysis and transplant populations [24]. A systemic review examining transition for young people with CKD identified that navigation of the gap between childhood and adult services may relate to psychological, developmental, socioeconomic, and other factors [3]: these could theoretically differ between groups examined in this study. Inequalities in this study cohort could therefore have multifactorial origin, relating to differences in risk factors for emergency secondary care use, wider socioeconomic determinants, or representing differential meeting of care needs.

We hypothesised that there could be effect modification of rural/urban status on the change in emergency care use with transfer given paediatric nephrology outpatient services tend to be based at tertiary centres which may be less accessible compared to adult services. However, Cohen et al (2013) found that children with chronic conditions tend to move more and not necessarily to be closer to secondary care services [25]. Thus, there may be differences in disease severity or economic circumstances between the rural and urban groups not detectable in this study.

Study Strengths & Limitations

This study utilizes whole population data, which is more representative than smaller cohorts, and utilizes routinely collected data providing high quality on the outcome measures studied [26].

However, the ICD-10 codes used to define the cohort have unknown specificity and sensitivity, and the method used to define transfer may prefer certain severities of CKD (more severe or patients with mild CKD seen in adult general medicine departments for non-nephrology issues). Poor epidemiological evidence of the prevalence and distribution of childhood CKD [27, 28] limits assessment of the representativeness of this cohort. A cohort of children under 16 in England with CKD stages 4 or 5 contained a higher proportion of males (64.3%), people of Asian ethnicity (23.6%), from the most deprived areas (30.7%) and few people in the tubulointerstitial disease category compared to the large proportion in this cohort [29]. These differences may be due to different inclusion criteria, reporting of CKD categories, or invalidity of this study's selection methods.

Jarvis et al. (2021) outline how the last paediatric method used here may reduce misclassification compared to other methods and therefore give a more precise estimate of the impact of transfer [14]. However, without stricter criteria regarding time between the last paediatric and first adult appointment, it could misclassify CYP who do not transition to secondary care as doing so. Using a different method to estimate transfer age results in small but statistically significant differences in some of the model outputs (online resource, supplementary appendix I). Loss to follow-up and discharge from care could also not be assessed, and individuals could be included in the cohort before CKD diagnosis.

Some possible confounding or effect modulating factors aren't accounted for: CKD severity, dialysis use, dual renal diagnoses, and co-morbidities [30-32]. Certain causes of care use or facility types could also skew results given they are not differentiated. Given the first component required to meet the study aim is to assess if there is a change in healthcare utilisation associated with transfer of care, we attempted to exclude causes of care use that could be confounders for or unrelated to the effect of transfer but cannot exclude all such causes. Excluding injuries and maternity-related admissions may mask some transfer-related differences in utilisation of emergency care among some sub-groups (particularly by sex and deprivation) and does not enable examination of total healthcare use. Moreover, maternity admissions were excluded from secondary care admissions but not A&E attendances (due to lack of available data in the HES A&E dataset), which could account for some of the differences observed by sex and confound transfer. There is also value in exploring the links between unplanned secondary care use in CKD and pregnancy, but this is outside the scope of this project and may not be possible with diagnostic information provided in the HES data.

Without a control population, it is not possible to state if the outcomes observed in this model are unique to the CKD population, although notably the relationship between transfer to adult care and emergency care use does differ compared to a previous study whose population had a range of chronic conditions [8]. The model may also not pick up all differences between sub-groups: despite being a full population cohort, the size of ethnicity sub-groups is smaller than the estimated population sizes required to find, with 80% power, a significant difference ($p<0.05$) where one is present at an effect size of 20%. Additionally, the retrospective nature of this study means results may not reflect current standards of care in England, particularly as transition has been a service development priority for the NHS [33,34]. The results of this study may not be applicable to other countries, particularly where there are different healthcare system configurations.

Finally, there is limited evidence for unplanned secondary care usage as a surrogate measure for disease control and as an outcome it only partially addresses the ‘triple aim’ of transition care [35–37]. There may also be reverse causality: multiple acute renal insults occurring during hospital admissions may lead to CKD progression [21].

Study implications and directions for future research

Notwithstanding the above limitations, the findings in this cohort of inequalities in rates of emergency care use by sociodemographic groups across transition and that transfer from paediatric to adult care could be a site of effect modification for these inequalities has significant implications for future research. Most studies on transfer do not focus on the differing experiences of CYP of different sociodemographic groups across this challenging life period. Differences in personal factors and wider social, structural, and biological determinants existing within and between sociodemographic groups could impact the type of support required during transition, and thus, importantly, could enable the development of targeted transition interventions designed to reduce inequalities between these groups.

This study demonstrates how population level data could be used to explore and monitor inequalities in unplanned healthcare use in CKD for different sociodemographic groups across the transition period. Limitations in this study's design could be overcome by developments in future research. The UK Renal Registry (UKRR) recently expanded its data collection to include children with CKD stages 4 and 5 [29]. The linkage of the UKRR cohort with HES data could enable prospective cohort studies examining secondary care use or CKD-specific outcomes across transition [38], using a validated population of CYP with CKD and with more accurate estimates of transfer to adult care. This linkage could also enable further epidemiological studies of childhood CKD through the derivation of a validated list of ICD-10 codes.

Conclusion

Our study explores a novel approach to examine outcomes at the population level for young people with CKD across the transition period, enabling differentiation of outcomes by sociodemographic factors. Inequalities in overall rates of emergency healthcare use (excluding accident-related and maternity admissions) across transition by sex, ethnicity and IMD are highlighted and there is evidence for different relationships in the change in rate of emergency care use with transfer to adult care for some sociodemographic sub-groups, although the magnitude of such differences are unclear. Such trends in healthcare utilisation may not reflect what is known in underlying CKD pathophysiology. The findings of this study should prompt further prospective, validated linkage studies or cluster-randomised trials in young people with CKD investigating the relationship between sociodemographic factors and transition; qualitative studies to understand social, psychological, and environmental factors which may explain any differences; and moreover, prompt those developing transition interventions to consider how they may support those in disadvantaged groups.

Declarations

Ethical approval: Acquisition and use of data in this manner was acquired by S.J. from the Health Research Authority (ref: 20/WA/0149) in accordance with the Declaration of Helsinki and the UK Policy Framework for Health and Social Care Research.

Consent to participate and publish: Patient consent to participate or to publication was not required for this study.

Funding: Data acquisition funded by National Institute for Health and Care Research (NIHR) fellowship held by S. J. (DRF-2018-11-ST2-013). J.A. was funded by Health Education England (HEE) – Yorkshire and Humber (Academic Foundation Programme No. EY018) for this research. L.F. is funded by a National Institute for Health and Care Research (NIHR) Career Development Fellowship (award: CDF-2018-11- ST2-002) for this research project. This publication presents independent research funded by the National Institute for Health and Care Research. The views expressed are those of the authors and not necessarily those of HEE, NHS, the National Institute for Health and Care Research or the Department of Health and Social Care.

Availability of data and materials: Access to the patient level data used in this study is governed by a Data Sharing Agreement with NHS Digital which does not permit sharing to third parties. Anyone wishing to replicate the study or perform similar analysis can request similar data from NHS Digital using the description of the data requested contained herein.

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Table 1: Descriptive statistics of the characteristics of the final cohort as defined in Figure 1. Data populations from APC and outpatient datasets. Sex and ethnic group are selected as the mode non-missing. Index of Multiple Deprivation (IMD) Quintile and Rural/Urban Index are the first recorded non-missing value for each characteristic and are derived from the recorded home postcode address. CKD Disease Group defined from the category of ICD-10 codes recorded for each individual (therefore each person may belong to more than one group if they have dual diagnoses). Further information regarding cohort descriptives in the online resources.

Demographic	Frequency in the final cohort (N = 4,505)	Percentage of final cohort (1dp, %)
Sex		
Male	2,228	49.5
Female	2,241	49.7
Missing	36	0.8
Ethnic group		
White	3,384	75.1
Pakistani	305	6.8
Indian	127	2.8
Bangladeshi	83	1.8
Other Asian Ethnicity	105	2.3
Mixed Ethnicities	93	2.1
Black	201	4.5
Other	100	2.2
Missing	107	2.4
IMD Quintile		
1 – Least deprived 20%	719	16.0
2	700	15.5
3	967	21.5
4	924	20.5
5 – Most deprived 20%	1,141	25.3
Missing	54	1.2
Rural/urban index		
Urban ≥ 10K Population	3,720	82.6
Town and Fringe	352	7.8
Village	280	6.2
Hamlet and Isolated Dwelling	112	2.5
Non-English Postcode (Unknown)	5	0.1
Missing	36	0.8
CKD Disease Group		
Congenital anomalies of kidney and urinary tract (CAKUT)	1,799	39.9
Glomerular diseases	1,363	30.3
Tubular and tubular interstitial diseases	849	18.6
Systemic diseases with renal involvement	717	15.9
Unknown type	573	12.7
Other defined cause	267	5.9
Malignancy (renal tumours and renal involvement in systemic malignancy)	20	0.4
Kidney Transplant	794	17.6
Dialysis	2	0.04

Table 2: Adjusted Incidence Rate Ratios (IRR) of number of emergency admissions in England per person per year to secondary care from negative binomial regression model with random effects modulation of final cohort (N = 4,505). Region is also included in the model but omitted from print here. Full unadjusted and adjusted IRR values from the regression model in the online resources.

	Covariate outputs without interaction terms				**Covariate outputs with interaction with transition status** Reference category = Pre-transfer		
Covariate	**Adjusted IRR**	**p-value**	**95% Confidence Intervals**		**Adjusted IRR**	**p-value**	**95% Confidence Intervals**
Age	0.97	0.001	0.96-0.99		-	-	-
Transition Age	1.05	<0.001	1.02-1.08		-	-	-
Year of Birth	0.96	<0.001	0.94-0.97		-	-	-
Transition Status	Reference category = Pre-transfer						
Post-transfer	0.75	<0.001	0.64-0.88		-	-	-
Sex	Reference category = Male						
Female	1.40	<0.001	1.29-1.49		1.40	<0.001	1.29-1.53
Ethnicity	Reference category = White						
South Asian	1.30	<0.001	1.16-1.46		0.80	0.001	0.71-0.91
Black	1.38	<0.001	1.16-1.65		1.09	0.33	0.91-1.30
Other	1.12	0.13	0.97-1.31		1.01	0.91	0.86-1.19
Index of Multiple Deprivation Quintile	Reference category = 1 – Least deprived						
2	0.98	0.72	0.86-1.11		1.14	0.11	0.97-1.35
3	1.10	0.13	0.97-1.24		1.19	0.03	1.02-1.38
4	1.24	<0.001	1.11-1.40		0.99	0.91	0.85-1.15
5 – Most deprived	1.15	0.02	1.02-1.29		1.08	0.31	0.93-1.25
Rural/urban index	Reference category = Urban (>=10K Population)						
Rural (Town, Fringe, Village or Other)	1.08	0.16	0.97-1.19		0.84	0.008	0.74-0.96

Table 3: Adjusted Incidence Rate Ratios (IRR) of number of unplanned accident and emergency attendances (A&E) in England per person per year from negative binomial regression model with random effects modulation of final cohort (N = 4,505). Region is also included in the model but omitted from print here. Full unadjusted and adjusted IRR values from the regression model in the online resources.

	Covariate outputs without interaction terms			**Covariate outputs with interaction with transition status** Reference category = Pre-transfer		
Covariate	**Adjusted IRR**	**p-value**	**95% Confidence Intervals**	**Adjusted IRR**	**p-value**	**95% Confidence Intervals**
Age	1.02	0.01	1.00-1.04	-	-	-
Transfer Age	1.00	0.77	0.98-1.03	-	-	-
Year of Birth	1.01	0.14	1.00-1.02	-	-	-
Transition Status	Reference category = Pre-transfer					
Post-transfer	1.10	0.18	0.95-1.27	-	-	-
Sex	Reference category = Male					
Female	1.45	<0.001	1.34-1.56	1.31	<0.001	1.22-1.42
Ethnicity	Reference category = White					
South Asian	1.13	0.05	1.00-1.27	0.80	<0.001	0.71-0.90
Black	1.11	0.24	0.93-1.33	0.96	0.71	0.82-1.14
Other	1.15	0.07	0.99-1.34	0.85	0.03	0.74-0.98
Index of Multiple Deprivation Quintile	Reference category = 1 – Least deprived					
2	1.16	0.03	1.02-1.32	0.93	0.38	0.80-1.09
3	1.29	<0.001	1.15-1.47	0.90	0.17	0.78-1.04
4	1.25	<0.001	1.11-1.42	0.90	0.14	0.78-1.04
5 – Most deprived	1.30	<0.001	1.15-1.46	0.92	0.22	0.80-1.05
Rural/urban index	Reference category = Urban (>=10K Population)					
Rural (Town, Fringe, Village or Other)	0.79	<0.001	0.70-0.88	1.08	0.23	0.95-1.23

Figure Legends

Fig. 3 Flowchart of cohort definition. Diamond boxes represent selection of records based on eligibility criteria definitions. N = number of individuals in sample. The figure shows an initial cohort selection of 66,892 individuals meeting the criteria for ICD-10 codes, decreasing to the final cohort size of 4,505 through the subsequent steps. Fig. 1 produced using Lucidchart (Lucid Software Inc., 2008).

Fig. 2 a) Emergency inpatient admissions by age per person per year, stratified by transition status and sex. Emergency inpatient admissions in this cohort are higher in females than in males across ages 14 to 21 (around 0.7-1.0 admissions per person year in females and 0.4-0.6 in males). In both males and females, the line of the rate of emergency admissions pre-transfer to adult care lies pre-dominantly above the line for the rate after transfer.

b) Unplanned A&E attendances by age per person per year, stratified by transition status and sex. Unplanned A&E attendances in this cohort are higher in females than in males across ages 14 to 21 (around 1.0-1.2 per person year in females and around 0.4-0.6 in males). In females, the line of the rate of A&E attendances pre-transfer lies below the line for the rate after transfer up to age 18, where it then overlaps. In males, the pre-transfer line lies below the post-transfer between ages 15 and 20. For both figures 2a and 2b, pre-transition indicates the individual has not yet transferred to adult care, whereas post-transition indicates the individual has been transferred. Graphics for figures 2a and 2b produced using R Studio [17].

Fig. 4 Adjusted incidence rate ratios (IRR) per person-year comparing post-transfer to pre-transfer values within sociodemographic groups (sex, ethnicity, Index of Multiple Deprivation (IMD) quintile and rural/urban index on the y-axis) for a) emergency inpatient admissions and b) unplanned A&E attendances. The circle or square represents the point estimate for each co-variate comparing the difference in the incidence rate (IR) after transfer to adult care compared with before transfer to adult care within that covariate group, with the whiskers representing the confidence interval for this estimate. Estimates are calculated from the negative binomial regression models generated in Stata 17 [16], as described in Table 2 (for figure 3a) and Table 3 for (figure 3b). Fig. 3 produced using Microsoft Excel (Microsoft Corporation, 2018).