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Prevalence, Mortality, and Access to Care for Chronic Kidney Disease in Medicaid-Enrolled Adults with Sickle Cell Disease: A Retrospective Cohort Study in California

Jhaqueline Valle Palomionos, Jeffrey D Lebensburger, Pranav S Garimella, Srila Gopal

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Jhaqueline Valle Palomionos[1] MPH; Jeffrey D Lebensburger[2] DO; Pranav S Garimella[3] MD, MPH; Srila Gopal[4] MD

[1]Tracking California Public Health Institute Oakland US
[2]Division of Pediatric Hematology-Oncology Department of Pediatrics University of Alabama at Birmingham Birmingham US
[3]Division of Nephrology and Hypertension University of California San Diego La Jolla US
[4]Division of Hematology/ Oncology Department of Medicine University of California San Diego La Jolla US

Corresponding Author:
Jhaqueline Valle Palomionos MPH
Tracking California
Public Health Institute
555 12th st
Oakland
US

Abstract

Background: Chronic Kidney Disease (CKD) is a significant complication in sickle cell disease (SCD) patients, leading to increased mortality. However, there is limited contemporary data on the prevalence, burden, and access to care for CKD in adult SCD patients, particularly those outside specialized clinics.

Objective: This study aims to investigate the burden of CKD in Medicaid-enrolled adults with SCD in California and assess mortality rates and access to specialized care.

Methods: This retrospective cohort study utilized the California Sickle Cell Data Collection (SCDC) program, which combines various data sources to identify and monitor individuals with SCD. Medicaid claims, emergency department, and hospitalization data from 2011 to 2020 were analyzed. CKD prevalence was assessed based on ICD codes, and mortality rates were calculated. Access to specialized care was examined through outpatient encounter rates with hematologists and nephrologists.

Results: Among the 2,345 adults with SCD, 24.4% met the case definition for CKD. Prevalence of CKD increased with age, with notable differences between males and females. Mortality rates were higher in the SCD-CKD cohort, particularly in males. Access to specialized care was limited, with a significant proportion of individuals having no encounters with hematologists or nephrologists. Deceased patients had lower rates of visits to both specialists compared to surviving patients.

Conclusions: Conclusion: This study provides robust estimates of CKD prevalence among Medicaid-enrolled adults with SCD in California. The findings highlight the need for improved access to specialized care for this population and increased awareness of the high mortality risk and progression associated with CKD.

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Abstract:

Background: Chronic Kidney Disease (CKD) is a significant complication in sickle cell disease (SCD) patients, leading to increased mortality. This study aims to investigate the burden of CKD in Medicaid-enrolled adults with SCD in California, examine differences in disease burden between males and females, and assess mortality rates and access to specialized care.

Methods: This retrospective cohort study utilized the California Sickle Cell Data Collection (SCDC) program to identify and monitor individuals with SCD. Medicaid claims, vital records, emergency department, and hospitalization data from 2011 to 2020 were analyzed. CKD prevalence was assessed based on ICD codes, and mortality rates were calculated. Access to specialized care was examined through outpatient encounter rates with hematologists and nephrologists.

Results: Among the 2,345 adults with SCD, 24.4% met the case definition for CKD. The SCD-CKD group (n=572) was older at the beginning of the study (average ages 44 vs. 34). CKD prevalence increased with age, revealing significant disparities by sex. While the youngest (18-29 years) and oldest (>65 years) groups showed similar CKD prevalences between sexes (11% and 12%, and 50% and 52%, respectively), males in the 30-50 age bracket exhibited significantly higher rates than females (17%, p<.0001; 29%, p<0.02; and 48%, p<.0001). During the study, 435 deaths (18.5%) occurred, predominantly within the SCD-CKD cohort (39.5%). The median age at death was 53 years for the SCD-CKD group compared to 43 years for the SCD group, with males in the SCD-CKD group showing significantly higher mortality rates (45.8%, p=0.009) than females (34.8%). Access to specialist care was notably limited: approximately half of the SCD-CKD cohort had no hematologist visits, and 61% did not see a nephrologist during the study period.

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Conclusion: This study provides robust estimates of CKD prevalence and mortality among Medicaid-enrolled adults with SCD in California. The findings highlight the need for improved access to specialized care for this population and increased awareness of the high mortality risk and progression associated with CKD.

Keywords: sickle cell disease, chronic kidney disease, prevalence, mortality, access to care, Medicaid, California

Introduction

Chronic Kidney Disease (CKD) presents a significant complication in sickle cell disease (SCD), marked by its high prevalence and a notable increase in mortality. Nearly 70% of adults with SCD develop albuminuria [1], and roughly 20% progress to overt CKD, characterized by a Glomerular Filtration Rate (GFR) of less than 60 ml/min/1.73 m2 [2]. Each year, over 100 patients with SCD advance to end-stage renal disease (ESRD) [3]. The mortality risk in patients with SCD-related ESRD is threefold higher compared to those without CKD [4], particularly with proteinuria. Key predictors of mortality in SCD are a reduced GFR and rapidly deteriorating kidney function [5-7], contributing to 16–18% of overall mortality in SCD [8]. Increasing age is a risk factor for CKD[9] and males are more likely to have a faster and rapid kidney function decline[10]. As life expectancy in SCD patients increases [11], the burden of SCD-associated CKD is expected to rise.

While the impact of CKD on SCD outcomes is well-recognized, contemporary data on its prevalence and burden, especially in the aging sickle cell population, are limited. This is particularly true for patients outside of specialized sickle cell clinics. Most current prevalence estimates are derived from pediatric sickle cell centers [2] or older patient cohorts [12]. However, the situation for adults with SCD is starkly different. Comprehensive care for adults is notably lacking [13], and most do not have

access to specialized hematological care [14]. Thus, patients who are followed at established sickle cell centers may not represent the entire population of SCD patients, and CKD in the SCD population may be under-recognized. Furthermore, the majority of SCD patients, often reliant on Medicaid, face significant barriers to accessing specialized care [15]. Access to timely and early nephrology care can impact the treatment of CKD and subsequent complications. Thus, more robust, and contemporary population-wide approaches may help us in improving our understanding of the burden and prevalence of CKD in adults with SCD.

To address the current limitations in the field, our study aims to investigate the burden of CKD among Medicaid-enrolled adults with SCD in California utilizing the Sickle Cell Data Collection (SCDC) program's large administrative database over a ten-year time frame (2011-2020). The Sickle Cell Data Collection (SCDC) program offers a comprehensive view as a state-based, population-wide public health surveillance system for SCD [16]. Our report estimates the prevalence of CKD in the SCD population by age groups, providing insights into mortality rates and access to specialized care, both hematology and nephrology, for adults with and without CKD.

Methods

This is a retrospective cohort study of Medicaid-enrolled people with SCD in California. All study data were obtained from the California SCDC program. The SCDC program leverages a variety of data sources to identify and longitudinally monitor individuals with SCD within the state. These data sources include newborn screening, non-federal hospital discharge records, emergency room visits, ambulatory surgery encounters, vital records death files, Medicaid claims, and enrollment data, as well as clinical case reports from SCD care centers within the state. The data is linked and deduplicated across various sources and multiple years. Detailed information about the SCDC

program and case definitions have been previously published [16-19].

Ethics Approval

The SCDC Program and this study were reviewed and approved by the California Committee for the Protection of Human Subjects, the Public Health Institute IRB, and the IRBs at clinical sites reporting case data. CA SCDC received a waiver of consent.

Data Sources

Data sources used in this analysis include Medicaid claims, hospital discharge data, and vital records data from 2011 to 2020. The source data included all outpatient provider claims, inpatient hospital, emergency department encounters, and all-cause mortality.

Study Population

Individuals aged 18 years and older, who met the case definition for SCD, and were enrolled in Medicaid in 2011, who maintained their Medicaid coverage for at least 75% of their time in the study. For example, if someone's enrollment spanned 6 years, they were required to be enrolled for at least 4.5 years cumulatively, regardless of whether the enrollment was continuous. .

Study Measures

The demographic characteristics of individuals are reported by the total study population. Age was calculated on the first date of the study, January 1, 2011. SCD subtype was recorded from State Newborn Screening records or clinical case reports from SCD centers. Subtypes were categorized as Hb-SS/Hb-Sβ° thalassemia (sickle cell anemia), Hb-Sβ^{+} thalassemia, Hb-SC, other compound homozygous forms of SCD, or unknown if laboratory confirmation was not available within the SCDC database. An individual was considered dual eligible, meaning they were enrolled in both Medicare and Medicaid, if any Medicaid claims data indicated dual eligibility. For the prevalence

estimation, age is calculated at the last date of the study, December 31st, 2020, or date of death, whichever came first. Disposition codes within the emergency department and hospitalization data as well as linked vital death records were used to identify all-cause deaths occurring during the study period. The proportion of deaths was calculated as the number of people with CKD who died, regardless of cause, by age group divided by the total number of people who developed CKD by age group, calculated at age at last date of the study, December 31st, 2020, or date of death, whichever came first.

We ascertained individuals' CKD status (none versus any, the latter encompassing stages 1 through 5, unspecified stage, and ESRD), stage of CKD is based on ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) and ICD-10-CM diagnosis codes. Individuals met the case definition for CKD if, within a 5-year period, they had 3 or more outpatient and/or emergency department encounters with CKD-coded diagnoses (ICD-9-CM: 585, 5851-5856, 5859; ICD-10-CM: N18, N181-N185, N188-N189) recorded in any diagnostic position, or at least 1 hospitalization with such codes in any position[20]. We identified a cohort of 572 individuals who by the end of the study period met the case definition for CKD. Subsequently, we will reference this subset as the SCD-CKD cohort. The remaining that did not meet the case definition will be referred to as the SCD cohort.

Hematologist and nephrologist encounters were identified using the National Provider Identifier (NPI) of the rendering provider, as listed in the Medicaid claims records [21]. Providers with any healthcare provider taxonomy (HPT) code listed as Hematologist: 207RH0000X, 207RH0003X, or 2080P0207X were categorized as a hematologist; Nephrologists were categorized as such if they had any HPT code listed as a Nephrologist: 207RN0300X. To calculate an individual's total number of encounters with a hematologist (both groups) or nephrologist (CKD only), Medicaid claims were de-duplicated by stipulating that an individual could only be recorded as having one encounter with a

specific provider per day. The outpatient encounter rate was calculated by dividing the total number of unique encounters by the total person-years attributed to each group. To calculate the proportion of individuals who had no visits with a nephrologist or hematologist, the entire study duration was examined, and those with no encounters with either specialist were identified.

Statistical Analysis

Categorical variables were summarized using frequencies and percentages and compared for statistical significance using Chi-square tests.Continuous variables were summarized by means and rates, and the Wilcoxon-Mann-Whitney test wasused to test for differences between SCD-CKD and the SCD group.All analyses were performed using SAS 9.4 (Cary™, NC).

Results

Characteristics of Study Cohorts

Table 1 presents the demographic characteristics of the 2,345 individuals in the study cohort from 2011 to 2020.

At the start of the study period, the SCD-CKD group (n=572) were older in age, nearly half fell into the 40–59-year age categories (25.8% 40-49 years, 23.8% 50-59 years of age). The mean age at the start of the study for the SCD-CKD cohort was 44 (SD 14.0) years. In contrast, the SCD cohort (n=1,773) had an average age of 34 (SD 12.6) years with 45% of them between the ages of 18-29 years. In both the SCD-CKD and SCD group, females were more predominant at 58% and 66% respectively. Among the people with a known genotype across both groups, sickle cell anemia was more prevalent than Hb-S/β+ Thal or Hb-SC. However, nearly 80% had unknown genotypes. More than half (58%) of the SCD-CKD cohort were considered dual eligible for Medicaid and Medicare.

Table 1. Demographic characteristics of individuals included in the study.

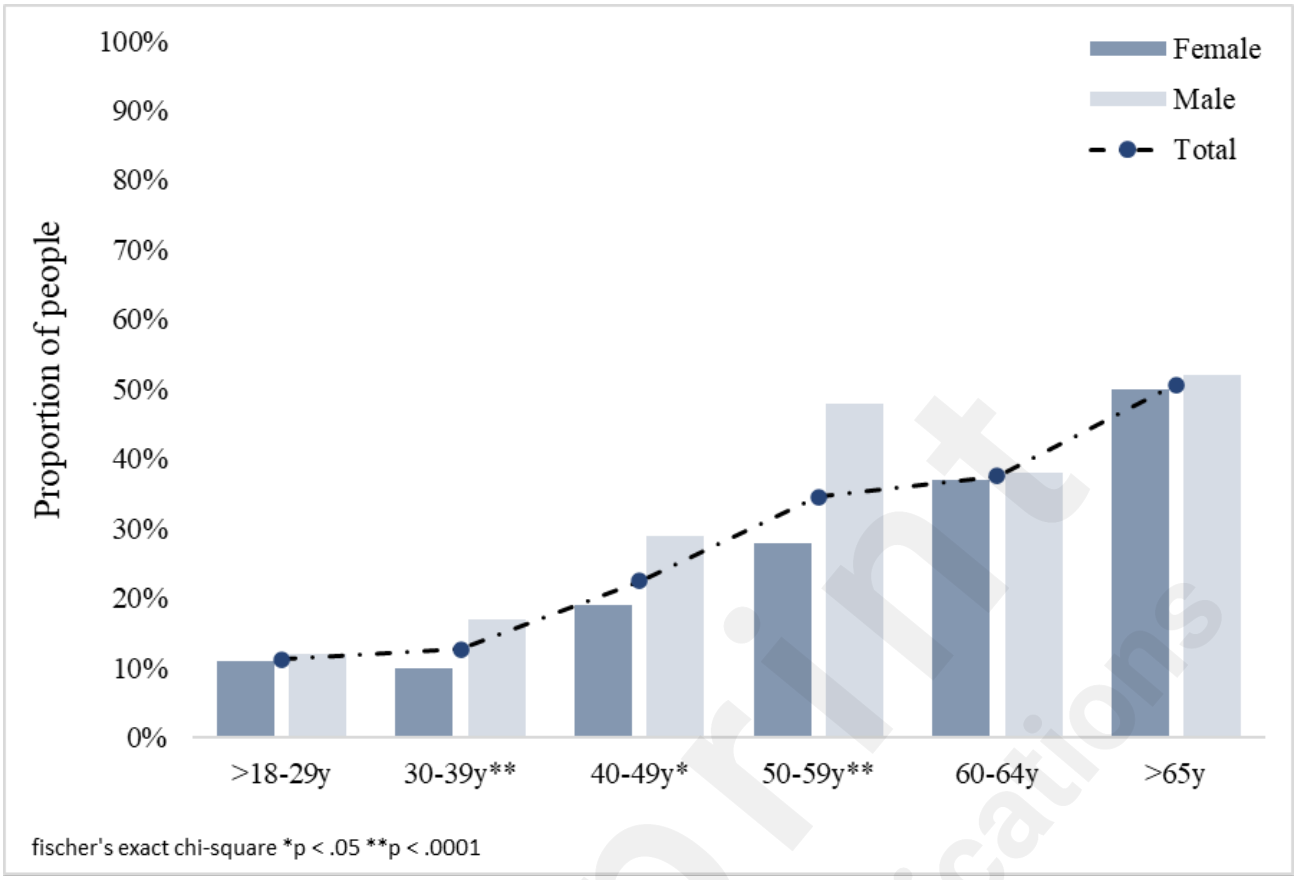
	Total (N=2,345)	SCD-CKD (N=572)	SCD (N=1,773)
Age Group	**N (col%)**	**N (col%)**	**N (col%)**
18-29	916 (39.1)	105 (18.4)	811 (45.7)
30-39	530 (22.6)	107 (18.7)	423 (23.9)
40-49	453 (19.3)	148 (25.8)	305 (17.2)
50-59	308 (13.1)	136 (23.8)	172 (9.7)
60-64	65 (2.77)	32 (5.6)	33 (1.9)
65+	73 (3.1)	44 (7.7)	29 (1.6)
Mean (SD) Age[+]	36y (17.7)	44y (14.0)	34y (12.6)
Sex			
Female	1495 (63.8)	330 (57.7)	1165 (65.7)
Male	850 (36.3)	242 (42.3)	608 (34.3)
SCD Subtype			
SCA (Hb-SS or S/β0 Thal)	332 (14.2)	96 (16.8)	236 (13)
Hb-S/β+ Thal or Hb-SC	144 (6.14)	28 (4.9)	116 (6.5)
Unknown	1869 (79.7)	448 (78.3)	1421 (80.2)
Dual Eligible	941(40.13)	333 (58.2)	608 (34.3)

*Met case definition by the end of the study period. [+]Age at the start of study, 01/01/2011.

CKD Prevalence by Age Group and Sex

The prevalence of CKD by age group and sex, as presented in Figure 1, shows a notable pattern of increasing prevalence with advancing age, alongside a distinct variation between females and males. In the youngest age group (18-29 years), and oldest age groups (> 65 %), the prevalence is similar between females and males, at 11% and 12%, and 50% and 52% respectively. Males have a significantly higher CKD prevalence in the 30 ($p<.0001$) ,40 ($p<0.02$) and 50 year age groups ($p<.0001$). The highest prevalence is observed in the age group of 65 years and above, with 50% in females and 52% in males, resulting in a combined prevalence of 51%.

Figure 1. Sex-specific prevalence of chronic kidney disease among individuals with sickle cell disease by age group, 2011-2020.



*By end of study period

CKD and mortality

There were 435 deaths (18.5%) that occurred during the study period, with the majority of deaths occurring in the SCD-CKD cohort (N=226, 39.5% of the SCD-CKD group). Median age at death was 53 years of age for the SCD-CKD cohort and 43 years for the SCD cohort. When compared to the SCD cohort, the SCD-CKD cohort had higher death rates for all age groups (Table 2). The lowest total number of deaths were identified in the youngest age group with SCD-CKD (>18-29 years); however, we identified a 63% mortality rate among individuals with SCD-CKD in this youngest age group. The remaining age groups also had high rates of mortality that ranged from 34% (30-39 years) to 45% among the 50–59-year age group (Figure 2). Males with SCD-CKD had a significantly higher rate of mortality (45.8%, p=.009) compared to females (34.8%) with SCD-CKD, a trend, though not significant, persisted across most age groups (Table 2).

Figure 2. Mortality trends by age group in individuals with sickle cell disease, with and without chronic kidney disease,2011-2020.

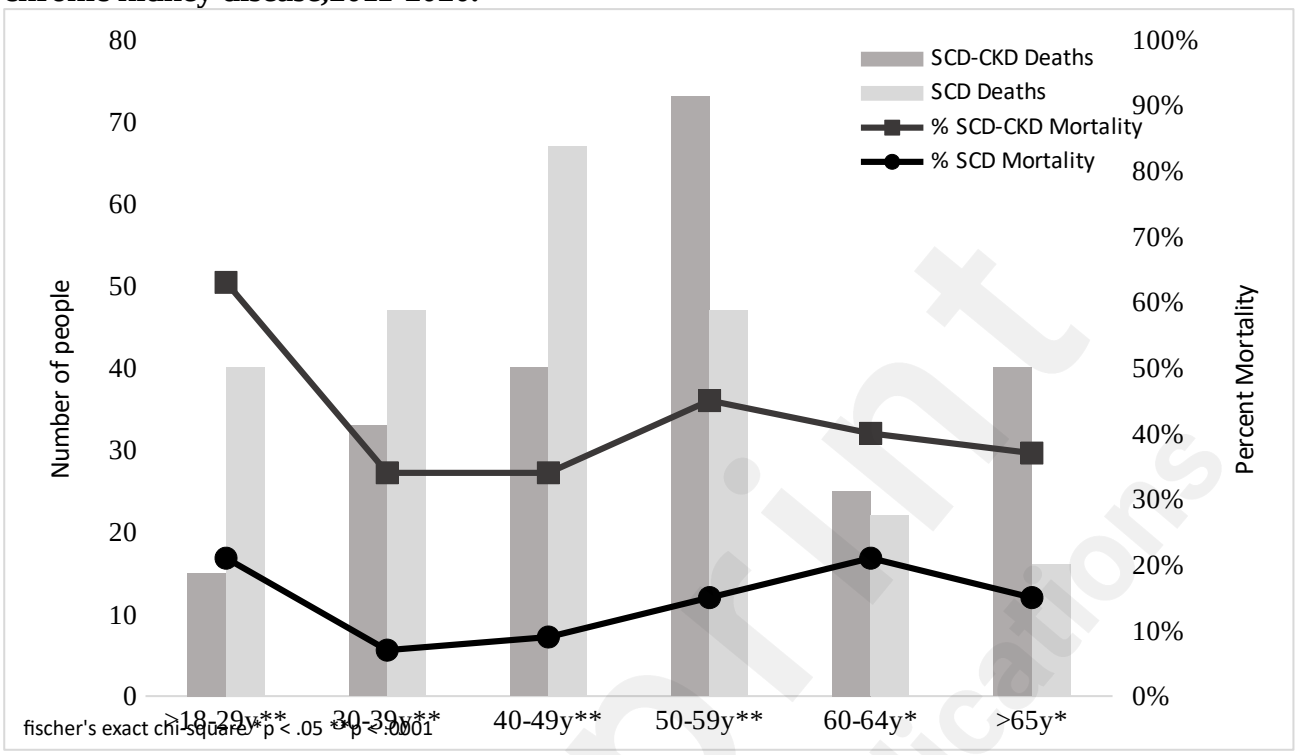


Table 2. All-cause mortality rates by age group, sex, and chronic kidney disease status among individuals with sickle cell disease, 2011-2020.

	SCD-CKD (N=226)			SCD (N=209)		
	Female n (%)	Males n (%)	p-value[a]	Female n (%)	Males n (%)	p-value[a]
Total	115 (34.9%)	111 (45.9%)	.009	124 (10.6%)	85 (14%)	.043
>18-29y	NA	NA	NA	17 (17%)	23 (26%)	0.16
30-39y	14 (30%)	19 (39%)	0.40	24 (6%)	23 (9%)	0.09
40-49y	21 (31%)	19 (37%)	0.56	21 (8%)	16 (12%)	0.14
50-59y	36 (41%)	37 (49%)	0.43	33 (15%)	14 (17%)	0.59
60-64y	NA	NA	NA	NA	NA	NA
>65y	25 (34%)	15 (44%)	0.39	NA	NA	NA

NA=cell suppressed; [a]Fischer's exact

Access to Care

Figure 3 and Table 3 shows the rate of outpatient encounters with a hematologist or a nephrologist per person year and the proportion of people with SCD-CKD who had zero visits with either specialist. Among those with SCD-CKD, visit rates with a hematologist were approximately 2 visits

per person-year, however, almost half (281/572) of people had no encounters with a hematologist over the entire study period. Access to nephrology care was also limited, in the group with SCD-CKD, individuals had only 1 visit to a nephrologist per person per year, and 61% (354/572) of people did not have any encounters with nephrologists throughout the entire study period.

Figure 3. Proportion of individuals with sickle cell disease, with and without chronic kidney disease, who had zero hematologist encounters over 10 years, 2011-2020

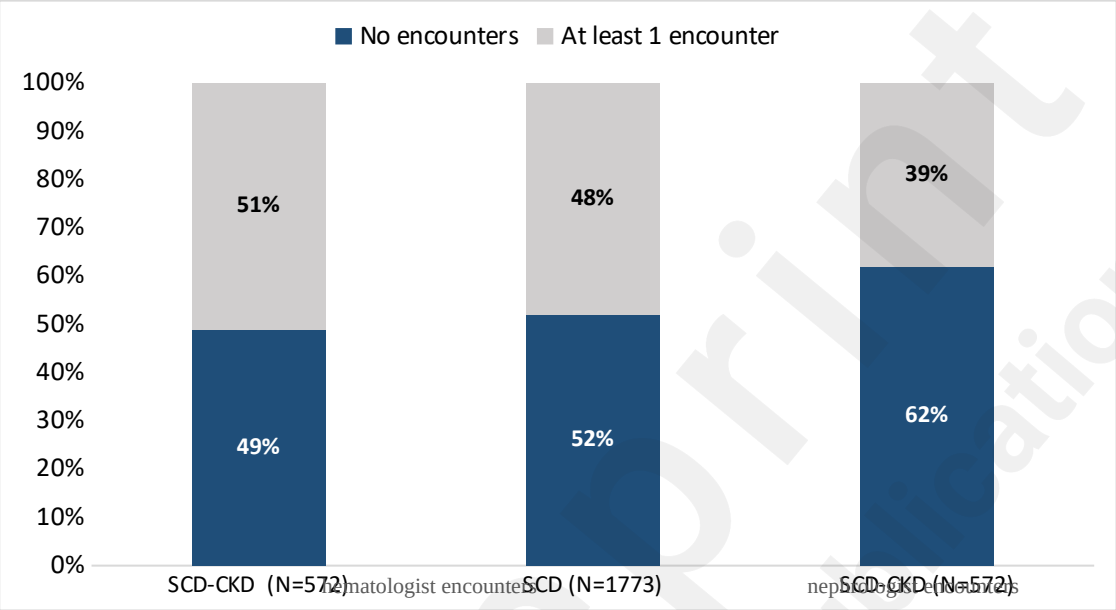


Table 3. Specialist outpatient visit rates in individuals with sickle cell disease, with and without chronic kidney disease, 2011-2020

	SCD-CKD N=572	SCD N=1773	P-value
Rate of outpatient hematologist visits per person-year	2.1	1.5	<.0001 [b]
# (%) of people with 0 visits with a hematologist*	281 (49.1%)	925 (52.1%)	0.205 [c]
Rate of outpatient nephrologist visits per person-year	0.9	--	
# (%) of people with 0 visits with a nephrologist *	354 (61.9%)	--	

[a]During the entire study period [b]Mann-Whitney [c]Fischer's exact

In our analysis of the SCD-CKD group, comparing deceased patients to those alive at the study's end, we found a significantly higher proportion of deceased patients had never consulted a hematologist (67.2% vs. 37.3%, p<.0001) or seen a nephrologist (68.1% vs. 57.8%, p=0.007), as

shown in Table 4.

Table 4. Rate of outpatient visits with a specialist by mortality among SCD-CKD

	Deceased n=226	Alive n=346	P-value
Rate of outpatient hematologist visits per person-year	2.2	2.1	.52[b]
# (%) of people with 0 visits with a hematologist[a]	152 (67.2%)	129 (37.3%)	<.0001[c]
Rate of outpatient nephrologist visits per person-year	1.3	0.8	<.0001[b]
# (%) of people with 0 visits with a nephrologist [a]	154 (68.1%)	200 (57.8%)	.007[c]

[a]During the entire study period [b]Mann-Whitney [c]Fischer's exact

Discussion

Our study estimates prevalence and mortality associated with CKD in Californians with SCD using a large administrative database. Similar to other single and multi-institutional cohorts, we found a high prevalence of CKD (24.4%) among adults with SCD. Prevalence of CKD increased with age, with significant differences between males and females. Mortality rates were higher in the SCD-CKD cohort. Access to specialized care was limited, with a significant proportion of individuals having no encounters with hematologists or nephrologists.

Prevalence of CKD by Age Group and Sex

We identified 2,345 adults (> 18 years of age) during a 10-year period within the SCDC cohort. Of these, 572 fulfilled case definitions for CKD, with an estimated CKD prevalence of 24.4%. Prior studies show a high prevalence of CKD in the SCD population, and our study confirms these findings. One observational study tracked 427 patients over four years, finding a baseline CKD prevalence of 21.4% in sickle cell anemia and 17.2% in Hb-Sβ^+ thalassemia, Hb-SC SCD [2]. Studies from countries like Nigeria and Ghana report even higher prevalence rates, around 38% and 39%, respectively [22, 23]. Another study, a 25-year cohort study [12], identified the prevalence of renal failure of 4.2% in patients with sickle cell anemia (mean age of onset: 23 yrs.) and 2.4% in

patients with Hb-SC SCD (mean age of onset: 50yrs). On additional follow-up, the prevalence increased to 12% [24]. The prevalence of CKD, calculated using the age at the end of the study or age at death, demonstrated an expected increase with advancing age. Our study continues to highlight the high prevalence of SCD-CKD in 18–29-year-old patients. By age >50 years, around 50% of patients will have developed SCD-CKD. Interestingly, our cohort predominantly comprised females (62.3%), this overrepresentation may be attributed to higher Medicaid coverage in females, especially during their reproductive years [25]. Despite this female predominance, males appear to have a higher prevalence of CKD compared to females for each age category, a higher percentage of males in our study had CKD (26.7% vs. 20.4%), deviating from the general population's CKD distribution where females slightly outnumber males[26]. This finding further confirms sex differences in the prevalence of SCD-CKD at a population level [27]. This may be explained by the fact that males with SCD have a higher rate of decline in GFR when compared to females [28, 29], leading to a greater burden of CKD.

While males appear to have a higher prevalence of CKD for each age category, CKD prevalence for males and females are the same in the age 60-64 group. This phenomenon may be partially explained by higher mortality rates for males in the SCD-CKD cohort, and hence the comparable CKD rates in the oldest age groups may be because more males with SCD-CKD are dying at a younger age. Taken together, these findings further emphasize the importance of early CKD screening and intervention in SCD, especially in younger and male populations.

CKD and Mortality

During the study period, 435 deaths occurred, translating to an overall mortality rate of 16%. Notably, the mortality rate in the SCD-CKD cohort was high at 39.5%. Males in the SCD-CKD cohort exhibited a higher death rate (45.8%) compared to females (34.8%), deviating from previous

studies that did not find a gender difference in mortality among CKD patients with SCD[1]. Notably, 50% of the deaths in the SCD-CKD cohort occurred in individuals with ESRD, reinforcing the association of kidney disease with heightened mortality risk in SCD. The high mortality rate seen in our study is notably higher than the 18% found in the Platt study [8]. One key difference is the level of healthcare access between the two populations, the Platt study followed patients enrolled and regularly seen at established SCD centers, whereas over half of the patients included in this analysis never had an encounter with a hematologist or nephrologist. In addition, the definition for renal failure was different in the Platt study where they defined renal failure as a 20% increase in baseline creatinine concentration and a creatinine clearance rate below 100 ml/min [8], while we used ICD codes to identify individuals with CKD. In our study, the median age at death was 10 years higher in the SCD-CKD cohort compared to the non-CKD SCD cohort, which was an unexpected finding given that CKD is a known risk factor for mortality in SCD [7]. This could be attributed to the older age distribution of the SCD-CKD cohort. This suggests that CKD may be more prevalent in the aging SCD population, potentially characterizing it as a complication of the aging SCD population and perhaps can be considered a disease of the “survivors”.

The significantly higher mortality rate in the SCD-CKD group, especially in younger age groups, is another important finding. The stark contrast in mortality rates between males and females with SCD-CKD in the youngest age group indicates a need for focused research on gender-specific factors contributing to these outcomes. This elevated mortality risk associated with CKD in SCD patients underscores the importance of early detection and management of kidney disease.

Access to care

Severe lack of access to specialty services remains a critical issue for adults with SCD [14]. Notably, while the SCD-CKD group had more hematologist visits than the SCD group, half had no specialist

visits over the 10 years, highlighting a critical gap in specialty care access for adults with SCD. This lack of access is even more considerable given that 67% of SCD-CKD individuals who died had not consulted a hematologist, compared to 37% among survivors. Furthermore, only 40% of those with CKD had consulted a nephrologist, and likely only in the advanced stages of their disease. This is not a surprising observation, since it is likely that patients who had more access to care also had more access to preventative care, early detection of CKD, and likely disease-modifying strategies. Despite ESRD qualifying for Medicare, only 58% were dual eligible, indicating that Medicaid coverage alone may not provide sufficient access to nephrology care [3]. This issue is not unique to the SCD population and reflects broader systemic disparities in healthcare access, particularly for younger, predominantly Black and Hispanic individuals on Medicaid [3]. These findings emphasize the need for improved access to specialized care to better manage CKD and potentially reduce mortality in the SCD population.

Limitations

While there are several strengths to our study approach as outlined above, there are also several limitations. The major limitation to our study is that it is a retrospective administrative data-based study. The use of ICD codes to capture CKD diagnoses has been validated previously[20], however, we are likely underestimating the burden of CKD for multiple reasons. We did not include ICD codes for proteinuria since we felt this would be less reliable when relying on administrative data alone for data collection. While we included all stages of CKD, we likely underestimated CKD 1 and 2 where the GFR is > 60 mL/min because not all of these may have been recognized and/ or coded correctly. In assessing the limitations of our methodology for calculating the prevalence, it is important to consider the following aspects. First, individuals were categorized as either having CKD or not based on meeting the case definition at any point within a 10-year timeframe. This approach simplifies the

classification process but may overlook cases of CKD who did not utilize healthcare or were not identified or documented with the relevant codes during the specified period. Additionally, because we used ICD codes within a set period of time, we could only identify when the first ICD CKD code appeared and not when a person was first diagnosed with CKD. Lastly, only Medicaid recipients were included in our study and about a third of patients with SCD may have commercial insurance or Medicare only and may not have been included in our analysis. In our assessment of care access, we focused exclusively on visits to hematologists, without distinguishing providers with specific training in SCD. Previous research indicates that adult SCD patients in California face significant access barriers, and including primary care providers with SCD expertise—defined as having 20 or more SCD patients—did not substantially improve access [14]. In addition, we could not ascertain whether individuals who dis-enrolled from Medi-Cal then enrolled in other health plans or became uninsured. While our data does not enable us to confirm whether individuals accessed specialty care during periods they were not enrolled in Medicaid, literature suggests that accessing specialist services without insurance is highly unlikely[30]. Since this was an administrative database-based study, we had limited access to detailed clinical information, and could not adjust for covariates or perform robust statistical analysis, hence our results are presented in a descriptive manner.

Conclusions

We used administrative data to estimate the prevalence of CKD in SCD among California state Medicaid recipients. Our prevalence estimates for CKD are higher than what has been reported previously. Those with SCD and concurrent CKD experienced significantly higher mortality rates compared to individuals with SCD that did not meet the case definition for CKD. In California, individuals with SCD face substantial barriers to accessing specialty care. Our findings highlight the critical need for this data to guide state healthcare stakeholders and government policymakers in

addressing these access issues. As the SCDC program expands to include additional states, similar studies may inform our understanding of the true burden of CKD in the SCD population, including its effects on mortality, morbidity, healthcare utilization, and quality of life.

Acknowledgements

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Data Availability Statement

These data are sourced from third parties, and data use agreements that prohibit sharing even de-identified person-level data. Should readers wish to explore gaining access to the data, they may contact the original data stewards. Requests for minimal dataset data can be directed to the corresponding author.

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Abbreviations

CKD: chronic kidney disease

SCD: sickle cell disease

GFR: glomerular filtration rate

ESRD: end-stage renal disease

HbSC: sickle cell hemoglobin SC

SCDC: sickle cell data collection program

ICD: international classification of diseases

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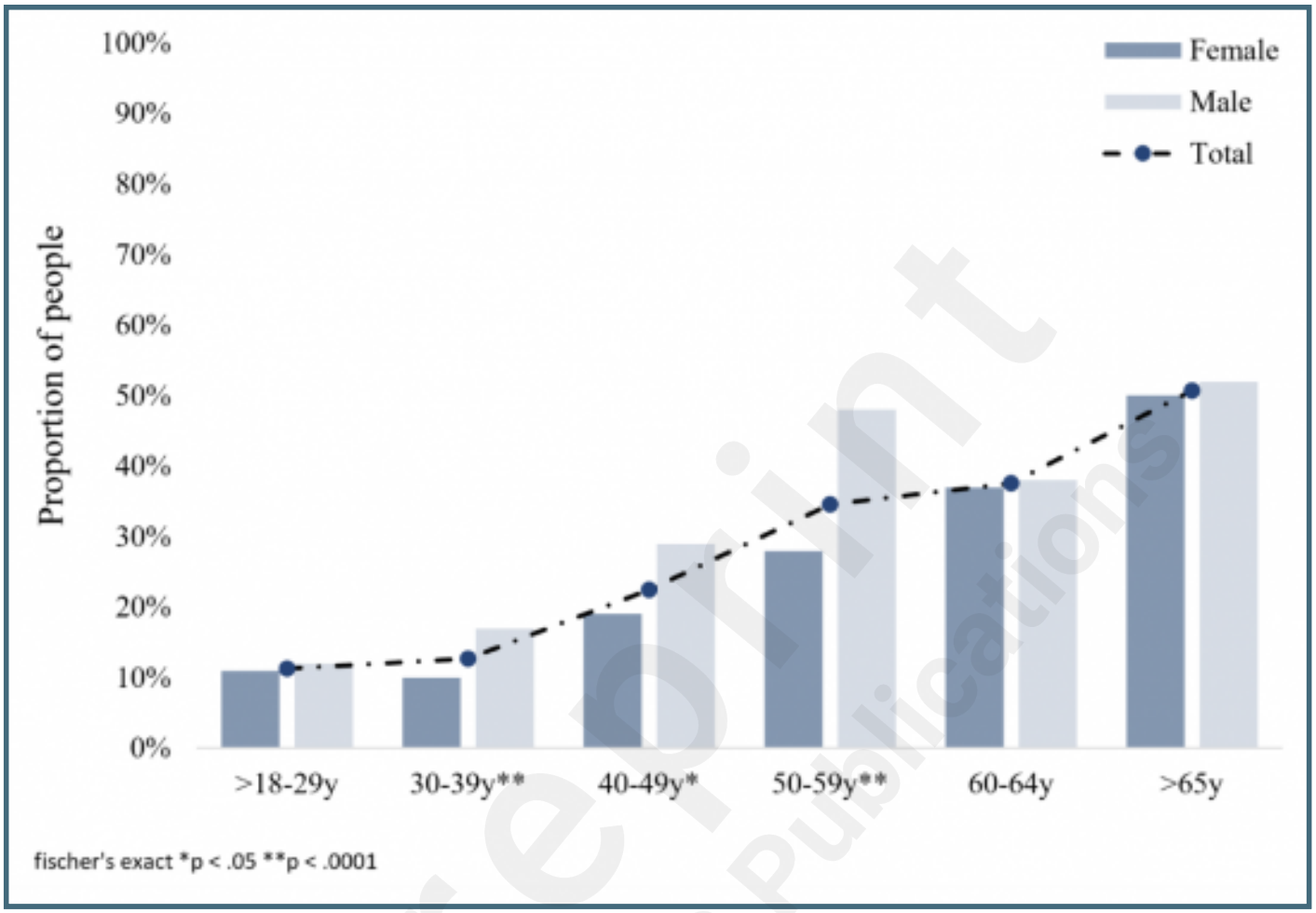
Sex-specific prevalence of chronic kidney disease among individuals with sickle cell disease by age group, 2011-2020.



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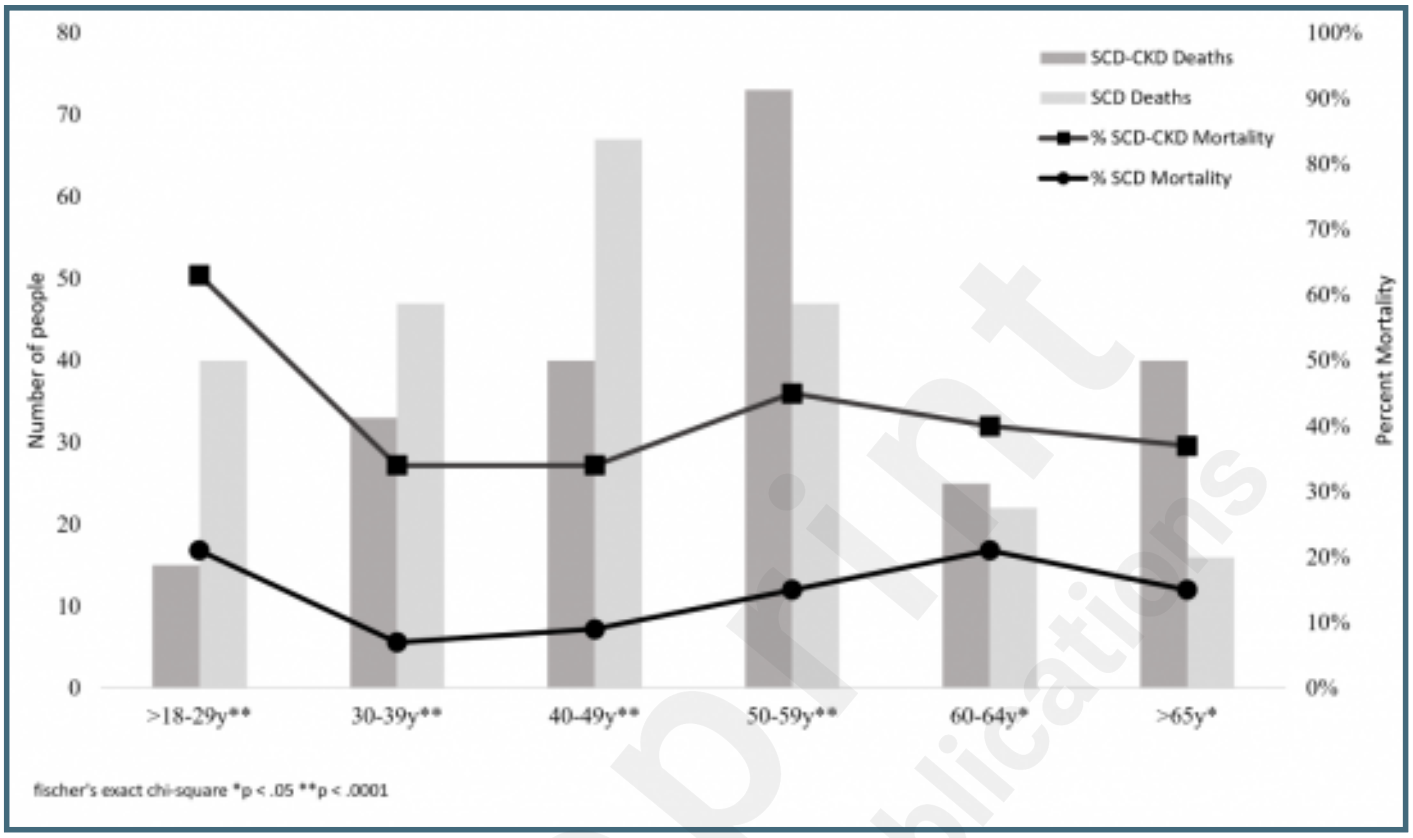
Mortality trends by age group in individuals with sickle cell disease, with and without chronic kidney disease,2011-2020.



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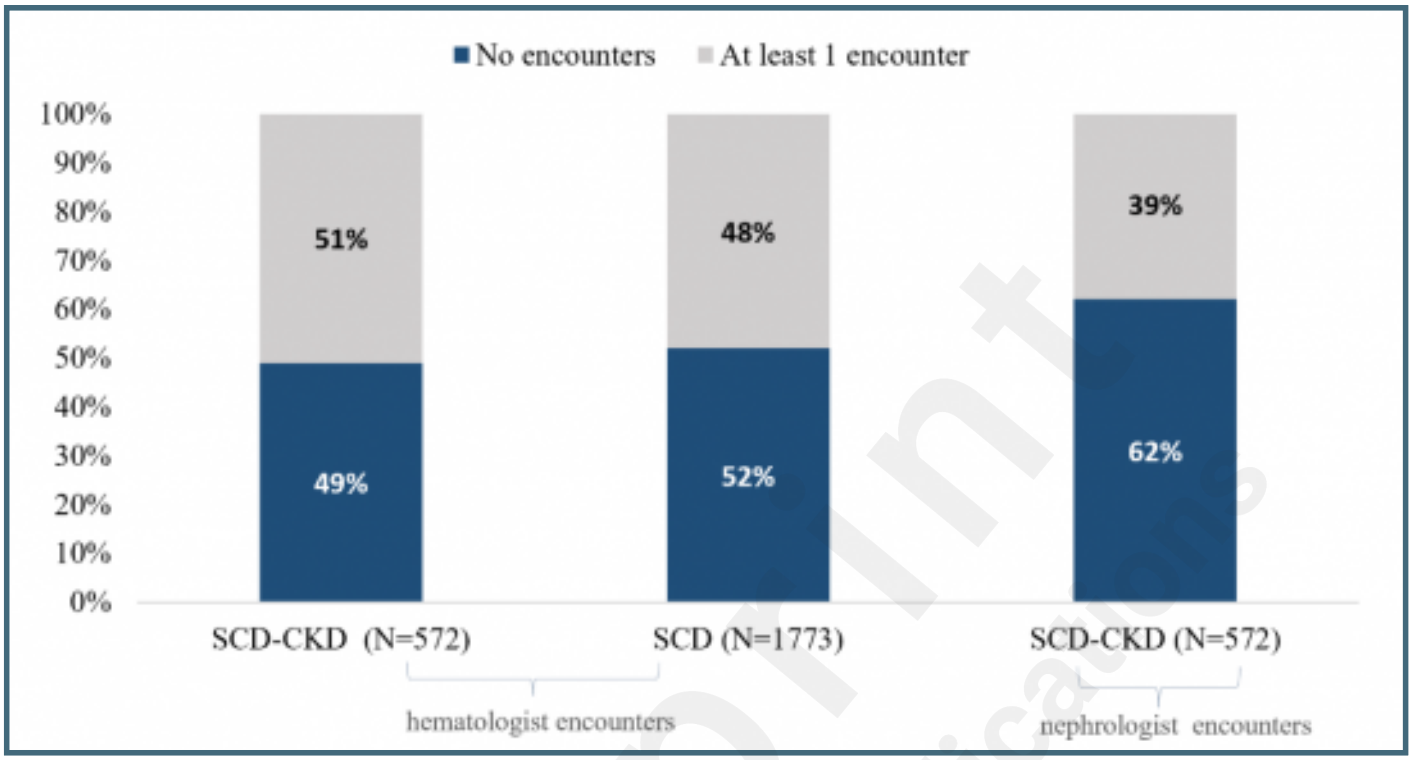
Proportion of individuals with sickle cell disease, with and without chronic kidney disease, who had zero hematologist encounters over 10 years, 2011-2020.



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