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NOTES FROM THE FIELD

National Mortality Databases to Assess Disease Burden in Systemic Autoimmune Diseases: A Valuable Resource But With Limitations

Ram Raj Singh

Introduction

Disease-specific mortality statistics are useful measures of disease burden. Population-based studies from a few US counties have reported mortality in systemic autoimmune diseases (SAIDs). However, due to substantial differences in the population structure of these counties as well as relatively small numbers of SAID deaths in these counties, it is difficult to extrapolate their findings to assess SAID national burden. In this regard, national mortality databases offer a large reference population, which is hard to assemble in individual SAIDs. However, two concerns are persistently raised regarding mortality databases for SAIDs: misclassification and underrecording. Although misclassification of SAIDs is common in health records and administrative databases, it appears to be rare on death certificates among decedents who did not have an SAID. However, SAIDs are underrecorded in death certificates. The underrecording of SAIDs does not differ by sex and race and ethnicity, but it is common in older adults who die of cardiovascular diseases, neoplasms, and chronic obstructive pulmonary disease. Underrecording of SAIDs may occur because it may be difficult to assign a specific SAID manifestation or treatment complication responsible for death. Furthermore, an SAID is commonly listed as a contributing, rather than as the underlying, cause of death on death certificates, which advocates using the multiple-causes-of-death database for SAIDs. Nevertheless, until we have large-scale prospective outcomes data, mortality data from the National Vital Statistics System offer valuable estimates of SAID national burden, which can be used for setting research priorities, health care policy planning, resource allocation, and precision public health.

The unmet need

SAIDs, such as systemic lupus erythematosus (SLE), systemic sclerosis (SSc), rheumatoid arthritis (RA), dermatopolymyositis (DPM), systemic vasculitis, and Sjogren disease, are chronic immune-inflammatory conditions with increasing prevalence.[1–4] With their onset at younger ages, SAIDs can incur substantial disease burden. Disease-specific mortality statistics are important measures of disease burden that can be used for setting research priorities, health care policy planning, resource allocation, and precision public health.

Most mortality reports on SAIDs are based on patient cohorts at referral centers,[5] but they do not capture changes in the incidence of these diseases over time and will not reflect the true burden of disease in the population. For example, it is well documented that Black persons experience worse morbidity and mortality from SSc.[6,7] However, in well-cared-for cohorts, such as the Scleroderma Lung Study cohort, time to death and survival were not different between Black and non-Black participants with SSc.[8]

A few studies have used population-based designs to quantitate mortality burden from SAIDs,[3,9–13] but they were limited to specific regions, specific patient populations, small samples, or relatively short durations (Table 1).[3,9,10,14] The racial and ethnic makeup of these counties/study populations was substantially different compared to the US population: White persons represented 85% of population in Olmsted County, Minnesota, from 1999 to 2018 as compared to 66% of the US population during the same time period; Asian persons represented 35% of the population in San Francisco County, California, versus 5% in the US population; Black persons represented 49% of the population in DeKalb and Fulton Counties, Georgia, versus 13% in the

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Table 1. Population structure in recent population-based studies on SLE mortality in the United States*

Location	DeKalb and Fulton Counties, GA[10]	Olmsted County, MN[3]	San Francisco County, CA[9]	Medicaid, 47 states[14]	Nationwide, 50 states and DC[18]
Duration	2002–2006	1999–2018	2007–2017	2000–2006	2000–2015
No. of SLE deaths	400	22	135	2,058	28,411
Population in the study period	7,451,017	2,816,126	9,125,648	1,226,467,530[a]	4,833,578,708
Population by race and ethnicity, %					
AI or AN[b]	0.2	0.3	0.3	1.1	0.8
Asian or PI[b]	4.5	5.7	35.4	3.3	5.0
Black[b]	49	5	6.1	22.7	12.7
Hispanic	7.4	3.9	15.1	26.9	15.4
White[b]	38.8	85.1	43.1	42.7	66.0
Population by age groups, %					
<44 y	69.2	62.4	60.2		61.8
45–64 y	22.6	24.9	25.6		25.1
>65 y	8.2	12.7	14.2		13.1

* AI, American Indian; AN, Alaska Native; CA, California; DC, District of Columbia; GA, Georgia; MN, Minnesota; PI, Pacific Islander; SLE, systemic lupus erythematosus.
[a] US population in the 18- to 65-year age group during the study period.
[b] Non-Hispanic.

US population; and Hispanic persons represented 27% of those on Medicaid versus 15% in the US population (Table 1). These limitations pose challenges in extrapolating their data to assess national disease burden.

Recognition of the need for large population-based data on SAIDs has led to the creation of databases such as the Rheumatology Informatics System for Effectiveness registry, which would be useful to assess SAID outcomes. In the meantime, a database maintained by the Centers for Disease Control and Prevention's (CDC) National Vital Statistics System provides a valuable resource to assess the national burden of SAIDs.

CDC's national mortality database

The CDC's database encompasses more than 99% of deaths of all US residents. Death certificates provide the *International Classification of Diseases* codes for the underlying or contributing cause of death (Supplemental Figure).[15] Information from death certificates can be used to assess disease-specific outcomes in an unbiased manner over a long time period in a large sample size. These data have been used to identify public health challenges and guide funding priorities. For example, to address the underdocumentation of maternal mortality, death certificates were changed in 2003.[16] The data obtained led to policy changes, such as expanding Medicaid coverage for women to a year after delivery.

For the mortality datasets to accurately capture disease burden, it is vital that primary physicians or nurse practitioners who usually fill death certificates have a clear understanding of the patient. However, some states allow individuals who have never interacted with the patient to sign the death certificate, which can lead to inaccuracy. Autopsies were performed to verify the accuracy of the cause of death in 40% to 60% of hospital deaths in the United States before 1970, but this rate has now gone below 5%.[17] Thus, difficulty to verify the accuracy of the coding on death certificates is a limitation of mortality datasets.

Changes in physicians' reporting/attributing a disease as a cause of death, the practice of recognizing a disease, and changes in diagnostic tools could influence trends in disease-specific mortality. Finally, data on clinical, laboratory, and socioenvironmental parameters are not available in mortality databases.

Assessing population-level mortality burden for SAIDs using national mortality databases

Population-level mortality statistics, such as the leading-causes-of-death ranking and mortality rates, serve as useful tools for assessing the relative burden of cause-specific mortality. For example, the cause-of-death ranking analysis revealed that SLE ranked among the top 10 leading causes of death in 15- to 24-year-old females.[18] Mortality databases have also been used to highlight persistent mortality burden in SAIDs over time.[6,7,15] Notably, the ratios of SLE or SSc mortality rates to all-cause mortality rates were higher in 2010s than in the 1970s.[7,15] However, there are at least two persistent concerns: (1) misclassification (ie, a specific disease recorded on the death certificate when the decedent did not have the disease) and (2) underrecording (ie, the decedent had the disease, but it was not recorded on the death certificate).

Is there a misclassification of SAIDs on death certificates?

In a chart review of patients in administrative billing and hospitalization databases, the specificity of SAID diagnoses ranged from 72.5% (lupus) to 96.4% (myositis).[19] However, unlike administrative databases, where possible and probable diagnoses are often recorded, death certificates usually have the most

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proximate illness recorded as the cause of death. Due to a limited awareness about these diseases among primary physicians and hospitalists who often care for dying patients, SAIDs are unlikely to be perceived and recorded as a cause of death for decedents who did not have these diseases. In contrast, cardiovascular diseases are often perceived to be the illness at the time of death; hence, death certificates tend to overestimate cardiovascular disease mortality.[20] In a study designed to capture all patients with SLE, for the 731 decedents for whom SLE was recorded on the death certificate, only 2 (0.27%) had SLE erroneously recorded as a cause of death (when decedents did not have SLE).[21] Although studies are needed to determine the extent of SAID misclassification on death certificates, it is unlikely to influence SAID mortality assessments in a substantial way.

Underrecording of SAIDs on death certificates

Patients with SAIDs die prematurely of complications such as cardiovascular events, pulmonary complications, infections, cancer, and renal failure. These proximate causes of death may be perceived by physicians who care for the patients at the time of death to be unrelated to SAIDs, when in fact the SAID or the medications used for it predispose the patients to these causes of death.

In cohorts for which the extent of SAIDs not being recorded on death certificates could be deduced, the extent of underrecording for SLE varied from 32% to 59% (Table 2).Cardiovascular diseases, heart failure, pneumonia, neoplasms, and chronic obstructive pulmonary disease were among the most prevalent causes of death among individuals with SLE who had SLE absent from their death certificate.[21]

The age at death was higher among those for whom SLE was omitted on the death certificates than those who had SLE included in death certificates.[22,23] Decedents 60 to 79 years old at death were approximately 2.5 times as likely to have SLE missing from their death certificates compared with those aged <40 years.[21] The extent of SLE underrecording was even higher (64%) among those aged over 80 years.[21] Some proportions of these deaths in older adults could be due to causes unrelated to SLE. Thus, older age and diseases that are the leading causes of death in older adults are associated with the lack of recording of SLE on death certificates. As a corollary, younger decedents and those who had renal failure listed as a cause of death were less likely to have SLE absent from their death certificate compared to those without renal failure listed.[21] Likewise, younger age, a greater number of deformities, higher Sharp score, lower socioeconomic status, and a certified physician's signature on the death certificate were associated with recording RA on death certificates, whereas comorbidities were inversely associated with listing RA on the death certificate.[24]

Is there a selective underrecording of SAIDs on death certificates in certain subpopulations?

SAID outcomes differ by sex and race and ethnicity. For example, the SLE mortality risk was higher in females (odds ratio [OR] 5.3, 95% confidence interval [CI] 5.1–5.6) than males and in Black (OR 3.9, 95% CI 3.8–4.1) and Hispanic persons (OR 1.4, 95% CI 1.3–1.4) relative to White persons.[15] SSc mortality rates were also higher in females than males and in Black persons than in White persons.[7] Black persons had a 13-year lower median age at death and 5.1 times higher odds of premature death from SSc compared to White persons.[6] Such disparities are unlikely to be artifacts from underrecording or misclassification of cause of death because greater underreporting would lead to greater underestimation of mortality in the underprivileged groups, but we found the mortality to be higher, for example, in females and Black and Hispanic persons. Furthermore, in the Lupus in Minorities, Nature Versus Nurture (LUMINA) and Carolina Lupus Study (CLU) cohorts, no difference in education and poverty levels was found between SLE decedents who had lupus recorded on their death certificates and those who did not.[22]

To address the differential recording of SAIDs in death certificates, I tabulated SLE deaths by sex and race and ethnicity in the

Table 2. Underrecording of SLE on death certificates in the United States*

Location	Duration	No. of SLE deaths in the cohort	SLE recorded on death certificates[a]	SLE not recorded[b]	% not recorded
LUMINA and CLU cohorts[22,c]	1999–2004	76	46	30	39.5
Olmsted County, MN[3]	1999–2018	22	15	7	31.8
DeKalb and Fulton Counties, GA[10]	2002–2006	400	190	210	52.5
San Francisco County, CA[9]	2007–2017	135	55	80	59.3
Total	–	633	306	327	51.7

* CA, California; CDC, Centers for Disease Control and Prevention; CLU, Carolina Lupus Study; GA, Georgia; LUMINA, Lupus in Minorities, Nature Versus Nurture; MN, Minnesota; SLE, systemic lupus erythematosus.
[a] SLE death counts were obtained from the CDC WONDER database for the corresponding county and study period, except for the LUMINA and CLU cohorts, for which the information was extracted from the death certificates obtained from the Offices of Vital Statistics.
[b] Assuming that potential relocation in and out of the counties did not majorly affect SLE death counts.
[c] LUMINA is a multiethnic (Hispanic [Mexican or Puerto Rican ancestry], African American, or White race and ethnicity), multicenter (the University of Alabama at Birmingham, the University of Texas Health Science Center at Houston, and the University of Puerto Rico Medical Sciences Campus) cohort.

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Table 3. Underrecording of SLE on death certificates by sex, race and ethnicity, and age in recent studies*

	DeKalb and Fulton Counties, GA[10,a] (2002–2006)		LUMINA and CLU cohorts[22] (1999–2004)		Medicaid (18–65 y)[14] (2000–2006)		Olmsted County, MN[3] (1999–2018)		San Francisco County, CA[9,a] (2007–2017)	
	Cohort	CDC	SLE recorded	Not recorded	Medicaid	CDC	Cohort	CDC	Cohort	CDC
SLE death count	400	190	46	30	2,058	9,402	22	15	135	53
Female sex, %	87	89	91	80	–	–	–	–	88	83
Race, %										
Asian	–	–	–	–	1	4	–	–	33	41
Black	81	84	63	53	51	41	–	–	31	15
Other	–	–	–	–	2	1	–	–	3	2
White	19	16	13	33	40	41	–	93	33	42
Hispanic ethnicity, %	–	–	22	13	6	13[b]	–	–	14	19
Race and sex, %										
Black female	72	75	–	–	–	–	–	–	–	–
White female	16	14	–	–	–	–	–	–	–	–
Age, %										
10–34 y	–	–	–	–	–	–	–	–	19	20
45–64 y	–	–	–	–	–	–	–	–	44	40
≥65 y	–	–	–	–	–	–	–	–	37	40

* SLE death counts reported in recent patient cohorts are tabulated by sex, race, ethnicity, and age ("Cohort"). SLE death counts were then obtained from the CDC WONDER database for the corresponding county/geographic location, age, and study duration ("CDC"). CA, California; CDC, Centers for Disease Control and Prevention; CLU, Carolina Lupus Study; GA, Georgia; LUMINA, Lupus in Minorities, Nature Versus Nurture; MN, Minnesota; SLE, systemic lupus erythematosus.
[a] Racial groups were not separated by Hispanic origin.
[b] $P < 0.001$, Fisher's exact test.

published population-based cohort studies and deduced the proportions of SLE deaths for the corresponding years, county/geographic region, and age from the CDC WONDER database. As shown in Table 3, the proportions of SLE deaths in females, Black persons, and Black females were similar or slightly higher in the CDC database than in the DeKalb and Fulton Counties cohort. There were also no statistically significant differences in the portions of SLE deaths in other cohorts versus the CDC database, except for an unusually low SLE death count in Hispanic persons on Medicaid (Table 3). These observations argue against differential underascertainment of SAID deaths by sex and race and ethnicity in national mortality databases in a substantial way.

Population-level mortality rates versus prevalence-adjusted mortality

Mortality rates measure disease burden in the general population but cannot distinguish whether differences in mortality rates are due to differences in the incidence/prevalence of disease or disease severity. This can be addressed by linking mortality data with prevalence data to estimate the mortality rate normalized for prevalence in a specific disease population (ie, case fatality rate).

For SLE, which is nine times more prevalent in females, the predicted annual mortality rate was only 5.3 times higher in females than males,[15] suggesting a relatively higher fatality rate in males with SLE. Consistently, when adjusted for prevalence, the case fatality rate was higher in males than females with SLE (RRS: unpublished observations). Likewise, in DPM, which is two to three times more common in females, the age-standardized mortality rate was only 1.6 times higher in females than males.[25] In SSc, which is four to seven times more prevalent in females, age-standardized mortality rates were only 1.9 to 3.5 times higher in females than males,[7] suggesting worse outcomes in males. Consistently, the median age at death was five years lower for males, and the risk of premature SSc death was higher for males than females (OR 1.8, 95% CI 1.6–2.0).[6] Hence, large population-based prevalence data are needed to address whether changes in SAID mortality rates are due to changing incidence/prevalence or SAID severity.

Underlying versus contributing causes of death in SAIDs

Cause of death is recorded as the underlying or a contributing cause on the death certificate. Because many patients with SAIDs die of complications of disease or of treatment, an SAID is likely to be listed as a contributing, rather than as the underlying, cause of death. For example, of 47,337 deaths from 1999 to 2020 in the United States, SLE was recorded as the underlying cause of death in 57% and as a contributing cause in 43%. These observations advocate using the multiple-causes-of-death database in SAID assessments.

Conclusions

The increasing prevalence of SAIDs calls for action to understand their population-level burden. National mortality databases offer a large reference population to assess disease burden.

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Importantly, misclassification of SAIDs in death certificates appears to be rare among decedents who did not have an SAID. Furthermore, underrecording of SAIDs on death certificates, which is substantial, does not differ by sex and race and ethnicity and mostly occurs in older adults with comorbidities. Because an SAID is commonly listed as a contributing, rather than as the underlying, cause of death on death certificates, I suggest using the multiple-causes-of-death database in SAID assessments. Increasing awareness of the importance of death certificates, enhancing certifier-of-death training, timely audits of death certificates, increasing autopsies, and enhancing awareness about the multiorgan and varied complications of SAIDs at the time of death may reduce overall errors on death certificates and help improve SAID recording. Nevertheless, until we have large-scale prospective outcomes data, national mortality statistics offer valuable estimates of SAID burden. An unequal assignment of the national burden of disease may have implications for research and health care allocation of our limited public health dollars.

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AUTHOR CONTRIBUTIONS

Dr Singh contributed to at least one of the following manuscript preparation roles: conceptualization AND/OR methodology, software, investigation, formal analysis, data curation, visualization, and validation AND drafting or reviewing/editing the final draft. As corresponding author, Dr Singh confirms that he has provided the final approval of the version to be published and takes responsibility for the affirmations regarding article submission (eg, not under consideration by another journal), the integrity of the data presented, and the statements regarding compliance with institutional review board/Declaration of Helsinki requirements.

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