
Prevalence of Limb Loss and Limb Difference in the United States: Implications for Public Policy

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Table of Contents

Introduction	1
Methods	1
Results	2
Discussion	4
Acknowledgements	6
References	6

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Introduction

“Limb loss” (LL) is the permanent removal or acquired amputation of a body part due to injury or disease¹. Specific health conditions such as diabetes, gangrene, and ischemic vascular disease increase the risk of LL². Past research shows that individuals living with LL experience substantial physical and psychological effects that impede daily functioning and quality of life, with prosthetics and other assistive devices frequently needed to regain mobility and independence³.

“Limb difference” (LD) is a condition in which an individual has a limb that is anatomically different in size, shape, or structure compared to “typical” limbs. Though these differences may be congenital or acquired, LD is generally prescribed to conditions arising during childhood and early development⁴. Specific examples of LD may include the absence or underdevelopment of a limb (e.g., missing hand), extra digits (polydactyly), or significant structural differences in the bones, joints, or muscles of a limb requiring medical intervention. As with LL, people with LD may have functional or mobility impairments ranging from those that have little to no impact on their daily lives, to those that require major modifications to their home or work, multiple custom assistive devices, or caregiver assistance.

A 2008 study predicted that by 2050, approximately 3.6 million people will be living with LL in the United States⁵. Past research into LD prevalence is relatively scarce, with most published research focused on LD revolving around prosthetic and surgical treatment options⁶.

Due to the physical limitations associated with each condition, individuals need accessible homes, workplaces, and communities, as well as rehabilitation, equipment, and medical care. Updated estimates are needed to gain a foundational understanding of who is living with LL or LD so that further research can focus on identifying their most pressing needs and the best ways to meet those needs. To fill this evidence gap, we analyzed claims data to estimate the overall incidence and prevalence of LL and LD, their underlying causes, and variation among demographic and clinical subpopulations.

Methods

We conducted a retrospective analysis of 2016–2021 claims data using the Inovalon MORE² Registry[®] of adjudicated claims from Inovalon health plan clients, which constitute 69% of managed Medicaid, 42% of commercial, and 25% of Medicare Advantage covered lives; Medicare Qualified Entity Standard Analytic Files, which provide claims data for 100% of all Medicare fee-for-service (FFS) enrolled beneficiaries; and the National Center for Health Statistics Vital Statistics for demographic information including age, gender, and race/ethnicity. We programmed the analysis using relevant procedure and diagnosis codes identified in

collaboration with the Amputee Coalition and clinical experts. We calculated the incidence using these codes and then used an adapted methodology derived from previous research on LL incidence data and mortality estimates to estimate prevalence⁵. We calculated and applied post-stratification weights (using enrollment year, state, payer, age, and sex) to the raw incidence counts of LL and LD patients from these sources in order for these estimates to be representative of the civilian non-institutional population in the United States.

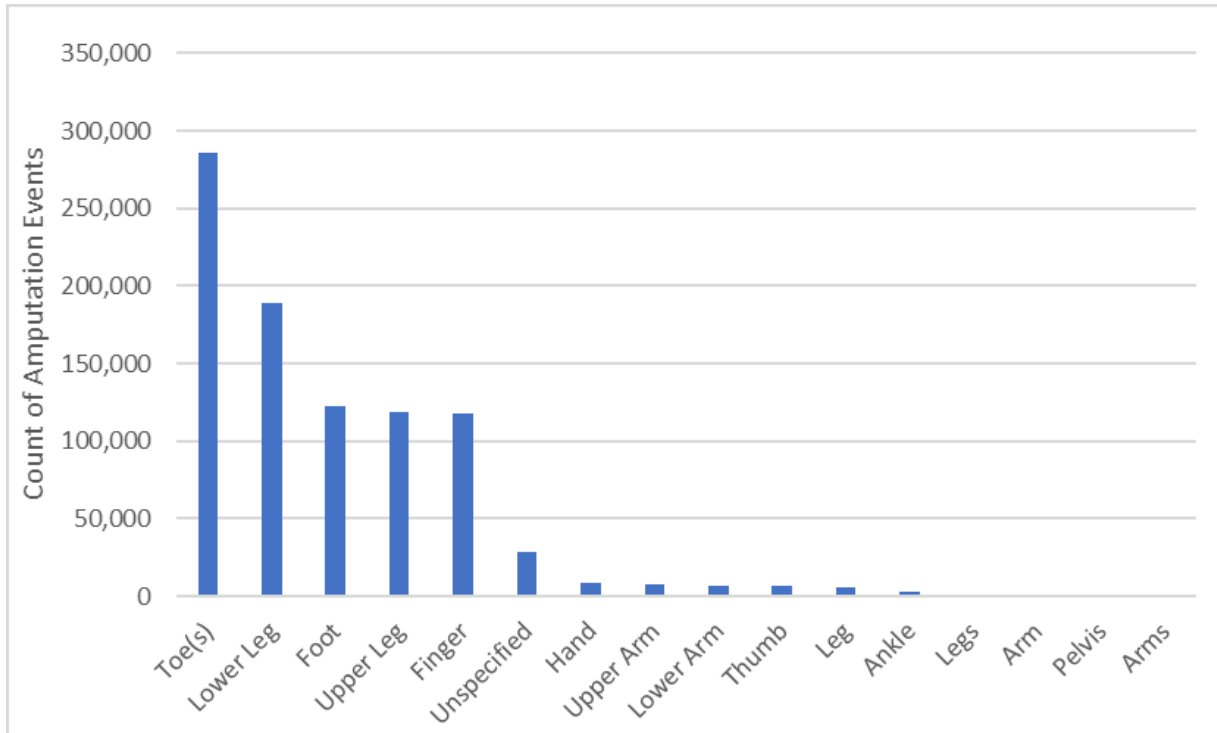
Data from 2016 through 2021 for any claim that included a relevant LL procedure or diagnosis code were used to calculate the incidence, which was converted to an average annual incidence by dividing the results by 6 (the number of years reflected in our data set). A slightly different approach was used to calculate the annual incidence of LD because the LD ICD-10 codes used for this study are specific to congenital LD. To allow for relevant LD codes to show up in claims data up to individuals' 3rd birthdays, data from 2016 through 2021 for individuals born between 2016 and 2019 were used to calculate LD incidence, with incident LD events counted as of the individual's date of birth. LD incidence was assumed to have occurred at birth regardless of when the first observed LD claim occurred.

Prevalence was then projected starting with 2005 using estimates of LL prevalence from Ziegler-Graham, et al. (2008) and incidence rates calculated as described above. These initial estimates were then updated through 2021 using incidence estimates combined with mortality rates for the respective cohorts, derived from a combination of the claims data, data from the National Center for Health Statistics (NCHS) Vital Statistics, the Census Bureau American Community Survey (ACS) Summary Tables, and previously published evidence on the mortality rates of individuals with birth defects^{7,8}.

Results

We found that, on average, each year 507,293 individuals experienced LL or were born with LD. For LL, lower body amputations (83%) were much more frequent than upper body amputations (17%), as shown in figure 1. Toe amputations were the most common procedure; likely associated with diabetes, as more than half of amputees had a history of that disease (57.6%) prior to the amputation. LL events most frequently occurred in older adults, with those 65 years or older at the time of amputation making up the largest share (44.7%), followed by those between the ages 45–64 (41.7%).

Figure 1: Annualized Incidence of Limb Loss by Body Part, 2016–2021



Note that these are counts of amputation, individuals may experience multiple amputations so counts will be higher than incidence of individuals with limb loss.

Besides diabetes, the other most common diagnoses noted prior to the amputation occurrence were infection (42.8% of individuals), vascular conditions (39.3%), ulcer (37.7%) and osteomyelitis (26.5%). Though amputation is often thought of as a trauma-related event, only 12.9% of amputations had a precipitating trauma event.

On average, 42,650 individuals were born with LD annually between 2016–2019. We limited our analysis to congenital LD but wanted to account for LD that may not be immediately diagnosed at birth, so we allowed for a diagnostic window through the 3rd birthday. The most common diagnoses, accounting for 16% of LD occurrences, were the non-specific “other congenital malformation of lower limb(s), including pelvic girdle” and “other congenital malformation of upper limb(s), including shoulder girdle” codes.

To estimate prevalence, we applied separate mortality rates for the LL population, the LD population, and the general population not experiencing either of these events (see **table 1**) using mortality rates from published sources as previously described. The mortality rate for the LL population was approximately 18.5%, much higher than the general population rate of 0.8%. The LD mortality rate was approximately 0.9%.

These mortality rates explain the dramatic switch in the proportions of LD to LL in the total population when moving from incidence to prevalence. While the annual incidence of LL

(464,644) is approximately 10 times higher than that of LD (42,650), the estimated number of individuals living with LD (3.4 million) is nearly 50% higher than the estimated number living with LL (2.3 million).

Table 1. Prevalence of People With and Without Limb Loss and Limb Difference, by Race/Ethnicity and Gender (at any point in 2016-2021)

Population	Total		Men		Women		
	Prevalence N	Prevalence N	White	People of Color	Prevalence N	White	People of Color
Total Overall	319,540,404	158,156,213	124,661,355	33,494,858	161,384,191	126,516,555	34,867,636
With Limb Loss or Limb Difference	5,687,420	3,342,746	2,803,531	539,215	2,344,674	1,936,628	408,046
With Limb Loss	2,278,822	1,575,099	1,390,265	184,834	703,723	628,646	75,077
With Limb Difference	3,408,597	1,767,647	1,413,266	354,381	1,640,951	1,307,982	332,969
Without Limb Loss or Limb Difference	313,852,984	154,813,467	121,857,825	32,955,642	159,039,517	124,579,927	34,459,591

Our analysis and methods include several limitations. Only 64.2% of claims data for individuals with LL or LD included self-reported race information, limiting the accuracy of our analysis of racial data. Additionally, for data sources other than Medicare FFS claims, reporting limitations impede identification of race/ethnicity for some beneficiaries. Data did not reflect VA/TRICARE insurance and individuals without insurance. Misdiagnosis and coding discrepancies may also have affected the accuracy of results pertaining to LL and/or LD in the claims. Further, only LD codes associated with congenital conditions were used in this analysis. It is possible to experience limb difference after birth, so total occurrence may be underestimated. Finally, the geographic distribution of patients represented by MORE² data is dependent on the Inovalon customer base during the specified study period and may be inconsistent.

Discussion

Our study shows that more than 5.6 million individuals are living with LL or LD in the United States. LL and LD are significant chronic health conditions that can negatively affect physical, psychological, financial, and social well-being. Homes, workplaces, educational settings, and communities are often not designed for individuals with physical limitations. Therefore, understanding the prevalence of LL and LD and demographic characteristics of people with these conditions is crucial for effective healthcare, housing, social welfare, and economic policy and programs. Our combined LL and LD prevalence estimate of 5.6 million was greater than

previously published estimates⁵. This notably includes the 3.4 million individuals living with congenital LD, for which there have not been recent prevalence estimates prior to this study. Given that these conditions occur at birth and have low mortality rates, the average individual is living with LD for many decades. The high prevalence of LL is likely associated with both the aging US population and the increasing prevalence of chronic conditions such as diabetes, hypertension, and resultant vascular disease⁹.

While improvements in medical care and technology may have increased survival rates of individuals with traumatic injuries that result in LL, overall mortality for LL is extremely high (18.5%). Given the high rates of diabetes and vascular conditions driving the incidence of LL, this is in line with clinical expectations, as amputations usually occur in the advanced stages of disease. There were also noted disparities in mortality rates by race and ethnicity, with people of color experiencing higher mortality rates than white individuals (20.2% vs. 18.5% for men and 25% vs. 18.3% for women, respectively). Successfully managing the chronic conditions associated with LL – including a specific focus on disparities in outcomes – would not only lower the mortality rate for this population but would shrink the population itself by reducing the overall incidence of amputations. The high incidence of LL further builds the case for funding comprehensive preventative and primary care with effective care coordination for individuals with chronic conditions.

Federal and state policies should consider how to maximize access to the necessary healthcare and support services—especially for vulnerable populations—that optimize clinical and functional outcomes. Enhanced training and support for physicians to manage conditions leading to LL as well as programs built with multidisciplinary care teams to address individuals' holistic support needs will be essential.

Funding for advancements in prosthetic technologies and regenerative medicine should also be prioritized as a strategy for reducing the burden of living with LL or LD. Such progress requires increased collaboration between researchers, healthcare professionals, policymakers, and life sciences companies spanning from funding and implementing research (including real-world and patient-reported data) to quality improvement once new interventions are implemented. It also requires more accurate and precise data on the epidemiology, patient journey, and long-term outcomes of LL and LD.

Past estimates of LL and LD in the US have likely not reflected the full burden imposed by these conditions and the disparities experienced by various subpopulations. Addressing the needs of individuals with LL and LD requires comprehensive healthcare coverage, access to affordable assistive devices, rehabilitation services, and support systems. Developing effective strategies for prevention, early intervention, and comprehensive care can help reduce excess healthcare costs associated with complications of these conditions while improving health outcomes and quality of life for those affected by LL and LD.

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