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Community Preventive Health Institute

552 Southern Boulevard ♥ Bronx, New York 10455 ♥ Phone: 718/585.8585 Fax: 718/585.5041 ♥ www.healthpeople.org

Chris Norwood, Executive Director

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New York State Diabetes-Related Amputation: A Horror Story

- **Estimated 50,000 New York Residents Lose Limbs/Feet to Diabetes-Related Amputations Since 2009**
- **New York's 84% Pre-Covid-19 Increase in Amputations from 2009-2017 is almost double the National Increase**
- **Pandemic Accelerates Limb Loss as Regular Care Collapses**

By Chris Norwood and Jesse Weiss, MSN, RN

New York State had an estimated 50,000 diabetes-related lower limb amputations from 2009 to 2021. These amputations can range from toe removals to amputation above the knee. Either way, they are a disaster. The 5-year death rate after "minor" amputations is 29% and it is 57% after major amputations.[1]

These amputations are also highly preventable. Early clinical intervention to address the ulcers, neuropathy and other foot pathology that is common in diabetes because of poor circulation, can slash amputation rates. Providing patients with effective self-management education also demonstrably reduces amputations rates. Diabetes-related lower limb amputations, in fact, are so preventable that they are one of only 14 categories of "potentially preventable hospitalizations" that the federal government annually monitors as a major gauge of a state's attention to preventive health.[2]

New York State has completely failed that test. Between 2009, the first year the state reported on preventable hospitalizations, until 2017, the most recent year New York State released this information, its reported rates of increase diabetes amputations meant that the number of amputations soared by 84.1%.[3] This included a staggering 92.4% increase for New York City, with three boroughs---the Bronx, Queens and Manhattan, where the number of amputations increased by 95% or more. This is compared to a 47% increase nationwide during the same time period. [4]

Unfortunately, New York State is now four years behind in actually reporting its hospitalization rate for Diabetes-related amputations. **But this has been a critical period and we need to analyze it as well as possible.** We know that, for multiple reasons, the Covid-19 pandemic vastly accelerated amputations in some localities; diabetes patients often did not receive regular care, for example, and early preventive treatment for foot and leg problems plunged.[5] Because some of this data is inconsistent across the country, it is important for every locality to have updated data. New York State does not.

Since the state has not provided mandated data after 2017, we have had to instead use New York's own trends and targeted national studies to try and estimate the state's diabetes-related amputations from 2018 through 2021. Based on New York's own trends of constantly accelerating amputations—at almost twice the rate of the national increase—we have estimated that New York State had a minimum 20% annual increase in diabetes-related amputations between 2018 and 2021—all told propelling a projected 80% increase in state amputations for the missing data years of 2018 through

2021. In numbers, this means a projected 25,996 more diabetes-related amputations occurred in New York State in those years which added to the state's 23,370 documented 2009 to 2017 amputations would mean a projected total of 49,367 New Yorkers were subjected to lower limb amputation during the years 2009 to 2021. As explained below, shocking as this is, it is almost certainly a conservative projection.

Data Sources and Projections:

We have projected New York's diabetes-related amputations from 2009 to 2017 using the county and state rates released by the state itself. The state releases this data as **rates of hospitalizations** for diabetes-related amputation per 100,000 population i.e. per 100,000 adults age 18 and over. This does not, however, give us the actual **number** of amputations that occurred. In order to calculate the numbers, we transposed the population rates into amputation numbers.

Chart A: The Rate of Diabetes-Related Lower Limb Amputations per 100,000 Adults in New York City by County and Statewide as Shown on the New York State website Health.Data.NY.Gov Hospital Inpatient Prevention Quality Indicators (PQI)[4]

	2009	2010	2011	2012	2013	2014	2015	2016	2017
Bronx	24.1	28.9	29.5	31.2	36.0	36.7	31.9	38.3	43.2
Kings	18.9	18.9	18.2	17.3	18.7	19.4	19.8	27.3	29.6
New York	12.3	11.2	14.6	13.2	15.1	16.2	15.7	19.9	24.2
Richmond	13.6	10.3	10.6	11.0	11.8	8.8	14.9	21.3	22.8
Queens	12.3	10.5	11.4	12.8	10.5	13.8	13.6	19.0	25.7
Statewide	14.5	14.1	14.5	14.5	15.3	15.8	15.7	21.4	25.7

Chart B New York Number of Lower Limb Amputations by County, New York City overall, and New York State overall

	2009	2010	2011	2012	2013	2014	2015	2016	2017	**% Increase 2009-2017**
Bronx	243	294	305	328	384	396	349	422	478	**96.7%**

Kings	364	369	355	342	374	392	403	559	607	**66.8%**
New York	166	151	201	184	211	228	223	283	345	**113.9%**
Richmond	49	37	39	40	43	33	55	79	86	**75.5%**
Queens	218	188	205	233	193	256	255	358	485	**122.5%**
NYC Overall	1040	1039	1105	1127	1205	1305	1285	1701	2001	**92.4%**
Statewide	2192	2127	2202	2221	2359	2453	2448	3332	4036	**84.1%**

We calculated amputation numbers by using an adult population base to transpose rates into amputation numbers. For the NYC population base we used NYC DOHMH population estimates, modified from US Census Bureau interpolated intercensal population estimates, 2000-2017, updated September 2018. For the state population base, we used American Community Survey data derived from the Public Use Microdata Files (PUMS)

Both amputations per population and actual numbers are important to know. The population rates show us that increases in amputations are not a simple reflection of increases in the numbers of New Yorkers with diabetes. New York State now has more than 2 million residents with diabetes compared with 1.5 million in 2011, **but for the population with diabetes, whatever its number, the fact that amputation rates almost doubled in both New York City and State between 2009 and 2017 underscores that the risk of being subjected to amputation has soared since 2009.**

The actual numbers themselves meanwhile tell us in clear, stark terms how many people with diabetes have been grievously harmed by this relentless—and unaddressed—amputation increase.

Projections for 2018-2021—the 4 Years of Missing State Data

To project amputations during the recent 4 years that New York State has failed to publicly post this important data, we first projected increases in amputation numbers for the years 2018 and 2019 by using the clear trends shown in available New York data. Specifically, in the two years from 2015 to 2016 and 2016 to 2017, based on state data Chart B shows that the number of amputations increased by 36% and 21%, respectively. The trend was clear: amputations were rapidly increasing, so to be conservative we estimated increases of 20% a year for 2018 and 2019. We consider that quite conservative given the larger increases of the previous years.

Meanwhile, in the prime Covid-19 pandemic years of 2020 and 2021 diabetes was a “condition” closely linked with poor outcomes and death. In some localities, the Covid-19 epidemic is known to have absolutely fueled diabetes-related lower-limb amputations. A major California hospital system, for example, has reported that in 2020, the first Covid-19 year, diabetes-related amputations jumped by 49%. Additionally, a major Ohio Hospital has reported that the risks of major amputation soared 12.5-fold, and of any amputation 10.8-fold.[6] Conversely, some studies have shown no increase in diabetes-related amputations during Covid-19.

Exactly what these inconsistent reports may mean for New York is not known. We have not been able to find any report from a New York health system reviewing its diabetes-related amputations during the Covid-19 pandemic---much less any available government data. We propose that two

contradictory trends in New York would have impacted its diabetes-related amputation numbers in 2020 and 2021. On the one hand, routine care virtually collapsed in many clinical centers as the city and state were overwhelmed by Covid-19 cases. Lack of routine care is well documented to accelerate diabetes-related amputation; on the other hand, in 2020, during the first Covid-19 surge, the city and state sustained astounding numbers of diabetes deaths. New York State had the highest diabetes death rate of any state and New York City had a 356% increase in diabetes deaths, the largest increase of any major city or state in the nation.[7] Almost certainly some portion of these deaths represented sicker people with diabetes already experiencing foot and limb issues who would have had an amputation if they hadn't died.

Given these trends---on the one hand, the Covid-19 epidemic greatly accelerating amputations and on the other hand causing earlier death perhaps before amputation---we are making, again, a conservative projection. For the years 2020 and 2021, we think it highly reasonable to assume that New York's amputations, at a minimum grew by 20% a year. Adding that to the estimated 20% increase for 2018 and 2019, and the confirmed 84% increased between 2009 and 2017, New York State would have had a projected 164% overall increase in diabetes related amputations between 2009 and 2021.

In numbers, projections for the "4 missing years" would now be 25,996 amputations, which added to the 23,370 amputations from 2009 to 2017, would bring the projected total number of New Yorkers who had suffered diabetes-related amputations from 2009 to 2021 to a total of 49,367 people---people who had lost all or part of a limb and now faced 5-year death rates of close to 30% or more depending on the extent of limb they lost.

Commentary

Diabetes-related lower limb amputations constitute a major sign of poor or failed care and after any level of amputation patients face enormous 5-year death rates. Their lives meanwhile are marked by pain, disability, depression and, often, horrific despair.

It is hard to find appropriate words to comment on the horrific trajectory of diabetes-related amputation in New York State. Even with its $13.2 billion in Covid-19 recovery funds, the state has not moved to address even the most basic improvements in diabetes care. **Yet we know it's perfectly possible to slash these amputations by both improved clinical care and real self-care education, especially when community groups provide education at local sites people can easily access**.

Led by a determined doctor, one county in Mississippi, for example—with very poor resources and funding compared with New York's very ample resources—slashed its amputations by 75% in a few years by heavily focusing on early clinical care for lower limb problems.[8] A University Hospital in Switzerland credits targeted patient education as a key to engaging patients and enabling it to reduce below knee amputations by half and above knee amputations 12-fold.[9] Even something as simple as assuring that people with diabetes on Medicare to go to one wellness visit a year prompts a 36% reduction in amputations.[10]

BUT New York State does none of this. The New York State Department of Health has for years absolutely refused to fund community groups to provide evidence-based, effective diabetes self-care education right in the neighborhoods overwhelmed by diabetes, where the people most at risk for amputations and other diabetes complications could most benefit.

This contempt—there is no other word—for the basic health of people with diabetes exists even though it is perfectly clear that logical, proven steps to reduce amputations can also slash New York's staggering Medicaid costs. The state's average $15,336 "excess cost" for Medicaid patients with diabetes—that is the annual cost beyond Medicaid patients who don't have diabetes—is double the national average. It is also a main driver of the state's huge Medicaid deficits. One above the knee amputation can now easily consume $200,000 or more in just the first year (surgeon, pain management, mental health counseling, prosthetics, physical therapy, etc.)

That cost is not only to the state budget; the multiplied cost of unnecessary amputations is so huge that it warps healthcare in New York, consuming billions that could be spent on truly improving health and wellness.

The Swiss academic hospital which slashed its amputations looked closely at the true cost. It calculated that "the direct cost of nine below-knee amputations equaled the annual salary of a clinical team of three doctors, five nurses, one dietitian, three auxiliary staff, and one secretary. For the same cost, it would be possible to hospitalize 440 patients a year, provide 1,500 foot consultations, give 820 hours of formal group lectures to patients, 45 roundtable discussions with patients and their families, and 1100 hours of individual instruction, and allow postgraduate training for 75 health-care providers (nurses and dietitians)."[11]

In sum, merely by decreasing unnecessary amputations, New York health systems would have the funds to actually present a new vision of health, where patients were attended to—not rushed through stressed, overcrowded clinics—and helped to develop knowledge and skills to maintain themselves in very good health.

In December 2021, New York State declared racism a public health crisis and Governor Hochul vowed to address health racism, "expanding equity and improving access for all."[12]

Evidently, however, this promise of change does not apply to diabetes-related amputations. Although the rate of amputation for Black people with diabetes is almost double the rate for white people, the state still has done nothing, making New York State, itself, a perpetrator of racism that results in outrightly maiming and crippling thousands of its citizens.

THIS MUST STOP!

About the Authors

Chris Norwood is the Executive Director of Health People, a community-based organization providing peer health education in the South Bronx for over 30 years.

Jesse Weiss is a PhD Candidate at the University of Iowa College of Nursing.

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