Great Lakes Regional Stroke Network

The Burden of Stroke in the Great Lakes Region 2008

We are *the* regional resource for stroke information and interventions.

Great Lakes Regional Stroke Network

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This document is dedicated to the more than one million[1] stroke survivors who are living in the Great Lakes region in 2007. Throughout this document, many of them were willing to share their life altering stroke survivor stories. So many, in fact, that not all of them could be included. To learn more about the courageous survivors from the Great Lakes Region, please see the new document, *Survivor Stories from the Great Lakes Region.* Photos of stroke survivors provided by the American Heart Association, National Stroke Association or the survivor.

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Executive Summary

- In 2005, stroke accounted for more than 26,000 deaths in the Great Lakes states (Table 10), which represented 5.96 percent of the mortality from all causes in the region.

- According to estimates from the Behavioral Risk Factor Surveillance System, more than one million persons were living with the aftermath of stroke in the Great Lakes region in 2007 (Table 9).

- In 2007, the estimated prevalence of stroke in the Great Lakes states ranged from 1.8 percent in Minnesota to 3.1 percent in Ohio (Table 9).

- In 2005, the overall age-adjusted stroke mortality rate per 100,000 in the Great Lakes region was 48.1, which exceeded the United States rate of 46.6 (Table 10).

- Black men have the highest age-adjusted stroke mortality rates in the Great Lakes region and in the United States (Table 12).

- Stroke prevalence and mortality increases with age (Figure 7 and Table 11).

- Severe sudden headache is the least recognized symptom of stroke, while sudden numbness/ weakness is the most recognized stroke symptom (Table 2).

- Stroke hospitalization charges amounted to approximately more than $3.3 billion in the Great Lakes region (Table 6).

- More than 157,000 Great Lakes residents were discharged from hospitals in the Great Lakes region. Approximately half of those were discharged home (Table 6).

- While caregivers are an important component of the stroke survivor's rehabilitation and recovery, little data about them exists (Page 26).

- Stroke mortality for men and women has been gradually decreasing since 2000 (Figure 8 and 9).

- High blood pressure increases the risk for stroke. The percentage of adults with high blood pressure is higher in four Great Lakes states (Michigan, Ohio, Illinois and Indiana) than the U.S. median (Page 9 and Figure 3).

- Ohio, Illinois, Michigan and Indiana have higher percentages of adults with diabetes than the U.S. median of 8.0 percent (Figure 3).

- As of March 2008, there were 100 Primary Stroke Centers in the Great Lakes region (Table 5).

What is Stroke?

A stroke occurs when the blood supply to part of the brain is suddenly interrupted or when a blood vessel in the brain bursts, spilling blood into the spaces surrounding brain cells. Brain cells die when they no longer receive oxygen and nutrients from the blood or there is sudden bleeding into or around the brain.

The symptoms of stroke include:

- Sudden numbness or weakness, especially on one side of the body;
- Sudden confusion or trouble speaking or understanding;
- Sudden trouble seeing in one or both eyes;
- Sudden trouble walking, dizziness, or loss of balance or coordination; and
- Sudden severe headache with no known cause.

A person may experience one or several of these warning signs. It is important to call 911 immediately if someone experiences these warning signs.

As shown in Figure 1 and 2, there are two forms of stroke:

- **Ischemic Stroke** - caused when there is a blockage in the blood vessels supplying the brain. This is the most common type of stroke. Figure 1.

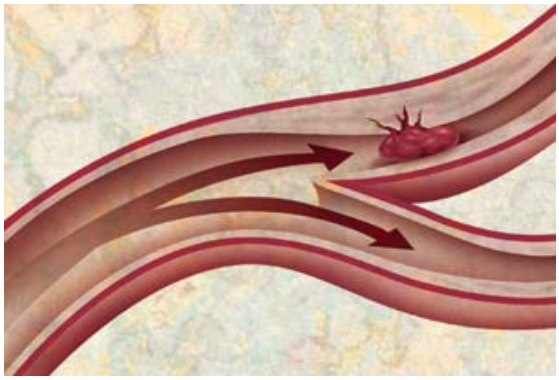


Figure 1

- **Hemorrhagic Stroke** - bleeding into or around the brain caused by a burst or leaking blood vessels. About 10 percent of strokes are hemorrhagic. Figure 2.[2,3]

Figure 2

In either case, when brain cells are deprived of oxygen, they begin to die and death or permanent disability can result.

Transient ischemic attacks or TIAs are temporary interruptions to the blood supply to an area of the brain. During a TIA, a person experiences a sudden onset of stroke symptoms. A TIA can last up to 24 hours, but most last only a few minutes and cause no permanent damage or disability. Sometimes called "mini-strokes," TIAs must be taken seriously because they are usually a precursor to full strokes.[3]

Demographic Characteristics and Trends in the Great Lakes Region

Stroke is the third leading cause of death in the United States after heart disease and cancer; and a leading cause of long-term disability.[4] Anyone can have a stroke, but adults ages 65 and older are more likely to have a stroke. More women than men die of stroke.[5] Blacks have higher stroke incidence and mortality than whites.[5] Table 1 highlights selected demographic characteristics for each Great Lakes state and the United States.

Though the Network states vary in population size, each state has a significant portion of older, minority, and lower-income residents who are at greater risk of having a stroke. The number of persons age 65 and older in the Great Lakes states will increase from almost 6.5 million in 2005[6] to 7.7 million in 2025.[7] In fact, it is projected that the population 65 and older will drastically increase in the Great Lakes region from 2000 to 2030. For example, in Minnesota, the percent change from 2000 to 2030 in those aged 65 and older will be 100.8.[8] As the population continues to age, the burden of stroke is expected to increase. This will have a significant impact on the Great Lakes region as more persons will require health care services.

The number of minorities in the Great Lakes states are expected to increase by 90,000 for American Indians, 972,000 for Asians, 1.5 million for blacks, and 1.9 million for Hispanics/Latinos from 1995 to 2025.[7] As the prevalence and mortality of stroke are notably higher among blacks in the Great Lakes region, this translates to additional lives impacted by stroke and additional resources needed.

While there are fewer people living in poverty (12.7 percent in 2004) than in the 1950s (22.4 percent), there is considerable variation between racial/ethnic groups. Poverty rates for blacks and Hispanics exceed the national average. In 2004, 24.7 percent of blacks and 21.9 percent of Hispanics were poor, compared to 8.6 percent of non-Hispanic whites and 9.8 percent of Asians.[9] If recent trends continue, disparities may widen, increasing the need for stroke surveillance, prevention, and quality improvement initiatives.[10]

According to a recent report by The Trust for America's Health (TFAH), Midwestern states receive less funding from the U.S. Center for Disease Control and Prevention than other states. As the lead federal agency devoted to disease prevention and control, the CDC distributes funds to state and local health agencies through grants and cooperative agreements for a wide range of public health programs. States in the Great Lakes Regional Stroke Network rank at the very bottom order of states receiving funding, with Michigan ranking #38 ($18.40/person) and Indiana ranking #49 ($13.69/person) out of the 50 states. Thus, the Great Lakes states are not benefiting from CDC funding for stroke prevention efforts in a manner similar to most of the other states. This situation is exacerbated by the fact that the public health budget for each of the states in the Great Lakes region falls below the national median public health budget of $33.26/person.[11]

Table 1: Most Recently Available Selected Demographic Characteristics

	Illinois	Indiana	Michigan	Minnesota	Ohio	Wisconsin	United States
Population*	12,852,548	6,345,289	10,071,822	5,197,621	11,466,917	5,601,640	301,621,157
Ages 65+*	12.0%	12.4%	12.5%	12.1%	13.3%	13.0%	12.4%
White**	79.3%	88.3%	81.2%	89.3%	84.9%	90%	80.1%
Black**	15%	8.9%	14.3%	4.5%	12.0%	6.0%	12.8%
American Indian & Alaska Native**	0.3%	0.3%	0.6%	1.2%	0.2%	0.9%	1.0%
Asian**	4.2%	1.3%	2.4%	3.5%	1.5%	2.0%	4.4%
Native Hawaiian & other Pacific Islander**	0.1%	Less than 0.1%	Less than 0.1%	0.1%	Less than 0.1%	Less than 0.1%	0.2%
Hispanic or Latino (of any race)**	14.7%	4.8%	3.9%	3.8%	2.3%	4.7%	14.8%
Median household income***	$50,270	$44,051	$46,072	$52,048	$43,547	$47,141	$46,242
People in Poverty***	12%	12.2%	13.1%	9.2%	13%	10%	13.3%
People without health insurance¶	13.6%	13.1%	10.6%	8.5%	10.7%	9.4%	15.3%
People 25+ yrs of age not high school graduates¶¶	15%	14.8%	12.8%	9.3%	13.8%	11.7%	15.9%

*Source: 2007 Annual Estimates of the Population for the United States Regions, States and Puerto Rico: April 1, 2000 to July 1, 2007(NST-EST 2007-01) Population Division, U.S. Census Bureau. Retrieved 3/31/08 from www.census.gov/popest/geographic/.

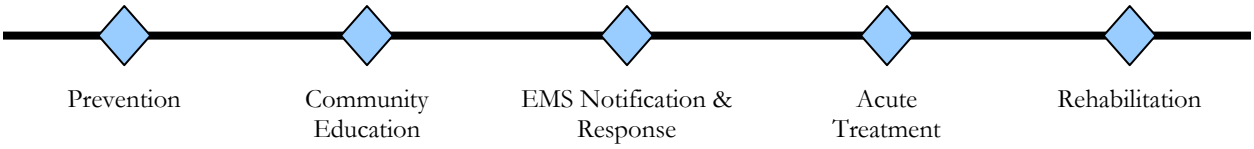
**Source: 2006 Estimates of the Population by Race and Hispanic or Latino Origin for the United States: July 1, 2006 (SC-EST2006-04). Population Division, U.S. Census Bureau. Accessed 3/10/08 from www.census.gov/popest/states/asrh/SC-EST2006-04.html.

*** Source: 2005 U.S. Census Bureau, Data Integration Division, Small Area Estimates Branch. http://www.census.gov/hhes/www/saipe/county.html.

¶ Number and Percentage of People Without Health Insurance Coverage by State Using Three-Year Average: 2004-2006. U.S. Census Bureau. Income, Poverty and Health Insurance Coverage in the U.S., 2006.

¶¶Source: U.S. Census Bureau, 2006 American Community Survey: S1501. Educational Attainment. Accessed last June 4, 2008 at: http://factfinder.census.gov/servlet/STGeoSearchByListServlet?_lang=en&_ts=230642619523.

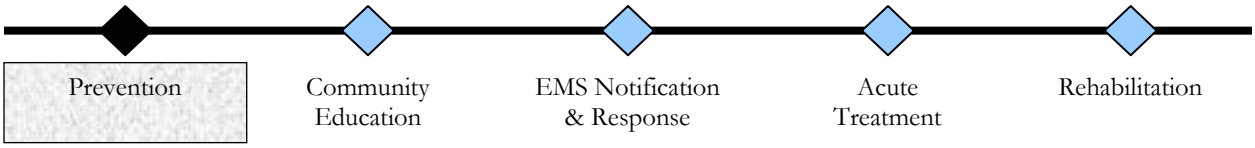
Stroke Systems of Care



The Stroke Systems of Care refers to the range and coordination of factors involved in preventing stroke as well as delivering treatment and care for stroke patients. The Systems of Care described here is adapted from the American Stroke Association's Task Force on the Development of Stroke Systems.[12] From primordial/primary prevention, community education, EMS notification and response, to acute treatment and rehabilitation, the Stroke System of Care describes the full breadth of stroke care, and encourages promotion and coordination with the full range of activities and services associated with stroke care. Rather than simply describing successive steps in stroke care, the system of care is a fluid model, showing that aspects of stroke care are equally important and not exclusive. For example, a person can receive stroke rehabilitation as well as simultaneously manage risk factors, such as high blood pressure, as part of primary prevention for stroke. In fact, because stroke patients are at greater risk for another stroke, a stroke survivor may experience points in the system more than once.

The Burden of Stroke in the Great Lakes Region 2008 presents data for each step in the stroke system of care as well as first-hand accounts of stroke survivors experience.

Stroke System of Care



Prevention refers to strategies aimed at reducing modifiable risk factors for stroke. These strategies can be divided into two categories, primary prevention and primordial prevention. Primary prevention refers to the treatment of established disease risk factors for stroke such as the management of hypertension, lipid levels, diabetes and other modifiable risk factors. Primary prevention strategies are aimed at individuals with these recognized risk factors for stroke and not the general population.

Primordial prevention specifically refers to strategies aimed at decreasing the development of risk factors for stroke among the entire population. Prevention efforts that target smoking cessation, obesity, increased physical activity and encourage a well-balanced diet belong in this category, as they promote healthy lifestyle changes that have a broad impact on reducing diseases such as stroke.

Stroke risk factors that cannot be modified or changed include: age, sex, race/ethnicity, family history and prior stroke. Geographic location, socioeconomic factors, excessive alcohol intake, and certain kinds of drug abuse are other, less well-documented stroke risk factors.[13] Data related to the following primary and primordial prevention presented here were obtained through the Behavioral Risk Factor Surveillance System (BRFSS), which is self-reported data.

Primary Prevention

High Blood Pressure

- High blood pressure, or hypertension, is a major risk factor for stroke.[14]
- In the Great Lakes region, the percentage of adults who have been told they have high blood pressure ranges from 21.4 percent (Minnesota) to 28.6 percent (Michigan).
- Michigan (28.6), Ohio (28.4), Illinois (28.1), and Indiana (27.9) have a higher percentage of adults with high blood pressure than the U.S. median (27.8 percent).

Classification of Blood Pressure

Category	SBP mmHG		DBP mmHG
Normal	<120	and	<80
Pre-hypertension	120-139	or	80-89
Hypertension	≥140	or	≥90

Key: SBP= Systolic blood pressure DBP = Diastolic blood pressure. JNC 7 Guidelines.[15]

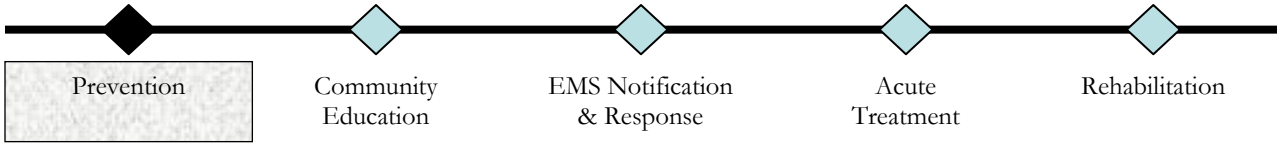
Diabetes

- The risk for stroke is two to four times higher among people with diabetes.[14]
- In the Great Lakes region, the percentage of adults with diabetes ranges from 5.7 percent (Minnesota) to 9.5 percent (Ohio).
- Ohio (9.5), Illinois (8.8), Michigan (8.8), and Indiana (8.5) have a higher percentage of adults with diabetes than the U.S. median (8.0 percent).

High Cholesterol

- High blood cholesterol is a major modifiable risk factor for stroke.[14]
- In the Great Lakes region, the percentage of adults with high cholesterol ranges from 32.4 percent (Minnesota) to 39.9 percent (Michigan)
- Michigan (39.9), Ohio (39.6), and Indiana (38.5) have a higher percentage of adults with high cholesterol than the U.S. median (37.6 percent).

Stroke System of Care



Primordial Prevention

Obesity

- Being overweight or obese increases the risk of many diseases and health conditions, including stroke.[16]
- In the Great Lakes region, the percentage of obese adults ranges from 25.3 percent (Wisconsin) to 28.2 percent (Michigan).
- Michigan (28.2), Ohio (28.1), and Indiana (27.4) have a higher percentage of obese adults than the U.S. median (26.3 percent).

Smoking

- Smoking almost doubles a person's risk for ischemic stroke, independently of other risk factors.[14]
- In the Great Lakes region, the percentage of adults who smoke ranges from 16.5 percent (Minnesota) to 24.1 percent (Indiana).
- Indiana (24.1), Ohio (23.1), Michigan (21.1) and Illinois (20.1) have a higher percentage of adults who smoke than the U.S. median (19.8 percent).

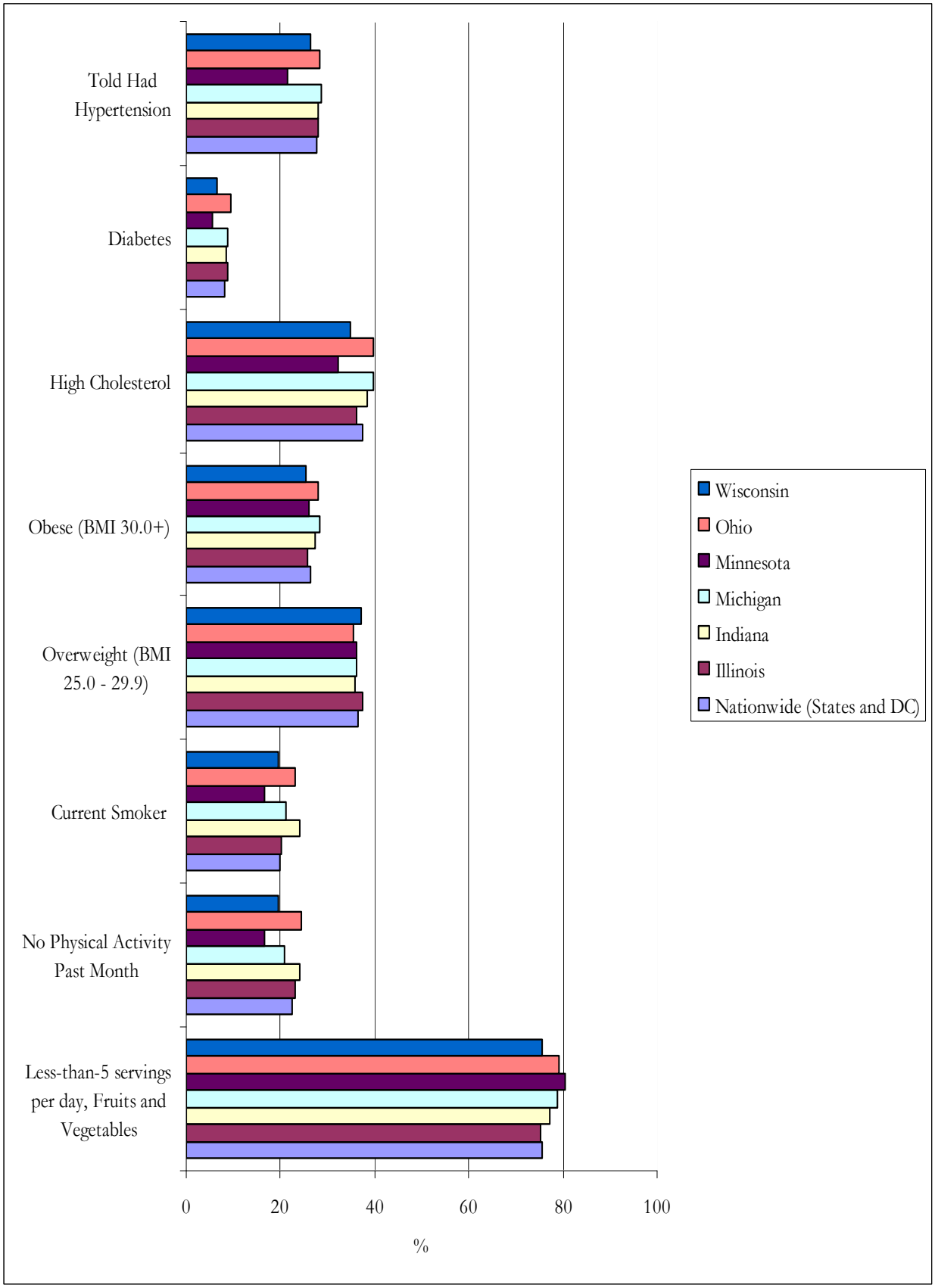
Physical Inactivity

- Regular physical activity reduces the risk for stroke.[17]
- In the Great Lakes region, the percentage of adults who report getting no physical activity in the past 30 days ranges from 16.7 percent (Minnesota) to 24.3 percent (Ohio).
- Ohio (24.3), Indiana (24.2), and Illinois (23.0) have a higher percentage of adults reporting no physical activity in the past 30 days than the U.S. median (22.6 percent).

Fewer than Five Servings/Day of Fruits and Vegetables

- Healthy diets rich in fruits and vegetables may reduce the risk of cancer and other chronic diseases.[18]
- In the Great Lakes region, the percentage of adults who eat less than the recommended five servings of fruits and vegetables per day ranges from 80.6 percent (Minnesota) to 75.4 percent (Illinois).
- Minnesota (80.6), Ohio (79.2), Michigan (78.7), and Indiana (77.2) have a higher percentage of adults who eat less than the recommended five servings than the U.S. median (75.6 percent).

Figure 3: Stroke Risk Factors



Source: BRFSS, 2007

Survivor Story: Stroke Risk Factors

By Mitch Reagan

Gwen and Mitch Reagan, Minnesota

It's hard to condense all the different things I've gone through since my stroke. I am 56 years young and had been an IT professional for 34 years. My wife, Gwen, and I have been married 35 years, and have two adult children and five grandchildren. I always took my personal and work life seriously but, unfortunately, was not giving my health the same attention. I was **overweight**, my **cholesterol was 298** and there were indications of **hypertension** and **elevated blood glucose**.

In November 2004, while at home, I suffered a stroke. My wife brought me to the emergency room and I spent the next month as a patient at North Memorial Medical Center. Having **high blood pressure, being overweight and diabetic** (which I discovered when I was admitted to the hospital) were the major contributors to my stroke. Another contributor was the stress from a very demanding job.

I knew I needed a lot of help with diet and exercise planning and stopped by Plymouth Lifetime Fitness in December 2005 to discuss their programs and to see if they might be tailored to address my needs. My stroke was in the left side of the brain so it affected my right shoulder, arm, hand, leg and foot. Range of motion in my right arm and shoulder were very limited. Fine motor skills in my right hand were such that I had trouble holding on to things. I walked with a pronounced limp and would occasionally catch my right toes on the ground due to a common stroke deficit called "foot drop." I also had a history of lower back problems that resulted in sciatic nerve pain in my right leg. I started out walking on the treadmill at a pace that was comfortable and safe. I remember the difficulty of walking, swinging my arms in rhythm and listening or talking to the trainer all at the same time.

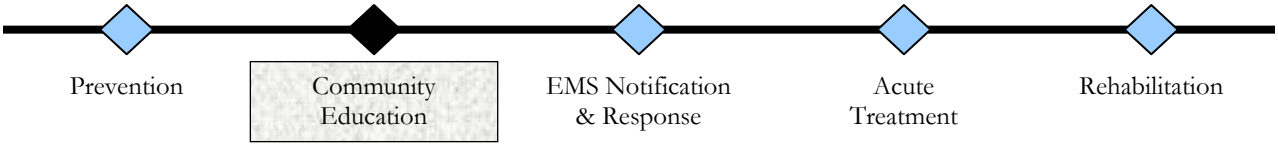
I am now running through most of my cardio exercises. When I started, I had to hold on to the treadmill rails anytime I went over 3.0 MPH. I'm not using the rails at all today and am able to run at speeds of 5.5 MPH. I've also run for 2 miles straight. This is in preparation of actually beginning to run outdoors, something I would not have expected to ever do again a couple of years ago.

I've always been a real 'data' guy. Some examples of my before and after numbers are:

	Pre–Stroke	With Rehab		Pre–Stroke	With Rehab
Weight	240	170	Glycohemoglobin A1C	9.0	5.4
Total Cholesterol	298	138	HDL/Good Cholesterol	39	70
LDL/Bad Cholesterol	163	72	Triglycerides	163	39

On May 24, 2007, my doctor took me off my diabetes medicine. This doesn't mean I don't have diabetes anymore or that I won't be required to take medicine in the future; but it does indicate that I have come up with a formula to control my diabetes today without prescription drugs. Twenty-five percent of people who have had a stroke will experience another stroke within five years. This number scared me. It also made me angry that no one could explain what the other 75 percent were doing who didn't experience a recurrence. I knew the major risks factors for stroke and knew I could do something about a lot of them. I can't change the fact that I am 56 and I can't change the fact that I have had a stroke in the past, but if I were to have another stroke in my lifetime no one will be able to say I didn't do everything I could to prevent it. I am now the Volunteer Coordinator for North Memorial's Stroke Center.

Stroke System of Care



Community education refers to improving the public's knowledge of stroke risk factors, the signs and symptoms of stroke, as well as the actions necessary for successfully handling a stroke emergency. Without an organized, coordinated public education effort, adapted to specific local needs, it is unlikely that society will realize the full potential of stroke prevention or intervention that scientific findings make possible.

Recognition of Stroke Symptoms

Stroke outcomes can be improved by timely care, so it is important for the general public as well as emergency medical services professionals to recognize the major stroke symptoms. The warning signs of a stroke include:

- Sudden numbness or weakness, especially on one side of the body;
- Sudden confusion or trouble speaking or understanding;
- Sudden trouble seeing in one or both eyes;
- Sudden trouble walking, dizziness, or loss of balance or coordination; and
- Sudden severe headache with no known cause.

A recent Morbidity and Mortality Weekly Report found that only 16.4 percent of respondents recognized all five stroke warning signs, identified an incorrect symptom and recognized the need to call 911.[19] As apparent in Table 2 below, severe sudden headache is the least recognized symptom of stroke, while sudden numbness/weakness is the most recognized stroke symptom in the Great Lakes states.

Table 2: Recognition of Stroke Symptoms

	Illinois	Indiana	Michigan	Minnesota	Ohio	Wisconsin
Severe headache	52.0%	64.7%	56.7%	60.0%	56.9%	59.4%
Severe dizziness/ imbalance/trouble walking	84.5%	89.0%	87.5%	83.7%	84.7%	88.8%
Sudden vision trouble	66.2%	73.2%	72.7%	68.3%	67.4%	71.9%
Sudden numbness/ weakness	91.2%	93.9%	95.4%	93.0%	95.1%	95.5%
Sudden confusion/ trouble speaking	86.8%	89.5%	89.8%	88.3%	91.0%	89.1%

Sources: Illinois Point-In-Time Survey (based on BRFSS methodology), 2005.
Minnesota, Wisconsin — Behavioral Risk Factor Surveillance System, 2005.
Indiana, Ohio Behavioral Risk Factor Surveillance System, 2006.
Michigan Behavioral Risk Factor Surveillance System 2007 preliminary data

Survivor Story: Recognition of Warning Signs

Lillian V. Jones-Tubbs, Ohio

It was a Saturday morning in July 1997. Lillian V. Jones-Tubbs, a nurse at MetroHealth's Clement Center, thought about what to wear to work. Standing at her closet, one arm against the door frame, she surveyed her options. Suddenly, her left side went dead. Jones-Tubbs fell against the door frame. Recovering, she realized she **couldn't move her left side**.

Jones-Tubbs stayed on the floor about 10 minutes until the incident had passed. Slowly she regained the ability to wiggle her fingers and toes. Progressively the majority of the feeling came back. Within a half hour she was moving. She got dressed and went to work – something she also did the week that followed. Some may say that as a nursing manager and staff nurse she should have known better. There had been warning signs, the most obvious a **blood pressure reading of 200/110** six months earlier. Instead, like many of us, she went into denial.

"I stayed in my office that week," she says. "I knew, but I didn't want to know. The weakness on my left side was unnoticeable so no one assumed anything was wrong." Following a normal EKG, her doctor ordered an echocardiogram. While the first part showed no signs of irregularity, the answer appeared at the end. Air had been injected into an IV tube. And, as her doctor watched the air bubble's progress through her heart, he discovered a hole. Jones-Tubbs had no prior history of heart problems.

Now 58 years old and 20 pounds lighter, she remains on a low-cholesterol diet. She works as many as seven days a week as a family practice nurse at two jobs. "I should have known there was a problem when my blood pressure went up, and [I should have] watched my diet and weight," she says. "But the hole in my heart is a big mystery."

As a professional and stroke survivor, she offers a bit of advice. "We pay attention to our kids and don't pay much attention to ourselves. We need to be more cognizant of ourselves, health-wise," she says. "If there's a family history of hypertension, get checked out frequently. Watch your weight, diet and cholesterol. If you experience stroke symptoms, seek medical attention immediately by calling 911. Time lost is brain lost. Be proactive and learn as much as you can about the warning signs and risk factors of stroke."

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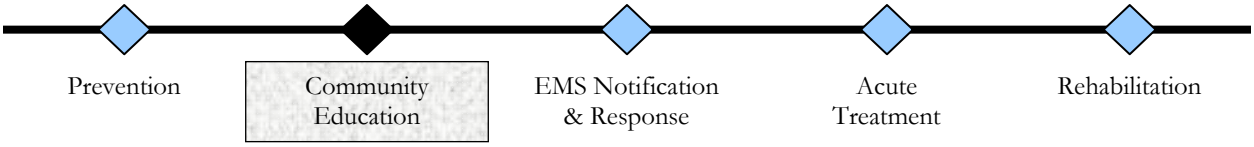
Stroke System of Care



Anticipated Response to Stroke Symptoms

It is especially important to call 911 when stroke symptoms occur. Studies show that patients calling 911 get treatment faster. Immediate emergency transport and immediate response at an acute care facility are key to the delivery of appropriate medical care that can reduce the risk of death or permanent disability. Intravenous (IV) delivery of tissue plasminogen activator (tPA) is effective for use in patients with acute ischemic stroke within three hours of symptom onset. The effectiveness is strongly linked to time since onset of symptoms, with shorter times demonstrating significantly better outcomes.[20]

Table 3 shows the number and percentage of respondents ages 18 and older in each Great Lakes state who would respond to stroke symptoms by taking the person to the hospital, calling a doctor, calling 911, calling spouse/family, or doing something else. Overall, 85.8 percent to 90.4 percent of survey participants responded they would call 911. Additional public education activities in the Great Lakes region about stroke signs and symptoms and the importance of calling 911 would increase knowledge of all stroke symptoms and the likelihood that appropriate action be taken.

Table 3: Anticipated Response to Heart Attack and Stroke Symptoms

	Illinois	Indiana	Michigan	Minnesota	Ohio	Wisconsin
Take to Hospital	7.0%	8.3%	5.7%	4.8%	4.2%	5.5%
Call Doctor	1.2%	0.6%	0.5%	0.4%	0.8%	0.6%
Call 911	85.8%	87%	86.4%	89.1%	90.4%	89.8%
Call Spouse/Family	0.2%	0.4%	1.1%	0.5%	0.4%	1.0%
Do Something Else	5.7%	3.4%	5.8%	4.6%	3.8%	2.8%
Don't Know/Not Sure	0.1%	0.2%	0.2%	0.6%	0.5%	0.3%

Sources: Illinois Point-In-Time Survey based on BRFSS methodology, 2005.
Minnesota, Wisconsin — Behavioral Risk Factor Surveillance System, 2005.
Indiana, Ohio — Behavioral Risk Factor Surveillance System, 2006.
Michigan — Behavioral Risk Factor Surveillance System, 2007 preliminary data.

Those who refused to answer the question were excluded from the denominator.

Survivor Story: Response to Stroke Symptoms

Christina Kavelman was at home on November 4, 2002, lifting weights. She had just finished running the Chicago Marathon two weeks before and enjoyed being physically active. Suddenly, her **right arm went numb**, then flaccid. She had no idea what was going on, but she went downstairs to tell her husband that she needed to go the hospital. While doing this, everything on her **right side started to get numb**. She sat on the floor but then fell over. While laying on her side, she realized she couldn't get up. Her husband **called 911** and the paramedics took her to a local hospital. By this time, she had completely **lost her ability to speak** and couldn't respond to questions. A feeling of peace came over her when she started to lose her vision and she lost consciousness.

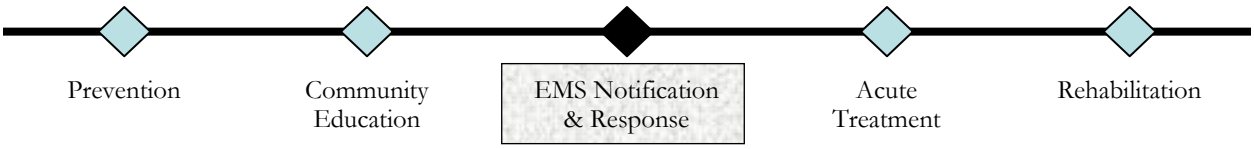
Christina and Aaron Kavelman, Illinois

This is the stroke survival story of Christina who had a hemorrhagic stroke when she was 26. Following her stroke, Christina began the hard work of rehabilitation; she could not read, write, walk or talk. She had to take two years off from her job as a structural engineer to focus on rehabilitation. After her hospital stay, Christina moved in with her parents for a short time to continue to recover and her husband took a semester off from school to help Christina get back to daily living.

Christina was told that she was lucky she was in such good shape prior to her stroke because she already had muscle to work with in rehabilitation. She had already made the decision that she was not going to allow her stroke to control her life. However, she does admit the stroke took some things away: her right hand still has no fine motor function, she takes medication to keep her seizures under control, she can no longer work as a structural engineer and she cannot compete in marathons anymore. Now she uses her left hand and is considering constraint induced therapy to regain some fine motor function in her right hand. She hasn't had a seizure in more than three years, she is using her master's degree in architecture designing buildings, and she still exercises quite a bit on her own. Most of all, she appreciates life much more.

Christina's message..."**Stroke can happen to anyone, at any age, at any time**."

Stroke System of Care



Responding quickly to stroke warning signs is essential for reducing stroke-related deaths and disability. An effective Emergency Medical Services (EMS) Notification and Response System requires a timely and coordinated response by the public, the EMS and the hospital emergency department. Each play a critical role in helping to initiate effective therapy as rapidly as possible. Table 4 presents the number of stroke deaths and the percentage of stroke decedents who died before transport to an emergency department in 1999. These data will be updated if resources become available.

Pre-hospital transport deaths occurred at a residence, in a nursing home, or in an extended-care facility before transport to a hospital or emergency room. Data are presented for the Great Lakes states and the U.S. stroke-related deaths that occurred pre-transport range from 45.4 percent (Illinois) to 62.1 percent (Minnesota), with Minnesota, Wisconsin, Ohio, Indiana and Michigan having a higher percentage than the United States at 47.6 percent.

The greatest percentage of pre-transport deaths occurred among persons aged 85 years and older (40.1%) followed by those aged 75-84 years (34.3%), those aged 65-74 years (14.4%), and those aged 65 years and younger (11.2%). The high percentage (63.9%) of stroke-related deaths that occurred pre-transport among adults aged 85 years and older might be partly due to do-not-resuscitate orders in nursing homes and long-term care facilities, especially for older persons disabled by previous strokes. However, approximately 25 percent of stroke-related deaths among persons younger than 65 occurred pre-transport, as death-on-arrival or in the emergency department, suggesting that persons in this age group might dismiss stroke and therefore delay their response to symptoms.

Few states in the region have access to emergency medical services data. The National EMS Information System (NEMSIS) is working to standardize EMS data collection elements across the United States. States in the Great Lakes region are working with their EMS partners to include stroke as a part of the data elements collected. In the future, if resources become available, we look forward to analyzing EMS data for the Great Lakes Region.

Table 4: Number and Place of Stroke-related Deaths, by State, 1999

		Place of Death				
State	**Number**	**Pre-transport***	**DOA****	**ED*****	**In-Hospital**	**Data Missing**
Illinois	7,487	45.4%	2.2%	4.0%	48.4%	0.0%
Indiana	4,128	52.3%	0.1%	3.2%	44.3%	0.0%
Michigan	5,951	50.6%	0.3%	3.7%	45.3%	0.1%
Minnesota	2,972	62.1%	0.1%	1.6%	35.5%	0.8%
Ohio	7,199	54.4%	0.5%	3.4%	40.6%	1.1%
Wisconsin	3,841	60.7%	0.1%	1.9%	37.2%	0.0%
United States	167,366	47.6%	0.5%	3.3%	48.0%	0.5%

International Classification of Disease. Tenth Revision (ICD-10) codes I60-I69.
*Percentages for place of death are based on state of occurrence.
**Dead on or before arrival at a hospital.
***Emergency Department
Source: CDC, 2002, *State-specific Mortality from Stroke and Distribution of Place of Death — United States 1999.*

Survivor Story: EMS Notification and Response

By Pat Rueth

Pat and Ken Rueth, Indiana

I had a stroke. This is my attempt to relate the experiences and share my feelings in the hope that in doing so, I might help someone, somewhere, cope through a similar event.

I am a 53-year-old-female. I am the mother of three children, and a new grandmother. I am more than a hundred pounds overweight, and have been overweight most of my adult life. I have high blood pressure, but manage it with medication. I am a retired schoolteacher, and a college graduate with a ,aster's degree. My husband of 28 years is recently retired. I feel that I am fairly active and my favorite hobby is quilting. I have always had a good sense of humor. I am independent, determined and, some would say, stubborn.

It was almost 1 a.m. I just finished reading a good mystery. I turned off the light and rolled over in anticipation of a good night's sleep. Then it hit me. It was a loud ringing in my ears and a sickening **dizziness**. I sat up, but it only got worse. I woke up my husband, Ken, and told him that I was in trouble. **He called 911**. I suspected a stroke because the **right side of my mouth was drooping**. I had **double vision** but both my hands and legs were still functioning. The paramedics arrived. I was taken to the emergency room where my stroke was confirmed, and so was my high blood sugar. It was over 500. I had gotten to the hospital in time to get tPA (medication that if given in time can lessen the effects of a stroke) but it cannot be given to those with high blood sugar. I was on my own.

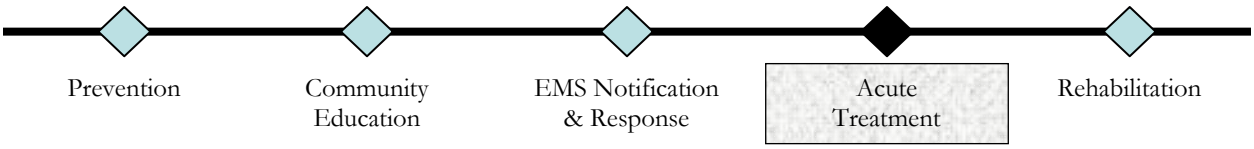
My stroke left me deaf in my right ear. The entire right side of my face is paralyzed but has feeling. My right eye does not close completely. The left side of my body is numb and paralyzed. The left side of my face works but has no feeling. My bladder won't relax and release urine. My bowels won't work without stimulants. The right side of my throat isn't functioning; I choke frequently, even when swallowing saliva. I have double vision. I am a stroke survivor and I know that many who experience a stroke never even get the chance to say that.

I am humbled by the support from my family and friends. The steady stream of visitors and cards lets me know people are supporting me and it really makes me face the work ahead of me with a positive attitude. I plan to deserve that support. Before I left for the rehab hospital, I was told, "Try to concentrate on what you CAN do." That advice served me well. I thought that the hardest part of rehabilitation would be all the work. I was wrong. The hardest part was being away from my family, specifically my husband, Ken.

Following inpatient rehabilitation, I had six months of additional rehab in a facility close to home. I lost 80 pounds. I eat a sugar-free diet. I am off all of my medications. Now I take a baby aspirin each day and laxatives as needed. Weight loss and diet have managed my blood sugar and blood pressure. With the help of my quilting friend, Wanda, I found that I could quilt. It is slow and clumsy work, but it feels good. Before the year is over, I will complete 14 new quilts. I was even asked to design a block to be included in Indiana's stroke awareness quilt.

I also was asked to participate in a new program called the Peer Visitor Program. It is a way to give back some of the help and encouragement that was given to me. Ken and I both visit new stroke patients when asked. He shares caregiving experiences. I share stroke patient experiences. We are a dynamic duo.

Stroke System of Care



Primary Stroke Centers

Timely and appropriate diagnosis and treatment of stroke is dependent on the availability of highly trained health care providers. Primary Stroke Centers are hospitals that are able to provide care that meets the specialized needs of stroke patients. Primary Stroke Centers must have acute stroke teams, stroke units, written care protocols and an integrated emergency response system as well as CT scans available 24 hours every day and rapid laboratory testing, criteria identified by the Brain Attack Coalition.

As of March 2008 there are 100 primary stroke centers in the Great Lakes states. The number of Primary Stroke Centers in each state (see Table 5) ranges from nine (in Indiana and Minnesota) to 23 (in Ohio). More hospitals are expected to become Joint Commission certified in the Great Lakes region. In addition, comprehensive stroke centers, hospitals with resources to diagnose and treat complex types of stroke or patients who require more complex care, are likely to emerge soon.

Table 5: Primary Stroke Centers, March 2008

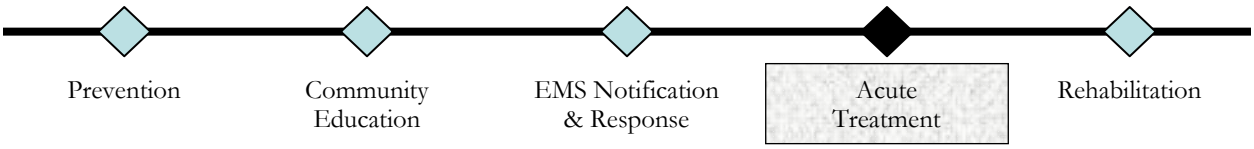
State/Region	Number of Primary Care Stroke Centers
Illinois	21
Indiana	9
Michigan	21
Minnesota	9
Ohio	23
Wisconsin	17
Great Lakes Region	**100**

Source: The Joint Commission at http://www.jointcommission.org/, March 2008

Typically, primary stroke centers are in hospitals with more resources to meet primary stroke center certification requirements. It is important to note that a hospital does not have to be a Joint Commission Certified Primary Stroke Center to adequately serve stroke patients. There are hospitals in the Great Lakes states capable of treating stroke patients according to recommended guidelines that are not Joint Commission Certified Primary Stroke Centers.

The Centers for Disease Control and Prevention recently released the Atlas of Stroke Hospitalizations Among Medicare Beneficiaries, 2008. To review this document, please visit http://www.cdc.gov/dhdsp. The Great Lakes Regional Stroke Network created an Atlas of Stroke Mortality in the Great Lakes Region to report county level mortality data with overlays of location of Joint Commission Primary Stroke Centers. This document can be accessed at our Web site: http://www.uic.edu/depts/glstrknet/glrsn/facts.html.

Stroke System of Care



Hospital Discharge Data

Administrative claims data from hospitals are a source of information about the patterns of care, the public health burden, and the cost associated with disease and injury. Table 6 presents hospital discharge data from inpatient hospital admissions for stroke. Data presented are for hospital discharges with a principal diagnosis of stroke (ICD-9 codes 430-438). The patient discharge status codes and definitions listed are used by hospitals to bill for patient services.

Table 6 presents the total number of hospital inpatients with a principal diagnosis of stroke and the number and percentage of those patients by discharge status for each Great Lakes state. More than 157,000 (n=157,043) discharges with a primary diagnosis of stroke were from hospitals in the Great Lakes region. The total charges for stroke patients also are listed for each state. The total hospital charges for those patients were more than $3.3 billion. These *hospital charges refer to the amount billed by the hospital for hospital services only. Physician's fees and emergency medical service fees are not included. The hospital does not actually collect this amount.* The true cost of care is unknown but is much greater than $3.3 billion, as most stroke patients require additional care after they leave the hospital.

In each state, more than half of all stroke inpatients were discharged to home care or self care. A significant percentage of stroke patients (13.4 to 19.6 percent) were discharged to a skilled nursing facility for continued care. In addition, a large number were discharged to a rehabilitation facility or to their home under the care of a home health service.

Table 6: Hospital Discharges* by State

		Illinois	Indiana**	Michigan	Minnesota***	Ohio	Wisconsin
Total charges for stroke discharges¶		$1,160,370,926	$327,108,157	$580,306,758	$221,700,084	$717,694,665	$324,695,123
Total number of stroke discharges¶¶		39,601	17,878	35,555	11,235	38,502	14,272
Status Code	**Patient Discharge Status**						
01	Discharged to home care or self care (routine discharge)	51.1%	51.9%	54.8%	50.9%	52.4%	54.0%
03	Discharged/transferred to a skilled nursing facility (SNF) with Medicare certification	16.4%	16.4%	13.4%	19.6%	18.9%	17.2%
04	Discharged/transferred to an intermediate care facility	1.3%	1.5%	0.6%	0.9%	2.2%	0.6%
05	Discharged/transferred to another type of institution for inpatient care	1.7%	1.3%	1.8%	0.8%	3.4%	0.5%
06	Discharged/transferred to home under care of organized home health service	8.0%	5.7%	11.8%	5.6%	8.0%	4.3%
07	Left against medical advice or discontinued care	0.7%	0.2%	0.5%	0.2%	0.4%	0.1%
20	Expired	5.4%	5.9%	4.4%	6.5%	5.4%	6.5%
50	Discharged/transferred to hospice-home	0.6%	0.4%	0.5%	0.3%	1.0%	0.6%
51	Discharged/transferred to hospice-medical facility	1.3%	1.1%	1.4%	0.9%	1.2%	1.3%
62	Discharged/transferred to another rehabilitation facility	—	11.4%	7.9%	8.2%	6.2%	7.1%
All other patient status types not listed		10.7%	4.1%	3.0%	1.6%	0.8%	0.3%

Sources: Illinois, Indiana Discharge Data, 2005. (Total charges for stroke event discharges, 2006)
Ohio State Hospital Discharge Data, 2003.
Michigan Inpatient Database, 2006.
Wisconsin Hospital Inpatient Discharge Data, 2005. (Total charges for stroke event discharges, 2006)

*Number and percent of state resident hospital discharges by discharge status for hospital discharges with a principal diagnosis of cerebrovascular disease (stroke). Cerebrovascular disease (stroke) was defined as ICD-9 codes 430-438.

**Indiana State Department of Health collapses its hospital discharge data into eight categories. For this report, Indiana State Department of Health has attempted to map its categories to the patient discharge status listed.

**Data for Minnesota residents are based upon claims shared by 124 out of 134 acute care hospitals in Minnesota, and 15 acute care hospitals in North Dakota. Mayo Clinic and some of its affiliated hospitals do not participate in the Minnesota Hospital Discharge Database.

¶Hospital charges refer to the amount billed by the hospital for hospital services only. (Physician's fees are not included.) This is provided as an indicator of direct medical expenses.

¶¶Patients discharged/transferred to a short term general hospital have been excluded to avoid double-counting stroke events. However, these patients are included in the total charges for stroke event discharges.

Survivor Story

Stevie K. Nelson, 35, was at his two-week annual military reserve training when he started getting **headaches**. His symptoms persisted for several weeks. Stevie continued going to work despite bumping into a wall and having trouble driving. Since he was only 35, he thought he had a bad case of the flu.

Stevie K. Nelson, Minnesota

One day, a co-worker looked at Stevie and knew something was wrong. This persistent co-worker contacted the paramedics over Stevie's protests. When EMS arrived, they rushed him to the hospital and it was there that he learned he had a hemorrhagic stroke. "Stroke is for older people in my world," said Stevie. He could not believe that he had a stroke at age 35.

After **many days in the hospital**, still more days in a long-term acute care facility, weeks at a rehabilitation facility and months at an independent living facility, Stevie was able to go home. It was six months after his stroke. Stevie is still surprised that he had a stroke. He did not smoke. He watched his sodium intake. No family members had ever had a stroke. Stevie had regular checkups in the military. He did not have high blood pressure and was not overweight or diabetic. He had heard his family members talk about people that, "had a crooked mouth," but he never thought it would be him.

"I didn't know what my purpose in life was until after I had a stroke," reported Stevie. He leads stroke support groups in the Minneapolis area. He visits stroke survivors in the hospital to answer their questions and be a friend. He has become a stroke advocate at his church, and tries to bring awareness to people about stroke everywhere he goes.

Stroke System of Care

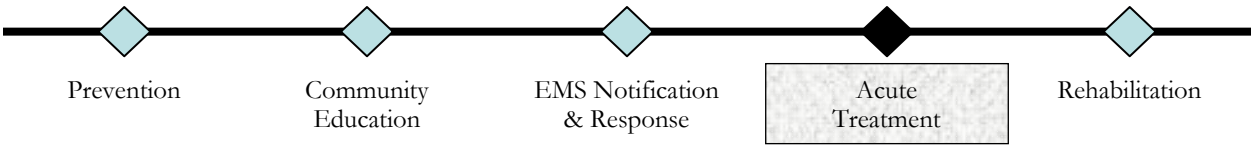
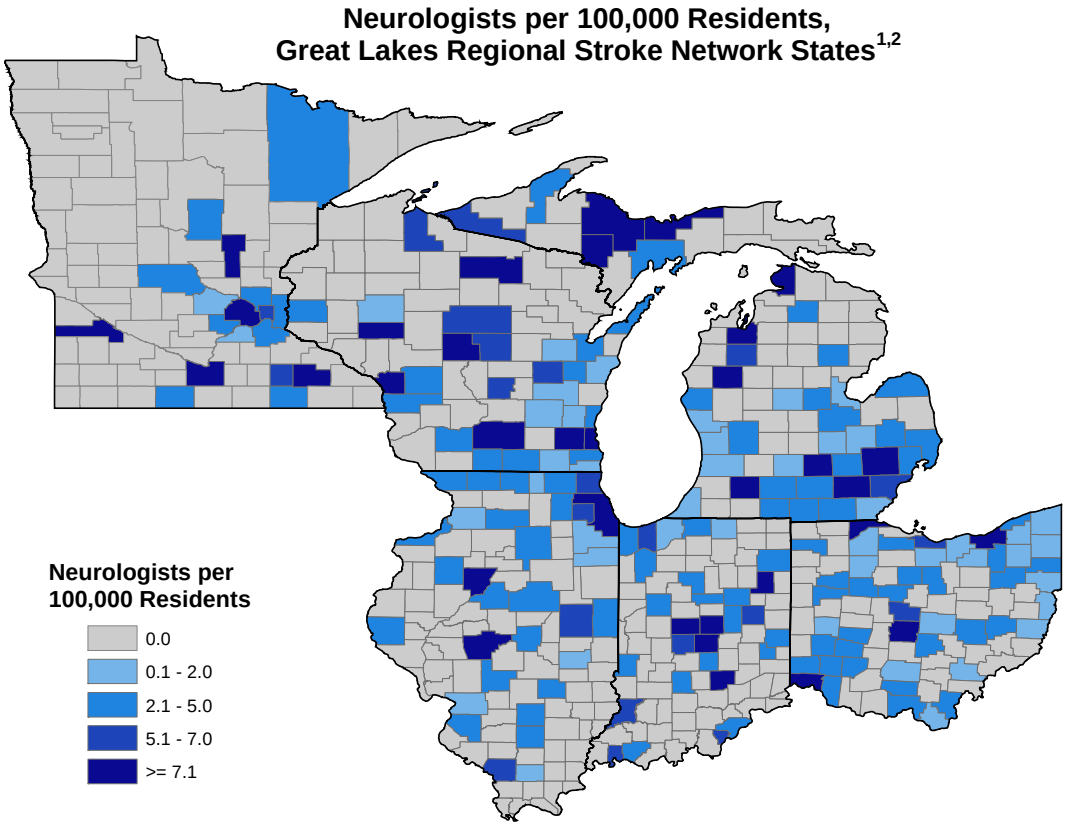


Figure 4: Neurologist Distribution



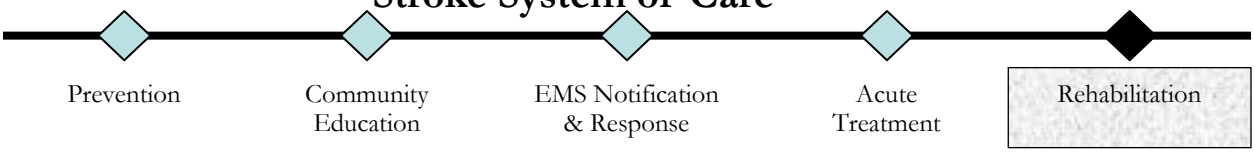
[1]The Number of neurologists for each county was obtained from AMA, Physician-Related Data Resources, updated 16 Dec 2005.
[2]The Number of neurologists per 100,000 residents was calculated using the 2005 census estimates.

Source: American Medical Association, Physician-Related Data Sources, 2005.

According to the American Medical Association, there were roughly 2,511 neurologists practicing in the Great Lakes Region. These numbers vary by state from a low of 245 neurologists in Indiana, to a high of 651 in Illinois. Geographic maldistribution exists for neurology just as it does for other medical disciplines.

Do note that the rate of neurologists per 100,000 residents that appear on the map are driven by the resident population of that county. Population density, geographic typography, and urbanization of counties in question are a few factors that should be taken in to account when comparing rates between states or within states.

Stroke System of Care



Because stroke is a leading cause of severe and long-term disability in the United States, rehabilitation is an important component of the stroke system of care.[5] Among those who survive, only 10 percent recover completely, and many of the remaining survivors need rehabilitation because of resulting impairments.[21] Long-term disability not only affects functional status and social roles among stroke survivors but also results in substantial costs; the combined direct and indirect costs of stroke are projected to be $65.5 billion in the United States in 2008.[5]

Within the GLRSN, only three states gather information on stroke rehabilitation through the BRFSS (See Table 7). In Minnesota, Ohio and Wisconsin, participants were asked, "Has a doctor, nurse, or other health professional ever told you that you had a stroke?" If the answer was "yes," the participants were asked an additional question: "After you left the hospital following your stroke, did you go to any kind of outpatient rehabilitation? This is sometimes called 'rehab.'" The stroke or rehabilitation could have occurred at any time in the past; no date restrictions were included. As of March 6, 2008, the Commission on the Accreditation of Rehabilitation Facilities (CARF) has recognized 44 programs (inpatient and outpatient) in the Great Lakes region for meeting internationally distinguished standards for excellence in stroke rehabilitation (See Table 8). Consumers may request a list of CARF accredited stroke programs at www.carf.org.

Table 7: "When you left the hospital following your stroke, did you go to any kind of outpatient rehabilitation?"

	% Responding "Yes"	% Responding "No"
Illinois	—	—
Indiana	—	—
Michigan	—	—
Minnesota	41.3	55.5
Ohio	33.3	66.7
Wisconsin	35.1	62.8

Source: Minnesota (2005), Ohio (2005), Wisconsin (2006) Behavioral Risk Factor Surveillance System. "—" indicates that state did not collect these data.

Table 8: Number of CARF Accredited Stroke Rehabilitation Programs, March 2008

State/Region	Inpatient	Outpatient	Total
Illinois	4	2	6
Indiana	5	1	6
Michigan	6	2	8
Minnesota	3	0	3
Ohio	11	4	15
Wisconsin	5	1	6
Great Lakes Region	34	10	44

Source: Council for the Accreditation of Rehabilitation Facilities, March 2008.

Survivor Story: Rehabilitation

Dave and Shari Moscinski, Wisconsin

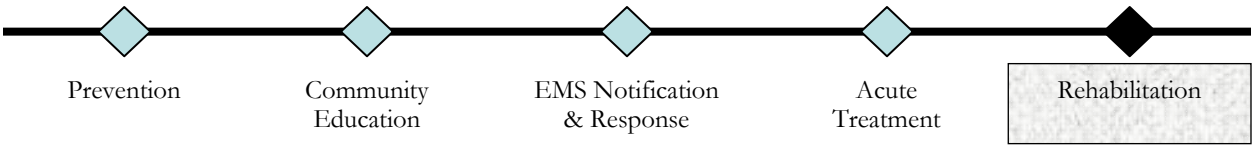
On December 18, 2005, Dave Moscinski was at home. Suddenly, the **worst headache of his life** struck him. He told his wife to **call 911**. He passed out and was unconscious when the paramedics arrived. He has no memory of what happened after that until February of 2006. Dave's hemorrhagic stroke or what the doctor's called his "freak bleed" left him in the hospital for 69 days. After that, he went to a nursing home for another 44 days for **rehabilitation**. Dave was unable to walk, talk, chew, swallow or breathe without assistance. He had a tracheotomy, external and internal shunt, a feeding tube and a stint in his femoral artery.

While in rehabilitation, Dave remembers thinking, "What if it never gets any better?" This thought was quickly replaced with, "I'm alive and people love me," which then gave way to, "Holy smokes! You're going to be a burden to the people you love. Let's see what you can do to make this situation better." This began Dave's focus on making the most of each of his therapy sessions. Within three weeks, Dave went from being bedridden, to using a walker, to walking 2 miles a day. Because of the nerve damage to Dave's face, which was now droopy, therapists would run ice cubes over his face. Because of his tracheotomy, he was unable to speak (for 16 weeks!). But before he could speak, he had to re-learn how to breathe on his own.

Prior to his stroke, Dave was the superintendent for Sciocton School District. In September of 2006, he started back to work on a part-time basis. In December, he returned full time — less than a year after his stroke. During his recovery, Dave did research on student performance data and did some journal writing. This study was published in November in the School Board Journal. He presented this study at the Wisconsin State School Board Convention in January, only two years after his stroke.

Dave is convinced that his attitude and the prayers of hundreds of people helped with his recovery. He is working on a presentation called, "Discovering Joy Daily" which is about finding joy in life. As Dave says, "If there's no dirt above me, its going to be a great day. It only helps to have a positive outlook." Dave's story is truly a miracle. As Kristin Randall, a nurse that cared for Dave says, "If you would have asked me when he was in the hospital if I thought he would be doing what he is doing today I would have said 'probably not.' He is a very amazing man! Dave's hard work and determination to get better is an inspiration to all of us that took care of him."

Stroke System of Care



Caregivers

The impact of stroke reaches significantly beyond the stroke survivor. Family, non-related caregivers and society all bear the heavy burden of stroke. According to the results of the North East Melbourne Stroke Incidence Study (NEMESIS), 68 percent to 74 percent of stroke survivors require the daily care of family members once they return home.[22]

Caring for stroke survivors, post hospitalization, is largely left to family members. A study conducted by Bakas et al. found that most caregivers are spouses, ex-spouses or fiancés, adult children or other relatives.[23] Many of these caregivers must reduce or quit their current job in order to provide the required care. According to the American Heart Association, national indirect costs for lost productivity due to stroke amounts to $21.8 billion.[5]

Caregivers often must learn new medical information, attend to the stroke survivor's personal care including emotional/psychological needs, institute dietary changes, make home adaptations, arrange for special equipment, manage finances, provide transportation and assist with rehabilitation efforts. The needs of the stroke survivor are frequently extensive. Usually, caregivers have found themselves thrust into these caregiving roles suddenly after a stroke event.

Because of the heavy demands placed on stroke caregivers, they are at particularly high risk of depression, psychosocial impairments and other negative health outcomes.[17] In particular, the poorest mental health indicators have been found among caregivers when stroke survivors are discharged home early. Estimates of the prevalence of depression in stroke caregivers range from 34 percent to 52 percent.[23,24]

When family members are not available to provide the necessary care, stroke survivors often must reside at skilled nursing facilities, at least for a period of time. Others spend the remainder of their lives in a skilled facility. Nursing home care for stroke is estimated to be $15.7 billion dollars.[5]

Survivor Story: Caregiver

Al Phillips's journey with cardiovascular disease started in 1989. He had a series of mini-strokes (TIAs) and needed quadruple bypass surgery. In August 1996, he had his first stroke. He woke up in bed with his **left side numb**, including his face, and he was having **trouble speaking**.

Val Jean and Al Philips, Michigan

Since 1989, Al has been hospitalized more than 90 times in less than 20 years. Al says that his wife, Val Jean, has been most affected. Val Jean was at his side for every procedure, providing him with much needed emotional support and a positive attitude. Despite his many medical problems, Al says that Val Jean has never allowed him to feel sorry for himself.

Al is passionate about heart disease and stroke issues. He's been very active in Mended Hearts, presenting at national conferences on advocacy issues. He was even chairman of the National Committee for Mended Hearts. Al estimates that he is now volunteering 40-50 hours a week, a decrease from the 60 hours he previously volunteered.

Over the years, Val Jean has done the bulk of the physical work at home, including the yard work, housework, shopping, toting luggage during travel, etc. Val Jean has driven Al to hundreds of appointments and meetings, doctors appointments and volunteer activities when he couldn't drive, often giving up the things she wanted to do. In addition to helping her husband, she has managed to be involved in various volunteer activities with groups such as Mended Hearts, the American Heart Association, Botsford Hospital, and Angela Hospice. As her husband, Al, wrote, "Val Jean epitomized the part of the marriage vows that she and (I) said almost 46 years ago: in sickness and in health."

Val Jean was recently recognized for her efforts by the American Heart Association.

The Impact of Stroke in the Great Lakes Region

Prevalence of Stroke

Prevalence of stroke refers to the number of people in the population at a particular time who have had a stroke. For example, it is estimated that 138,004 individuals in Indiana were living with the effects of a stroke in 2007. The percentages in Table 9 are estimates of the total number of all individuals in the state, Great Lakes region, and the United States who have had a stroke, at any time in the past, divided by the number of persons in the population aged 18 and older at the time the information was collected. Prevalence estimates for the six states range from 1.8 percent (Minnesota) to 3.1 percent (Ohio) of the adult population. The estimated percent of adults in the United States who have had a stroke is 2.6 percent. In the Great Lakes Region, 2.7 percent of the population has had a first or recurrent stroke. Figures 5 - 7 illustrate the disparities in stroke prevalence by gender, age and race for each Great Lakes state.

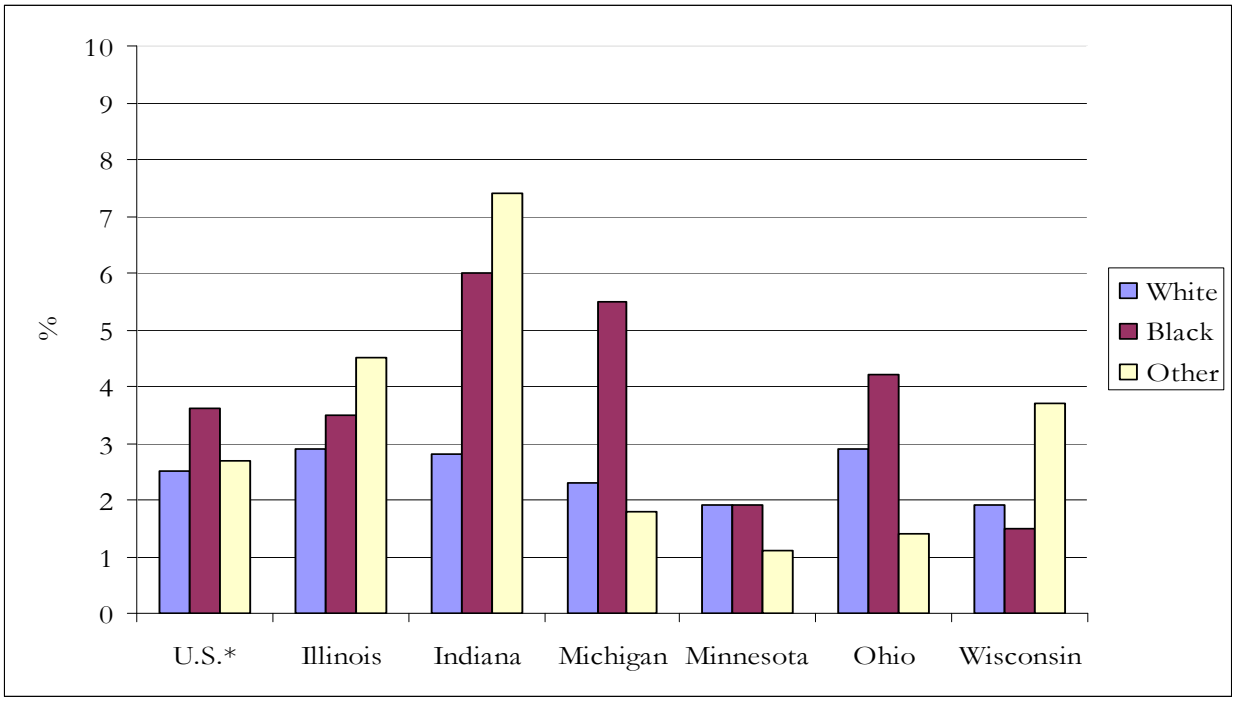
Table 9: Estimated Prevalence of Stroke

	Estimated Number	Percentage
Illinois	270,295	2.8
Indiana	138,004	2.9
Michigan	213,499	2.8
Minnesota	70,872	1.8
Ohio	270,166	3.1
Wisconsin	81,327	1.9
Great Lakes Region	1,044,164	2.7
United States	5,920,705	2.6

Sources: Stroke Prevalence (*Ever Told Had a Stroke*): BRFSS, 2007 - http://apps.nccd.cdc.gov/brfss/list.asp?cat=CV&yr=2007&qkey=5021&state=UB

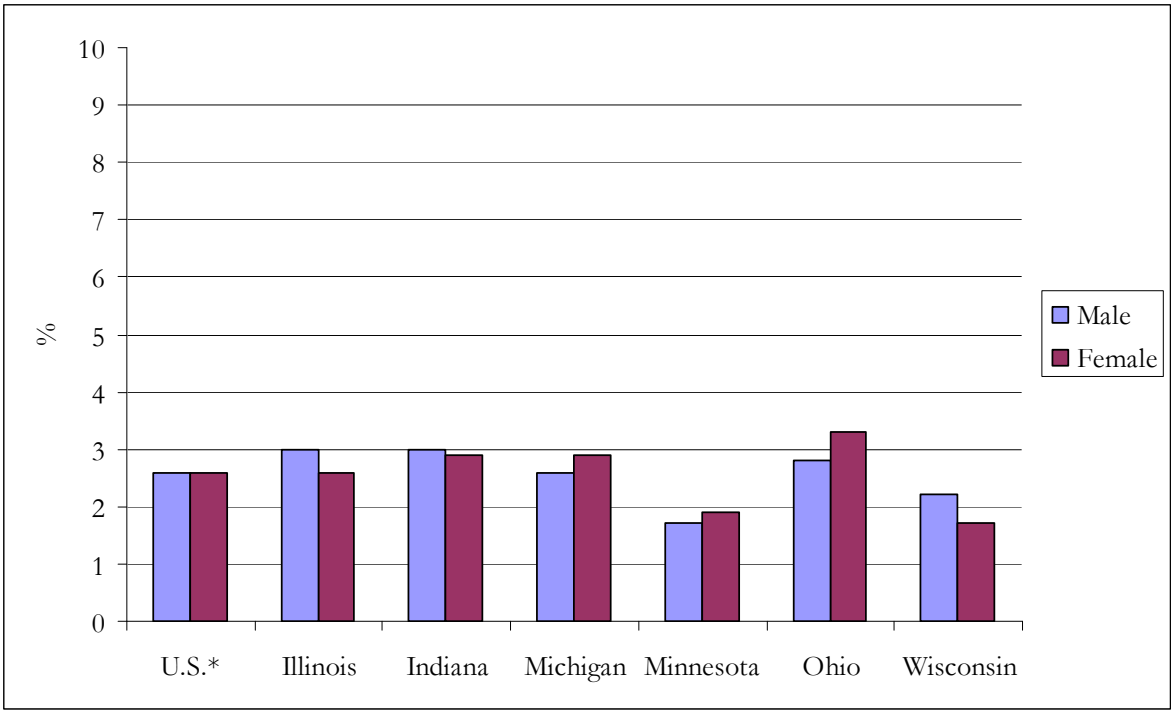
18+ years population estimate source: Estimates of the Population by Selected Age-groups for the United States, States, and Puerto Rico: July 1, 2007 (SC-EST2007-01). Source: Population Division, U.S. Census Bureau. Release Date: May 1, 2008.

Figure 5: Self-reported Stroke Prevalence by Race



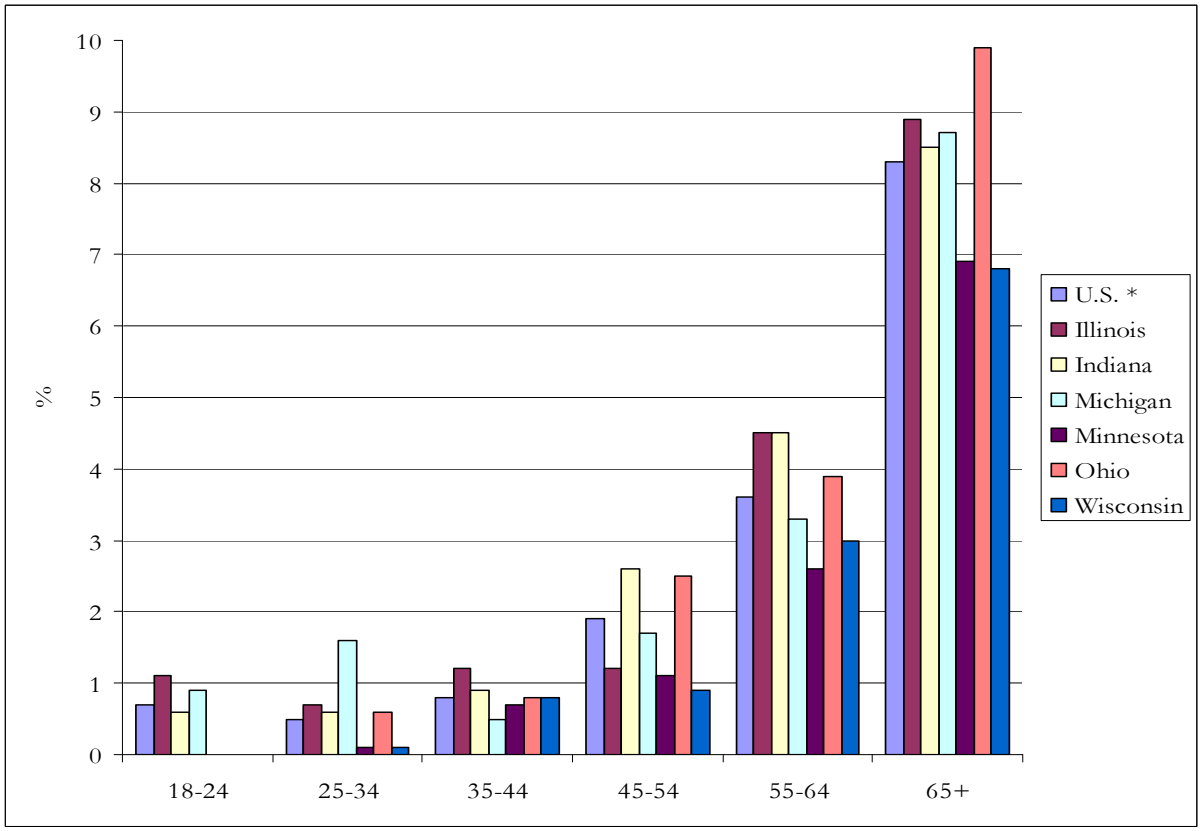
Source: Behavioral Risk Factor Surveillance System, 2007 * Median Percent Stroke Prevalence (51 States).

Figure 6: Self-reported Stroke Prevalence by Gender



Source: Behavioral Risk Factor Surveillance System, 2007
* Median Percent Stroke Prevalence (51 States)

Figure 7: Self-reported Stroke Prevalence by Age



Source: Behavioral Risk Factor Surveillance System, 2007
* Median Percent Stroke Prevalence (51 States)

The Impact of Stroke in the Great Lakes Region

Stroke Mortality

Stroke mortality refers to the number of deaths from stroke in a population within a certain time period. Age is a major factor affecting the risk of death from stroke. Populations differ in age composition and a population with a higher percentage of older residents will likely have a higher crude death rate for all deaths as well as for stroke than a younger population. Age-adjustment takes into account these age differences in the population. Adjusted rates allow for comparisons of mortality across states.

Table 10 presents the age-adjusted stroke mortality rate and number of stroke deaths for each Great Lakes state and the United States for 2005. The age-adjusted stroke mortality rate per 100,000 for the Great Lakes states ranges from 41.9 per 100,000 (Minnesota) to 50.2 per 100,000 (Indiana). Indiana, Ohio, and Illinois, have a higher age-adjusted stroke mortality rate than the U.S. rate of 46.6 per 100,000. Stroke deaths account for 26,223 deaths in the Great Lakes region in 2005. Table 11 shows the 2005 stroke mortality rate per 100,000 by age for each Great Lakes state and the United States. As expected, the stroke mortality rate increases with age in each state and the Great Lakes region.

Table 10: Age-adjusted Stroke Mortality Rate, 2005

	Stroke Mortality Rate	Number of Stroke Deaths
Illinois	47.3	6,232
Indiana	50.2	3,284
Michigan	46.5	5,049
Minnesota	41.9	2,372
Ohio	48.3	6,280
Wisconsin	45.6	2,952
Great Lakes Region*	48.1	26,223
United States*	46.6	143,579

Overall age-adjusted to the 2000 U.S. standard population.

Table 11: Stroke Mortality Rate (per 100,000) by Age, 2005

	25-34	35-44	45-54	55-64	65-74	75-84	85+
Illinois	0.8	4.4	12.4	30.7	97.8	389.3	1,161.1
Indiana	—	6.2	15.3	35.4	118.0	387.2	1,195.8
Michigan	1.31	5.5	13.7	32.4	107.5	353.2	1,139.8
Minnesota	—	4.6	10.5	20.8	84.5	323.6	1,129.2
Ohio	1.7	4.6	16.0	33.0	106.4	379.5	1,164.3
Wisconsin	1.4	4.0	10.0	29.0	87.0	364.9	1,199.4
Great Lakes Region*	1.3	4.9	13.4	31.2	100.2	377.0	1,222.7
United States*	1.4	5.2	15.0	33.0	101.1	359.0	1,141.8

Sources for both tables: Illinois Department of Public Health, Vital Statistics, 2005; Indiana State Department of Health, Data Analysis Team, 2005; Michigan Department of Community Health, Vital Statistics, 2005; Minnesota Department of Health, Vital Statistics, 2005; Ohio Department of Health, Vital Statistics, 2005; Wisconsin Department of Health and Family Services, Vital Statistics, 2005.

*CDC Wonder, 2005

" —" indicates insufficient data

Stroke Mortality Rate by Gender and Race

Table 12 shows the 2005 overall age-adjusted stroke mortality rate by gender and race per 100,000 for each Great Lakes state. Except for Ohio, stroke mortality rates are higher for men than women for each state and across race categories. Overall, black men have the highest stroke mortality rates ranging from 82.9 per 100,000 (Wisconsin) to 61.7 per 100,000 (Ohio). Data on other race and ethnic groups are not available because of unreliable rate estimates.

Table 12: Stroke Mortality Rate* (per 100,000) by Gender and Race, 2005

	Men	Women	Black Men	Black Women	White Men	White Women
Illinois**	49.5	46.3	74.3	62.6	46.7	44.4
Indiana	50.6	49.6	82.9	71.0	48.7	48.3
Michigan	46.9	45.6	68.7	58.4	44.6	43.4
Minnesota	42.1	41.0	***	***	41.0	40.6
Ohio	47.7	47.7	61.7	56.5	46.4	46.7
Wisconsin	47.3	44.0	67.5	42.5	46.3	43.7
Great Lakes Region¶	48.9	47.2	70.4	60.5	46.9	45.7
United States¶	46.9	45.6	70.5	60.7	44.7	44.0

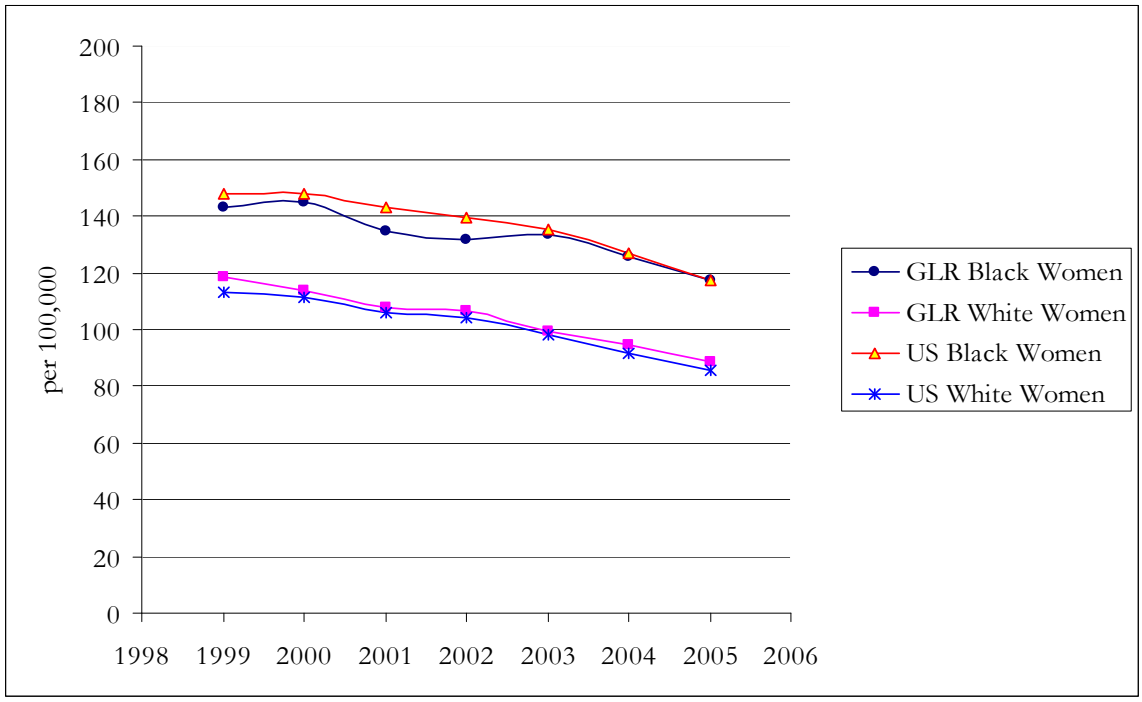
Sources: Illinois Department of Public Health, Vital Statistics, 2005; Indiana State Department of Health, Data Analysis Team, 2005; Michigan Department of Community Health, Vital Statistics, 2005; Minnesota Department of Health, Vital Statistics, 2005; Ohio Department of Health, Vital Statistics, 2005; Wisconsin Department of Health and Family Services, Vital Statistics, 2005.

*Age-adjusted to U.S. 2000 standard population.
**Illinois stroke mortality data for race/ethnicity are grouped as "white" and "non-white." For comparison purposes, Illinois data provided here taken from the CDC Wonder Data 2005.
*** Not enough events in Black Men and Women to calculate a rate.
¶CDC Wonder, 2005.

Figures 8 and 9, on the following page, show a declining trend in stroke mortality. As in the nation, stroke mortality has gradually decreased since 1999 in the Great Lakes region. In fact, our analysis shows that stroke mortality rates in the region follow closely the nation's corresponding trends for both blacks and whites since 1999.

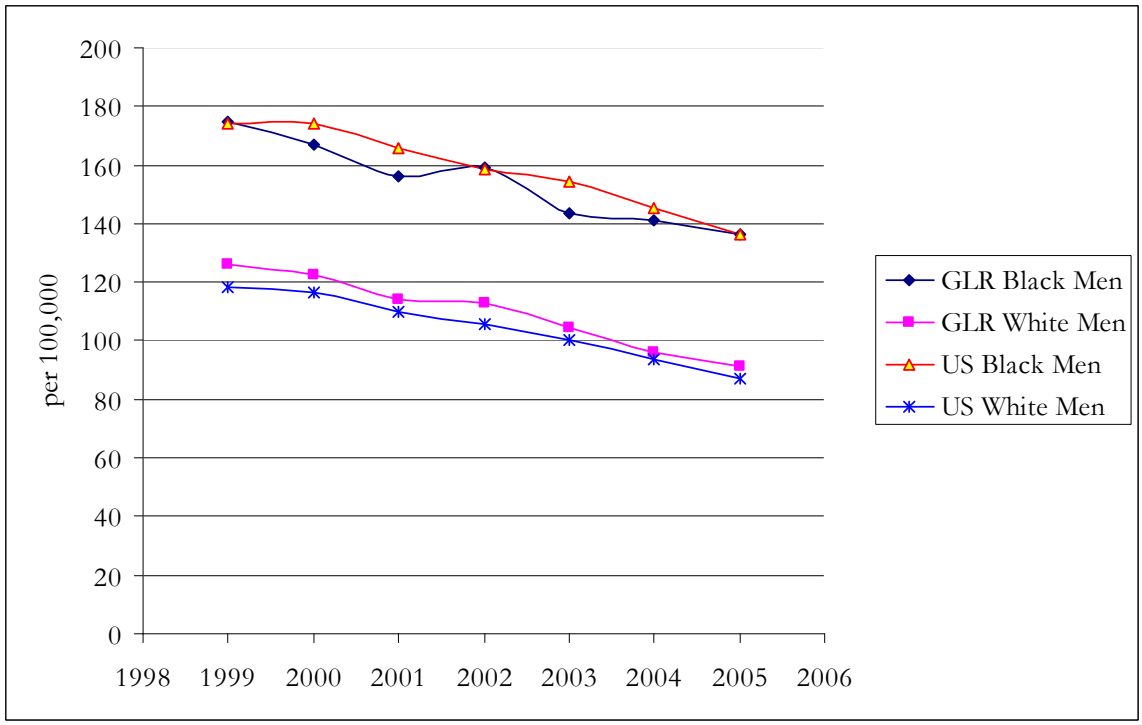
However, as previously discussed, stroke mortality is higher in persons 35 years and older, regardless of race and gender. Comparative trends between black and white men and women, 35 years of age and older, can be examined in Figure 8 and Figure 9. These findings may be indicative of a persistently higher risk of stroke mortality in blacks older than 35, particularly in black men, who have notably higher mortality than white men of same age. This also underscores the need for tailored interventions based on closer examination of the causes for these disparities.

Figure 8: Stroke Mortality Trends for Women by Race, 35 years and Older, in the Great Lakes Region Compared to the United States (Age-adjusted Rates, 2000 U.S. Standard Population)



Source: CDC Wonder, 1999-2005.

Figure 9: Stroke Mortality Trends for Men by Race, 35 Years and Older, in the Great Lakes Region Compared to the United States (Age-adjusted Rates, 2000 U.S. Standard Population)



Source: CDC Wonder, 1999-2005

Limitations

In 2006, the Great Lakes Regional Stroke Network released its first report, "The Burden of Stroke in the Great Lakes," to assess the burden of stroke in the Great Lakes region. The report presented data from a regional perspective including: prevalence, age-adjusted mortality, distribution of risk factors, recognition of and response to stroke symptoms, pre-transport deaths, and hospital discharges.

In the creation of that document, it was noted that states in the Great Lakes region have various and sometimes dissimilar data related to stroke recognition of and anticipated response to stroke symptoms. In this updated report, states are more consistent in asking the BRFSS questions, however, not all states ask them on a regular basis. BRFSS data has limitations. First, BRFSS data are based on self-reports and, thus, subject to recall bias. Second, BRFSS excludes households without landline telephones, so the results might not be representative of certain segments of the U.S. population. Another limitation is that BRFSS data are collected through a cross-sectional telephone survey. Therefore, institutionalized persons and persons not able to answer questions because of stroke-related disability are not included. This exclusion might result in underestimates of the stroke burden and create certain biases in survey data.[19,27]

There are many other limitations. Identified in the previous burden document was that hospital discharge data came from different years or was unavailable. This remains an issue, as does reporting of hospital charges. Hospital charges are different from the actual costs of the hospital stroke care and from what was actually paid to the hospital for that care. There are still no data on incidence and quality and costs of medical care. Rehabilitation statistics are extremely limited, and there is no regional data on caregiving for stroke survivors. It is especially challenging to find reliable numbers on American Indian/Alaskan Native, Asian, Hawaiian/Pacific Islander, and Hispanic populations. These limitations make it difficult to compare the stroke burden between states within the Great Lakes region and with other regions in the United States. Better coordination and timely data analysis is needed to improve efforts to reduce the burden of stroke in the Great Lakes region.

A Few Words about The Great Lakes Regional Stroke Network

The mission of the Great Lakes Regional Stroke Network is to optimize collaboration and coordination among the Great Lakes states to reduce the burden of stroke and disparities. The Network collaborates across six states to implement a common public health plan for stroke. A copy of the Regional Public Health Action Plan for Stroke can be found at http://glrsn.uic.edu. The Network includes state health department heart disease and stroke prevention staff; state stroke task force members in Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin; as well as partners with national organizations such as the American Heart Association/American Stroke Association, National Stroke Association and numerous hospitals throughout the Great Lakes region.

The State Advisory Board and Program Manager of the Great Lakes Regional Stroke Network.

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Appendix A: Glossary of Terms

Age-Adjusted Mortality Rate - The expected number of deaths that would occur if a population had the same agedistribution as a standard population, expressed in terms of deaths per 1,000 or 100,000 persons.

Cause of Death - For the purpose of national mortality statistics, every death is attributed to one underlying condition, based on the information reported on the death certificate and utilizing the international rules for selecting the underlying cause of death from the reported conditions.

Crude Death Rates - total deaths in relation to total population during a year.

Demographics - Characteristic data, such as size, growth, density, distribution , and vital statistics, that are used to study human populations.

Incidence - A measure of the disease or injury in the population, generally the number of new cases occurring during a specified time period.

Morbidity - A measure of disease incidence or prevalence in a given population, location, or other grouping of interest.

Mortality - Expresses the number of deaths in a population within a prescribed time. Mortality rates may be expressed as crude death rates (total deaths in relation to total population during a year) or as death rates specific for diseases and sometimes for age, sex, or other attributes (e.g., the number of deaths from cancer in white males in relation to the white male population during a given year).

Prevalence - A measure of the burden of disease or injury in a population, generally the number of cases of a disease or injury at a particular point in time or during a specified time period. Prevalence is affected by both the incidence and the duration of disease in a population.

Quality of Care - The degree to which health services for individuals increase the likelihood of desired health outcomes and are consistent with established professional standards and judgments of value to the consumer. Quality also may be seen as the degree to which actions taken or not taken maximize the probability of beneficial health outcomes and minimize risk and other undesired outcomes, given the existing state of medical science and art.

Rehabilitation - An intervention strategy that seeks to return individuals to the maximum level of functioning possible.

Risk Factor - A behavior or condition that, on the basis of scientific evidence or theory, is thought to influence susceptibility to a specific health problem.

(Source: Turnock, B.J. Public Health: What It Is and How It Works. Maryland. Aspen Publishers. 2001.)

Appendix B: Data Sources

1) The Census Bureau conducts many censuses and surveys. The most well-known is the official population census of the United States, called the decennial census. It is conducted every 10 years, most recently in April 2000. During each decennial census, the Census Bureau collects data from every household in the United States and its territories. Besides the decennial census, the Census Bureau conducts nearly 100 other surveys and censuses every year including:

A) The American Community Survey (ACS), a nationwide survey, began in 1996. It collects information from U.S. households such as income, commute time to work, home value, veteran status, and other important data. The ACS collects and produces population and housing information every year instead of every 10 years. About 3 million households are surveyed each year. (Source: U.S. Census Bureau, American Community Survey, http://factfinder.census.gov/jsp/saff/SAFFInfo.jsp?_pageId=sp1_acs&_submenuId=&ds_name=&_ci_nbr=&qr_name=&_industry=; accessed last on 06/04-08).

B) The Current Population Survey (CPS) is a monthly survey of about 50,000 households conducted by the Bureau of the Census for the Bureau of Labor Statistics. The survey has been conducted for more than 50 years. The CPS is the primary source of information on the labor force characteristics of the U.S. population. The sample is scientifically selected to represent the civilian non-institutional population. Estimates obtained from the CPS include employment, unemployment, earnings, hours of work, and other indicators. They are available by a variety of demographic characteristics including age, sex, race, marital status, and educational attainment. They are also available by occupation, industry, and class of worker. Supplemental questions to produce estimates on a variety of topics including school enrollment, income, previous work experience, health, employee benefits, and work schedules are also often added to the regular CPS questionnaire. (Source: Current Population Survey (CPS) Web site: http://www.census.gov/cps/; accessed last on 5-30-08).

3) The Behavioral Risk Factor Surveillance System (BRFSS) is a collaborative project of the Centers for Disease Control and Prevention (CDC) and United States and its territories. The BRFSS is an ongoing data collection program designed to measure behavioral risk factors in the adult population (18 years of age or older) living in households. Data are collected from a random sample of adults (one per household) through a telephone survey. There are sets of questions on specific topics such as cardiovascular disease that states can opt to use on their BRFSS questionnaires, so every state may not collect the same information each year. A person was considered to have had a stroke if they answered "yes" to the question: "Has a doctor, nurse or other health professional ever told you that you had a stroke?"

The following variables were obtained from BRFSS: age, gender, race, fruit and vegetable consumption, high cholesterol, high blood pressure, physical activity, cigarette smoking, body mass index (BMI) and diabetes. Stroke symptom awareness was measured by the respondent answer "yes" to the following questions: 1) "Which of the following do you think is a symptom of a stroke. For each, tell me Yes, No or Not Sure."

A. "Do you think sudden confusion or trouble speaking are symptoms of a stroke?"
B. "Do you think sudden numbness or weakness of face, arm or leg; especially on one side, are symptoms of a stroke?"

C. "Do you think sudden trouble seeing in one or both eyes is a symptom of a stroke?"
D. "Do you think sudden trouble walking, dizziness or loss of balance are symptoms of a stroke?"
E. "Do you think severe headache with no known cause is a symptom of a stroke?"

The response of calling 911 to someone having a heart attack or stroke was measured by answering "call 911" to the following question: "If you thought someone was having a heart attack or a stroke, what is the first think you would do?"

A. "Take them to the hospital."
B. "Tell them to call their doctor."
C. "Call 911."
D. "Call their spouse or a family member."
E. "Do something else."
F. "Don't know/Not sure."
G. "Refused."

Diabetes
A person was considered to have had diabetes if they answered "yes" to this question: Have you ever been told by a doctor that you have diabetes other than diabetes during pregnancy?

Hypertension Awareness
A person was considered to have hypertension if they answered, "yes" to this question: Have you ever been told by a doctor, nurse or other health professional that you have high blood pressure other than during pregnancy?

Cholesterol Awareness
A person was considered to have high cholesterol if they answered, "yes" to both questions: Have you ever had your cholesterol checked and have you ever been told by a doctor, nurse or other health professional that your blood cholesterol is high?

Weight
BRFSS used the following BMI classification for overweight and obesity status: overweight (BMI 25.0 - 29.9); obese (BMI 30.0+).

Exercise
Measured by respondent's answer to the following question, "During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?"

Tobacco
A current smoker is defined as a person reporting smoking at least 100 cigarettes in their lifetime and currently smokes either some or every day.

Fruits and Vegetables Consumption
Defined as adults who report on average consuming fruits and vegetables five or more times per day.

The BRFSS provides the best estimate of stroke prevalence and the prevalence of risk factors for stroke. However, it has its limitations: 1) the BRFSS only measures prevalence, not incidence, 2) it only surveys the non-institutionalized population (nursing homes are omitted), 3) only people capable of participating in a telephone survey are able to participate (i.e. those with a disability preventing them would not be included), 4) it relies on self-reported information; 5) it only surveys people with a landline phone and 6) it only includes adults age 18 and older, so it most likely is an underestimation of the people who have had a stroke (Source: CDC, Behavioral Risk Factor Surveillance System survey, http://www.cdc.gov/brfss/).

4) The purpose of the Illinois Department of Public Health 2005 Point-In-Time Survey is to provide information about cardiovascular health knowledge and behavior; particularly, about the prevalence of cardiovascular risk factors for Illinois residents. A total of 500, 10-minute telephone interviews of household residents in Illinois was conducted. The study used questions from the Cardiovascular and Stroke modules developed by the Centers for Disease Control and Prevention (CDC). All procedures were developed according to the guidelines promulgated by the CDC for the Behavioral Risk Factor Surveillance Survey (BRFSS), which articulate calling rules as well as procedures for protecting the confidentiality of data.

5) Data on stroke mortality were provided by each state health department and the National Center for Health Statistics on causes of death; and come from a database of death certificates collected and maintained by each state health department's vital statistics unit. The International Classification of Disease (ICD) code indicates the underlying cause of death. ICD-9 codes 430-438 were used for death certificates prior to 1999 to classify stroke. From 1999 on, death certificates are coded with ICD-10 codes I60-I69. (Source: http://www.cdc.gov/nchs/about/major/dvs/icd10des.htm). U.S. and regional stroke mortality data comes from the Centers for Disease Control and Prevention, National Center for Health Statistics: Compressed Mortality File 1999-2005. CDC WONDER On-line Database, compiled from Compressed Mortality File 1999-2005 Series 20 No. 2K, 2008. Accessed at http://wonder.cdc.gov/cmf-icd10.html on April 14, 2008 2:05:58 PM.

6) The Joint Commission (formerly JCAHO) evaluates and accredits health care organizations and programs in the United States. An independent, not-for-profit organization, the Joint Commission also awards Disease-Specific Care (DSC) Certification to health plans, disease management service companies, hospitals and other care delivery settings that provide disease management and chronic care services. The Joint Commission's certification program for DSC provides a comprehensive evaluation of disease or condition-specific services including primary stroke care. The number and location of Primary Stroke Centers in the Great Lakes states were obtained from the Joint Commission's Web site in March 2008. (Source: Joint Commission, www.jointcommission.org). Date accessed March 17, 2008.

7) Data on pre-transport stroke deaths in this report are from the CDC's *Morbidity and Mortality Weekly Report*. The report presents national and state-specific death rates for stroke in 1999, which indicate state-by-state variations in both stroke-related death rates and the percentages of stroke decedents who die before transport to an emergency department. (Source: State-Specific Mortality from Stroke and Distribution of Place of Death—United States, 1999, CDC, MMWR, May 24, 2002/51 (20); 429-433.)

8) Hospital discharge data are from inpatient hospital admissions for each Great Lakes state. Data did not include specialty treatment centers or state institutions. Data presented are for hospital discharges with a principal diagnosis of stroke (ICD-9 codes 430-438). Data limitations include a lack of a defined denominator and the same person may be counted more than once in the event of two or more hospital separations during the year.

9) American Medical Association Physician-Related Data Resources was the resource for the neurologist data. This resource generates counts of physicians by specialty within county. The physician's preferred professional mailing address is used to designate the state and county in which the physician is located. This address may be home or office. All physicians and residents with a U.S. preferred professional mailing address are included in the application. Physicians who may be retired or inactive are also included. (Source: http://www.ama-assn.org/cgi-bin/sserver/datalist.cgi). Date accessed May 29, 2008.