



Message from Director Shah

Welcome to the fifth issue of the Illinois Morbidity and Mortality Bulletin (IMMB), an IDPH publication created to present topics of interest to public health communities and professionals in Illinois through scientific analysis and interpretation of data.

In this issue, Theresa Sandidge and Jane Fornoff examine the results of the most recent survey of families of Illinois children who are born with birth defects and other adverse outcomes to assess family satisfaction with services provided through the High Risk Infant Follow-Up program.

In the second article, Mohammad Shahidullah, Nelson Agbodo, and Lutfun Nahar examine temporal life expectancy and mortality trends in Illinois from 1990 to 2015.

We encourage contributions from public health professionals at the state and local levels, as well as those in hospitals and academic institutions. Please send your manuscripts to IMMB's editor, Tiefu Shen, M.D., Ph.D. at Tiefu.Shen@illinois.gov (217.785.1873)

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High Level of Satisfaction among Families Receiving High Risk Infant Follow-up (HRIF) Services

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Temporal Trends in Life Expectancy and Mortality in Illinois, 1990-2015

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High Level of Satisfaction among Families Receiving High Risk Infant Follow-up (HRIF) Services

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Abstract

Families of Illinois children who are born with birth defects and other adverse outcomes are eligible for follow-up services upon the infant's discharge from the hospital. These services include a series of home visits provided by community health agency nurses through the High Risk Infant Follow-Up (HRIF) program administered by Illinois Department of Human Services (IDHS). Nurses provide information about the infant's health condition(s), perform infant health assessments, and arrange referrals to other services as needed. The Illinois Department of Public Health's (IDPH) Adverse Pregnancy Outcomes Reporting System (APORS) works with IDHS to support the HRIF program both by collecting information on eligible high risk infants and providing this information to local community health agencies throughout the state to ensure timely follow-up. APORS also oversees a yearly survey to assess family satisfaction with services provided through HRIF. This article reviews the results of the most recent family survey. In 2017, APORS found high satisfaction with services received through the HRIF program. These findings offer valuable feedback to local community health agencies and assist in validating the importance of the program to families in the state of Illinois.

Introduction

Birth defect registries serve an important purpose, summarized concisely by the U. S. Centers for Disease Control and Prevention (CDC): "Accurately tracking birth defects and analyzing the collected data is a first step in preventing birth defects." ¹ Illinois's birth defect registry, the Adverse Pregnancy Outcomes Reporting System (APORS), collects information on Illinois infants born with birth defects or other abnormal conditions. The purpose of APORS is threefold: (1) to conduct surveillance on birth defects, (2) to guide public health policy in the reduction of adverse pregnancy outcomes, and (3) to identify children who require special services in order to correct and prevent developmental problems and other disabling conditions.

Families of infants reported to APORS are eligible for follow-up services through IDHS' HRIF program. After the infant is discharged from the hospital, community health agency nurses contact the family to offer case-management services, including a series of home visits and assistance with any identified needs. The family is eligible to receive six visits during an infant's first two years of life. The community health nurse conducts physical and developmental assessments, provides information, and makes referrals for additional services as needed. Home-nursing services are recognized as an appropriate part of post discharge care for high risk infants by the American Academy of Pediatrics.² Programs such as HRIF in Illinois ease the transition to the home environment, connect the family to other services, and ultimately contribute to improving outcomes for high risk infants.^{3,4}

While HRIF programs are recognized nationally as a good standard practice, it is important to assess periodically whether the services are of value to families. To that end, the IDHS HRIF contract with community health agencies in Illinois requires a survey be administered annually to a random sample of families to assess their views on the assistance provided. Respondents were asked to indicate their degree of satisfaction with

follow-up services and the age of their infants participating in the program. The results are used to provide community health agencies specific feedback to improve the quality of follow-up services.

Methods

The 80 community health agencies that provided HRIF services in 2017 were required to participate in the family survey. The surveys were provided to families either at first contact (regardless of whether they accepted services) or at a subsequent visit, if the family had already accepted services. The survey, available in English, Spanish, Arabic, Burmese, Chinese, French, and Vietnamese, was offered if an APORS-eligible family was seen in their home, or if the family came into the health agency. Surveys were distributed in May 2017. Each parent was given the opportunity to fill out the form during the face-to-face contact or to complete it afterward. Postage-paid envelopes were provided for respondents to keep the survey responses confidential and to facilitate the surveys' return.

Survey results were compiled and examined by APORS staff at IDPH. As the sample size was small, the Fisher's exact test was used to test for significance when comparing overall responses to survey questions. Differences in survey results by age of infant and geography of residence were also considered.

Results

Eighty community health agencies were eligible to participate in the survey. Sixteen agencies did not distribute surveys as no clients were seen during the survey period, while two additional agencies didn't participate for other reasons. A total of 887 surveys were distributed using forms provided by the APORS Program. Of these, 726 surveys were returned by families participating in the program for a response rate of 81.8 percent. Table 1 below shows characteristics of the respondents, including infant age group and whether the family resided in an urban or rural area of the state. Two-thirds of infants were under one year old while one third were 12 months or older. Most respondents resided in a county of urban designation as opposed to a rural designation.

Table 1: Survey Respondent Characteristics

	Number	Percent
<u>Infant Age¹</u>		
< 6 months	310	43.4
6-11 months	166	23.2
12 or more months	239	33.4
<u>Geography²</u>		
Urban	595	82.0
Rural	131	18.0

¹Age was not provided for 11 respondents

²Urban counties include Champaign, Cook, DeKalb, DuPage, Kane, Kankakee, Kendall, Lake, Macon, McHenry, Sangamon, St. Clair, Will and Winnebago counties.

The survey questions assessing the satisfaction with the services are listed in Table 2, together with the responses. Statistically significant agreement was found for each question asked. Similar results were found when examining data by child’s age and geographical residence.

Table 2: Responses to Survey Questions Assessing Satisfaction with Services

	Agree	Disagree	Fisher’s Exact Test P-Value
1. The nurse explained the services my baby or I might receive	723 (99.7%)	2 (0.3%)	<.001**
2. I found the visit helpful	722 (99.6%)	3 (0.4%)	<.001**
3. The visit made me feel less worried	712 (98.6%)	10 (1.4%)	<.001**
4. The nurse helped me understand my baby’s health concern	721 (99.6%)	3 (0.4%)	<.001**
5. I need the services	697 (96.3%)	27 (3.7%)	<.001**
6. I feel comfortable contacting the nurse if I have more questions	720 (99.4%)	4 (0.6%)	<.001**

**significant at p<.01

Eighty-eight (12.1%) of the respondents provided comments. Their remarks were overwhelmingly positive, with just a couple of unfavorable statements regarding the follow-up program. Some examples are listed on the next page:

“(Nurse) explained everything very well. She is knowledgeable and thorough. I did not know these services were available, but I am glad to see they are-very needed!”

“I love that this program is available! It’s very informative and educational. As new parents there is always worry and concerns about how to properly take care of an infant, and this program has helped me address these issues.”

“I think the program is very helpful because they talk to you one on one and explain a lot more things in detail.”

“...Already connected with EI and other specialists...”

Family surveys in previous years had been conducted during the month of November, but in 2017 the survey month was changed to May. APORS found that the overall response rate remained robust, exceeding the previous year's rate (81.8% in May 2017 compared with 75.8% in November 2015). However, more agencies were not able to distribute surveys because no clients were seen during the survey period (16 agencies in 2017 compared with 14 in 2015). APORS will continue to monitor response rates and agency participation in the future as the survey continues to be offered in the spring rather than the fall.

The APORS program will partner with community health agencies again next year, asking APORS eligible families to participate in the family survey. To ensure all agencies fully participate in the survey process, APORS will recommend to the IDHS HRIF program coordinator that language specifically addressing family surveys continue to be included in the provider contracts. The APORS and HRIF partner programs are clearly appreciated and valued by the families they serve. Together they will seek to further improve the effectiveness and efficiency of the programs.

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¹Birth Defects Research and Tracking. U. S. Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/birthdefects/research.html>. Accessed October 13, 2017.

²Hospital Discharge of the High-Risk Neonate, Committee on Fetus and Newborn, American Academy of Pediatrics. *Pediatrics* 2008;122;1119-1126.

³Issue Brief, Partnering to Promote Follow-up for Premature Infants, March 2013. Association of Maternal and Child Health Programs. <http://www.amchp.org/programsandtopics/womens-health/resources/Documents/Follow-Up-Care-for-Premature-Infants-FINAL-Mar2013.pdf> . Accessed October 13, 2017.

⁴High Risk Infant Follow-up (HRIF) Fact Sheet. Illinois Department of Human Services. <http://www.dhs.state.il.us/page.aspx?item=32857>. Accessed October 13, 2017.

⁵FYQ4 HRIF Summary Report. Illinois Department of Human Services. <http://www.dhs.state.il.us/page.aspx?item=97464> . Accessed October 13, 2017.

Temporal Trends in Life Expectancy and Mortality in Illinois, 1990-2015

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Abstract

This report provides temporal trends in life expectancy and mortality in Illinois from 1990 to 2015, using death data from IDPH and the National Center for Health Statistics (NCHS). Joinpoint regression analysis and life expectancies were used to study the trends in mortality. Age-adjusted mortality rates by sex for all causes combined declined consistently from 1990 to 2015. Further examination of rates from 2009 to 2015 for 10 leading causes of death by sex, race, and ethnicity showed declines in mortality for most selected causes. These declines were consistent with the mortality changes for the nation.

Introduction

The study of long-term life expectancy and mortality patterns provides useful information for health planning, program evaluation, and policy development for preventing diseases. In recent years, mortality rates have declined, along with significant increases in life expectancies for both males and females in Illinois. This report provides more details about gender, race, ethnicity, and leading causes of death and their impact on mortality trends. The report covers the period 1990-2015 and provides life expectancies by sex, age-adjusted death rates by sex for all causes combined, age-adjusted death rates for 10 leading causes of death by sex, race, ethnicity, and neonatal, post-neonatal, and infant mortality rates.

Data and Methods

This study used the abridged life table^{1,2,3,4} technique to compute life expectancies by sex for Illinois for 1989-1991, 1999-2001, 2009-2011, and 2013-2015. IDPH provided death data by age and sex. Decennial census populations from the U.S. Census Bureau by age and sex for 1990 and 2010 and population estimates by age and sex for July 1, 2014 were used to compute the age specific death rates to construct the life tables. Age-specific death rates for all causes combined were obtained from the Annual Illinois Vital Statistics Reports from 1990-2003 and 2004-2015 National Center for Health Statistics (NCHS) reports. Age-adjusted death rates were computed using Illinois Vital Statistics data from the Illinois IQuery Online Information System. The study used the U.S. 2000 standard population by age and sex to compute direct standardized death rates for all causes and for each of the 10 leading causes of death. The age groups used for standardization for deaths for all causes combined and 10 leading causes of death (for both sexes) were 0-4, 5-14, 15-24, 25-44, 45-64, 65-84, and 85+ and for 10 leading causes of death by sex and race were 0-4, 5-14, 15-24, 25-44, 45-64, and 65+. Standardized rates may differ slightly depending on age intervals used. Infant mortality rates (deaths under one year old), neonatal mortality rates (deaths under 28 days old), and post-neonatal mortality rates (deaths for ages 28 days to less than 1 year) were calculated from Illinois Vital Records System data.

This study used Joinpoint method^{5,6} “to test whether or not an apparent change in mortality trend is statistically significant” and identify the year in which significant changes occurred.

NCHS coded leading causes of death based on underlying causes of death using the International Classification of Disease Codes (ICD-9 for 1990-1998 and ICD-10 for 1999 to 2015). The World Health Organization⁷ defines an underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury.

Results

Life Expectancy, 1990-2015

Life expectancy is a measure of the overall health of a population. In Illinois, mortality decreased along with significant increases in life expectancy for both males and females from 1990 to 2015. Between the 1990-1991 and 2013-2015 periods, life expectancy at birth increased by 5.5 years for males and increased by 3.4 years for females (Figure 1). Life expectancy for females was consistently higher than that of males and this observation remained true at ages 65 and 85 (Figure 2 and Figure 3).

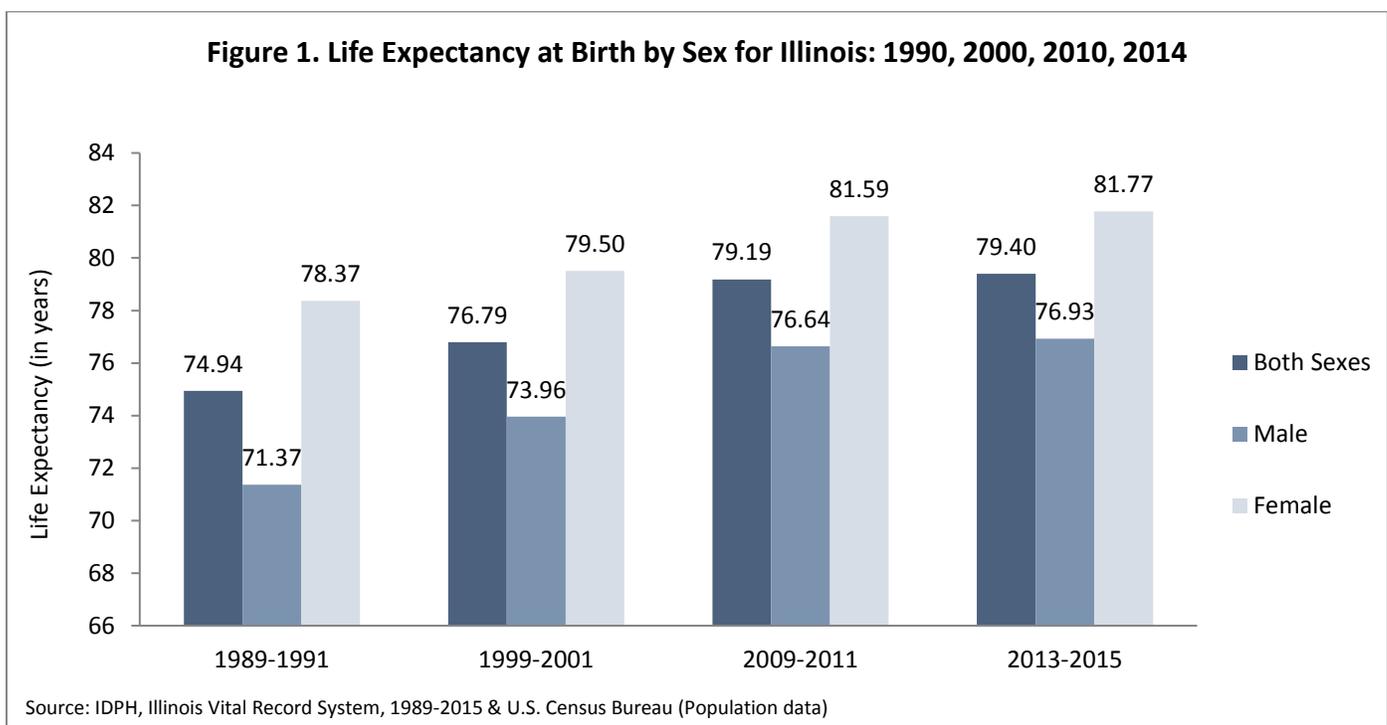
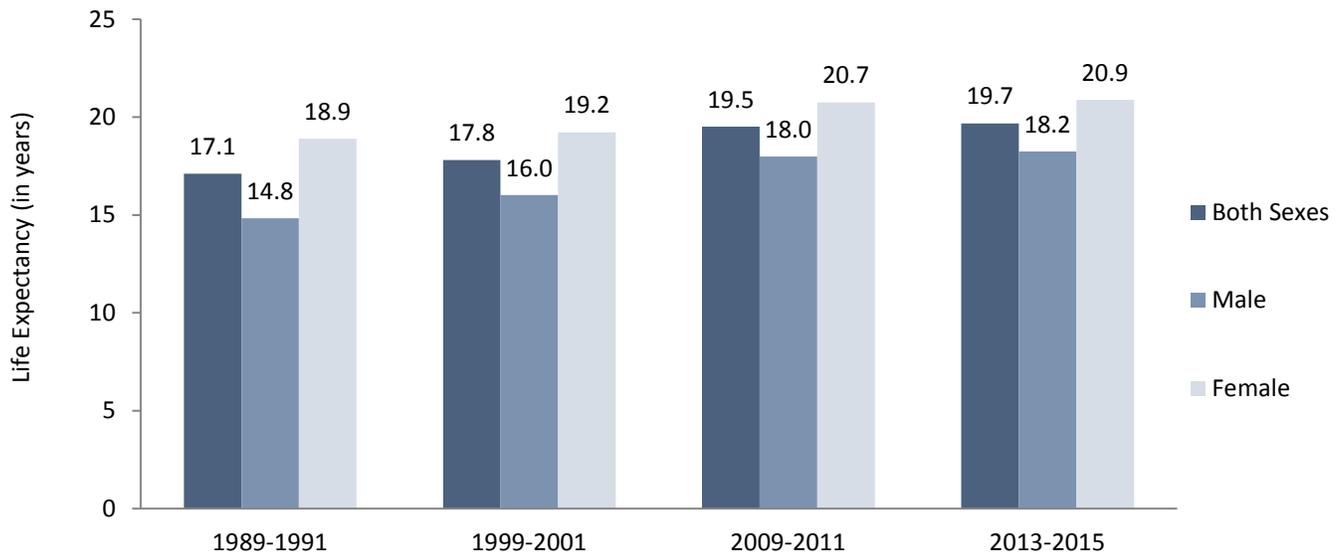
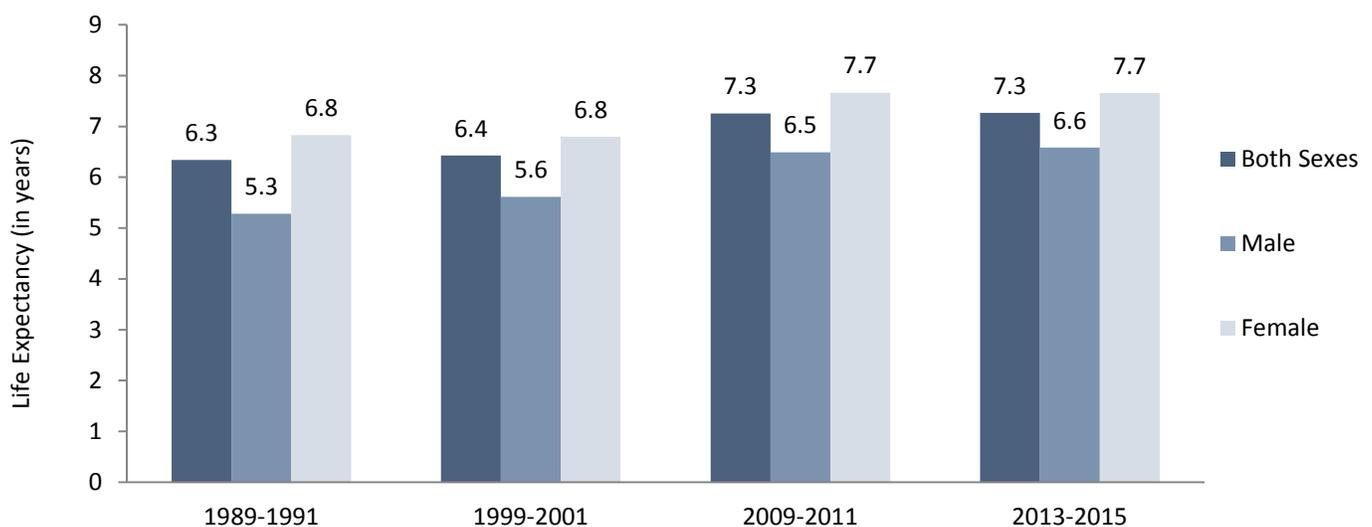


Figure 2. Life Expectancy at Age 65 by Sex for Illinois: 1990, 2000, 2010 and 2014



Source: IDPH, Illinois Vital Record System, 1989-2015 & U.S. Census Bureau (Population data)

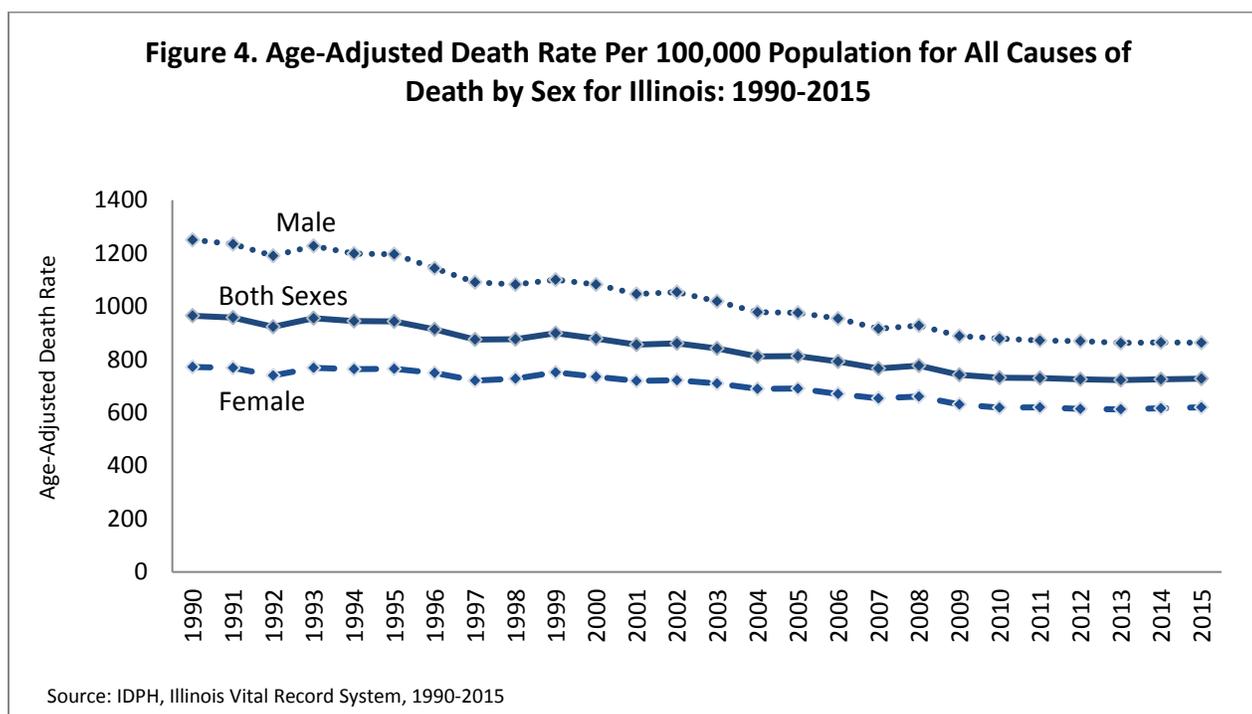
Figure 3. Life Expectancy at Age 85 by Sex for Illinois: 1990, 2000, 2010 and 2014



Source: IDPH, Illinois Vital Record System, 1989-2015 & U.S. Census Bureau (Population data)

Age-Adjusted Death Rates for All Causes Combined, 1990-2015

Between 1990 and 2015, the age-adjusted mortality rate for all causes combined decreased by 31.0% among males and 19.7% among females (Figure 4). The age-adjusted death rate for males per 100,000 populations decreased from 1250.8 in 1990 to 863.2 in 2015. For females, this rate was 771.9 in 1990 and 619.5 in 2015.



The Joinpoint analysis shows that the death rate for males significantly decreased at an annual percentage change (APC) of -1.8% (95% CI, -1.9% to -1.7%) from 1990 to 2011 and then stabilized during the 2011-2015 period with an APC of -0.3% (95% CI, -1.9% to 1.4%) (Table 1 and Figure 5). The analysis of the death rate for females shows three different stages: over the period 1990-2002, the death rate significantly decreased at an APC of -0.5% (95%CI, -0.8% to -0.3%); the observed decrease accentuated over the period 2002-2011 with an APC of -1.8% (95%CI, -2.3% to -1.3%); from 2011 to 2015, the death rate leveled off at an APC of 0.2 (95%CI, -1.3% to 1.6%). Overall, the death rate remained higher at all time among males, compared to females, and males showed a larger decrease in death rate per year over a longer period of time than females. It's noticeable, however, that the death rate has plateaued and trends were not significant for both sexes in recent years.

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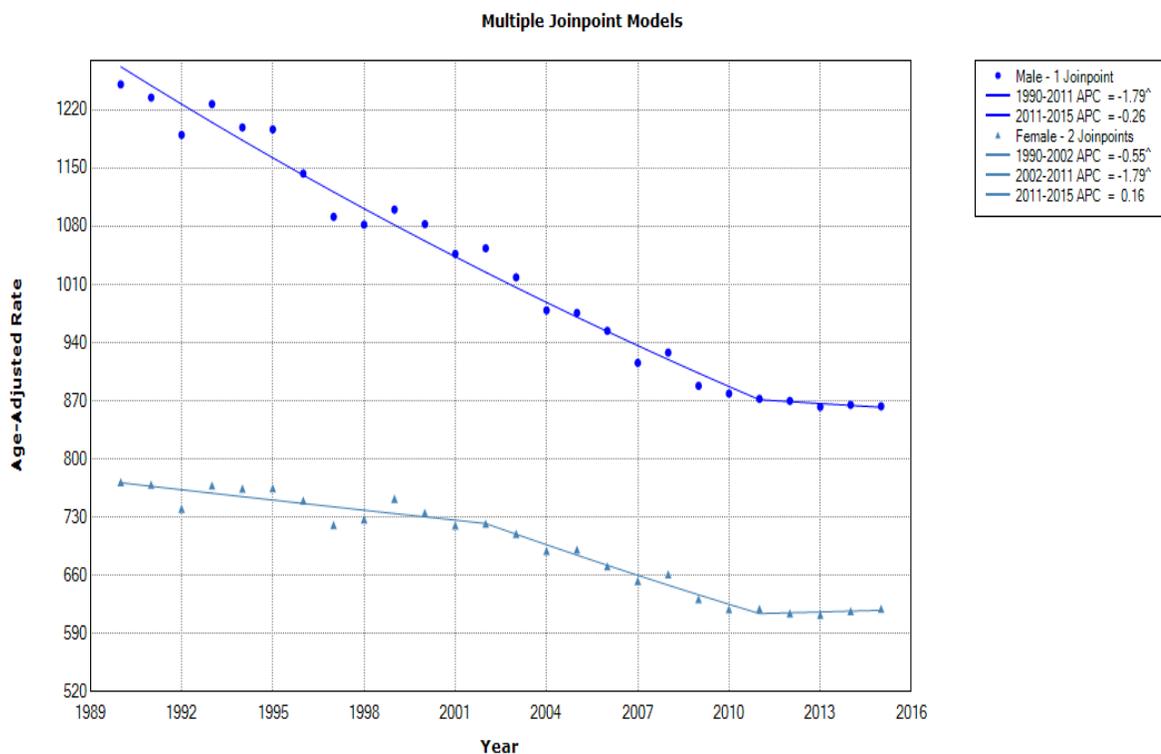
Table 1. Joinpoint Analysis of Trends in Illinois Mortality for All Causes of Death by Sex, 1990-2015

Sex	Trend	Starting Year	Ending Year	Annual% Change (APC)	Lower CI	Upper CI	p- value
Male	1	1990	2011	-1.8*	-1.9	-1.7	0.0
	2	2011	2015	-0.3	-1.9	1.4	0.7
Female	1	1990	2002	-0.5*	-0.8	-0.3	0.0
	2	2002	2011	-1.8*	-2.3	-1.3	0.0
	3	2011	2015	0.2	-1.3	1.6	0.8

Source: IDPH, Illinois Vital Record System & National Center for Health Statistics, 1990-2015

Note: Annual% Change (APC) was statistically different from zero at the p<0.05 level.

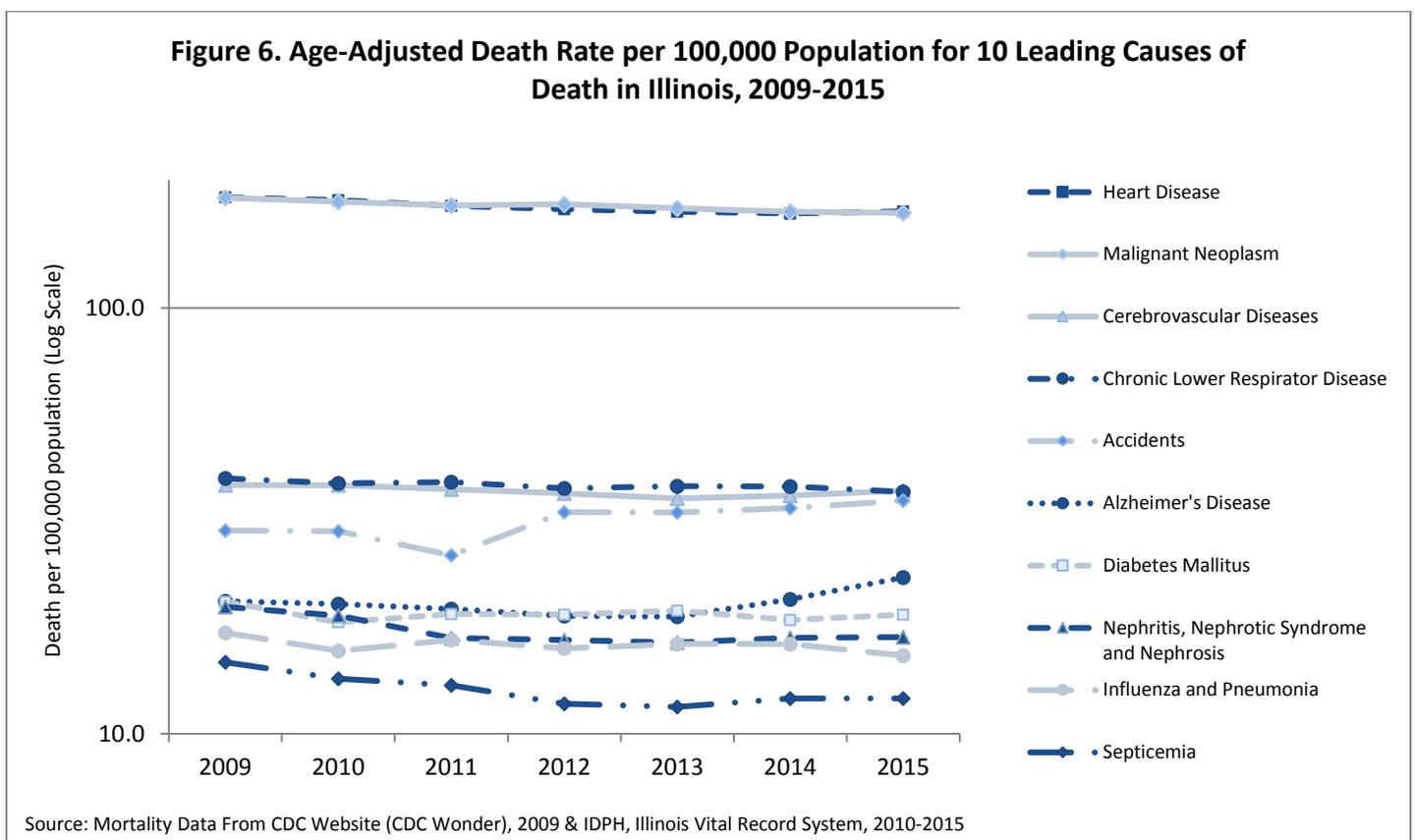
Figure 5. Joinpoint Models for Age-Adjusted Death Rates for Males and Females, 1990-2015



Source: IDPH, Annual Vital Record & National Center for Health Statistics (2000 U.S Standard Population)

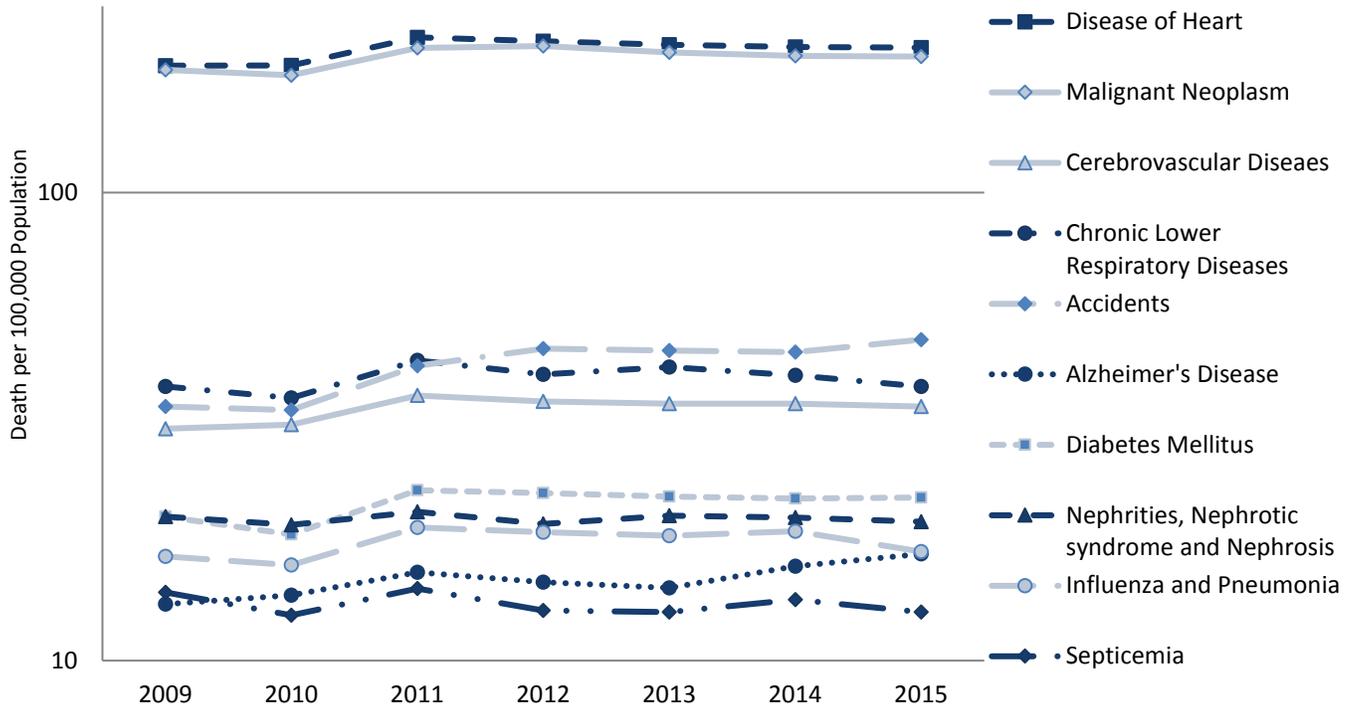
Selected Causes of Death by Sex, 2009-2015

From 2009 to 2015, age-adjusted death rates, for both sexes combined, decreased for eight of the 10 leading causes of death (Figure 6). The rates decreased 7.4% for heart disease, 7.8% for malignant neoplasm, 2.9% for cerebrovascular disease, 7.0% for chronic lower respiratory disease, 6.9% for diabetes mellitus, 15.1% for nephritis, nephritic syndrome and nephrosis, 11.6% for influenza and pneumonia, and 17.7% for septicemia. However, the rates increased 17.7% for accidents and 13.7% for Alzheimer's disease for the same time period.



Age-adjusted death rates among males increased for heart disease (9.2%), malignant neoplasm (6.9%), cerebrovascular disease (11.5%), chronic lower respiratory disease (16.1%), accidents (39.0%), Alzheimer's disease (28.0%), and diabetes mellitus (7.0%) (Figure 7). The rates decreased for nephritis, nephritic syndrome and nephrosis (2.5%), influenza and pneumonia (0.7%), and septicemia (1.6%).

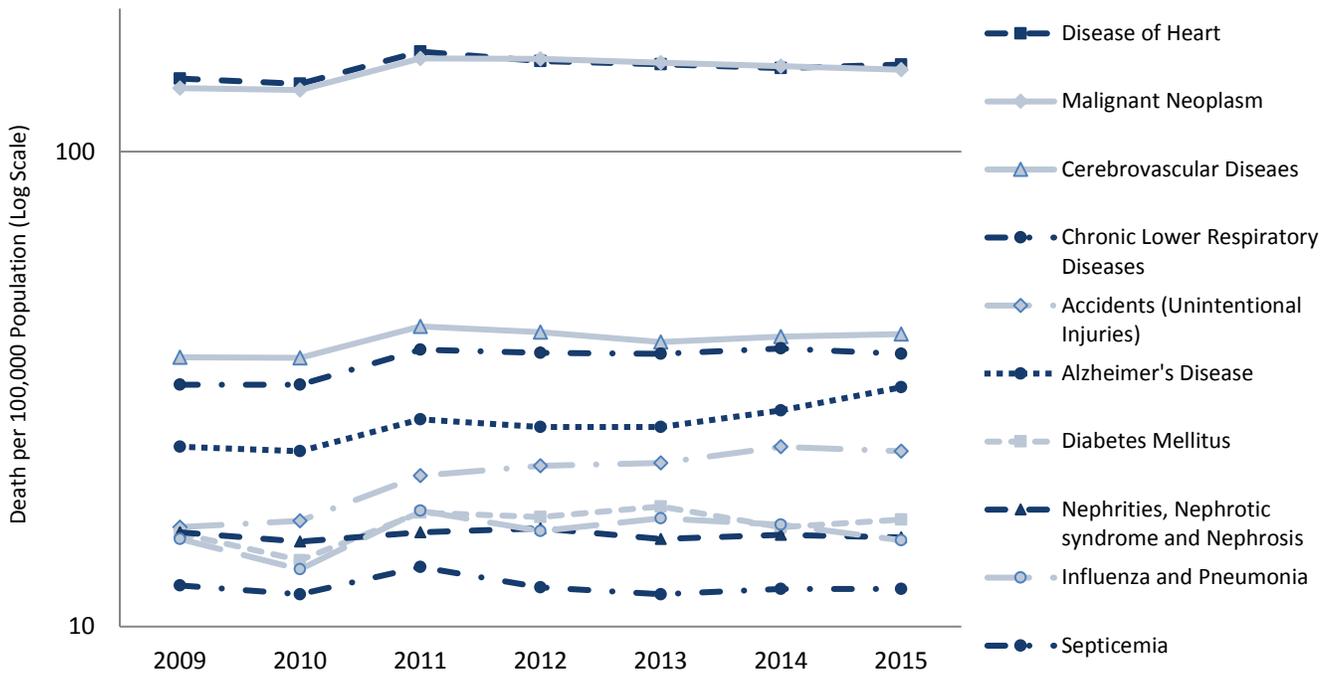
Figure 7. Age-Adjusted Death Rate for 10 Leading Causes of Death for Males in Illinois, 2009-2015



Source: IDPH, Illinois Vital Statistics Record System, 2009-2015 & National Center for Health Statistics, 2009-2015

Among females, age-adjusted death rates increased for seven out of 10 leading causes of death and decreased for two causes (Figure 8). The rates increased for heart disease (7.0%), malignant neoplasm (9.4%), cerebrovascular disease (11.9%), accidents (44.4%), Alzheimer’s disease (33.5%), diabetes mellitus (9.9%), and influenza and pneumonia (2.4%). The rates decreased for nephritis, nephritic syndrome and nephrosis (2.5%), and septicemia (9.3%). There were no noticeable changes in the rate for chronic lower respiratory disease.

Figure 8. Age-Adjusted Death Rate for 10 Leading Causes of Death for Females in Illinois, 2009-2015

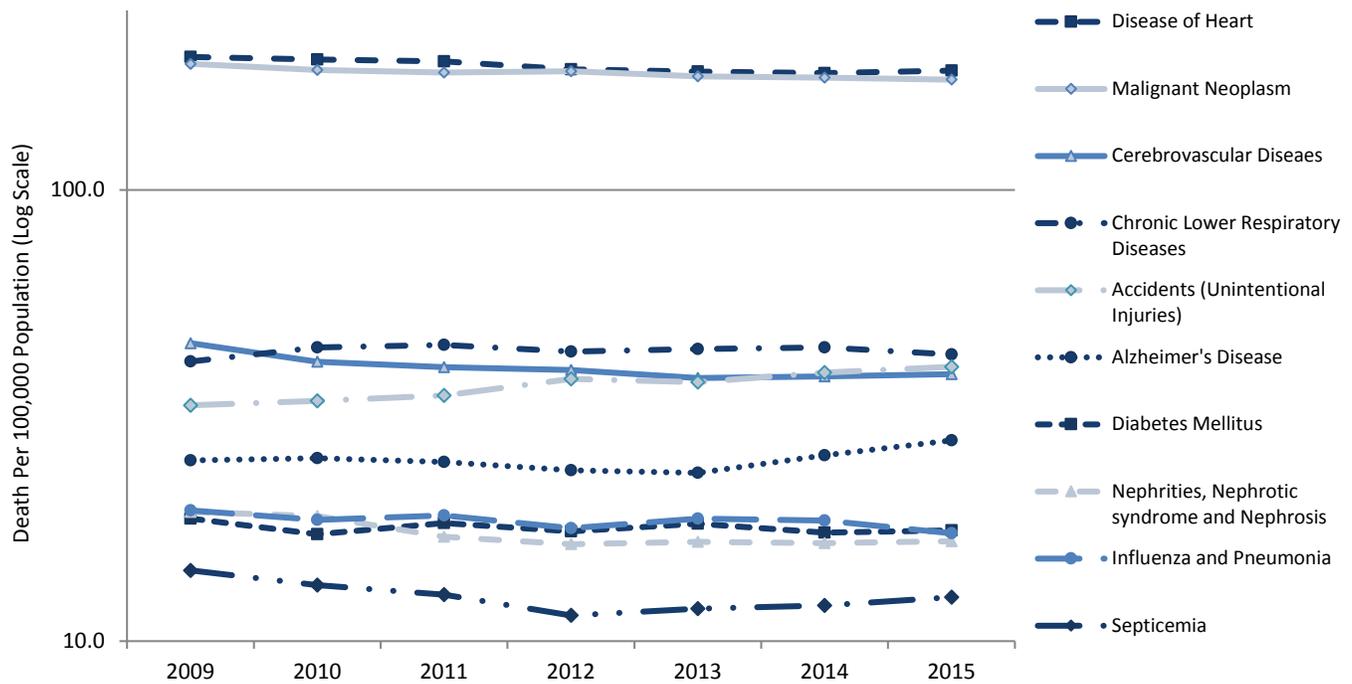


Source: IDPH, Illinois Vital Record System, 2009-2015 & National Center for Health Statistics, 2009-2015

Selected Causes of Death by Race and Ethnicity, 2009-2015

During 2009 to 2015, age-adjusted death rates for Non-Hispanic Whites decreased for seven of 10 leading causes of deaths and increased for three leading causes (Figure 9). The rates decreased for heart disease (6.7%), malignant neoplasm (7.8%), cerebrovascular disease (14.6%), diabetes mellitus (5.9%), nephritis, nephritic syndrome and nephrosis (13.5%), influenza and pneumonia (11.3%), and septicemia (12.6%). However, the rates increased for chronic lower respiratory disease (3.6%), accidents (21.9%), and Alzheimer's disease (10.7%).

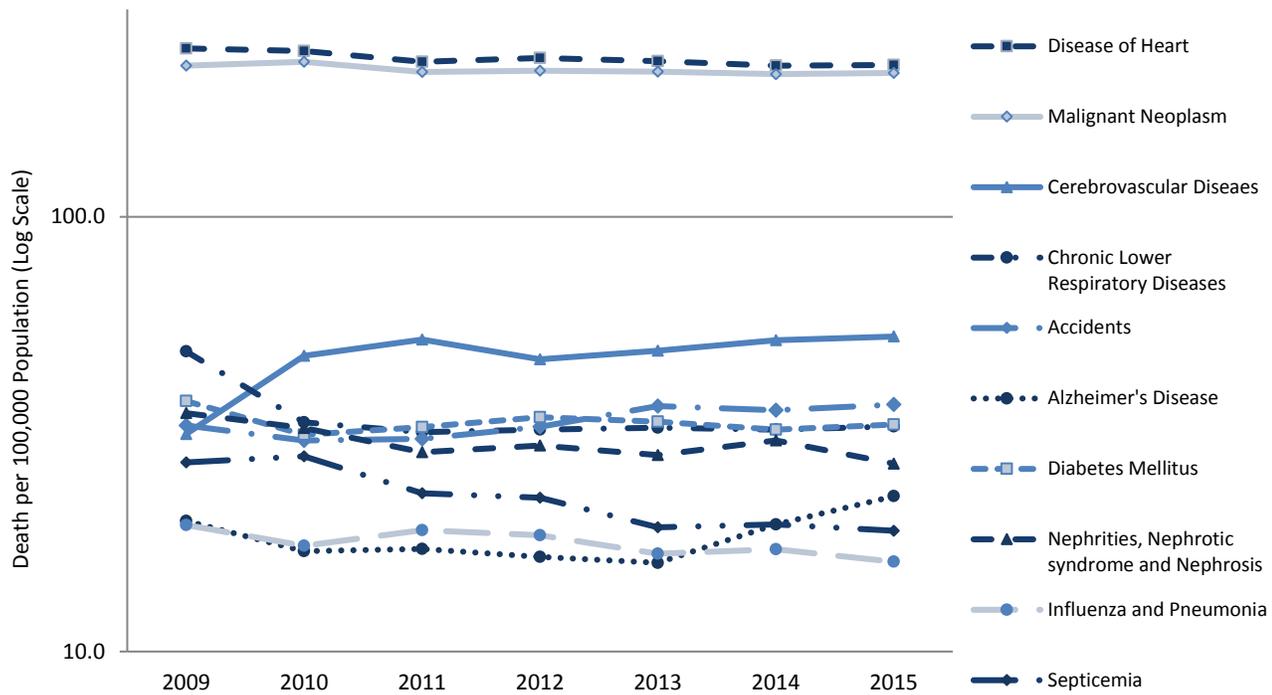
Figure 9. Age-Adjusted Death Rates for 10 Leading Causes of Death for Non-Hispanic Whites in Illinois, 2009-2015



Source: IDPH, Illinois Vital Statistics Record System and National Center for Health Statistics (NCHS), 2009-2015

Age-adjusted death rates for Non-Hispanic Blacks decreased for seven of 10 leading causes of deaths and increased for three leading causes (Figure 10). The rates decreased for heart disease (8.6%), malignant neoplasm (3.8%), chronic lower respiratory disease (32.7%), diabetes mellitus (11.7%), nephritis, nephritic syndrome and nephrosis (23.2%), influenza and pneumonia (17.4%), and septicemia (30.1%). However, the rates increased for cerebrovascular disease (67.2%), accidents (11.8%), and Alzheimer's disease (14.0%).

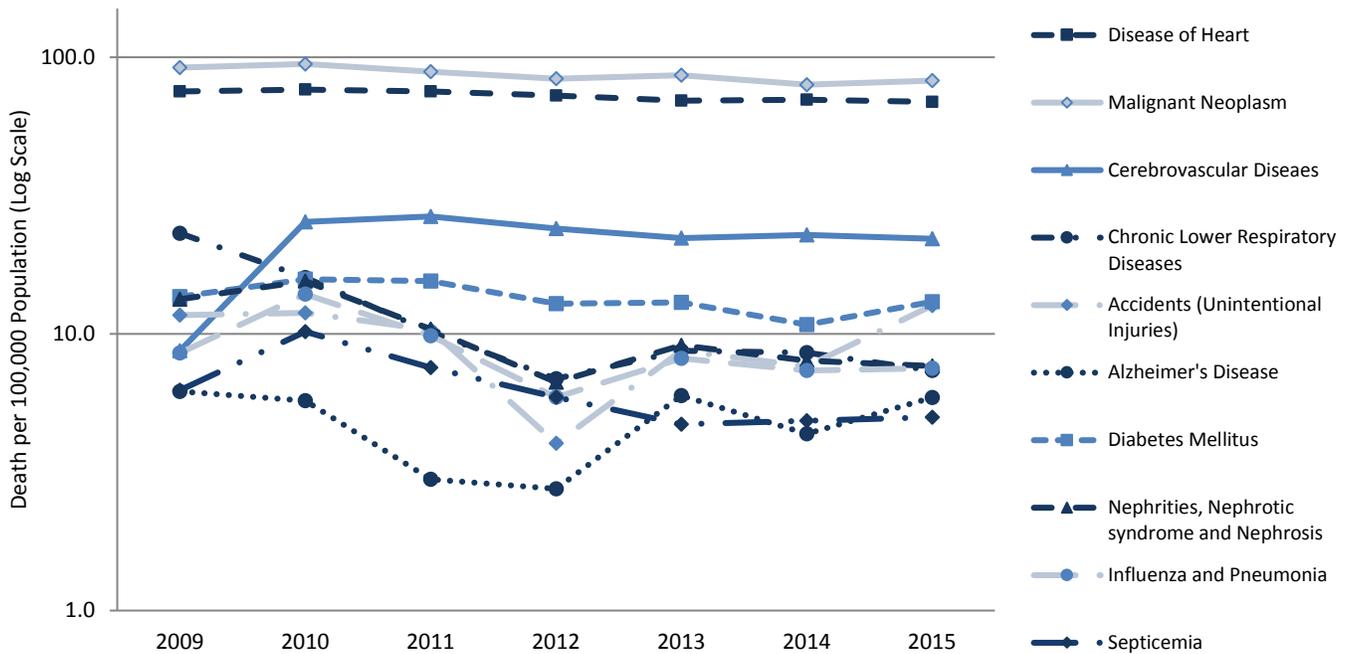
Figure 10. Age-Adjusted Death Rate for 10 Leading Causes of Death for Non-Hispanic Blacks in Illinois, 2009-2015



Source: IDPH, Illinois Vital Record System & National Center for Health Statistics (NCHS), 2009-2015

Age-adjusted death rates for Non-Hispanic Others decreased for eight of 10 leading causes of death and they increased for two leading causes (Figure 11). Age-adjusted death rates decreased for heart disease (8.4%), malignant neoplasm (10.1%), chronic lower respiratory disease (68.0%), Alzheimer’s disease (4.8%), diabetes mellitus (3.7%), nephritis, nephritic syndrome and nephrosis (42.1%), influenza and pneumonia (11.8%), and septicemia (20.6%). The rates increased for cerebrovascular disease (154.0%) and accidents (8.5%).

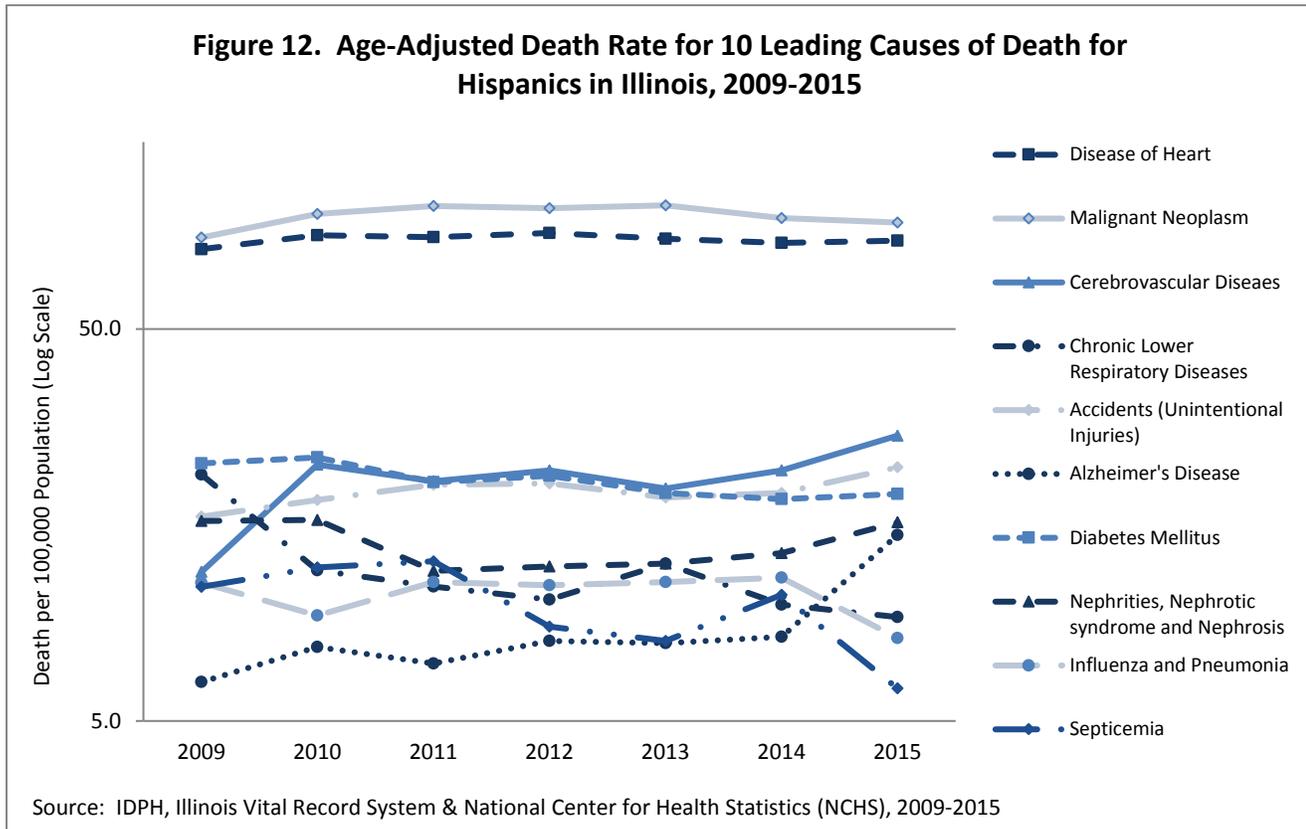
Figure 11. Age-Adjusted Death Rate for 10 Leading Causes of Death for Non-Hispanic Others in Illinois, 2009-2015



Source: IDPH, Illinois Vital Record System & National Center for Health Statistics (NCHS), 2009-2015

Hispanic age-adjusted death rates decreased for five of 10 leading causes and increased for the other leading causes (Figure 12). Rates increased for heart disease (5.0%), malignant neoplasm (9.2%), cerebrovascular disease (122.5%), accidents (33.7%), and Alzheimer’s disease (136.5%). On the other hand, the rates decreased for chronic lower respiratory disease (56.8%), diabetes mellitus (16.3%), nephritis, nephritic syndrome, and nephrosis (0.6%), and influenza and pneumonia (28.3%), and septicemia (44.5%).

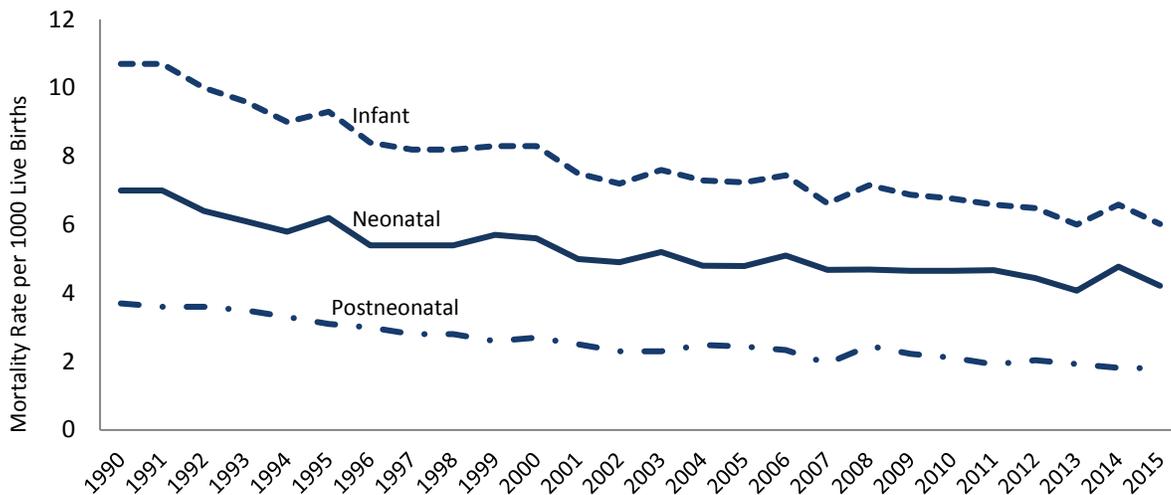
Figure 12. Age-Adjusted Death Rate for 10 Leading Causes of Death for Hispanics in Illinois, 2009-2015



Infant Mortality Rates for All Causes Combined, 1990-2015

The infant mortality rate is measured as the number of infant deaths per 1,000 live births. The 2015 infant mortality rate (IMR) of 6.0 was 43.9% lower compared to the 1990 IMR of 10.7 (Figure 13). During the same period, the neonatal mortality (death rate among infants under 28 days) decreased 40.0% to 4.2, and the post-neonatal mortality rate (death rate among infants 28 days through 11 months) declined 51.4% to 1.8 per 1,000 live births.

Figure 13. Neonatal, Postneonatal, and Infant Mortality Rates per 1,000 Live Births in Illinois, 1990-2015



Source: IDPH, Annual Vital Record Book, 1990-2003 & Vital Record System, 2004-2015

Discussion and Limitations

Standardized mortality rates help compare rates over time. The observed differences in the mortality rates by sex and by race and ethnicity may be associated with underlying distributions of health determinants, risk factors, and access to health care.

This report establishes the following key findings regarding mortality trends in Illinois:

- Overall age-adjusted mortality rates for all causes combined have declined consistently for males and females.
- Life expectancies have been increasing for both sexes.
- For the 2009-2015 time period, seven of 10 leading causes of death for Non-Hispanic Whites have declined; however, mortality rates for chronic lower respiratory disease, accidents, and Alzheimer’s disease have increased.
- One of the possible reasons for the increase in accidental deaths may be related to the significant increase in opioid overdose deaths in recent years. Further research is needed to quantify the contribution of drug overdose deaths to accidental deaths and to loss of life expectancy in Illinois.
- The infant, neonatal, and post-neonatal mortality rates declined consistently in Illinois. These findings on life expectancies by sex and age-adjusted death rates by sex were consistent with those at the national level⁸, although the increase in life expectancies and decline in standardized mortality rates for Illinois were higher than those for the nation^{9,10}.

This study has some limitations. Compiled data from different secondary sources were used to compute the death rates. Death certificates may have some inaccuracies in terms of information recorded. Also, causes of

death were coded using ICD-9 for the period 1990 and 1998 and ICD-10 from 1999 to 2015 which might cause some comparability problems for cause-specific mortality rates. However, the comparability issue does not affect the analysis of all causes of deaths.

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