



Center for
Healthcare
Innovation

Social and Financial Costs of Millennial Dementia Caregivers



Table of Contents

Abstract	3
Introduction	4
The Burden of Dementia	6
a. Scope and Impact	6
b. Ethnocultural Diversity	9
c. Shift to Millennial Caregiving	10
Economic and Social Impacts of Millennial Caregiving	11
a. Educational and Financial Impact	12
b. Employment Impact	13
Role of Public Health Policy	15
a. Health Effects	15
b. Financial Well-being	16
c. Employee Productivity	16
Calls for Action	18
Conclusion	19
References	20
Key Contacts	21

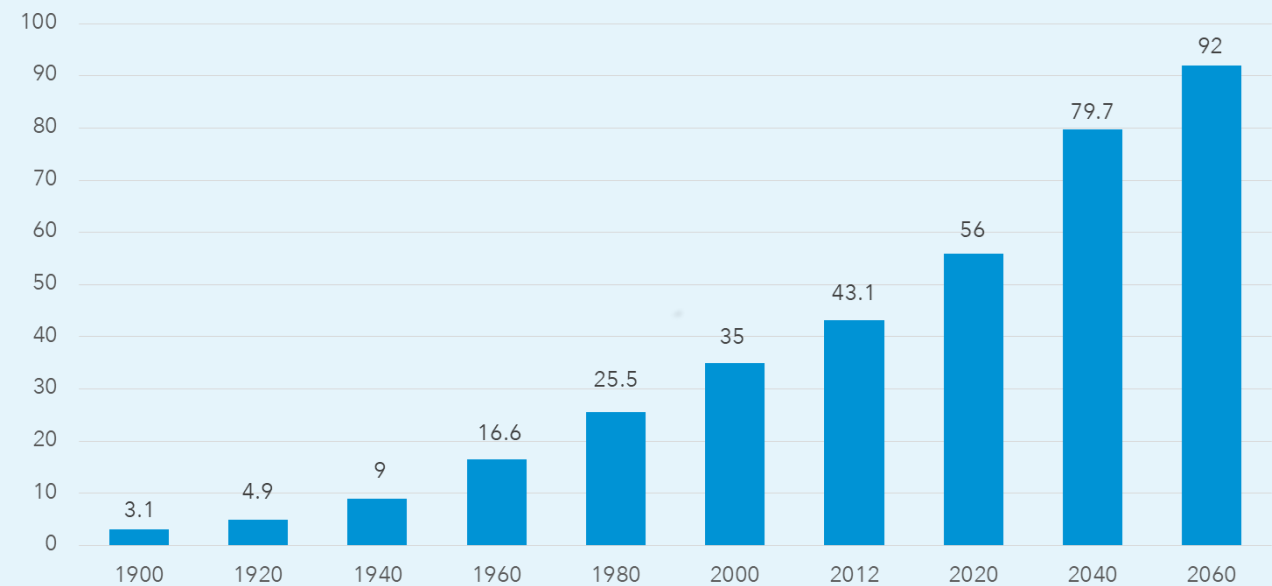
Abstract

With the prevalence of Alzheimer's disease expected to impact 16 million individuals by 2050, younger generations will increasingly assume caregiving responsibilities. More than a third of today's caregivers are employed full-time. As millennials take on informal caregiving responsibilities, public and workplace policies must consider financial assistance or other support (e.g., family leave or allocated time off). This report explores the economic impact of the shift to millennial caregivers and the higher rate of incidence of Alzheimer's disease in minority groups. The report concludes with a discussion of strategies at the organizational- and system-level to support millennial caregivers.

Introduction

This report evaluates the social and economic implications of the shifting U.S. demographics on dementia and caregiving within vulnerable, at-risk populations. The U.S. Census Bureau projects that the population aged 65 and older will nearly double, increasing from 43.1 million in 2012 (13.7% of the total population) to 83.7 million in 2050 (19.1%).¹ Additionally, the population aged 85 and older is projected to triple by 2050, increasing from 2.5% in 2030 to 4.5% of the total population in 2050.¹ Older adults, in general, will also be more racially and ethnically diverse. As of 2012, there were 76.4 million baby boomers.² The growth mentioned above in the aged population will mostly occur between 2010 and 2030 as these baby boomers reach age 65.

The U.S. Population Is Aging



Sources: United States Census Bureau and United States Department of Health and Human Services.

Figure 1. U.S. population 65+ (in millions)

Population aging will have vast implications, particularly in the healthcare and social service sectors. The rapid growth in the older population will challenge both healthcare professionals and policymakers. Some older individuals will require long-term care for progressive illnesses, such as Alzheimer's disease (AD) and other types of dementia, as well as increased physician visits and hospitalizations to manage complex chronic conditions, such as cardiovascular disease and diabetes. This will also challenge policymakers to allocate resources, particularly for the financing and delivery of caregiver services.

Without proper support, family caregivers will be faced with financial hardships, as the trend of millennials supporting parents and grandparents increases with the aging population. This situation means that family caregivers may be forced to leave the workforce, reduce their work hours, or get passed over for a promotion as a result of their demanding responsibilities at home. In addition to lost wages, pensions, and Social Security benefits, this may also affect the physical health of young caregivers in today's workforce. This report explores the growth of the aging population, the effect of this growth on the level and frequency of family caregiving responsibilities, and the resulting economic impact of this issue at the individual and national levels.

The Burden of Dementia

Millions of individuals worldwide have dementia, a chronic condition marked by an individual’s cognitive, behavioral, and functional decline. Due to the disproportionate impact of dementia and its enormous social and economic costs, it has become a growing public health concern.

Scope and Impact

In 2015, the World Health Organization (WHO) estimated that there were 47.5 million people with dementia worldwide³. With approximately 7.7 million new cases diagnosed annually, the number of individuals with dementia is projected to reach 75.6 million by 2030 and 135.5 million by 2050.³ This growth could be related to increased longevity, the growing aging population, and the associated rise in chronic conditions. As a result, dementia may become the leading cause of dependency and cognitive impairment among older adults.⁴

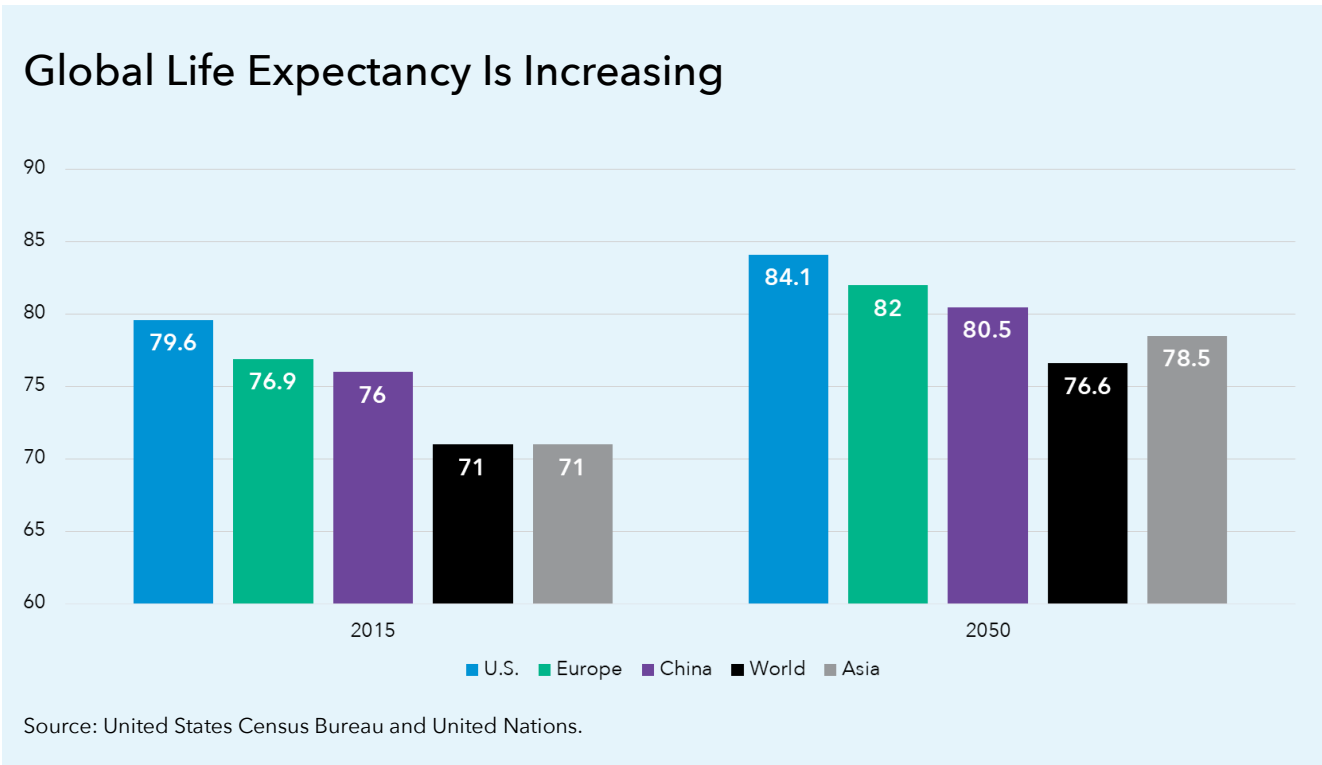


Figure 2. Projected number of years of life

AD is the most common form of dementia and accounts for an estimated 60-80% of cases.⁵ Similar to other types, it is characterized by a progressive deterioration in memory, communication abilities, and other cognitive abilities that affect one's capacity to perform everyday activities. Currently, AD affects approximately 5.7 million Americans.⁵ By 2050, one new case of AD is expected to develop every 33 seconds in the U.S., and the total projected prevalence is expected to be 14 million.⁵

At present, most types of dementia have no known prevention or cure. As medical research progresses, public policy must address the following issues:

1. Racial, cultural, and socioeconomic disparities in the incidence and prevalence of AD.
2. Economic and social impacts of dementia on families, medical systems, and the nation's workforce.

2018 ALZHEIMER'S DISEASE FACTS AND FIGURES

ALZHEIMER'S DISEASE IS THE

6TH leading cause of death
in the United States

16.1 MILLION AMERICANS
provide unpaid care for people with
Alzheimer's or other dementias

These caregivers provided an estimated
18.4 BILLION HOURS
of care valued at over
\$232 BILLION

Between 2000 and
2015 deaths from heart
disease have decreased

11% 

while deaths from Alzheimer's
disease have increased



123%



1 IN 3

seniors dies
with Alzheimer's
or another
dementia

It kills more than
breast cancer and
prostate cancer

COMBINED



EARLY AND ACCURATE DIAGNOSIS
COULD SAVE UP TO

\$7.9 TRILLION
in medical and care costs

IN 2018, Alzheimer's and other
dementias will cost the nation

\$277 BILLION

BY 2050, these costs
could rise as high as

\$1.1 TRILLION

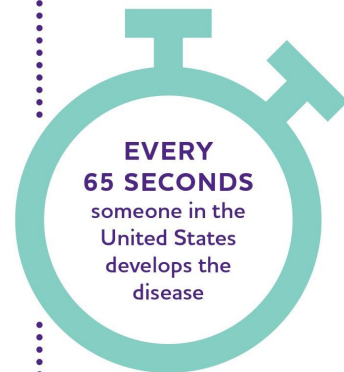


**5.7
MILLION**

Americans are living
with Alzheimer's

BY 2050, this
number is projected
to rise to nearly

**14
MILLION**



alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS®

Ethnocultural Diversity

By 2044, the U.S. will be a majority-minority nation.⁶ At that time, the sum of the various minorities will be larger than the “majority” white population. In the older population, racial minorities will account for 39.1% by 2050.⁷ It is projected that minorities with AD will more than double by 2030, increasing to 6.9 million.⁸ As the population becomes increasingly diverse, the social and economic burden of AD on minority communities is expected to grow rapidly.

Recent data from the Centers for Disease Control and Prevention indicate that between 1999 and 2014, AD deaths increased by 54.5%.⁹ However, in that same period, they increased by 99.4% and 107.2% in the African-American and Latino populations, respectively.⁹ Compared with Caucasian Americans, African-Americans are twice as likely, and Latinos are at least 1.5 times as likely to develop AD.¹⁰ These statistics highlight the disproportionate impact of AD on minority communities, who are more vulnerable and at higher risk.

Despite the higher rate of incidence in these minority groups, such patients generally receive delayed diagnosis and inadequate treatment for dementia. This concern is likely a result of the following factors:

1. *Inadequate education:* Due to lack of resources with information about the aging process, AD, and preventative care, patients and families are less likely to recognize the signs and symptoms of the disease. Thus, patients are unlikely to receive early intervention or therapies.
2. *Deterioration of trust:* In minority populations, trust in the medical community has been eroded as a result of negative experiences, such as the Tuskegee syphilis experiment, poor standards of care, and communication barriers. This general distrust can be passed on through generations.
3. *Cultural beliefs:* Some groups stigmatize illnesses, patient dependencies, and reliance on third-party care because of strong cultural roots. For example, families may overlook behavioral changes and memory loss because of respect for their elders.
4. *Lack of access:* These populations often have fewer resources and financial options, including lack of or inadequate health insurance coverage. Also, the complex healthcare system impairs patients and families ability to seek appropriate care or manage chronic conditions.

The implications of this demographic shift are further complicated by the underrepresentation of racial and ethnic minorities in clinical trials and

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Social and Financial Costs of Millennial Dementia Caregivers

research. With biomarker-based diagnostic tools and precision medicine at the forefront of research, it is imperative that participants must mirror the broader U.S. demographic.

Shift to Millennial Caregiving

Due to the increasing racial and cultural diversity among older adult populations, understanding the influence of cultural values on caregiving is important to provide support for individuals affected by dementia. As baby boomers and later generations continue to age and become increasingly ethnoculturally diverse, their care needs will continue to increase. These needs will be fulfilled by informal caregivers, such as spouses and children.

Additionally, as the older population becomes increasingly diverse, various cultural factors may influence the caregiving experience. In many minority communities, the family is considered the primary support system. That is, the younger generations take full responsibility in caring for family members with dementia and other illnesses. Minority populations may face barriers to accessing services, stigma, language barriers, and cultural conflicts leading to less usage of formal caregiving services.

Nearly a quarter of America's estimated 43.5 million caregivers are millennials (born 1980 - 1998).¹¹ When it comes to caring for someone with dementia, about one out of six millennials are caregivers, with an average age of 27 years.¹² Roughly 42% of millennial dementia caregivers are sole caregivers, and 79% reported that accessing affordable support was very difficult.¹² Additionally, lower-wage positions are often less likely than higher-wage positions to offer paid leave. Thus, individuals in these positions are more likely to face adverse circumstances, when they need to provide caregiving services to their family members. Due to the competing demands of caregiving and employment, working caregivers often report emotional distress, psychological illness, and physical health concerns.

Many family caregivers experience financial hardships as a result of lost wages, pensions, and Social Security benefits. Their careers are often negatively affected by their need for flexible schedules, family leave, reduced hours. This burden also negatively affects businesses because of decreased employee productivity and potentially greater employee health risks. Finally, as millennials and later generations leave the workforce to assume caregiver positions, the nation's economic growth may be impeded, and gender and socioeconomic inequalities may be further widened.

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Economic and Social Impacts of Millennial Caregiving

More than half of millennial caregivers are minorities and are more likely than any other generation to balance caregiving with employment. Latino millennials work more hours each week, on average, and spend more time providing care than young adults of other backgrounds.¹³ This is partly because Latino culture is built around families and they are, therefore, more likely to live in multigenerational households.

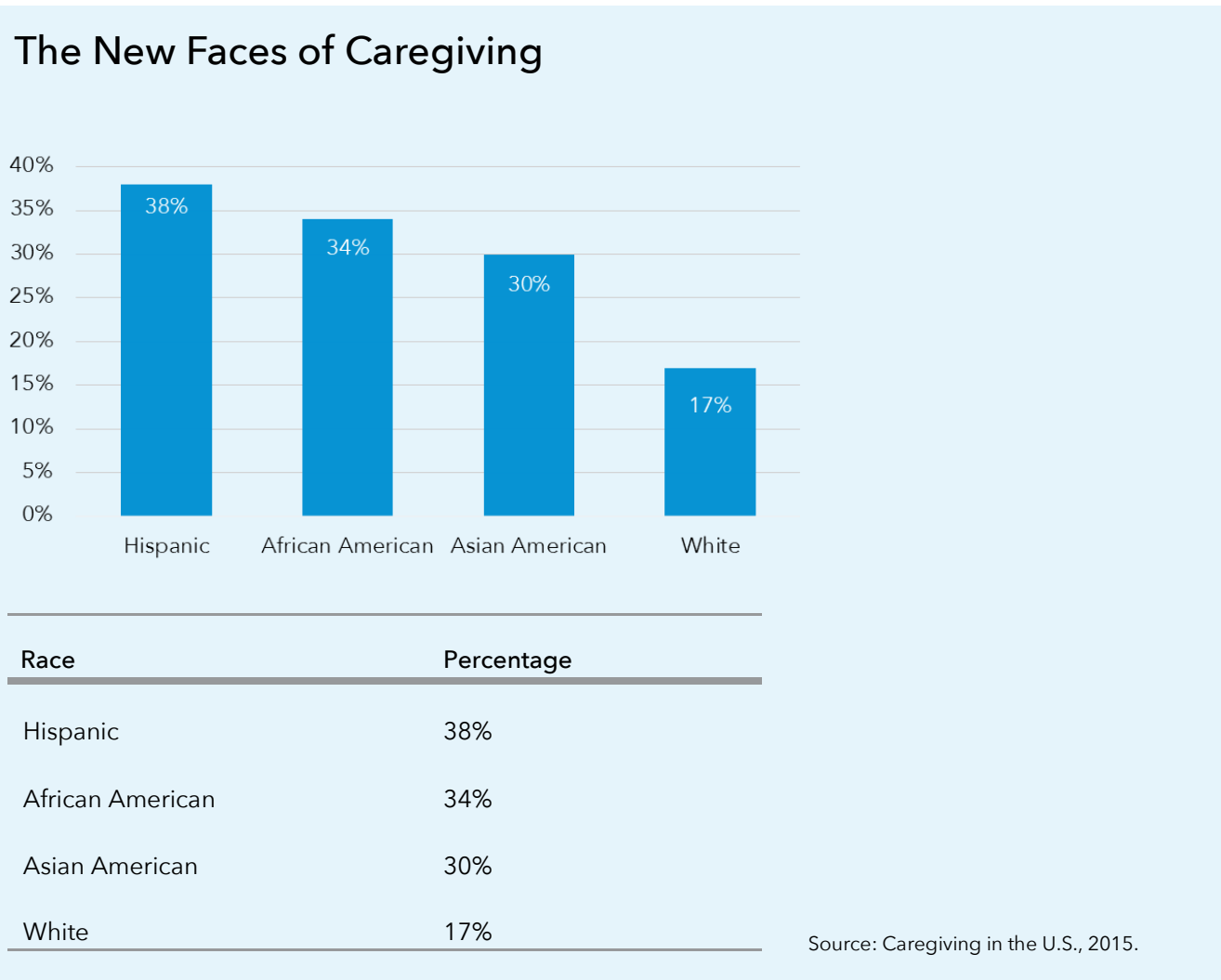
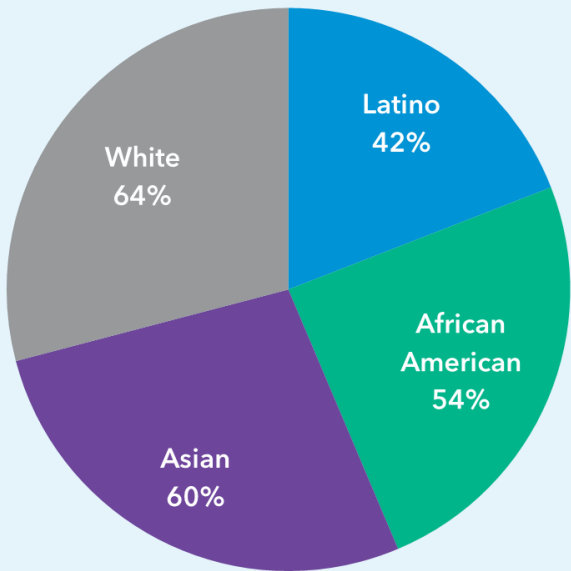


Figure 3. Millennial Caregivers by Race/Ethnicity

Educational and Financial Impact

Caregiving has a negative effect on millennial education. A recent report titled *Millennial and Dementia Caregiving* showed that only 45% of millennial caregivers have a high school degree.¹² Whites and Asians have higher high school completion rates, closely followed by African Americans, and then Latinos.¹² Latinos were also more likely to live with a dependent family member. Their caregiving and/or financial responsibilities may have contributed to the lower education level.

More Than High School Education



Race	Percentage
Latino	42%
African American	54%
Asian	60%
White	64%

Source: *Millennial and Dementia Caregiving in the United States*, 2017.

Figure 4. Caregiver High School Education Achievement by Race/Ethnicity

Social and Financial Costs of Millennial Dementia Caregivers

Student learning and success are often adversely affected by poor health. Overall, student caregivers are at higher risk for stress-related illnesses than traditional students.¹⁴ Hence millennial caregivers need a flexible learning environment to succeed academically and develop healthy coping skills.

In addition to decreased access to education, millennial caregivers experience financial difficulties and time constraints because of student debt and hours spent providing care. These factors can complicate their relationship with their loved ones due to the time spent on caregiving which impacts their future savings and investments in their education. The majority of millennial caregivers assist without paid help, significantly contributing to the estimated \$470 billion worth of unpaid care provided by family caregivers.¹⁵ Limitations in time can lead caregivers not to prioritize life goals, including saving for a comfortable retirement, buying a house or starting a business.

Caregiving responsibilities can also affect work experience, leading to increasing education gaps. Today's job market puts millennial caregivers at a disadvantage because education and work experience have been shown to be critical.

Employment Impact

Caregiving has a negative impact on millennial employment. About one out of two millennial dementia caregivers stated that caregiving interfered with their work, and 33% reported losing their job benefits or being fired, among other issues.¹² This can be challenging when dealing with tasks like navigating the health care system or coordinating care between multiple providers while employed. Depending on the stage or severity of a family member's dementia, millennial employment can be severely affected. When they try to return to the workforce without much formal education or when they have significant gaps in employment, they might not be as competitive compared with their peers. Without financial, employer, or community support, this demographic group can be unfairly disadvantaged regarding economic mobility, and those who are most at risk will experience greater difficulties.

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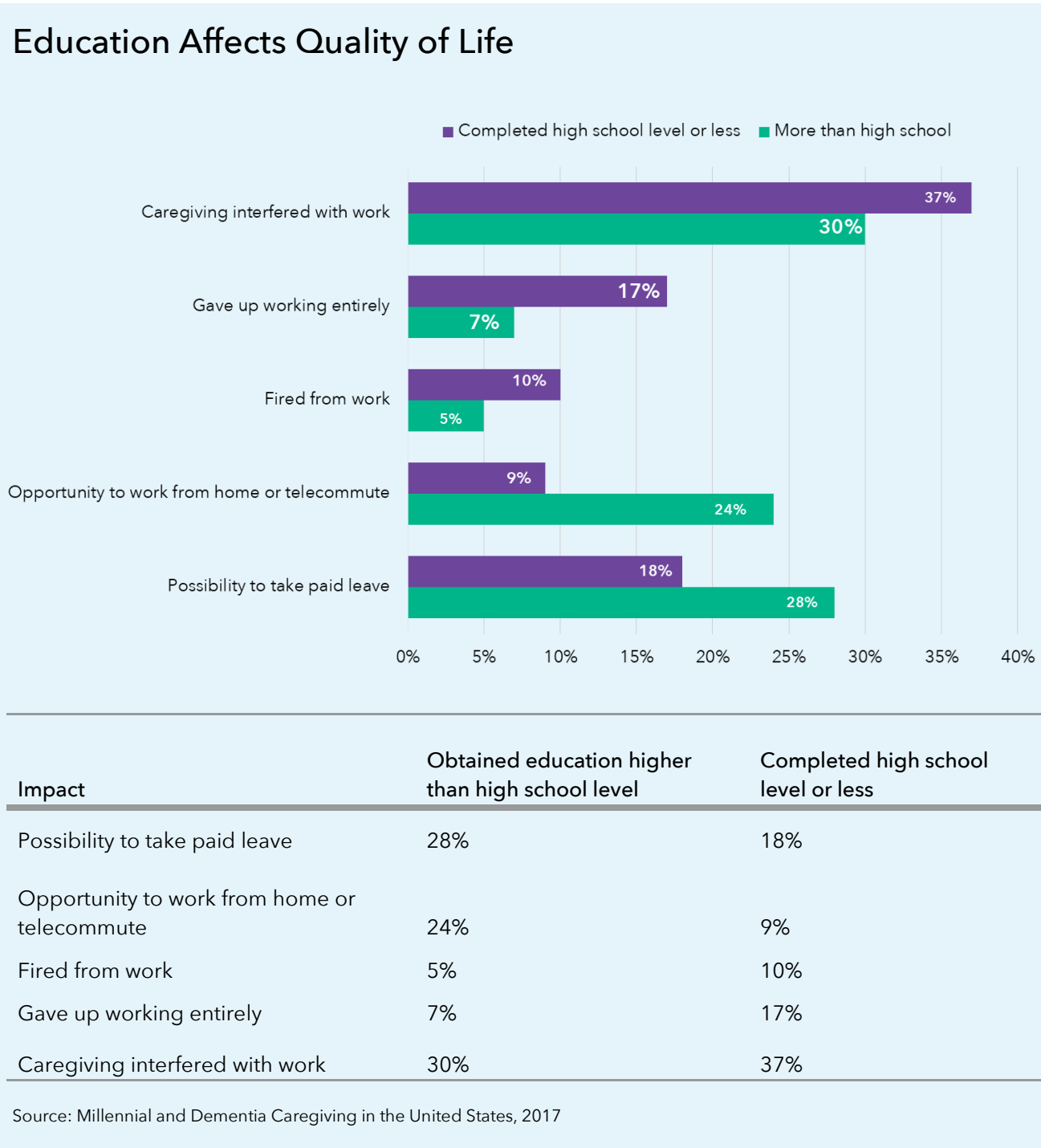


Figure 5. Impacts by Differences in Educational Attainment

Role of Public Health Policy

With challenges come opportunities to promote policies that enable active engagement and quality of life for millennial caregivers who are ethnoculturally diverse. Both the public and private sectors must collaborate to create culturally sensitive resources and implement innovative strategies affecting the millennial caregiving experience. While by no means exhaustive, the below provides some ideas that could lead to a substantial impact.

Health Effects

Not surprisingly, the key to achieving good health is dependent on a person's geographic location, level of education, income, ethnicity, job, and social connections within his/her community more so than access to healthcare. These factors are collectively known as the social determinants of health (SDoH), a relatively new term in healthcare describing "the conditions in which people are born, grow, live, work and age," as defined by the WHO. Research, while not widespread, has shown the positive correlation between social determinants of health (SDoH) and quality of life among family caregivers in different settings.¹⁶

As SDoH is complex, loss of employment opportunities and a lower educational level can affect the social status of millennial caregivers, especially those who are from different racial and ethnic backgrounds. Millennial caregivers for people with dementia face significant challenges that can affect health equity, including increased pressure and caregiver stress, which can lead to burnout and higher levels of anxiety and depression. 79% feel emotional distress was a major caregiving burden, and only 37% of those who are active unpaid caregivers reported receiving adequate emotional support.^{12,17} Majority of caregiving involves significant sacrifices in health, finances and family dynamics leading to long-term health effects, such as a weakened immune system, high blood pressure, and post-traumatic stress disorder.

Potential policy recommendations include better training for informal caregivers to understand the signs of dementia and the family caregiving experience. This can help identify and tackle stressors to reduce caregiver burnout and depression. Also providing home health care professionals with incentivized training in geriatrics will help alleviate the national shortage of geriatric health care professionals, a shortage that will only worsen as dementia cases rise with increasing longevity.

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Social and Financial Costs of Millennial Dementia Caregivers

Improved coordination between long-term care services and other social services can help increase respite and emotional support for caregivers. Additionally, greater public awareness and availability of palliative care is essential to improve the quality of life for both caregivers and patients.

Financial Well-being

By about 2033, working-age Americans (millennials) will support more people over 64 than under 18.¹⁸ Millennials are in a significant period of transition as they start families, careers, and wealth building. As they face more caregiving responsibilities because of population aging, their economic well-being can be severely affected. Population aging also raises serious questions for policymakers and on the financial viability of the healthcare system. The economic and personal strain of long-term care is worsened by the fact that Medicare generally does not cover long-term care. Additionally, Medicare only offers benefits to people with low income in the U.S. Without substantial savings, an employment history, and financial relief from the federal government and employers, millennial dementia caregivers face an uphill battle that can affect not just their economic well-being but also their mental health.

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Potential policy recommendations include permitting Medicare Advantage plans to offer a respite care benefit as a distinct and optional benefit. Medicare currently covers respite as a part of its hospice benefit, but the beneficiary qualifications are more appropriate for patients who are terminally ill. An alternative policy recommendation entails expanding that requirement to include beneficiaries who are not terminally ill. Employers can also offer caregiver respite in the workplace as a fringe benefit. Additionally, increasing insurance coverage for long-term care services as well as making long-term care insurance more affordable could reduce the burden on individual families and minimize labor market side effects.¹⁹

Employee Productivity

The U.S. is one of the few developed countries that does not guarantee paid leave for employees to care for family members. Additionally, most employers do not offer paid leave at all, leaving many without guaranteed job security, flexibility, or a financial safety net. Data from the Family Caregiver Alliance showed that informal caregiving costs U.S. businesses as much as US\$33 billion in lost productivity each year.²⁰ This amount includes the costs of replacing workers, shifting employees from full- to part-time positions, dealing with absenteeism, and making workday adjustments. As the caregiving crisis looms for aging Americans, lost productivity can negatively affect the economic success of the country, as well as the current and future financial security of workers.

Potential policy recommendations include supporting caregivers through flexible work policies, including offering paid or unpaid caregiving leave beyond the requirements of the Family and Medical Leave Act (FMLA). This is a promising but still emerging trend that has shown to boost an employer's competitive advantage in recruitment and retention.²¹ Currently, FMLA covers only 55 to 60% of workers due to limitations on eligibility, for instance, employees must have worked for at least 12 months.²² Another recommendation involves partnerships between employers and care providers to find affordable options that are easy to implement for working caregivers. Moreover, employers can consider setting up a Staff Emergency Fund to provide financial assistance for home health care, especially during early-stage dementia. Such support can help companies realize increased productivity as well as decreased absenteeism (lost workdays) in the workplace.²¹

Calls for Action

1. Define public policy in supporting family caregivers in providing care.

Regulators should create an Inter-Agency Respite Care Task Force to coordinate engagement efforts and drive the conversation on how respite can support prevention and wellness for both caregivers and patients. Regulators can also expand respite care options to support caregiver choice and preferences.

2. Address how universities can better support student caregivers.

Universities should promote effective student-centered teaching and encourage instructors to make accommodations for student caregivers as emergencies arise. Universities can also ensure access to institutional support and resources to promote persistence and success.

3. Companies and employers take the lead in supporting working caregivers.

Companies can employ innovative business interventions to support and enhance caregiving, such as phone-based therapy sessions, online support forums, and social group chat apps that will benefit the broader society.

Employers should implement cost-effective financial wellness programs in the workplace. This unique benefit helps reduce employees' financial stress and supports employees' financial stability.

4. Caregiver supports begin in communities.

Families can build a caregiver support system to provide assistance and emotional support to manage burnout. The support system can include close friends and family connections.

Conclusion

Dementia is a growing public health concern with the prevalence of AD expected to increase to 16 million in 2050. An examination of the shift in informal family caregiving and the changing racial and ethnic composition of the U.S. population aligns with the need for increasing caregiver support. As the U.S. becomes majority-minority, disparities impacting racial and ethnic minorities as patients and caregivers, specifically informal caregivers for family members with dementia, will have detrimental impacts on the economy and personal well-being. Thus, public policies and workplace programs must identify solutions to reduce the stress and burden associated with informal caregiving. The goal is to prevent a further caregiving divide in the U.S. population.

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[Sophie Okolo, MPH](#), is the Project Lead for AtSelah Health. She is a researcher and science writer with experience in healthy aging, patient engagement, and scientific research. Her work focuses on preventing Alzheimer's disease and cognitive decline, improving the quality of life for older people, and increasing awareness of preventive healthcare strategies. Sophie has researched the role of patient navigators in eliminating health disparities, as well as advance directives and Medicare spending at the end of life. Her articles regarding the intersection of technology and healthcare, including how innovations transform the management of chronic disease for diverse populations, have been published extensively, most notably appearing in PBS Next Avenue, Forbes, MarketWatch, Brandchannel, Pfizer Get Old and other media outlets. She has a master's degree in public and community health from Armstrong Atlantic State University and bachelor's degree in bioinformatics from Ramapo College of New Jersey. An advocate for diversity and inclusion in STEM, Sophie supports various causes that advance female and minority representation.

[Joseph Gaspero](#) is the CEO and Co-Founder of CHI. He is a healthcare executive, strategist, and researcher. He co-founded CHI in 2009 to be an independent, objective, and interdisciplinary research and education institute for healthcare. Joseph leads CHI's research and education initiatives focusing on including patient-driven healthcare, patient engagement, clinical trials, drug pricing, and other pressing healthcare issues. He sets and executes CHI's strategy, devises marketing tactics, leads fundraising efforts, and manages CHI's Management team. Joseph is passionate and committed to making healthcare and our world a better place. His leadership stems from a wide array of experiences, including founding and operating several non-profit and for-profit organizations, serving in the U.S. Air Force in support of 2 foreign wars, and deriving expertise from time spent in industries such as healthcare, financial services, and marketing. Joseph's skills include strategy, management, entrepreneurship, healthcare, clinical trials, diversity & inclusion, life sciences, research, marketing, and finance. He has lived in six countries, traveled to over 30 more, and speaks 3 languages, all which help him view business strategy through the prism of a global, interconnected 21st century. Joseph has a B.S. in Finance from the University of Illinois at Chicago. When he's not immersed in his work at CHI, he spends his time snowboarding backcountry, skydiving, mountain biking, volunteering, engaging in MMA, and rock climbing.

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About the Center for Healthcare Innovation:

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CHI Memberships are on annual basis. Memberships terms can be on a calendar year or fiscal year, based on the preferences of the member organizations. Members can also join on a pro-rated basis for those organizations seeking memberships midway through the current year. As part of the membership process, new members will meet with CHI staff and Board of Director(s) to discuss how to best utilize the membership, as well as help us understand how to create the most valuable membership experience for your organization.

Why Become Member?

CHI Memberships provide members with comprehensive access to [research](#) and [education](#) throughout the year.

Together, CHI and members aim to:

- Understand opportunities, challenges, trends, and best practices related to healthcare innovation, value, quality, access, and cost, as well as understand how the health sector can best serve patient communities
- Create dialogue among organizational leaders and professionals, CHI Board of Directors, and CHI staff on some of the most pressing healthcare issues and challenges

	Platinum	Gold	Silver	Bronze
MEMBER BENEFITS	\$25,000	\$15,000	\$10,000	\$5,000
Premier branding opportunities on event programs, research reports & website banners	●	●	●	●
Website advertising and logo placement	●	●	●	●
Special acknowledgement as CHI patron & supporter in widely-distributed programs & other overviews	●	●	●	●
Attendees at CHI's annual educational events (minimum 3 events across the nation)	20	15	10	5
Opportunity to serve as distinguished panelist(s) at CHI's educational events (Based on representative's area of expertise & current role)	5	3	2	1
Guest blogging & other thought-leadership opportunities	6 times / year	4 times / year	3 times / year	2 times / year
Get exclusive early access (30 days earlier) to CHI's research reports	●	●	●	●
Organizational logo & branding opportunities on CHI's research reports	3 times / year	2 times / year	once / year	N/A
Opportunity to make Opening Remarks at CHI's Board of Directors Strategic Retreat (June)	2 attendees & opportunity to make remarks	1 attendee	N/A	N/A
Receive special briefing from Chairman & Vice Chairman of the Board on CHI's annual report	●	●	N/A	N/A
Sponsor research reports & white papers (assist in shaping topic or become a collaborator)	●	N/A	N/A	N/A

Please call (773) 330-2416 or reach out to info@chisite.org for more information.

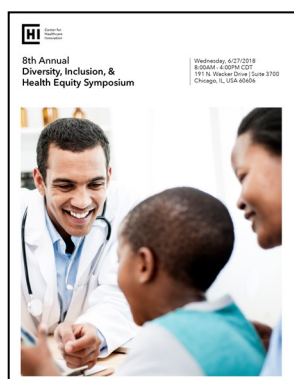
Recent and Upcoming Research and Events

Developing the Next Generation of Culturally Competent Healthcare Leaders Workshop

Friday, April 5, 2019 | Austin, TX, USA

This workshop brings together healthcare leaders, medical school academics and leaders, providers, patients, pharma, and other stakeholder groups for an innovative and collaborative discussion on how to best equip our future healthcare leaders with the knowledge, skills, and attitudes that allow them to adequately treat all patients and communicate with their families. Medical school and other healthcare training curriculums must be designed to appropriately train cultural competence. By proactively beginning to think about culturally competent healthcare leaders of tomorrow, we can begin to take steps towards addressing the broader healthcare disparities and health inequities that afflict the U.S. healthcare system.

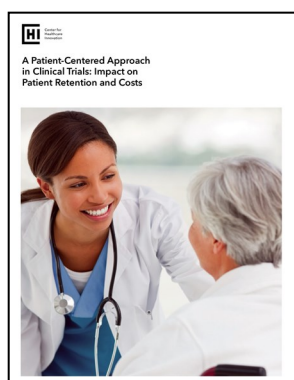
[Learn More](#)



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Diversity, Inclusion, Health Equity Symposium Executive Summary

This Executive Summary is based on CHI's 8th Annual Diversity, Inclusion, & Health Equity Symposium, a leading annual, collaborative event focusing on health equity and health disparities in the U.S. The symposium brings together leading healthcare professionals, executives, physicians, patient groups, patients, researchers, academics, clinical trial professionals, and diversity and inclusion advocates to discuss health equity in the life sciences and the health sectors. This executive summary captures some of the insights, ideas, best practices, and new perspectives from the Symposium's distinguished speakers, panelists, and other experts. It is meant to serve as a summary of the innovative ideas and insights regarding diversity and inclusion for healthcare and the life sciences. We hope it can be a resource for you and your organization as you think about diversity in the 21st century.



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A Patient-Centered Approach in Clinical Trials: Impact on Patient Retention and Costs

This white paper reviews the patient-centered care (PCC) model and examines how several PCC metrics may be influential in reducing clinical trials dropouts, ultimately resulting in reduced costs. In particular, we analyze how the adoption of a patient-centric model in clinical trials recruitment and retention has potential for cost savings by improving patient education, engagement, and retention of chronically ill patients in clinical trials. In an era of increasing complexity and rising costs, the drug development industry is increasingly focusing on personalized medicine in their patient recruitment and retention strategies. However, there is limited research on the use of patient-centric approaches to retain patients with chronic disease such as cancer. Often, these patients have functional limitations, difficulty accessing care, or lack the proper education and awareness of clinical trials. Patient-centric interventions, including increasing access to transportation and health information technology (HIT) or improving patient-centeredness among providers can help increase engagement and retention of the most vulnerable patient populations.



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Our vision is to
be the leading
global platform
for meaningful
change in health
equity.



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