The Role of Social Determinants of Health in Epilepsy

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By

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**Cambridge
Scholars**
Publishing

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This book first published 2022

Cambridge Scholars Publishing

Lady Stephenson Library, Newcastle upon Tyne, NE6 2PA, UK

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN (10): 1-5275-8008-3
ISBN (13): 978-1-5275-8008-4

The authors would like to dedicate this book to all the
scientists, academics, health care professionals, researchers,
industry representatives, advocates, policymakers, community
members and especially, individuals with epilepsy, that work
tirelessly to improve the lived experience, outcomes,
and social determinants of the epilepsy community.

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FOREWORD

Epilepsy is a disorder of the brain that affects millions in the US and across the world, but it doesn't affect everyone equally. Health disparities in epilepsy are a long-standing issue. While the age of onset, types of seizures, syndrome diagnosis and presence of comorbidities certainly drive outcomes for individuals with epilepsy (IWE), a person's social and economic situation also plays a major role. Health disparities in epilepsy occur across factors such as race/ethnicity, socioeconomic status, gender, age, disability, sexual orientation and gender identity, and geographic location. As highlighted in the text that follows, one of the most serious consequences of these disparities is a delay in appropriate treatment for the newly diagnosed.

People with epilepsy within certain population groups experience disparities in hospitalization rates and emergency department visits, lower rates of epilepsy surgery, higher rates of treatment non-adherence, and increased morbidity and mortality (Szaflarski 2014). Why do these differences exist? Many, though not all, arise from structural issues including a lack of access to adequate healthcare. In the United States, the complex patchwork of private and public insurance forces many people of low and middle-income to forgo diagnostic procedures and treatment options that they can't afford to pay for. For decades in the US, individuals of color have had higher rates of being uninsured than white individuals. Even people who are insured report cases of being denied access to specific testing or treatments that could help them. The many options for treatment that exist in epilepsy – medications, therapeutic diets or devices, and surgical interventions – are not equally available to all who need them.

But other determinants can be barriers for IWE, too: distance, language, and cultural attitudes and beliefs can play a role. As one example, in the US the number of neurologists per 100,000 people can vary five-fold across the country. States in the Southeast and West have more diverse populations, but the least availability of neurologists. Trust in providers and the healthcare system itself can influence outcomes. Although surgery is currently the only curative option in epilepsy care, only half of African American participants said they would consider epilepsy surgery if they were eligible.

Disparities arise from a complex set of interrelated factors, but they are not inevitable. Health equity is achievable, but not without proactive strategies that disrupt existing systems and practices. The 10 Essential Public Health Services offers a framework for protecting and promoting the health of all people in all communities. It promotes policies, systems, and overall community conditions that enable optimal health for all and seek to remove systemic and structural barriers resulting in health inequities (CDC 2021b).

The Epilepsy Foundation (EF) has developed resources and staff to strengthen its contributions to the 10 Essential Public Health Services for IWE. As a direct result of these strategies, EF has increased the number of individuals from racial and ethnic minorities who are trained in seizure first aid and/or have become instructors; diversified the instructors of the School Nurse Training Program; trained more than 400 minority health providers in epilepsy awareness and recognition; increased awareness of racial epilepsy disparities among our Network and other public health organizations; increased the availability of epilepsy resources in various languages, including Arabic, Navajo, and Korean; and enhanced outreach efforts to ensure IWEs from all races, ethnicities, locations, religions, etc. are included in epilepsy services, and are comfortable seeking support for physical, mental, and social health needs through the helpline.

We applaud Dr. Sirven and Dr. Reddy for producing a definitive text on the impact of social determinants on the health and treatment of people with epilepsy. We hope that by calling attention to these disparities, the medical community will be better equipped to connect people with epilepsy to the care they need and the health outcomes the Epilepsy Foundation strives to achieve.

Laura Thrall
President and CEO
Epilepsy Foundation of America

Brandy Fureman, PhD
Chief Outcomes Officer
Epilepsy Foundation of America

September 2021

INTRODUCTION

Epilepsy is a spectrum disorder comprising more than 25 syndromes and many types of seizures that vary in severity. It is also one of the most common neurological disorders, with 1 in 26 people estimated to develop epilepsy at some point in their lives. In the United States (US), approximately 3.4 million people, or 1.2% of the population, are currently living with the condition (Institute of Medicine 2012).

Epilepsy often adversely affects patients' and caregivers' health and quality of life. Individuals with epilepsy (IWE) also face a wide variety of challenges. Untreated epilepsy can result in poor health outcomes (e.g., continued seizures resulting in neurological deficits) and psychological and social consequences such as limitations on employment, loss of driving privileges, strains on personal relationships, and social isolation or marginalization associated with the stigma of having epilepsy. More seriously, IWE have an approximately threefold increased risk of premature death compared to those who do not have seizures (Nevalainen et al. 2014).

In the majority of cases, epilepsy is a treatable condition—with antiseizure medications (ASMs) being the most suitable treatment option. In colloquial settings as well as the literature, you may see the terms antiseizure drug (ASD) or antiepileptic drug (AED) used synonymously with ASM. Once a clear diagnosis of epilepsy can be made, clinical practice guidelines recommend beginning treatment with ASMs as early as possible if other, more invasive, interventions are not warranted (Krumholz et al. 2015; Marson et al. 2005). Moreover, it is approximated that up to 70% of IWE could become seizure-free with appropriate diagnosis and use of cost-effective, and commonly available, antiseizure medications (American Epilepsy Society 2013). This can lead IWE to continue, or return to, a full and productive life. However, even with the low cost associated with the most common ASMs, more than 75% of IWE in low-income countries do not receive treatment (Meyer et al. 2010). Left untreated, IWE face devastating social consequences, including stigma, discrimination, and human rights violations—especially in low-income countries.

Despite the availability of upwards of 30 common ASMs in the US, and several more in the developmental pipeline, initiation of ASMs are often significantly delayed (American Epilepsy Society 2018; Epilepsy Foundation 2021d). A recent study shows that in the US one-third of newly diagnosed patients remain untreated up to 3 years after epilepsy diagnosis (Kalilani et al. 2019). This significant treatment gap increases the risk of adverse medical events (including burns, falls, fractures, motor vehicle accidents, and suicidality), emergency department (ED) visits, and hospital admissions. While there is limited evidence to explain the delay in ASM initiation, the emerging body of literature on the impact of the social determinants of health (SDoH) suggests they may play a critical role in this gap in care.

SDoH broadly include factors such as socioeconomic status, education, neighborhood and physical environment, employment, and social support networks, as well as access to health care and the quality of care received. The relationship between communities and health is becoming widely recognized, with experts attesting that zip code is a stronger predictor of a person's health than their genetic code (Graham, Ostrowski, and Sabina 2015). Assessing community-level SDoH factors will play a pivotal role in future research assessing the fundamental root causes of epilepsy treatment disparities.

Because epilepsy is a complex spectrum of disorders that vary in etiology (i.e., cause) and present with a range of severities and comorbidities, the work on determining the impact of SDoH on epilepsy treatment disparities is inherently difficult. The same social factors that may have an impact on one IWE can have varying effects on other IWEs depending on the type and severity of their epilepsy. Part I of the textbook includes chapters that will discuss many social factors that have the potential to impact the lives of those with chronic conditions like epilepsy.

Measures of Treatment Disparities

The literature that focuses on epilepsy treatment disparities often includes references to "treatment gaps" or "treatment delays". For the purposes of this textbook, it is important to acknowledge what these terms mean—and how to properly distinguish between them.

A "*treatment gap*" refers to the number of people that have a certain condition and require medical intervention but do not receive it. Treatment gaps serve as a useful parameter to assess the adequacy of access and quality of care for patients across populations. Research has shown the existence of treatment gaps both for epilepsy and many other conditions—in the US as well as around the world (Meyer et al. 2010; Faught et al. 2018).

The epilepsy treatment gap is generally defined in the literature as the proportion of individuals in a given population at a given time that have been diagnosed with epilepsy, but have not yet been appropriately treated (i.e., initiated ASM therapy or undergone surgery) (Meyer et al. 2010; Meinardi, Scott, and Reis 2001).

In a similar scope, a "*treatment delay*" measures the length of time in which patients diagnosed with a certain condition fail to receive appropriate treatment. Pertaining to epilepsy, it can be thought of as the length of time elapsed after a clear diagnosis of epilepsy is reached and the patient begins treatment (i.e., started on ASM therapy).

Both treatment gaps and treatment delays signify a lapse in the quality of care needed by patients to manage their condition and sustain a healthy life. Inadequate treatment has been shown to have significant consequences on clinical outcomes and quality-of-life, as will be discussed.

Treatment gaps and treatment delays impact individuals in populations across the world—but particularly those in low-income countries and those living in underserved communities, both in the US and abroad (Meyer et al. 2012; Burneo et al. 2009; Mbuba et al. 2008). Better understanding of the *causes* for these treatment gaps and delays, especially for lower-income populations, necessitates a deeper examination of the upstream factors—more commonly known as the "social determinants of health"—that impact lived experiences. Research surrounding SDoH has become a major focus in recent years within population health and medical communities seeking to better understand the drivers of treatment gaps. SDoH have already been shown to affect a wide range of health, functioning, and quality-of-life outcomes and risks (US Department of Health and Human Services 2020). The term "SDoH" encompasses a range of social, economic, environmental, and systemic factors—many of which will be discussed as likely contributors to epilepsy treatment disparities.

The purpose of this textbook is to improve our understanding of epilepsy treatment disparities, identify best practices regarding initiation of ASM treatment and more closely examine the relationship between SDoH and other variables that contribute to treatment disparities and health outcomes for individuals living with epilepsy. Incorporated throughout each chapter are anecdotes, based on real patient stories, that highlight the role those social determinants play in the lived experiences of those living with epilepsy.

PART I:

THE SOCIAL DETERMINANTS OF HEALTH

CHAPTER 1

OVERVIEW OF THE SOCIAL DETERMINANTS OF HEALTH

"Health inequalities and the social determinants of health are not a footnote
to the determinants of health. They are the main issue."
—Michael Marmot

Learning Objectives

- Define social determinants of health.
- Recognize that social determinants of health can impact an individual or community's health.
- Identify five key social determinant categories, guided by the *Health People 2030* framework.
- Understand that social determinants of health impact health outcomes for individuals living with epilepsy.

Case Study:

A 39-year-old Hispanic male presented to the epilepsy clinic at an institution in California. He had been in previously good health until he was involved in a motor vehicle accident two years ago, in which he was ejected from his vehicle after being struck by a car that ran a red light. As a result of the accident, he suffered a brain hemorrhage primarily affecting his right temporal lobe. He fully recovered from his injury; however, he was left with weekly focal seizures that impaired his consciousness and manifested primarily as blank staring and mouth movements lasting for one minute. On rare occasions, these events would lead to a full-blown convulsion. Given that the patient had no recollection of the events, he perceived them as though they were not occurring at all. The patient had tried at least two antiseizure medications, and both had failed to stop the seizures. Further complicating this picture was the fact that the patient may have forgotten to take his medications because of his poor short-term memory.

Prior to the accident, the patient was a manager at a big box retailer, having completed high school and two years of college. He was married with two young kids, both of whom are healthy. His wife worked at a local hotel in the cleaning department. After the seizures started, the patient lost his driving privileges according to state laws that mandate the suspension of driving licenses for individuals with uncontrolled seizures. As a result, his wife had to drive him to work, as well as stay at home to make sure he is okay, causing her to miss work herself. When the patient lost his job because he was making numerous analytical errors with supplies, he ultimately lost his health insurance, and he could no longer afford his antiseizure medication. In the meantime, they had applied for state Medicaid health coverage. His job prospects were poor, and his wife was under considerable stress at home trying to work to provide for the family, as well as care for her husband and her children. Their marriage was strained from the situation and the children were struggling in school because they were worried about their father. The family wanted to seek a definitive cure for his case of epilepsy by getting evaluated for epilepsy surgery. However, their state Medicaid plan did not adequately cover the cost and they could not afford the co-payments.

—Joseph Sirven, MD

The term social determinants of health (SDoH) is used to describe the health-related impacts of the physical and socio-cultural environments on individuals and populations. The World Health Organization (WHO) defines SDoH as, “the conditions in which people are born, grow, live, work and age...shaped by the distribution of money, power and resources at global, national and local levels” (World Health Organization 2021b). It is important to note that the term “social determinants of health,” in and of itself, carries neither a positive nor negative connotation. It is the actual lived experience of social determinant factors by people in their own lives, or how individuals experience the social determinants, that can result in positive or negative health outcomes.

Healthy People 2030, an initiative launched by the Department of Health and Human Services (HHS) and Centers for Disease Control and Prevention (CDC), developed a place-based organizing framework reflecting five key areas of SDoH (Fig. 1-1).

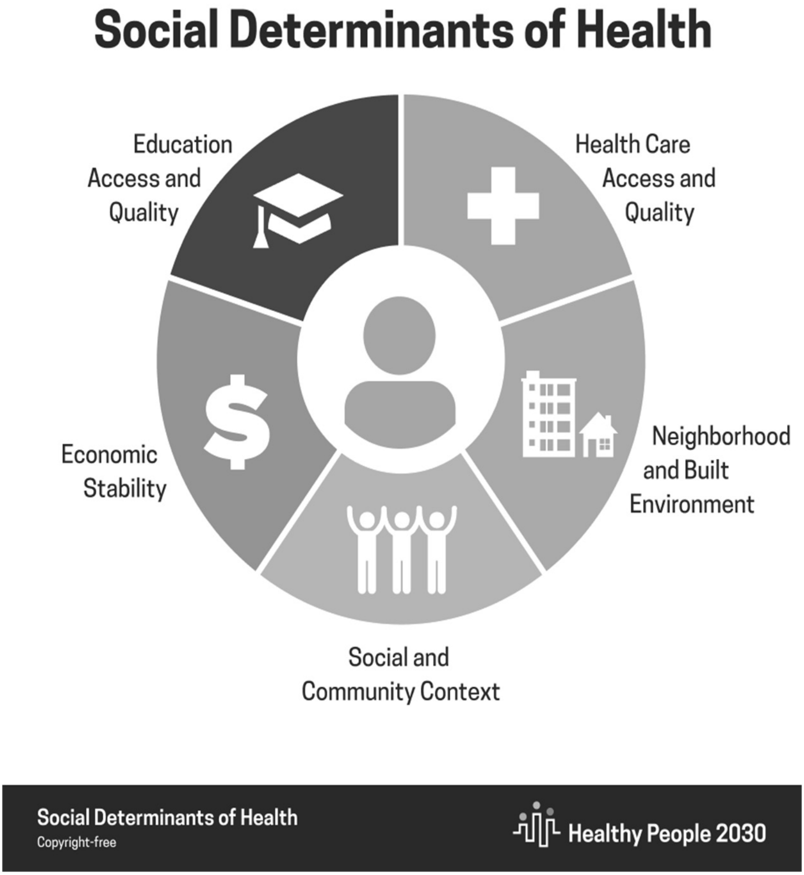


Fig. 1-1: The five key social determinant categories of the CDC's *Healthy People 2030* place-based organizing framework.
Source: Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved [June 1, 2021], from https://health.gov/healthypeople/objectives-and-data/social-determinants-health.

Under each of these five key determinant areas, the *Healthy People 2030* framework considers a number of key issues that now constitute the underlying factors of interest in the arena of SDoH. For the purpose of this textbook, we will use the five key *Healthy People 2030* areas as a guiding framework. Each of the five categories are described in greater detail in the following chapters, accompanied by informative snapshots of relevant statistics for each.

When examining the factors of life that drive health outcomes for individuals, most would likely guess that health care—that is, the delivery of clinical services—plays the largest role. In reality, although the delivery of health care is crucial, it ends up serving a much more minor role in driving health outcomes from a population health and lifestyle perspective. An emerging body of literature increasingly demonstrates that health outcomes are largely influenced by a confluence of factors other than health care—including behavioral patterns, underlying genetics, and social and environmental determinants (i.e. SDoH) (Fig 1-2). Therefore, if we wish to understand the true drivers of health outcomes, we must acquire a deeper understanding of the unique role played by behavior, social circumstances, and the environment through the lens of SDoH across a variety of populations.

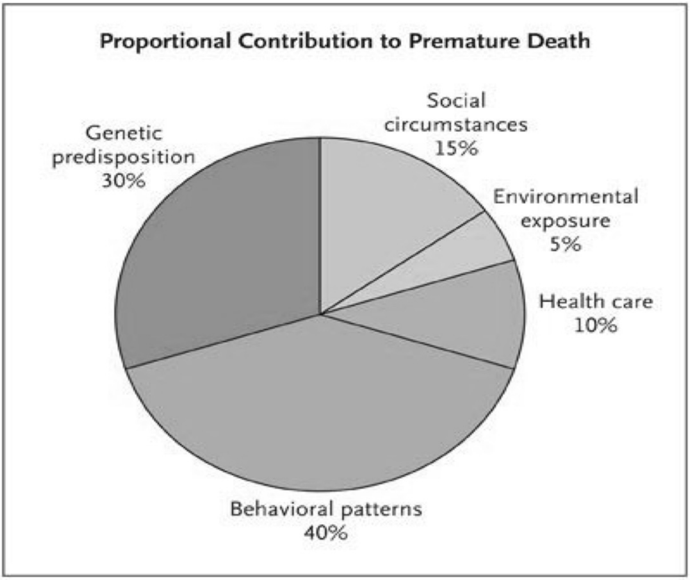


Figure 1-2: Determinants of Health and Their Contribution to Premature Death
Source: Schroeder, SA. (2007) We Can Do Better – Improving the Health of the American People. NEJM. 357:1221-8.

The Americans with Disabilities Act

The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination based on disability and is considered civil rights legislation. Under the ADA, discrimination on the basis of disability is prohibited in aspects of life such as: employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. ADA protection is given to those with a disability or those who have a relationship or association with an individual with a disability. The ADA defines an individual with a disability as “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” (US Department of Justice 2020). As federal legislation, the ADA equally protects all those qualified under its protections, regardless of state of residence.

Important to our discussion, IWE are covered under the protections of the ADA. Those with seizure disorders are considered to have a condition that impedes and, in some cases, can significantly limit the ability to participate in necessary life activities and therefore qualifies as a covered disability. ADA protections can play an important role in improving the lifestyle of IWE by impacting many SDoH factors. Examples of key social determinants impacted by ADA protections for IWE include: public and private transportation, employment, medical examinations, health insurance coverage, and others that will be discussed in subsequent chapters.

COVID-19 and the Social Determinants of Health: Never Let a Good Crisis Go to Waste

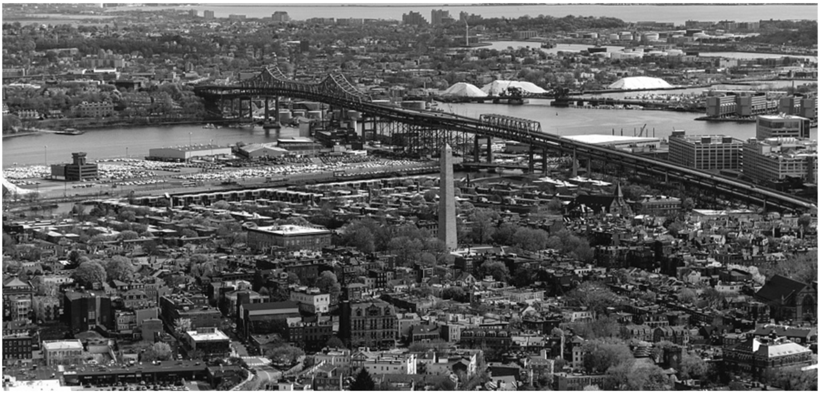
In December 2019, the outbreak of a novel coronavirus, SARS-CoV-2, emerged as arguably the foremost public health crisis of our time. Unprecedented in the speed and severity with which it has impacted all aspects of life both in the US and throughout the world, COVID-19 has taken the lives of more than 3.5 million and infected more than 169 million at the time of this writing (Johns Hopkins Coronavirus Resource Center 2021). The enormous burden that the pandemic has placed upon every corner of our health care system and economy cannot be understated, and we likely will not fully appreciate the impacts it continues to make for years to come. Frequently characterized in the popular press and literature as a “great equalizer”, it has become increasingly clear that deeply entrenched social inequities predating the pandemic profoundly influence COVID-19 morbidity and mortality. Many populations in the US, especially low-income and communities of color, have been disproportionately impacted, further justifying the role that social factors play on health outcomes (Koma et al. 2020). As governments at every level across the globe mobilized resources to respond, the inadequacies of many social protections including tax relief, unemployment benefits, health benefits, housing assistance, and food and nutrition assistance have never been more visible.

For the epilepsy community specifically, the pandemic appears to have increased hesitation or ability to seek out medical services—causing patients to avoid EDs and delay surgical and diagnostic interventions in the hospital setting due to safety concerns. At least 1 in 5 IWE cite difficulty accessing health care services and 1 in 4 report experiencing more seizures at some point during the pandemic (Epilepsy Foundation 2021j). Tumultuous economic conditions could also prevent patients from filling prescriptions due to concerns of price as well. All these factors have the potential to negatively impact epilepsy treatment disparities in the years to come.

While the COVID-19 pandemic has unquestionably been horrific in its impact around the world, it also represents a critical learning opportunity for world leaders, decision makers, researchers, and students—an opportunity to improve upon the gross inequities illuminated and exploited by the virus. Throughout the following five chapters describing the SDoH domains, we will also include some of the latest relevant data and figures exposing how the pandemic is known to have influenced these outcomes thus far.

CHAPTER 2

THE NEIGHBORHOOD AND BUILT ENVIRONMENT



Learning Objectives

- Define the neighborhood and built environment.
- Describe how an individual's neighborhood and built environment act as a social determinant of health.
- Identify specific factors of an individual's neighborhood and their built environment that may positively or negatively impact their opportunity for good health.
- Discuss how neighborhoods and built environments can impact treatment opportunities and health outcomes for individuals living with epilepsy.

Case Study:

A 33-year-old African American female was recently promoted to regional manager of a bank and purchased a new townhouse for her to reside in with her dog. Coming home late from work one day, her car was struck by another vehicle, causing her to be ejected from her car and suffer a traumatic brain injury. She recovered with almost no residual deficits and returned to work. After about one year, the patient started having periods of time lapses that she could not account for. Soon thereafter, a colleague witnessed her have a convulsive seizure while at work. The patient started taking an antiseizure medication after being diagnosed with post-traumatic epilepsy, but had difficulty tolerating them because they caused sedation and inattentiveness. She began to make financial errors in her accounting at work, enough that the bank placed her on medical leave. As the patient was not improving, she went on short term disability and after reaching a maximum of time on short term leave, she was terminated from her job. She could no longer afford the mortgage on her townhome and foreclosed on the property, forcing her to move in with her sister and mother. However, her sister and mother both work and given that the patient had occasional seizures, her sister and mother decided it was best to lock her in her room to make sure she was safe and did not wander about the home. They also placed a camera in the room to monitor her from their workplaces. The patient was despondent over her loss of freedom and, to add salt to the wound, she had to give the dog away as the dog could not handle the room confinement. She expressed all of this to her neurologist, hoping some medical solution can be found that will give her hope for independence or at least a better living situation.

—Joseph Sirven, MD

Introduction to Neighborhood and the Built Environment

The ‘Neighborhood and Built Environment’ social determinants of health (SDoH) domain is comprised of sub-determinants that include:

- Location (e.g., rural or urban environments)
- Access to healthy foods
- Housing quality & availability

- Environmental conditions (e.g., air pollution or exposure to hazardous substances in the air, water, or food)
- Available modes of transportation
- Walkability

All of these factors are key determinants of health, as research has long demonstrated that aspects of the neighborhood environment independently influence overall mortality (Yen and Kaplan 1998). The following sections will dive into each factor of the ‘Neighborhood and Built Environment’, explain their importance as they pertain to life and health, and add in special emphasis to their potential impacts on the lives of individuals with epilepsy (IWE).

Location

Where one lives is arguably the most important social determinant to impact the quality and longevity of one’s life and overall health. This statement is qualified by many experts who now attest that zip code is a stronger predictor of a person’s health than their genetic code (Graham, Ostrowski, and Sabina 2015). “Location”, as an SDoH factor, is also invariably intertwined with almost all other SDoH factors that are to be discussed within this textbook. The interconnected relationship between where you live (i.e., your community) and your overall health will be shown when we discuss the importance of access to health care resources (especially specialist services for chronic conditions like epilepsy), healthy foods, housing, modes of transportation, and many other factors that relate to the availability of resources based on location.

The character of a community and its makeup—including all its health-promoting or health-impeding factors—can likely only be understood fully by those who live in that specific community. However, research up to this point has focused heavily on differentiating communities and their respective health outcomes based on ‘rural’ or ‘urban’ distinctions. The US Census Bureau classifies locations as ‘urban’ or ‘rural’ after each decennial census using specific criteria related to population thresholds, density, distance, and land use. In general, rural areas are sparsely populated, have low housing density, and are far from urban centers.

Pertaining to health, as we will discuss further later in the textbook, ‘rural’ settings also commonly have less access to health care resources, particularly specialist care.

National Context

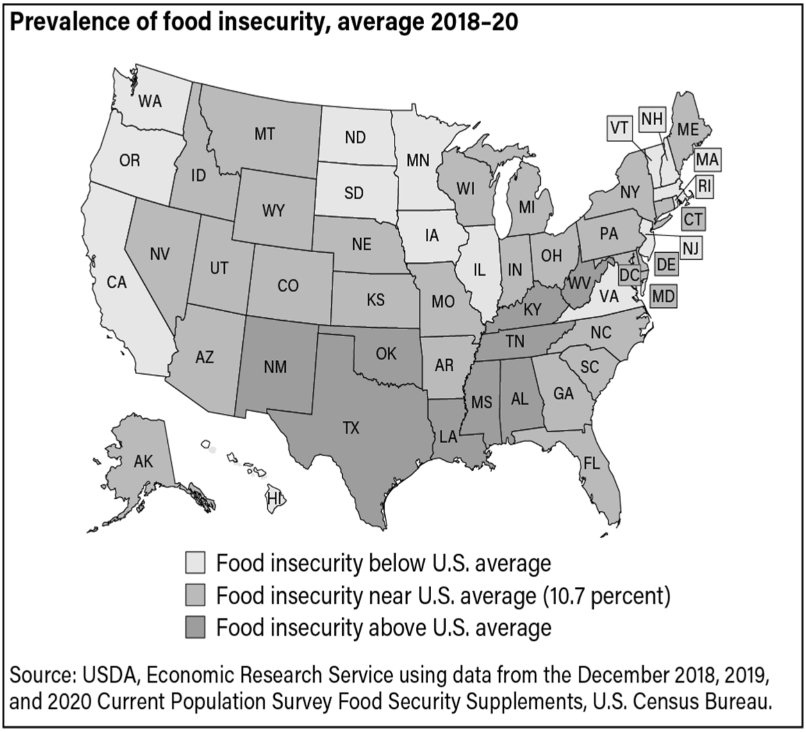
- Current census data estimate that 1 in 5 Americans live in rural settings, which equates to roughly 60 million people.
- Despite containing over 80% of the US population, urban areas only make up about 3% of US land area.
- 19.3% of the population lives in rural areas, which cover 97% of the United States' land mass (US Census Bureau 2020b).

Impact of 'Location' on the Lives and Health of Individuals with Epilepsy

The connection between health outcomes and rural versus urban environments has been extensively studied in the context of epilepsy care. Analyses have demonstrated that individuals residing in rural locations have significantly higher risks of untreated epilepsy—contributing to the higher epilepsy treatment gaps seen around the world in rural communities. It is also known that individuals living in rural communities face more difficulty in accessing care, particularly specialty care. Those living in rural environments are more likely to be characterized as having low socioeconomic status (SES) and lower educational attainment—both factors that have been demonstrated to have negative impacts on health (Meyer et al. 2012). A recent study used US regions as a predictor of epilepsy treatment among US adults, finding that people residing in the Northeast (widely considered as more urban) as more likely to visit a neurologist (Szaflarski et al. 2020). However, the statement was qualified with the fact that the Northeast is known for its high concentration of medical centers and supply of neurologists that exceeds their states' demand.

Food Access

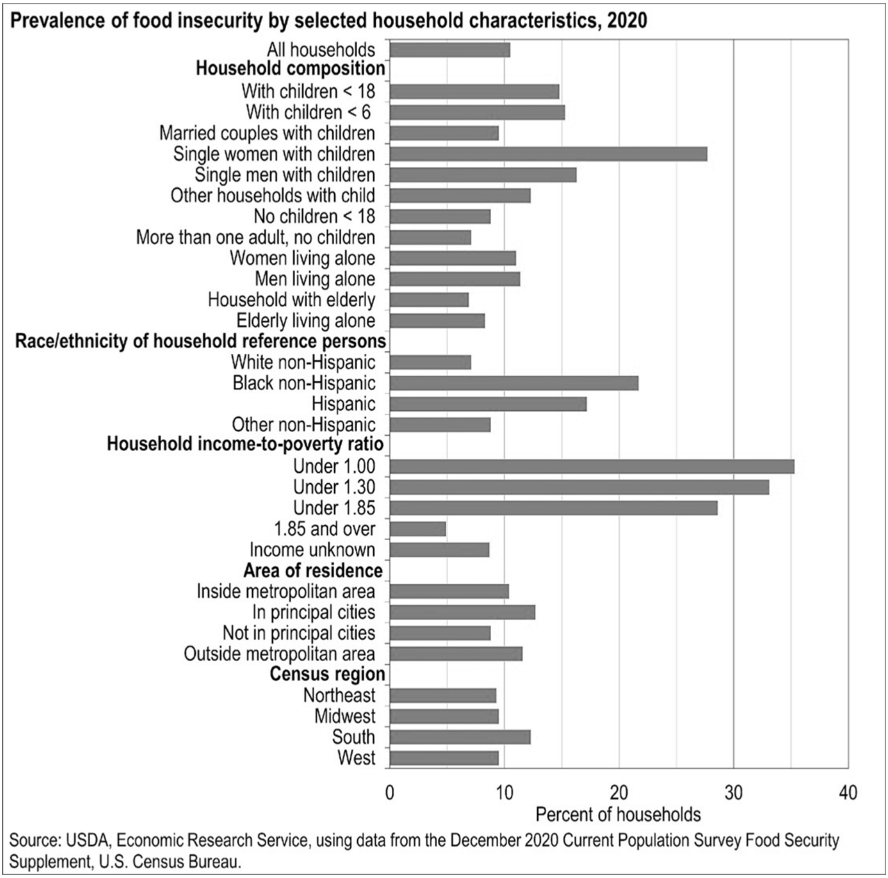
Food insecurity is defined as "the disruption of food intake or eating patterns because of lack of money and other resources." In 2020, nearly 14 million U.S. households were food insecure at some time during the year. You can examine the prevalence of food insecurity by state in Figure 2-1. Prevalence of food insecurity can also be broken down by household characteristics, showing single women with children and household of low SES express the highest incidences of food insecurity (Fig. 2-2). Food insecurity does not necessarily cause hunger, but hunger is a possible outcome of food insecurity and certainly has many negative health impacts, especially for children during their developmental years (Coleman-Jensen et al. 2020).



Source: USDA, Economic Research Service using data from the December 2018, 2019, and 2020 Current Population Survey Food Security Supplements, U.S. Census Bureau.

Figure 2-1: Prevalence of food insecurity in the US.
Adapted from the US Department of Agriculture Economic Research Service Key Statistics & Graphics. Data obtained from the 2018-2020 Current Population Survey Food Security Supplements of the US Census Bureau (US Department of Agriculture 2021).

Some risk factors for food insecurity include a lack of transportation, travel distance, and a simple lack of supermarkets. These factors tend to disproportionately affect those with chronic diseases and disabilities, residents of rural areas, and some minority groups more than others. Access to full-service supermarkets is much more limited for people living in some urban areas, rural areas, and low-income neighborhoods.



Prevalence of food insecurity by selected household characteristics, 2020

Source: USDA, Economic Research Service, using data from the December 2020 Current Population Survey Food Security Supplement, U.S. Census Bureau.

Figure 2-2: Prevalence of food insecurity by selected household characteristics. Adapted from the US Department of Agriculture Economic Research Service Key Statistics & Graphics. Data obtained from the 2018-2020 Current Population Survey Food Security Supplements of the US Census Bureau (US Department of Agriculture 2021).

Going beyond food insecurity (which concerns a lack of food, in general) is the issue of access to healthy, nutritious foods. Poor nutrition and an unhealthy diet are important risk factors for a variety of chronic diseases, such as diabetes and high blood pressure (Dietz, Douglas, and Brownson 2016). However, the availability and accessibility of healthy foods often act as barriers toward building healthy eating patterns. Areas in which food sources of high nutritional quality (i.e., grocery stores selling fresh fruits and vegetables) are either nonexistent or limited within one mile have been deemed “food deserts” by the US Department of Agriculture (USDA). It can be expected that individuals living within food deserts likely have greater difficulty obtaining healthier foods. Inadequate access to healthy foods is particularly prominent among members of racial and low-income communities, ethnic minority communities, and those living in rural areas (Ploeg et al. 2009).

National Context

- In 2020, prior to the COVID-19 pandemic, 10.5% of all US households (13.8 million households) had reportedly experienced food insecurity at some point during the year (Coleman-Jensen et al. 2020). During and after the pandemic, nearly 1 in 4 households are estimated to be experiencing food insecurity (Silva 2020).
- Before the pandemic, about 13.6% of households with children reportedly were experiencing food insecurity, which equates to nearly 1.5 times more than households without children (Jones et al. 2013).

Impact of ‘Food Access’ on the Lives and Health of Individuals with Epilepsy

Although epilepsy is most successfully controlled with one or more ASMs, alternative non-pharmaceutical nutrition-based treatments such as the ketogenic diet have also been shown to improve seizure management. Evidence dating back to the 1920s has linked the ketogenic diet (most known for its elimination of sugar and sweets) with significantly positive outcomes for the treatment of refractory epilepsy (D’Andrea Meira et al. 2019). Less restrictive diets, such as the Atkins diet and Low Glycemic Index treatment have also been shown to improve seizure control. Fundamentally, the common dietary thread running through these changes is the elimination or reduction of sugar.

Yet, as discussed previously, there are still barriers that contribute to one’s ability to access healthier foods that are classically required to maintain a ketogenic, Atkins, or Low Glycemic Index diet. These challenges for IWE in particular are vastly under-studied, though a national survey conducted in Canada did highlight the fact that food insecurity was significantly more likely among IWE than those without epilepsy (10.8% compared to 5.2%) (Gordon and Dooley 2015).

Housing Quality & Availability

The stability, quality, safety, and affordability of housing can play a substantial role in affecting health outcomes. Unsurprisingly, studies have shown that being without a stable home is detrimental to one's health. Those who experience chronic homelessness are faced with significantly increased mortality and morbidity with respect to both their physical and mental health. Similar disparities are experienced by people who may not necessarily be chronically homeless but face housing instability (e.g., couch surfing, frequent moves, etc.). In that same vein, initiatives providing people with access to stable housing present an opportunity not only to improve health outcomes, but also decrease health care costs (Taylor 2018). When more than 10,000 Oregon residents received housing assistance through a local Medicaid Coordinated Care Organization (CCO), total Medicaid expenditures declined by 12%, while utilization of primary care increased 20% and ED visits decreased by 18% (Sandel 2016).

National Context

- The number of housing units in the US has increased from 78.82 million in 1975 to 140.8 million in 2020 (Statistica 2020a).
- The composite Housing Affordability Index (HAI) measures whether a family earning the national median income can afford monthly mortgage payments. The lower the index value, the less affordable a house becomes. The HAI value fell to 162.9 in 2019, which was its lowest value since 2008 (Statistica 2020b).
- Roughly 40% of low income individuals in the United States are either homeless or pay over half their income for rent, and do not receive federal rental assistance ("Federal Rental Assistance Fact Sheets" 2021).

Impact of 'Housing Quality & Availability' on the Lives and Health of Individuals with Epilepsy

Housing is a critical issue for people with epilepsy. Among adults with active epilepsy, 1 in 5 live alone (US Centers for Disease Control and Prevention Epilepsy Program 2015). Those with more severe forms of epilepsy, many of whom also have intellectual disabilities, require more extensive accommodations (e.g., higher staff-to-resident ratios) in order to live independently. And while the federal *Fair Housing Act and Section 504 of the Rehabilitation Act of 1973* prohibit discrimination and establish some rights for those with disabilities, there is still much work to be done at the community level to meet the quality of life needs for those with epilepsy.

Environmental Conditions

Air pollution, water contamination, and extreme heat are other examples of environmental conditions that can adversely impact health outcomes, with members of racial and ethnic minority communities encountering more of these hazards than their white counterparts (Gee and Payne-Sturges 2004). Pregnant women and young children are particularly vulnerable to air pollution, both indoors and outdoors (Sram et al. 2005). As a connection to chronic disease, the prevalence of pediatric asthma among children living in public housing (which is often located in areas with poorer environmental conditions) has consistently shown to be higher than rates in single-family homes (Urban Institute 2017). Pertaining to racial disparities, those who live in predominantly black or African American communities were found to suffer a greater risk of premature death from particle pollution than those who live in communities that are predominantly white (Kioumourtzoglou et al. 2016, 2).

National Context

- Air pollution
    - In 2020, the US emitted 68 million tons of pollution into the atmosphere ranking 84th out of 106 countries for total air pollution produced in 2020 (US EPA 2020)
- Water Contamination
    - More than 200 million people in the US have tap water contaminated with a mixture of a class of chemicals known as PFOA and PFOS at concentrations of one part per trillion or