1

INTRODUCTION

Will I be able to get the care I need if I become seriously ill?

(Institute of Medicine 1993)

This fundamental question is at the basis of healthcare access. It implies the opportunity of gaining appropriate healthcare when needed, where needed, and at the level needed. It involves utilization of healthcare services and provision of appropriate services. Toward this end, health systems must achieve health(care) of all individuals and populations by delivering healthcare services to those who need them and benefit from them.

Local and national resources as well as personal resources must be available for the materialization of healthcare access. First, health policies set the stage for various approaches to healthcare delivery. Secondly, health personnel, facilities, and/or technology must be available where people live, work, or pursue their education. Thirdly, people must have the means and know-how to obtain the services. Thus, healthcare access in all its dimensions impacts all levels of the healthcare system, including people, processes, providers, organizations, and policy makers (Rouse and Serban 2015). This book is intended to present a synthesis of concepts, principles, models, and methods for addressing healthcare access within a system rife with complexity coming from all its levels.

This chapter proceeds as follows: I will first discuss the complexity of the concept of healthcare access, a multidimensional construct, going beyond its (mis)interpretation as a financial barrier in the existing political discourse on healthcare in the United States and beyond. I will address the relevance of understanding access in the context of public health, expanding on the system levelers for change and potential approaches to drive change. Then, I will proceed by pointing out that access is not an end in itself; it moderates healthcare utilization, with both intended consequences, such as improving health outcomes through appropriate utilization, and unintended consequences, such as over-utilization and potentially higher costs. I will subsequently consider methodological approaches to addressing healthcare

Healthcare System Access: Measurement, Inference, and Intervention, Nicoleta Serban.

access problems, focusing on the use of quantitative approaches to explore a wide range of solutions. Finally, this chapter provides an overview of the remaining chapters in this book and how they address the framework presented in this chapter.

ACCESS AS A MULTIDIMENSIONAL CONSTRUCT

The current political discourse around healthcare access primarily focuses on financial barriers; it has been taken as synonymous with the availability of financial and health system resources. Limiting the access discussion to affordability or provider availability is understandable. It is however a simplistic approach for regulatory agencies charged with advancing access (Khan and Bhardwaj 1994). Simply measuring affordability or provider availability is neither adequate nor appropriate to understand healthcare access. Construing the conceptual framework for access requires a richer perspective.

There is a very large literature on the conceptual construct of healthcare access. Many organizations have been promoting and publishing on this topic (Healthy People 2020 2010; RAND Corporation 2010; www.kff.org). To distil this entire literature would not serve the reader of this book well, but several references to the existing proposed conceptual approaches will be provided.

One of the earliest access frameworks is the behavioral model by Ronald Andersen (Andersen 1968), initially developed in the late 1960s. In the early literature, access has also been differentiated between realized and potential, where *realized access* refers to the direct utilization of the services and *potential access* refers to the opportunity to utilize services (Khan 1992; Guagliardo 2004; McGrail and Humphreys 2009). Guagliardo (2004) stages first the potential for care delivery, followed by realized delivery of care. Potential access exists when a population in need for specific healthcare services lives in a community with access to "a willing and able healthcare delivery system." Realized care follows when all barriers to provision of healthcare are overcome. Guagliardo (2004) fundamentally describes "access" as both a noun referring to potential for healthcare use, and a verb referring to the act of using or receiving healthcare.

When Andersen revisited the behavioral access model, he introduced the concepts of *effective access*, established when utilization improves health status, and *efficient access*, established when the level of health status increases relative to the amount of healthcare services consumed (Andersen 1995). More generally, access can be placed under the framework of the 3 E's: Efficiency, Effectiveness, and Equity (Aday et al. 2004), discussed further in Chapters 2 and 3.

Penchansky and Thomas (1981) have usefully grouped access barriers into five dimensions: availability, accessibility, affordability, acceptability, and accommodation. Healthy People 2020 redefines the five dimensions of access, including insurance coverage, health services, and timeliness of care. Access as a multidimensional construct has been defined within multiple other frameworks as reviewed by Ansari (2007) and the Rural Policy Research Institute (MacKinney et al. 2014), among others. Further references to other multidimensional constructs will be

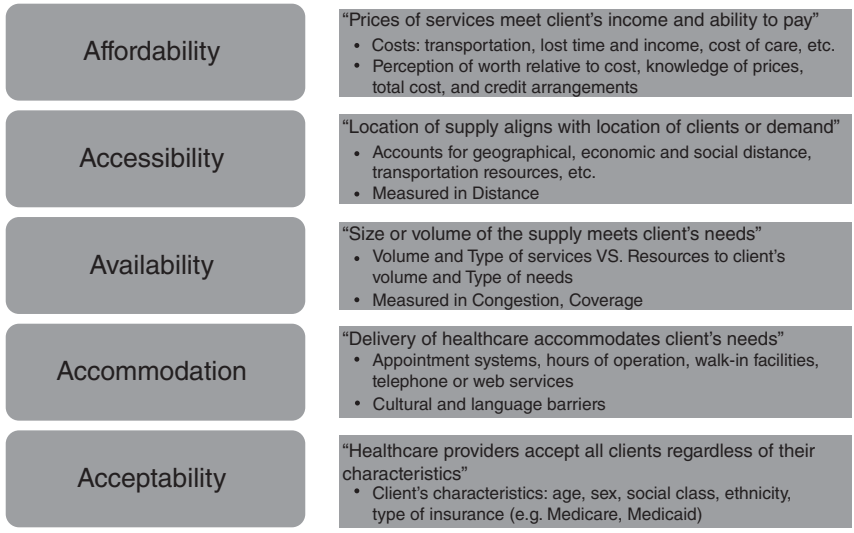

FIGURE 1.1 The access framework as a five-dimensional construct following the model by Penchansky and Thomas (1981).

provided in Chapter 2, however this book will primarily employ the simple but relevant framework provided by Penchansky and Thomas (1981). The diagram in Figure 1.1 shows the five dimensions of access within a service science framework for a broader understanding of service access. This access framework can apply to other fundamental services, for example, education, financial services, and healthy food stores, among others.

ACCESS FOR PUBLIC HEALTH

Urban and rural communities face many challenges to improving public health. Economic initiatives, changing demographics, and growth at the community level have resulted in changes that offer new opportunities for improving health while requiring that health systems be adapted to residents' health needs. One important integration of the community health needs into the directions of the healthcare system transformation is redesigning public healthcare delivery to achieve equitable, efficient, and effective access to healthcare.

Materialization of healthcare access in public health can take many forms, including prevention of emergency department visits and hospitalizations; quality of life of those with unmet health needs and with delays in receiving appropriate care; a cumulative decline in mortality and disability; and an overall improvement in mental health status, life expectancy, and general sense of wellbeing, among others.

While it is well understood that healthcare access is an actionable approach to improving public health, its conceptualization suggests the type of actions that need to be taken. For example, the current understanding of access as a financial

barrier (affordability dimension) has brought forward national and state policies with a focus on coverage of healthcare benefits and insurance. As highlighted in the conceptualization of access as a multidimensional construct in this chapter, there are multiple dimensions of access that are interrelated; affordability is one of them but other dimensions are equally relevant to public health.

Importantly, access dimensions also have different relevance depending on the sub-population in need for care. For example, children in the United States are generally insured through commercial or public insurance, with only about 3.2% of children being uninsured (National Center for Health Statistics 2016). Thus, for the child population, affordability is not the primary dimension of relevance. Since children access the healthcare system with the effort and time commitment of their parents, accessibility and availability of the services may have a higher priority over other dimensions. Parents need to take time away from work and the children may miss school days. Timeliness through reducing travel and wait time may be essential to the decision as to whether to seek care.

There is also a wide variation in the relevance of access dimensions by healthcare services sought and/or needed. Mental and behavioral health services present challenges in access across all five dimensions for the majority of the population in the United States. In contrast, dental care is viewed as an axillary service for most health benefits programs hence insurance coverage is low. In many cases, dental care is an out-of-pocket expense; however, for children from low-income families, it is covered by Medicaid. But Medicaid participation by dentists is low (Serban and Tomar 2018). In one of my recent studies for Georgia, USA, my collaborators and I showed that there is a very large gap in accessibility and availability of dental care services between children with public insurance and those whose parents have other forms of affordability (Cao et al. 2017).

Compared with specialized care, primary care has become more available due to comprehensive coverage across all healthcare insurance programs, with a denser network of providers, including physicians. Scope of practice and/or independence practice acts have added supply to the network in many states due to the availability of licensed healthcare providers. Participation in public insurance programs by primary care providers is also higher than specialized care. In one of my recent studies on access to primary care for seven states in the United States, my collaborators and I have found that there is not a significance gap in access to pediatric primary care when comparing public and private insurance access (Gentili et al. 2018).

Thus, each access dimension cannot be considered in isolation from other dimensions in the public health setting. For example, accessibility and availability will be highly dependent on whether providers participate in public insurance programs, one form of acceptability. Affordability precedes other types of access dimensions; however, there are community-focused and federally funded programs opening the door to gaining healthcare for the uninsured, thus such programs must be where most needed; moreover, the population in need for such programs must be knowledgeable about the extent of care provided in these programs.

This discussion points to the fact that access is actionable through targeted policies and interventions taking various forms, depending on the population in need,

the healthcare service needed, the access priorities established by policy makers, and the status quo of the healthcare system. Policies and interventions include scope of practice and independence practice acts, integration of services, mobile health, telehealth, home healthcare, community-based care, location and relocation of service providers, school programs, among many others. Such access interventions will be discussed in more detail in Chapter 5.

Most importantly, healthcare access goes beyond enabling healthcare for public health. When policymakers debate the merits of increasing access to healthcare, they must also consider improvements in the education of the population, economic opportunities, and a general sense of wellbeing. Healthcare access for public health is healthcare access for public wellbeing. Public health policies and interventions must reach the population in need for care holistically. Local initiatives such as the Two Georgias Initiative (Healthcare Georgia Foundation 2010) and California's Center for Collaborative Planning (Public Health Institute 2010) are test beds for learning how the integration of life priorities and opportunities can empower a population and individual health.

ACCESS FOR IMPROVING HEALTH OUTCOMES

Much has been said about the importance of healthcare access; but access is not an end in itself. Access to healthcare does not guarantee good health and appropriate health outcomes. Nevertheless, access to healthcare is necessary to ensuring that society enjoys optimal health, economic opportunities, productivity, and well-being.

The link between improving healthcare access and health outcomes depends greatly on the healthcare services needed, the geographical location, national and state policies in place, the population in need for healthcare services, among many others. In one study, my collaborators and I assessed the impact of access to pediatric asthma specialists on the rate of emergency department visits and hospitalization (Garcia et al. 2015). The study found that geographic access is explained by the rate of severe pediatric asthma outcomes, but the association varies with other geographic factors. Thus, interventions to improve access can be targeted to the areas with the greatest potential for improvement and tailored to each community's health needs. In another study, my collaborators and I analyzed the impact of geographic distance to cystic fibrosis care centers on lung function in children, young adults, and adults with cystic fibrosis (Johnson et al. 2018). We found that geographic access measured by travel distance was not associated with health outcomes among patients who do not change their geographic access over the study period. In fact, we found that overall socioeconomic and genetic factors appeared to be associated with health outcomes to a greater extent. The findings were also different for children, young adults, and adults.

It is not surprising that there are not consistent findings on the relationship between different dimensions of access and health outcomes. In fact, it may also be possible that improving access could lead to over-utilization of services, increasing costs of care while bringing little improvement in the outcomes.

The Rural Policy Research Institute (MacKinney et al. 2014) has provided a synthesis of the existing literature on access measurement and outcomes. The report differentiates access measures into process measures or outcome measures where *process measures* quantify how the system works and *outcome measures* quantify results or final products. However, the outcome measures are not necessarily directly influenced by healthcare access as I pointed out in the examples above. The access measurement alone will not provide an understanding of the impact of interventions for improving access on outcomes; such a relationship can be established by assessing the relationship between access and outcomes in the presence of many other factors potentially influencing outcomes. I will expand more on this topic in Chapter 4 of this book.

ANALYTICAL APPROACHES

Measures do not define access, but rather evaluate access. As described earlier in this chapter, the existing literature on access differentiates between realized and potential access.

On one hand, realized access can be directly measured based on the observed utilization, for example, the travel distance one has incurred to utilize a service or the time one has waited for an appointment. However, it does not reflect access since it does not account for latent barriers that can hamper demand based on true need for care. Realized access or utilization of services will be hindered if access does not fully materialize (Khan 1992; McGrail and Humphreys 2009).

On the other hand, potential access indirectly measures access to services. It requires knowledge about the network of healthcare providers called *supply* for most of this book in the spirit of economic engineering and service science. It also requires understanding and knowledge about the network of the population needing or demanding a service, called *need* for most of this book. Potential access can be measured by overlaying the two networks given one or more access objectives, for example, improving affordability, expanding *spatial access* referring to accessibility and availability together (Guagliardo 2004; McGrail and Humphreys 2009), or increasing acceptability of public insurance.

Conceptualizing access as a multidimensional construct within the decision-making framework is particularly important when deciding which objective is to be achieved (Ansari 2007). Should access be thought of as a multidimensional construct while the access dimensions are viewed as separate pillars of the construct? Or, is access a single concept, with the access dimensions playing the role of influencing barriers or enablers? Depending on the perspective on access, one could influence one access dimension where all other dimensions can be viewed as constraints of the system, or one could influence multiple objectives defined by the access dimensions differently weighted. For example, if spatial access is to be optimized, in other words, reducing travel distance while ensuring some pre-specified maximum wait time, the objective is then a weighted aggregate of accessibility and availability where the weights can be fixed for the entire population or can be different across sub-populations, for example, different for rural and urban communities. Such

considerations are significant in the understanding of the access frameworks, and the actionable policies and interventions to be implemented.

In conceptualizing and measuring access, the challenges are on specifying the *assumptions* on the two networks, the *constraints* of the system under which the two networks interact, and the *preferences* of those participating in the two networks. Assumptions are often specified by policies or standards, for example, travel access standards established by states for the Medicaid programs (Department of Health and Human Services 2014). Constraints reflect access barriers for the population in need, for example, whether a provider participates in public insurance or not, or system supply restrictions, for example, restricted scope of practice for nurse practitioners.

Preferences are most difficult to integrate into estimation and evaluation of access since they can be subjective to biases or beliefs. Nonetheless, they are real and can influence one's access to care to a great extent. Examples are one's preference to seek care from a physician instead of a nurse practitioner, if one is available within access constraints (Dill et al. 2013); one's preference to have all care performed by one system or clinic due to integration and coordination of services (Corrigan and Adams 2003); one's choice of recommended physician even if out-of-network, hence incurring higher out-of-pocket expenses; or one's choice not to seek care at all due to religious beliefs.

Another important challenge is availability of data on the supply and need networks, financial resources, and of data and knowledge on system constraints and preferences as expanded in Chapter 6. Figure 1.2 illustrates a sample of potential data sources that can be used to specify the supply and need/demand networks and the associated constraints. The specification of supply includes the location of the

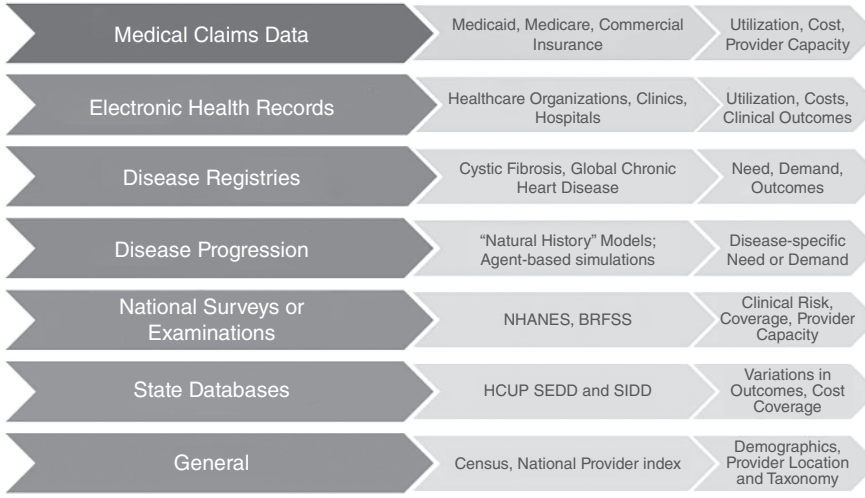

FIGURE 1.2 Data landscape for estimation and evaluation of healthcare access, with a focus on data for specifying the supply and need networks. BRFSS, Behavioral Risk Factor Surveillance System; HCUP, Healthcare Cost and Utilization Project; NHANES, National Health and Nutrition Examination Survey.

healthcare providers and their potential caseload to provide the services needed to be accessed. The specification of demand requires estimation of the population in need, the quantity of services needed, and the health risk influencing the level of service utilization.

Knowledge about system and access constraints can be specified by state policies, providing information on enacted laws, differences across similar legislation acts if enacted in multiple states (e.g. supervision of licensed providers), and standards imposed by states, among others. Such constraints can also be informed by surveys, data repositories or medical records that can provide information on provider-level or patient-level constraints, for example, Medicaid participation of a provider.

Considerations of the access objectives to be achieved with specifications of the assumptions, constraints, and preferences are at the core of measuring potential access. But specifications of the constraints and preferences often come with some level of uncertainty, which will further propagate into the estimation and evaluation of the access measures. In most existing studies on access measurement, uncertainty of the input parameters, thus uncertainty in the access measures, is not accounted for, assuming access is deterministic, meaning no variation due to small changes in the model parameters or assumptions.

While more challenging, decision making can be more statistically reliable and accurate when considering access within an uncertain environment. Insights on the uncertainty of a decision can come in various forms, for example, an estimate of the risk of making the decision or a measure of the plausibility of the decision made to address the issue at hand. Such inferences are essential in decision making because in some cases they may suggest that more data need to be acquired to provide stronger evidence for a decision; in others, they may prompt not making a decision at all because of the high uncertainty of the decision environment.

While access measures alone can make for nice maps, in order to make statistical statements on whether there are disparities in access across communities and sub-populations, or to identify communities and sub-populations for targeted interventions, statistical inference plays a key role. In most studies, access measures are estimated, but most commonly, statistical inferences are not provided. This last step is essential for actionable policies and interventions.

To conclude, while there is an extensive literature on access frameworks and access measurement approaches, there is a need for bridging the conceptualization of healthcare access to the access measurement and inference using rigorous analytical approaches. At the core of this endeavor is a cross-disciplinary approach, integrating many areas of research including health services research, health policy, operations research, and statistical learning, among others.

PEDIATRIC HEALTHCARE

Most of my research on healthcare access has been centered on pediatric healthcare as illustrated by most of the case studies presented in this book. It is particularly important to eliminate health disparities among children because investing in pediatric healthcare will have the highest long-term return as it will reduce the

burden of future healthcare costs and foster a healthy and productive population. Child development affects subsequent life, education and occupational opportunities, and the risks of unhealthy behaviors, chronic diseases, malnutrition, mental-health problems, and criminality in later life. Along with good nutrition and wellness, healthcare is a paramount ingredient for healthy child development.

ACCESS IN THE TWENTY-FIRST CENTURY

The diseases of the twenty-first century will be chronic conditions, "those that steal vitality and productivity" (Jackson and Kochtitzky 2012). Managing chronic and high-risk conditions is a complex enterprise, requiring the right balance between best outcomes and limited resources. Improving access particularly is important in the management of chronic conditions; regular and appropriate care can reduce severe outcomes, can slow down the progression of a condition, and/or maintain the well-being of those burdened with chronic conditions.

For best outcomes, improving access has to be aligned with the goal of maximizing value. Thus, additional value and cost constraints have to be integrated into the overall access interventions to make the most out of the return on investment. Many case studies in this book focus on chronic conditions, emphasizing the added value of integrating improvement in access to care into the overall healthcare system.

OVERVIEW OF THE BOOK

The foregoing has provided a broad outline of the comprehensive framework for studying healthcare access from measurement to inference to decision making. The remainder of this chapter provides an overview of each of the other chapters in this book.

A Multidimensional Framework for Measuring Access (Chapter 2)

This chapter begins with an overview of frameworks, models, and definitions, with the focus on their applicability to measurement of and inference on healthcare access. This overview will provide the basis for the general model for access measurement, emphasizing the importance of considering all model components: objective, assumptions, constraints, and preferences. The general model will be contrasted to existing measurement approaches and will be demonstrated with approaches for spatial access. Last, the general model will be applied to one specific case study, measuring access to asthma care.

Disparities in Healthcare Access (Chapter 3)

This chapter first summarizes the concept of systematic disparities, with an overview of various measures, differentiated into social-group disparity measures and disproportionality measures, introduced in the existing literature. It then follows with a statistical framework for making inference on disparities with application to

geographic disparities in healthcare access. I will illustrate the statistical inference approach to identify systematic disparities using two case studies, one on access to pediatric primary care with an emphasis on geographic disparities between sub-populations differentiated by the health insurance status, and another case study related to the 2009 H1N1 campaign with a focus on an analysis of disparities with respect to demographic and economic factors.

Linking Access to Health Outcomes (Chapter 4)

This chapter begins with a taxonomy of health outcomes, specifically those targeted through improvements in healthcare access. Access is then introduced as a moderator of healthcare utilization, with potentially both intended and unintended consequences for improving utilization. Discussions on the link between access and outcomes will include methodological considerations and statistical models, depending on the type of outcome, and with an overview of factors influencing outcomes. Two case studies will be provided, one in which I consider the link between healthcare outcomes and access to specialized pediatric asthma care, and another study in which I consider the link between clinical outcomes and access to care centers for patients with cystic fibrosis.

Healthcare Interventions for Improving Access (Chapter 5)

This chapter first introduces a taxonomy of interventions, distinguished into health policy, in-home and in-school healthcare, telemedicine and mobile healthcare, and network interventions, with multiple illustrations of interventions discussed with reference to the access dimensions. Particularly, the challenge of addressing access to improve outcomes holistically will be highlighted. The chapter will continue with a presentation of statistical modeling to address a series of important questions in decision making: Are interventions needed? Where are the interventions needed and for what population groups? What interventions are needed? How to evaluate interventions? Case studies on access to dental care will be used to illustrate approaches to study policy and network interventions toward improving access, addressing substantive questions: *Why*, *Where*, and *How* to intervene? *Which* intervention?

Data Analytics (Chapter 6)

This chapter begins with a discussion of the complexity of the data analytics for studies on healthcare access, highlighting the importance of integrating all data processes from data acquisition and processing to data translation, to data modeling and finally decision making. Multiple data sources are described in detail, covering protected health information (PHI) data, survey data collected by public and private organizations and secondary health and healthcare data. The chapter will continue with data analytics for the primary components of access measurements, supply, need and constraints of healthcare. Then it will focus on data analytics for the analysis of health

outcomes commonly employed in the analysis of targeted interventions for improving access. Challenges on data science, data modeling and dissemination are discussed in the more general context of healthcare data analytics. The chapter will illustrate data analytics with a case study on the derivation of the provider-level caseload of mental and behavioral health for the Medicaid-insured population nationwide. Two data portals are also briefly presented within the context of advancing community health.

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