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TECHNOLOGICAL CHANGE
AND THE PRACTICE OF HEALTHCARE COMMUNICATION:
IMPLICATIONS FOR PATIENT-CENTERED CARE,
FROM A COMMUNICATION ETHICS PERSPECTIVE

A Dissertation

Submitted to the McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Emmalee C. Torisk

August 2021

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Emmalee C. Torisk

2021

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ABSTRACT

TECHNOLOGICAL CHANGE
AND THE PRACTICE OF HEALTHCARE COMMUNICATION:
IMPLICATIONS FOR PATIENT-CENTERED CARE,
FROM A COMMUNICATION ETHICS PERSPECTIVE

By

Emmalee C. Torisk

August 2021

Dissertation supervised by Craig T. Maier, PhD

Written in a historical moment marked in many ways by the COVID-19 pandemic and the changes it has wrought, including the increased availability and use of telehealth services, this project attempts to consider the implications of the continued integration of technology into health care, centering on the following essential question: *How do technological changes affect the contemporary practice of healthcare communication, particularly that which occurs between the patient—the consumer of health care—and their provider?* This dissertation thus considers the ways in which such linkages of technology and health care seem to fit into a larger shift within health care that has occurred over recent decades: the move away from a paternalistic model of health care to one that is more patient-centered and respectful of the autonomy of the individual patient. As is argued throughout—drawing from literature ranging from the role of technology in

health care to patient–provider communication, and from social justice issues within health care to communication ethics—technology offers considerable promise for the healthcare setting, in that it is helping to empower patients and providers alike, as well as potentially democratizing health care itself. At the heart of this is the communication that transpires during the patient–provider encounter and in the context of this healthcare relationship.

DEDICATION

To healthcare providers and their patients—past, present, and future.

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The list of those I would like to thank for their contributions is quite lengthy. It's been a long but wonderful journey to this point.

First and foremost, thank you to everyone in the Department of Communication & Rhetorical Studies at Duquesne University for this opportunity. Dr. Ronald C. Arnett, Dr. Pat Arneson, and Dr. Janie Harden Fritz were my first contacts at Duquesne, back when I was still only thinking about going back to school for a PhD. They were welcoming and informative, and helped me see how I might fit into the Duquesne community, including what potential contributions I could make. I later had the chance to work more closely with both Drs. Arnett and Fritz, and their guidance and encouragement, as well as their confidence in me and in my work, have been invaluable.

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Before I arrived at Duquesne, my educational home was Youngstown State University (YSU), where I earned both my bachelor's and master's degrees. It was during the latter that I first thought that a PhD was something I could, maybe, one day pursue. I'm grateful for the advisement and support from so many at YSU, including Dr. Mary

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Chapter 1: An Introduction to Patient–Provider Communication—Past, Present, and Future

The timing of the *Clinical Journal of Oncology Nursing's* (CJON's) supplement on eHealth in June 2020 could not have been more apt. Although the supplement to the journal, published by the Pittsburgh-based Oncology Nursing Society (ONS), had been in the works since August 2019, the majority of its content was edited by ONS staff—the current author included—and the supplement itself published in the midst of the COVID-19 pandemic. None of the authors developing content for the supplement in the summer of 2019 could have anticipated just how different the world would look not even a year later. As CJON Editor Ellen Carr (2020a) wrote in a commentary titled “eHealth During a Pandemic,” this supplement, rather fortuitously, “presents expert content on a vital, staple component of clinical care that has been propelled into widespread application because of the COVID-19 pandemic” (p. 3). Carr (2020a) continued, anticipating that “because of the effects of the virus that causes COVID-19, clinicians will, for the foreseeable future, practice in a different healthcare environment,” with eHealth applications becoming “a more prevalent operational component of the standard of care” (p. 3).

As of this writing in late September 2020, many months into the COVID-19 pandemic, with no apparent end in sight, Carr's (2020a) predictions seem to ring true. The SARS-CoV-2 virus, as it is officially known, continues to replicate among us. (It was formally identified by scientists in China on January 7, 2020 [Burdick, 2020].) According to the Centers for Disease Control and Prevention (CDC, 2020a), in the United States alone, as of September 25, 2020, the number of total cases is quickly encroaching on 7

million, with more than 200,000 deaths. It is likely that the actual numbers are even higher. (A little more than a month prior to this, on August 13, 2020, when I finished my first draft of this chapter, those figures were about 5 million and 165,000, respectively.) There are attempts to return to normalcy, with many businesses, including stores and restaurants, having reopened after the extended shutdown of the spring, and schools welcoming students back into the classroom, both virtually and in person. Still: Other businesses have remained shuttered. Millions have lost their jobs, with unemployment benefits all but dried up. Wearing a face mask, a simple act of public health, has become contentious and politicized. Terms like “social distancing” and “Zoom fatigue” and “quar,” which would have been incomprehensible, or, at the very least, meaningless, at the start of this year, have new currency. It is clear that the novel coronavirus—and the massive, overarching changes it has brought with it, not least of all to health care—is here to stay for a while longer.

Quite frankly, health care postpandemic, whenever that may be, will look a lot different than health care prepandemic, with a number of these rapidly deployed changes likely to stay, becoming a part of the new normal. For example, as will be discussed in more detail later in this chapter, the pandemic has ushered in many changes to the practice of health care in the United States, including the increased availability of telehealth services. Communicating remotely with one’s healthcare provider in a virtual space looks much different than does communicating with them face-to-face in, say, the typical doctor’s office or emergency department setting, with important implications for that relationship. Accordingly, considering the COVID-19 pandemic and other societal shifts that have ultimately continued to integrate technology into health care, this

dissertation will center on the following essential question: *How do technological changes affect the contemporary practice of healthcare communication, particularly that which occurs between the patient—the consumer of health care—and their provider?* The current historical moment has much to reveal about this shift, especially in regard to the confluence of technology and health care.

I am interested in interrogating the current historical moment to determine both the societal and individual impacts of such changes involving the intertwining of technology and health care, with particular attention paid to their effects on patient–provider communication. Of considerable importance is the way in which these changes seem to fit into a larger shift within health care that has occurred over recent decades—that is, a move away from a paternalistic model of health care, in which the doctor always knows best, to one that is more patient-centered and respectful of the autonomy of the individual patient. Of course, this is still a work in progress, with some important limitations, but, as I argue in this project, technologies, especially those that have been thrust into more frequent and widespread use because of the COVID-19 pandemic, are offering considerable promise for the healthcare setting, in that they are helping to empower patients and providers alike, as well as potentially democratizing health care itself. (It is important to clarify the use of the term “patient” in this work, which is defined here as an individual accessing health care and seeking the assistance of a healthcare provider. Use of this term has been recently debated and discussed within the literature, with alternatives like “client” proposed as terms more closely aligned with a patient-centered model of health care; it has also been suggested that such terms may be more empowering and be representative of greater equality between the various

participants in health care decision-making. However, Costa et al. [2019] examined the labeling preferences of individuals accessing health care and found that healthcare recipients appear to prefer the term “patient” over other options. Costa et al. [2019] thus recommend continuing to use “patient” within general clinical and research contexts, when an individual’s preferences in terms of labeling are unknown; this is guidance that the current author has followed in this work, while remaining attentive to the fact that alternative terms do exist and may be preferred by some individuals.)

This chapter will ground the discussion of the research question by first giving the reader a glimpse into the current historical moment—in particular the convergence of technology and health care during the COVID-19 pandemic and beyond. Next, it will provide a historical overview of medicine as it pertains to the relationship between patient and provider, and the communication that occurs therein, including the perceptible shift as of late toward a relationship that is more fair and balanced, particularly in terms of medical decision-making, rather than skewed in one direction: toward the provider. Finally, the chapter will conclude with an explication of the relevance of this project, especially in light of the current historical moment, as well as provide an outline of the remaining five chapters.

This project attempts to employ various technologies as a way for understanding recent and emerging changes in the contemporary practice of healthcare communication, including within the context of the patient–provider relationship. As previously described, at the time of this writing, the COVID-19 pandemic is ongoing, and it seems unrealistic to think that even once things return to “normal,” the world of health care will return exactly to the way it was in early 2020, before the pandemic necessarily thrust

technology into the everyday practice of medicine in a way never seen before.

Accordingly, the next section of this chapter will explore the COVID-19 pandemic, with a focus both on the increased use of certain technologies to facilitate health care during this public health crisis and the potential long-term implications of this integration of technology and medicine, particularly for the patient and the provider.

COVID-19 and Technology in Health Care

Spurred by the COVID-19 public health emergency, the U.S. Department of Health and Human Services (HHS, 2020a), for one, has moved toward making it easier for healthcare providers to offer telehealth services, encouraging them to both adopt and use telehealth (sometimes referred to as telemedicine, but which refers to the use of two-way communication technology for various healthcare services) as a way to safely provide care to patients in appropriate situations including routine health care, medication consultation, and mental health counseling. According to HHS (2020b), the option of telehealth prevents patients from having “to choose between medical care and social distancing,” explaining that “when patients can get health care through telehealth — and doctors can provide it — we protect ourselves and our communities” (para. 1). This expanded access to telehealth services has been extended to those enrolled in Medicare, Medicaid, and the Children’s Health Insurance Program, thus “allowing more patients to avoid clinical care at hospitals, physicians’ offices, and clinics, reducing their risk of exposure to the virus that causes COVID-19” (Carr, 2020a, p. 3).

Because of these temporary policy changes, providers can offer telehealth services for patients in their homes, even if they reside outside of designated rural areas; practice remotely, even across state lines; deliver care to all patients, both new and

established; and bill for these video and audio-only services as if they were delivered in person (HHS, 2020a). The list of covered telehealth services that can be provided in Medicare through telehealth has similarly enlarged in scope, now including emergency department visits, initial nursing facility and discharge visits, home visits, and therapy services (HHS, 2020a). These changes also include guidance on the use of remote communication technologies and applications—like FaceTime, Facebook Messenger, Google Hangouts, Zoom, and Skype—by healthcare providers covered by the Health Insurance Portability and Accountability Act (HIPAA) of 1996; such applications can be used for telehealth services, even if the application does not fully comply with HIPAA rules (HHS, 2020a). (Public-facing platforms, like Facebook Live and TikTok, should not be used to provide telehealth, however.)

There are many definitions of telehealth, telemedicine, eHealth, and the like, depending on the source consulted. In some ways, the distinctions among these terms have become even more blurred as the COVID-19 pandemic has required the rapid expansion or adoption of such services by providers. For example, the Health Resources Services Administration (HRSA, 2019), an HHS agency, states that telehealth involves “the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration,” with telehealth technologies including videoconferencing, the internet, streaming media, and terrestrial and wireless communications (para. 1). Telemedicine, according to HRSA (2019), is more limited, referring to specifically remote clinical services, whereas telehealth can refer also to remote nonclinical services (e.g., provider training, continuing medical education).

The Centers for Medicare and Medicaid Services (CMS, n.d.) maintains that “telemedicine seeks to improve a patient’s health by permitting two-way, real time interactive communication between the patient, and the physician or practitioner at the distant site” (para. 1). At minimum, per CMS (n.d.), this involves the use of audio and video equipment. In contrast, according to CMS (n.d.), telehealth, or telemonitoring, “is the use of telecommunications and information technology to provide access to health assessment, diagnosis, intervention, consultation, supervision and information across distance” (para. 11). Telehealth thus includes technologies like telephones, fax machines, email, and remote patient monitoring devices, “used to collect and transmit patient data for monitoring and interpretation” (CMS, n.d., para. 12).

The World Health Organization (WHO, 2010), noting that the term “telemedicine” was coined in the 1970s and literally means “healing at a distance,” recognizes that there is no one definition of telemedicine, but offers up the following broad definition:

The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities. (p. 9)

According to WHO (2010), the many definitions of telemedicine—and the many terms that exist to describe the practice of providing healthcare services not in person and with the use of technologies—only serve to demonstrate “that telemedicine is an open and

constantly evolving science, as it incorporates new advancements in technology and responds and adapts to the changing health needs and contexts of societies” (p. 9). WHO (2010) acknowledges that some differentiate between telemedicine and telehealth, with the former focusing on service delivery by physicians only and the latter implying services provided by healthcare professionals in general (e.g., nurses, pharmacists), but in its 2010 *Telemedicine: Opportunities and Developments in Member States* report chose to view them as synonymous and use them interchangeably. The current work, while acknowledging the distinctions made by various organizations and entities among the terms, will treat these terms similarly. For the purposes of this work, telehealth, telemedicine, eHealth, and so forth mean one thing: the use of technology in the provision of healthcare services. In particular, telehealth in the context of the COVID-19 pandemic has come to mean health care delivered via a virtual visit, in contrast to the traditional in-person healthcare encounter.

Returning to the June 2020 *CJON* supplement on eHealth, a commentary titled “Championing eHealth in Clinical Care” takes a brief but holistic look at the use of technology, noting that “increased technological advancements, as well as the widespread availability of these technologies and their application to Americans’ daily lives, have become the norm” (Hickey, 2020, p. 4). For instance, the first smartphone—the iPhone by Apple—was released only a little more than a decade ago (Hickey, 2020), but today there are about 275 million smartphone users in the United States (Holst, 2020). Hickey (2020) adds that such technologies have touched most every area of life, including the clinical nursing care of patients with cancer. Consequently, this *CJON* supplement tackles this topic, in particular how technology can extend and enhance such care.

One article reviews various technologies applied to clinical care in oncology, finding that eHealth may transform cancer care by extending services directly to the patient, wherever they reside (Doyle-Lindrud, 2020). Similarly, another article explores how eHealth activities, like teleoncology (the application of telemedicine to the practice of clinical oncology), televisits (patient–provider communication through interactive video- or audioconferencing), and remote patient monitoring, help to bridge gaps of physical distance and time, as well as barriers to access, between patients and providers (Baldwin-Medsker et al., 2020). Other articles look at the role of telenavigation (care that is coordinated by nurse navigators in conjunction with the interprofessional care team via technology) in improving patient outcomes (Rowett & Christensen, 2020), the continued advancement of eHealth as a platform for supportive oncology care (Haase et al., 2020), and education delivery via eHealth for clinical oncology nurses, patients, and caregivers (Doorenbos et al., 2020).

Of course, the realm of medicine is no stranger to technological development and its continued integration into the practice and provision of health care, and oncology is just one of many areas within this realm that has been significantly influenced by technology, including those technologies that make telehealth, telemedicine, eHealth, and the like possible. What is particularly striking, though, is that the use of these technologies is, in many ways, bringing about a shift, a fundamental reshaping of the roles of patient and provider, along with the patient–provider relationship and, in particular, the communication that occurs within that context.

Telehealth, for example, brings the provider directly to the patient, removing barriers and burdens, physical and otherwise, that might ordinarily prevent access. The

existence of the internet itself gives patients the ability to seek out information about their health on their own terms; no longer are they shut out and excluded from this knowledge because they lack a medical degree. Even the ubiquitous smartphone is contributing on this front, with countless healthcare-oriented applications available for everything from managing heart disease to tracking fertility and reproductive health. What all of these (and countless other examples) have in common is that the patient is now front and center, an active participant in their own health care.

Autonomy in Health Care:

The Shift to the Active, Informed Patient and the Influence of Technology

This shift—from patient as passive bystander to active, informed participant—did not necessarily begin with recent technological advances. Only a few decades ago, the principle of respect for autonomy, which holds “that patients have a moral claim to direct the course of their own medical care and to be given reasonably full information in order to make medical decisions” (Baumgarten, 1999, para. 1), emerged as part of the bioethics movement, effectively transforming the highly paternalistic patient–provider relationship. However, interconnected technologies like the internet and the smartphone have certainly hastened and intensified this change, particularly as they have become more commonplace and more readily available to a larger swath of the population.

Although for centuries, “the dominant model [had] been the paternalistic, in which the doctor adopts the role of the guardian of the passive patient,” models of care today tend to “feature some form of shared power, and emphasize the importance of information as resource for encouraging patients and doctors to work together to develop a treatment or investigation plan” (Pearce et al., 2011, p. 138). In other words, whereas

once patients were willing and trusting subjects, submitting to what their physicians thought best, today they are actively involved, seeking out and interpreting medical information obtained, on their own, from a number of sources both inside and outside of the healthcare arena and taking a keen personal interest in the management of their own health and wellness. As previously noted, one way in which they are doing so is via technology.

Lee and Zuercher (2017) write that “scholars have long speculated that the emergence of computer-mediated communication . . . will transform the traditional, paternalistic doctor–patient relationship into a more deliberate and empowering relationship” (p. 22). Although Lee and Zuercher (2017) refer specifically to computer-mediated communication, which they define as email and web messaging systems, for example, this statement can be applied to other forms of technology as well.

Eric Topol, a cardiologist and geneticist who researches digital medicine, would likely agree. Topol, in fact, has argued that technology is directly linked to increased patient involvement in health care and even devoted 2015’s *The Patient Will See You Now: The Future of Medicine Is in Your Hands* to this topic. In the early 21st century, says Topol (2015), “a new model of medicine is taking hold, one that is democratized—not difficult, but easy” (p. 4) and attributes the dawning of this era to “unplugged digitization, with the smartphone as the hub” (pp. 4–5). After all, this model is one that has already been adopted in almost every other industry, from retail, to dining, to entertainment, with “getting things done in a flash” having become the norm in all realms except for medicine (Topol, 2015, p. 5). But, Topol (2015) says, this change in medicine too is “now inevitable” (p. 5).

Such a change will put “the individual at center stage” (Topol, 2015), with dramatic implications for the patient–provider relationship, which will be “radically altered” (p. 5). Referring to the possibilities of telehealth, Topol (2015) explains that patients will still see providers, but “the doctor will see you now via your smartphone screen without an hour of waiting, at any time, day or night” (p. 5). Although this provider may not be your usual primary care doctor, he says, “it will likely be a reputable physician who is conducting part of his or her practice through secure video consults . . . and those consults will involve doing parts of the standard physical examination remotely” (Topol, 2015, p. 5).

These video consultations will also “incorporate sharing your data”—data well beyond what can be encompassed in the standard electronic health record and including that gathered from “sensors, images, labs, and genomic sequence” (Topol, 2015, p. 5). These “lots of terabytes of data about you . . . will someday accumulate, from the womb to tomb, in your personal cloud, stored and ready for ferreting out the signals from the noise, even to prevent an illness before it happens” (Topol, 2015, p. 5). Today’s smartphones, for example, have the ability to check blood pressure or do an electrocardiogram or capture blood-glucose information. In many instances, smartphones can even go beyond recording these data—they can analyze and interpret these data too.

Topol (2015) specifically refers to all this as “a serious challenge to medical paternalism” (p. 12). What is thus on the horizon may be the full and complete democratization of health care, in which medical data not only flow down to the patient—instead of upward, to the provider—but are also generated by the patient on

their own device. Information will be available to all. Furthermore, “medical emancipation,” says Topol (2015), will occur

when each individual owns and takes part in generating their entire set of medical data and information, including records, notes, labs, images, omics, sensors; when they have complete assurance of privacy and security, such that their identity will not be revealed and their data will not be sold or misused; when individuals become fully respected by their doctors and on equal footing; when the individual now unabashedly asks the right questions, drives the process, and makes the choices; when individuals have full access to the cloud, supercomputing, and telemedicine; and there is total transparency for data on doctors and hospitals with respect to outcomes, costs, and ratings; when it is for all ordinary people, anywhere in the world. (p. 13)

A Historical Look at the Patient–Provider Relationship

It is important, vital even, to take a step back in order to grasp the full historical context of the patient–provider relationship. In particular, from the very start of the medical profession, there has been evidence of what can only be referred to as extreme paternalism—a harmful tradition that has, in many ways, persisted even into the present. Based on one-way trust, the beneficence model, or what today would be termed medical paternalism, allowed providers, for example, to make decisions for their patients based on what *they* believed was best for the patient, without necessarily asking for or considering the wishes of the patient. This model is a perfect illustration of the well-known phrase “doctor knows best.”

Taken as a whole, the practice of medicine remained relatively stable from the fifth century BCE, with the writing of the Hippocratic oath and the texts that make up the Hippocratic tradition, to the end of the 19th century (Govind, 2013; Will, 2011a). In fact, although medical practice “looks very different than it did 2,500 years ago . . . there has been greater change in the last 100 years or so than in the previous 2,400” (Will, 2011a, p. 669).

This was a time during which silence about matters related to disease and death was simply routine, and when both “the paternalistic authority and knowledge monopoly of physicians” and “the dutiful compliance and forged ignorance of patients” were reinforced (Klawiter, 2008, p. xxvii). Although the Hippocratic oath, which is considered to be the foundation of the beneficence model, offers basic principles for healthcare providers and outlines their core responsibilities, including keeping the sick free from harm and injustice, it noticeably lacks a meaningful role for the patient to play in the decision-making process (Will, 2011a). It “speaks of a group of high-minded, male individuals with specialized training, determined to keep their practice internal to a select group” (Will, 2011a, p. 670). In addition, the language employed in the Hippocratic oath implies that physicians stand apart from others, in that they alone are qualified to diagnose illness because of their unique knowledge and skill and, subsequently, offer treatment to the ill.

Implicated in the oath’s wording, too, is the notion that not only should physicians avoid causing harm to patients, but that they should also “affirmatively attempt to prevent harm, remove harm, and promote good” (Will, 2011a, p. 670). The tradition promoted by the Hippocratic oath viewed physicians as having “an ethical obligation to act, to the best

of their judgment, for the medical benefit of their patients,” which included exercising their supreme authority over dutiful and submissive patients (Will, 2011a, p. 670).

Still, the Hippocratic oath and other medical codes of conduct from this period bear more resemblance to guides on etiquette rather than ethics, in part because of the state of medical practice at the time. For instance, the primitive medical treatments of the period and their uncertain and variable outcomes meant that early physicians could not rely solely on skill and competence to grant legitimacy to their claims of authority. Consequently, “behavior and etiquette that cultivated a sense of respect and propriety were the keys to a physician gaining a positive reputation through which increased patient trust and obedience would follow” (Will, 2011a, p. 670).

Because gaining patient trust and confidence was viewed as so essential and so critical, the practice of benevolent deception—in which the physician would assess whether disclosure would benefit or harm the patient, and if it was the latter, “it was the clinician’s duty to withhold . . . to use a euphemism, to use jargon, or to just plain lie” (Veatch, 2009, p. 45)—was accepted and encouraged. It was thought that if “the truth would compromise the patient’s faith in the cure and, thus, the overall medical prognosis,” it should not be revealed (Will, 2011a, p. 671). Again, the provider here is assuming the role of “the knowledgeable and concerned father, who is active,” with the patient as “the passive child, dependent on the father” (Mazilu et al., 2010, p. 183).

It is not surprising, then, that the term “silence” is used often in discussions of the patient–provider relationship viewed from a historical context (Katz, 1984; Topol, 2015). But it is important to keep in mind that this “history” is often not as far in the past as we might like to believe. For example, a study based on a questionnaire and interviews with

219 doctors that was published in the *Journal of the American Medical Association (JAMA)* in 1961 found that just 12% of doctors would tell patients they had cancer, with the 88% who would elect to withhold this information doing so based on personal judgments (Oken). Further illustrating this point, in Tennessee Williams's classic play *Cat on a Hot Tin Roof*, which premiered in 1955, "the character Dr. Baugh does not disclose to Big Daddy that he is dying of an incurable cancer," which "would have been typical for that period" (Schudson, 2015, p. 11). (Thankfully, a follow-up study published in *JAMA* in 1979 determined that 98% of doctors reported speaking frankly and candidly with their patients about cancer [Schudson, 2015].)

By the 16th and 17th centuries, approximately 2,000 years after Hippocrates and the Hippocratic oath, some physicians had begun to acknowledge that perhaps patients "might or should have a voice in their care" (Topol, 2015, p. 20), though this belief was not widespread. Physicians like Benjamin Rush and John Gregory were advocates for truthful physician disclosure in interactions with patients, but they did not push for a wholesale move away from the prevailing beneficence model or describe in their writings a newfound respect for patient decision-making (Will, 2011a). Instead, Rush, for instance, believed that "rational patients," with whom physicians shared medical information, would "appreciate the wisdom of their physicians and graciously comply with the physician orders" (Will, 2011a, p. 671).

Ultimately, Thomas Percival, a student of Gregory's, brought the beneficence model into the modern era with his *Medical Ethics*, along with other works on the subject, all of which were very much consistent with the Hippocratic tradition. In these works, Percival questioned patients' capacity for "reason and rationality, given their

dependence on physicians and the physicians' superior knowledge as to what information would be detrimental to the patients' health" (Will, 2011a, p. 671). Percival did acknowledge that lying could be harmful to the profession, but only because it was ungentlemanly; he did not find truth telling or disclosure to have any benefits to patient health and, thus, did not see the utility of these actions.

Many American physicians of the period agreed with Percival's assessment, particularly his continued maintenance of the idea of the authoritative physician and the obedient patient. These principles were ultimately codified by the American Medical Association (AMA), now the largest professional organization of physicians in the United States, in its first ethical code in 1847. The original AMA *Code of Ethics* "has set a lasting tone," says Topol (2015), with much of the language conveying "the sense of a self-congratulatory orgy" and "nobility, authoritative command, and eminence . . . pervasive" (p. 24).

The first revision to this document, which is considered by AMA to be the predominant guide to ethics for practicing physicians, was not made until 1903. It was then that the following statement concerning communication to the patient was added: "A solemn duty is to avoid all utterances and actions having a tendency to discourage and depress the patient" (Topol, 2015, p. 24). Informed consent—which in the patient-provider context means that the provider has educated a patient "about the risks, benefits, and alternatives of a given procedure or intervention," with the patient being "competent to make a voluntary decision about whether to undergo the procedure or intervention" (Shah et al., 2020, para. 1)—was not mentioned until the 1957 revision (Topol, 2015). The specific context in which informed consent was mentioned is striking, too—a

surgeon had to disclose facts related to the need and performance of a given operation, and an experimenter using new drugs and procedures had to obtain voluntary consent of the individual using said drugs or procedures.

Later revisions to the AMA's code and documents concerning matters of ethics in the 1980s continued to grant "considerable authority to physicians based on their judgment" (Topol, 2015, p. 25). For example, physicians had the authority to treat without consent in situations where consent would be medically contraindicated, such as when disclosure of risk presented a significant psychological threat to the patient. Topol (2015) observes that over the years there has been a marked shortening of AMA codes and policies—from 5,600 words in 1847 to 250 words in 1980. Yet, in these substantial revisions, "there were never any [words] added to raise awareness that patients need a voice" (Topol, 2015, p. 25).

At the time of the AMA's first ethical code, in 1847, when the organization was founded, physicians in the United States—and the profession as a whole—were struggling to gain legitimacy. The efficacy of treatments promoted during this period was questionable, for example, and there was a lack of unified, formalized medical education. However, it was likely the prevailing ideology of the United States, which stressed freedom and independence, that had the most significant effect on the eventual emergence of the autonomy model in the mid-20th century. As Will (2011a) explains, "the emphasis on liberty, individualism, and self-sufficiency encouraged the lay populace to be skeptical of any group making self-interested claims of status and authority, particularly when there appeared to be no legitimate basis for such claims" (p. 672). In addition, by the end of the 18th century, the movement toward domestic medicine

promoted the idea that physicians were simply not needed to treat most illnesses, and medical manuals detailing home-based treatments for these illnesses were available to laypersons.

In the early 19th century, though, a discovery by French physicians was, in part, responsible for rerouting this initial path toward patient autonomy. It was found, by way of empirical methods, that “many of the accepted medical treatments of the time had limited to no therapeutic value,” which ushered in “increased emphasis on disease prevention and on developing alternative treatments with scientifically measurable efficacy” (Will, 2011a, p. 672). This effectively transformed the medical profession and firmly moved the practice of medicine beyond the skill and ability of laypeople for good.

The standardization of American medical education further legitimized providers’ claims of authority and allowed for continuation of the beneficence model through much of the 20th century. This period, termed “the regime of medicalization” by Klawiter (2008), was characterized by its norms of nondisclosure, hampering the ability of patients—and female patients in particular—to participate in their own health care, including decision-making, in any significant way.

With their advanced medical knowledge, providers were simply presumed to be in the best position to make decisions for their patients, as they knew what would be of greatest medical benefit. In addition, they found the values and beliefs of the individual patient to be irrelevant to the medical decision-making process, as they were unrelated “to the issue of what decision would best treat the patient’s illness” (Mazilu et al., 2010, p. 183). There was no consideration or even acknowledgment of the fact that medical benefit and patient benefit are not always the same or that they are, in fact, two separate

and distinct entities. Similarly, human bodies were often not contemplated on an individual basis and were instead “expected to adhere to a standard norm,” with providers consistently working “through a paradigm of definition, diagnosis, classification, and treatment” (Dubriwny, 2012, p. 14).

Today, for the most part, the roles and responsibilities of both patients and providers have been redefined. Today’s “regime of biomedicalization,” as it is called by Klawiter (2008), involves questioning, on the part of patients and the public at large, of the blind “trust in and obedience to physicians upon which the beneficence model depended” (Will, 2011b, p. 1,491). With this shift, “patients gained the right to ‘gaze back’ at their physicians, ask questions, and become participants in their own treatment decisions,” even seeking out more information concerning their health care on their own (Dubriwny, 2012, p. 37). Under the autonomy model, the values and choices of patients are respected, with patients and their providers sharing in the decision-making, and patient benefit is viewed as an entity fully separate from medical benefit—in theory, at least.

The Concept of Informed Consent

As previously noted, much of what led to this transformation in medicine (i.e., the move from the beneficence model to the autonomy model) was the concept of informed consent. Although obtaining consent from patients was a practice that was somewhat familiar to physicians in past eras, doing so was not directly, if at all, related to allowing patients to be actively involved in the decision-making process or respecting their wishes. As Will (2011b) explains,

it was not until lawyers, philosophers, and others external to the medical profession suggested an inherent value in respecting the decision-making capacity of patients as autonomous agents that the duty to obtain consent became the duty to obtain informed consent recognized under current legal and medical standards. (p. 1,492)

Much of what pushed the concept of autonomy to the forefront within medicine was the need to erect “a barrier to abuse in the name of science,” particularly in light of medical experimentation on unwilling research subjects during and after World War II (Agledahl et al., 2011, p. 212). The Nuremberg Code of 1947, for example, “declared that the voluntary consent of the human subject is absolutely essential” (Agledahl et al., 2011, p. 212).

Today’s understandings of informed consent maintain that prior to initiating any treatment, a physician must obtain informed consent from the patient, which means that the patient can refuse to consent and, thus, refuse the treatment. The issue here is that patient refusal of treatment that results in the patient’s condition worsening, or even culminating in death, is in direct opposition to “the government’s interest in preserving life and the physician’s duty (dating back to the Hippocratic tradition) to use his or her medical skill and judgment to act in the patient’s best interests” (Will, 2011b, p. 1,492). In general, though, patients experience limited opportunities for the full exercise of choice—they do not necessarily have the ability to choose whatever treatment they desire, for instance.

In addition, as Topol (2015) explains, “most physicians seek consent the same way that a software company does when you download an update or a smartphone app:

by presenting you with an extremely long legal document and asking you to press ‘I agree’” (p. 29). This is instead “quasi- or pseudo-informed” consent, because “most individuals don’t read the materials, or if they try to they often find they are not understandable” (Topol, 2015, p. 29). Topol (2015) also acknowledges the compulsory aspect of informed consent—the patient is often “left with little viable or practical alternative” (p. 29). Although today’s patients are better informed, they are usually not fully informed or even engaged in the process.

The Principle of Respect for Autonomy

Respect for autonomy in medicine is “explicitly formulated as respecting autonomous choice” (Agle Dahl et al., 2011, p. 212) in Beauchamp and Childress’s (2001) seminal *Principles of Bioethics*, which was first published in 1977. Explaining that the term “autonomy” derived from the Greek *autos* (“self”) and *nomos* (“rule,” “governance,” or “law”), Beauchamp and Childress (2001) state that it “originally referred to the self-rule or self-governance of independent city-states” but “has since been extended to individuals” (pp. 57–58). In doing so, autonomy has come to mean “self-governance, liberty rights, privacy, individual choice, freedom of the will, causing one’s own behavior, and being one’s own person” (Beauchamp & Childress, 2001, p. 58). This may be undercut “by coercion, persuasion, and manipulation,” however (Sedig, 2016, p. 13).

Personal autonomy “is, at a minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (Beauchamp & Childress, 2001, p. 58). Beauchamp and Childress (2001) also contrast the autonomous individual with a “person of diminished

autonomy”—the former “acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and sets its policies,” whereas the latter is “controlled by others or incapable of acting on the basis of his or her desires and plans” (p. 58).

The literature suggests that the concept of autonomy has led to the central positioning of the patient in health care (Agle Dahl et al., 2011). Some criticism has been levied against the way in which the principle of respect for autonomy often overshadows other principles (i.e., nonmaleficence, or providers’ doing no harm; beneficence, or providers’ doing all they can to benefit the patient; and justice, or providers’ ensuring that there is an element of fairness in all medical decisions). For example, as one critic writes, “By holding autonomy to be *the* governing principle, I believe we only obscure the doctor-patient relationship and confuse the moral standing of the patient” (Tauber, 2001, p. 300).

However, others argue that when the concept is properly understood, it implies “that part of respecting a patient with decisional capacity involves allowing them to choose or not to make their own decisions, to relegate their medical decisions to a surrogate, or to simply follow their physician’s recommendations” (Frank, 2013, p. 60). Furthermore, respect for patient autonomy is foundational to the patient–provider relationship and transforms interactions, such as the obtaining of informed consent, into processes, rather than mere events, that “involve careful listening and a dialogue that takes patients’ concerns seriously” (Frank, 2013, p. 60).

The Idea of Justice

The *Belmont Report*, released in its final form in 1979 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, ties together three ethical principles—beneficence, justice, and respect for persons—and holds these as a necessary foundation of biomedical and behavioral research involving human participants (Office for Human Research Protections, 2016; Sims, 2010). Further, the *Belmont Report* includes guidelines to ensure that such research is conducted with those principles in mind.

The current ethical framework for research involving human participants began to take shape in the 1940s with the Nuremberg Code of 1947. The *Belmont Report* itself states that although “[s]cientific research has produced substantial social benefits,” such research “has also posed some troubling ethical questions,” with public attention being pulled toward such questions after learning of reported abuses of human participants in medical experimentation, particularly during World War II (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 3). The Nuremberg Code was, accordingly, a product of the Nuremberg trials and was established “as a set of standards for judging physicians and scientists who had conducted biomedical experiments on concentration camp prisoners” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 3).

In many ways, the Nuremberg Code became a prototype for the codes that would follow, with all “intended to [ensure] that research involving human subjects would be carried out in an ethical manner” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 3). For example, the

Declaration of Helsinki followed in 1964, with this first version of the document adopted by the World Medical Association “as guidance for medical doctors undertaking biomedical research involving human subjects” (Office for the Protection of Research Subjects, n.d., para. 3). The policy statement has been amended seven times since, most recently in 2013 (World Medical Association, n.d.).

Although the *Belmont Report* came out of the National Research Act of 1974 and directly addresses research concerns, it also deals with the practice of medicine itself. In particular, the *Belmont Report* is an important document that forever altered the relationship between individuals and their medical providers. One of the driving forces behind the creation of the *Belmont Report* was acknowledgment of the Tuskegee syphilis study (Sims, 2010), in which “disadvantaged, rural black men [were used] to study the untreated course of a disease that is by no means confined to that population” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 6). Further, these individuals “were deprived of demonstrably effective treatment in order not to interrupt the project, long after such treatment became generally available” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 6).

There are countless other examples of medical injustice, particularly involving the ethics of research with human participants, in American history. According to the *Belmont Report*, in the 19th and early 20th centuries, “the burdens of serving as research subjects fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 6). The *Belmont Report*, then,

was designed to offer more protection for human research participants than could be provided by existing codes (Sims, 2010).

The *Belmont Report* holds that, in the context of the benefits and burdens of research, “equals ought to be treated equally” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 5). However, this conception of justice, of equality, of fairness can be extended to the practice of health care—and to health care itself—as well. For instance, the WHO Constitution of 1946 declares, in a statement that seems almost controversial today, “the highest attainable standard of health” to be “a fundamental right of every human being” (WHO, 2017, para. 1). It further added that governments are responsible for the health of their people, something that can be fulfilled only through adequate social and health measures (Christopher & Caruso, 2015). By doing so, “the WHO achieved two important milestones: defining health in the context of social determinants and codifying the right to health as international law” (Christopher & Caruso, 2015, p. 958).

The passage of the Patient Protection and Affordable Care Act in 2010 did much to improve health insurance coverage in the United States, and was the most substantial move toward universal health care in the United States since the passage of Medicare and Medicaid in 1965, but it fell short of establishing health as a human right (Christopher & Caruso, 2015; Perkins, 2018). It is important to point out that in the United States, there is no legal or constitutional right to health or health care, unless incarcerated (Perkins, 2018), as well as that the terms “health” and “health care” are often conflated.

The so-called “healthcare system” in the United States can more accurately be described as “a health insurance system” (Gerisch, 2018). In addition, clinicians

“necessarily focus on the provision of health care and its role in providing for the health of populations,” but “a right to health care is only one aspect of a larger right to health,” such as described by WHO (Christopher & Caruso, 2015, p. 961). A right to health, then, would include the provision of social measures as well, including “sufficient food and drinking water, adequate housing and working conditions, satisfactory education, racial and gender equality, and freedom from cruel or inhumane treatment” (Christopher & Caruso, 2015, p. 961). As will be described further in this project, there are many barriers that stand in the way of health—and health justice—for various populations.

Contributions of the Patient in Health Care

Patient-centered, people-powered health care holds that patients should assume an active role in helping to improve care, sharing responsibility, and thinking for themselves (deBronkart, 2015). Although it is well understood that the practice of medicine requires specialized skills and years of training and experience, the unthinking acceptance of the paternalistic “doctor knows best” model may have reached its natural end point. Instead, what is emerging is recognition of the potential contributions that may be made by patients, who are beginning to be viewed as “genuine, value contributing partners in the work of medicine” (deBronkart, 2015, para. 4). (It must be acknowledged here—and this will be further explicated later—that there are disparities in health care for various populations, especially minorities, and that not all patients are treated equally by providers in healthcare encounters. For example, even in today’s largely patient-centered healthcare environment, the experiences of women are often discounted and dismissed, a phenomenon known as medical gaslighting. Known biases in health care aside from sex include race and ethnicity, disability, and sexual orientation.)

It is true that providers offer medical expertise, but patients make their own contributions to the healthcare conversation as well: “their life experience, their deep investment in the outcome of their case, their skills and resilience, and a unique perspective on needs and priorities” (deBronkart, 2015, para. 7). As noted earlier, thanks in no small part to various technologies that have allowed for more than a top-down flow of knowledge, and the move from a closed system to an open one, patients can now access information that was once privy only to providers, and they also have the ability to share and discuss this information with others. A patient-centered, people-powered model of health care would consider “the voice of thinking patients” and involve new forms of collaboration in the relatively static patient–provider relationship (deBronkart, 2015, para. 7). The author of a Society for Participatory Medicine blog elaborates on the potential of this shift:

Autonomy is true empowerment. It promotes patient responsibility and holds the promise to lead us to more engagement and better health. We must move beyond participatory medicine and focus on educating, enabling, and equipping patients with the tools necessary to master autonomy and the art of self care. (Campos, 2014, para. 18)

Discarding the term “patient,” Topol (2015) instead chooses the phrase “individual, active participant,” or IAP, to describe “an individual who is an active participant in his or her care, who commands the same level of respect as the doctor, and who is privy to any and all data and medical information that is about that person” (pp. 27–28). Topol (2015) describes a “move away from the paternalistic model to one of partnership, from autocratic to far more autonomous,” writing that this requires both “a

change in culture within the medical community” and a driver from the outside. The latter, perhaps, is technology.

Continued recognition of the agency of patients in health care, propelled forth by various technologies, has significant implications for the practice of medicine, and especially for the patient–provider relationship and the communication that occurs within it—particularly as, in this current historical moment, interactions with technologies often stand in for interactions with others. In the healthcare setting, interactions typically occur within a patient–provider dyad in one or more encounters and have a significant impact on shaping that relationship. Such communication between the patient and their provider is described as “the backbone of the primary care visit,” influencing everything from patient satisfaction to treatment adherence, from clinical outcomes to patient trust (Asan et al., 2016, p. 1). It is a topic worthy and deserving of continued interrogation.

Relevance of Project and Outline of Chapters

As has been demonstrated thus far, patients are more engaged than ever in their health care, and the flow of information, particularly healthcare data, which can now be generated by the patient on their own devices, has drastically, irrevocably changed. Topol (2015) draws a comparison between the impact of Johannes Gutenberg’s printing press in 1440—which not only launched the era of typography but also led to a communications revolution with effects including enhanced access to information and the cultivation of the individual—and the impact yet to come of mobile devices and other technologies, which will lead to a medical revolution in their own right. Both instances are marked by exponential shifts in the ways in which information is created, distributed, and consumed, with lasting residual impacts. Topol (2015) writes that “just as Gutenberg democratized

reading, so there is the chance that smartphones will democratize medicine” (p. 54). According to Topol (2015), “instead of the command ritual of data going first to doctors and trickling down to patients, this deep-rooted practice is about to be turned upside down,” thanks to the smartphone, which will “convey all the relevant data pertaining to an individual directly to that individual” but perhaps also perform “the lab tests or medical scans, parts of the physical examination traditionally done by a doctor, or processing the data that is graphically displayed or used for predictive analytics” (pp. 50–51).

Topol (2015) speaks specifically of smartphones and social networks in galvanizing this “bottom-up movement . . . for improving the future of medicine” (p. 51), saying that such devices “empower both the patient and the doctor” (p. 52). This is true. However, while acknowledging the role of the smartphone and various social networks in this shift, as Topol (2015) does, it is important to be attentive to other ways in which technology is helping to manifest such changes in health care and in the patient–provider relationship, especially in regard to the communication that occurs within it.

There are countless examples. The rapid expansion of telehealth, especially with the COVID-19 pandemic, is one; patients now even have the option to choose between established healthcare institutions and direct-to-consumer startups for their telehealth services (Seabrook, 2020). There are also a host of direct-to-consumer health products that offer the ability to test everything from genetics to fertility hormones to COVID-19 status in the safety, comfort, and privacy of one’s own home. (Of course, there are few protections related to genetic privacy [Molteni, 2019], and it is not out of the realm of possibility that an individual’s genetic information could end up in the hands of, say, a

private equity firm, which happened when Blackstone acquired genealogy and home DNA testing company Ancestry in August 2020 [Truong, 2020].) The implementation and integration of the electronic health record in medicine—it is typically used to review patient results, track healthcare maintenance, prescribe medication, offer patient referrals, and document patient visits—is ongoing, but it has already begun to be referred to in the literature as the third party in the traditionally dyadic patient–provider relationship and has produced mixed results, especially in regard to its impact on communication in healthcare encounters, in its first several years of widespread use.

So far, this project has spoken to the role of technology in health care, especially in the current historical moment, and looked at it alongside patient–provider communication—past, present, and future. The second chapter, Chapter 2, explores the current state of patient–provider communication via a review of the literature, with attention paid to the significance of such communication to this dyadic relationship, as well as to numerous other factors, like patient health outcomes. The idea of communication ethics literacy, as detailed in Arnett et al.’s (2018) *Communication Ethics Literacy: Dialogue and Difference*, among other works, will be introduced as one way of further examining this topic, including the way in which it helps to reveal the goods that patient–provider communication is both protecting and promoting, the philosophy of communication that offers a reason for why this communication takes place, the applied communication context that shows how a given issue is spoken about, and the narrative ground that shapes communication as it transpires between individuals. The chapter will also look toward patient-centered communication and its connections to the communication ethics concepts previously discussed.

Drawing from the foundation laid in Chapter 2, Chapter 3 further examines the current state of patient–provider communication through the relevant literature and is attentive to how this communication affects the patient–provider relationship, especially within healthcare encounters. Chapter 3, though, adds another level of complexity to this discussion, as it looks at the changing dynamics of this relationship over time through the interconnected foci of gender and race and ethnicity in health care. By doing so, the chapter places social justice issues in the context of healthcare communication, including the communication ethic of patient–provider communication.

Next, Chapter 4 tackles questions related to how technology is bringing about a restructuring of the patient–provider relationship and the communication occurring therein. The influence of technology in the healthcare setting is complex: For instance, although technology has equipped patients with the means to become more active and willing participants in their own health care, it also extends existing barriers within health care—and even creates new ones. Chapter 4 addresses both past and present technologies and how they have shaped the realm of medicine, and touches on the immediate and likely lasting effects of the COVID-19 pandemic in relation to technology and health care.

Among the issues raised in Chapter 4 is how patient-centeredness can be established or retained in the context of communication within the healthcare setting. Chapter 5, in response, looks to the profession of nursing as a potential solution to this challenge, drawing from the work of Fritz (2013), who sees professions, like nursing, as practices that work toward a particular good that is significant to human life. Through an examination of the profession of nursing, Chapter 5 understands the contact and

connection created with patients in the context of the patient–nurse relationship as one of the fundamental goods of nursing. This good, among others, can be protected and promoted even when, and especially when, technology is integrated into the healthcare setting; in addition, this good can be extended beyond nursing, to influence and guide other professions and practices.

Finally, Chapter 6 provides some concluding thoughts and reflections related to findings determined over the course of this project, including anticipating what the future of communication in the technology-driven realm of health care might look like and posing additional research questions worthy of further scholarly inquiry. After all, the impact of technology on the practice of health care and the communication that transpires within it is a subject that will only continue to grow in relevance, especially during and after the COVID-19 pandemic.

Chapter 2: Importance of the Interpersonal Relationship to Patient–Provider

Communication: A Communication Ethics Perspective

To this point, this project has opened up a discussion of the role of technology in health care, particularly in the current historical moment, which is marked in many ways by the COVID-19 pandemic, and examined it through the lens of patient–provider communication and the patient–provider relationship. As was detailed in Chapter 1 of this project, the current historical moment has much to reveal about the impacts of the conjoining of technology and health care, especially in regard to the interpersonal relationship between a patient and their provider and the communication that takes place within it. For example, there is evidence that the continued integration of technology into the healthcare setting aligns with a much larger shift within health care that has occurred in recent decades; this shift involves a heightened sense of patient-centeredness, with paternalistic, passive approaches to health care appearing to fade from practice. This chapter will expand on these ideas and further explore the importance of the interpersonal relationship to communication in the patient–provider context, which is necessary for understanding how technology affects and influences it.

As was noted in the preceding chapter, communication between the patient and their provider is viewed as “the backbone of the primary care visit,” a fundamental, integral part of clinical practice (Asan et al., 2016, p. 1). Furthermore, patient–provider communication “is the primary process by which medical decisions are made and patients are diagnosed and treated,” and it is an important indicator of patient-centered care and, subsequently, care quality (Cené et al., 2009, p. 1,057). The communication occurring during medical encounters and consultations is essential to the care that patients receive

(Jefferson et al., 2013), with such communication intimately tied to the practice of medicine—gathering information to facilitate an accurate diagnosis, counseling appropriately, providing instructions, and establishing relationships with patients—and to the aim of “achieving the best outcome and patient satisfaction, which are essential for the effective delivery of health care” (Ha et al., 2010, p. 38). Accordingly, exploration of this topic is vital in order to grasp how factors, like technology, are changing it.

The current chapter, Chapter 2, will begin with a review of the literature on patient–provider communication, with attention paid to its importance to the patient–provider relationship, as well as to a myriad of other factors, including patient health outcomes. Next, the chapter will offer one way of further explicating and understanding this topic via Ronald C. Arnett, Janie M. Harden Fritz, and Leeanne M. Bell McManus’s conception of communication ethics literacy. Through the idea of communication ethics literacy, as detailed in Arnett et al.’s (2018) *Communication Ethics Literacy: Dialogue and Difference*, among other works, it becomes easier to see the goods that patient–provider communication is both protecting and promoting. Further, this discussion opens up to include contemplation of the philosophy of communication, either implicit or explicit, that provides a reason for why this communication takes place; the applied communication context, which reveals how a given issue is spoken about; and the narrative ground, which shapes and molds communication as it emerges between individuals. Finally, this chapter will conclude with further discussion of what is held as perhaps the ideal for patient–provider communication—patient-centered communication—melded with communication ethics concepts, including implications for practice.

Patient–Provider Communication in the Literature

The study of patient–provider communication is a study of interpersonal communication. The construct of interpersonal communication may be understood in varying ways, depending on the individual scholar and their approach to the field. Most scholars, however, would likely agree that interpersonal communication is much “like the phenomenon it represents—that is, dynamic and changing” (Knapp et al., 1994, p. 8). More specifically, it can generally be assumed that the study of interpersonal communication will involve “at least two communicators; intentionally orienting toward each other; as both subject and object; whose actions embody each other’s perspectives both toward self and other” (Bochner, 1989, p. 336). In addition, interpersonal communication itself is often viewed as a process, or “an ongoing, ever-changing event,” which makes “understanding the communication process . . . largely a matter of understanding what happens over a given period of time” (Knapp et al., 1994, p. 9).

This idea has particular relevance in the healthcare setting, where interactions typically occur within a patient–provider dyad in one or more encounters and have a significant effect in shaping that relationship. After all, much of interpersonal health communication research is centered on relationships, such as those between patients and providers (Wright et al., 2008), and Bylund et al. (2012) are blunt in noting the interconnectedness of the setting in which this relationship occurs and interpersonal communication itself: “By its very nature, the provider–patient encounter *is* interpersonal communication” (p. 261). Similarly, Beaulieu et al. (2011) operationally define interpersonal communication in the context of the patient–provider relationship as “the ability of the provider to elicit and understand patient concerns, to explain healthcare

issues and to engage in shared decision-making if desired” (p. 109). (It should be noted that in this work, this chapter especially, the term “provider” is used loosely to mean an individual who provides healthcare services to a patient. When a specific type of provider, such as a physician or a nurse, is described, this will be noted.)

Interpersonal communication between patients and providers is essential to the provision of “equitable, high-quality care” (Martin et al., 2013, p. 151), and, in many ways, the provider’s relationship with their patient “is built on effective communication,” both verbal and nonverbal (Travaline et al., 2005, p. 14). Verbal communication, or spoken language, and nonverbal communication, which “includes extratextual elements of a face-to-face exchange such as posture, facial expression, and dress . . . [that] can support, modify, or even contradict verbal messages” (Dyche, 2007, p. 1,035), are thought to play equally important roles in patient–provider interactions (Asan et al., 2015), as the two are “highly interdependent” (Thompson, 1994, p. 703).

The literature shows that the quality of interpersonal care matters to patients (Cooper-Patrick et al., 1999). When done well, the communication that transpires within the context of this relationship can lead to many positive outcomes and influences: a higher likelihood of the patient’s acknowledging their health problems, fully understanding their options for treatment, making behavior modifications, and adhering to their prescribed treatment (Travaline et al., 2005). Communication can aid information exchange and facilitate patient inclusion; good communication in particular can assist in regulating the emotions of patients, allow for increased comprehension of medical information, and permit better identification of the needs, perceptions, and expectations of patients (Ha et al., 2010). Encounters centered on the patient are linked to better

patient *and* provider satisfaction, and, unsurprisingly, “satisfied patients are less likely to lodge formal complaints or initiate malpractice claims,” proving advantageous for providers in relation to “greater job satisfaction, less work-related stress, and reduced burnout” (Ha et al., 2010, p. 39). Effective patient–provider communication even may “improve a patient’s health as quantifiably as many drugs” (Travaline et al., 2005, p. 13). In many ways, the way in which a provider “communicates information to a patient is as important as the information being communicated” (Travaline et al., 2005, p. 13). After all, “medicine is an art whose magic and creative ability have long been recognized as residing in the interpersonal aspects of the patient-physician relationship” (Hall et al., 1981, p. 18).

However, the inverse holds true, too; if this communication is *not* done well—and many providers tend to overestimate their communication skills and abilities—patient and provider satisfaction, not to mention the patient’s health and medical care, may suffer (Ha et al., 2010). For example, the patient interview is a key part of the patient–provider encounter, and the ability of the provider to “connect, to understand the patient’s expectations of the encounter, and to ask the right questions affects the quantity and quality of the information obtained” (Kennedy et al., 2014, p. 56). The literature shows much dissatisfaction with communication experienced by both patients and providers (Thompson, 1994), with most complaints about medical services concerning communication, not competencies (Beaulieu et al., 2011). And there are certainly numerous barriers to effective communication. Among these, as identified in the literature, are patient anxiety and fear, burden of work, fear of litigation, fear of physical and verbal abuse, and unrealistic patient expectations (Ha et al., 2010). Also observed are

the deterioration of providers' communication skills, as well as their focus on holistic patient care, over time; nondisclosure and miscommunication of information; avoidance of discussion of the social and emotional impact of patients' problems, because of the provider's inability to handle these issues or inadequate time to do so sufficiently; discouragement of patient collaboration, leading to disempowerment; and resistance on the part of patients (Ha et al., 2010).

In addition, the list of such barriers is only growing. Although the length of provider visits has held consistent since at least the 1990s (approximately 13–24 minutes) (Mobius MD, 2019), there are challenges related to communication that may arise from linguistic and cultural differences, as well as from technology, including the implementation and integration of the electronic health record into the traditionally dyadic patient–provider relationship and the prevalence of medical information—some reliable, some not—on the internet, which calls into question the provider's traditional role as authority figure and “most trusted counselor” (Travali et al., 2005, p. 13).

Overall, a majority of patients desire better communication with their providers (Chou, 2018). Even a cursory search of the literature on patient–provider communication reveals that it is an oft-discussed topic and one with countless dimensions—how to break bad news to patients, whether provider gender matters in interactions with patients, why some patients are more involved in their medical encounters than others. Happily, while acknowledging the problems and challenges inherent in such communication, the literature also offers up strategies for improvement on the part of the provider. This is a relatively recent take on the subject, as only a few short decades ago, providers, particularly physicians, were expected to develop and hone these “soft” communication

skills at patients' bedsides, in their rounds as residents, and as students at the elbows of master clinicians" (Travaline et al., 2005, p. 13). Today, though, the communication skills of providers are not viewed as absolute or irreversible but rather "as a set of measurable and modifiable behaviors that can evolve" (Travaline et al., 2005, p. 13).

It is clear that that communication within this complex relationship and setting affects countless variables (Thompson, 1994). Accordingly, numerous studies have demonstrated that communication skills, including those of providers, "can be improved with effective training," as well as that "effective communication improves medical outcomes, safety, patient adherence, patient satisfaction, and provider satisfaction and efficacy" (Boissey et al., 2016, p. 756). Similarly, there is growing recognition of the fact that patient experience influences "clinical health outcomes, and, in turn, how organizations deliver care," thanks, in part, to Centers for Medicare and Medicaid Services requirements to publicly report such patient experience scores to receive full reimbursement of services (Boissey et al., 2016, p. 755). Of course, skilled (or unskilled) provider communication is a significant component of patient experience. Realizing this, Boissey et al. (2016) investigated the impact of systemwide relationship-centered communication skills training for attending physicians at a large multispecialty academic medical center, finding that it "improved patient satisfaction scores, improved physician empathy, self-efficacy, and reduced burnout" (p. 755).

In terms of tangible, specific changes that providers can make to improve their communication with patients, the literature offers this as well. For instance, strong communication skills on the part of the provider, particularly their ability to explain, listen, and empathize, can profoundly affect biological and functional health outcomes,

along with patient satisfaction and the care experience (Institute for Healthcare Communication, 2011). Marked increases in patient satisfaction in particular increased when providers took problems seriously, clearly explained information, attempted to understand the patient's experience, and offered viable options (Institute for Healthcare Communication, 2011). Furthermore, a strong connection has been identified between healing and human relationships, particularly how providers can employ behaviors that are mostly verbal in nature to promote "positive patient relationships and health outcomes" (Dyche, 2007, p. 1,035).

Considering interpersonal communication, the healthcare setting is unique, in that it is "characterized by [an] urgency or life-and-death nature" and "by frequent interaction among those with pronounced status differences," creating a power imbalance between patient and provider (Thompson, 1994, p. 698). Although patient-provider interactions are social, the relationship between the patient and their provider is inherently different than that between family members and friends, for instance, particularly when noting issues related to equality, power, task expectations, and anticipated outcomes (Bylund et al., 2012).

There are important distinctions. For example, because of the power differential intrinsic to this relationship, providers often maintain control of interactions, and ambiguity on the part of the patient, stemming from provider language use, is not uncommon (Thompson, 1994). Issues of health literacy, and illiteracy, also come into play. It is a fundamentally unequal relationship "established by members of two distinct social groups in terms of their prestige [and] power" (Chichirez & Purcarea, 2018, p. 119). Even in the contemporary healthcare environment, in which patient autonomy has

largely become a taken-for-granted concept, the provider still assumes a position of authority and the patient one of vulnerability in asking for support and help in maintaining their health or addressing a health problem.

Although communication aids transaction of the foundational tasks of health care between patient and provider, much more is in play—“there are other dimensions of relationship being exchanged in the medical encounter” (Dyche, 2007, p. 1,035).

Communication is reciprocal; as such, a provider must be able to “interpret patient cues and adapt communication to individual patients,” as well as recognize their personhood, or “the fact that . . . [their] characteristics and internal experience impact the interaction and its outcome” (Dyche, 2007, p. 1,035). Furthermore, much of interpersonal communication “is a spontaneous expression of inner feelings, attitudes, and values,” as Dyche (2007) explains further:

It cannot be effectively feigned or consistently performed in the course of relationship building. When a physician asks a patient, “How are you feeling” embedded in the question are her convictions about the appropriate doctor–patient hierarchy, her feelings about the particular patient she is addressing, even her level of fatigue. The patient’s response and the relationship that ensues will be shaped by each of these. In the art of medicine, physicians learn to bring the best of their unique interpersonal capacities to finding a rhythm and resonance with each patient seen in care. (pp. 1,035–1,036)

Basic communication skills alone are often insufficient to form and sustain what has been referred to as “a successful therapeutic . . . relationship” that involves “shared perceptions and feelings regarding the nature of the problem, goals of treatment, and

psychosocial support” (Ha et al., 2010, p. 38). A more collaborative model of communication has been suggested as a possible strategy for improvement, which makes sense in the context of the more active role and decision-making responsibilities now assumed by many patients within the realm of health care (Wright et al., 2008). Patients, no longer seen only as passive recipients of health care, are able to counter the power and authority granted by society to their medical providers, and they can “implicitly and explicitly resist the monologue of information transfer” (Ha et al., 2010, p. 39). It has been suggested that patients do so “by actively reconstructing expert information to assert their own perspectives, integrate[d] with knowledge of their own bodies and experiences, as well as the social realities of their lives” (Ha et al., 2010, p. 39).

A more collaborative model, too, would involve a two-way information exchange, with providers collaborating with their patients to offer the best care available. A successful version of this type of information exchange would entail the full exploration of patient concerns, as well as the provision of balanced information to facilitate informed shared decision-making. As Ha et al. (2010) detail, this approach would feature provider “discussion and negotiation with patients” and evaluation of treatment options that are ultimately “tailored to the context of the patients’ situation and needs, rather than a standardized protocol” (p. 40). Patient expectations, preferred outcomes, acceptable risk levels, and costs should be taken into account to ensure patient adherence and the best possible outcomes.

In general, as previously noted, healthcare encounters that are patient-centered lead to better patient and provider satisfaction (Ha et al., 2010), and this sense of patient-centeredness can be manifested through communication practices (Beaulieu et al., 2011).

In addition, in the current historical moment, in which interactions with technologies often stand in for interactions with others, including within the realm of health care, “interpersonal communication skills have never been more important” (Chou, 2018, para. 9).

Looking Ahead: Patient-Centered Communication

In *Crossing the Quality Chasm: A New Health System for the 21st Century*, the Institute of Medicine (2001) noted that although healthcare providers at that moment had more research and technology available to them than ever before, there were serious concerns regarding the quality of health care in the United States at the start of the millennium. Viewing healthcare organizations as complex systems, the report calls for fundamental change to address this quality gap, looks at practices that hinder quality care, and examines approaches that can help to usher in change. Specifically, the Institute of Medicine (2001) identifies six aims for the healthcare system, maintaining that it should be safe, effective, timely, efficient, equitable, and, perhaps most important to this project, patient-centered; this is defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (p. 6).

Patient-centered communication is an important aspect of “high-quality health care,” foregrounding “the patient’s orientation and experience during patient–provider interactions” (Hawkins & Mitchell, 2018, p. 57). Medical interactions that are patient-centered promote things like caring, trust, shared decision-making, rapport-building, and the individual patient’s social and emotional well-being, all of which are important to actions that contribute to both short- and long-term health outcomes. As a concept,

patient-centered communication consists of four core components: “regarding the patient’s unique perspective, needs and preferences,” “encouraging patients to share power and responsibility for decision-making with their providers as they are capable and willing,” “promoting shared understanding between patients and providers about the medical issues and treatment,” and “situating the patient within their individual psychosocial context, including meeting patients’ informational and emotional needs” (Mitchell & Perry, 2020, p. 3).

Of course, as has been previously discussed, particularly in the first chapter of this project, health care that is largely focused on and guided by the patient is “an idea alien to the ethos of medicine” (Katz, 1984, p. xvi). The medical tradition is, instead, predicated on the idea that patients would trust their providers, particularly their physicians, without question. It has only been in relatively recent years that providers “have been asked to trust patients by conversing with them about medical options and soliciting their views on how to proceed” (Katz, 1984, p. xiv).

This idea, of a more balanced relationship between patient and provider, has been embraced as of late for a number of reasons, including various societal trends. For example, the current historical moment is defined in many ways by “increasing choice, consumerism and abundance of information,” along with challenges like “the ‘co-modification’ of healthcare, the profusion of alternative means of accessing information, the phenomena of medicalisation, the pressure to improve population health, the perennial tension between choice and continuity and . . . the availability of resources” (Taylor, 2009, p. 150). In a somewhat brief period of time, there has been a drastic shift from a paternalistic model of patient–provider communication to one that is pluralistic,

involving the democratization of decision-making, promotion of shared understanding, and empowerment of individuals.

As has been noted, despite this transition concerning the roles of patients and providers, the healthcare encounter still plays a highly significant role in the delivery of health care. It is a “transaction between two individuals” but also, importantly, “the interface between the medical profession and society” (Taylor, 2009, p. 150). One could argue that because of various challenges, including the intertwined abundance of both technology and information, the healthcare encounter, especially the patient–provider communication that occurs within it, is even more important than ever. This personal interaction between two individuals—the patient and the provider—should certainly continue “to be the cornerstone of an effective and humane healthcare system” (Taylor, 2009, p. 151). With this in mind, taking a deeper look at patient–provider communication, here from a communication ethics perspective, is surely warranted.

Communication Ethics Literacy

In the second edition of *Communication Ethics Literacy: Dialogue and Difference*, Arnett et al. (2018) seek to establish the relevance of communication ethics in postmodernity, and especially in the 21st century, a “time of narrative and virtue contention, a time of explicit and recognized disagreement about the shared stories that give our lives meaning” (p. xii). The “consistent refrain” of this work, then, is that “we live in a time of rival understandings of the ‘good,’ an era defined by competing narrative and virtue structures” (Arnett et al., 2018, p. xi). Difference is the dominant fact or characteristic of the current historical moment; as such, “the study of communication

ethics [is] necessary in order to live and work with others effectively” (Arnett et al., 2018, p. xi).

Difference thus implies that there exist “multiple views of the good,” with communication ethics literacy assuming “the importance of understanding and learning from difference, from the Other,” referring to “any human being embedded within a set of assumptions about right and wrong, good and bad, appropriate and inappropriate ways of engaging human life grounded within and definitive of . . . a tradition with whom we may come into contact” (Arnett et al., 2018, p. xi). The Other can be seen as representative of “our general responsibility to the entire human community”—but it is imperative to also recognize that “human life is lived one conversation at a time, within constraints of particular settings and concerns” (Arnett et al., 2018, p. xi).

For the purposes of Arnett et al.’s (2018) book, as well as for the current project, “ethics” is considered to be “practices that enact or support a good, a central value or set of values associated with human life and conduct” (p. xii). This particular definition of ethics, therefore, “lies at the heart of communicative practices” (Arnett et al., 2018, p. xii). Arnett et al. (2018) establish that if viewed historically, the discipline of communication has long recognized “the importance of the audience, the Other, the speaker, and the message” (p. xii). In the current historical moment, an era in which common public agreement does not exist, communication ethics becomes even more imperative, vital even. The current historical moment is defined by the act of sorting through differing views of what is and what is not the good.

As Arnett et al. (2018) make clear, though, these conditions of the current historical moment—including the lack of “public and private rules for engagement with

one another,” as well as “common spaces and places of agreement” no longer being “the normative background for communicative life”—are not necessarily a bad thing (p. xii). Instead of “a time for lament,” the current historical moment may instead be “an occasion for rejoicing if one wants to learn or has been on the outside of what a dominant group attempted to claim as universal when it was actually empowering only a select few” (Arnett et al., 2018, pp. xii–xiii). One must learn how to negotiate difference. Arnett et al. (2018) elucidate this, and the main idea of *Communication Ethics Literacy*, thusly:

Let us expect the different, learn from the unknown, and not take for granted that the Other holds dear the same sense of the good that gives our individual and collective communicative lives meaning. Pragmatic communication ethics action begins with learning, withholding the impulse to tell until one understands the context, the topic, and the persons. Learning is the pragmatic good of communication ethics in an era of narrative and virtue contention. (p. xiii)

Learning, according to Arnett et al. (2018), is the first principle of communication ethics, with a primary aim being “encouraging from and about differing understandings and enactments of the good” and “meeting and learning differing understandings of the good in a time of normative disagreement” (p. xv). Further, a “minimal ‘ought’ of learning” is “the importance of knowing one’s own ground and the ground of others,” which “informs continuing conversations about understandings of the good” (Arnett et al., 2018, p. xvi).

Arnett et al. (2018) importantly point out that communication ethics exists “within the realm of temporal decision making, not answers for all time” as it responds “to the demands and needs of the context, persons, and topics that shape our lives together” (p. xvi). Because of the demands of the current historical moment, particularly its being an

era of disagreement that requires learning about and negotiating difference, Arnett et al. (2018) connect communication ethics with dialogue, “a communication model opposed to demand and open to learning” (p. xvi). The realm of dialogic ethics is one that is “ever skeptical of demand, ever attentive of learning, every wary of the impulse to stand above history and proclaim ‘the truth’ with an air of unquestioned authority” (Arnett et al., 2018, p. xvii).

Communication ethics literacy that works from a dialogic perspective commences with “a pragmatic ‘why’ to learn about differing ‘hows,’ communication ethics, or goods in action” (Arnett et al., 2018, p. xvii). According to Arnett et al. (2018), “there is much that we do not share in common with one another, which moves us . . . from trying to impose ourselves on another to trying to learn from the differences that meet us” (p. xvii). Again, it is possible to understand the current historical moment as an opportunity to better our communicative lives. In this historical moment, all must adopt a communication ethic that matters and that is skeptical of a singular answer. In *Communication Ethics Literacy*, the conception of communication ethics literacy that is shared is one that is “tied to understanding of the ‘good’ we protect and promote and the ‘good’ protected and promoted by those we meet” (Arnett et al., 2018, p. xviii). This idea, as will be further detailed in the current chapter and later in this work, is important to understanding patient–provider communication, particularly in terms of the good or goods that are being protected and promoted.

The Good

As previously noted, the current historical moment (which makes itself known through the questions that demand our attention), a period of disagreement termed

postmodernity, reveals that there no longer is one overarching, universal sense of the “good,” defined as “a central value or set of values manifested in communicative practices that we seek to protect and promote in our discourse together” (Arnett et al., 2018, p. 2). As Arnett et al. (2018) explain, “we cannot assume that any given person—not even a neighbor—protects and promotes the same goods as we do,” with “the clashing of goods or views of what should be ‘ethical’” defining this historical moment (p. 2). The good is at the center of a particular communication ethic, and it is both protected and promoted via communicative practices. Goods often reveal “what is right and appropriate for humans to be and to do,” and they involve questions related to what living a good life or what being a good person might look like “in a time of narrative and virtue disagreement” (Arnett et al., 2018, p. 3).

To understand the origin of ethics being tied to the idea of the good, at least in the West, though, it is necessary to look back to Aristotle, who believed happiness to be the greatest good (importantly, Aristotle conceptualized happiness not as pleasure, which was seen as a vulgar virtue, but instead as more similar “to labor worthy of being done”) (Arnett et al., 2010, p. 112). The good is situational and contextual. For example, “the good of Athens rested in what was good for the polis,” whereas “in medieval life, the good was identified with the Church; in the Renaissance, the notion of the good shifts from a place to an attribute of action identified with creativity” (Arnett et al., 2010, p. 112). Then, “in modernity, the good of *progress* becomes the guide,” with postmodernity having as its “fundamental good . . . difference itself” (Arnett et al., 2010, p. 112). Again, “[p]ostmodernity does not deny the notion of the good; this era is more like a juncture, a reminder that we cannot agree on a single defining view of the good” (Arnett et al., 2010,

p. 112). Questions have long surrounded the good, but these questions are perhaps more contentious in the current historical moment because of the multiplicity of perspectives and options.

If we look to religious traditions and academic disciplines, for example, we can see that they are built on some idea or conception of the good. Some goods span traditions; others do not, and they then “come into conflict with one another when citizens seek to take action in an increasingly fragmented society” (Arnett et al., 2018, p. 4). In the current historical moment, which is marked by difference, “[g]oods are often in conflict” (Arnett et al., 2018, p. 4). It is thus necessary to ask this question: “What good does a person, group, institution, society, culture, or other social formation seek to protect and promote?” (Arnett et al., 2018, p. 4).

Importantly, each communication ethic reflects two related goods: (a) a substantive good that is protected and promoted, and (b) a set of communicative practices that ensures “the active protection and promotion of a given good” (Arnett et al., 2018, p. 4). The first good draws from a belief or virtue system, “an encompassing framework that works as a standard or guide and that organizes and directs contributing or smaller goods” (Arnett et al., 2018, p. 4). To borrow a term from Charles Taylor, “this encompassing good [is] a ‘hypergood’ or a ‘subordinate good’” (Arnett et al., 2018, p. 4). An individual consequently aims to actively protect and promote a given hypergood or subordinate good, along with its supporting goods, via communicative practices. It follows, then, that communication ethics literacy would entail “the sorting out and discernment of goods that we protect and promote” (Arnett et al., 2018, p. 5).

Important to this conversation is the idea of fragmentation, or “the reality of differing views of the good held by groups of persons and individuals” (Arnett et al., 2018, p. 5). Again drawing from the work of Taylor, Arnett et al. (2018) explain that there exists a tendency to link the idea of the good with the idea of the self, which gives rise to what Alasdair MacIntyre calls “emotivism,” or decision-making that is guided by personal preference; in contrast to this is recognition of “a larger story or narrative within which one is situated as a source of the good” (p. 5).

When fragmentation is engaged constructively, however, it “opens the door to learning from difference, the necessity of dialogue, and the pragmatic recognition of the first communicative gesture of communication ethics as learning before telling” (Arnett et al., 2018, p. 5). Difference requires learning about the goods that we and others aim to protect and promote; it is imperative that we acknowledge the goods held by others, even if (and especially if) we do not share them. At the heart of this is the idea that communication ethics does not exist in the abstract, “in codes or principles,” but rather “in the willingness of communicators to show up for the communicative task of protecting and promoting a given good” (Arnett et al., 2018, p. 6). After all, “[g]oods live and die in communication ethics by the communicative actions of persons,” with a particular good needing “communicators to bring the idea and/or practice into action” (Arnett et al., 2018, p. 6).

Engagement and participation are, therefore, requirements in communication ethics. A failure to show up results in not only a physical sense of absence but also the absence of reflection. Reflection and deliberation, as stressed by Aristotle, are needed “to identify the good needed for a given moment and situation” (Arnett et al., 2018, p. 7).

Without reflection, there is a “loss of the ability to deliberate, to reflect upon the implications of a given good”; further, “[w]ithout recognizing and reflecting on the good or set of goods that drives communicative practices, one cannot assess the ethical consequences of communication” (Arnett et al., 2018, p. 7). Ultimately, communication with a failure to recognize “the ethical consequences of what we say and do as communicators reflects an absence with major consequences” (Arnett et al., 2018, p. 7). It is vital to take part in reflective engagement with the good, noting what set of ethics we and others aim to protect and promote—and why.

Arnett et al. (2018) establish the following tenets of the pragmatic communication ethics literacy position: “[W]e will not agree with everyone on what is good”; “all communication has an ethical dimension”; and “the commonality of ethical differences requires one to learn to read what good a communication ethic seeks to protect and promote” (p. 9). Further complicating matters is that there exists a multiplicity of goods, meaning that “multiple goods compete for allegiance” (Arnett et al., 2018, p. 10). As such, it is even more important that we “show up and . . . take the time and energy to learn and reflect upon the goods at hand,” with particular attentiveness paid to the historical moment, which shapes understandings of the good. In the current historical moment of postmodernity, there are many competing goods, making learning and dialogue essential to communication ethics.

According to Arnett et al. (2018), the study of communication ethics can be connected to communicative practices via the following four metaphors of communication ethics praxis: (a) multiplicity of communication ethics, (b) philosophy of communication, (c) applied communication, and (d) narrative. The preceding discussion

touched on the first of these metaphors, multiplicity of communication ethics; the reality of the current historical moment is that it is “an era of recognized difference” that lacks “public consensus on what counts as virtuous behavior and what is good for human beings to be and to do” (Arnett et al., 2018, p. 30). There are multiple communication ethics.

Arnett et al. (2018) understand and situate communication ethics “as a creative juncture” between philosophy of communication and applied communication (p. 30). Explaining this further, Arnett et al. (2018) write that “[c]ommunication ethics is the recognition that we take a given philosophy of communication, an understanding of the good, and apply it in interaction with others,” with the study of communication ethics being the study of philosophy of communication “brought into engaged communicative application in the marketplace of ideas” (Arnett et al., 2018, p. 30). Importantly, although there is no singular communication ethic, it is possible to understand, in theory, the construction of communication ethics. Philosophy of communication moves us closer to that aim.

Philosophy of Communication

Earlier in this chapter, it was noted that the current historical moment is one that is defined by difference. Accordingly, as Arnett et al. (2018) explain, “having a ‘why’ for the doing, for communicative action, is pragmatic” in such an era (p. 25). This is where philosophy of communication comes in; it “seeks to provide a coherent understanding of the importance, or the ‘why,’ of communication” (Arnett et al., 2018, p. 30). Arnett et al. (2018) state, “To understand what one does and to discern the communicative action of another opens the door to communication ethics assessment and change” (p. 25). Further,

“a communication ethic finds shape in the ongoing conversation of ‘why’ in interplay with the demands of a given historical moment” (Arnett et al., 2018, p. 25). Importantly, the term “philosophy of communication” can be defined in a broad sense, as a way of thinking generally about communication, or it can suggest a particular philosophy of communication.

The metaphor offered by Arnett et al. (2018) in *Communication Ethics Literacy* is apt: A philosophy of communication is similar to an operations manual for a vehicle, as it “explains how each part connects to the others and, at the same time, is contingent, responsive to the demands before us that we often do not expect” (p. 30). Taking this metaphor a step further, Arnett et al. (2018) write that “[e]ach time one attempts a repair, there is a *why*, not only in the significance of a given part and its function for the machine, but also in the coherence of its connection to other parts” (p. 30).

A philosophy of communication brings together the “why” and the “how,” with the “why” being retained as primary and central. Questions arising from philosophy of communication “are why each item connects to the other, why we do what we do, and their meaningfulness to you and me” (Arnett et al., 2018, p. 31). Philosophy of communication offers “richness, depth, texture, and meaning” to life; when we lack a philosophy of communication, then, “we meet only a technical manual or a set of isolated recipes that assumes that we already know why what we are doing matters” (Arnett et al., 2018, p. 33). A philosophy of communication, in contrast, “never takes for granted why something matters” (Arnett et al., 2018, p. 33). Understanding the “why,” or why we do the things we do, is imperative.

The importance of practical application is evident even in the shift from philosophy to philosophy of communication. A philosophy of communication can be developed concerning any subject; this provides “an argumentative rationale that can propel and guide action” (Arnett et al., 2018, p. 31). Application involves a carrying of philosophy into the human community. As Arnett et al. (2018) write, “The study and practice of communication ethics brings philosophy, community, and application together, contrasted with the abstract engagement characterizing the history of philosophical ethics” (p. 31). In other words, whereas a “philosophy of communication understanding of communication ethics provides the ‘why’ for communicative action,” it is “applied communication [that] carries the ‘why’ into interaction with others” (Arnett et al., 2018, p. 33). The “why” provides the foundation needed to broach the “how,” with applied communication consisting of the connection between communication ethics and the “how.”

Applied Communication

Applied communication as a recognized area of communication study emerged in 1972, with the founding of the *Journal of Applied Communication Research* (Arnett et al., 2018). This realm of communication stemmed from a desire to make the findings of communication research and scholarship more relevant to human life, in particular to issues related to social justice and its practice. As Arnett et al. (2018) write, “[a]ppplied communication moves theory into action” (p. 33). In the intervening years, applied communication has tackled social problems and issues but also those of the marketplace, including the objective of making meaningful and important connections between marketplace practices and social goods.

As previously noted, applied communication reveals “the ‘how’ of communicative doing” (Arnett et al., 2018, p. 25). The “how” also “tests any philosophy or theory and ultimately is the laboratory of communication ethics” (Arnett et al., 2018, p. 25). Applied communication permits communication ethics to move beyond the abstract and shows how a difference may be made through action. Such “[a]pplication is the place where communication ethics comes to life” (Arnett et al., 2018, p. 25). The definition of applied communication offered by Arnett et al. (2018) thus refers to “taking communication into engagement, whether that engagement be in an organization, a small group, a hospital, an interpersonal relationship, or a family” (pp. 33–34).

At its core, “[a]ppplied communication attempts to make a difference,” just as “communication ethics seeks to make a difference” (Arnett et al., 2018, p. 34). The history of ethics “as an application of the everyday,” not simply “a form of study,” is a long one, with its roots tracing back to the origins of civilization in the West. Aristotle, for instance, understood ethics as involving practices and their performance within the polis of Athens. According to Arnett et al. (2018), it is necessary to “take the risk of bringing ideas to the public, to the marketplace of ideas, to the test of ideas in application” (p. 34). Otherwise, one is a dilettante, “unable to assist self or others” (Arnett et al., 2018, p. 34).

Important to the conception of communication ethics is that it “is a philosophy of communication area of emphasis with a practical, applied outcome”—“the unified home of philosophy of communication and applied communication” (Arnett et al., 2018, p. 35). Communication ethics brings together philosophy of communication and applied communication; philosophy of communication and applied communication work with

each other to supply both the theoretical grounding and the practical application that underlie a communication ethic.

There is, of course, no one communication ethic, so learning and understanding push forward the study of communication ethics, with learning occurring “as we understand the construction of a given communication ethic and recognize its result in the marketplace of ideas,” personally or professionally (Arnett et al., 2018, p. 35). The primary question that the confluence of philosophy of communication and applied communication raises is as follows: “What is the good that inheres in a given philosophy of communication, and how does one apply that good in communicative practices?” (Arnett et al., 2018, p. 35). A given communication ethic originates with a good (or set of goods) and moves that good into application, with those practices of application (i.e., the “how”) and the philosophy (i.e., the “why”) encompassing what Arnett et al. (2018) term a narrative.

Narrative

Narrative, defined by Arnett et al. (2018) as “a story agreed upon by a group of people that provides limits within which we dwell as embedded communicative agents,” both limits and illuminates “the knowing and doing of communication ethics” (p. 25). A narrative is a public story that provides an explanation for “the way the world works and the meaning of human life, including what is good for humans to be and do” (Arnett et al., 2018, p. 35).

Further, a narrative offers standards or parameters for human action; in this way, a religious tradition, for example, can be understood as a narrative. Importantly, narratives need “agreement from a group of people who moves a story into a communicative

background that offers interpretive guidance for decision making” (Arnett et al., 2018, p. 36). Human communication as viewed from a narrative perspective “understands people as full participants in the making and interpreting of their communication from a story-laden context” (Arnett et al., 2018, p. 36).

A narrative is the ground that articulates a good or a set of goods. According to Arnett et al. (2018), “[c]ommunication ethics in action requires a dwelling place from which the good originates and then enters into persuasive engagement,” with a narrative acting as this dwelling place and “working rhetorically to protect and promote a given sense of the good” (p. 36). Building on prior discussion, the postmodern historical moment involves a multiplicity of narratives “within which persons and communities find meaning,” which breeds “rival understandings of virtues and competing views of the good” (Arnett et al., 2018, p. 36).

These competing narratives are termed by Arnett et al. (2018) as “petite narratives,” which reveals that there exists more than one understanding of human life and the good. Arnett et al. (2018) find that the “[c]ompeting communication ethics situated within petite narratives give rise to the currency of rhetoric” in the current historical moment (p. 36). Accordingly, communication ethics is rhetorical: “The multiplicity of narratives, with each capable of carrying different virtue structures, moves rhetoric into a primary position in postmodern scholarship” (Arnett et al., 2018, p. 36).

A given communication ethic is, by its very nature, persuasive; it argues, either implicitly or explicitly, for a particular understanding of the good. Communication ethics, therefore, involves examination of these various competing understandings of the good manifested in communicative action. The good, as well as the communicative action

pushed into being because of that good, inhabits narrative structures, which “find their identity through practices” (Arnett et al., 2018, pp. 36–37). Also dwelling within narrative structures, alongside our understanding of the good, are moral and ethical decision-making.

Consequently, communication ethics lies within the realm of persuasion; it “is not universally normative” because “a given communication ethic does not guide action for everyone” (Arnett et al., 2018, p. 37). Rather, “each communication ethic lives within narrative structures or communities of discourse that argue for the importance and value of a given set of communicative goods” (Arnett et al., 2018, p. 37). Arnett et al. (2018) also hold that “a given ethic reflects a particular bias about the manner in which we ‘should’ understand and engage others,” with differing ethical positions existing among different narratives reflecting differing and perhaps competing views of the good; they note that although there may be some overlap in understandings of the good across traditions, the current historical moment encourages learning from the differences (p. 37). These differences, rather than the similarities, are what offer up challenges: “A particular communication ethics position resides within and emanates from a particular narrative that carries ideas and practices that shape a philosophical and pragmatic view of the good, and not all views will conform to our own position” (Arnett et al., 2018, p. 37).

Our everyday discourse, write Arnett et al. (2018), has important rhetorical implications because it stems from our understanding of the good, influencing ourselves and others. Accordingly, the study of communication ethics calls forth this question: “What is the narrative ground that shapes a philosophy of the good and sanctions given practices in application of that good?” (Arnett et al., 2018, p. 37). Such philosophies of

the good matter, as does the way in which they are implemented, with “the ‘why’ and the ‘how’” coming together “in importance in the study and practice of communication ethics” (Arnett et al., 2018, p. 37). Philosophies of the good and their strategies for application pull from the narrative that cultivates them.

Because a particular communication ethic has the potential to unite as well as to divide, basic rhetorical skills are a requirement for navigating the current historical moment. Arnett et al. (2018) explain that it is first necessary to “discern the narrative, the story-housed content out of which a given ethic finds shape,” which is followed, second, by a discerning of the goods “within a given narrative that shapes or constitutes the ‘ethical’” and then, third, by an understanding “that any ‘web of goods’ lives within a particular timeframe” (p. 38). Individuals communicate from a “temporal narrative ground,” where a communication ethic is engaged “in foreground communicative action that simultaneously points to a particular narrative background that nurtures a given virtue structure, framing the good of that narrative” (Arnett et al., 2018, p. 38). Again, because one’s communication ethics action derives from an understanding of the good, “it is persuasive—rhetorical and attentive to the temporal nature and unique particularity of application” (Arnett et al., 2018, p. 38).

The “central communication ethics engine” is oughtness, as varying views of oughtness supply various understandings of the good, which then leads to a multiplicity of communication ethics. The oughtness of these differing goods “rests within a narrative that unites a philosophy of communication,” again, a sense of “why,” “with communicative practices of applied communication, the doing of the ‘how’” (Arnett et al., 2018, p. 38).

Oughtness applies a persuasive hue to a particular communication ethic, with the good persuading the communicator and the communicator taking “that good, or a particular understanding of that good, into persuasive engagement with others who reciprocate with their own articulation of a good that may or may not be consistent with the original communicator’s good” (Arnett et al., 2018, pp. 38–39). Communication ethics brings together philosophy of communication and applied communication responding to narrative ground and the current historical moment; this calls for “a rhetorical turn that seeks to protect and promote a given sense of the good that must fend against other goods in a time of challenge and change” (Arnett et al., 2018, p. 39). The next section of this work will take and apply these communication ethics concepts—particularly the good, philosophy of communication, applied communication, and narrative—to the realm of health care, with important implications for the larger project.

Communication Ethics and Health Care: Implications for the Current Project

Arnett et al.’s (2018) *Communication Ethics Literacy* also specifically tackles the issue of healthcare communication ethics, the understanding of which “broaden[s] our understanding of the notion of health, taking it beyond obvious optimism to an active place of communicative response, a place of hope” (pp. 199–200). There is a clear distinction between hope and optimism that Arnett et al. (2018) note—put succinctly, “[h]ope endures even in the face of disappointed expectations; optimism fades when faced with the reality that life does not grant one’s demand” (p. 200).

In terms of the good, healthcare communication ethics “protects and promotes the good of responsive hope and the good of care for the Other in meeting moments of robust health, normal difficulties, the tragic, and the inevitable” (Arnett et al., 2018, p. 200).

Importantly, Arnett et al. (2018) define many of these terms, including healthcare communication, which is “the study of communication practices within the broad domain of health care, from patient–professional interaction to institutional communication about health”; health, which is “the interplay of communicative responses to conditions of mind, body, and soul, from the beginning to the end of a life”; responsiveness, which is “responsibility that meets the call of the Other, even when the call is unwanted”; and care, which is “a human answer to the call of the Other . . . a willingness to meet and attend to someone other than oneself” (p. 200). These terms, as defined and detailed by Arnett et al. (2018), will be further explored within this section.

Healthcare Communication

Issues of health and health care are often at the forefront of our daily lives. The current historical moment, defined in a number of ways by the COVID-19 pandemic, brings these issues into even sharper relief. Just as the health and healthcare issues we deal with every day are diverse, so is the realm of healthcare communication, which emerged as a field of study in the 1980s, followed in 1996 by the start of the *Journal of Health Communication* (Arnett et al., 2018). The field covers everything from health communication campaigns and their mediated contexts to patient–provider communication, the latter of which is the subject of this project. Again, though, Arnett et al. (2018) present the following as “the heart of health care communication ethics” and are attentive to it in *Communication Ethics Literacy*: “a responsive sense of hope in the ongoing meeting of questions of human health” (p. 201).

Health

The term “health” encompasses “beginnings, endings, and intermediate moments,” with healthcare communication ethics, “at its best,” responding to what Viktor Frankl (1967) referred to as the final freedom, or “the stand we take toward a fate we no longer can change” (p. 15). Consequently, “[t]he goal of health care communication ethics is to protect and promote a sense of gratitude and knowledge of a final freedom—our response to health, its absence, and the eventuality of death” (Arnett et al., 2018, p. 202).

In *Communication Ethics Literacy*, Arnett et al. (2018) join healthcare communication ethics with “an understanding of health that, in its fullness, points to what it means to be human,” as healthcare communication ethics “assumes a life that includes vigor, its lack, and the inevitability of death” (p. 202). Arnett et al. (2018) mention the work of Lynn M. Harter and Arthur P. Bochner (2009), in which they explore questions related to health care and to the meaning of life and death in the context of narrative rationality; they also propose the notion of “narrative medicine.” For example, because “[h]ealth is a term that requires an adjective for us to know what kind or state of health is present at a given moment,” responding “to the question, ‘How is your health?’ requires some sense of what it means to be in ‘good’ health” (Arnett et al., 2018, pp. 202–203). This, then, is “a narrative that defines health quality and permits us to report on our health with a modest degree of interpersonal accuracy” (Arnett et al., 2018, p. 203).

Responsiveness

According to Arnett et al. (2018), healthcare communication ethics “rests in the response”—it “understands health not in what happens to us, but in our *response* to that

which meets us” (p. 203). The significance of response here stems from the following “pragmatic realization”: “[W]hen there is no longer an easy answer given to us, we must find a creative response that breaks free of our demand for options no longer available. At such a moment, we choose the manner in which we meet the inevitable” (Arnett et al., 2018, p. 203).

Because of this, healthcare communication ethics “is a dialogue with life, an ongoing set of responses that shapes our living as we prepare for our end” (Arnett et al., 2018, p. 203). Further, the good of healthcare communication ethics can be found in the communicative action of response; this action “is the antithesis of equating health with a ‘demand’ for life on our terms” (Arnett et al., 2018, p. 203). Just as dialogue calls for and requires a response, so does this attempt to bring forth a fuller and more comprehensive view of health; as Arnett et al. (2018) write, “Health care communication communication ethics is a call to responsibility defined not by demand or acquiescence, but by responsiveness” (p. 203).

Accordingly, responsiveness is key to engagement of healthcare communication ethics—on the part of the healthcare provider, the patient, and the patient’s family and other loved ones. According to Arnett et al. (2018), “one looks for ways to respond to the illness in the larger context of a life, not just for answers to ‘fix’ ill health” (p. 204). In this way, healthcare communication ethics is driven by action, with responsiveness being “the responsibility for doing the task of health care communication ethics” (Arnett et al., 2018, p. 204).

It is important that what Arnett et al. (2018) term “our final freedom of response” starts not right before death, but instead “in daily living, in repeated practice” (p. 205).

They write that “[e]ach time health not wanted by us meets us in our lives, we have the opportunity to practice the pragmatic necessity of response, readying ourselves for the final freedom—our response to the inevitability of death” (Arnett et al., 2018, p. 205). After all, “[r]esponse is the active reaching out to another and to one’s own problems,” with responsiveness leading “to communicative action that, when directed toward another, outlines the necessity of human care” (Arnett et al., 2018, p. 207).

Care

Care—“the communicative action or practice that links the good of responsiveness to the Other”—is what drives and pushes healthcare communication ethics, which aims to protect and promote care (Arnett et al., 2018, p. 207). Arnett et al. (2018) explain that healthcare communication ethics “does not pivot upon the question of information; it stands firmly on the question, ‘How do we provide communication that cares for another?’” (p. 207). In addition, healthcare communication ethics “points to an active, caring responsive to all stages of life, offering meaning through the doing of human assistance,” protecting and promoting “care, human caring of one for another, in a professional context and in all contexts where decisions affect the quality of life and . . . life itself” (Arnett et al., 2018, p. 207).

The significance of responsiveness to healthcare communication ethics reveals a certain approach to caring that “calls forth our engagement with the human condition, requiring something of us—care” (Arnett et al., 2018, p. 207). Health care should be “attentive to patient evidence and the trajectory of a life,” based on the assumption that the individual will become ill and lose, temporarily and then forever, their robust health (Arnett et al., 2018, p. 207). By “[r]ejecting health as physical alone, health care

communication ethics works with our final freedom . . . keeping before us the importance of our response” (Arnett et al., 2018, p. 207). Such a focus on responsiveness, both in practice and in “the final freedom of humanness,” helps to define care in the context of healthcare communication ethics: It “becomes the protection, the promotion, and the facilitation of human responsiveness as the defining characteristic of the good of health care communication ethics” (Arnett et al., 2018, p. 207).

Importantly, write Arnett et al. (2018), although all surely benefit from care as consumers of that care, the responsibility we have to care “begins with a responsive first principle, foregoing the impulse to blame those who do not meet our standards of care” (p. 207). The emphasis placed on responsiveness in healthcare communication ethics thus centers discussion on being “a doer of care, not a consumer of care” (Arnett et al., 2018, p. 207). Of course, it is also significant to keep in mind the “labor of care.” Labor is a necessity of the human condition, something that is required doing, and healthcare communication ethics reminds us of that, according to Arnett et al. (2018), who note that healthcare communication ethics “finds responsiveness in a sense of ‘why’ that gives one a reason to bear the ‘how’” (p. 209).

To enact a labor of care, particularly in difficult and challenging moments, Arnett et al. (2018) state that it is necessary to “find an engine for the doing of this care,” as “a labor of care depends upon a sense of ‘why’ that gives one a reason propelling the human tenacity to engage the ‘how’ of the doing of care for oneself and for others” (pp. 209–210). A labor of care, after all, needs an engine that continues to propel one forward, even “when the routine breaks and the demands of the inconvenient or the frightening are before us” (Arnett et al., 2018, p. 210). Such “attachment of a sense of ‘why’ to a labor of

care” is what prevents healthcare communication ethics from becoming merely “a technique, a simple set of actions learned in the abstract and brought to communicative life without attention to the specific needs and the specific face of another” (Arnett et al., 2018, p. 210). Healthcare communication ethics calls for “labor and a ‘why’ for the doing of what is beyond our normative request for a good life” (Arnett et al., 2018, p. 210).

Before one can determine what should be done, there must be a sense of “why.” This is what makes the asking of the question significant. Healthcare communication ethics “works with a good that gives us reason(s) to pursue health, endure recovery, and meet the ongoing demands and repeated anguish of human life,” and it is necessary to “find a ‘why’ to meet the inevitable challenges ahead” (Arnett et al., 2018, p. 210). According to Arnett et al. (2018), “The Holy Grail of health care communication ethics is a sense of ‘why’ that permits us to bear any ‘how’” (p. 210).

Arnett et al. (2018) state that although “[t]here is no magic in communication about health . . . communication that inspires and guides us is powerful beyond description” (p. 211). The sense of “why” previously mentioned may derive from ideas and theories, but it most frequently “comes from a human face that reminds us of the importance of finding the tenacity to meet the demands before us” (Arnett et al., 2018, p. 211). Drawing from Emmanuel Levinas, Arnett et al. (2018) write that “one finds the light of ethics in the face of another” (p. 211). In addition, “[h]ealth care communication ethics is more than accuracy of information; it takes us close to the human heart, a heart that finds a “why” to carry on” (Arnett et al., 2018, p. 212).

Healthcare communication ethics is focused on “a good that gives us a ‘why’ for seeking information, for seeking help, for a reason to fight, for a reason to think about

others in the final moments of our own lives,” and it “protects and promotes the good of responsiveness that carries the possibility of hope in a discovered sense of ‘why’ for engaging a situation that most of us do not want to encounter” (Arnett et al., 2018, p. 212). It is healthcare communication ethics that “reminds us of our humanness” (Arnett et al., 2018, p. 213).

A Dialogic Ethic

Through all this, healthcare communication ethics looks toward a dialogic ethic in terms of listening, attentiveness, and negotiation (Arnett et al., 2018). In terms of listening, this occurs without demand; we must ask, “What is happening in a given moment?” It does not matter whether we like or dislike a given moment—it is necessary to engage the question or questions of that particular moment regardless. We must “meet what is before us” and fight “the common impulse for life to conform to our demand,” which is “a constructive way of fighting to secure good health” (Arnett et al., 2018, p. 213). The means of the engagement, after all, do matter.

Attentiveness—“to the nature of the response called for in the act of caring”—is also needed; the question here is, “What are the coordinating grounds upon which stand the self, the Other, and the historical moment?” (Arnett et al., 2018, p. 213). The ground of self encompasses the ethical and narrative commitments that guide us, the ground of Other involves the ethical narrative commitments that guide the Other, and the ground of the historical moment represents the characteristics or elements of the time in which we live. The first two—the ground of the self and of Other—reflect “a commitment to something beyond the communicative partners, a call to protect and promote human responsiveness, and a call to a labor of care” (Arnett et al., 2018, p. 213). The last

recognizes that the “appropriate communication ethics response is not static and changes with the demands of the historical moment” (Arnett et al., 2018, p. 213).

Dialogic negotiation asks, “What temporal communicative ethics answers emerge ‘between’ persons, pointing to communicative options for action, belief, and understanding?” (Arnett et al., 2018, p. 213). Healthcare communication ethics calls for repeated negotiations—“in friendships, in relationships with significant others, within particular institutions and cultures, all working together to try to figure out the ‘best’ response in a given historical moment for a particular person or persons” (Arnett et al., 2018, p. 213). Responsiveness and the labor of care for another act as dialogic guides as we navigate the questions before us.

Arnett et al. (2018) write that listening, attentiveness, and dialogic negotiation make up “temporal dialogic ethical competence” (p. 214). This work must be followed by evaluation and self-reflection that includes the individual’s own ethical and narrative commitments. “Constant monitoring” of the dialectic involving “the human face of a particular person and implications for a larger culture”—a “unity of contraries”—provides insight, ultimately, “into the pragmatic consequences of our decisions” (Arnett et al., 2018, p. 214). In addition, it is vital to recognize that a healthcare communication ethic is not “set in stone,” because “as the historical demands change, so do our responses” in healthcare communication ethics (Arnett et al., 2018, p. 214).

Finally, Arnett et al. (2018) characterize dialogic ethics in this way:

Dialogic ethics listens to what is before communicative partners, attends to the historical moment, and seeks to negotiate new possibilities. Dialogic ethics is a conceptual form of marketplace engagement, ever attentive to conversational

partners and their “ground,” the historical moment, and the emerging “possible” that takes place in the “between” of human meeting. (p. 214)

Thinking of healthcare communication ethics in particular, it “listens for the call that invites a particular response, ever attentive to limits and demands that form responsibility for caring” (Arnett et al., 2018, p. 214). The answer, then, to healthcare communication ethics involves “the communicator who is responsive, understands the labor of care, and is tenacious when optimism fails, taking up . . . a gritty sense of hope that stands firm in a final freedom” (Arnett et al., 2018, p. 214). Even though there is no answer driven by technique, Arnett et al. (2018) hold that there exists a great deal of hope when caring is met by response within healthcare communication ethics.

Understanding the Communication Ethic of Patient–Provider Communication: Implications for Practice

As has been established up to this point, the interpersonal relationship, created and built on by communication, that exists between patient and provider is highly significant, affecting everything from the quality of care provided to the health of the patient. This chapter sought to establish this significance, as it provides the groundwork for later discussions related to how technology, when applied to the realm or setting of health care, affects and influences this relationship and the communication occurring within. In addition, this chapter aimed to bring in one way of examining such healthcare communication: via communication ethics, as described by Arnett et al. (2018). From the work of Arnett et al. (2018), we can begin to better understand patient–provider communication on a level that moves us beyond, for example, quantitative data and findings. Armed with the foundation of communication ethics, it becomes easier to see

the goods that healthcare communication, especially between patient and provider, is protecting and promoting; the philosophy of communication that drives and brings into existence such communication; the applied communication context that pushes these theories into action; and the narrative ground that shapes and explains the communication that occurs between and among individuals, including patient and provider.

The first part of this chapter, which examined the literature on patient–provider communication, including the move toward patient-centered communication, looked at what could be considered a typical understanding of the patient–provider communication ethic. This ethic can be said to protect and promote “the good of responsive hope and the good of care for the Other” in moments ranging from good health to tragedy (Arnett et al., 2018, p. 200). As has been previously discussed, this ethic, and the goods it protects and promotes, does not exist merely in the abstract—it comes to life and is made visible through communicative practices. It is possible to see this ethic, as well as the goods that it brings into play, emerge from the literature on patient–provider communication; for example, the literature consistently holds that communication between patient and provider has multifarious implications, both good and bad, particularly in terms of health. What materializes from this communication reveals much about the good or goods that are being protected and promoted in a particular philosophy of communication, as well as how they are applied in communicative practice; the “why” and the “how” behind this philosophy and application, respectively, help to constitute the narrative, or ground, offering an explanation for these understandings.

What is helpful for understanding this ethic, in addition to the selected findings from the literature offered here, is the American Medical Association’s (AMA’s) *Code of*

Ethics, also mentioned in Chapter 1. The principles guiding medical practice were first codified by the AMA in 1847 (the *Code* was adopted at the AMA’s founding meeting), and this document, revised and updated in the ensuing years, reveals much about the practice of medicine—including those who practice it. As Topol (2015) writes, the AMA *Code*, even in its earliest iterations, “has set a lasting tone” (p. 24). It was, after all, created by what is now the largest professional organization of physicians in the United States.

The 1847 version of the *Code* emphasizes the “nobility, authoritative command, and eminence” of the physician (Topol, 2015, p. 24). This is evidenced by statements like the following (Topol, 2015, p. 23):

- “As it is the duty of a physician to advise, so he has a right to be attentively and respectfully listened to.”
- “A patient should never weary his physician with a tedious detail of events or matters not appertaining to his disease.”
- “The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them.”

The goods being protected and promoted within this original *Code*, along with the narrative driving this understanding of the practice of medicine, and particularly of the provider’s relationship to and interactions with patients, differ quite substantially from contemporary expectations. The current version of the *Code*, last updated in 2017, reflects these expectations; it was a primary intention of this revision that “ethical guidance [be] improved for relevance, clarity and consistency to help physicians keep

pace with emerging demands they face with new technologies, changing patient expectations and shifting health care priorities” (AMA, 2017, para. 1).

The 11 chapters of this work cover the ethics of patient–physician relationships; consent, communication, and decision-making; privacy, confidentiality, and medical records; genetics and reproductive medicine; caring for patients at the end of life; organ procurement and transplantation; medical research and innovation; physicians and the health of the community; professional self-regulation; interprofessional relationships; and financing and delivery of health care. Again, the inclusion of these topics reveals their significance to the profession and to the provider today.

At the heart of the *Code*, though, are the nine Principles of Medical Ethics, which define the essential ethical principles of the profession. Important to this discussion are the following principles:

- “A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights” (AMA, 2016, para. 2).
- “A physician shall, while caring for a patient, regard responsibility to the patient as paramount” (AMA, 2016, para. 9).
- “A physician shall support access to medical care for all people” (AMA, 2016, para. 10).

These principles thus, in theory, are informing the ethic that drives communication in the healthcare setting between patient and provider.

There is a great deal related to the communication ethic of patient–provider communication that can be inferred from the shift toward patient-centered communication in the healthcare setting. After all, the current historical moment is one

characterized by difference, requiring a willingness to learn from this difference and from the Other. No longer can we take for granted that the Other shares the same good that we do; again, the current historical moment necessitates our “learning, withholding the impulse to tell until one understands the context, the topic, and the persons” (Arnett et al., 2018, p. xiii).

In regard to patient-centered communication, which places the patient at the center in terms of the provider’s understanding their preferences, needs, and values and allowing those characteristics to guide decision-making in the healthcare setting, this becomes even more important. As was previously established by Arnett et al. (2018), a “minimal ‘ought’ of learning” involves awareness of “one’s own ground and the ground of others,” which contributes to “understandings of the good” (p. xvi). In the current historical moment, defined, in many ways, by narrative and virtue contention, there is much that individuals do not share with each other; in the patient–provider relationship, and in the interactions, encounters, and conversations that comprise it, these differences may appear even starker. Learning from the Other and “the differences that meet us,” though, is one way of countering the impulse to impose the goods we protect and promote, our philosophy of communication, or our narrative ground on another (Arnett et al., 2018, p. xvii).

Throughout their discussion of healthcare communication ethics, Arnett et al. (2018) emphasize responsiveness. After all, they write, healthcare communication ethics “rests in the response,” as it sees health more as one’s response to “that which meets us” rather than “what happens to us” (Arnett et al., 2018, p. 203). Communication ethics in terms of healthcare communication is a call to responsibility that is defined by

responsiveness on the part of many: the healthcare provider, the patient, the patient's family and loved ones. In addition, health care must take place within the larger overall context of an individual's life; a simple fix is not the solution. Communication that cares for another must be provided.

Patient-centered communication is a start—and a good one, at that. It is a long way from the paternalistic, patriarchal approach to health care once unreflectively favored. Aristotle emphasized the need for reflection and deliberation, necessary for identifying the good in a particular situation or moment. Reflection and deliberation are also called for here, especially in considering what may be being overlooked, ignored, or left out of the contemporary communication ethic that bolsters patient–provider relationships and communication within that context.

For example, the literature shows that there are issues with patient–provider communication, as has been noted, particularly for some patient populations, like women and racial and ethnic minorities. Effective communication—with information that is “complete, accurate, timely, unambiguous, and understood by the patient”—is absolutely crucial to the success of the healthcare encounter, but the communication needs of patients are often unmet or incorrectly addressed (Patak et al., 2009, p. 372). Patients have the right to effective communication between themselves and their providers, a fact that is supported by various accreditation standards, regulatory guidelines, and declarations of patients' rights (Patak et al., 2009). They “have the right to be informed about the care they receive, make educated decisions about [this care], . . . and be listened to by their providers” (Patak et al., 2009, p. 373).

We know all this. Yet, problems remain, for specific populations and for patients overall. Part of the problem might be that although “[w]e have spared no effort to make better [medical] tools . . . we have paid little attention to learning how to communicate better with one another” (Katz, 1984, p. xiv). In the current historical moment, as health care is becoming increasingly more complex and is further complicated by changes brought on by the COVID-19 pandemic, it is more important than ever that we refocus our attention on the individual healthcare encounter and the communication and relationship-building occurring within, especially as it begins to occupy a larger, more permanent place in the digital space. Patients and providers “must learn to converse with one another,” engaging in meaningful, trusting conversation while also acknowledging the obstacles and barriers that stand in the way of this ideal (Katz, 1984, p. xxi). After all, “[i]n an era of choice and profusion of [information interpersonal care may yet remain invaluable” (Taylor, 2009, p. 154).

Those populations of patients who face even more challenges in the healthcare setting have the right to receive the same high-quality health care as do others; better, more *responsive* patient–provider communication, guided by a communication ethic centered on the individual patient and their primary role in the healthcare relationship, is no small part of ensuring that that happens. Accordingly, the next chapter, an example of applied communication, will begin to explore issues of social justice, particularly regarding gender and race, and how the dominant communication ethic pushing forward patient–provider communication and the patient–provider relationship is in need of reflection and perhaps revision in the current historical moment.

Chapter 3: Social Justice and Rethinking the Communication Ethic Behind the Patient–Provider Relationship

While Chapter 2 explored a standard understanding of the communication ethic that drives patient–provider relationships, the current chapter furthers this understanding by revealing how questions of social justice, especially those related to gender and race and ethnicity, call it into question. The previous chapter provided examples from the literature on patient–provider communication, showing just how significant such communication is to a number of factors and outcomes, including patient health itself. The literature also helped to uncover much about the contemporary communication ethic behind patient–provider communication, including the goods that it protects and promotes, the philosophy of communication that brings to life such communication, the applied communication context that moves these theories into action, and the narrative ground that molds and illuminates communication occurring between patient and provider. Essential to an understanding of communication ethics is the idea that the current historical moment is, in many ways, defined by difference. There must be a willingness to learn from the Other—to meet this difference, rather than to impose our understandings of the good, our philosophy of communication, or our narrative ground on another.

Healthcare communication ethics, according to Arnett et al. (2018), is grounded in the goods of responsive hope and of care for the Other. Relatedly, it requires a call to responsibility, a responsiveness, that is shouldered by many, as well as the demand that health care be addressed in the larger context of a life, and not as an isolated, distinct incident requiring a quick fix. Patient-centered communication puts the patient—their

values and preferences, their decision-making ability—front and center, yet in some important ways, the contemporary communication ethic behind patient–provider communication may be overlooking or ignoring some patients and patient populations. This chapter, therefore, helps to bring to light how issues of social justice may intersect with patient–provider communication, including how they may be introducing new aspects and angles to the communication ethic behind patient–provider communication. Again, as in Chapter 2, communication ethics, as presented by Arnett et al. (2018), will provide the foundation for contemplating such applied communication issues.

Accordingly, Chapter 3 will continue to explore the current state of patient–provider communication via an examination of the relevant literature, paying attention to the role that such communication has on this relationship, particularly within healthcare encounters. However, as previously noted, this chapter will examine the changing dynamics of the patient–provider relationship over time through the related lenses of gender and race and ethnicity in health care. The chapter will open with a discussion of social justice issues in relation to health care and how they connect to the patient–provider relationship and patient–provider communication. Next, the chapter will look at gender and race and ethnicity and how they affect health care. The chapter will conclude with some implications for practice, bringing together the communication ethic of patient–provider communication and these issues of social justice.

Dynamics of the Patient–Provider Relationship: Past and Present

As described in the first chapter of this work, the relationship between a patient and their provider has a long historical precedent, with major, significant change coming only in recent decades (and, in some cases, as will be later described, not even then). To

briefly summarize, for much of its history, the medical profession has been characterized by paternalism and the beneficence model, in which the authority of the provider (typically the physician) always reigned supreme and the patient could do little but passively submit to it. Today, under the autonomy model, the patient often assumes a more active role in their health care, participating in the healthcare decision-making process, making their own contributions to the healthcare conversation, and having their values and choices respected, for instance.

This idea, of patient-centered health care, sounds good, and it works well in theory. However, countless patient populations experience disparities in health care, with many of these disparities traced back to unequal treatment—even as the result of unconscious bias—by providers in healthcare encounters. Awareness of this calls into question the taken-for-granted communication ethic of patient–provider communication. As has been discussed, communication is a vital part of such encounters between patient and provider, and it may also be a key component of alleviating some of these disparities for groups including women and racial and ethnic minorities.

Gender and Health Care

Women as Healthcare Consumers

According to data from the 2018 National Health Interview Survey, 74.7% of U.S. women aged 18 years or older had had contact with a doctor or other healthcare professional in the past six months or less, compared to 61.6% of men (U.S. Department of Health & Human Services, 2018). In addition, per data from the 2016 National Ambulatory Medical Care Survey, 512,192 of 883,725 visits to U.S. physician offices in 2016 were made by women of all ages, compared to 371,533 visits by men of all ages in

the same year (U.S. Department of Health and Human Services, 2016). Data from the same survey also revealed that an average of 332 such visits were made per 100 persons per year, but 371.6 visits per 100 women per year and 290 visits per 100 men per year (U.S. Department of Health and Human Services, 2016). Female patients have also been shown to generally receive more information, ask more questions, and engage in more partnership-building work with physicians in medical encounters than male patients (Cooper-Patrick et al., 1999).

These data clearly indicate that women are important consumers of health care, as they make up a significant portion of those who use such services in the United States. Research has found that healthcare consumers in the United States and elsewhere are overwhelmingly female, and that they have substantial unmet needs within this realm. For instance, a multimarket survey of more than 9,000 respondents in the United States, United Kingdom, Germany, Japan, and Brazil found that 35% of women do not fully trust their physician, and more than half (58%) of these women reported lacking confidence in their ability to make good decisions regarding health care for themselves and their families, primarily because they feel as though they do not have the time, information, and trusted relationships that support informed decision-making (Luce & Kennedy, 2015).

Such findings are alarming in the current patient-centered age of medicine that emphasizes the concept of patient autonomy and the importance of active, shared decision-making between patient and provider. However, the history of women and health care, particularly in the United States, is fraught with inequality, notably in the context of discounting and dismissing the experiences of women. (It bears repeating here

that women are certainly not the only population subject to such discounting and dismissal in the healthcare environment, as will be later explored.) Biases, particularly those related to gender, race and ethnicity, sexual orientation, disability, and so forth, within health care that persist today may be implicit, or not linked to a consciously held prejudice, but they are no less harmful. Thinking specifically of the gender bias in health care, as the Boston Women's Health Book Collective (1973) presciently wrote in the first edition of *Our Bodies, Ourselves: A Book By and For Women*, a product of second wave feminism and the Women's Health Movement of the 1960s and 1970s, "Naturally, some women fare better than others, but all of us suffer as a group from the effects of male-dominated medicine" (p. 237).

As this quotation reflects, it should be noted that the gender-related health disparities that women face are not equal among all women. Although the current discussion concerns the insidious ways in which gender bias affects medical knowledge and the care that women receive within the contemporary U.S. healthcare system, many women face sometimes unsurmountable obstacles that preclude their receiving access to the medical system at all; these may include financial (e.g., women may be uninsured or underinsured) or other barriers (e.g., women may be unable to take time off from work to receive health care, or lack transportation or childcare) (Dusenbery, 2018a). Individuals who identify other than the sex assigned at birth face significant challenges in healthcare access as well. (It also should be noted that in this section in particular, the term "women" is used primarily to refer to those whose gender identity, expression, and role does conform to what is culturally associated with their sex at birth.) With that being said, the troubling situation described here becomes even more so: Women who *are* able

to see a provider to address their healthcare concerns often leave these visits unsatisfied and without resolution of their problems—but “less privileged women simply go undiagnosed and untreated altogether” (Dusenbery, 2018a, p. 15).

Many of the systemic issues related to gender bias in medicine can be traced to the power of providers, particularly physicians, who have in much of recent history (and even today) been male. According to data from the Henry J. Kaiser Family Foundation, of the more than one million professionally active physicians in the United States as of March 2020, 651,434 were male and 369,540 were female (Kaiser Family Foundation, 2020). It bears mentioning that many studies have examined communication differences between male and female healthcare providers, finding, for example, that “physician gender may be a source of differences in communication between physicians and their patients, which may in turn contribute to patient satisfaction and other outcomes” (Jefferson et al., 2013, p. 242).

Jefferson et al. (2013) determine in their study that female doctors seem to engage in more behaviors designed to build rapport, including encouragement and reassurance, and that they demonstrate more affective behaviors, like concern, empathy, and sympathy. Similarly, female physicians also appear to “exhibit more empathy and engage in more positive talk, partnership-building, question-asking, and information-giving compared with their male counterparts” (Cooper-Patrick et al., 1999, p. 584). This all may reflect a more patient-centered communication style, which, in other studies, has been shown to improve adherence and patient enablement (Taylor, 2009), as well as lead to greater efficacy of care, such as through fewer diagnostic tests and referrals, and improved health status (Stewart et al., 2000). However, Jefferson et al. (2013) found that

female doctors also spend about two minutes longer with patients during healthcare encounters, which, consequently, limits the number of such encounters they can provide.

Mast and Kadji (2018) echo these findings in their exploration of how female and male physicians' communication is both perceived and evaluated differently. They observe, for example, that female physicians adopt a patient-centered communication approach, which is preferred by patients. It should follow, then, that patients should report more satisfaction with female providers than male providers, but Mast and Kadji (2018) explain that this is not the case. Importantly, male physicians facilitate good patient outcomes when verbally expressing patient-centeredness, whereas female physicians help to produce good patient outcomes when they adapt their nonverbal communication to the varying needs of patients (Mast & Kadji, 2018).

Relatedly, Roter and Hall (2001) emphasize that the literature has shown differences in the ways in which male and female physicians conduct healthcare encounters, with female physicians, for instance, having longer visits and engaging “in more partnership building, emotionally focused talk, positive talk, and psychosocial exchange” than male physicians. Roter and Hall (2001) state that these key differences—which they group into three larger areas of impact, namely patient–physician partnership, exploration of the patient’s psychosocial context, and patient expectations and judgment—may have significant implications for the relationship developed by physicians and their patients. They insist that these findings go beyond a proverbial “turning of the discriminatory tables’ once favoring males now to favor females, at least in some contexts,” and offer “a challenge for a more positive transformation in the everyday practice of medicine,” which includes “the establishment of medical practice

norms that value communication skills and interpersonal sensitivity” (Roter & Hall, 2001, p. 675).

Women and Medicine: A Brief History

It is important to note here that healing had for a good portion of Western history “been the prerogative of women” (Ehrenreich & English, 2005, p. 38). Caring for the sick traditionally “was linked to the tasks and the spirit of motherhood; it combined wisdom and nurturance, tenderness and skill” (Ehrenreich & English, 2005, p. 38). As noted in the first chapter of this work, though, the 19th century professionalization of medicine, as well as the accompanying focus on empirical, quantitative methods of measuring disease prevention and treatment efficacy, did much to change this. The transformation of medicine into a profession moved it outside of the purview of the “female lay healer” and inside that of the “male medical professional” (Ehrenreich & English, 2005, p. 38). As a profession, medicine now demanded training and mechanisms of accountability, and it was defined by its exclusiveness, as Ehrenreich and English (2005) describe:

While the female lay healer operated within a network of information-sharing and mutual support, the male professional hoarded up his knowledge as a kind of property, to be dispensed to wealthy patrons or sold on the market as a commodity. His goal was not to spread the skills of healing, but to concentrate them within the elite interest group which the profession came to represent. Thus the triumph of the male medical professional . . . involved the destruction of women’s networks of mutual help—leaving women in a position of isolation and dependency—and it established a model of expertism as the prerogative of a social elite. (p. 38)

In the introduction to the second edition of *Witches, Midwives and Nurses*, first self-published as a booklet in 1973, Ehrenreich and English (2010) explain that this “document from the second wave of feminism in the United States” was “written in a blaze of anger and indignation” (p. 7). They describe the early 1970s as a time of awakening—for feminists, who “were becoming aware of a variety of ways women were abused or treated unjustly by the medical system”; by female healthcare providers, who “were largely confined to subordinate roles as nurses and aides”; and as consumers of health care, who were “subject to both insensitive and hazardous treatment,” including “unnecessary hysterectomies, over-medicated childbirth, insufficiently tested contraceptives, involuntary sterilizations, and the almost universal condescension of male doctors” (Ehrenreich & English, 2010, p. 8).

At that time, women “were not supposed to know anything” about their own bodies or “to participate in decision-making” about their own care (Ehrenreich & English, 2010, p. 8). What little advice and guidance there was surrounding health care was doled out in paternalistic, prescriptive medical advice columns like “Tell Me, Doctor,” which appeared in the popular *Ladies’ Home Journal*. But women with too many questions or opinions running counter to those of the medical establishment “found themselves labeled, right in their medical records, as uncooperative or neurotic” (Ehrenreich & English, 2010, p. 8). Even serious complaints were liable “to be dismissed as ‘psychosomatic’ and attributed to women’s assumed suggestibility” (Ehrenreich & English, 2010, p. 8).

One particularly salient example of the systemic patriarchy of the medical profession at the time Ehrenreich and English (2010) are describing (and one instance in

which substantial change *has* been made in the intervening years) involves the diagnosis and treatment of breast cancer. To further establish the context here, recall that, as described in the first chapter of this work, a *Journal of the American Medical Association* study from 1961 found that a majority of doctors—a staggering 88%!—would withhold a cancer diagnosis from their patients based on personal judgments (Oken, 1961). Providers of this period also typically avoided explicit discussions or even mentions of cancer, preferring instead to use euphemistic language—for example, terms like “cyst,” “nodule,” and “lesion” were favored, because they are more loosely descriptive and have fewer frightening connotations—or disclose as little information as possible (Klawiter, 2008).

The taboo and stigma surrounding breast cancer at this time forced women’s continued dependence on paternalistic medicine, and “authoritative doctor–patient relationships, inaccessible medical language, invasive procedures, lack of concerns for women patients, and the predominance of male models of disease” served to intensify medical control over both the disease and those affected by it” (Sulik, 2011, pp. 27–28). Illustrating this extremely well is what was, at the time, the standard surgical protocol for breast cancer treatment: “[T]he patient was biopsied and then, if the result was positive, rushed into a radical mastectomy without ever being wakened from anesthesia to discuss her options” (Ehrenreich & English, 2010, pp. 8–9).

The Halstead radical mastectomy, in which diagnosis occurred simultaneously with treatment, was a debilitating and deforming procedure pioneered in the 1890s that involved removal of the chest muscles and surrounding lymph nodes in addition to the breast tissue; it remained standard practice into the late 1970s (Mukherjee, 2010). For

almost a century, it remained largely unchallenged as the dominant form of treatment, with the result being that “a certain percentage of patients who entered the hospital expecting nothing more than a surgical biopsy awoke to discover that they had been treated for breast cancer by radical mastectomy before learning of their condition” (Klawiter, 2008, p. 76).

Providers of the period framed their combining of the two procedures (again, surgical biopsy followed by radical mastectomy if cancer was found) as both ethically defensible and sensible: Patients did not have to endure the risk of a second general anesthesia, and a second operation did not have to be scheduled, performed, or undergone (Klawiter, 2008). However, this process dramatically removed agency from the patient, positioning her as merely a passive, unknowing observer of the male-dominated realm of medicine: She awoke to learn “that she had been successfully treated for a condition that was not called by name, at least not in front of the patient” (Klawiter, 2008, p. 77).

It is no surprise, then, that the ascent of the male (and usually White and wealthy) medical professional as expert largely restricted access of health care and healthcare information, particularly among women (Dusenbery, 2018a). Ehrenreich and English (2010) write of their role in the “emerging ‘women’s health movement’” of the 1970s and their project “to confront women’s ignorance of their own bodies” (p. 9). They were not alone. In Boston, for example, there was a series of “Know Your Body” courses intended for the layperson concerning everything from the menstrual cycle to pregnancy to menopause; the core of these courses eventually became the book *Our Bodies, Ourselves*, with both emerging in response to the lack of publicly accessible information concerning

women's health (Ehrenreich & English, 2010). (Ehrenreich and English created a similar course in New York City.)

Our Bodies, Ourselves refers to this as “imperialism of knowledge,” in which medical professionals have elected to restrict their knowledge rather than share their skills, effectively serving as gatekeepers of health care (Boston Women's Health Book Collective, 1973). The text continues, stating that “the American doctor has claimed for himself unusually broad powers,” as decisions concerning “which patients are treated and where, the cost of treatment, who goes to the hospital, which treatment is given and for how long, and which drugs are administered and in what quantities” are left entirely to him (Boston Women's Health Book Collective, 1973, p. 240). *Our Bodies, Ourselves* also notes that the experience of seeing a provider, particularly a gynecologist, is often not a pleasant one, as provider attitudes—“their condescension, their technical manner, their assumption of women's ignorance, and their stereotyped view of us”—are off-putting (Boston Women's Health Book Collective, 1973, p. 240).

Writing in 2010, Ehrenreich and English (2010) state that today, “anyone can learn about these things in high school courses, by reading women's magazines, or just by googling” (p. 9). Then, though, women “packed . . . [the] classes, eager for whatever information we had to offer” (Ehrenreich & English, 2010, p. 9). Soon, as Ehrenreich and English (2010) describe, they had the suspicion “that women had not always, in all circumstances, been so disempowered with respect to their own bodies and care,” as “medical technology and the medical profession that monopolized it were relatively recent historical developments” but “somehow our female ancestors had, however imperfectly, negotiated the challenges of the female life cycle” (p. 9).

Drawing from the limited resources available at the time, including “conventional histories of American medicine” that described “how ‘primitive’ American medicine had been before the rise of the modern medical profession,” or “a time when women predominated as healers,” Ehrenreich and English (2010), in *Witches, Midwives and Healers*, craft a persuasive history of women’s once-active involvement in health and healing—and their subsequent banishment from it (p. 10). The heart of their argument is that “the medical profession . . . had replaced and driven out a much older tradition of female lay healing, including both midwifery and a range of healing skills, while closing medical education to women” (Ehrenreich & English, 2010, p. 11). As they explain, the “ignorance and disempowerment of women” felt so acutely in the 1970s were not “longstanding conditions” but rather were “the result of a prolonged power struggle” taking place in the United States in the early 19th century (Ehrenreich & English, 2010, p. 11).

In *Witches, Midwives and Healers*, Ehrenreich and English (2010) look as far back as the Middle Ages, paying particular attention to the witch hunts that occurred then and in the years that would follow. The victims of these witch hunts, they explain, were multifold: the individual women who were tortured and killed, of course, but also “all the people who were consequently deprived of their healing or midwifery skills” (Ehrenreich & English, 2010, p. 21). The witch hunts were a step backward—“toward ignorance and helplessness”—with consequences for the occupation and the field (Ehrenreich & English, 2010, p. 21). Attempts would be made much later to “recapture some of the lost knowledge of the natural world” by “members of the educated elite,” but only remnants remained (Ehrenreich & English, 2010, p. 21).

They compare this suppression of the “witches” to “the later, less violent elimination of midwives and aspiring female doctors in the United States” (Ehrenreich & English, 2010, p. 22), saying that “the suppression of women health workers and the rise to dominance of male professionals was not a ‘natural’ process, resulting automatically from changes in medical science, nor was it the result of women’s failure to take on healing work” (Ehrenreich & English, 2010, p. 28). Instead, “it was an active *takeover* by medical professionals” (Ehrenreich & English, 2010, p. 28). Further, Ehrenreich and English (2010) offer another perspective on this shift; they argue that it was not science that pushed men to the forefront of the medical profession—“the critical battles took place long before the development of modern scientific technology” (p. 28). Instead, the suppression of women in medicine was both a political (women healers’ status has ebbed and flowed with women’s status on the whole) and a class struggle (male medical professionals served the ruling class, whereas women healers were the doctors of the people). Ehrenreich and English (2010), in the introduction to the first edition of *Witches, Midwives and Healers*, view this erasure of women as healers as practically criminal:

Women have always been healers. They were the unlicensed doctors and anatomists of Western history. They were abortionists, nurses, and counselors. They were pharmacists, cultivating healing herbs and exchanging secrets of their uses. They were midwives, travelling from home to home and village to village. For centuries women were doctors without degrees, barred from books and lectures, learning from each other and passing on experience from neighbor to neighbor and mother to daughter. They were called “wise women” by the people,

witches or charlatans by the authorities. Medicine is part of our heritage as women, our history, our birthright. (p. 25)

It is important to point out here that much of this so-called takeover involved making a very clear distinction between formally trained doctors, ever growing in number, and the existing lay practitioners. As of the early 1800s, this distinction primarily consisted of the formally trained, or regular, doctors' being male, likely middle class, and more often than not more expensive than their lay competition. These doctors treated the people of their own class and above (Ehrenreich & English, 2010). At this time, the distinction ended there—the “formal training” they claimed did not mean much, as medical programs were disparate in terms of both length, ranging from a few months to a couple of years, and access to clinical facilities. In addition, medical school admission requirements were scant; a high school diploma was not needed to enroll.

During this period, there was not much that a medical program could impart on its students. According to Ehrenreich and English (2010), “there was no body of medical science to be trained in” (p. 66). Ironically enough, because the formally trained doctors were drawn to “heroic” measures, like massive bleeding and opium, to prove their worth, the lay practitioners practicing at this time “were undoubtedly safer and more effective than the ‘regulars,’” preferring remedies like mild herbal medications and dietary changes (Ehrenreich & English, 2010, p. 68).

Still, the formally trained doctors were the ones who “knew the right people” and “had legislative clout” (Ehrenreich & English, 2010, p. 68). As of 1830, 13 states had passed medical licensing laws establishing formally trained doctors as the only legal healers and outlawing other healing practices. Ehrenreich and English (2010) call this

premature: There was no popular support for the professionalization of medicine; there was no way to enforce these licensing laws; and “this early grab for medical monopoly” resulted in the “radical” Popular Health Movement of the 1830s and 1840s (p. 69).

Sometimes dismissed as “quackery and medical cultism,” the Popular Health Movement was, in reality, “the medical front of a general social upheaval stirred up by feminist and working class movements” (Ehrenreich & English, 2010, p. 69).

With women as its backbone, the Popular Health Movement “was a radical assault on medical elitism, and an affirmation of the traditional people’s medicine” (Ehrenreich & English, 2010, p. 70), as well as a push for not just increased and improved health care but also a different type of health care. For instance, women created “Ladies’ Physiological Societies” to educate themselves about their bodies and to share home remedies; these popped up across the country, offering audiences simple guidance on anatomy and personal hygiene, and promoting preventive care instead of the “heroic” approaches pushed by the medical establishment. They championed things like frequent bathing, loose-fitting clothing for women, whole-grain cereals, temperance, and even, in some factions of the Popular Health Movement, birth control. Of note is how the Popular Health Movement was closely intertwined with the emergence of an organized feminist movement—the former was concerned with women’s rights, while the latter was concerned with health and the role of women in medicine, including their access to medical training.

Although medical licensing laws were repealed in most states by the 1840s, in part because of the Popular Health Movement that made it nearly impossible to distinguish the “real” doctors from all others, the formally trained doctors had had

enough and were ready to take action. They formed the American Medical Association in 1848 and ceaselessly engaged in attacks of other healers: lay practitioners, sectarian doctors, women practitioners overall (Ehrenreich & English, 2010). Regarding women doctors, these formally trained doctors fighting for dominance questioned how respectable women could travel at night to attend a medical emergency, for example. If a woman did manage to enroll at a medical school, she was constantly harassed and subject to the sexist whims of even her professors, some of whom refused to speak about subjects like anatomy in her presence (Ehrenreich & English, 2010). If she made it through this medical training, she faced even more obstacles: hospitals closed to female doctors, other doctors unwilling to refer patients to her and against her membership in professional medical societies.

At the same time, the history shows that middle-class women had “accepted the terms set by the emerging male medical profession” (Ehrenreich & English, 2010, p. 79). The convergence of (a) science, including the germ theory of disease, which offered a foundation for disease prevention and treatment, and (b) patronage offered to doctors the opportunity to become a profession, once and for all. The turn of the 20th century was marked by the establishment of a standard medical school curriculum and education, which “barred most working class and poor people from the possibility of a medical education” (Ehrenreich & English, 2010, pp. 80–81). The United States also “was emerging as the industrial leader of the world,” and “for the first time in American history, there were sufficient concentrations of corporate wealth to allow for massive, organized philanthropy” (Ehrenreich & English, 2010, p. 81). Medical reform, involving the professionalization of medicine, was a key priority. Among these medical reform

efforts was the creation of the Flexner Report, a survey of American medical schools published in 1910. Unsurprisingly, the report found that “smaller, poorer schools, which included most of the sectarian schools and special schools for blacks and women” were not “worth saving” (Ehrenreich & English, 2010, pp. 82–83). Finally, “medicine was established . . . as a branch of ‘higher’ learning, accessible only through lengthy and expensive university training” (Ehrenreich & English, 2010, p. 83). Further, “doors were slammed shut to blacks, to the majority of women, and to poor, white men,” with medicine having firmly “become a white, male, middle-class occupation,” nay “profession” (Ehrenreich & English, 2010, p. 84).

With all opportunities for independent practice behind them, women were relegated to the newly invented occupation of nursing, which was branded with an image inspired by women like Florence Nightingale and Dorothea Dix:

Training emphasized character, not skills. The finished product, the Nightingale nurse, was simply the ideal Lady, transplanted from home to the hospital, and absolved of reproductive responsibilities. To the doctor, she brought the wifely virtue of absolute obedience. To the patient, she brought the selfless devotion of a mother. To the lower level hospital employees, she brought the firm but kindly discipline of a household manager accustomed to dealing with servants.

(Ehrenreich & English, 2010, pp. 90–91)

Accordingly, in the late 19th century, the number of nursing students rose as the number of female medical students declined: “Woman had found her place in the health system” (Ehrenreich & English, 2010, p. 93). At the same time, the role of the doctor became even more pronounced:

He diagnosed, he prescribed, he moved on. He could not waste his talents, or his expensive academic training in the tedious detail of bedside care. For this he needed a patient, obedient helper, someone who was not above the most menial tasks, in short a nurse. (Ehrenreich & English, 2010, p. 96)

Although healing as performed by lay healers had once combined both curing and caring, now the two functions were forevermore divided: “Curing became the exclusive province of the doctor; caring was relegated to the nurse” (Ehrenreich & English, 2010, p. 96). At the same time, the nurse embodied “idealized Woman,” whereas the doctor “was idealized Man” (Ehrenreich & English, 2010, p. 97). As such, according to Ehrenreich and English (2010), the doctor could claim credit for the patient’s treatment and subsequent recovery, as he melded “intellect and action, abstract theory, and hard-headed pragmatism” (p. 96) and “participated in the mystique of science” (p. 96). Ehrenreich and English (2010) continue, saying that the nurse, with “her tenderness and innate spirituality,” was at odds with “the harsh, linear world of science” (p. 97); her work was basically that of a servant, and “[s]he had no power, no magic, and no claim to the credit” (p. 96).

As will be later discussed in this work, much has been done in the intervening years to change this image of nurses as merely an extension of the feminine roles of wife and mother in the workplace. Nursing is no longer exclusively a female profession, and, as previously discussed, neither is the practice of medicine. In nursing, though, women still dominate the profession, just as men make up the majority of doctors: 88.2% of registered nurses are women, yet the average female salary for a registered nurse is \$64,351, compared to the average male registered nurse salary of \$76,273 (Data USA,

n.d.). Nursing continues to be women's primary role in the healthcare system, and there is much about the nursing role itself that is entrenched in and relies on sexism.

Subservience and passivity are prized; rebellion is a violation of professionalism. After all, "doctors are the bosses in an industry where the workers are primarily women"

(Ehrenreich & English, 2010, p. 102).

Pushing Back and Speaking Up: Progress and Setbacks

Whether speaking of nurses and doctors or of patients and providers, there remains a sense of inequality and imbalance inherent in this relationship. Viewed from a historical perspective and even continuing into the present day, there has long been a pattern of individuals' acceding to the so-called "experts," particularly when science, with its presumed objectivity and lack of bias, is involved. However, there have been instances in which individuals, namely women, pushed against the medical establishment, including in the context of the Popular Health Movement of the 1830s and 1840s, as described previously. For example, in the early 20th century, women fought for public health campaigns to battle infant and maternal mortality, and they pushed for birth control legalization (Dusenbery, 2018a). Later, in the 1960s and 1970s, the Women's Health Movement, as mentioned earlier, arose from a widespread sense of dissatisfaction felt in regard to the current system of health care (Nichols, 1999). The movement strove to improve health care for all women and to end sexism in the healthcare system, as well as to reclaim power and control over women's health from the paternalistic, condescending medical community (Nichols, 1999).

On the whole, the Women's Health Movement of this period claimed several victories: the legal right to abortion, the establishment of women's health clinics, various

patient rights (Dusenbery, 2018a). At this same time, even nonprofessional women returned in some ways to their previous role as facilitators of women's health care, such as by providing clandestine abortion services via the Chicago-based Jane Collective, an underground network, when the procedure was illegal in the United States (Roe v. Wade, decided in 1973, recognizes the constitutional right to safe, legal abortion access) (Haberman, 2018). Although the Women's Health Movement flourished during the "liberal political environment of the 1960s and 1970s," the election of Ronald Reagan as president in 1980 ushered in a political environment that was increasingly conservative (Nichols, 1999, p. 57).

The ensuing years contained both ups and downs in terms of women's progress on the healthcare front, and systemic change is clearly still needed (Nichols, 1999), especially with battles still being waged concerning issues like access to contraception and abortion. Former President Donald Trump's appointment of Amy Coney Barrett to the Supreme Court in October 2020 places these contentious issues, as well as the fate of the Patient Protection and Affordable Care Act, which has extended healthcare access to more than 20 million Americans, in further jeopardy (Biskupic, 2020; Rovner, 2020).

In addition, the current historical moment is filled with "instances of women's voices being suppressed and belittled," such as "in the accounts of assault and harassment emerging in the #MeToo moment . . . or in the recent studies showing how frequently men interrupt women in meetings and how rarely women are quoted as experts" (Sehgal, 2018, para. 9). Among these voices are those of women openly sharing, maybe for the first time, the neglect and unhelpfulness they or their family members or friends have experienced at the hands of the healthcare system. Everyone seemingly has one of these

“doctor stories” (Sehgal, 2018, para. 9). They “are bubbling up to the surface—being documented, circulated, and acknowledged by public discourse” (Fetters, 2018, para. 3), even though these “stories of medical practitioners dismissing, misdiagnosing, or cluelessly shrugging at their pain” are nothing new (Fetters, 2018, para. 2).

In *Belabored: A Vindication of the Rights of Pregnant Women*, Lenz (2020) defends the autonomy and dignity of pregnant people, blending her own experiences with pregnancy with discussions of outdated religious, historical, and cultural myths that continue to shape the world today. Lenz (2020) states that “[w]e are taught to believe in the supremacy of science, to celebrate the men of modern medicine” and that she fully “bought into this idea” for both of her pregnancies (p. 125). She explains her reasoning, or lack thereof, further:

After all, if this was the tried and tested way, why should I resist? I didn’t need to be difficult. I didn’t need to cause a fuss. I could just hand myself over to the professionals. I could trust them to do right by me. After all, it was science. It was dispassionate. It was not ruled by the whims of culture. Or so I believed. (Lenz, 2020, p. 125)

However, the medical history of birth follows a similar trajectory as the history of medicine on the whole. As previously elucidated, “scientific progress was codified into practice” and “medicine began to favor formal education, which was largely accessible only to men” (Lenz, 2020, p. 128). This placed birth squarely in the realm of male doctors, “who treated pregnancies as medical abnormalities, little more than diseases to be cured” (Lenz, 2020, p. 128). Birth had been removed from the purview of the mother and her community, including the midwife—according to Lenz (2020), “[t]his was a

natural next step in the sidelining of women from their births and bodies, rendering them unqualified, voiceless, and dependent on men's expertise" (p. 128).

Lenz (2020) also looks at the present day, particularly the modern birth experience, which too often involves "trauma from the loss of control that's become a standard part of the birth experience in the United States" (p. 130). Practices like episiotomies, surgical rupturing of membranes, and the use of forceps "are often forced on people giving birth," with the expectation, of not male doctors necessarily but a medical system with deeply paternalistic roots, "that a good patient will passively accept whatever the doctor orders—and it always seems to be an order" (Lenz, 2020, p. 130). Lenz (2020) herself writes of the vacuum, "a tool used to remove babies from the womb," and her insistence that it not be used while she was giving birth (p. 130). She adds that after four hours of labor, "the doctor pulled out the vacuum" and said she was going to use it: "I wanted to object," Lenz (2020) writes, "but her tone left no room for discussion" (p. 130).

Further, Lenz (2020) says, "[e]veryone I talk to who's given birth has a similar story," and "the violence women experience during birth is nothing new" (p. 130). There are attempts to reclaim control over the birth experience, such as via modern midwifery movements, but these, too, have faults. Natural birth, for example, can be just as disempowering, Lenz (2020) explains: "[I]t's positioned as the thing our bodies are made for, leading to a sense of failure if 'natural birth' is not achieved" (pp. 130–131). This option also is not accessible to many, for financial and other reasons. (It is also important to point out that midwifery in the United States is very much the purview of White women. Historically speaking, Black women delivered both Black and White babies as

midwives, but they were ultimately sidelined as well, portrayed as “unkept, unprofessional, a danger to the fragile white women who used their services” [Lenz, 2020, pp. 128–129].)

The main issue at play here concerns who has power—and who is powerless. Implicated within that is “class, race, gender, and who is allowed to speak for themselves (and for others)” (Lenz, 2020, p. 131). Women’s agency and voices “have been suppressed, silenced” (Lenz, 2020, p. 131). In the case of pregnancy, though, “the only relevant voice in that room is the pregnant person’s. They are the one who chooses. They are the only one who can speak on their own behalf and that of their body” (Lenz, 2020, p. 132).

Perhaps what is different in the current historical moment is that these voices and these stories, many related to that feeling of powerlessness in the face of medicine, are finally being openly acknowledged, by both those who share similar experiences and the wider public. Twitter, for example, is a fount of such experiences, with users sharing their problematic healthcare encounters and others stating their support and even chiming in with stories of their own. A December 13, 2018, tweet from Twitter user Coffee Spoonie (@coffeespoonie) relays the story of a family member:

Last week my cousin (28) had an urgent care doctor send her home, saying she was fine & her difficulty breathing was due to “anxiety”. The next day she went to her doctor, was [diagnosed] with pneumonia and admitted to the hospital; they ran her [white blood cell] count & found she has [acute myeloid] leukemia.

Twitter user @LilacZebra, whose profile lists diagnoses of hypermobile Ehlers-Danlos syndrome, postural orthostatic tachycardia syndrome, autoimmune disorders, and other

chronic illnesses, on August 1, 2019, defines this phenomenon as #MedicalGaslighting, writing that it is

when a doc doesn't know what is going on, and has zero idea for a diagnosis, so tells the patient . . . it's all in her head. This happens way more often for patients who ID as women. This is also why I almost died.

User @ReaStrawhill, on October 28, 2020, said that such treatment “caused [her] immense distress” and “made [her] doubt [herself] completely at times.” She continues: “It took a lot to rebuild my confidence. No patient should ever bear the consequences of a doctor's lack of knowledge.” The number of similar accounts is staggering. Such experiences have become archetypal as well: They often involve “some variation on the same character: the doctor who waves a hand and says, ‘You'll be fine,’ or ‘That's just in your head,’ or ‘Take a Tylenol’” and adhere to “an ominous three-act structure” that features a woman expressing concern about a particular health issue to a provider, the provider demurring, and, “after either an obstacle course of doctor visits or a nightmare scenario coming to life,” the provider finally acknowledging that “her pain was real and present the whole time” (Fetters, 2018, para. 1).

On December 2, 2019, user @JourneyFog thanked all those who had shared their personal #MedicalGaslighting stories, saying that it “makes [her] so angry to hear all these accounts of medical #neglect & abuse.” However, what made her even angrier: “100% of cases are from #women! Does this neglect happen to men as well?”

There are certainly male patients who have had unsatisfactory encounters with their healthcare providers. However, medical gaslighting (Booth, 2018) is more likely to be experienced by women than men (Brennan, 2020). The term “medical gaslighting”

comes from “gaslighting,” which is defined by the Office on Women’s Health (2018), part of the U.S. Department of Health and Human Services, in the context of domestic abuse, as “a form of emotional abuse that abusers use to maintain power and control” and “is the word used when an abuser makes you feel like you are losing your mind or memory” (para. 5).

The term “gaslighting” comes from the 1938 play and 1944 film *Gaslight*; in it, “a husband manipulates his wife into thinking she has a mental illness by dimming their gas-fueled lights and telling her she is hallucinating” (Huizen, 2020, para. 2). Generally and bluntly speaking, gaslighting is “a form of psychological abuse where a person or group makes someone question their sanity, perception of reality, or memories,” with those who are being gaslighted “often feel[ing] confused, anxious, and unable to trust themselves” (Huizen, 2020, para. 1). Gaslighting can be experienced by anyone, but it is particularly prevalent in both intimate relationships and in relationships involving an imbalance of power. It can exist within intimate partner or child–parent relationships, or be driven by race, politics, or institutions, for example (Huizen, 2020).

Medical gaslighting is systemic and stems from “a crisis of authority,” in which “women are regarded as unreliable narrators who can’t even be trusted to speak for themselves or testify to their own pain” (Sehgal, 2018, para. 4). For many, like Claire Richmond (2020), the cycle of “speaking up about [her] body’s sensations and . . . feeling rejected by doctors” led her to have less confidence in her “pain experience,” losing “trust in her judgment” and beginning “to question the validity of symptoms” (para. 4). Medical gaslighting can take many forms and, at its most fundamental level, is when healthcare providers minimize or entirely disregard an individual’s symptoms: “This can

be by refusing to perform lab tests or insisting that symptoms are related to mental health disorders” (Richmond, 2020, para. 16). This insidious “cultural distrust of women” seemingly affects every time point in the healthcare process (Sehgal, 2018, para. 5), and its existence is supported by a not-insignificant amount of research.

For example, a review of gender disparities in healthcare experience and treatment by Kiesel (2017) reported that women in pain are considerably more likely than men to receive prescriptions for sedatives, instead of pain medication, to treat their ailments, and that women wait in the emergency department an average of 65 minutes before receiving an analgesic to treat acute abdominal pain, compared to an average of 49 minutes for men. A study of women at one hospital found that they were at considerably greater danger of dying from preventable blood clots than men because providers were less likely to provide them with the appropriate blood clot prevention treatment (Nordell, 2017).

In addition, women are seven times more likely than men to be misdiagnosed and discharged in the midst of having a heart attack; medical understandings of the majority of conditions and diseases are based on male physiology, but women experience entirely differently symptoms than do men when having a heart attack (Kiesel, 2017).

Furthermore, in terms of pain, 70% of those who experience chronic pain are women, but 80% of pain studies are conducted on male mice or human men—even though it has been found that women tend to feel pain more often and more intensely than men (Kiesel, 2017). On the whole, the healthcare system is inattentive to differences between men and women, “instead taking a one-size-fits-all approach to clinical research and practice” (Dusenbery, 2018a, p. 3).

In other words, a “gender data gap” exists, in which data collected reflect men’s experience, not women’s (Samuel, 2019, para. 4). Men are thus the default user for “most things and spaces,” including pain medications, cars, air-conditioned workplaces, and city streets, and “they often don’t work well for women” (Samuel, 2019, para. 4). Such biased design occurs in a number of places, but it is particularly worrying in the arena of health, where the consequences can be dangerous, even fatal. It is apparent that the healthcare system is “from root to tip, systematically discriminating against women, leaving them chronically misunderstood, mistreated and misdiagnosed” (Criado Perez, 2019, p. 196).

Much of this can be traced to the simple fact “that the male body has always been taken as the standard human being,” with the “female body seen as the atypical body” (Samuel, 2019, para. 10). Take over-the-counter medications, which offer dose recommendations for “child” and “adult,” not, say, “man” and “woman.” What is presumed to be a gender-neutral dose actually is the dose for “the standard human and he is a man,” “[u]sually a white man in his 30s, around 70 kg [155 pounds]” (Samuel, 2019, para. 25). This is concerning, especially because women are known to have more adverse reactions to drugs than men, with the most common being nausea and sheer ineffectiveness. Again, this “is partly because [in drug testing] we are—from the cell stage to the animal stage to the human stage—not testing in women” (Samuel, 2019, para. 21). It is not that there is “some giant conspiracy and medical researchers all hate women and want us to die. It’s just that this way of thinking is so pervasive that we don’t even realize we’re doing it” (Samuel, 2019, para. 11).

Women are also more likely to be told that their pain is psychosomatic, or affected by emotional distress (Pagán, 2018), which is rooted in the history of hysteria

(Boston Women's Health Book Collective, 1973; Dusenbery, 2018b; Ehrenreich & English, 2011; Norman, 2018). Over time, hysteria has been linked to a variety of causes, including the wandering uterus or womb (Allison & Roberts, 1994). The "tendency to attribute women's physical complaints to mental illness" is based on the theory that the unconscious mind is able to produce physical symptoms, and this concept persists in medicine today, having never entirely disappeared; often, a psychosomatic diagnosis allows providers to believe that their diagnosis has conclusively solved the patient's medical mystery, whether or not this is actually the case (Dusenbery, 2018b, para. 12). It is a catchall diagnostic category that is too often employed in health care and by providers to avoid getting at the real problem.

In addition, gender stereotypes only worsen this issue. Women are assumed to respond to pain in overly emotional ways and are thought to seek care not only readily but perhaps *too* readily (Dusenbery, 2018a). Men, in contrast, are seen as less willing to seek out medical care and, thus, are virtually guaranteed to be taken seriously no matter their outward reaction: "[I]f they're stoic, they're just being a typical 'macho' guy, and if they're emotional . . . it must be really, *really* bad" (Dusenbery, 2018a, p. 98).

Dusenbery (2018a) posits two interconnected reasons for the dismal quality of health care that many women receive: a knowledge gap (i.e., "the average doctor does not know as much about women's bodies and the health problems that afflict them") and a trust gap (i.e., "women's accounts of their symptoms are too often not believed") (p. 11). The healthcare experience that results is one that is invalidating and disorienting, as women often must fight to be taken seriously and to prove that their symptoms and pain are real and valid. It is important to note that medical gaslighting is also manifested via a

provider's assumption that "symptoms or a diagnosis are based on race, sex, gender identity, ethnicity, age, weight, or income level" (Richmond, 2020, para. 16). After all, "[y]our chances of being subjected to medical gaslighting increase if you are not white, cisgender or able-bodied — essentially any marginalized group" (Gaudon, 2020, para. 8).

This can be observed in the current historical moment, particularly in regard to COVID-19. An NBC News article from July 2020 shared the stories of several women reporting lingering symptoms of the virus lasting weeks or even months beyond the initial infection (Chuck, 2020). A 35-year-old woman interviewed said that four months after having COVID-19, she was still experiencing shortness of breath, achiness in her lungs, and tingling in her calves. She visited an urgent care center in May, concerned that her memory loss, migraine, chest tightness, and leg numbness were symptoms of something serious, like a stroke or other neurological problem. A physician's response? Rolling his eyes at her. Dismissing her. Saying these concerning symptoms were acid reflux, or a vitamin deficiency. She told the NBC News interviewer that she could not help but feel that a male patient with the same health concerns would have been taken more seriously. On another occasion, her primary care provider said that maybe she was just "stressed because of the economy" (Chuck, 2020, para. 2). "I'm so ill and some people are telling me this is a figment of my imagination," she was quoted as saying. "It truly feels like a nightmare" (Chuck, 2020, para. 5). She added, "I have to remind myself I'm not making this up" (Chuck, 2020, para. 31).

Another woman interviewed for the same article, a 38-year-old Black woman, said she had not witnessed explicit sexism or racism during her multiple emergency department visits since contracting the virus in mid-June. She had experienced shooting

pains around her heart, increased blood pressure, and arm and leg tingling; her emergency department visits were from worry that she might be having a heart attack. Providers have prescribed anti-anxiety medications to her, even though she says that these symptoms are not a product of anxiety. She has stayed away from mentioning to providers that her father died of COVID-19, “since it usually prompts them to suggest her problems are a manifestation of grief and stress” (Chuck, 2020, para. 16).

Of course, it must be acknowledged that this coronavirus is novel, meaning that it has not been seen before. Providers are learning about it at the same time that they are treating it. (There is now some recognition that COVID-19 symptoms can last for longer periods of time than the initial infection.) Similarly, there is not yet a protocol, used to guard against unconscious biases that can affect treatment, for providers to follow when treating those who are experiencing long-term issues from COVID-19. Still, when communicating with patients who have symptoms connected to COVID-19 that are unfamiliar to the provider, “there are ways to show patients they are still being heard” (Chuck, 2020, para. 23). Essential to this is the provider’s recognition that these symptoms are valid, that they exist: “We have to acknowledge that what the patient is telling us is real, and we have to seek to understand how best to address it,” said one provider (Chuck, 2020, para. 23). Part of this involves understanding one’s implicit biases as a provider, which are not limited to gender but may also include race and ethnicity, as will be discussed in the next section.

Race and Ethnicity in Health Care

Much of what has been detailed about women and their relationship with the sometimes-paternalistic healthcare system can be applied to other populations as well.

After all, the history of women and medicine is also a history of the Other and medicine—anyone who was not fairly well off, male, and White was, ultimately, excluded. For example, the story that Ehrenreich and English (2005, 2010, 2011) tell of the professionalization of medicine to benefit a certain group (again, wealthy, male, White doctors) is in a feminist context, with attention paid to how this shift suppressed women healers and stripped them, in many ways, of their autonomous practice within medicine, but it can be taken beyond this, to show how women were not the only ones to receive unfair, unequal treatment at the hands of medicine. Accordingly, this section will attempt to explore the ways in which race and ethnicity affect the healthcare experience for members of these populations.

Healthcare Disparities in the Literature

To start, it is a well-known fact that race and ethnicity play no small part in contributing to the type of medical care that individuals receive (Chuck, 2020). Minority patients “often receive differential and less optimal technical health care” (Cooper-Patrick et al., 1999, p. 583). The Institute of Medicine (2003) report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, for example, states, matter-of-factly, that even when access-related factors (e.g., insurance status, income) are controlled, “racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities” (p. 1). The report acknowledges that these disparities are “complex,” being rooted as they are “in historic and contemporary inequities” and involving “many participants at several levels,” such as health systems, healthcare providers, and patients themselves (Institute of Medicine, 2003, p. 1). Important to the current project, the Institute of Medicine (2003) report, which focuses on the clinical encounter, “found

evidence that stereotyping, biases, and uncertainty on the part of healthcare providers can all contribute to unequal treatment” (p. 1). Of course, this is only compounded by the many other barriers to accessing care that minority patients (and others) may face, such as those related to “language, geography, and cultural familiarity” (Institute of Medicine, 2003, p. 1).

More recently, the Agency for Healthcare Research and Quality’s (2019) *National Healthcare Quality and Disparities Report*—which looks at the performance of the U.S. healthcare system, assessing strengths and weaknesses, along with disparities related to healthcare access and quality—found that, on the whole, some disparities were decreasing from 2000 through 2016–2017, but that they continue to persist. For example, according to the report, Blacks, American Indians and Alaska Natives, and Native Hawaiians/Pacific Islanders received worse care than Whites for approximately 40% of the quality measures examined. In addition, Hispanics received worse care than Whites for about 35% of quality measures, and Asians received worse care than Whites for 27% of quality measures, but better care than Whites for 28% of quality measures.

The literature is replete with examples of unequal care presumably linked to race and ethnicity, with communication in the patient–provider context—or the lack thereof—playing a key role. Cooper-Patrick et al. (1999), in their study concerning how the race and ethnicity and gender of patients and physicians are related to the quality of interpersonal care provided during healthcare encounters, determined that African American patients found their visits to be significantly less participatory than Whites, even when adjusting for patient age, gender, education, marital status, health status, and length of the patient–provider relationship. However, in that same study, patients seeing

providers of the same race or ethnicity rated those providers' decision-making styles as more participatory, suggesting that "racial and ethnic differences between physicians and patients do influence physicians' communication and decision making" (Cooper-Patrick et al., 1999, pp. 583–584).

According to Cooper-Patrick et al. (1999), there are a host of factors linked to the provider that may explain why such racial and ethnic differences between providers and their patients sometimes act as "barriers to partnership and effective communication" (p. 588). For one, providers "may unintentionally incorporate racial biases, such as racial and ethnic stereotypes into their interpretation of patients' symptoms, predictions of patients' behaviors, and medical decision making" (Cooper-Patrick et al., 1999, p. 588). In contrast, providers and patients from a shared race or ethnic group "are more likely to share cultural beliefs, values, and experiences . . . allowing them to communicate more effectively and to feel more comfortable with one another" (Cooper-Patrick et al., 1999, p. 588). What Martin et al. (2013) term "race concordance between patients and physicians" is tied to "longer visits with more positive patient affect, higher levels of patient trust, greater patient satisfaction, and ratings of visits as being more participatory" (p. 151).

Beach et al. (2011) uncovered similar findings, in that there may be interpersonal communication barriers that exist between patients of a racial and ethnic minority and their providers, who are predominantly of non-minority populations. For example, according to 2018 data from the Association of American Medical Colleges (2019), the most recent year for which data are available, most active physicians were White (56%) and male (64%). Looking specifically at race and ethnicity, 17% of active physicians

were Asian, 6% were Hispanic, and 5% were Black or African American (Association of American Medical Colleges, 2019). As previously described, racial and ethnic minority patients often have stronger relationships with providers who share their race or ethnicity—but most racial and ethnic minorities, at least in the United States, do not see providers who share their race or ethnicity. To that point, race has been shown to affect the relationship between patients and providers in a number of ways, including differences concerning communication quality. For example,

in their interactions with black patients, physicians exhibit less nonverbal attention, empathy, and courtesy; give less information; adopt a more “narrowly biomedical” communication style; spend less time providing health education, chatting and answering questions; are more verbally dominant; and exhibit more negative emotional tone than with white patients. (Beach et al., 2011, p. 806)

This disparity, of lower-quality interactions, is perceived by racial and ethnic minority patients, too, who have reported their physicians being less participatory with them than with White patients (Beach et al., 2011). Black and Hispanic patients are more likely than White and Asian patients to feel that they had been treated with disrespect during the medical encounter, with all racial and ethnic minority groups reporting that they “were more likely than whites to believe that they would have gotten better care if they belonged to a different race/ethnic group, and that medical staff judged them or treated them unfairly based on their race” (Beach et al., 2011, p. 806). In their own study, Beach et al. (2011) observed that providers were more verbally dominant in conversations with Black patients versus White patients, mostly because of Black patients’ talking less than White patients; this suggests, perhaps, that providers “should

consider making conscious efforts to engage black patients to become more involved in the process of the medical encounter” (p. 810).

Perceived discrimination, which is “defined as the perception of differential and negative treatment because of one’s membership in a particular demographic group,” also affects patient–provider communication and the overall healthcare relationship (Hausmann et al., 2011, p. 626). According to Hausmann et al. (2011), perceived discrimination is linked to negative mental and physical health outcomes, and it has been shown to negatively affect patients’ engagement with health care in a number of ways: “delays in obtaining medical care or prescriptions, less utilization of some preventive services, less adherence to physician recommendations or treatments, more missed medical appointments, and substituting alternative medicine for conventional care” (p. 626).

It is important to understand that perceived discrimination in health care can lead to patient disengagement in the long term. For example, patients who have perceived discrimination in past healthcare encounters may then anticipate future encounters to follow a similar pattern; their verbal and nonverbal communication may, therefore, be affected. The patient’s behavior, then, has the potential to influence and be influenced by that of the provider, with patient–provider communication affecting the patient’s “overall reactions to the encounter and subsequent engagement with that provider or the healthcare system” (Hausmann et al., 2011, p. 626). In their study, Hausmann et al. (2011) determined that perceived racism and classism were reported by more African American patients than White patients (70% versus 26%, respectively), with the most common types of racism and classism reported by patients being “feeling that a provider

was not listening to them and being treated with less respect than others” (p. 631). When Black patients feel “that they are not being listened to, respected, or given enough time to ask questions or interact with clinicians during medical visits, and that this treatment may be due to their race,” they, as a result, are more likely to distrust providers and delay preventive care, for example (Mitchell & Perry, 2020, p. 11). Further, Black patients frequently see “poor and ineffective clinical communication” as a product of discrimination, especially in instances in which they feel that their perspectives or symptoms are overlooked or discredited by the provider (Mitchell & Perry, 2020, p. 11).

With Black patients in particular, providers tend to “provide less information, engage in more narrowly biomedical conversations, spend less time building rapport, and are more verbally dominant and less patient-centered” (Cené et al., 2009, p. 1,058). In their study, Cené et al. (2009) found that Black patients with uncontrolled blood pressure experienced worse communication than White patients with controlled blood pressure for all but one measure: physician positive affect (affective behaviors include those related to rapport and the interpersonal relationship). Among patients with controlled blood pressure, Black patients had less communication with physicians than White patients. No significant differences were found in communication between White patients with controlled and uncontrolled blood pressure, meaning that “patient race influenced patient-physician communication more than [blood pressure] control did” (Cené et al., 2009, p. 1,062).

In addition, according to Cené et al. (2009), Black patients, with controlled and uncontrolled blood pressure, had shorter office visits than White patients with controlled blood pressure, which has important implications. Both patients and providers have

reported length of visit being important to quality of care, with longer visits “associated with higher communication quality, greater ease of discussing problems, and more participatory decision-making by patients” (Cené et al., 2009, p. 1,062). One reason offered by Cené et al. (2009) for poor communication between physicians and their Black patients may be related to illness perceptions, including providers’ attempts to promote their own “professional” views, which “may exacerbate black patients’ feelings of distrust and emotional distance” and cause patients to see providers as “being insensitive to their needs and therefore communicate less with them” (Cené et al., 2009, p. 1,062).

Trust between racial and ethnic minority patients and their providers is another issue that shows up in the literature. For instance, there is substantial evidence to support the idea that lower levels of trust in healthcare providers are connected to lower patient satisfaction among these populations, particularly African Americans (Martin et al., 2013). Patient trust is connected to a host of outcomes—patient satisfaction, adherence to treatment, care continuity, and improved health among them. When African American men, for example, sense differential treatment because of their race during medical encounters, “they are distrustful of their physician and the health care system overall,” which may lead to a future “reluctance to engage with the health care system for future needs and critical delays in the diagnosis and treatment of serious illnesses” (Hawkins & Mitchell, 2018, p. 57).

As previously noted, interpersonal communication between patients and providers is also linked to many of these positive outcomes, as well as to racial and ethnic disparities within health care. Patient–provider communication has several key functions, including “exchanging information, fostering healing relationships, making medical

decisions, and enabling patient self-management” (Palmer et al., 2014, p. 4,087). When done effectively, as reported in Palmer et al.’s (2014) study of cancer survivors, the benefits are manifold: “Effective [patient-provider communication] helps survivors cope with their illness, comprehend health information, communicate with multiple providers, and engage in their own health care” (p. 4,087).

Of note is that effective patient–provider communication may also help to facilitate patient activation in health care; so-called “activated patients are more likely to be engaged in improving and maintaining their health by confidently communicating with health care providers, making decisions, and using their knowledge, skills, and belief they have control over their life” (Palmer et al., 2014, p. 4,087). In addition, patient–provider communication has both direct and indirect connections to “health care access, advocacy, resources, self-efficacy and self-management, improved knowledge, shared understanding and health decision-making” (Mitchell & Perry, 2020, p. 2).

However, the literature has reported racial and ethnic disparities concerning patient–provider communication, the perceived quality of care received, and patient activation, including the ability and willingness of patients to manage their health care and the level of control they perceive having within the healthcare system. Palmer et al. (2014) recommend that providers working with racial and ethnic minority patients “be aware that [they] may view communication with their providers and their health care quality as less than ideal” (p. 4,082).

African Americans in particular often receive poorer interpersonal communication from their providers, which includes lower levels of affective behaviors (e.g., rapport building, overall affective tone), greater verbal dominance on the part of the provider, and

less patient-centeredness (Martin et al., 2013). Conversely, there are communication behaviors on the part of the provider that are associated with greater patient trust, “particularly those that explore and validate the disease and illness experience of the patient and encourage patient involvement in the dialogue” (Martin et al., 2013, p. 151). Martin et al. (2013) determined that Black patients had lower trust and experienced less patient-centered communication behaviors than White patients; however, they also found that positive emotional tone on the part of providers is associated with higher trust, especially in primary care visits among African American patients.

It has been reported, for example, that some primary care physicians have negative perceptions of African American patients, affecting “their ability and willingness to engage in patient-centered communication and care, resulting in objectively different content, tone, and overall quality of communication” with these patients versus White patients (Hawkins & Mitchell, 2018, p. 57). In addition to what has previously been noted, providers may also view African American patients as “noncompliant, less-effective communicators, and less educated during medical encounters” (Hawkins & Mitchell, 2018, p. 57). Some providers may treat such patients “more contentiously,” be less likely to use “supportive talk,” and “misunderstand or misinterpret cultural values, beliefs, and relational needs that inform African American patients’ health decisions and behaviors” (Hawkins & Mitchell, 2018, p. 57).

Black men specifically experience a number of poor health outcomes, including higher incidence, morbidity, and mortality, as well as worse prognoses, for various diseases (Hawkins & Mitchell, 2018; Mitchell & Perry, 2020). A confluence of factors contributes to these disparities. For one, such disparities have been blamed on poor

lifestyle choices or behaviors, including smoking, alcohol use, physical inactivity, obesity, unhealthy eating, and suboptimal use of preventive health care services; in addition, men of racial and ethnic minority populations have also been seen as having a “general disinclination to engage with the health care system” because of medical mistrust linked to perceived provider bias (Mitchell & Perry, 2020, p. 2).

Increasing Awareness of—and Addressing—Disparities

Raising providers’ awareness about healthcare disparities among racial and ethnic minority populations and promoting their engagement in addressing these disparities is a challenging proposition, even though healthcare leadership and policymakers alike agree that healthcare providers play a vital role in eliminating them (Burgess et al., 2019; Gollust et al., 2018). Particularly alienating is the concept “that providers may contribute to racial inequality in care,” which “can be professionally and threatening to some and may contradict underlying beliefs about the existence and causes of racial and ethnic healthcare disparities” (Burgess et al., 2019, p. 149). According to the literature, providers have a growing awareness of the existence of healthcare disparities in the United States—but they see them as unlikely to occur in their own practice or institution. Many also attribute such healthcare disparities to patient-level factors, not provider-level factors. This “white framing” emphasizes healthcare issues experienced by racial and ethnic minority patients but simultaneously neglects the role played by the “white perpetrators or racist practices and institutions creating these problems” (Feagin & Bennefield, 2014, p. 8). One consequence of such a perspective—providers’ believing that these disparities “result from factors internal to their patients of color”—is that “they may be less inclined to feel that they have a responsibility to address disparities than

when they perceive the causes of those disparities to lie with health care providers and the larger health care system” (Gollust et al., 2018, p. 2).

Gollust et al. (2018) note that participants in their study “were more likely to indicate social and economic conditions as playing a role compared with patient behaviors, in contrast to earlier societies,” which is a promising finding that demonstrates “growing provider recognition of the literature on racial disparities and the social determinants that influence patient care” (p. 7). They continue, stating that “[p]roviders rarely offered reductionist explanation that located disparities solely with patient behaviors, instead describing numerous multilevel pathways through which social and economic conditions, provider behavior, and the health care system shape patient outcomes” (Gollust et al., 2018, p. 7).

Still, this finding was not homogenous across the study’s participants, with important differences concerning how much providers acknowledged the role played by race and racism in health care. According to Gollust et al. (2018), among some providers, “behavioral or social attributes dwarfed or even eliminated the direct role of race in health care disparities” (p. 7). Some providers listed factors like access to care and health literacy “as the most plausible rationales for any racial or ethnic group differences that they observed, more plausible than racial discrimination and bias” (Gollust et al., 2018, p. 7). Importantly, write Gollust et al. (2018), this may suggest

that efforts to directly name and confront race and structural racism in health care may be met with resistance from the group of providers who either do not acknowledge racism or who judge the other social determinants as more valid explanations for inequalities. (p. 7)

This being said, racism must be understood at an institutional and systemic level as well. The following tweets help to illustrate past and present understandings of racism in relation to health care. On December 16, 2020, Twitter user @ADocNamedDani wrote, “Is it ‘Black people don’t trust medicine’? Or is it that the U.S. medical system has a history of disrespecting, disregarding, and losing the trust of the Black community?” On the same day, user @jdesmondharris wrote, “Everyone keeps saying the reason for skepticism about the vaccine in the Black community is the Tuskegee experiment but might it also have to do with actual, recent bad and trust-destroying experiences with healthcare in people’s own lives?” (A March 2021 *NPR* piece echoes the latter comment, referring to Tuskegee as a “scapegoat” [“Stop Blaming Tuskegee,” 2021, para. 4]. In discussions about the vaccine among Black seniors in Los Angeles, for instance, “Tuskegee rarely comes up. People in the community talk about contemporary racism and barriers to health care . . . while it seems to be mainly academics and officials who are preoccupied with the history of Tuskegee” [“Stop Blaming Tuskegee,” 2021, para. 3].)

Of course, the history of medicine is, in many ways, the story of how “medicine established itself on the bodies of the disenfranchised” and how “racism was encoded into our healthcare system” (Lenz, 2020, p. 137). The examples are manifold. According to Feagin and Bennefield (2014), “[s]ystemic racism and medical/biological science, including the latter’s medical and public health practices, evolved together in society” (p. 9). Take, for instance, the astoundingly racist history of medical experimentation. Slaves granted physicians economic security, as well as “clinical material that permitted the expansion of medical research, improvement of medical care, and enhancement of

medical training” (Evans et al., 2020, p. 274). In the 19th century, the shift toward empirical, scientific medicine, which involved a push to discover various technologies and treatments that would primarily if not exclusively benefit White individuals, led to the carrying out of medical experiments on African Americans, particularly women. Many enslaved women died as a result of these experiments that would not dare be tried by White physicians on White women (Feagin & Bennefield, 2014). This practice also “set the model for continued use of African Americans as guinea pigs for medical progress, as well as for white physicians’ provision of inadequate care for them,” as “Black women were often denied treatment for real ailments, resulting in excruciatingly painful deaths for many” (Feagin & Bennefield, 2014, p. 9). It is incredibly harmful, too, that those who committed such atrocities are today still venerated for their “contributions” to medicine. For example, James Marion Sims is viewed as “the father of gynecology,” but “[r]arely do mainstream accounts assess his sadistic treatment of blacks” (Feagin & Bennefield, 2014, p. 9).

In addition, into the mid-20th century and perhaps even beyond, many Black women underwent involuntary sterilization and hysterectomies. In 1932, the U.S. Public Health Service collaborated with the Tuskegee Institute for the “Study of Syphilis in the Untreated Male,” in which Black participants were not fully informed about the study or its true purpose and, ultimately, were never given adequate treatment for their disease, even after a highly effective treatment was discovered. The stolen blood cells of Henrietta Lacks, a Black woman, were found to survive significantly longer than other cell samples and were mass-produced for profit; although HeLa cells, as they have been termed, have been used to help develop a polio vaccine and have contributed to cancer research since

they were obtained in 1951, Lacks received only posthumous credit for her “donation,” which was revealed in the 1970s, and her children have never received any money generated from their mother’s cells (Feagin & Bennefield, 2014).

Similar examples abound throughout history. Boyd et al. (2020) state outright that “racism is, perhaps, America’s earliest tradition,” predating the founding of the country itself (para. 1). The United States, according to Feagin and Bennefield (2014), “is a country with systemic oppression—centuries of genocide, 336 years of slavery and legal segregation, about 85 percent of U.S. history” (p. 7). The legacy of slavery is one of “racism, injustice, and brutality” running from 1619 to the present and infecting “medicine as it does all social institutions” (Evans et al., 2020, p. 274). For about 20 generations, stretching all the way to the present day, “Americans of color have been economically impoverished and unhealthy because white Americans have long used extensive discrimination and resistance to change to [e]nsure they as a group are economically much better off and generally healthier” (Feagin & Bennefield, 2014, pp. 7–8). As a consequence, “unjustly inherited white resources and continuing discrimination restrict access of many Americans of color to better jobs, quality education, healthy neighborhoods, quality health care, and political power” (Feagin & Bennefield, 2014, p. 8). This racism is structural, deep-seated, manifested “in differential access by race to opportunities, resources, conditions, and power” (Ehrenfeld & Harris, 2020, para. 7). Despite “centuries of legal advancements that endeavored to excise racism from the roots of this republic, racism remains a bloodying force, structuring every facet of US life” (Boyd et al., 2020, para. 1).

As has been explicated in this section, racism is a significant driver of health inequity. It is, for example, quite telling that COVID-19 has been shown to be considerably more life-threatening in racial and ethnic minority populations. Age-adjusted COVID-19–associated hospitalization rates from the Centers for Disease Control and Prevention (2020b) reveal that the rate for Hispanic or Latino individuals, non-Hispanic American Indian or Alaska Native individuals, and non-Hispanic Black individuals were about 3.7, 3.5, and 3.2 times, respectively, the rate among non-Hispanic White individuals. Nationwide, Black individuals are dying at 1.7 times the rate of White individuals—this means that *at least* 50,000 Black individuals have died of COVID-19 as of late December 2020 and that, when race is known, Black people account for 17% of COVID-19 deaths (CovidTracking.com, n.d.). It is apparent that “COVID-19 is affecting Black, Indigenous, Latinx, and other people of color the most” (CovidTracking.com, n.d., para. 1).

Interviewed for *Pitt Med*, the magazine of the University of Pittsburgh’s School of Medicine, Jeannette South-Paul, recently retired Andrew W. Mathieson Professor and chair of family medicine at Pitt, said it was not surprising “that COVID-19 [had] not turned out to be the ‘great equalizer’ that politicians, celebrities and the media predicted in the early days of the pandemic” (Vitone, 2020, p. 16). Instead, “[t]he novel coronavirus is much more lethal to Black and Brown people across the United States . . . ‘not because they are genetically less valuable or weaker,’ [South-Paul] says. . . . The death toll . . . is the sum total of the realities of American life that stare us all in the face every day” (Vitone, 2020, p. 16).

Realities like these: Service-sector and other jobs that need to be performed in person, not from home, for which Black and Latinx populations are overrepresented. Reliance on public transportation. More densely populated housing. Multigenerational homes. A higher likelihood of living near industrial facilities and their associated toxins, which are connected to asthma. Neighborhoods that are food deserts, limiting access to nutritious foods. South-Paul “can give example after example through [her] career. Every time there is a crisis, that crisis is superimposed on longstanding structural inequities” (Vitone, 2020, p. 16).

It is vital that the important distinction between race and racism here be understood. As Vitone (2020) writes, medical education has, in recent years, increasingly included examination of social determinants of health, such as socioeconomic status and healthcare access. *Pitt Med* magazine has covered these, along with bias and race, but therein lies the problem: “We’ve called race a ‘risk factor’ and failed to fully explain that it’s inequities and discrimination—not Blackness—that cause disease. We missed the story” (Vitone, 2020, p. 16). She continues: “The point we’ve been missing—the one that should not have been such a shock to anyone—was that it wasn’t race, but racism and its legacy, that sickens, maims and kills” (Vitone, 2020, p. 16). There is nothing “inherent in Americans of color” that leads to health inequalities—instead, these inequalities “are health consequences of systemic racism’s pathways of negative impact” (Feagin & Bennefield, 2014, p. 10).

Patrice Peck (2020), writing for *The Atlantic*, says she is not among the 31% of Black Americans who personally know someone who has died of COVID-19, but she sees her loved ones, even herself, in the photographs alongside obituaries “that announce

yet another Black life lost to the coronavirus” anyway (para. 1). Like South-Paul, Peck (2020), who founded the newsletter *Coronavirus for Black Folks*, writes that she was unsurprised “that the coronavirus would disproportionately devastate our already vulnerable communities” (para. 3). “As the death toll crept up and up, the brutality of American racism became even clearer,” Peck (2020) says (para. 3). She continues:

Black people with clear symptoms of COVID-19 were turned away from receiving tests, sometimes on multiple occasions, only to die at home. Black families were entirely destroyed as members died within weeks and days of one another. By the end of July, twice as many Black children as white children had died of COVID-19: In Michigan, the first child to die from the virus was a 5-year-old Black girl who spent two weeks on a ventilator. (Peck, 2020, para. 3).

Again echoing South-Paul and Vitone (2020), Peck (2020) explains that although many Americans are able to stay at home, “Black people are disproportionately essential workers, who have no choice but to brave the pandemic and head to work” (para. 4).

Still, it is not uncommon to see literature implying that “unmeasured genetic or biological factors may account for racial differences in health outcomes,” even though these unsubstantiated theories have long been refuted and disproven (Boyd et al., 2020, para. 7). There are also assertions that mistrust on the part of the patient causes racial disparities in health care; however, “any mistrust Black patients may harbor toward the US health care system is a result of their never-ending mistreatment, not the cause of it” (Boyd et al., 2020, para. 8). Solutions can emerge only when racism itself is positioned “as a potential driver of the inequity” (Boyd et al., 2020, para. 9) and when color is seen,

in contrast to the supposed ideal of a “postracial” society (Evans et al., 2020, p. 274).

Evans et al. (2020) state,

By looking through a racially impervious lens, clinicians neglect the life experiences and historical inequities that shape patients and disease processes.

They may inadvertently feed the robust structural racism that influences access to care, quality of care, and reluctant health disparities. (p. 274)

“Even the simplest efforts” are overlooked, Evans et al. (2020) write. It is well known by now that COVID-19 disproportionately affects Black individuals, yet “when physicians describing its manifestations have presented images of dermatologic effects, black skin has not been included. The ‘Covid toes’ have all been pink and white” (Evans et al., 2020, p. 274). Twitter user @DaniAtomicus, on December 14, 2020, wrote of a similar experience:

My family has COVID & the health authority told my mom that if her lips turn blue to go to the hospital. She’s Black. Her lips will not turn blue. This is how public health sets us up for poor health outcomes + nudges us towards death by operating with whiteness as the norm.

A New England Journal of Medicine letter to the editor by Sjoding et al. (2020) published in December 2020 reports findings that in people with dark skin, pulse oximeters—which are clipped onto a fingertip to measure blood oxygen by shining light through the finger and are used to indicate whether a patient requires urgent medical care—can provide misleading results in more than 1 in 10 individuals (Rabin, 2020). They were more than three times more likely to give such readings in people with dark skin (Rabin, 2020), again demonstrating the way in which White skin, in medicine and elsewhere, is often

unthinkingly the default, the standard. During the COVID-19 pandemic, providers have encouraged patients with COVID-19 to use pulse oximeters to monitor their oxygen levels at home when they are deemed not ill enough to require hospitalization; even a small difference in pulse oximetry values could be meaningful, the difference between serious illness and not (Rabin, 2020).

There is also the case of Susan Moore, a Black physician who posted a video to Facebook on December 4, 2020, from a suburban Indianapolis hospital, saying that she had been mistreated while receiving treatment for COVID-19 (Eligon, 2020). In the video, Moore reports that a White doctor had downplayed her reports of pain and said he felt uncomfortable giving her more narcotic pain medication; Moore said she was “crushed” and that the doctor made her feel like she was “a drug addict” instead of a medical provider herself (Eligon, 2020, para. 3). Although Moore states in the video, which has circulated on social media, that she advocated for herself with hospital staff, knowing what to ask for with her knowledge of medical terminology and treatment protocols, it was not enough: “I put forth and maintain if I was White, I wouldn’t have to go through that” (Eligon, 2020, para. 5). Moore, who received a positive test result on November 29, died less than one month later, on December 20, from coronavirus complications at age 52 years (Eligon, 2020). “This is how Black people get killed,” Moore says in the video. “When you send them home and they don’t know how to fight for themselves.” Twitter user @privatedutysw, responding to @AutismDrMom’s December 22 tweets about how Moore’s “symptoms were ignored, downplayed and dismissed,” wrote, “Being black and female while sick. Double discrimination.”

Despite all this, or perhaps because of it, according to a Kaiser Family Foundation study, 35% of Black adults reported that they definitely or probably would not get vaccinated; about half of these Black adults stated that they do not trust vaccines in general or that they are concerned that they may get COVID-19 from the vaccine (Hamel et al., 2020). Peck (2020) explains it this way: “A long-standing mistrust in America’s predominantly white medical institutions is only deepening, and so the number of Black lives lost to this virus will continue to rise, even though we now have a way to end it” (para. 5). (It is important to note, though, that other research, including an NPR/PBS NewsHour/Marist survey, has found little difference in vaccine hesitancy among White and Black Americans—among those who responded to the March 2021 NPR/PBS NewsHour/Marist survey, 73% of Black individuals and 70% of White individuals reported that they had either planned to get a coronavirus vaccine or had done so already; 25% of Black respondents and 28% of White respondents said they did not plan to get the vaccine. In that same survey, Latino respondents were slightly more likely to report that they would not get vaccinated [37%], compared to 63% who either had already been vaccinated or intended to get a vaccine [Summers, 2021].)

There is hope, though: In mid-December 2020, Sandra Lindsay, a Jamaican-born nurse in New York, became the first person to be vaccinated for the novel coronavirus in the United States. She was vaccinated by another Black woman. In an interview with *The New York Times*, Lindsay said she was driven to volunteer by “lingering skepticism about the vaccine, even among some on her own staff” (Otterman, 2020, para. 2). Lindsay “wanted to lead by example — particularly as a Black woman who understands the legacy of unequal and racist medical treatment and experimentation on people of color”

(Otterman, 2020, para. 2). Her goal, she said, was “[n]ot to be the first one to take the vaccine, but to inspire people who look like me, who are skeptical in general about taking vaccines” (Otterman, 2020, para. 3).

If anything is to change, there must be a major “step away from dominant white racial framing” and a *learning* of “counter-framing from Americans of color” (Feagin & Bennefield, 2014, p. 13). Evans et al. (2020), in their *New England Journal of Medicine* editorial on the diagnosis and treatment of systemic racism, urge providers to recognize racism as a vital sign, alongside things like blood pressure, pulse, and temperature that offer key information about a patient. Looking at the current historical moment, in which the COVID-19 pandemic is transforming medicine, Evans et al. (2020) recognize that this may also be an opportunity to reset and reimagine the patient–provider relationship, including the communication and interactions that occur therein. They write,

We can become more conscious of our biases when we care for minority patients and push ourselves to go the extra mile. Even if we can’t change the social determinants of health for any individual patient in any given encounter, we can think more seriously about how they affect what the patient can and can’t do, tailor the patient’s care accordingly, and show that we’re invested. (Evans et al., 2020, p. 275)

This reconception of health care should provide health equity, not inequity, for all, regardless of gender, race or ethnicity, or other factors. Even such a fundamental, systemic transformation has the potential to begin at a small, individual level, such as within the context of the patient–provider relationship and the communication that helps to build it.

The Culture-Centered Approach to Health Communication: Application and Implications for Practice

Mohan Dutta, Dean's Chair in Communication and director of the Center for Culture-Centered Approach to Research and Evaluation (CARE) at Massey University in New Zealand, is one scholar whose work examines issues of social justice in relation to health care, including marginalization and inequalities within health care. Dutta is particularly known for his research on the culture-centered approach (CCA) to health communication, which looks at the ways in which individuals co-construct cultural meanings when they interact with the structures surrounding their lives; such co-constructions of meaning allow "participants [to] discuss possibilities of resisting a healthcare system that continues to locate them at the peripheries of the mainstream, and [to] co-create narratives of social change that transform the silences carried out by mainstream structures of knowledge production" (Massey University, n.d., para. 4).

Using the CCA in his research, Dutta interrogates the interactions existing among structure, culture, and agency in co-creating "transformative practices for challenging marginalizing communication practices in healthcare settings," with the goals of understanding "the location of communication within the complex interplay of structure and culture," "the ways in which individual and collective agencies are enacted within and in resistance to structural constraints," and "the interactions of human agency and communicative processes in bringing about social change and structural transformation" (Massey University, n.d., para. 5). Through Dutta's work, it is revealed how "communication structures, practices, and messages participate in the marginalization of certain sectors of the population, and draw attention to the processes through which these

silencing structures are resisted by those that are typically disenfranchised” (Massey University, n.d., para. 5).

Dutta’s work, by emphasizing participatory communication strategies, helps to create space and spaces “for listening to those voices that have historically been rendered silent by . . . institutional practices” (Massey University, n.d., para. 5). The CCA, for example, combines “postcolonial deconstruction, resistive strategies for performance and dialogue-based reflexive participation” in an attempt “to create entry points for listening to the voices of marginalized communities that have historically been stripped of agency in modernization discourse and constructed as recipients of messages of development targeted by experts” (Dutta, n.d., para. 4). At the heart of Dutta’s work is the decentering of hegemonic constructions of knowledge via the participation of those existing outside of the mainstream.

In *Communicating Health: A Culture-Centered Approach*, Dutta (2008) explains that meanings related to health and illness are diverse, constituted in various ways by different cultures and societies. The once-dominant biomedical model of health care, as was discussed in Chapter 1 of this work, has, in many ways, fractured, destroying with it other “grand narratives of health” (Dutta, 2008, p. 1). At the same time, awareness has increased regarding other interpretations, or narratives, of health, often guided by one’s membership in a given cultural group or society, and the need to open up the realm of health to these other voices.

To Dutta (2008), much of “how and what we communicate about health is embedded in our taken-for-granted assumptions about what it means to be healthy, what it means to be ill, and how we approach disease and illness” (p. 2). This narrative ground

makes up, in no small part, the dominant communication ethic that guides communication between patient and provider in the healthcare setting, consequently determining the goods to be protected and promoted, the purpose—or the “why”—of such communication, and the application—or the “how”—of such communication. As has been demonstrated in the current chapter, although this communication ethic may be serving many patients, it certainly is not—and should not be taken as—a one-size-fits-all approach in the current historical moment.

The CCA, as elucidated by Dutta (2008), offers a contrasting approach. It exists in opposition to the biomedical model, which has been “widely circulated” but understands health as “a universal concept based on *Eurocentric* understandings of health, disease and its treatment” (Dutta, 2008, p. 2). The biomedical model promotes one particular understanding of health that is “built upon a *Eurocentric ideology* that privileges certain assumptions about health and downplays other approaches” (Dutta, 2008, p. 2). The CCA offers a criticism of this and provides openings for the engagement of culture within health in ways that “are meaningful to the experiences of cultural communities hitherto marginalized” and “creates openings for alternative ways of knowing” (Dutta, 2008, p. 2). In other words, the CCA becomes “an alternative lens for understanding health communication” and, by extension, health (Dutta, 2008, p. 2).

The main idea of the CCA is that it is value-centered, “built on the notion that the various ways of understanding and negotiating the meanings of health are embedded within cultural contexts and the values deeply connected with them” (Dutta, 2008, p. 3). Such values, or goods, reveal knowledge and ways of knowing; the CCA brings them to light. Further, the CCA flips the biomedical model on its head by also questioning the

values that underlie it; it interrogates the “hidden agendas embedded in the top-down frameworks underlying health communication” and provides “a critical entry point for interrogating them” (Dutta, 2008, p. 3). As this occurs, emphasis is placed on the voices of communities that have been marginalized, and these voices are foregrounded, rather than silenced.

More specifically, the CCA looks to understand the health meanings and experiences of those who have experienced marginalization at the hands of health care. The structure of the CCA involves three concepts—structure, culture, and agency—and the interactions that occur among them. As Dutta (2008) explains,

The intersection of structure, culture, and agency creates openings for listening to the voices of marginalized communities, constructing discursive spaces which interrogate the erasures in marginalized settings and offer opportunities for co-constructing the voices of those who have traditionally been silenced by engaging them in dialogue. (p. 5)

According to Dutta (2008), structure here involves aspects of social organization both constraining and enabling individuals “to seek out health choices and engage in health-related behaviors,” such as medical services and transportation services, but also refers to “the ways the healthcare system is organized and its services are delivered, and to the organization of healthcare organizations” (p. 6). Structure limits opportunities for obtaining health care in that it determines healthcare choices that are available to certain populations; however, it also presents opportunities for change in challenging the frameworks that construct health.

Culture describes “the local contexts within which health meanings are constituted and negotiated” (Dutta, 2008, p. 7). To Dutta (2008), culture offers the “communicative framework for health meanings,” in that members of a given population develop understandings of health based on cultural beliefs, values, and practices. In other words, culture offers the narrative, or the story, that guides a population’s conceptions of health. Of course, these cultural beliefs, values, and practices—goods—are contextual, with meanings of health localized within these contexts. In addition, culture is dynamic, with ever-shifting meanings. According to Dutta (2008), “Culture is constituted by the day-to-day practices of its members as they come to develop their interpretations of health and illness and to engage in these day-to-day practices,” with cultural meanings supplying “the locally situated scripts through which structures influence the health choices of cultural participants” (p. 7).

Agency, then, is the ability of members “to enact their choices and to participate actively in negotiating the structures within which they find themselves” (Dutta, 2008, p. 7). In addition, agency reveals “the active processes through which individuals, groups, and communities participate in a variety of actions which directly challenge the structures that constrain their lives, and, simultaneously, work with the structures in finding healthful options” (Dutta, 2008, p. 7). Agency is where a given community becomes “an entry point for the articulation of knowledge” (Dutta, 2008, p. 7).

The intersections among these concepts are manifold. For example, structures become meaningful through the things that comprise a culture, like rituals, codes, and beliefs; agency is also performed through the presentation of the narratives and symbols of a given culture. Furthermore, meanings emerge where these three concepts collide, and

it is within these intersections that “the structures of oppression and inequality” can be challenged (Dutta, 2012, p. 13). Again, among the contributions of the CCA are its attempts to use listening as a tool for recognizing marginalized voices and to foster spaces within mainstream public spheres that these voices may be represented. Relatedly, the tool of listening opens up space for alternative meanings coming both from and with the margins.

As has been shown in the current chapter via a review of the literature concerning the experiences of individuals whose gender or race and ethnicity played a role in the health care they received, health care—and the communication that occurs between patient and provider in that context—is not equal for all. Much of the problem here can be traced to those taken-for-granted assumptions about health that not all individuals share. The CCA helps to illuminate the significance of culture to understandings of health, for example, and offers solutions for moving forward, including the decolonization and decentering of dominant perspectives.

In many ways, the CCA offers necessary revisions to the contemporary communication ethic of patient–provider communication that occasionally fails to consider the multiplicity of perspectives—the multiple views of the good—that exist in the current historical moment. Although responsiveness is a key tenet of healthcare communication ethics, as articulated by Arnett et al. (2018), it must be taken a step further to recognize the potential contributions of the patient and their culture; ultimately, the improved communication ethic driving patient–provider communication should be one that looks to the culture of patients to determine what new goods are coming into play, being both protected and promoted, as well as what existing goods are being

reinterpreted, for example. This can be observed in this chapter in the discussion of healthcare experiences related to gender and to race and ethnicity; emerging from those experiences are varying conceptions of what constitutes health and health care, and even desirable (and undesirable) communication in the patient–provider context.

Providers must first acknowledge that the healthcare experience is not the same for all—and, perhaps, nor should it be. The CCA recognizes the differences existing among cultures and societies, and in postmodernity, it is vitally important that we learn from these differences (Arnett et al., 2018). Further, the current historical moment benefits from these multiple perspectives and understandings, which further enrich the extant narrative ground. This historical moment is rich with voices and perspectives, many of which have long been marginalized and suppressed. Providers must also be willing to reexamine and reimagine the understandings that have long dominated within the field, which, consciously or not, influence the communication ethic that lies behind their communication with individuals in the healthcare setting. Listening and learning are imperative if change, including a more democratic understanding and ownership of health, is to follow.

The University of Pittsburgh School of Medicine Class of 2024 has the right idea (Pittwire, 2020). Instead of merely reciting the Hippocratic oath, as is tradition during the School of Medicine’s White Coat Ceremony for incoming medical students, the Class of 2024 was tasked with “writing their own class oath to acknowledge their ever-evolving responsibilities as physicians” (Pittwire, 2020, para. 2). Their oath recognizes issues facing them as they embark on their medical journey: COVID-19, healthcare disparities, racial injustice. A key line reads, “I will care for my patients’ holistic well-being, not

solely their pathology. With empathy, compassion and humility, I will prioritize understanding each patient’s narrative, background and experiences while protecting privacy and autonomy” (Pittwire, 2020, para. 19). Recognition of the individual patient and their “narrative, background and experiences” is an important first step in making sure that patients feel heard in conversations with their providers and that they have the right to participate in their own health care, which should be a key aspect of the communication ethic driving patient–provider communication. With this in mind, the next chapter of this project will examine the integration of technology into health care, which both facilitates and hinders that communication.

Chapter 4: The Confluence of Technology and Medicine

While the preceding chapter, Chapter 3, discussed questions of social justice, particularly those regarding gender and race, and brought into focus how these matters are calling normal or dominant understandings of the communication ethic that underlies the patient–provider relationship into question, Chapter 4 further adds another layer of complexity to this relationship between the patient and their provider in its examination of the integration of technology into health care. This chapter is central, vital even, to the issues that this project seeks to examine, namely how changes in technology affect the contemporary practice of healthcare communication, especially that which occurs between the patient and their provider, and the contemporary communication ethic of patient–provider communication. Much like the issues of social justice taken up in Chapter 3, technology has led to a reckoning within health care that includes questions surrounding how medical care is provided, as well as by and for whom.

As will be explored throughout this chapter, the realm of medicine is no stranger to technological development and its continued integration into the provision of medical care. However, it is important to acknowledge that there are certain characteristics of the current historical moment that make this conversation especially timely and relevant. For instance, as Eric Topol (2015) writes in *The Patient Will See You Now: The Future of Medicine Is in Your Hands*, the current era of medicine—and, one could argue, culture and society in general—is defined and “powered by unplugged digitization” (p. 4). Even prior to the COVID-19 pandemic, there was a move (a slow one in some cases, but a move nonetheless) toward digitization in medicine, observed in everything from the implementation and integration of a third party, the electronic health record (EHR), into

the traditionally dyadic patient–provider relationship to the availability of virtual healthcare visits, which could supplement or even replace in-person, face-to-face encounters.

Chapter 1 noted many of the changes rapidly brought upon by the COVID-19 pandemic, including the drastic expansion (and coverage) of telehealth services, which will be a focus of the current chapter. In this way, the long-heralded digitization of health care is coming to fruition, with more individuals than ever before realizing its benefits, in theory at least. However, as was revealed in Chapter 3, despite what might be an expansion in access to such services, barriers and burdens that extend much deeper remain. The current chapter will thus attempt to grapple with how technology is bringing about a restructuring of the patient–provider relationship and the communication occurring therein, including how the patient is now equipped with the means to become a more active, willing participant in their own health care, but also perpetuating existing barriers within health care and creating additional ones. As previously noted, this also has implications for the communication ethic underlying patient–provider communication.

Chapter 4 will begin with an exploration of technology and medicine on the whole, including how within medicine there is a long history of technological invention, implementation, and use. Next, the chapter will move to an examination of more recent technologies and how they have shaped the realm of health care, including a zeroing in on the COVID-19 era and the role of technology in continuing healthcare services, via telehealth, even during a pandemic. Finally, the chapter will conclude with a look ahead, to possibilities for the future. Although technology has shown much promise in conjunction with medicine, especially during the current historical moment in which it

has helped to remove some barriers and burdens to healthcare access, challenges remain before its potential as a tool for equality and empowerment can be fully realized.

A Brief and Selective Overview of Technology in Medicine

As stated previously, there is certainly a lengthy history of technological invention, implementation, and use within the realm of medicine. Thinking even of the past several decades, it is clear that medical technology has both come a long way and become even further integrated into the practice of medicine—and, in some instances, into the once strictly dyadic patient–provider relationship. Technology has transformed medicine, with techniques, practices, and procedures scarcely imagined at one time now routine and commonplace. Because of digital technologies in particular, developments in medicine are multiplying and emerging quicker than ever. The relationship of technology with medicine is dynamic, influencing and shaping “modern medical science on the basis of new technical possibilities” (Kramme & Kramme, 2011, p. 3).

Consider technologies like computed tomography, magnetic resonance imaging, and ultrasound that produce images of the inside of the body (Brodsky, 2010). Or 3D printing, which can quickly and cheaply create everything from medical equipment, to implants, to prosthetic parts, to biomaterials (Medical Futurist, 2017). Take, too, robotic surgery, which allows surgeons to perform complex, highly difficult procedures with greater precision and control (Ellis, 2019). There’s also the shift to precision medicine, aided by technology, in which health care is able to become more and more personalized to the individual patient; for example, within cancer care, specific information can be used about a patient’s tumor to aid in diagnosis, treatment planning, prognosis, and surveillance throughout the cancer trajectory (Brant & Mayer, 2017). And, as mentioned

earlier in this work, there are also ways in which technology is helping to put more control into patients' hands—wearable health devices, often tied to a smartphone, can be used to track steps taken in a day, patterns of sleep, heartbeats and rhythms, and more (Ellis, 2019).

In many ways, though, this is just the beginning—as Ira Brodsky (2010) writes in his *The History and Future of Medical Technology*, “the era of life saving and enhancing medical technology is just getting started” (p. 1). This hopeful sentiment rings true, particularly at the time of this writing, when although the COVID-19 pandemic continues to rage in countries across the world, and especially in the United States, massive advances in treatment have been made—which is remarkable in the context of a virus first observed barely a year ago—and multiple vaccines with high levels of effectiveness have been approved and have begun to be distributed. Also emerging from the COVID-19 pandemic is the expansion and increased use of telehealth services, a change that undoubtedly will persist postpandemic as well.

Still, medical technology is valuable only if the benefits outweigh the costs (Cutler & McClellan, 2001). With medical technology in particular, there is the oft-repeated concern that it has or will lead to the dehumanization of health care, for one (Booth, 1985). This is not by any means a new argument, however, as will be further discussed later in this chapter. Importantly, it is possible to trace the intertwining of medicine and technology all the way back to the earliest days of medical practice. Technologies and tools have always been a part of medicine. Acupuncture needles have been used in Far Eastern medicine since 2500 BC, and Hippocrates, a prominent physician of classical Greece who is today widely considered to be the father of scientific

medicine, used a proctoscope, a hollow tube used to inspect the intestines, and provided descriptions of numerous instruments employed to treat wounds. Further, evidence from ancient Rome has revealed rather sophisticated surgical devices and instruments; glasses were invented near the end of the 13th century (Kramme & Kramme, 2011).

It was in the 19th century, though, that one of the most dramatic breakthroughs in the history of medicine occurred, with important and lasting implications: the invention of the stethoscope. Invented in 1816 by French doctor René Laennec, the stethoscope allowed physicians to identify chest diseases that had previously been concealed (FitzGerald, 2017; Postman, 1993). Prior to its invention, what was happening inside of the patient's body was essentially unknowable; a physician could check the patient's pulse, examine them by touch, or ask for a self-report of their symptoms, but those practices certainly had their limitations, and "[t]he living body [was] like a black box that [could not] be opened" (FitzGerald, 2017, para. 1).

As we know today, though, the stethoscope allows access into that black box, giving providers a way to "clearly hear what [is] happening inside the body. The heart, the lungs, the breath" (FitzGerald, 2017, para. 3). It was inspired by a technique known as percussion, "in which doctors tap their fingers against a patient's chest and listen to the sound to try and hear what's going on inside" (FitzGerald, 2017, para. 4). This technique had limitations, though, too. One day, inventor Laennec reportedly attempted to percuss a patient but struggled to hear anything, so he rolled up a notebook into a cylinder and put one end on the chest of the patient and the other in his ear—this was the original stethoscope, "a way to hear the inner workings of the human body" (FitzGerald, 2017,

para. 6). Later modifications included flexible tubing and the binaural stethoscope design with two earpieces, which is still used today.

Eventually, connections were made between the sounds that could be heard via the stethoscope with what was going on, anatomically speaking, in the patient's body. Driven, in part, by these findings, understandings of disease started to shift, from being centered around symptoms to focused on objective observation. Likewise, ways of thinking about disease also changed; this was a move that changed providers' dynamic with patients and gave them much more power: "Before the stethoscope, to be sick, the patient had to feel sick. After the stethoscope, it didn't matter what patients thought was wrong with them, it mattered more what the doctor found" (FitzGerald, 2017, para. 10).

Laennec, who set much of this in motion with his invention of the stethoscope, believed in the continued importance and value of patients' own accounts, "but the quest for objective information about disease was underway, and the stethoscope was just the beginning" (FitzGerald, 2017, para. 11). Even the technologies in use within health care today, like X-rays and computed tomography, "are basically trading upon the same paradigm that the stethoscope created," that is, "that doctors should be able to detect abnormalities inside the body to reach a diagnosis, regardless of how the patient is feeling" (FitzGerald, 2017, para. 11).

Of course, such technologies are undoubtedly beneficial. Imaging techniques can spot tumors before they grow. Genetic tests can signal that an individual has or is at risk of having a particular disease or condition. High blood pressure can be addressed before it leads to heart disease or stroke. Still, the paradigm that drives the contemporary approach to health care "has also pushed doctors and patients farther apart, as "[t]he

doctor is no longer in your bedroom interviewing you about every detail of your experience” (FitzGerald, 2017, para. 12).

Interestingly, many physicians and patients shunned the stethoscope when it was introduced in the 19th century. Patients were fearful of it and felt “that its presence implied imminent surgery, since, at the time, only surgeons used instruments, not physicians” (Postman, 1993, p. 98). Physicians did not want to carry it; they also did not want to be mistaken for surgeons, considered then to be “mere craftsmen” (Postman, 1993, p. 99). Most significant, though, was the concern that “interposing an instrument between patient and doctor would transform the practice of medicine,” leading to “the traditional methods of questioning patients, taking their reports seriously, and making careful observations of exterior symptoms . . . becom[ing] increasingly irrelevant” (Postman, 1993, p. 99). Physicians also were worried that with the stethoscope they “would lose their ability to conduct skillful examinations and rely more on machinery than on their own experience and insight” (Postman, 1993, p. 99).

On the whole, the impact of this instrument—the stethoscope—on the practice of medicine was so substantial that its effects were compared to those of the printing press on Western culture. Both created a revolution in their own right. The stethoscope “helped to create the objective physician, who could move away from involvement with the patient’s experiences and sensations, to a more detached relation, less with the patient but more with the sounds from within the body” (Reiser, 1978, p. 38). Furthermore, the stethoscope embodied two specific and important ideas about medicine: first, that “medicine is about disease, not the patient,” and second, that “what the patient knows is untrustworthy; what the machine knows is reliable” (Postman, 1993, p. 100). These ideas

then “were amplified with each new instrument added to the doctor’s arsenal,” like the X-ray, invented in 1895 (Postman, 1993, p. 100).

That being said, the role of the stethoscope in medicine today is particularly intriguing. With an arsenal of powerful and accurate medical technologies at their disposal, many providers have found the traditional stethoscope examination to be less critical to the diagnostic process and rely on it less. In addition, newer providers, including those in or just out of medical school, are simply less adept at using the stethoscope (FitzGerald, 2017).

Andrew Bomback, a nephrologist and faculty member at Columbia University interviewed for a *99% Invisible* podcast episode on the stethoscope, says he continues to use his stethoscope but finds that for many providers its use has “become almost a ritual more than an actual tool in terms of making a diagnosis” (FitzGerald, 2017, para. 16). Bomback notes, too, the “relatively recent fashion trend, probably borrowed from TV shows like *ER* and *Scrubs*” of providers’ wearing the stethoscope “like a shawl around the back of the neck” (FitzGerald, 2017, para. 18). Before, it was common to wear the stethoscope “dangling down the front of the shirt like a tie, which was practical” because “[i]f you needed to use it quickly you could just pop it into your ears” (FitzGerald, 2017, para. 18). Bomback says this trend “is almost a concession that it’s more a fashion accessory than actually a tool that we’re using” (FitzGerald, 2017, para. 18).

Bomback is not planning to trade in his stethoscope, however. In contrast to how some providers and patients felt at the time of its invention, Bomback says that today the stethoscope is “an important conduit to connecting with . . . patients,” as physical contact between patient and provider is becoming increasingly rare (FitzGerald, 2017, para. 19).

In addition, healthcare encounters are often short (time is money, after all), and “providers often spend much of [the] time staring at a computer screen,” even during in-person visits, as will be discussed later in this chapter (FitzGerald, 2017, para. 19).

The stethoscope, then, is a way to bring intimacy back into medicine. As Bomback states, the stethoscope continues to be a part of the examination that is “aligned with the laying on of hands,” which has long been associated with healers and the healing process (Fitzgerald, 2017, para. 20). He continues: “When we go to do the physical exam, we move away from our desk, we move away from the computer, and we stand right next to the patient and it’s a much more intimate conversation” (FitzGerald, 2017, para. 20). In this way, the stethoscope “lives on . . . to keep doctors and patients from drifting too far apart. To make sure doctors keep close to their patients, and keep listening” (FitzGerald, 2017, para. 21).

Technological Values

Today, in terms of medical technologies, accuracy is prized. Media ecologist Neil Postman, particularly in 1993’s *Technopoly: The Surrender of Culture to Technology*, has much to say about the way in which technology “imposes its values on us” and “restructures and even recreates us and our world in its own image” (van der Laan, 2004, p. 145). In *Technopoly*, Postman (1993) takes a largely negative stance on technology and its integration into contemporary life; the title of this work reflects this, too, as it is a confluence of the words “technology” and “monopoly,” referring to the overbearing role that technology plays today but also alluding to the famous board game and reflecting the way in which many current technologies are more frivolous toys than useful tools (van der Laan, 2004). Postman (1993) writes that living in Technopoly involves

the beliefs that the primary, if not the only, goal of human labor and thought is efficiency; that technical calculation is in all respects superior to human judgment; that in fact human judgment cannot be trusted, because it is plagued by laxity, ambiguity, and unnecessary complexity; that subjectivity is an obstacle to clear thinking; that what cannot be measured either does not exist or is of no value; and that the affairs of citizens are best guided and conducted by experts. (p. 51)

Further, within Technopoly, technology “has become autonomous” (van der Laan, 2004, p. 145). Humans have lost control and are controlled by technology. Technology on the whole, and certain technologies in particular, is the object of our unquestioning obsession and devotion; it has become an integral part of our daily lives, and one that we cannot imagine living without. Why would we choose otherwise, when “technology is an indisputable boon to human existence,” showering “us with countless and constant blessings” (van der Laan, 2004, p. 147)?

Postman (1993) does state that “technology is a friend” that “makes life easier, cleaner, and longer” (p. xii). He also says that technology is the very type of friend who “asks for trust and obedience, which most people are inclined to give because its gifts are truly bountiful,” but that these gifts also come with “a heavy cost” (Postman, 1993, p. xii). The cost of “the uncontrolled growth of technology” is a destruction of those “vital sources of our humanity,” with the resulting culture created being one that lacks “a moral foundation” (Postman, 1993, p. xii). Technology also has the potential to undermine “certain mental processes and social relations that make human life worth living” (Postman, 1993, p. xii). It is thus “both friend and enemy” (Postman, 1993, p. xii).

As stated previously, Postman’s views on technology, particularly in *Technopoly*, are a bit pessimistic, but it is easy to see from where his concerns stem. Keep in mind, too, that Postman was writing circa 1993, when technology had hardly become as integrated with our day-to-day lives as it is in 2021. It was a time before the smartphone, a time before a computer in most every examination room, a time before the option to meet with (and actually *see*) a provider from the comfort of your home. But even then, almost 30 years ago, Postman was aware of both the dangers and the benefits of technology. It was both a welcoming and a warning—a call to make sure that in our rush to adopt the latest and the greatest technological tools and devices (which, undoubtedly, did have their advantages) we did not lose sight of our very humanity.

This becomes especially important within the healthcare setting, and the patient–provider relationship in particular. That relationship is, after all, “the rawest, purest form of medicine” (Thornley, 2018, para. 18). In an article on *Op-Med*, which publishes pieces by members of medical professional online networking service Doximity, neurologist Virginia Thornley (2018) argues that there is much today that is “getting in the way of the genuine whole-hearted connection between patient and physician” (para. 2).

At one time, the healthcare encounter was much more straightforwardly dyadic, consisting simply of patient and physician, and with “nothing to separate the physician from caring for his patients”—not health insurance, the electronic health record, or countless other providers (Thornley, 2018, para. 4). Thornley (2018) looks back fondly on the days of doctors’ making house calls, when “[t]he relationship between a doctor and his patient was at its best and humblest — to care for the sick. Not to cure, not to treat, but to comfort always. . . . That relationship was pure and untouched” (para. 4).

Thornley (2018) identifies that this incredibly important connection is in danger, “threatened by a huge number of . . . outside forces” (para. 5), but notes a potential solution: returning “to the roots of medicine” (para. 15). Listening is key. It provides comfort, and when this is achieved, the physician has done their job, Thornley (2018) says. Thornley (2018) reports that she now sees each of her patients for longer appointments, giving them the chance to talk “until they have nothing left to say” and no further questions to ask (para. 12). She “make[s] eye contact and take[s] in everything they have to say, the furrowing of their brows, the tone of their voices, and . . . hear[s] what they are saying” (Thornley, 2018, para. 15).

From this change, a better way of practicing medicine, Thornley (2018) says her patients “are unique stories again, not templates that you copy and paste and change with a few details according to the patient” (para. 12). She urges others to do the same: to “[g]o back to the basics of communication and human connection,” as “[t]hat’s probably the reason why you entered medicine” (Thornley, 2018, para. 16). The art of listening has been lost “in the world of electronic recording, the need to generate copious amounts of data on one patient encounter, in the new team service approach” (Thornley, 2018, para. 16), and this alters (and perhaps may even extinguish) that unique, special relationship between patient and doctor. Thornley (2018) writes, “Anything that keeps you apart from your patient widens the chasm and becomes a barrier, an impediment. . . . When you strip it back down to the bare bones, you return to the rawest, purest form of medicine — the relationship between doctor and patient” (para. 18).

Keeping this human connection in mind—and preserving it—is maybe more important today than ever. However, the vast amount of technology and its complete

integration into our lives, as well as into the realm of health care, makes this also perhaps trickier than ever. Take, for example, the ubiquity of the computer in medicine. Postman (1993) devotes an entire chapter of *Technopoly* to computer technology, explaining that the computer “is the dominant metaphor of our age” and one that has led to “a new relationship to information, to work, to power, and to nature itself” (p. 111).

Further, Postman (1993) calls the American Technopoly’s adoption of the computer “hurried and mindless” but also “inevitable” and “unfortunate” (p. 107). The implications of this are significant and numerous. For example, the computer has turned humans into processors of information and the natural world into information that must be processed. Escaping this is impossible. The computer—“the quintessential, incomparable, near-perfect machine for Technopoly”—has begun its march to reduce humans to machines, claiming “sovereignty over the whole range of human experience” (Postman, 1993, p. 111). Because of the computer, humans believe that they “are [at] their best when acting like machines,” which has led to “a loss of confidence in human judgment and subjectivity” (Postman, 1993, p. 118).

What Postman (1993) says reigns supreme is “faith in the powers of technical calculation” with emphasis on “the technical processes of communication” but “very little in the way of substance” (Postman, 1993, p. 118). The computer has given us the fast, efficient acquisition and movement of information, along with its storage; consequently, we now place a premium on those who have internalized the skills needed to perform those tasks. Postman (1993) explains that Technopoly wants us to ignore the skills being replaced in the process of acquiring new ones: “It is important to remember

what can be done without computers, and it is also important to remind ourselves of what may be lost when we do use them” (p. 120).

Postman (1993) further describes one of the values of Technopoly: accuracy. He writes that “in Technopoly . . . subjective forms of knowledge have no official status, and must be confirmed by tests administered by experts. Individual judgments . . . are notoriously unreliable, filled with ambiguity and plagued by doubt. . . . Tests and machines are not” (p. 93). In Technopoly, there is no “intellectual struggle,” because “machines eliminate complexity, doubt, and ambiguity” (Postman, 1993, p. 93). In addition, “they work swiftly, they are standardized, and they provide us with numbers that you can see and calculate with” (Postman, 1993, p. 93).

It is easy to see why technology, especially computers, would thus find favor in medicine. Take, for example, the long-held American belief in technology as “the weapon with which disease and illness would be vanquished” (Postman, 1993, p. 97), as well as the characteristic aggressiveness of American medicine (Payer, 1988). After all, “American doctors want to *do* something, preferably as much as possible” (Payer, 1988, p. 124).

Many Americans do, in fact, think that more tests mean better medicine, which may be directly linked to the finding that American physicians perform more diagnostic tests than physicians in a number of other countries, like France and England (Payer, 1988; Postman, 1993). Such medical aggressiveness, along with a distrust of nature, can be connected to an aggressiveness in the American character itself, stemming from the settling of the wild and vast frontier, and can be traced to even before the American Revolution (Payer, 1988). Even today, it is obvious that this aggressive, “can-do”

approach remains in favor; it implies “that the doctor can do something for the patients” and that medicine consists of a simple identification and solving of problems (Payer, 1998, p. 131).

Enter the computer. By the dawning of the 20th century, “medicine was well on its way to almost total reliance on technology”—it had fully “entered a new stage” (Postman, 1993, p. 100). In contrast, the first stage was “characterized by direct communication with the patient’s experiences based on the patient’s reports, and the doctor’s questions and observations, whereas the second stage involved “direct communication with patients’ bodies through physical examination” (Postman, 1993, p. 100). The current stage of medicine relies on “indirect communication with the patient’s experience and body through technical machinery,” at the cost of providers losing “the skills and insights that predominated in the previous stage” (Postman, 1993, p. 101).

We are seemingly still in this stage, but with many added layers of complexity. Postman likely could not have predicted a smartphone—a computer in miniature—in almost every pocket. Of the current stage, Postman (1993) says that technology “is chang[ing] the practice of medicine by redefining what doctors are, redirecting where they focus their attention, and reconceptualizing how they view their patients and illness” (p. 105). He posits that “we may well wonder what other human skills and traditions are being lost by our immersion in a computer culture” (Postman, 1993, p. 122). The next part of this chapter will explore these and other questions by examining the integration and influence of two somewhat interrelated technological tools within medicine: the electronic health record (EHR) and telehealth.

How Technology Shapes Health Care Today

The Third Party in the Patient–Provider Dyad: The Electronic Health Record

The medical record, in one form or another, has apparently nearly always existed in medicine. This document is “a thorough record of a patient’s medical history and clinical data,” containing information including “demographics, vital signs, diagnoses, surgeries, medications, treatment plans, allergies, laboratory results, radiological studies, [and] immunization records” (CareCloud, n.d.). The medical record, in other words, gives healthcare providers an overview of a patient, medically speaking, and equips them with the information necessary to make clinical decisions.

Ancient Egyptian hieroglyphic inscriptions and papyri dating from 1,600 to 3,000 B.C. reveal the long-time use of medical records (Evans, 2016), as do early medical writings from the Hippocratic school of medicine in the fifth century B.C., which feature “systematic notes describing events in a patient’s illness” organized chronologically (“early aspects of illness precede later ones”) (Reiser, 1978, p. 205). Physicians thought to keep such records “to sustain their memory of clinical events, to teach students, and to preserve knowledge,” yet “they sometimes wrote only brief histories, or carried the facts in their heads” (Reiser, 1978, p. 205). Keeping of the medical record—also called the medical chart and the health record—was very much an imperfect and inconsistent practice.

Even into the 20th century, records kept by physicians were incomplete, if they were kept at all. Take studies of private medical practice, which “revealed that fewer than one-fifth of the physicians evaluated regularly maintained complete records of the patients’ symptoms and illness, diagnosis, and therapy” (Reiser, 1978, p. 205). Record

keeping in hospitals was apparently just as irregular, with the records that were taken “stored . . . in bundles” with “only the better institutions . . . b[inding] them in volumes and order[ing] them chronologically” (Reiser, 1978, p. 206). Paper medical records, written on paper and maintained in folders divided into various sections depending on the type of note recorded, did not become steadily used until 1900–1920 (Evans, 2016), and it was not until 1915 that a push for standardization of the medical record emerged. At this time, recommendations consisted of the standardization of data collection itself and the creation of a single unified record for each patient.

There were problems inherent in this method, including the fact that just one copy of a given patient’s medical record was available. Records could easily be misplaced or lost. New computer technology emerging in the 1960s and 1970s offered one solution, laying the groundwork for what today is known as the EHR. In the late 1980s and early 1990s in particular, a number of technological innovations opened the door to the possibility of the EHR:

[H]ardware become more affordable, powerful, and compact and the use of personal computers, local area networks, and the Internet provided faster and easier access to medical information and initiated the use of web-based EHRs. The personal computer provided a mouse interface which made use easier with pull-down menus, pop-up lists, buttons, multi-page forms, and scrolling fields. Other features included help screens, control functions, audit trails, and export of data to statistical packages for analyses. An initial obstacle for EHR ease of use was the need for portable computers and soon computers were being classified as laptop, palmtop, notebook, and pen-based. (Evans, 2016, p. S49)

Around this time, in 1991, the Institute of Medicine (IOM) stated in *The Computer-Based Patient Record: An Essential Technology for Health Care* that computer-based patient records and the accompanying systems “have a unique potential to improve the care of both individual patients and populations and, concurrently, to reduce waste through continuous quality improvement” (Dick et al., 1997, p. xi). The IOM, among others, realized the increasingly apparent inadequacies of the paper medical record and pushed for a shift from the paper-based record to the EHR (Evans, 2016).

Initially, benefits from the move from the paper record to the EHR could be seen in time saved with the elimination of “filing and retrieval of charts, photocopying, and chart location control” (Evans, 2016, p. S49). In terms of clinical use, the so-termed “physician workstation” consisted of “personal computers integrated with EHRs that allowed access to physician notes, orders, consults, laboratory reports, radiological studies, direct patient measurements, nursing assessments and notes, and patient care procedures,” along with tools like drug references, clinical manuals, and medical textbooks (Evans, 2016, p. S49). Even so, many physicians, although they began to use electronic documentation, did not believe that it saved time; they did appreciate its administrative functions and the ability to produce printouts, though. Patient and hospital costs also were reduced, but the EHR and its systems required more time of physicians than paper-based records.

Today, use of the EHR “has not only made patients’ medical information easier to read and available from almost any location in the world, but also changed the format of health records, and thus changed health care” (Evans, 2016, p. S48). Most would agree that the EHR, “the digital version of a person’s medical history,” is “essential to

providing optimal health care throughout the U.S.,” but a complete move to and wholehearted adoption of the EHR is, in some ways, still very much incomplete (Badalucco, 2015, para. 4).

Initially, the widespread use of EHRs was delayed by a number of factors, including high costs, errors in data entry, poor physician acceptance (especially at first), and lack of any true incentive to make the change (Evans, 2016). Furthermore, the goal to replace the paper record in its entirety with an electronic record was seen as problematic, mostly because of cost; this led to the suggestion that only key data be computerized, which made the EHR ancillary to the paper record, not its replacement. Still others felt that the cost and effort to implement the EHR in some settings would not be balanced by any efficiency gains, as well as that paper records were simply more efficient (Evans, 2016).

There is also the fact that literal life and death are tied up with the EHR. As Chuck Christian, then-board chair of the College of Healthcare Information Management Executives, was quoted as saying in a *U.S. News and World Report* article, “If an ATM puts somebody else’s money in your account, nobody dies. But if we mess something up, it could very well impact someone’s life” (Badalucco, 2015, para. 3). Christian continued, saying, “We are doing a heart transplant on a marathon runner while he is still in the race,” in reference to “the rapid rate of change” from a paper-based system to an electronic one (Badalucco, 2015, para. 5).

The government has also become involved in an attempt to further accelerate the pace. For example, the American Recovery and Reinvestment Act of 2009 aimed to expend billions of dollars over a decadelong period to support the adoption of EHRs; it

was “the first substantial commitment of federal resources to support adoption and help providers identify the key functions that will support improved care delivery” (Centers for Medicare and Medicaid Services, 2010, para. 2). As part of the Health Information Technology for Economic and Clinical Health Act, federal incentive payments were available to providers and institutions when EHRs were adopted and when their use was demonstrated in ways improving the quality, safety, and effectiveness of care.

A press release describing this plan explained that EHRs improve care in part because they enable “functions that paper records cannot deliver” (Centers for Medicare and Medicaid Services, 2010, para. 6). For example, EHRs “can make a patient’s health information available when and where it is needed”; “can bring a patient’s total health information together in one place, and always be current”; and “can reduce costs through reduced paperwork, improved safety, reduced duplication of testing, and most of all improved health through the delivery of more effective health care” (Centers for Medicare and Medicaid Services, 2010, para. 7).

Importantly, one condition of this federal funding was that of meaningful use. According to the press release, the simple transfer of information from a paper record to an electronic record was not sufficient, as “EHRs can only deliver their benefits when the information and the EHR are standardized and ‘structured’ in uniform ways” (Centers for Medicare and Medicaid Services, 2010, para. 8). Standards for EHR systems needed to be identified.

Another goal of meaningful use was involving patients in the process, such as by their accessing a portal—where they could make appointments, fill prescriptions, and communicate with providers—after a healthcare encounter. Providers reported that it was

sometimes difficult to encourage patients to use the portal and, relatedly, to meet the government's quota for patient use of the portal (Badalucco, 2015). One contributing factor to the lack of use identified was the lack of user-friendliness of the technology, for both patients and providers. There are drop-down menus and long lines of text that make the process tedious; the resulting documents can be lengthy and even overwhelming (Badalucco, 2015).

There have certainly been challenges in the move away from paper-based medical records and the related "paradigms that had remained largely unchanged for a century" (Liebman et al., 2018, p. 331). This move to bring medicine into the digital space was guided by a vision of the future in which "health care could enter the burgeoning information age, revolutionizing not only medical office record keeping, but also the entire ecosystem through which health care providers would access, synthesize, and internalize an ever-expanding body of medical knowledge" (Liebman et al., 2018, p. 331).

It is an attempt that has, on the whole, succeeded. EHRs and their corresponding computer-based platforms are ubiquitous within the U.S. healthcare system, including in hospitals and primary care practices as well as specialty practices. Further, "EHR records are now being created, used, edited, and viewed by multiple independent entities," including physicians, patients, and insurance companies, and they are "increasingly being used in primary-care rooms to document and access patients' records along with online medical information and decision-making tools, and prescribe medications" (Evans, 2016, p. S51).

Benefits of the EHR include quick and easy access to pertinent medical or scientific information; more efficient medical record management; follow-up planning for preventive medicine, chronic disease management, and immunization; better adherence to guidelines; prevention of medical errors; and facilitation of communication between those within the healthcare system and patients. However, despite large-scale adoption of the EHR, “a cursory examination of the medical literature and blogosphere—or a walk through any clinic or medical ward—quickly reveals a litany of frustrations and deep concerns about the impact of digital medicine” (Liebman et al., 2018, p. 331).

A primary problem with the EHR relates to its purpose and its use in practice: Although providers were lured in “with promises of curated data and coordinated care,” what has materialized are “impersonal and unintuitive platforms that seem to have been designed for billing and compliance rather than clinical care: in other words, death by a thousand keystrokes and checkboxes” (Liebman et al., 2018, p. 331). The promised “bright technomedical future envisioned . . . has yet to truly materialize,” while the resulting “journey has left many in the medical profession feeling coerced, discouraged, and in jeopardy of permanent damage to the doctor–patient relationship” (Liebman et al., 2018, p. 331). For many of these reasons, instead of enhancing the clinical practice of providers, EHRs have been blamed as a primary source of provider burnout. The EHR, as it exists today, has a number of design flaws and inefficiencies, and it is largely “unintuitive, time intensive, and siloed” (Liebman et al., 2018, p. 331).

Especially important here is that the EHR has significantly “changed the dynamics of the patient-clinician interaction through clinician-patient email, virtual consults, and telemedicine” (Evans, 2016, p. S51), in addition to the fact that the EHR

has pulled a third party into the traditional dyadic patient–provider relationship: the computer. By its very nature, the EHR requires provider use of a computer during patient interactions; this has been a sticking point for many at the same time that it has been a boon to others.

Even decades ago, in the 1960s and 1970s, when what we know today as the EHR was barely an idea and when computer integration into medical practice began to inch closer to reality, this ambivalence could be seen: “Many physicians who resisted computers feared that the machines might push them even farther away from an interest in human relationships, and convert them to analysts who cared more about measuring than understanding patients” (Reiser, 1978, p. 223). In addition, “this possibility deeply troubled those physicians who were convinced that only by preserving a deep interest in their patients as persons could they retain mastery of their medical art,” as well as caused some providers to feel anxious over the possibility that they too could “become machinelike” and automated (Reiser, 1978, p. 223).

The literature reveals that some of these concerns still persist. For instance, Rathert et al. (2017) write that although “EHRs generally improve the accuracy, organization, and presentation of biomedical data by prompting its gathering, sharing, and reporting,” they are also responsible for “new problems,” despite being touted as one way within health care to save time (p. 52). As Rathert et al. (2017) observe, “even very simple tasks can require physicians to scroll through numerous menus, pages, and long lists during patient encounters, which diverts attention from the patient to the computer for significant periods of time” (Rathert et al., 2017, p. 52). In addition, the EHR’s “built-in templates, pre-populated data fields, copy-and-paste features, and checklists that

automatically generate written summaries . . . create new opportunities for errors and ethical dilemmas,” and they force providers to ask questions and engage in conversations with patients based on the EHR, rather than “on their expertise and experience” (Rathert et al., 2017, p. 52).

Relatedly, in an invited commentary for *JAMA Internal Medicine*, Richard M. Frankel (2016), a professor of medicine at the Indiana University School of Medicine, makes reference to “a timeless principle of medical care: the importance of direct contact in the process of providing care” (p. 128). Frankel (2016) mentions the stethoscope, itself a medical technology, saying that it “came to mediate the relationship between physicians and their patients” and that the ways in which technology comes into play in contemporary medical practice are many (p. 128).

More specifically, he mentions the examination room computer, noting its benefits and drawbacks, and offers up the mnemonic POISED (prepare, orient, information gathering, share, educate, debrief) “as a memory aid for developing and reinforcing good computer use habits” (Frankel, 2016, p. 129). Furthermore, Frankel (2016) insists that “medicine is fundamentally a human enterprise that is still practiced one conversation at a time” (p. 129). The challenge today involves finding “the best ways to incorporate computers in the examination room without losing the heart and soul of medicine: the physician-patient relationship” (Frankel, 2016, p. 129).

Frankel’s (2016) take is representative of much of the current literature on the EHR. There are obvious advantages to the EHR but also just as significant disadvantages, particularly in regard to the impact of the EHR on communication between patient and provider. Findings from studies that have examined the EHR’s impact on patient–

provider communication are diverse. For one, nonverbal communication, which is thought to be just as important as verbal communication in patient–provider encounters, is affected by the EHR: Computer use related to the EHR results in decreased eye contact and less attention paid to the patient, as demonstrated by changes in provider gaze and body positioning (Asan et al., 2015).

Asan et al. (2016) note that alongside the “promised benefits” of the EHR, like improved quality, safety, decision-making, information exchange, and efficiency, is the glaring presence of a computer in the examination room; the act of EHR documentation itself can negatively influence patient–provider communication, the rapport that is developed with patients, and psychological and emotional talk (p. 1). Still, even though some patients interviewed in the study by Asan et al. (2016) reported that their provider may have paid less attention to them because they were instead focused on the computer, they appreciated that the EHR offered access to all their medical records and data, storing it in a single location for later retrieval by their providers (perhaps in different medical centers and doctors’ offices) or themselves.

However, Ratanawongsa et al. (2016) issue the warning that the EHR may inhibit patient–provider communication, finding that high levels of computer use by providers were connected to lower patient satisfaction and obvious differences in communication. Although providers tended to employ more “social rapport-building,” which can help to establish trust and increase satisfaction, “concurrent computer use may inhibit authentic engagement, and multi-tasking clinicians may miss openings for deeper connection” (Ratanawongsa et al., 2016, p. 3).

As has been established so far in this project, the importance of effective patient–provider communication cannot be overstated. Sobral et al. (2015) emphasize that it becomes even more so when a “patient-centered approach” is adopted (p. 1,568). The presence of the computer in the consultation or examination room, for the purposes of the EHR, though, may be threatening to or even erode “this therapeutic relationship” (Sobral et al., 2015, p. 1,568).

Sobral et al. (2015) report that patients and providers have opposing perceptions of the impact of computer use in clinical communication: Although providers in their study, who spent 42% of the visit in contact with the computer, acknowledged that the computer was useful to gather and provide information during consultations with patients, they also said “it negatively influenced consultation length, confidentiality, and their ability to look, listen and understand the patient” (Sobral et al., 2015, p. 1,575). Patients, in contrast, found the computer to have a positive influence on communication between themselves and their provider, and viewed it “as a useful tool” to have during visits (Sobral et al., 2015, p. 1,575).

Within the literature, there certainly exist concerns related to providers “who pay more attention to the ‘iPatient’ on the computer screen than to the real patient during a clinical interaction” (Alkureishi et al., 2016, p. 548). Still, it overwhelmingly recommends adoption of the EHR as a communication tool in patient–provider interactions, albeit with the following caveat: Much work needs to be done “to better understand how to enhance patient–doctor–[electronic medical record] communication” and “provide patient-centered care in the digital age” (Alkureishi et al., 2016, p. 548).

Often emphasized is the need to “actively” use the EHR “in a more patient-centered manner,” which is representative of the central role that patients play in health care today (Alkureishi et al., 2016, p. 557). As Rathert et al. (2017) state, this recommendation is necessary “in an era when physicians are expected to be increasing the patient-centeredness of their communication and care”—they warn that “the combination of extended focus on the computer and time pressures during care encounters may cause physicians to miss subtle cues which are essential for developing trust, rapport, and optimal treatment plans” (p. 62). Rathert et al. (2017) also find that “EHR use may empower patients, and get them more involved in collaborative relationships with their physicians and engaged in their care” (p. 62).

With the EHR clearly here to stay, the literature does offer suggestions for improved use. Asan et al. (2015) note that “the potential pitfalls of EHRs can be avoided if physicians are taught how to communicate effectively with patients when using EHRs in the exam room” (p. 311). For example, Asan et al. (2015) recommend EHR “screen sharing,” which involves providers inviting patients to review the computer screen—in other words, to share healthcare information with them. According to Asan et al. (2015), “sharing a screen with a patient may help to improve real-time patient–clinician communication, facilitate more accurate documentation, aid shared decision making, increase shared understanding and patient involvement, and reduce patient alienation while a physician looks at the computer screen” (p. 311).

Based on patient interviews, Asan et al. (2016) further identified two types of screen sharing behavior: The first type featured an active invitation from the provider to “see the screen and share information from the screen,” whereas the second type

consisted of “side seeing,” which happened when patients “were not necessarily invited by doctors to share the screen, but they could still see the screen from the side and could see what the doctor was typing or doing” (p. 4). This distinction was significant to patients, with many reporting feeling more involved and engaged when the screen, with their medical information, was shared with them.

Patients said that screen sharing also acted as a reminder (for example, the EHR contains the names and reasons behind medications), provided helpful visuals, and fostered the creation of a more collaborative environment between patient and provider (Asan et al., 2016). However, there were also some downsides to screen sharing, like patients’ not understanding the information displayed on the screen unless it was explicitly interpreted for them and feeling as though their providers were frustrated when they did ask for further interpretation or information. However, when the screen was not shared at all, patients said they felt that the information belonged to providers, that more attention was paid to the EHR during the visit than to the patient, that the provider was being secretive, that the provider interacted more with the EHR than the patient, and that the patient felt like a spy, with furtive glances made toward their own medical information (Asan et al., 2016).

White and Danis (2013) report on the promise of the EHR, saying that it is capable of facilitating “patient activation, which is a characteristic of patients who view themselves as active collaborators in their own healthcare management” (p. 1). They advocate for screen sharing because such an invitation from the provider to the patient “not only avoids uncomfortable periods of idle silence that sometimes accompany EHR-

related tasks, but it may enhance the relational aspect of patient-physician communication in a way that fosters patient activation in real time” (White & Danis, 2013, p. 1).

After briefly greeting a patient before a visit, many providers make the mistake of heading directly to the computer to complete EHR-related tasks before again engaging the patient; this, White and Danis (2013) say, is a pattern of EHR use that can lead to “patient detachment rather than active involvement” (p. 1). Recommendations offered include a verbal introduction of the EHR (e.g., “If you don’t mind, I am going to be typing as you speak. I’m happy to show you what I’m writing”; “I’m going to look up your test results, would you like to look at them together?”; “Now that we’ve seen how you’re doing, let’s talk about how you can continue to improve”) and patient-centered body language; the latter might entail “positioning the screen as a bridge rather than a divider” (White & Danis, 2013, p. 1).

All of this could go a long way toward encouraging active patient involvement in the healthcare encounter. Patients who are already self-motivated and empowered in regard to their health care may view such interactions as promoting transparency and enhancing collaboration between patient and provider, whereas those who are more passive may consequently become more active participants. There are limitations to screen sharing, though; for example, it may be difficult for providers to candidly record sensitive patient issues, so “caution may be necessary when choosing how to document socially stigmatizing health conditions” (White & Danis, 2013, p. 2). White and Danis (2013) suggest that providers work to develop the needed writing skills and sensitivity to the perceptions of patients when documenting appearance, emotional state, symptoms, substance abuse, and incomplete adherence to medical regimens, among other issues, in

the EHR. Another limitation is time pressures, which may impose a limit on patient involvement with the EHR during visits; thus, screen sharing may be most feasible for providers with strong computer and typing skills. Still, based on the literature, screen sharing seems to have numerous advantages and few disadvantages.

Discussing research done on the ways in which computer use may affect the quality of patient–provider communication and relationships, Sobral et al. (2015) note that such computer use decreases the amount of information that is disclosed by the patient, as well as provider responses to patient doubts. It also increases the average time of the interview, without a corresponding increase in patient satisfaction, and is linked to reduced eye contact and psychosocial information gathering. But what is also significant is acknowledgment of the impact that placement of the computer in the consultation or examination room for the purposes of the EHR may have on communication between patient and provider.

Sobral et al. (2015) say that this placement is “critical to communication,” and identify that although no optimal placement yet exists, “it is useful if the physician and patient can both see the computer monitor” (p. 1,569). Ultimately, Sobral et al. (2015) conclude that the usual placement of computers by physicians is *not* the placement that most providers would consider to be ideal; a computer at the left-hand side of the desk that is angled toward the provider, who is seated behind the desk, and the patient, who is seated on the side of the desk (opposite from the computer screen), was reported as being more favorable to patient–physician communication by almost half of the provider participants.

They explain further: “It seems that physicians have the insight of what would be better to patient–physician communication but do not take the initiative to change the setting,” likely because “computers are located where the wiring is most physically convenient, and the clinician has little chance or motivation to change it” (Sobral et al., 2015, p. 1,575). Even if they cannot physically change the setting, there is much providers can do to promote patient-centered communication while using the EHR. Street et al. (2014) note that the educational curriculum for providers should move beyond the traditional focus on communication skills to also include EHR management skills, like keyboarding and screen sharing, “that will not impede and even facilitate the interaction with the patient” (p. 319).

Liebman et al. (2018) write that despite the challenges and deficiencies of the EHR, “the modern digital record platform is not necessarily a lemon; rather, it is a race car prototype we have yet to learn to drive beyond first gear” (p. 331). They explain that “the key mechanical ingredients to make manifest the lofty predictions of decades past” are there,” with the “remaining work . . . no longer a matter of furthering technological sophistication or accessibility, but rather of design thinking, user centricity, and moving ‘outside the box’” (Liebman et al., 2018, p. 332). Of course, Liebman et al. (2018) are speaking specifically of the EHR, but their words could just as easily be applied to another technology within health care in need of some refinement and finessing: telehealth.

The Remote, Asynchronous Delivery of Health Care: Telehealth

In a continuation of a conversation begun in Chapter 1 of this work, telehealth—also sometimes referred to as telemedicine and eHealth, among other terms—involves the

use of two-way communication technology to provide various healthcare services in real time. Although many terms exist to describe this practice of providing healthcare services not in person and with the use of technologies, and although some bodies distinguish among these terms, this work understands telehealth, telemedicine, eHealth, and the like in a similar way: All use technology in the provision of healthcare services.

With that being said, there is significant overlap between what has been reported about the EHR and what has been reported about telehealth, particularly in terms of recommendations for better, more patient-centered use. As White and Danis (2013) said of the EHR (and the related placement of the computer screen), it is possible to position “the screen as a bridge rather than a divider” (p. 1). The main difference here is that whereas with the EHR, the computer is physically in the consultation or examination room alongside the patient and physician, the third party in a once solely dyadic relationship and a witness to the communication that takes place therein—with telehealth, the computer is now the vehicle by which patient–provider communication itself occurs. With telehealth, too, the potential exists for the computer—or the smartphone, the tablet, or another device—to act more as a bridge between patient and provider, rather than a divider. Communication is key to understanding how that might happen.

The origins of telemedicine go back much further than one would expect. In *History of Telemedicine: Evolution, Context, and Transformation*, for example, Bashshur and Shannon (2009) trace telemedicine to ancient Greece, framing it as one piece of a lengthy, perhaps never-ending quest to provide equitable healthcare access and to re-form the medical landscape, all the while also ensuring quality and reining in cost. Bashshur and Shannon (2009) argue that, in this work, they are telling the “full story of

telemedicine, including its continuity in medical practice in one form or another from ancient times to the present, the enduring necessity of connectivity in the delivery of medical care, [and] the various transformations of telemedicine over the ages” (p. 4).

In their exploration of the history of telemedicine, Bashshur and Shannon (2009) point to important technologically oriented moments, like Willem Einthoven’s long distance transfer of electrocardiograms in 1905 and the groundbreaking era of teleradiology and telepsychiatry in the 1950s. They also note telemedicine’s coming of age in the 1970s, its maturation in the 1990s, and its transformation and mainstream adoption in the 2000s. But what is perhaps most important within that is “the continuing underlying theme of connectivity between those in need of care and those who provide it” (Bashshur & Shannon, 2009, p. 5). They continue: “Indeed, connectivity, in one form or another, has been a necessary component of medical care delivery throughout history. Telemedicine provided the tools for connectivity when providers and recipients of care could not be in the same place and time” (Bashshur & Shannon, 2009, p. 5).

They also, rather significantly, “place telemedicine development in its proper context,” viewing it “not simply as a technological innovation but as an effective solution to persistent problems in healthcare delivery,” such as “inequitable access to care in the population at large, uneven distribution of quality, and unabated cost inflation” (Bashshur & Shannon, 2009, p. 5). The unfailing “persistence of these problems,” they say, “has provided the strongest rationale for the development and growth of telemedicine” (Bashshur & Shannon, 2009, p. 5).

Throughout history, it is possible to see the way in which providers “tried to reach their patients through the existing methods which were acceptable at the time,” ranging

from patients being “brought to temples for spiritual healing” in ancient times to providers visiting “well-heeled patients in their homes” (Bashshur & Shannon, 2009, p. 7). Then came the movement of medical care “to clinics and medical centers because of scientific and technological advances, specialization, and increased complexity of care” (Bashshur & Shannon, 2009, p. 7). “[T]oday’s telemedicine applications and the technology in use is the culmination of a long historical process” that also has much to reveal about the current historical moment, including understandings of health care and healthcare communication, particularly that between patient and provider (Bashshur & Shannon, 2009, p. 7).

Nesbit and Katz-Bell (2018) similarly record a lengthy history of “[c]ommunications over distance for health purposes,” noting the flying of signal flags on ships and over ports to warn of contagious disease outbreaks and the practice of medical consultation via written correspondence (p. 2). They hold that the first use of electronic communication for health reasons in the United States occurred during the Civil War, with the Union Army’s use of the telegraph to communicate reports of casualties, coordinate the transport of patients, and request medical supplies. Thus, a new era of medicine was begun.

In 1925, the idea of the “radio doctor” providing distance care using audio and video” was mentioned in a *Science and Invention* magazine article, but it was just that: an idea (Nesbit & Katz-Bell, 2018, p. 3). However, the years that would follow, namely the five decades between 1940 and 1990, laid the groundwork for the “radio doctor”—and for what we understand and know as telehealth today. This period was characterized by the “conceptualization of new ideas” and the proliferation of “innovative

experimentation,” but also by the limitations of existing technology and the lack of a telecommunication infrastructure (Nesbit & Katz-Bell, 2018, p. 3). Also notable is that this period featured the invention of vocabulary still employed today; for example, in 1950, the term “telognosis” first appeared in the medical literature in reference to the 1948 transmission of radiologic images by telephone.

The 1990s, though, are seen as the “‘developmental years’ of telemedicine” (Nesbit & Katz-Bell, 2018, p. 5). According to Nesbit and Katz-Bell (2018), during this decade, “many large state and system projects emerged, telecommunications evolved to the point that it was more available and affordable, and passage of state and federal legislation propelled the field forward by recognizing telemedicine as a reimbursable mode of care provision” (p. 5). Accordingly, the 2000s were marked “by a maturation of the field in both outpatient and inpatient telehealth, as well as a renewed interest in and broadening of services to the home,” with “telehealth outpatient services includ[ing] nearly every outpatient clinical service” (Nesbit & Katz-Bell, 2018, p. 7).

It is also important to point out that the 2000s were when “the Internet and e-commerce exploded and changed the world economy and culture”—after all, “[a]s people began to conduct more of their banking, shopping, and communicating with friends and family online, there was a growing expectation that health care should be as easily accessible,” available any time and any place (Nesbit & Katz-Bell, 2018, p. 8). Telehealth “evolved rapidly as well, forever changing how providers and patients would interact and deliver care” (Nesbit & Katz-Bell, 2018, p. 8). This shift was also abetted by drastic improvements related to internet service speeds and affordability, plus

telecommunications options that could provide delivery of healthcare services to many organizations and to the home.

Today, according to Nesbit and Katz-Bell (2018), “[d]evelopment and innovation in telehealth continues at an exponential rate” (p. 8). Within health care, telehealth has become mainstream, legitimate, and, sometimes, preferred as a method of care delivery. Again, changes to state- and federal-level policy “are removing barriers to a seamlessly functioning technology-enabled health care system” (Nesbit & Katz-Bell, 2018, p. 8). For instance, as mentioned in Chapter 1, as a response to the COVID-19 pandemic, the U.S. Department of Health and Human Services (2020a) has taken steps to make it easier for healthcare providers to offer telehealth services, as well as for telehealth to be accessible to more patients. In addition, the infrastructure of telecommunications has continued to improve and is, in many ways, no longer “an unwieldy barrier” (Nesbit & Katz-Bell, 2018, p. 9). Both computers and mobile devices are capable of supporting high-quality video, for example, so “the threshold for doing telehealth is much lower than in years past” (Nesbit & Katz-Bell, 2018, p. 9). The digital world of today means that “the difference between in-person and distance communication is less significant,” with many providers being willing to provide (and even expecting to provide) care via telecommunication technology (Nesbit & Katz-Bell, 2018, p. 9).

There are countless benefits to telehealth, too, for both the patient and the provider. For instance, a telehealth visit may allow the patient to take less time away from work, interfere less with child or elder care responsibilities, eliminate travel expenses and time, and maximize privacy; for the provider, telehealth may lead to increased revenue, better efficiency, improved patient follow-through and health

outcomes, and a reduction in missed appointments and cancellations (Chiron Health, n.d.).

And although telehealth was once largely used to connect providers working with a patient in one location, particularly one that was rural or otherwise hard to reach, to a specialist elsewhere, it has greatly expanded, thanks in no small part to the “[t]he rise of the internet age,” which has “opened up the possibility of delivering remote healthcare to patients in their homes, workplaces, or assisted living facilities as an alternative to in-person visits for both primary and specialty care” (Chiron Health, n.d., para. 4). Today, telehealth is very much “becoming an increasingly important part of the American healthcare infrastructure” (Chiron Health, n.d., para. 1).

The American Telemedicine Association (ATA) would very much agree with that assessment. Founded in 1993, the ATA began when telehealth, at least how we currently understand it, was in its infancy, and has been devoted to “working to change the way the world thinks about healthcare” since (ATA, n.d.-a, para. 1). In other words, the ATA (n.d.-a) “is committed to ensuring that everyone has access to safe, effective, and appropriate care when and where they need it, enabling the system to do more good for more people” (para. 2). Telehealth may be particularly helpful for members of rural communities, vulnerable and underserved patient populations, and those who cannot receive in-person care.

The ATA, like others, emphasizes that telehealth is a way to effectively connect patients and their providers, particularly in those instances when an in-person visit is not feasible or clinically necessary. Through telehealth, patients can receive much of the same care as they would from a traditional in-person visit: They can consult with a

provider, obtain information about their health, and receive a diagnosis, for example.

According to the ATA (n.d.-b), telehealth has consistently been shown to be safe and convenient, as well as a method of providing quality care. Jonathan Linkous, the CEO of the ATA, holds that health care is simply the latest institution to be affected and changed by the digital age, saying that “[i]n an age where the average consumer manages nearly all aspects of life online, it’s a no-brainer that healthcare should be just as convenient, accessible, and safe as online banking” (James, 2020, para. 1).

In conceptualizing telehealth, it is important to understand that there are various approaches within this larger label, including the following common approaches. There are virtual visits, “or live, synchronous, interactive encounters between a patient and a healthcare provider via video, telephone, or live chat” (ATA, n.d.-b, para. 3). There are also chat-based interactions, which are asynchronous communications involving the transmission of “a patient’s personal health data, vital signs, and other physiologic data or diagnostic images to a healthcare provider to review and deliver a consultation, diagnosis, or treatment plan at a later time,” whereas remote patient monitoring features “the collection, transmission, evaluation, and communication of individual health data from a patient to their healthcare provider . . . from outside a hospital or clinical office” through the use of technologies like “wireless devices, wearable sensors, implanted health monitors, smartphones, and mobile apps” (ATA, n.d.-b, para. 4).

The remainder of this chapter—and, to some extent, the rest of this work—will focus on that first form of telehealth: the virtual visit. The virtual visit is closest in nature to the traditional meeting between patient and provider—the in-person visit—and similarly relies on interpersonal communication for its success. As has previously been

established, particularly in Chapter 2 of this work, the quality of patient–provider verbal and nonverbal communication “is a critical and predictive factor of . . . outcomes, including physician–patient agreement, understanding of medical problems, satisfaction with care, and patient compliance” (Agha et al., 2009, p. 830). In addition, it “affects objective health outcomes, including early resolution of pain, shortened hospital stays, and improved blood pressure, blood sugar control, perceived health status, and daily functioning” (Agha et al., 2009, p. 830). Patient–provider communication also is complex, affected by a number of factors and variables, such as the patient’s and the provider’s personality and communication style (Sabesan et al., 2014).

The literature on patient–provider communication and the in-person medical encounter is vast; however, much less is known about the communication that transpires during a virtual visit. As Agha et al. (2009) explain, virtual visits “fundamentally differ from [in-person encounters] due to the physical separation of physician and patient” (p. 830). One estimate revealed that only about 7% of emotional communication occurs verbally, whereas 22% is communicated via tone of voice and 55% via posture, gaze, and eye contact. Of course, with telehealth, where “the patient and the specialist are not in the same room, the dynamics observed in a video consultation can differ from a traditional face-to-face consultation” (Sabesan et al., 2014, p. 101). For example, in a virtual visit, “direct physical examination and interview are not possible . . . and a virtual environment replaces the familiar physician’s office” (Agha et al., 2009, p. 830). Accordingly, concerns about telehealth “include depersonalization of care, lack of physical presence, decreased nonverbal communication, third-party participation, inhibition of patient

participation, and physician dominance of the medical encounter” (Agha et al., 2009, p. 836).

Importantly, Agha et al. (2009) also point to the conceptual model that positions patient–physician communication as either “physician-centered” or “patient-centered” (p. 836). Whereas physician-centered communication is characterized by “gathering information via closed-ended questions, testing hypotheses to make a diagnosis, giving medical directions, and controlling the visit,” all of which are “less successful in addressing the patient’s needs,” patient-centered communication involves “open-ended questions, partnership building, shared decision making, information sharing, counseling, and using statements of concerns, agreement, and approval” (Agha et al., 2009, pp. 836–837).

Although patient-centered communication has been shown to better address patients’ needs and is correlated with higher patient satisfaction and improved health outcomes, among other variables, the literature has, at times, suggested that virtual visits “promote a physician-centered style of communication,” as they may limit patient participation, shared decision-making, and partnership building (Agha et al., 2009, p. 837). Agha et al. (2009) found the contrary, though; in their study, patients reported higher satisfaction with physicians’ interpersonal and clinical skills and their use of patient-centered communication during telehealth visits versus in-person visits. Furthermore, patients in the study by Agha et al. (2009) rated telehealth visits as significantly more convenient than in-person visits.

Schwamm (2014) similarly acknowledges the advantages of telehealth, calling it a disruptive innovation similar to “automated teller machines, self-service gas stations,

drive-through windows at various businesses, and vending machines”—all “have provided consumers with new and alternative ways to more efficiently obtain goods and services” (pp. 200–201). Schwamm (2014) writes, “These innovations are disruptive because they have displaced prior ways of doing things” (p. 201). Health care, on the other hand, “has remained a largely local and synchronous service, meaning that patients and providers must be in the same place (local) at the same time (synchronous)” (Schwamm, 2014, p. 201). Telehealth opens up the possibility for health care to be delivered both remotely and asynchronously. It also is an excellent complement to traditional health care, which has a tendency to be “provider-centric, by creating delivery systems that are more patient centered and that use technology to increase access and quality, decrease cost, and help providers manage an ever-increasing volume of information and relationships” (Schwamm, 2014, p. 200).

Still, it is important to consider the “traditional face-to-face office or clinic visit” and its many parts (Schwamm, 2014, p. 202). Although telehealth has its advantages, like reducing “traffic, anxiety, and wasted time,” a virtual visit “might also remove fundamental elements of the in-person encounter . . . that are important for the effective functioning for the office practice or for ensuring that key health measurements or interventions occur” (Schwamm, 2014, p. 203). Aside from the feeling “that a virtual visit lacks or interferes with the human connection of a face-to-face visit,” there may be other things lost as well; Schwamm (2014) suggests that because of privacy concerns with telehealth, patients may be reluctant to discuss sensitive, personal matters (p. 203). Thus, any decision to replace an in-person visit with a virtual one must be carefully considered.

The potential for more patient-centered, equitable health care exists within telehealth. According to Schwamm (2014), “[t]elehealth should deliver care that is respectful and responsive to individual patients’ preferences, needs, and values and that includes patients’ values in clinical decision making”—telehealth, and virtual visits in particular, “have great potential to meet patients’ needs and respond to their preferences and values” (p. 204). Virtual home visits also quite literally bring care to those who cannot access it otherwise, including patients who live far from medical care or those with limited mobility. They also allow remotely located family members or other caregivers to take part in the patient’s health care, potentially supporting more effective shared decision-making.

Relatedly, “[t]elehealth should deliver care that does not vary in quality because of the personal characteristics of the patient or provider, including sex, race or ethnicity, geographic location, and socioeconomic status” (Schwamm, 2014, p. 204). As Schwamm (2014) explains, “[t]elehealth has tremendous potential” within this realm (p. 204). Still, one significant risk is that low socioeconomic status or other factors might, in fact, increase health disparities among patients with limited technological literacy or access. With the expansion of telehealth in the U.S. healthcare system and its becoming “a major avenue of care delivery, these disparities could rapidly accelerate” (Schwamm, 2014, p. 204).

But Schwamm’s (2014) overall take on telehealth is one that is overwhelmingly positive. Virtual visits could, for example, “provide needed ongoing medical care when transportation to the hospital is difficult or impossible to obtain, as well as “decrease the use of urgent care clinics, reduce hospital admissions and readmissions, and even

facilitate the return of ‘house calls’—although they, too, would be virtual” (p. 205). This last point is a particularly intriguing one: a return to the house call, albeit in a virtual form, via technology. Perhaps technology is, in some ways, enabling a that long-desired return to patient-centered—person-centered—health care once more.

Herendeen and Deshpande (2014) elaborate on this idea. They state that the house calls of the 1800s “may have been the ultimate” in patient-centeredness “but lacked in treatment options” (Herendeen & Deshpande, 2014, p. e29). In contrast, a century later, in the 1900s, “sophisticated medical treatments and diagnostic equipment moved the site of patient care to hospitals and doctor offices with a very ‘provider-centered’ approach” (Herendeen & Deshpande, 2014, p. e29). Today, though, health care has “come full circle with high-quality, patient-centered house calls being provided in homes, schools, and workplaces” (Herendeen & Deshpande, 2014, p. e29). As Herendeen and Deshpande (2014) explain, “[i]t is hard to imagine a more respectful or responsive approach than having a technician bring a telemedicine unit directly to you to get the health care you need” (p. e29).

Relatedly, the literature abounds with suggestions for improving the quality of patient–provider communication via telehealth. For example, Sabesan et al. (2014) note that most of the communication techniques used in face-to-face consultations are also applicable to virtual ones, such as introducing and greeting parties at both ends (patient and provider) of the consultation; explaining that the same content will be covered in the virtual visit as would be in an in-person visit and that the level of service will be the same; and spending time discussing social matters, like family and home, to build rapport. Also key is the provider’s maintaining (or appearing to maintain, as this can be

tricky when screens are involved) eye contact with the patient; suggestions include “effectively using the camera and zoom[ing] in and out to pick up any non-verbal cues” (Sabesan et al., 2014, p. 102). Importantly, Sabesan et al. (2014) state that “[s]creens can be barriers to effective doctor–patient relationships,” and urge providers to connect “with the patient on the screen at human level rather than an image on the screen” for a better, more effective “therapeutic relationship” (p. 103).

Telehealth and COVID-19

Any recent research on telehealth inevitably addresses the elephant in the room: the COVID-19 pandemic. Of course, as has been detailed in the current chapter, telehealth existed and was in use long before the pandemic, but in early 2020, COVID-19, and the restrictions necessarily put into place by the virus, pushed telehealth to the forefront of medical practice. Similarly, telehealth was a hot topic within the medical literature prior to COVID-19, but it has exploded in the past year, as providers rapidly adopted telehealth and developed best practices in real time.

Communication is only one of many aspects of health care affected by the COVID-19 pandemic, but it is a significant one. Weinstein (2020) calls “[t]he momentum for telehealth and the need for virtual clinical encounters . . . a watershed moment for clinicians and patients alike” (p. 47). While also acknowledging “the many downstream consequences of the COVID-19 pandemic,” Weinstein (2020) encourages providers to take advantage of the opportunities it has offered, including ensuring that patients “are counseled to be proactive in communicating with healthcare providers virtually” and that providers “attempt to fill the vacuum in the health care space by communicating

effectively so that patients and providers are informed on how best to maximize hearing, listening, and understanding during clinical encounters” (p. 48).

Ted James (2020), a medical director and vice chair at Beth Israel Deaconess Medical Center/Harvard Medical School, explains in a *Lean Forward* blog post that he, like many other healthcare providers, “found it difficult at first to establish an effective rapport with patients using telehealth, especially for new patient consults” (para. 2). The learning curve was steep, James (2020) says, and his first couple of visits were “disengaged and sterile,” and compounded by technical problems (para. 3). Improving your “web-side manner” can be done, though, he notes. For one, the provider’s being familiar with the equipment and technology is important, as is making sure that the patient is similarly comfortable with telehealth and providing orientation, as needed, before the virtual visit. James (2020) also suggests explaining to the patient why telehealth is being used; assuring the patient that the visit is secure and private; and providing a telehealth checklist that helps the patient understand the process, establish expectations, and prepare appropriately.

There are also numerous ways to improve video presence, James (2020) writes, including having adequate front lighting, adjusting the camera so that the provider’s face fills the screen, choosing a neutral background, and dressing professionally. Again, eye contact is emphasized, along with the importance of natural facial gestures and body language. Maintaining connection with the patient during a virtual visit is more important than ever, so James (2020) recommends practices that allow the provider to give their full attention to the patient, like reviewing the patient’s chart in advance (this “will minimize the need to have to look up information during the encounter, which can break the

perceived connection”); minimizing background noise; and turning off other phone and computer applications and notifications (para. 13).

Similar to Sabesan et al.’s (2014) recommendations, James (2020) states that although “[t]elemedicine requires some new techniques . . . the main principles of patient-centered communication still apply” (para. 17). For example, at the start of the virtual visit, providers should introduce themselves, then acknowledge both the patient and anyone attending the visit with them. They should begin with some small talk, as well as “[a]sk patients about their goals, preferences, and priorities” in order “to build rapport and [ensure] that the virtual encounter focuses on the patient’s needs” (James, 2020, para. 18). Somewhat unique to the virtual visit is confirming to see if the patient can see and hear the provider well, and consciously speaking slowly and clearly, as well as pausing for any lags in transmission. With the virtual visit in particular, patients should be empowered “to speak up if something is not clear or needs repeating” (James, 2020, para. 14).

Similar to a face-to-face encounter, James (2020) also recommends the following techniques for patient-centered communication:

Practice active listening by summarizing what patients say and verbally reflecting on their statements. Ask questions to clarify points and try not to interrupt when they are speaking. Giving people space to be heard conveys respect and caring. Use open-ended language and invite questions. Allow the patient’s priorities to guide the discussion. Employ shared decision-making and ask patients to repeat-back the plan to ensure they understand. Ask if there is anything else you can do

for them at the end of the virtual visit. Provide follow-up contact information and thank them for their time. (paras. 19–20)

James (2020) concludes by stating that his experience with telehealth has improved and that he is hopeful that it will be an option for patients even beyond the COVID-19 pandemic. The crux of the issue, he says, is that “patients need to be heard and understood, whether in-person or via video” (para. 22). Instead of seeing technology as undermining providers’ ability to engage with patients on a personal level, it can actually be a tool that enhances that ability.

A blog post for *PatientEngagementHIT*, an online publication that reports on leveraging health information technology to engage patients, communities, and populations, echoes many of James’s (2020) recommendations, including ensuring that patients are being heard and understood by their provider regardless of the type of visit (Heath, 2020). Important, too, is establishing that the quality of the virtual visit “is on par of that delivered on in-person basis,” which can be established, for one, through the provider’s “looking the part” and using various physical cues (Heath, 2020, para. 10). Relatedly, the telehealth examination room should also look the part and resemble the traditional clinical setting; for example, clutter should be cleared, and doors “might be off-putting for patients who are concerned someone could walk in and disrupt the encounter or overhear sensitive health information” (Heath, 2020, para. 23).

As previously noted, before the COVID-19 pandemic, full adoption of direct-to-consumer telehealth was tepid for a number of reasons, including patients not knowing how telehealth worked or if it would be covered by their health insurance, and feeling apprehensive about the quality of health care provided via telehealth (Heath, 2020).

However, with expanded access to telehealth because of the COVID-19 pandemic (and stay-at-home recommendations that have made in-person health care impossible or at least discouraged), many of these concerns have been allayed. Furthermore, it is widely expected that even as more in-person visits are resumed as the pandemic begins to be controlled, “telehealth will be a significant, permanent component of our value-based care practice when compared to the pre-COVID environment” (Syed, 2020, para. 2).

That said, “the long-term future of telehealth beyond the COVID pandemic remains uncertain” in many ways (Syed, 2020, para. 13). There are a number of regulatory hurdles that persist; health insurance companies must adjust their policies; and issues connected to equity related to technology access need to be resolved. Still, the benefits of telehealth—to the healthcare system at large, as well as to individual providers and patients—are too great to ignore. Thus, the onus is, in some ways, on providers and their patients to make telehealth the best possible communicative experience that it can be.

Possibilities and Implications

As has been demonstrated in this chapter, the possibilities related to the confluence of technology and health care are many, with important implications for the patient–provider relationship and communication, as well as the communication ethic behind it. Technology certainly complicates this relationship and the communication that goes on within it in a number of ways, but it also goes a long way toward, to quote from the ATA (n.d.-a) “enabling the system to do good for more people” (para. 2).

This chapter has also shown that despite some resistance to technology, contemporary digital technologies in particular, and its continued infiltration into

medicine, the practices it is modifying are ones that have long existed within the field. In regard to the examples from this chapter, the EHR is just another form of the medical record; telehealth is merely another way for patients and providers to connect over some distance or barrier.

It is imperative to keep this fact in mind, as both patients and providers, as we forge forward into the technological future. In addition, and thinking about this issue more broadly, we must seek to retain our humanity, the human touch, the human element, in medicine, even as parts of it become digitized. This, then, becomes an important good, worthy of being protected and promoted, within the communication ethic of patient–provider communication. A possible solution to this challenge is, again, centering the patient, particularly in regard to communication. Patient-centered communication puts the patient—and their unique preferences, needs, and values—at the heart of the healthcare encounter, letting them guide decision-making and, by extension, their own health care.

Technology undoubtedly has made—and continues to make—important, perhaps even life-saving contributions to health care. It has also helpfully simplified and streamlined some of the complex processes of health care. But for patient-centered communication to be enacted and to truly be effective, providers must see their patients as unique individuals, not as collections of symptoms recorded in an electronic chart or pixelated faces on the other side of a computer screen. Providers must look to the patient, the Other, and not only see but welcome “the differences that meet us,” rather than imposing themselves in the form of their own preferences, needs, and values (Arnett et al., 2018, p. xvii).

Healthcare communication ethics, after all, is based in the goods of responsive hope and care for the Other. It necessitates a responsiveness, as well as the addressing of health care within the larger context of a life, with all its complexity and messiness. The preceding chapter, which looked at gender and race and ethnicity in the context of health care, exposed some of the cracks in the healthcare system that appear when difference is not attended to or responded to. This chapter added technology to the mix, which can either compound the problem further or open up the possibility of a more democratized future, at least in terms of health care.

The next chapter, then, aims to bring together ideas from preceding chapters and offers one potential solution to the challenge of retaining a sense of patient-centeredness, or person-centeredness, within health care, even in the midst of technological change and upheaval. By understanding professions as practices with particular purposes or goods that help to define human life, à la Fritz (2013), Chapter 5 examines the profession of nursing and one of its primary goods: the contact and connection with patients created within the context of the patient–provider relationship. In this way, nursing, and in particular this good of human connection within the healthcare setting, may offer a framework for other providers seeking to provide patient- or person-centered health care, even as much of this relationship and the communication that occurs within it has necessarily moved to the digital space.

Chapter 5: Nursing: Profession as Practice

An idea central to this project as a whole is the way in which technology and medicine have long been and continue to be intertwined, with important implications for the patient–provider relationship and the communication that helps to establish and build it. Preceding chapters, particularly Chapter 1 and Chapter 4, worked to establish the immediacy and timeliness of this discussion, as they looked at the impact of the COVID-19 pandemic on medicine, especially in terms of further integrating telehealth into routine health care. Previous chapters also have explored the significance of patient–provider communication to health care, as well as the way in which technology both complicates and aids it. Discussion therein raises the question of how patient-centeredness can be established or retained in the context of communication in the healthcare setting; this becomes even more relevant when technology disrupts business as usual.

This chapter, then, furthers the conversation by examining the profession of nursing—or, rather, that which undergirds it—as a potential solution to this problem. Janie M. Harden Fritz (2013), in particular in her work *Professional Civility: Communicative Virtue at Work*, understands “the tasks of professions . . . as meaning-filled human action . . . relevant to human life and flourishing” (p. 45). As will be explicated later on in this chapter, within the tradition of a given profession are “virtues that enable the achievement of goods defining the practice of professions,” and “those who practice professions are embedded in, and interact in, communities that protect and promote the goods of practice” (Fritz, 2013, p. 46). In sum, Fritz (2013) sees “professions as practices that have as their purpose or end a ‘good’ that partly defines human life” (p. 11). This chapter argues that, in many ways, a primary good of nursing is the contact and

connection with patients created within the context of the patient–provider relationship. This connection, of course, is established in no small part through communication.

In the past year, the nursing literature has dealt extensively with how connection can be maintained in the face of the major changes that the COVID-19 pandemic has brought on, particularly in relation to the rise of telehealth services, demonstrating that it is a core tenet, or good, of nursing. This chapter will explore that literature, including narratives from providers that describe firsthand these experiences. However, the chapter will first further examine Fritz’s (2013) conception of profession as practice, with its accompanying goods. Next, the chapter will look to nursing, briefly tracing a history of the profession to the present; within this will be a discussion of what, exactly, nursing is and does, with attention paid to the relationship between nurses (oncology nurses in particular) and patients, especially when technology enters that once-dyadic relationship. Finally, the chapter will conclude with implications that contemplate ways in which (a) the goods of the nursing profession can be both protected and promoted even when technology is involved and (b) how these goods can be extended beyond nursing, to other professions and practices.

Understanding Professions as Practices

In her *Professional Civility: Communicative Virtue at Work*, Fritz (2013) is concerned with the “crisis of incivility . . . in workplaces in the United States,” which “carries significant implications for organizations and their members” (p. 1). There are also many potential reasons behind this rise in incivility, and it has been suggested that civility is no longer a taken-for-granted communicative practice in a world “lacking a shared virtue structure” (Fritz, 2013, p. 2) and defined by difference. In *Professional*

Civility, Fritz (2013) draws from Arnett et al.'s (2009, 2018) *Communication Ethics Literacy: Dialogue and Difference*, including the conception of the good outlined therein. Fritz (2013), in *Professional Civility*, proposes, for example, “that civil communicative practices fostering coordinated action in institutional settings establish a minimal common ground of the good . . . for life together in organizations” (p. 3). Thus, “civility as an interactive norm reflects an ongoing concern for order and structure in public and private life that permits the accomplishment of personal, institutional, and community goals,” even though these goals may be contested at various time points (Fritz, 2013, p. 3).

In this work, Fritz (2013) focuses “on the role of the professions in embracing a communicative ethic of civility” and sees “civility in interpersonal interaction in public and private settings as a communicative virtue,” protecting and promoting “respect for human beings” and supporting “the various social contexts within which human lives find meaning and significance” (p. 3). After all, viewed “[f]rom a virtue ethics perspective, behaving with civility toward others is an integral part of a flourishing human existence that defines the good of, and for, human life,” with civility contributing “to the well-being of others with whom one comes into contact in the course of daily life” (Fritz, 2013, p. 3). Civility in the workplace allows for the creation of “a constructive, humane environment that makes the context of work functional and even enjoyable” (Fritz, 2013, p. 3). A civil work environment goes beyond this, though, as well—seen from “the perspective of the professions,” it “creates conditions for the accomplishment of a larger project that contributes something good and necessary to the world,” which is a defining feature of the professions (Fritz, 2013, p. 4).

Professions, according to Fritz (2013), in the current historical moment encompass a number of occupations that are “engaged in specialized and/or knowledge work in a service economy” (p. 4). Although there were once four original “learned” professions—theology, law, medicine, and education—today occupations that hold professional status have the following characteristics: “an expectation of relative autonomy stemming from their specialized knowledge base, and an expectation of adherence to ethical norms, which professionals bring to the workplaces in which they practice” (Fritz, 2013, p. 5). It is these ethical norms, which bind members of a profession and guide their practice, that “define what it means to be a ‘good’ member of a profession”; in addition, they “provide a basis for self-evaluation of professions as communities of practice, defining the good that is protected and promoted by a given profession” (Fritz, 2013, p. 5).

Again using language from Arnett et al. (2009, 2018), Fritz (2013) writes of the “narrative of the professions,” which “carries with it an implied ethic of civility as a marker of professional identity” (p. 7). Further, those who work within the professions (i.e., professionals) are “marked historically by a tradition of service to the human community defined by their position as bearers of elements of the ‘good’ in life necessary for human flourishing” (Fritz, 2013, pp. 6–7). Vocations within the professions have “value both as a practice . . . and as a contribution to the human community,” with members of professions “pursu[ing] their callings within communities of others both within and external to the boundaries of their specific professions” (Fritz, 2013, p. 7).

As noted earlier in this chapter and in this work overall, the current historical moment of postmodernity is one in which there are multiple conceptions of the “good,”

or “competing virtue structures” (Fritz, 2013, p. 9). There are a number of ways in which this “lack of consensus on what constitutes the good for human life” takes shape, like “the public recognition of varying conceptions of what is good for human beings to be and to do and disputes about what practices contribute to furthering a given good for human life” (Fritz, 2013, p. 9). It is possible to observe such competing virtue structures in public contexts, including “complex organizations . . . that support the bulk of contemporary professional work today” (Fritz, 2013, p. 9).

Fritz (2013) acknowledges that “the idea of professions as important callings necessary for human flourishing remains fixed in the popular imagination,” despite challenges to the status, power, and reputation of professions and professionals (p. 9). Looking to professional codes of ethics and various understandings of professional ethics that are grounded in the virtues, Fritz (2013) writes that these may be alternative ways of conceptualizing and “considering how professions and those who practice them may contribute a renewed sense of hope to organizations that host their work and to larger communities to which their practices contribute” (p. 9). This allows for professions to again be understood “as necessary contributors to the good life for human beings,” something that Fritz (2013) sees as “part of the history of the professions in the United States,” “part of the tradition that defines the professions as practice,” and “part of a legacy unique to professionals that can be recalled, restored, and reenacted” (pp. 9–10).

According to Fritz (2013), “Professions are communities of practice grounded in a tradition that carries their contribution to human flourishing understood as goods internal to their practices” (p. 11). The community of a profession defines the goods for a particular vocation, with “professional virtues enacted by professional practitioners

help[ing] to support those goods, which, in turn, participate in and support the general good of human flourishing” (Fritz, 2013, p. 23). Fritz (2013) employs within *Professional Civility* an Aristotelian approach to virtue ethics, which “assumes a telos or ‘good’ of human life defined by the nature of human beings”; here, virtues are defined as “character traits that enable a person to pursue and embody a good human life, a life characterized by human flourishing” (p. 24). Professions are important to the ends, or purposes, of human life, so professions and professionals can be seen as residing within the purview of virtue ethics. Professions also “have a teleological structure of their own that is agreed upon by those who practice the profession”—accordingly, “[w]ith shared agreement on a professional telos, the good that grounds virtue can be identified,” which allows for a viable “virtue ethics perspective specific to professions” (Fritz, 2013, p. 24).

The existence of an end, or a purpose, of human activity reveals much about human nature, including that human beings have particular aims or goals that they move or work toward. Relatedly, this concept “provides a standard against which to judge action as it assists or impedes achieving the end or purpose of human activity” (Fritz, 2013, p. 25). Fritz (2013) explains that there are various ways to evaluate professions; for example, they can be evaluated in relation “to their contribution to the good of human flourishing,” but they can also “be understood as a practice with a defined end, aim, or good against which particular instantiations of practices can be evaluated as meeting, or failing to meet, that end, aim, or good, as defining more or less well the particular good internal to that practice” (p. 25). There are certain acknowledged practices that correspond to understandings of what a professional working within that profession “is

expected to know and do that make up the content of professional practice” for that profession (Fritz, 2013, p. 25).

Fritz (2013), borrowing from MacIntyre (2007), states that the tradition or history of a profession defines its end, or the good it pursues. She continues, saying that the “notion of a tradition as a context for practice provides a narrative framework within which one can define the scope of a practice as an activity or endeavor, the characteristic ends of that practice, and the goods that define those ends—goods that emerge through the practice itself and by which the particular telos is realized” (Fritz, 2013, pp. 25–26). In other words, a “profession can be understood as a practice within a tradition that defines its good or goods both as an end to the practice itself and within the larger picture of the good of human life,” states Fritz (2013), adding that as professions achieve “their particular telos, they contribute to larger human goals and are thus understood to be integral contributors to the good of human life” (p. 26).

As stated earlier, Fritz (2013) sees the work of professions as action that is filled with meaning, and that has relevance to human life and flourishing. In addition, professions are communities of practice with their own tradition and history, including understandings of the good life. Within the tradition of a profession are virtues permitting the achievement of goods that define the practice of a profession; in addition, “[m]embers of the professions, or professionals, as the embodiment of professional ideals, carry the goods of professions through their engagement of professional practice and interaction” (Fritz, 2013, p. 46).

According to MacIntyre (2007), a practice is as follows:

[A]ny coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended. (p. 187)

There have since been characteristics added to this definition of practice, including the following: “technical skills, a distinct overriding purpose, a moral community that can maintain a level of relationships needed to achieve the practice’s internal goods, partial definition of members’ way of life, operation within an institutional context, and formal social organization to push back institutional corruption” (Fritz, 2013, p. 48). Generally speaking, a profession is thus “a socially established and cooperative human activity embedded within a tradition and aimed at some good end” (Fritz, 2013, p. 48). Likewise, a tradition is a “historically situated, ongoing argument about what constitutes the good life” (MacIntyre, 2007, p. 13). Understanding a profession as having a tradition allows for the defining “of what the goods and telos of a profession are . . . and what is required to be a good professional,” or “a good practitioner of a profession” (Fritz, 2013, p. 48).

In short, a profession can be viewed as a practice with a history, with goods realized only through professional practice. Again, it is possible to see nursing as a profession—it is, after all, a practice with its own tradition and history, and accompanying goods that are protected and promoted via professional practice. As will be demonstrated in the remainder of this chapter, a primary good of nursing is, I believe, the contact and connection with patients that is established in the context of the nurse—

patient relationship and via patient–provider communication. This becomes especially important to maintain when that relationship and the communication that transpires within it shifts in format, from in-person to digital, as in telehealth.

The Profession of Nursing

As was detailed in Chapter 3, the history of women and healing is a lengthy one. However, one casualty of the professionalization (and, therefore, masculinization) of medicine was the stripping of women’s opportunities for independent medical practice; instead, if women desired involvement in medicine, they could pursue the newly invented occupation of nursing, which had been branded as feminine and ladylike by the likes of figures including Florence Nightingale and Dorothea Dix. Of course, “[f]rom the beginnings of mankind, persons have been designated, called, or educated to perform the functions we now refer to as nursing care,” with the history of nursing intimately linked to “a tradition of caring” (Egenes, 2009, p. 23). However, with the professionalization of nursing, and its transformation into an acceptable occupation for women, nursing entered a new era, and one that continues to shape the field today.

A Brief History of Nursing

Nightingale in particular is largely considered to be the founder of modern nursing (Winkelstein, 2009), having not only reformed nursing as it then existed but also laying the groundwork for nursing as a profession and a practice (Egenes, 2009). Born into a wealthy British family, Nightingale had eschewed the traditional path for an upper-class woman of the Victorian period, which included getting married and rearing children, and instead chose to follow her calling, dedicating her life to serving humanity and, in particular, to caring for the sick (Egenes, 2009). Nightingale’s parents were

reportedly at first appalled by her decision; during this time, in the mid-19th century, this type of work was thought to be improper for a woman of her class and standing.

Nightingale first gained notice for her nursing work during the Crimean War, when she led a team of female nurses to Turkey in late 1854 to provide care to British soldiers (Egenes, 2009; Winkelstein, 2009). Although unsanitary conditions at the military hospital had been reported on, Nightingale and the other nurses found them to be much worse than expected; for example, “[t]he wards were vastly overcrowded, patients were covered with rags soiled with dried blood and excrement, the water supply was contaminated, and the food inedible,” with sewage discharging onto the floors of wards and dead animals rotting in the courtyards (Winkelstein, 2009, p. 311). The British army lacked nurses to care for the troops, and the mortality rate for British soldiers was high, with most dying from disease rather than from their injuries (Egenes, 2009).

Fortunately, Nightingale was able to draw from “her travels, observations of nursing care provided in hospitals abroad, and practical experiences of nursing” and, thus, “had a far greater knowledge of the elements of skilled nursing care than the majority of medical workers of her time” (Egenes, 2009, p. 5). Although Nightingale believed that dirt caused disease (rather than microscopic pathogens), she set out to address some of the basic problems at the military hospital, including by thoroughly cleaning and ventilating the wards. As a result, “[w]ithin months, the number of deaths decreased dramatically” (Egenes, 2009, p. 5). Nightingale documented the care provided and the results it produced, using this documentation to guide future interventions; this is one way in which Nightingale also “laid the foundation for modern evidence-based practice” (Egenes, 2009, p. 5).

When Nightingale returned to England a few years later, she received a hero's welcome (Egenes, 2009; Winkelstein, 2009). A trust fund was established in recognition of Nightingale's work, and it ultimately was used to start the Nightingale School of Nursing at St. Thomas's Hospital in London (Egenes, 2009). The school, aimed at educating professional nurses, was a departure from previous forms of nursing education in that students took classes in theory but also had clinical experiences; in addition, a set curriculum guided students' education, and they received training in various aspects of nursing care and specialties (Egenes, 2009). Through this, "[e]mphasis was placed on the proper education of the nurse, rather than on the needs of the hospital" (Egenes, 2009, p. 6).

Not even a decade after Nightingale's groundbreaking work in Crimea, the United States faced its own war: the Civil War. At the start of the war, no provisions had been made for military nurses on either side, but during this period, there were also "no nursing schools, no 'trained' nurses, and no nursing credentials" (Egenes, 2009, p. 6). The female volunteer nurses who cared "for sick or wounded soldiers on the battlefields, in field hospitals, in hospitals removed from battle sites, or even in their own homes" did so with a basic knowledge of nursing care taken "from their personal experiences caring for loved ones" (Egenes, 2009, p. 6).

In doing so, these women helped to establish professional nursing in the United States. Because many Civil War nurses had left their husbands or families to work within this realm that had previously been considered improper for women, they helped to change "the public's perception of work by women outside of their homes" (Egenes, 2009, p. 6). In addition, the work of Civil War nurses "also changed public opinion about

women's work in health care" (Egenes, 2009, p. 6). For example, although not formally trained as a nurse, Dix was among those women who felt compelled to serve and was appointed to be the superintendent of the Union Army's nurses. Dix convinced skeptical military officials that women could perform nursing duties just as well as men, and subsequently recruited thousands of women to serve as nurses; nursing care markedly improved under her leadership (Reddi, 2005).

Post-Civil War, the value of formal education in the care of the sick also became apparent, with many of the women who had served as nurses during the Civil War helping to establish some of the first schools of nursing in the United States. In 1868, the president of the American Medical Association endorsed the formation of such nursing schools (Egenes, 2009). Relatedly, the success of England's Nightingale School of Nursing became known worldwide, and the idea that the "provision of safe nursing care was important and could best be delivered by persons who had received a formal education in nursing" only grew (Egenes, 2009, p. 8). It is notable that the schools of nursing that emerged during this period did so via the efforts of committees made up of laywomen, as many physicians opposed nursing education that went beyond the most elementary training.

Because schools of nursing in the United States during this period were economically dependent on the hospitals in which they were located, the needs of the hospital were often prioritized over those of students (Egenes, 2009). One consequence of this was a reliance on student labor, termed "clinical training," which was "cheap, efficient, and more cost effective than if graduate nurses had been trained by hospitals" (Egenes, 2009, p. 10). In other words, "student nurses . . . traded their labor for the

opportunity to be educated in a profession” (Egenes, 2009, p. 10). Students’ education came second to hospital staffing, and so shifts were long and had minimal (or no) clinical supervision, and classes were irregularly scheduled and even canceled when students were needed to work at the hospital. The 19th century was a pivotal period in nursing also for advances in science and medicine; such “expansion of scientific knowledge and the increased [use] of complex technological procedures were linked to the growth of schools of nursing” (Egenes, 2009, p. 11). As medical care expanded, the need for educated nurses did too, in order for them “to aid in the care and treatment of patients with increasingly more complex conditions and needs” (Egenes, 2009, p. 11).

The ensuing years, from then to now, included further professionalization of nursing and increased education of nurses. Mandatory licensure laws, making it unlawful for anyone to practice nursing without a valid nursing license, were established by states in the 1940s (Egenes, 2009). The Goldmark Report of 1923—in response to the apprentice system employed in nursing education, which often lacked intellectual rigor and exploited student labor—recommended educational standards within nursing education and insisted that schools of nursing focus on education, not on patients; in addition, the report suggested that nursing education be housed in universities (Egenes, 2009). Additional reports made the same or similar recommendations, but even decades later, most schools of nursing continued to be hospital-based diploma programs that were dependent on hospitals for financial support and prioritized the hospitals’ needs.

A nursing shortage followed World War II; in response, an associate degree in nursing (ADN) was begun in an attempt to supply many nurses in a short period of time (two years). ADN programs also opened up another path to the profession of nursing for

those who had traditionally been excluded from admission to nursing programs, like men, married women, and nontraditional students. By the late 1970s, there were more ADN program graduates than graduates from baccalaureate programs and diploma programs (Egenes, 2009). The 1970s also was marked by a considerable increase in graduate nursing programs centered on clinical specialties, which set up the forthcoming expansion in advanced practice nursing roles (e.g., clinical specialist, nurse practitioner, researcher, nurse administrator). All helped to enlarge nurses' clinical purview and grant them further autonomy in the healthcare setting.

Nursing Today

Today, nursing remains deeply shaped by this history. For example, the early days of nursing's professionalization, and Nightingale's influence in particular, can still be felt. Take the past and present logos of the Oncology Nursing Society (ONS), a professional association of more than 35,000 members established in 1975 that promotes excellence in oncology nursing and the transformation of cancer care. An internal document from ONS on the creation of a new brand identity notes that both logos incorporate a nod to Nightingale as "the Lady With the Lamp," a name inspired by her tireless care for patients, even at night when she would roam the darkened rooms of the hospital to check on them by lamplight (Katz, 2020). The first ONS logo, created in 1976, features the image of a gas lamp outright, whereas the current logo offers a more subtle approach with a stylized reflection of the light or flame from Nightingale's lamp within a polar area diagram or coxcomb, a graphic representation used by Nightingale to present statistics.

In addition, in honor of the 200th anniversary of Nightingale's birthday, the World Health Organization designated 2020 as the International Year of the Nurse and the Midwife, heralding Nightingale as "a visionary nurse and leader" (Jakel, 2020, para. 1) who "continues to serve as a symbol of the power of nursing and demonstrates nurses' critical role in global healthcare" (Jakel, 2020, para. 10). The timing was prescient, as 2020 was marked in so many ways by the COVID-19 pandemic and the contributions of frontline workers, including nurses.

In an article published in *ONS Voice*, ONS's news magazine, ONS Public Affairs Director Alec Stone (2020) shares a well-known quotation of Nightingale's: "I am of certain convinced that the greatest heroes are those who do their duty in the daily grind of domestic affairs whilst the world whirls as a maddening dreidel" (p. 30). To Stone (2020), Nightingale was, of course, referring to nurses; the COVID-19 pandemic has only "cemented the fact that nurses are an integral part of patient-centered care and should be able to practice to the full extent of their education and licensure" (p. 30). Recognizing the shortage of healthcare providers during the COVID-19 pandemic, the Centers for Medicare and Medicaid Services granted temporary waivers concerning nursing scope of practice, expanding the role of nurses in health care. Stone (2020) writes that "[t]he nurse is the provider that patients turn to in times of trouble" (p. 31), adding that although many nurses "say and feel that their impact is marginal," nursing is consistently rated as the "most trusted profession year after year" (p. 30).

It is clear that nurses are valuable members of the healthcare team and as providers in their own right, particularly in their connections to patients. According to the American Association of Colleges of Nursing (AACN, 2019), the national voice for

academic nursing, nursing is the largest healthcare profession in the United States, with more than 3.8 million registered nurses (RNs) across the country; of all licensed RNs, about 85% are employed in nursing. Today, the majority of RNs enter practice with a baccalaureate degree from a four-year college or university or an associate degree from a community college. As of 2018, about 17% of RNs held a master's degree, and about 2% held a doctoral degree; AACN (2019) notes that the current demand for nurses with advanced degrees “far outstrips the supply” (para. 11).

Nurses make up the largest part of the healthcare workforce; they are the primary providers of hospital patient care and long-term care (AACN, 2019). It is anticipated that more than 200,000 new RN positions will be created annually through 2026, with employment growing 15% from 2016 to 2026, which is faster than the average for all occupations. Growth in this workforce can be attributed to a host of factors, including an increased emphasis on preventive care and more individuals living with chronic conditions (e.g., diabetes, obesity). Most healthcare services and settings also involve some type of care that is provided by nurses, ranging from private practices to public health agencies, and from primary care clinics to hospices.

Importantly, AACN (2019) makes clear that although nurses often work collaboratively, “nursing does not ‘assist’ medicine or other fields,” as “nursing operates independent of, not auxiliary to, medicine and other disciplines” (para. 7). RNs also far outnumber physicians—there are more than three times as many RNs as physicians in the United States (AACN, 2019). Accordingly, nurses provide a variety of healthcare services, including primary and preventive care by nurse practitioners who have specialized education in areas like pediatrics and women's health; the scope of nursing

also encompasses the provision of care by certified nurse-midwives and nurse anesthetists, along with care in various clinical specialties.

The Specialty of Oncology Nursing: Tenets of Care

Among the various clinical specialties within nursing is oncology nursing. Because of the very nature of their work, oncology nurses face unique challenges and rewards, even among other nurses. Cohen and Sarter (1992) explain the “essence of oncology nursing” as

being on the front lines of a war against death, disfigurement, and intense human suffering. It requires the performance, prioritization, and coordination of multiple complex tasks. It involves handling frequent unexpected crises, both physiologic and psychological. It carries the rewards of reversing a fatal illness, balanced by the ever-present reality of death. Working with patients with cancer requires constant vigilance in monitoring for sudden problems and life-threatening errors. The cancer nurse’s empathy is sharpened by the awareness that “this could be me or my loved one.” Finally, working with patients with cancer means “being there” for people in their most private moments of suffering and responding to the heights and depths of their responses to this suffering. (p. 1,485)

From Cohen and Sarter’s (1992) words, the fundamental, foundational essence of oncology nursing can be glimpsed; for example, that elemental contact and connection with patients is woven throughout. Thinking of Fritz (2013), it becomes apparent how nursing, and oncology nursing in particular, can be understood as a profession with a long tradition that offers a context for practice, and that has goods defined “both as an end to the practice itself and within the larger picture of the good of human life” (p. 26).

Oncology nursing, in the achievement of the goods outlined by Cohen and Sarter (1992), also clearly makes important contributions “to larger human goals” and is “understood as an integral [contributor] to the good of human life” (p. 26). Drawing from Arnett et al. (2018), too, the ethics of healthcare communication, and oncology nursing in particular, remind “us of our humanness” (p. 213).

Fritz (2013) states, too, that various ethical norms hold members of a profession accountable and direct their practice, defining “what it means to be a ‘good’ member of a profession” (p. 5). Nursing, like other professions, is guided by its own ethical standards that pervade all aspects of nursing care (RegisteredNursing.org, 2021). Among these is the American Nurses Association’s (ANA’s, 2015) *Code of Ethics for Nurses With Interpretive Statements*. ANA (2015) is a full-service professional organization representing RNs, and its *Code of Ethics* “establishes the ethical standard for the profession and provides a guide for nurses to use in ethical analysis and decision-making” (p. vii). Further, the *Code of Ethics* “arises from the long, distinguished, and enduring moral tradition of modern nursing in the United States” and “is foundational to nursing theory, practice, and praxis in its expression of the values, virtues, and obligations that shape, guide, and inform nursing as a profession” (ANA, 2015, p. vii). According to ANA (2015), nursing involves “the protection, promotion, and restoration of health and well-being; the prevention of illness and injury; and the alleviation of suffering, in the care of individuals, families, groups, communities, and populations” (p. vii). There is the expectation that those who become nurses “adhere to the values, moral norms, and ideals of the profession” but also “embrace them as a part of what it means to

be a nurse”—accordingly, the *Code of Ethics* “informs every aspect of a nurse’s life” (ANA, 2015, p. vii). Nurses are expected to embody these tenets within their practice.

Among the nine provisions of the ANA (2015) *Code of Ethics* is Provision 1, which states, “The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person” (p. v). This provision is particularly relevant to this project, as it acknowledges that “[t]he need for and right to health care is universal, transcending all individual differences” (ANA, 2015, p. 1). Per the *Code of Ethics*, nurses must “consider the needs and respect the values of each person in every professional relationship and setting”; in addition, they “establish relationships of trust and provide nursing services according to need, setting aside any bias or prejudice” (ANA, 2015, p. 1). ANA (2015) notes also that “[f]actors such as culture, value systems, religious or spiritual beliefs, lifestyle, social support system, sexual orientation or gender expression, and primary language are to be considered when planning individual, family and population-centered care” (p. 1). These considerations “must promote health and wellness, address problems, and respect patients’ or clients’ decisions” (ANA, 2015, p. 1).

The nursing process is shaped and influenced “by unique patient preferences, needs, values, and choices,” with “[r]espect . . . extended to all who require and receive nursing care in the promotion of health, prevention of illness and injury, restoration of health, alleviation of pain and suffering, or provision of supportive care” (ANA, 2015, p. 2). Implicated within this is that the “worth of a person is not affected by illness, ability, socioeconomic status, functional status, or proximity to death”—according to ANA

(2015), “[n]urses respect the dignity and rights of all human beings regardless of factors contributing to the person’s health status” (p. 1).

Considering again the specialty of oncology nursing, these ethical tenets guiding the profession of nursing as a whole can be observed in documents like ONS’s (2019a) position statement on access to quality cancer, which maintains that “[q]uality cancer care requires safety, efficacy, timeliness, and a patient-centered approach” and that “[a]ll people should have access to comprehensive, affordable healthcare without discrimination, including populations who are at risk, vulnerable, underserved, or underrepresented” (p. 1). The concept of patient-centered care also comes through in ONS’s (2020) position statement on the specialty of oncology nursing, especially in the following description of the role of oncology nurses in conjunction with their patients:

Oncology nurses are leaders in ensuring access to and providing quality cancer care. Oncology nurses advocate for people at risk for or with a diagnosis of cancer, deliver education throughout treatment decision making and planning with attention to individual health literacy levels, coordinate care delivery across the cancer continuum, ensure safe delivery of cancer treatments, assess for complications of therapy, help manage symptoms, optimize quality of life, support patients with cancer and their caregivers, advocate for the unique needs of patients with cancer, and collaborate with an interprofessional team to improve outcomes and reduce the impact of cancer on patients, families, communities, and populations. (p. 1)

It is abundantly clear that the patient is at the heart of this work. The position statement continues on, detailing that oncology nurses “provide a holistic approach to care . . .

caring for the entire patient . . . with attention paid to the cultural, ethical, and spiritual preferences of their patients” (ONS, 2020, p. 1).

Another ONS (2019b) position statement, this one on palliative care for people with cancer, further establishes the importance of patient- and family-centered care and communication, with particular attention paid in the palliative care setting to “aggressively managing symptoms . . . and coordinating care across settings to ensure that the patient’s goals of care are being met” (p. 1). Palliative care is defined as “a philosophy of care” that is “focused on providing relief from the symptoms and stress of a serious illness,” whereas hospice care is a type of palliative care but one that is provided to patients with a limited life expectancy (ONS, 2019b, p. 1). In palliative care in particular, the complexity of the patient and family experience, as well as the patient’s and the family’s needs and goals of care, must be recognized. As a result, oncology nurses need to have knowledge and skills in a variety of domains to deliver safe, high-quality palliative care, including the following aspects of care: physical; psychological and psychiatric; social; spiritual, religious, and existential; cultural; and ethical and legal. In no small way, patient and family characteristics and attributes determine the delivery of such care, making the importance of communication and connection between the patient and family and the provider even clearer.

The literature, and in particular the oncology nursing literature, abounds with examples of the significance of patient-centered communication (both verbal and nonverbal) and care, with the related ideas of contact and connection implicated within this. For example, an *ONS Voice* article by guest author Lisa Zajac (2020a) titled “Always Search for Ways to Connect With Patients” describes how the author, while

working in a palliative care clinic, connected with one of her patients through “an unexpected medium: word search puzzles” (para. 1). Zajac (2020a) explains that “this medium, this mutual hobby, provided the foundation for developing our therapeutic relationship” (para. 5). As nurses, there is the tendency to focus only on whatever task is at hand, Zajac (2020a) writes, adding that “[w]hen patients present to the unit or patient care area, we are quick to welcome them but then immediately move onto what we as healthcare providers need to do” (para. 6). However, without pausing or taking a moment at that initial introduction, “we may lose the opportunity to build our therapeutic relationship” (Zajac, 2020a, para. 6).

Zajac (2020a) states that she now consciously takes the time “to find one thing we have in common or something meaningful to them” after quickly assessing the patient’s physical status”—in this way, she lays “the foundation for this connection before moving onto discussing the disease process” (para. 7). This can be as simple as a quick observation of the patient or their belongings, with consideration of the activity they are performing, snacks they brought with them, identifying apparel (e.g., a sports jersey), or mementos brought from home. According to Zajac (2020a), patients enjoy and appreciate “talking about something meaningful prior to the more clinical conversation” (para. 10). In this way, a patient becomes more than their medical diagnosis—they are again a person, with their humanity restored.

In another article for *ONS Voice*, Zajac (2020b) describes how, during a service-learning trip to Mexico through her baccalaureate nursing program, she found that care is a universal language. Although she did not know much Spanish at the time, she realized that “we can display our care and effectively communicate through our actions, no matter

what language our patients speak” (Zajac, 2020b, para. 2). So much of each interaction or encounter is nonverbal, says Zajac (2020b), that it is possible to demonstrate the “ability to care without saying a word” (para. 6). Reflecting on her experiences in Mexico, Zajac (2020b) finds that she “had developed a therapeutic relationship through [her] actions” (para. 6). She continues:

Often, we are so worried about saying the wrong words to patients and their families. Yes, we must focus on our wording, but we also need to be aware of our actions. Our nonverbal cues are powerful and can traverse any language barriers. (Zajac, 2020b, para. 7)

Zajac (2020c) expounds on the power of presence possessed by nurses, including oncology nurses, in another *ONS Voice* article. She shares an experience early in her nursing career in which she was tasked with “caring for the family and their needs” during a final admission, with her colleagues handling her other patient assignments (Zajac, 2020c, para. 2). Prior to this, as a new nurse, Zajac’s (2020c) shifts “functioned as consistently as clockwork,” with each hour “dedicated to a different task, including her dinner break” (Zajac, 2020c, para. 1). This experience, though, “jostled [her] from [her] systematic routine” and showed her that not only was she “a caring person” but also that she “possessed the ability to care” (Zajac, 2020c, para. 5).

Zajac (2020c) had been able to establish therapeutic relationships—a connection—with her patients before, but this experience “was the monumental moment” in her career in which she knew she had become a better nurse: She realized “the power of being present” (para. 5). She writes that her caring “did for this patient what medications could not,” and her “calming presence allowed his family to say goodbye

and helped him peacefully transition into eternity” (Zajac, 2020c, para. 5). This connection made between people, says Zajac (2020c), is “what truly makes the difference when it comes to patient care” (para. 6). From that point, Zajac (2020c) knew with her “whole being” that she “was called to be a nurse,” and never again did she let her nursing routine interfere with her “ability to be present for [her] patients and their families” (para. 7).

Humanistic, Patient-Centered Care

Zajac’s (2020a, 2020b, 2020c) words overlap with common themes in the nursing literature, particularly the ideas of humanistic, patient-centered care. A humanistic or holistic approach to care involves seeing “the patient as a whole person rather than simply an illness or injury” (Nursing-Theory.org, n.d., para. 1). Such an approach emphasizes “the nurse-patient relationship, in which both people influence the outcome of the nursing interventions” (Nursing-Theory.org, n.d., para. 3). Relatedly, and echoing Zajac (2020c), the relationship that exists between the nurse and the patient contributes to healing just as much as, if not more, than actual medical interventions. Within this model of care, the patient is seen as an individual, with each situation or encounter also viewed as unique: “[T]here is no formulaic method or process in order to care for patients. Each patient is assessed and treated on a case-by-case basis” (Nursing-Theory.org, n.d., para. 4).

Furthermore, the meaning of humanistic nursing is located in the everyday lived experience, with “the nurse–patient relationship . . . characterized by interactions designed to promote wellbeing and existential growth in the context of the lived world” (Wu & Volker, 2011, p. 472). In this way, the nurse demonstrates or shows care for the

patient “by presence or being with the patient, and other nursing actions or activities” (Wu & Volker, 2011, p. 472). Importantly, both the nurse and the patient are unique individuals, and the viewpoint of each party is just as important as that of the other. Still, because the patient is “the nursed,” or the “person-as-patient,” whereas the nurse is the person “nursing,” or the “person-as-nurse,” nursing can be understood as “a purposeful ‘call-and-response’ in which the nurse responds to the call by caring for the person who has health-related unmet needs,” with nursing thus being “a goal-directed activity that nurtures a person’s human potential” (Wu & Volker, 2011, p. 472).

Despite the nurse’s and the patient’s being unique individuals with their own unique viewpoints and perspectives, it is important to understand that both parties are meeting for and working toward the same goal. According to Wu and Volker (2011), “[w]hen the nurse responds to the person’s health needs, a purposeful transaction occurs between the person and the nurse,” with the two parties being “interdependent . . . free to open, to know and to interact with each other” (p. 473). Of course, just as with all other types of human interactions, “the mutual relationship is determined and experienced differently by the patient and the nurse,” with differences coming from various factors like “differences in values, beliefs, emotions, experiences and expectations” (Wu & Volker, 2011, p. 473).

A central concept within this discussion is that of “genuine presence,” which Wu and Volker (2011) call “a basic and necessary component of humanistic nursing” (p. 473). Zajac (2020c) references this idea as well. As Wu and Volker (2011) explain, presence builds off of the idea that, generally speaking, “nurses are open or available to patients in a certain way; that is, they are ‘open-as-a-helper’ to patients,” with “[o]pen,

available nurses reveal[ing] themselves as ‘present’ to the patient” (p. 473). Wu and Volker (2011) further note that that humanistic nursing also emphasizes the concept of community, or “the ‘we’ that develops between the nurse and the patient, the patient’s family, professional colleagues and other health professionals” (p. 473). Each nurse within a given community is “a microcosm (with the community as the macrocosm), and each microcosm is coloured by certain biases and labels, depending on the individual’s experiences, values and goals” (Wu & Volker, 2011, p. 473). A sense of openness on the part of the nurse, then, aids them in seeing beyond their biases. As Wu and Volker (2011) explain,

By reflecting on themselves and their experiences, nurses can broaden their views to include the endless innovative possibilities in themselves and their communities. Through awareness, openness, sharing and caring, nurses can increase their understanding and expand their personal views. . . . [A]s their selves expand, they increasingly connect with their patients and other colleagues. (p. 473)

Through all of this, it is possible to see a humanistic approach to nursing as “an expression of the nurse’s authentic, existential commitment to the nurturing of human potential” (Wu & Volker, 2011, p. 473). Again, becoming a nurse is an intentional, conscious choice—what many, including Zajac (2020c) even refer to as their calling. They do so to “help patients meet their health needs,” experiencing and sharing in “the major life events of other persons, events such as birth, recovery, loss, grief and death” (Wu & Volker, 2011, p. 473). Each nurse’s professional commitment is unique, but all nurses are connected, professionally speaking, by this “kind of ‘being with and doing

with' that aims at developing human potential," which involves "the nurse's active presence" (Wu & Volker, 2011, p. 473). With this in mind, it becomes quite clear how nursing is a profession with a practice whose purpose or end is a good that, in part, defines human life (Fritz, 2013). However, as previously discussed in this work, challenges arise when a barrier is erected, physically or metaphorically, that stands in the way of nurses' providing patient-centered, humanistic care, including demonstrating genuine presence, to patients. The COVID-19 pandemic is illustrative here, as it not only has put a stop to traditional healthcare practices and processes but has also introduced or increased the use of new ways of "being with and doing with" in the healthcare setting, including telehealth.

Telehealth and Nursing

In the context of nursing, telehealth is not an especially new concept. Since at least the 1970s, "nurses have communicated via telephone to discuss various healthcare issues with patients, including lab results, medication refill needs, and advice on how to manage minor illnesses at home" (Mataxen & Webb, 2019, p. 11). Relatedly, "[l]abor and delivery nurses often receive phone calls from expectant mothers about possible labor symptoms and fetal well-being," whereas emergency department nurses "field calls about illnesses and injuries" (Mataxen & Webb, 2019, p. 11). Such calls or inquiries are more than just a simple phone call, though—"the nurses who respond to those calls are participating in the healthcare continuum" via telehealth, "a tool for delivering nursing care remotely to improve efficiency and patient access to healthcare" (Mataxen & Webb, 2019, p. 11).

Even in 2019, prior to the COVID-19 pandemic, Patti A. Mataxen and L. Denise Webb, a clinical supervisor and a telehealth RN, respectively, and the authors of an article titled “Telehealth Nursing: More Than Just a Phone Call,” identified the important role played by nurses in relation to telehealth, as well as that of telehealth in larger healthcare processes. In the past two decades in particular, they write, “the function of telehealth nursing has expanded . . . blossoming into an extension of some healthcare providers’ offices, hospitals, and health plans” (Mataxen & Webb, 2019, p. 11). This expansion also encompasses “services not related to specific entities, such as independent nursing practices, corporations where multiple telehealth nurses work in a single location, or nurses working remotely from their homes,” along with “regional, statewide, and hospital contact centers” (Mataxen & Webb, 2019, p. 11). Within some settings, telehealth nurses are available and accessible 24/7 “for inquiries regarding symptoms and evidence-based guidelines,” and are tasked with “a broad range of responsibilities, from calming the nerves of new parents to assisting with ambulance dispatch in life-threatening situations” (Mataxen & Webb, 2019, p. 11). In addition to the accessibility and flexibility of telehealth nursing, the benefits are many: “[N]urses can assist with patient retention, decrease on-call hours for healthcare providers, and offer versatility for use during any time interval, including around-the-clock, weekend, or afterhours care” (Mataxen & Webb, 2019, p. 11).

Of course, a key component of telehealth nursing, and telehealth in general, is communication. The process of telehealth nursing, for example, “evolves as nurses interact with patients over the phone to identify and prioritize their health needs through questioning, information interpretation, symptom review, and skillful assessment of the

urgency and level of care necessary to safely and effectively meet the caller’s needs” (Mataxen & Webb, 2019, p. 12). Effective communication between nurse and caller—or provider and patient—is necessary. It has been reported that caller, or patient, satisfaction usually “increases when patients believe the nurse correctly comprehended their issues, expressed empathy, and provided them with a sense that their needs were met” (Mataxen & Webb, 2019, p. 12). These elements of effective communication echo the precepts of humanistic nursing, especially in terms of genuine presence, and can be extended even beyond nursing, to all patient–provider interactions.

Mataxen and Webb (2019) also report that in the context of telehealth, nurses “must be critical thinkers,” knowing “when and how to probe for accurate descriptions of rashes, cuts, bruises, or any other signs and symptoms reported by a caller” (p. 12). It is also imperative that the nurse is a good listener, especially in the context of telehealth performed via telephone: “Hearing a description and visualizing what is being communicated over the phone helps nurses perform an accurate assessment” (Mataxen & Webb, 2019, p. 12). In conjunction with “assessing and constructing a mental image from the caller’s description, the nurse can [also] quickly develop a rapport with the caller,” leading to the “final clinical decision” and prioritization of care (Mataxen & Webb, 2019, p. 12). In sum, Mataxen and Webb (2019) see telehealth as “more than just a phone call” or a video chat; instead, “it is a resource for both patients and their families,” and with training, nurses can confidently take on telehealth roles “to provide safe and quality care to individuals through a variety of technologies” (p. 3).

Telehealth nursing also has the potential to ease the blow of the anticipated nationwide nursing shortage. More than half a million experienced RNs are expected to

retire by 2022, and over one million new RNs are needed to replace them and ease the shortage; if this does not happen, it is likely that nurse stress will increase, quality of care will decrease, and patient lives will be lost (Teledoc Health, n.d.). Telehealth, though, can improve nurse utilization among hospital departments, and “it eases the burden of limited time for nurses who often find themselves stretched thin” (Teledoc Health, n.d., para. 3). In addition, telehealth nursing reduces healthcare costs in that it decreases visits to the emergency department and admissions to the hospital. Research has also shown that telehealth access is important to patients: According to studies by the American Hospital Association, 70% of patients surveyed reported that they are comfortable communicating with their healthcare providers via text, email, and video, and 76% said they prioritize simple access to health care over the need to have a face-to-face interaction with their providers (Teledoc Health, n.d.).

Because of its very form, telehealth nursing is able to “be practiced almost anywhere,” allowing “nurses to connect with patients without lost time spent traveling, registering, and waiting like there would be with traditional appointments and visits” (Teledoc Health, n.d., para. 4). Other benefits include the ability of “providers to build relationships with patients over the course of the entire disease process” and the time for “meaningful contact with patients due to the lack of intrusions, interruptions, and distractions that plague traditional office visits” (Teledoc Health, n.d., para. 5). Relatedly, nurses practicing via telehealth “are able to spend more time with patients that would otherwise be spent traveling, charting, or running from one patient to another on-site” (Teledoc Health, n.d., para. 5).

Patients also gain easier access to their providers, who “can better focus on patient care and satisfaction without all the ‘red tape’ of traditional on-site appointments,” thus improving efficiency (Teledoc Health, n.d., para. 6). The quality of patient care does not change despite the shift in format: “Nurses must continue to use listening skills, critical thinking, and assessment skills just as they do in traditional settings in order to support their telehealth patients” (Teledoc Health, n.d., para. 6). With telehealth nursing, nurses “are able to take the time to build rapport and trust, working through health barriers together with patients,” with no sacrifices or concessions made in terms of care (Teledoc Health, n.d., para. 7). This is good news, particularly as the American Telemedicine Association predicts that within the next few years, half of all healthcare services could be provided via telehealth. After all, “[p]roviding guidance and support to patients is the main role of nurses; telehealth has already proven that it improves patient access, ultimately contributing to successful healthcare” (Teledoc Health, n.d., para. 8).

As the Agency for Healthcare Research and Quality’s *Patient Safety and Quality: An Evidence-Based Handbook for Nurses* points out, “[a]lthough the use of technology changes the delivery medium of nursing care and may necessitate competencies related to its use to deliver nursing care, the nursing process and scope of practice does not differ with telenursing” (Schlachta-Fairchild et al., 2008, p. 3-135). After all, nurses engaged in the practice of nursing delivered via telehealth, or telenursing, “continue to assess, plan, intervene, and evaluate the outcomes of nursing care, but they do so using technologies such as the Internet, computers, telephones, digital assessment tools, and telemonitoring equipment” (Schlachta-Fairchild et al., 2008, p. 3-135). Telenursing does not fundamentally change the practice of nursing, except in that it is performed using a

different medium. This work notes, too, that the platforms for telehealth are diverse, “yet all increase the ability of telenurses to communicate with and receive data about their patients” (Schlachta-Fairchild et al., 2008, p. 3-139). When telehealth is employed, “accepted and proven nursing practice must not be compromised”—nurses should view telehealth “as a medium for care, and not a tool to replace high-quality nursing practice,” with “patient safety . . . maintained with telenurses who are able to focus on patient care and not the technology itself” (Schlachta-Fairchild et al., 2008, p. 3-139). The essential goods of the profession remain, no matter the medium.

Peck (2005) calls readers to “[r]emember when using one’s senses and instinct for the assessment and care of patients was standard nursing practice”—when “[n]urses were taught to *touch* the patient (is their skin warm and dry or cool and clammy?), *see* the patient (is the patient’s skin color normal?) and *listen* (is the patient alert to person, place, and time?)”—and asks them to question how “these important nursing skills and common nursing practices . . . [which] actually define nurses as caring professionals, as well as clinicians . . . [can be assimilated] into the current state of healthcare technology” (p. 339). Again, as Mataxen and Webb (2019) also noted, Peck (2005) states that “exchanging medical information and delivering nursing care through wires and hardware is not a new role for nurses,” and points to telephone triage, a forerunner of telehealth (p. 339). Of course, Peck (2005) states, telehealth “will change the way nurses interact with patients and other members of the interdisciplinary team,” but nurses play a significant “role in bringing telehealth to healthcare,” with benefits to the profession and patients (p. 342). According to Peck (2005), “the best nursing practices from the past will be incorporated into the future of healthcare technology” (p. 342).

Nagel et al. (2013) likewise look to the future, recognizing that the continued integration of technology into clinical practice provides an opportunity to transform nursing for the better. With telehealth in particular, “challenges [in nursing practice] often manifest as tensions between traditional perspectives of nursing practice and delivery of nursing care through electronic modes” (Nagel et al., 2013, p. 104). What has made this historical moment especially challenging, too, is that “the pace of technology uptake has allowed little time for either the nursing profession or society to adjust to provision of nursing care through this mode of delivery” (Nagel et al., 2013, p. 104). Of importance here is “the capacity of nurses to demonstrate how they come to *know* persons and provide holistic nursing care through telehealth technology to facilitate healing and promote health for individuals” (Nagel et al., 2013, pp. 104–105). Traditionally, such knowing and the provision of nursing care has been linked “with physical presence and face-to-face encounters . . . properties not typically associated with use of technology” (Nagel et al., 2013, p. 105). Consequently, “adjustment to telehealth technology necessitates developing an understanding of competencies required to facilitate knowing a person in virtual environments and adapting nursing practice to this milieu” (Nagel et al., 2013, p. 105).

Technology has long been used in medicine; within nursing, it is the same story: “For decades nurses have used various forms of technology to augment provision of care to individuals, ranging from simple technology, such as the stethoscope, to more advanced types of technology, such as intravenous pumps, cardiac monitors, and ventilators” (Nagel et al., 2013, p. 105). What makes telehealth stand apart from these other technologies, though, is that despite facilitating enhanced healthcare access and

bridging healthcare delivery gaps among some populations, “it creates a physical distance between the nurse and the person receiving care,” which “perpetuates a perception of nursing losing physical proximity and presence” (Nagel et al., 2013, p. 105). These characteristics have historically been viewed as “important to knowing and caring for a person in nursing practice” (Nagel et al., 2013, p. 105). In their absence, concerns are raised:

In this paradox of increased access to care and creation of distance between nurse and person, the influence of telehealth technology on the nurse’s ability to know the person, a component of caring and of nursing’s professional identity, generates concern for the nurse’s ability to facilitate healing and promote health. . . . There are also concerns that nurses become increasingly reliant on technology in place of clinical skills when providing care and that fragmentation of holistic care occurs with technology use. (Nagel et al., 2013, p. 105)

Accordingly, Nagel et al. (2013) contemplate how nurses might use themselves “in a therapeutic manner via telehealth technology that demonstrates presence and intentionality to create an environment that fosters relationships and to attain a complete understanding of that person” (p. 107).

This is a significant question, especially as nursing has grown into “a highly visual-oriented professional culture that demonstrates caring through physical presence and verbal communication,” with a “natural tension” arising “when nurses use technology that creates distance between themselves and the person requiring care” because “the nurse is no longer *here* with the person, but rather *there*—a significant shift in physical proximity, ability to visualize the person, and perception of being present”

(Nagel et al., 2013, p. 107). The physical distance inherent in telehealth imposes limitations on other types of expression, too, like touch and additional forms of nonverbal communication. Thus, telehealth “not only alters what the nurse can actually observe of the person but changes the way in which, and the degree to which, the nurse perceives and interacts with the person,” affecting “the ability of the nurse to demonstrate key aspects of nursing care,” like empathy and compassion (Nagel et al., 2013, p. 107).

“Knowing” the patient, or understanding them in a more complete way as a unique individual, has importance to clinical judgment and decision-making; “it allows the nurse to provide individualized care and ensure patient safety” (Nagel et al., 2013, p. 108). Nagel et al. (2013) contemplate, then, how it is “possible to know the person in a holistic and complete manner . . . if technology focuses on one or few aspects of a person’s health” (p. 108). In this way, technology may be seen as reductionist and depersonalizing, but Nagel et al. (2018) urge nursing “to reexamine the degree to which a person needs to be known, or what aspects of the person must be known, to provide care” (p. 108). In other words, “it is necessary to consider how nursing may need to reframe and adapt aspects of professional practice to align with these changes in health care” (Nagel et al., 2013, p. 109).

The opportunity has emerged for nursing “to make contributions in knowledge development related to care and the human body in the context of the virtual environments that are currently emerging” (Nagel et al., 2013, p. 109). As Nagel et al. (2013) explain, “an adapted way of knowing and a means for virtual presence can be envisioned and developed to support nursing care through technology” (p. 111). And the time for this is now, especially with the rapid expansion in telehealth services and

availability because of the COVID-19 pandemic. In addition, nurses are increasingly the providers called upon to deliver or coordinate this virtual care. As a result, the role of nurses within telehealth “is expanding, and quickly” (Miller, 2020, para. 4), with important future implications for the profession of nursing and for health care in general.

The COVID-19 Pandemic and Nursing

As has been previously discussed in this work, the emergence of a novel coronavirus (SARS-CoV-2, which causes the illness now known as COVID-19) has caused massive disruptions across the globe, including to the U.S. healthcare system. These disruptions “were rapid in onset and protracted with continued viral spread” (Yackzan & Shah, 2021, p. 41). The Centers for Disease Control and Prevention confirmed the first positive case of COVID-19 in the United States on January 20, 2020, and the virus (and viral transmission) became widespread across the country by mid-March. Around the same time, on March 11, 2020, the World Health Organization issued its pandemic declaration (Sheldon, 2021).

Many aspects of life—and health care—have been unsettled or delayed as a result of the COVID-19 pandemic. Those working within the realm of oncology have felt this acutely; individuals providing care for patients with cancer have been faced with a host of challenges. For one, having cancer increases an individual’s risk of severe illness from COVID-19, as does older age and other medical conditions, like a weakened immune system from organ transplantation, obesity, and type 2 diabetes (National Cancer Institute, 2021). In addition, providers of oncology care, including nurses, have had to consider the nature of essential care within the oncology setting (Tariman et al., 2021).

When patients without COVID-19 were excluded from the medical setting, for instance, patients with cancer had to go without their chemotherapy, radiation therapy, and surgical treatments. In some cases, patients could take oral medications at home in lieu of traditional treatment; however, others had to forgo treatment for the time being, something Tariman et al. (2021) call “unthinkable under conventional ethics” (p. 64). Consequently, the COVID-19 pandemic has produced “a bevy of patients with cancer who are receiving suboptimal and delayed care,” as they are “sacrificing their immediate needs for the benefit of the broader population” (p. 64). In addition, it is likely that in the next decade, cancer-related deaths will increase because COVID-19 has delayed cancer diagnosis and treatment (Tariman et al., 2021).

Relatedly, as in other infectious disease epidemics, vulnerable populations, defined as those who have a disproportionate risk for poor health, “are bearing the brunt of COVID-19 . . . and are being disproportionately affected” (Tariman et al., 2021, p. 65). Vulnerability may be multidimensional, as several characteristics or factors can contribute to an individual’s vulnerability (e.g., comorbidity, age, race or ethnicity, lack of health insurance coverage, socioeconomic status, low education and literacy levels, living in rural or urban communities). As was discussed in Chapter 3 of this work, in terms of race and ethnicity, for example, members of Black and Brown communities are more often “essential workers, earning low wages, and are not able to stay home from work, which puts them on the COVID-19 front lines and significantly exposes them to COVID-19,” and they also experience higher rates of non-COVID-19 medical conditions than the general population, further increasing their risk of COVID-19 (Tariman et al., 2021, p. 65).

Again, generally speaking, patients with cancer are more vulnerable than others in the current historical moment, particularly when their status as a patient with cancer is compounded by other factors. The COVID-19 pandemic “highlights the urgent need to address health disparities,” particularly in relation to cancer in vulnerable populations. As Tariman et al. (2021) write, “Preserving the integrity of vulnerable individuals, strengthening their fundamental rights (i.e., human dignity and human rights), and respecting their specific needs and life history are the responsibility of all health professionals” (p. 65). The failure to do so has dire consequences.

Oncology nurses have striven throughout the COVID-19 pandemic to provide optimal care for their patients, which has necessitated a number of changes in nursing practice (Houlihan, 2020). Some of these changes have been positive, too—they’ve “opened new opportunities for nursing innovation and brought much-needed change to health care” (Sheldon, 2021, p. 22). Take, for example, the rapid implementation of telehealth strategies and services to permit patient care at home; the use of telehealth for various healthcare services “provides a link between patients and oncology conditions while minimizing exposure risk” (Yackzan & Shah, 2021, p. 45). The most common ways in which nurses can communicate via telehealth include telephone calls, video visits, and web-based applications (Braithwaite & Walker, 2020). Duncan et al. (2021), describing the impact of COVID-19 on their institution (a National Cancer Institute–designated cancer center), note that although their “health system had already embraced the use of telehealth, it was not widely used prior to the COVID-19 pandemic and was not a standard of practice in oncology clinics” (p. 50).

Even though routine clinic visits and elective surgeries at Duncan et al.'s (2021) institution were deferred at the pandemic's peak, patients in their care still required evaluation and monitoring. Duncan et al. (2021) state that the benefits of telehealth during the pandemic were manifold and included "the provision of care for low-acuity patients who did not require in-person visits, reduction of human exposure for healthcare workers and patients, reduction of in-person clinic visits for patients with chronic illnesses, and conservation of medical supplies" (p. 50). As of February 2021, the oncology team at their institution was averaging between 110 and 150 telehealth visits each day—a more than 100% increase from before the pandemic.

Abigail Baldwin Medsker, associate director of Memorial Sloan Kettering Cancer Center's Digital Transformation Office, is quoted in an *ONS Voice* article as saying that "[t]elehealth enables us to extend our reach and meet patients and caregivers where they are when they need us" (Karam, 2020, p. 20). In addition, says Baldwin Medsker, telehealth "really enables us to transition the traditional brick-and-mortar care into the home" (Karam, 2020, p. 20). The research also supports use of telehealth, showing that it is linked to 38% fewer hospital admissions, 31% fewer hospital readmissions, 63% greater likelihood of spending fewer days in the hospital, and more engagement in their care (Karam, 2020).

Telehealth in the nursing setting, however, does present some challenges of its own. Increased use of technology within the healthcare setting has implications for patient safety, as well as barriers related to digital literacy, fear and acceptability of telehealth, and access to technology (Karam, 2020; Sheldon, 2021). (To the point that not all patients have the knowledge of or access to technology for telehealth services, as was

reported in *ONS Voice*, the Digital Sherpa program is working to pair “tech-savvy volunteers with patients and families who want to become more technologically fluent,” with workshops covering internet use and social media skills, among other topics; the existence of such programs helps nurses, too, as it lets them focus on other aspects of patient care—the program’s sherpas “have successfully provided a path to empowerment and self-care for patients” [Karam, 2020, p. 23]). Concern also exists regarding how well connection and presence can be maintained by nurses when a screen has been erected between themselves and their patients. As Stockdill et al. (2021) describe in the context of providing palliative care via telehealth, “[o]ncology clinicians who were accustomed to developing relationships with patients and families in person were challenged with establishing and maintaining these same relationships in a way that seemed foreign” (p. 17).

In the case of Stockdill et al. (2021), it was once thought that palliative care was “too high-touch to be delivered via telehealth” (p. 17). Palliative care has numerous benefits, including improved quality of life and caregiver health, as well as longer survival; in addition, there is evidence supporting the early delivery of palliative care provided concurrently with disease-directed treatment for patients newly diagnosed with cancer (Stockdill et al., 2021). Even prior to the COVID-19 pandemic, the early integration of palliative care was a challenge for patients in rural and remote locations, as most palliative care services are housed within large, urban medical centers. In addition, there is a limited palliative care workforce, yet the need exists to offer access to high-quality palliative care to all patients with cancer.

Proposed solutions to this problem, including telehealth, have been an area of active research, in particular because of the health-related disparities among underserved populations. However, there has been slow adoption of telehealth in palliative care clinical practice for various reasons, including that “enduring misconception that telehealth is less appropriate for palliative care services” because of its very nature (Stockdill et al., 2021, pp. 17–18). Stockdill et al. (2021) argue, though, that a host of studies have demonstrated the positive effects of palliative care delivered via telehealth, and maintain that “[b]ecause the COVID-19 pandemic has quickly shifted how health care is delivered to patients with cancer, particularly because of their immunocompromised status and the risks associated with unnecessary exposures in the clinic,” these previous lessons can be used to inform current practice (p. 17). After all, if palliative care, which requires high levels of sensitivity and intimacy, can be delivered via telehealth, the possibilities are endless for the virtual delivery of other types of care.

In particular, Stockdill et al. (2021) emphasize that various evidence-based communication strategies adapted for the COVID-19 pandemic “can be used for more effective communication, including building rapport and establishing trust with patients and families dealing with serious illness” (p. 17). These include the nurse-led early palliative care telehealth intervention ENABLE[®] (Educate, Nurture, Advise, Before Life Ends), which was developed to prepare and empower patients with cancer to be active participants in their health care,” and the *COVID Ready Communication Playbook* created by VitalTalk, “a nonprofit organization dedicated to teaching empathetic and effective communication techniques to clinicians, particularly in the areas of disclosing

serious news, addressing goals of care, bearing witness, and establishing rapport among the care team, patient, and caregivers” (Stockdill et al., 2021, p. 18).

Stockdill et al. (2021) maintain that “[a]lthough the issues surrounding COVID-19 may have increased the adoption of telehealth practices and interventions, the momentum of telehealth adoption must be sustained by oncology and palliative care clinicians for telehealth to remain an enduring part of practice” (p. 21). Various resources, including those previously mentioned, “are available for oncology nurses as they seek best practices in communicating with patients” via telehealth, which has been shown to be “an effective approach,” both during the COVID-19 pandemic and “in a post–COVID-19 context” (Stockdill et al., 2021, p. 21).

On the whole, the struggle to provide patient-centered, humanistic care has touched nearly all aspects of nursing practice. The Clinical Moment department that appeared in the December 2020 issue of the *Clinical Journal of Oncology Nursing (CJON)* posed the following question in its title: “How do you provide humanistic care during a pandemic?” The article’s authors, two nurse practitioners and one physician assistant at a cancer center in New York state, “the initial epicenter of COVID-19 in the United States,” write that as nurses, tasked with caring for the institution’s patients, they “are facing the brutal force of this pandemic together” (Lee et al., 2020, p. 711). They describe the many requirements they must follow in the provision of that care, including “mandatory mask wearing, social distancing, wearing goggles to ensure patient and staff safety” (Lee et al., 2020, p. 711). Visitors are not permitted. At surge points during the pandemic, cancer care could not be provided, which Lee et al. (2020) say was distressing to their patients.

Despite all this, they “attempted to provide comfort to patients behind personal protective equipment (PPE), yet frequently believed we fell short because human touch is integral in oncology nursing” (Lee et al., 2020, p. 711). It was challenging to witness tragedies daily “while staying physically distant and attempting to provide humanistic care to . . . patients” (Lee et al., 2020, p. 711). Lee et al. (2020) say that “essential to the art and practice of oncology nursing is its humanism: the interactions between human beings, as between nurses and patients” (p. 711). During the COVID-19 pandemic, though, nurses must face “the difficulty of providing humanistic care virtually and with PPE as a physical barrier” (Lee et al., 2020, p. 711). Patients need nurses’ humanistic care, particularly at a moment like the current one, and so the question becomes, “How do we reach out to touch and hug our patients and family members virtually?” (Lee et al., 2020, p. 711). Although writing from the frontlines of the pandemic, Lee et al. (2020) maintain that nurses “can move forward from this tragedy to better care” for patients and themselves (p. 711).

In an editorial appearing in the same issue, *CJON* Editor Ellen Carr (2020b) classifies the year 2020 as the year of “I don’t know.” She writes, “Let’s face it. How many times this year have you said, ‘I don’t know’ to yourself or to others?” and the examples she offers are myriad (Carr, 2020b, p. 603). Carr (2020b) wonders about the reuse of PPE, about when a patient’s rising temperature is only a side effect of cancer treatment and not a symptom of COVID-19, about where to go for COVID-19 testing and where to quarantine. But the next couple of questions Carr (2020b) asks speak to the impact of the pandemic on the nurse–patient relationship, and humanistic nursing care in particular:

How can I ease the fear in my patient’s eyes—the only part of her masked face that I can see—when I, also masked start her induction chemotherapy? *I don’t know*. Can I be enough comfort to my patient whose spouse cannot be by her side during her weekly chemotherapy treatment because of COVID-19 visitor restrictions? *I don’t know*. When will I be able to exchange smiles and hugs with my patients again without multiple barriers, such as face masks, shields, gloves, and gowns? *I don’t know*. (p. 603)

Carr (2020b) tells the nurse readers of this editorial to brace themselves for more unknowns in the new year as well. However, she adds that “an environment saturated with *I don’t know* does not mean that there cannot also be extraordinary patient care” (Carr, 2020b, p. 603). Nurses, and clinical oncology nurses in particular, are backed by “solid competencies as their bedrock for safe, evidence-based, compassionate care”—after all, clinical nurses are “built to be resilient,” and they are “perceptive critical thinkers . . . and savvy communicators” who have, for example, “learned how to really listen to . . . patients through sometimes iffy telecommunications, picking up on their new but vague symptoms” (Carr, 2020b, p. 603). This, writes Carr (2020b), she knows for sure.

A few months later, in the February 2021 issue of *CJON*, which brought together “foundational content about clinical oncology care in the environment of a virulent pandemic,” Carr (2021) provides an update of sorts, noting that “clinical oncology care continues, but the environment of this pandemic has required clinicians to revisit the structure and delivery of oncology care, revising the standards of care, policies, and underlying principles that form best practices” (p. 11). She states that such care in the

current moment “is inevitably disruptive and saturated with unknowns,” but that, “over time, we can build a more solid foundation for clinical oncology care based on what we have learned from practice during the pandemic and what evolves from our collective clinical expertise” (Carr, 2021, p. 11). Along these lines, Duncan et al. (2021) write that “healthcare providers and teams” will “emerge stronger and wiser” from the COVID-19 pandemic, “resulting in better and sustained outcomes for patients and healthcare providers in the post–COVID-19 era” (p. 54).

Implications for Practice

From the discussion in the current chapter, it is clear that moving forward, the practice of health care will be, in some ways, different from how it once was. Of course, the COVID-19 pandemic and the disruptions it has wrought are no small part of this, but in general, health care appears to be moving in the direction of more equitable, more inclusive, and more patient-centered for all. One of the ways in which this is occurring is through the provision of telehealth services not only for patients who cannot be seen in person because of the risk of COVID-19 but also for those who live in remote or rural areas and others who cannot easily access health care (or a certain type of healthcare service, like palliative care).

This is, on the whole, a very good thing, particularly when providers using telehealth services can keep true to the idea of person-centered care and convey this to the patients they serve. Based on what has been explored in this chapter, it seems clear that nurses, and the nursing profession overall, have adapted to the environment and conditions of the current historical moment, despite initial frustrations, and have learned how to maintain and promote patient-centered, holistic, humanistic care, even in the

midst of a pandemic. Although the nature of care has changed, including the provision of care from in-person to virtual, it can be gleaned from the literature that that contact and connection with patients—a primary good of nursing—can continue to be maintained.

At the heart of this, and building on the work of Arnett et al. (2009, 2018), is Fritz's (2013) conception of the work of professions “as meaning-filled human action . . . relevant to human life and flourishing” (p. 45); again, Fritz (2013) understands “professions as practices that have as their purpose or end a ‘good’ that partly defines human life” (p. 11). Viewed in this context, the profession of nursing has at its core this idea of contact and connection that is created within the patient–nurse relationship and within the communication, both verbal and nonverbal, that transpires between the two parties.

The literature abounds with tangible suggestions and recommendations for improving communication via telehealth, but an almost unspoken and invisible, yet absolutely necessary, component of any encounter is what Wu and Volker (2011) and others term “presence.” Simply put, presence reveals that the nurse is open, available, present to the patient, regardless of any physical or metaphorical barriers. Presence is a key component, an essential good, of humanistic nursing care. As described earlier, many nurses feel called to the profession because they desire this type of role: a direct, intimate connection with patients. It is intertwined with their professional identity, even—nurses are the ones who are *present* with their patients: comforting them, talking to them, holding their hand. But nurses—and other healthcare providers—can extend this presence to the virtual setting, too, creating genuine, authentic connection even with the barrier of

a screen. With presence, this barrier can actually become a facilitator of humanistic, patient-centered care.

Other healthcare professions, and the providers within them, can certainly (and should) apply the goods that are foundational to nursing practice to their own work. Because of the ingenuity and resourcefulness and adaptability inherent in nursing and in nurses—the history of nursing is particularly illustrative here—the profession has been able to rise to the occasion of a once-in-a-century pandemic and adapt, and even thrive, while continuing to stay true to its core values and ethical tenets. As a result, not only were patients able to still receive care in some form during the pandemic (i.e., via telehealth) but also the future seems promising for those vulnerable populations whose access to care is limited. By demonstrating that the goods of the nursing profession can be both protected and promoted even when technology shakes up the traditional ways of doing things, nurses have proven that even postpandemic, these changes will be lasting, with incredible benefits to patients.

This chapter has revealed that various goods of the nursing profession—namely nurses’ connection to patients and their presence—can transcend physical separation and be conveyed through a computer screen. In addition, because even more patients can be reached via telehealth, this technology may even *improve* the way that nurses, and providers on the whole, connect with their patients. Other professions need only to look to nursing to find inspiration in nurses’ “kind of ‘being with and doing with’ that aims at developing human potential” (Wu & Volker, 2011, p. 473). Doing so has the potential to make health care more equitable, more person-centered, and more humanistic for all. With all this in mind, Chapter 6, the final chapter of this work, will act as a concluding

reflection that brings together ideas and concepts from the preceding chapters, as well as present some of the lingering questions that remain—i.e., potential subjects of future inquiry—concerning patient–provider communication and technology in the context of the healthcare encounter.

Chapter 6: Closing Reflections on Patient–Provider Communication and Technology

This dissertation has argued for and recognized the importance of communication in the healthcare encounter, and particularly to the relationship that transpires between patient and provider. In Chapter 1, I explored the role of technology in health care, particularly in the current historical moment, and examined it alongside patient–provider communication in the past, present, and future. Building on this, Chapter 2 looked at the current state of patient–provider communication through a review of the literature, and noted the importance of this communication to that dyadic relationship and to a host of other factors, including patient health outcomes. The chapter also introduced the idea of communication ethics literacy, and shared ways in which it can be used to reveal goods that patient–provider communication is protecting and promoting, the philosophy of communication that gives a reason for why such communication takes place, the applied communication context that reveals how a particular issue is spoken about, and the narrative ground that shapes and molds communication as it occurs between individuals; in particular, the chapter examined patient-centered communication and the ways in which it can be connected to those communication ethics concepts. Chapter 3 built on the groundwork laid in Chapter 2, in that it also looked at the current state of patient–provider communication through the relevant literature and how this communication affects the patient–provider relationship. However, in Chapter 3, I added an additional layer of complexity to the discussion by examining this relationship through the lenses of gender and race and ethnicity in health care, thus placing social justice issues in the

context of healthcare communication, including the communication ethic of patient–provider communication.

Chapter 4 then involved the integration of technology, tackling questions related to how technology is leading to a restructuring of the patient–provider relationship and the communication that occurs within that context. In this chapter, I examined past and present technologies and the ways in which they have shaped the realm of medicine, with attention paid to the immediate and perhaps lasting effects of the COVID-19 pandemic in connection to technology and health care. One important point made within this chapter was that although technology has given patients the opportunity to become more active participants in their own health care, it has also exacerbated existing barriers within health care and created new ones; for example, a key question is how patient-centeredness can be established or retained in healthcare communication, especially with the continued integration of technology. In response, Chapter 5 presents the profession of nursing as a possible solution, finding the contact and connection created with patients in the context of the patient–nurse relationship to be one of the primary goods of nursing. This good, as well as others, can be protected and promoted even when, and especially when, technology becomes a key part of health care—it can also be extended beyond nursing, to influence other healthcare professions and practices.

Over the course of this project, I have explored literature concerning the role of technology in health care, patient–provider communication, and social justice issues within health care. In addition, I have approached this overall topic from a communication ethics perspective, borrowing from the work of Arnett et al. (2009, 2018), as well as from Fritz (2013). In doing so, I have aimed to contemplate, as a

philosophically oriented communication scholar, the implications of such a change within medicine, both for contemporary providers and consumers of health care. Accordingly, the final chapter of this project will provide concluding thoughts and reflections related to findings made over the course of this project, then note some of the questions that still remain, which may be appropriate for and should be explored via future inquiries.

The Technological Future of Health Care

When I began working on this dissertation in the summer of 2020, the United States—along with the rest of the world—was several months into the first wave of the COVID-19 pandemic. I wrote in the first chapter of this work that, as of late September 2020, there was “no apparent end in sight” to the pandemic; happily, as of early April 2021, that is now a different story. Although variants of the SARS-CoV-2 virus have emerged around the world, threatening to complicate efforts to return to a state of normalcy, vaccines are available and are being distributed. Since vaccine distribution began in the United States on December 14, 2020, and as of April 7, 2021, more than 168 million doses have been administered—about 19% of the total U.S. population, or 63.1 million people, has been fully vaccinated (Huang & Carlsen, 2021). Still, the total number of cases in the United States has exceeded 30 million (30,596,830, to be exact, as of April 7, 2021), and 554,420 people have died from COVID-19 (Centers for Disease Control and Prevention, 2021).

Although this work was heavily influenced by the current historical moment, my scholarly interest in the intertwining of health care and technology predated the COVID-19 pandemic. In particular, through my work as an associate staff editor for the Oncology Nursing Society (ONS), I have been able to glimpse real-world impacts of the integration

of technology into the clinical setting, including from providers' perspectives. But, as I have written elsewhere in this dissertation, ONS, like many other professional organizations, met the COVID-19 pandemic by addressing members' concerns and quickly building resources to help providers, especially nurses, to navigate the changing landscape of health care—cancer care in particular—in the current historical moment. The work I do at ONS was likewise drawn up into those efforts. A major part of that was helping nurses, and healthcare providers overall, to adapt to these changes in real time, including how to adapt the profession and their practice to another medium entirely: telehealth.

It would have been nearly unthinkable to attempt to write a dissertation in this historical moment about technology, health care, and its effects on both patients and providers, especially in the context of communication, without acknowledging that elephant in the room: the COVID-19 pandemic. It was inevitable that the pandemic would become a major part of this project—and also that it would likely continue to influence health care for many years to come. This project has attempted to grapple with not only technology and health care but also with what the pandemic has revealed within the practice of health care and the healthcare system at large, including a host of inequities and inequalities. The prognosis is hopeful, though: Echoing voices from throughout this project, what emerges in terms of health care in the wake of the COVID-19 pandemic has the potential to be better, and for more people, than what existed before.

All that has been discussed within this dissertation, including the COVID-19 pandemic, has a considerable influence on how health care of the future might look, with important implications for everything from how hospitals are designed, to how care is

delivered (such as virtually versus in person), to just how equitable that care being delivered actually is. In an article published by *Bloomberg CityLab*, which reports on cities, communities, and neighborhoods across the world, architecture critic and journalist James S. Russell (2021) contemplates the way in which “the pandemic has been a powerful engine of transformation, for better and worse,” for healthcare institutions:

It’s accelerated the trend to adopt remote technology and move care out of big acute-care complexes to ambulatory complexes to ambulatory settings closer to patients. It’s exposed the huge disparities in hospitalizations and deaths by poorer and minority patients. And it’s changing the ways hospitals look and feel, as the extraordinary stresses that Covid has put on staff, patients and families has health providers focusing on wellness as well as disease treatment. (para. 5)

In the past year, Russell (2021) writes, the COVID-19 pandemic has “exposed the weaknesses of a fractured U.S. health-care system,” revealing to the world “horrifying scenes of frantic clinicians running among patient beds parked in hallways, families saying goodbye to loved ones via iPad, and refrigerator trucks stacked with bodies because funeral homes are full” (para. 3). Quoted in Russell’s (2021) article, Neil Shaw, an obstetrician who leads the Delivery Decisions Initiative at Boston’s Ariadne Labs, a center for health systems innovation associated with Brigham and Women’s Hospital and Harvard University’s Chan School of Public Health, states that “Covid has taken every inequity in society and thrown them into a pressure cooker” (para. 3).

But there is also a more positive and optimistic reading of the pandemic. Says Russell (2021), “U.S. health care could emerge from the pandemic with better, more resilient infrastructure and practices” (para. 5). The changes necessitated by COVID-19

essentially forced hospitals and other healthcare institutions to “adopt new regulations and habits,” many of them “[t]hings that advocates have pursued for decades” (Russell, 2021, para. 5). Particularly relevant to this project is the following change: “As schools and workplaces went remote in 2020, so too did health care” (Russell, 2021, para. 6). Russell (2021) says that the “Covid-era turn to telehealth . . . dovetails with several trends affecting the future of hospitals” (para. 6), adding that there is already considerable investment from innovators and health technology companies that supports the migration of care from the traditional medical setting to elsewhere. According to one estimate, as many as 25% of outpatient services could move to a telehealth model, meaning, for instance, that it would “reduce the need to bring a fragile patient from a rural town to a big-city hospital for a 20-minute examination” (Russell, 2021, para. 7). The possibilities also exist for “emergency medical personnel to use telemedicine to treat patients at the scene,” something already practiced by NYC Health + Hospitals, which is the country’s largest public hospital system, and for 911 calls to be “diverted to videoconference exams if immediate hospital treatment is not needed, conserving ambulances and [emergency room] resources for those most in need” (Russell, 2021, para. 7).

Although this dissertation primarily dealt with the use of telehealth in circumstances similar to those just described—the virtual visit in particular—Russell (2021) mentions “its tech-driven sibling, digital health,” and the possibilities existing there. For example, picture a “hospital overwhelmed by Covid cases — or a terror attack, natural disaster or other mass-casualty event — [in which] assistance can be patched in with video and electronic diagnostic tools to support overburdened staff” (para. 8). Wearable health monitoring devices also “will play a role in this technological

transformation,” as many consumers already know and use consumer-grade products intended for health monitoring, like FitBits, which have the potential to be used in COVID-19 detection (Russell, 2021, para. 9). Russell (2021) is careful to say, though, that “[f]or all the optimism about using this crisis to improve care delivery, the rickety U.S. health-care system resembles an old house where you pull up a broken floor board to reveal rotting beams and a cracked drain pipe” (para. 18). But the time may have come for repair—or a complete renovation. In the case of digital health, for instance, which has taken over “many diagnostic functions once conducted in clinics, ambulatory care centers and hospitals,” it “is likely to further disrupt legacy business models and ‘break things,’ as tech has done in so many other aspects of life” (Russell, 2021, para. 20). This is not necessarily a bad thing.

A June 2020 *New Yorker* article by staff writer John Seabrook tackles many of these same topics, including the simple fact that for literal years, telehealth, telemedicine, and other forms of virtual care made up just a tiny part of the United States’ \$3.6 trillion healthcare industry. Because of the COVID-19 pandemic, though, among other reasons, “millions of people are discovering its benefits and shortcomings for the first time” (para. 13). Seabrook (2020) describes the various iterations of virtual care, including “the type of hardwired hospital-to-clinic setup that allows workers in a large hub hospital to assist in complex emergency procedures in distant spokes” (para. 14) and the type that this project is primarily concerned with—that is, “virtual interactions between individual doctors and patients, in which the participants rely on an audiovisual hookup instead of an in-person visit” (para. 15). He continues:

You have a bad sore throat but don't want to wait to see a doctor—or you are among the thirty per cent of millennials who don't have one. You could go to the E.R. or to a brick-and-mortar urgent-care center. Or you could download the telehealth app you saw advertised on MSNBC. Before long, you are connected to a physician, who, using your phone to look down your throat and relying on your description of the swollen glands in your neck, can prescribe antibiotics and other noncontrolled substances. You've saved yourself a trip to the clinic, and you haven't made other people sick or caught something else yourself. (Seabrook, 2020, para. 15)

Such visits can even be improved through the use of various “Internet-connected devices that collect patient data at home and then send it to a doctor,” like fitness trackers (Seabrook, 2020, para. 16). Thanks to these capabilities, it has been estimated that remote monitoring and checkups could replace anywhere from 50% to 70% of visits to the doctor's office (Seabrook, 2020).

Again, though, Seabrook (2020) says, “until the pandemic, most Americans weren't interested” in telehealth (para. 17). Exemplifying this, telehealth totaled only 0.1% of all medical claims filed in 2018, according to data from FAIR Health, a nonprofit that collects and manages data concerning insurance claims (Seabrook, 2020). Relatedly, according to the National Business Group on Health, which shares results from an annual survey of employee health benefits offered by large companies, although 70% of companies included telehealth in their plans in 2016, just 3% of their employees used the benefit; employees did not know the benefit existed in some cases, and in others they reported that they did not trust an anonymous doctor (Seabrook, 2020). A 2019 survey

conducted by market research company J.D. Power revealed that 49% of patients thought the quality of virtual care was inferior to an in-person visit (Seabrook, 2020).

As was mentioned earlier in this work, reimbursement for telehealth services has also been an issue. Until the pandemic necessitated changes to telehealth coverage, Medicare covered these services only in rural areas, and visits had to be conducted in a clinical setting (Seabrook, 2020). In addition, many people “clearly want to be in the physical presence of their physician, undergoing the familiar rituals of a checkup—the doctor’s scrubbed hands emerging from the crisp cuffs of a white lab jacket—that no screen can yet provide” (Seabrook, 2020, para. 23). Some of the most vulnerable patients, those who need care the most, like older adults and the poor, “don’t have smartphones or broadband connectivity, or can’t afford extra minutes on their wireless plans” (Seabrook, 2020, para. 20). Telehealth can also be a hard sell for, say, “rural clinics and community hospitals in small American towns,” who “fear that their already meagre medical staffing, and the revenues generated from procedures that can be performed on-site, will be further hollowed out by remote medicine” (Seabrook, 2020, para. 20). The economic bedrock of many healthcare facilities is, after all, in-person visits and procedures. In-person primary care alone makes up almost 50% of medical visits (Seabrook, 2020).

As for providers themselves, according to a 2019 survey conducted by the American Medical Association, only one in three specialists reported feeling confident that virtual care would benefit their medical practice, compared to two in five primary care providers. Seabrook (2020) points out that compounding “the diagnostic and therapeutic limitations of seeing patients on a screen” are economic considerations—“virtual doctors’ visits can actually take longer than in-person ones, owing in part to the

widely varying ability of patients to operate the necessary technology” (para. 23). In addition, just 10 states require that private insurers “reimburse virtual visits at the same rate and with the same freedom from restrictions as in-person visits” (Seabrook, 2020, para. 23). Asks Seabrook (2020), “Tele-doctors could spend more time with fewer patients for less money. What’s the appeal in that?” (para. 23).

With all this in mind, the primary question that Seabrook (2020) ponders over the course of that *New Yorker* article is this: “If virtual care is the future of health care, is it a future that we want?” (para. 13). The question is a timely one. After all, in response to the pandemic, there have been a flood of changes to regulations governing telehealth. The Coronavirus Preparedness and Response Supplemental Appropriations Act, signed on March 6 by then-President Donald Trump, allowed Medicare beneficiaries to use their benefits for telehealth—even for health care like physical therapy and psychotherapy—without the restrictions that once existed. (In response, Medicare claims for telemedicine went from 10,000 a week in March 2020 to more than one million a week just a month later, in April 2020.) Health Insurance Portability and Accountability Act privacy rules were temporarily waived to allow patients and providers to meet virtually, such as via Zoom or FaceTime. Encouraged by the federal government, individual states even suspended rules limiting doctors’ practices to only the states in which they are licensed, and similar changes were observed in relation to providers’ writing prescriptions for patients who reside out of state.

Corey Siegel, a doctor within the Dartmouth-Hitchcock healthcare system who is quoted in Seabrook’s (2020) article, is reluctant to say that “anything good has come out of COVID-19” (para. 43). However, Siegel reported that as of April 2020, barely a month

into the pandemic, his practice had done close to 700 telehealth visits: “Already my colleagues are saying, ‘This is great, let’s do this after the pandemic ends.’ We might have learned in a very scary way that this is a great way to deliver care to patients” (Seabrook, 2020, para. 43). But even though telehealth offers advantages like the ability to talk with providers outside of normal office hours, including via chat for less formal, more unstructured interactions, it does have its limitations, particularly those of a diagnostic nature. Seabrook (2020) reports that “it’s one thing to offer tele-care to a patient you know; it’s another to try to distinguish a bowel disease from indigestion during a virtual first visit,” adding that a “tele-doctor who misdiagnoses a stomach ache that turns out to be stomach cancer has the same liability that a traditional doctor does,” so virtual providers “are supposed to tell patients whose symptoms suggest a more complicated underlying condition to make an in-person visit to an office, for lab tests and a hands-on physical exam” (para. 44).

Providers interviewed for Seabrook’s (2020) *New Yorker* piece call telehealth doable, especially within the context of a deadly pandemic, but share their concerns about the rush to replace in-person care with virtual care. Thomas Nash, a New York City internist, says he worries “that it’s going to delay a good exam, and get in the way of deeper interactions between people and their doctors” (Seabrook, 2020, para. 46). David Avram, a dermatologist in New York City, says that telehealth is OK for doing things like checking moles, “because you can look at a mole with a smartphone”; however, “he’s postponing full-body exams until he can return to the office” (Seabrook, 2020, para. 46). Martin Beitler, another New York doctor, offers the example of a “belly exam” as one procedure that cannot be performed via a screen, and notes that at its worst,

telehealth encourages a “knee-jerk, give them antibiotics for every cold that they get” attitude. That’s the kind of medicine you are going to get if you switch to all telehealth” (Seabrook, 2020, para. 45).

What has been established over the course of this project, though, is the simple fact that despite some drawbacks, telehealth and other forms of virtual care have the potential to do more good than harm. In some ways, telehealth, especially when viewed from a highly idyllic perspective, “is a way of returning the doctor-patient relationship to the pre-insurance days,” when a doctor’s making house calls was typical and commonplace (Seabrook, 2020, para. 47). Going back to Russell’s (2021) metaphor of the U.S. healthcare system as an old house in a state of disrepair, perhaps the time has come for disruption. As Seabrook (2021) writes, the current healthcare system “is user-unfriendly and wasteful,” with, for example, the average patient needing to wait 29 days to get an appointment with a physician; in addition, “in most cases you don’t know what the visit and the lab work will cost until you receive a bill,” and if you also require a prescription, “you have to make a separate trip to the pharmacy” (para. 49). As has been demonstrated in this project, too, the prepandemic model of health care certainly had its issues and presented significant barriers to a not insignificant number of patients.

Relatedly, the average annual deductible in traditional employee health insurance plans exceeds \$2,000. Direct-to-consumer telehealth companies offer virtual appointments starting at about \$80 for those without insurance, with some even having annual memberships with access to certain virtual specialists instead of billing for each visit. Interest in a more consumer-driven model of health care is only growing; after all, “[w]hen you turn patients into more traditional consumers, they get to determine what

they find valuable,” says Zachariah Reitano, co-founder of telehealth company Ro, which gives customers the ability to request medications and get them delivered to their home (Seabrook, 2020, para. 50). Reitano adds that patients can “Google” and “compare,” demanding “price transparency, metrics on the quality and efficacy of care, and the consumer-driven experience they get from Amazon, Apple, or Nike” (Seabrook, 2020, para. 50). The benefits of this are manifold, Reitano notes: “The technology dramatically improves, prices come down, and the patient experience becomes better” (Seabrook, 2020, para. 50).

There is, to be sure, a major difference between having a telehealth appointment with a virtual—but real—provider and listing “your symptoms on an Amazon or a Google portal” and getting “a diagnosis from an A.I.” (Seabrook, 2020, para. 52). And even though some providers say that the telehealth encounter is artificial and unlike a normal human interaction—internist Nash states that “eyeball to eyeball,” as in telehealth, is very different than an in-person visit, where “you shift your body a little, you look to the left for a second, you gather your thoughts, you take a pause, which you really can’t do in this compressed screen-to-screen interaction”—proponents of telehealth feel that it is actually more appealing for this reason (Seabrook, 2020, para. 57). During the first 10 minutes or so of an in-person visit, providers are often on a computer reviewing electronic records “while you sit across from them looking at their framed degrees and family photos” (Seabrook, 2020, para. 56). During a virtual visit, though, “the doctor meets you face to face, and her gaze mostly stays on you (or on your records on her screen—it can be hard to tell the difference)” (Seabrook, 2020, para. 56). Roy Schoenberg, co-CEO of Amwell, a telehealth company that aims to connect patients with

providers, calls it “a very intimate encounter,” adding that “once you get exposed to it, at some point you’re going to say, ‘If this is available to me, why should I revert to the laborious, dangerous, hard effort of going into the practice?’” (Seabrook, 2020, para. 56). This is a question that many have begun to seriously contemplate.

Next Steps, Additional Questions

And this question, as well as others, will only be further contemplated as we move out of the pandemic and into the new frontier of health care that waits on the other side. Already, there are signs that changes brought about by the COVID-19 pandemic are sticking around for perhaps the long haul. In late 2020, for instance, the Centers for Medicare and Medicaid Services made the additional telehealth coverage introduced as a temporary measure because of the COVID-19 pandemic a permanent part of the Physician Fee Schedule (“What Oncology Nurses Need to Know About Telehealth,” 2021). It is clear that the rapid expansion of telehealth services—and the demand for them—has moved health care several years ahead into the future; what was expected in 5 or 10 years is now, well, now. And even if demand for telehealth falls from its pandemic highs, it is hard to argue with the fact that telehealth has become an important, integral part of health care that likely is not going away anytime soon. Patients and providers alike have recognized the important role it plays within the larger healthcare continuum, and it is not likely that many will be willing to give that up to return to an era of health care that failed to meet the needs of many of those it was supposed to serve.

On the whole, the central question of this project has examined how technological changes, namely the use of telehealth in healthcare encounters, have affected this practice and, really, the whole of health care. Although I do not have clinical experience in this

arena, my position as a communication scholar working within healthcare publishing, specifically for a nonprofit membership organization of oncology nurses, has afforded me a unique perspective on this subject. Accordingly, I believe, first and foremost, that telehealth, particularly postpandemic, is an excellent complement to in-person health care. If health care is driven by professional goods like equity, connection, and patient-centeredness, it should make little difference whether that care is delivered in person, via a traditional brick-and-mortar office visit, or virtually, via telehealth. And as we have seen, this choice—the ability to choose how you would like to receive health care, as well as when, where, and from whom—is important to patients. This choice places more control over health and health care into the patient’s hands, and even puts patient and provider on a more level playing field in terms of the power imbalance inherent in the healthcare encounter and in this healthcare relationship. In the current historical moment, or at least prepandemic, health care was one of the few remaining institutions in which this type of flexibility and control was largely absent. The COVID-19 pandemic, though, is helping to change all that—and it would be a major step backward to simply, unthinkingly revert to past practices postpandemic, when the demand clearly exists for something different.

The combination and convenience of virtual health care and in-person health care may even create an overall better patient experience, fostering better patient–provider relationships and communication. There is the potential for the ethic of patient–provider communication to be, in a sense, rewritten to achieve this; one suggestion for this revision is to look toward the profession of nursing, which, at its heart, emphasizes the goods of contact, connection, and presence, even when physical barriers attempt to stand

in the way. Although Chapter 5 in particular dealt specifically with the profession of nursing, these goods can, and should, be taken up as part of the communication ethic of most all healthcare professions, namely those that involve as well as depend on communication between patients and providers. As has been established, the fundamental practice of nursing—or the provision of high-quality health care—does not change with the medium; those deeply ingrained goods of the profession remain regardless.

With that being said, one important question that will guide my future work as both a practitioner and a scholar is how the healthcare encounter at large—whether virtual or in person—can become a better experience for all involved. As has been explored in this dissertation, no matter the medium, there remain issues inherent in communication between the patient and their provider that must be addressed for the vision of a more democratic, more equal, and simply *better* practice of health care, with the patient at the forefront as the empowered healthcare consumer, to materialize. We know conclusively that communication is valuable, an important component of care affecting numerous outcomes. Thus, conscious work must be engaged and undertaken to center such communication within health care and within the patient–provider encounter, while acknowledging the ways in which issues of social justice become enmeshed within the context of healthcare communication.

Relatedly, a second question that requires further interrogation and investigation involves the role of telehealth and how it can fulfill its promise as an equalizer of health care. This dissertation has shown that telehealth, as well other healthcare technologies, has both burdens and benefits. In terms of the latter, for example, it can provide access to care for those in remote areas or who cannot physically come to a healthcare facility to

receive care, for whatever reason (including a dangerous, life-threatening pandemic). However, despite removing these physical barriers to care, access may continue to be a challenge for patients who lack the needed technology (e.g., computer, smartphone) or sufficient data or internet service, who have low technological literacy, or who are fearful of technology. That hope of an equitable future in terms of health care will forever remain out of reach if these issues remain ignored. Additional research must be done, by both practitioners and scholars, to determine how best to reach populations in need and grant them the same access (both in terms of the technology itself and the skills needed to use the technology) to telehealth, among other services, that other populations have. For example, some institutions are already delivering tablets and mobile hot spots to patients who need them, conducting practice appointments between patients and providers prior to the actual appointment, and using intermediaries (e.g., medical assistants, healthcare ambassadors) to help patients log in and connect them to their remote provider (“What Oncology Nurses Need to Know About Telehealth,” 2021).

In addition, although this dissertation has made clear that the same goods of healthcare professions should exist whether care is delivered virtually or in person, it is necessary to recognize that the medium does influence the healthcare encounter, and particularly the communication that transpires within it. A third question that has been raised over the course of this project and that deserves immediate inquiry is how a provider’s “web-side” manner may be improved—or how providers, and even patients, can use technology, like telehealth, to its fullest extent for effective yet authentic connection and communication. The challenge here is to find ways to convey the primary goods of a given healthcare profession, such as nursing, when the nature of care has

changed. After all, “the same empathy and understanding” employed “at the bedside, chairside, and exam room” should be carried over onto “the video screen” (“What Oncology Nurses Need to Know About Telehealth,” 2021, p. 26). Guided by the profession of nursing, this dissertation has introduced the idea of “presence,” which is maintained by the provider regardless of any physical or metaphorical barriers; this is a good place to start in terms of creating genuine, authentic connection between patient and provider, even with the barrier of a screen. With presence, this barrier may actually become a facilitator of humanistic, patient-centered health care.

Again, with communication ethics in mind, it becomes imperative that the following is recognized: that the healthcare experience, including communication that transpires during the patient–provider encounter, is not the same for all. In the current historical moment especially, there are multiple perspectives and understandings, many of which have long been marginalized and suppressed. Future work in this realm must be attentive to this multiplicity, with listening and learning being necessary for change, like the emergence of a more equitable version of health care, to occur. Because healthcare technologies, including telehealth, abound with possibilities for this arena, they will be vitally important in moving forward toward a reshaping and democratizing of the practice of medicine that, ultimately, benefits all, patients and providers alike.

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