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The Ethical Implications of Telemedicine and the Internet for Home Healthcare

Keith Alan Bauer
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To the Graduate Council:

I am submitting herewith a dissertation written by Keith Alan Bauer entitled "The Ethical Implications of Telemedicine and the Internet for Home Healthcare." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Philosophy.

Glenn Graber, Major Professor

We have read this dissertation and recommend its acceptance:

John Hardwig, Richard Aquila, Susan Dimmick, Jay Sanders

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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John Hardwig

Richard Aquila

Susan Dimmick

Jay Sanders

Accepted for the Council:

Dr. Anne Mayhew
Vice Provost and
Dean of Graduate Studies

(Original signatures are on file in the Graduate Student Services Office.)

THE ETHICAL IMPLICATIONS OF TELEMEDICINE AND THE
INTERNET FOR HOME HEALTHCARE

A Dissertation
Presented for the
Doctor of Philosophy Degree
The University of Tennessee, Knoxville

Keith A. Bauer
May 2002

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DEDICATION

To my wife, Debbie,
whose giving nature and unyielding belief in my abilities
allowed me to actualize my potential and to achieve a long sought after goal
and
to Daisy, my fuzzy and lovable Golden Retriever, who reminds me that the best things
in life can be a belly rub and an old tennis ball.

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Second, I want to thank Ken W. Goodman at the University of Miami whose own work in medical informatics and ethics inspired me to write my dissertation in the first place. At a very early stage of my research, he exposed me to a universe of scholarship previously unknown to me and encouraged me to pursue my dissertation topic.

Third, I want to thank Jeff Collmann at Georgetown University Medical Center. Through his efforts, I was able to “do” applied medical ethics by participating in a 1999 FDA/NSF task force on the future of home health technologies and by conducting interviews with peritoneal dialysis patients about their experiences using telemedicine- and Internet-supported dialysis in their homes.

I also want to acknowledge certain members at the Institute for Ethics at the American Medical Association in Chicago. During my fellowship year at the Institute, Kayhan Parsi, Karine Morin, and Art Derse showed genuine interest in my work and facilitated the completion of my dissertation through their expertise and collegiality.

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ABSTRACT

Information and communication technologies, such as the Internet, are transforming our business, education, and leisure practices. The healthcare industry is no exception to this trend and the burgeoning field of home-based telemedicine is evidence of this. As with many technological innovations in healthcare, assessments of home-based telemedicine and correlative policies are being driven by economic and technological criteria that emphasize cost reduction and technologic efficiency. These are important considerations, but these assessments neither identify the ethical values involved in home-based telemedicine nor address its possible ethical implications. Since the economic and technologic viability of home-based telemedicine is not identical with its ethical appropriateness and justification, this is a serious oversight. Hence, the use of telemedicine and the Internet in home healthcare invite a discussion about their ethical implications for the traditional goals and moral ideals of healthcare practice.

The purpose of this study is to argue that the ethical implications of telemedicine and the Internet for home healthcare should be better understood and incorporated into future home-based telemedicine research and policy development. To this end, this study reviews the home-based telemedicine literature and examines the normative connections between home-based telemedicine and the following: (1) provider-patient relationships, (2) healthcare privacy and confidentiality, (3) distributive and family justice, and (4) informed consent.

This study concludes that given the traditional values and goals of healthcare, information and communication technologies present both possible harms and benefits for home healthcare recipients and providers, but that on balance the benefits are more

likely to outweigh the harms. However, because the exact benefits and harms of home-based telemedicine are unknown at this time, additional empirical research and outcome studies are needed. Finally, as part of a general technology assessment of home-based telemedicine, future research should include an ethical evaluation of all information and communication technologies that will be employed. If this is not done, home-based telemedicine policies will be inadequately informed and many of the possible harms of home-based telemedicine that could be prevented will not be prevented.

PREFACE

History can be conceived of as a series of Ages, each of which has developed and applied new technologies. This was the case with the Stone Age, the Bronze Age, the Iron Age, and the Industrial Age. Take, for example, the industrial revolution. During this period, the manner in which products were manufactured and distributed was drastically altered. Semi-automated factories that relied on assembly lines were constructed and a network of railway lines on which steam-powered locomotives rode spread out across continents. More importantly, however, the industrial revolution also transformed social organization by increasing urban populations. This, in turn, created new social and psychological pressures for persons and had significant public health consequences for millions of people.

We are now in a new Age—the Information Age—and we live in an information society where cellular phones, satellites, television, handheld computers, and the Internet, have and continue to influence how and where we work, play, and live. The healthcare industry is not exempt from the revolution in telecommunication technologies, as can be readily observed in its growing use of electronic medical record systems and Internet websites that provide health-related information and services. Like the Industrial Age before it, the Information Age will likely have profound consequences for the way the healthcare industry is organized and, subsequently, the way healthcare information and services are delivered to individuals and populations.

One sector of the healthcare industry in particular, home healthcare, is being dramatically changed by the use of information and communication technologies and is

giving rise to a new field known as *home-based telemedicine*. Home-based telemedicine uses communication and information technologies to provide healthcare services to patients in their homes from a distance. Home-based telemedicine is promising because of its potential to reduce healthcare costs, augment patient access to services, improve quality, and facilitate the management of patient information. There is, however, a sizable gap in the philosophical and medical ethics literature on home-based telemedicine. *The Ethical Implications of Telemedicine and the Internet for Home Healthcare* attempts to fill this gap by examining some key ethical issues associated with using communication and information technologies to provide healthcare services to patients in their homes.

Chapter 1 provides background on telemedicine. It looks at various operational definitions of telemedicine and provides a synopsis of telemedicine's history and identifies common telemedical applications, technologies, and tools such as the Internet. The advent of home-based telemedicine has not occurred within a social vacuum, but has arisen as a result of very real demographic and economic pressures. This chapter explores the rise of home-based telemedicine in light of these demographic and economic variables.

Chapter 2 explores the ethical implications of home-based telemedicine for provider-patient relationships. Addressed here are questions about how machine- and electronic-mediated relationships (e.g., the Internet, e-mail, and video-visits) could affect the distribution of power between patients and providers, as well as patient autonomy and well being, medical paternalism, trust, empathic communication, and overall patient health outcomes. In the process, various normative models of the provider-patient

relationship and their application to the relationships of home-based telemedicine are analyzed.

Chapter 3 begins with a general discussion of the ethical significance of privacy and confidentiality in healthcare. Particular attention is given to how telemedical technologies, such as the Internet, could affect the decisional, physical, and informational privacy of patients and family caregivers who use home-based telemedicine technologies. This chapter also addresses the possibility of conflicts among these three types of privacy and the need for tradeoffs among them.

Chapter 4 examines home-based telemedicine from a healthcare justice perspective. First, distributive justice is discussed and the specific benefits and burdens of home-based telemedicine are identified. Here, both the democratizing and stratifying potential of home-based telemedicine for healthcare access, availability, fairness, and quality are explored. The second half of this chapter examines family justice and the goal of attaining healthcare justice within families, the need for a family-centered model of healthcare in home-based telemedicine practice, and the possibility of conflicts between distributive and family justice.

Chapter 5 explores the ethical implications of home-based telemedicine for patient and family caregiver informed consent. First, a brief history of informed consent is provided and its ethical significance is discussed. Next, both the requirements of informed consent and the difficulties of achieving it in the context of patients' homes are examined. This chapter also looks at how information and communication technologies can be used to inform and obtain the consent of patients and family caregivers.

Chapter 6 builds on previous chapters and provides a case analysis of a specific application of home-based telemedicine by home health patients diagnosed with end-stage renal disease. Patients' use of information and communication technologies to support their home peritoneal dialysis is evaluated in terms of its implications for quality of life, privacy, confidentiality, provider-patient relationships, justice, and informed consent.

Chapter 7 concludes with a discussion of the remaining knowledge gaps in home-based telemedicine research and looks at the technical, economic, regulatory, and social barriers that prevent its wide-scale adoption. Specific policy recommendations are made to overcome these knowledge gaps and barriers. Finally, key ethical issues associated with home-based telemedicine are summarized and ethics recommendations for home-based telemedicine research and practice are presented.

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INTRODUCTION

Digital technology, fiber optics, cellular phones, satellite television, computers, the Internet, and interactive software programs now fill our offices, our homes, and even our cars. These technologies are becoming so tightly woven into the fabric of our daily lives that their ubiquity frequently goes unnoticed. Ironically, the growing transparency of these technologies is proof that we are in the midst of a revolution—an information and communications revolution—that is profoundly transforming the way we do business, provide services, educate children, and spend leisure time.

The healthcare industry is also changing. Evidence of this can be found in the burgeoning field of home-based telemedicine, which uses communication and information technologies, such as the Internet, to provide healthcare services and information to patients in their homes from a distance. Home-based telemedicine is significant because of its potential to reduce healthcare costs, augment patient access to healthcare services and information, improve the quality of care patients receive, and facilitate the management, storage, and transmission of health-related information.

A growing number of home-based telemedicine programs are being funded, developed and implemented throughout the United States. The majority of these programs are federally funded pilot projects that are required to provide outcome studies to demonstrate their effectiveness (Baquet 1999). The limitation of these studies is that the majority of research has and continues to emphasize the economic, technical, and clinical viability of home-based telemedicine while ignoring its ethical aspects (Sanders and Bashshur 1995; Jerant and Epperly 1997; Baines 1999).

Moreover, although a good amount has been written on the ethical issues associated with high-tech medicine and home healthcare, the medical ethics literature is just beginning to take notice of the ethical significance of the Internet and other telemedical technologies for home healthcare and for the healthcare industry in general. To date, very little has been written on the ethical implications of telemedicine and the Internet for healthcare. There is, however, a notable exception. In his book, *Ethics, Computing, and Medicine: Informatics and the Transformation of Health Care*, Kenneth Goodman provides the first and only systematic survey of this intersection and says the following about ethics, medicine, and computing:

While each domain is huge, it is not clear how large the intersection is. One might picture a Venn diagram with the circles labeled “ethics,” “medicine,” and “computing.” We already have the two-way intersections or classes *medical ethics* (or more broadly and accurately *bioethics*), *medical computing*, and *computing ethics* (Goodman 1998: 2).

Owing to a dearth of ethical reflection in this area, there is a real danger, according to Goodman, of either a “slavish boosterism” or a “hyperbolic skepticism” toward the use of information and communication technologies in healthcare. Home-based telemedicine faces similar dangers. Research into home-based telemedicine is supposed to assess the quality of patient life by informing us how it compares to traditional healthcare approaches as well as meeting, if not establishing, a standard of care. The problem, however, is that inadequate attention is being given to the ethical implications home-based telemedicine. This is a mistake and could eventually lead to either slavish boosterism or hyperbolic skepticism of which Goodman speaks.

The Ethical Implications of Telemedicine and the Internet for Home Healthcare examines, at best, only a small area within this growing intersection of ethics, computers,

and medicine. In addition to bioethicists, this work may be of interest to persons who are interested in the philosophy of technology and to a larger universe of scholarship, theoretical and empirical, that deals with the cultural, ethical, and social ramifications of what has become known as the “information age” or “information society” (Martin 1988). The primary aim of this study, however, is to provide an ethical assessment of home-based telemedicine in terms of core medical ethics values, goals, and issues.

By “an ethical assessment of home-based telemedicine” is understood an inquiry into general normative considerations of what “ought to be” and what “ought not to be” the case for home-based telemedicine. It also covers what is “good,” “bad,” “right,” “wrong,” “appropriate,” and “inappropriate,” in the use of information and communication technologies in home healthcare (Beauchamp and Childress 1994). Also understood is the extent to which home-based telemedicine meets generally accepted norms of professional, medical, and research ethics, e.g., appropriate quality of care, as well as safeguards for privacy, confidentiality, autonomy, and informed consent (Agich 1993; Pellegrino and Thomasma 1993; Nichols and Mirvis 1998). An ethical evaluation of home-based telemedicine also includes considerations of equity in the distribution of healthcare services and whether it is defensible to extend access to care even if it were at the cost of lowered quality of care (Daniels 1993; Gutmann 1998).

First, home-based telemedicine raises questions about the informational privacy of patients and family caregivers. There are concerns about electronic transmission of medical information. Are these transmissions secured? Do health-related websites track their users? There are also concerns that the introduction into the home of more information and communication technologies will transform the private sphere of the

home into a porous public sphere, in which physical and decisional privacy is threatened and family intimacy eroded (Arras 1994; Arras 1995). The sorts of tradeoffs among physical, decisional, and informational privacy in the context of home-based telemedicine require ethical reflection.

Second, home-based telemedicine is likely to affect provider-patient relationships. Analyses of how modern technology can lead to a mechanistic reduction of human experience are commonplace in the philosophical literature on technology. Along these lines, it is argued that mass computerization is leading to the atomization of human task performance, which, in turn, is leading to a greater impersonalization of society where people live in physical isolation from each other (Ferre 1988). It is important to know how electronic- and machine-mediated provider-patient relationships of home-based telemedicine differ ethically and socially from traditional approaches. How, for example, do videophones and the use of electronic mail affect the quality of patient care? Moreover, computer- and Internet-based medical information services may encourage patients and families to be more responsible for their own care. This, in turn, may increase autonomy and reduce medical paternalism. However, telemedical services in the home may unnecessarily burden patients and families with excessive information and do-it-yourself healthcare.

Third, home-based telemedicine raises questions about distributive justice generally and within families. How information technologies can simultaneously democratize and stratify societies and what sorts of responsibilities we have to promote the former and minimize the latter have been a central concern of information and communication theorists (Mumford 1991). Although home-based telemedicine has the

potential to increase healthcare access to underserved populations, the social stratification of home healthcare by means of computer-based and networked information systems in the household should not be underestimated. The digital divide applies to healthcare as much as it does to education. With home-based telemedicine, it is possible that some groups, the well off and educated Internet users, will have access to medical information and services that other groups, the poor and uneducated, will not (Department of Commerce 2000).

In addition to macro-oriented distributive justice concerns, it is important to understand how and in what way home-based telemedicine could affect justice within families. What are the consequences of home-based telemedicine for the well being and dignity of patients and family caregivers? What are the benefits and burdens and who should make the decisions to distribute them? Moreover, if large-scale social policy decisions about home-based telemedicine should come into conflict with the wants and desires of patients and families, how should these conflicts about benefits and burdens be adjudicated? Home-based telemedicine and communications policy ought to consider these healthcare justice concerns.

Fourth, home-based telemedicine raises concerns about informed consent. Given the potential for added responsibilities and burdens, at what point are patients and families truly informed about the use of home-based telemedicine and when is it ethically appropriate to employ it? In general, what are the benefits and burdens of home-based telemedicine and are they ethically acceptable? It will be necessary to understand what information patients and family caregivers will need and how the process of informed consent works in the context of home-based telemedicine.

CHAPTER 1

BACKGROUND ON TELEMEDICINE AND THE INTERNET

1.1 Defining Telemedicine

The literal meaning of the word *telemedicine* is *medicine from a distance*. This definition is produced by combining the word *medicine* with the Greek root word *tele*, which means *end, far off, or distance*. We see similar combinations in the word *telephone*, which literally means, *sound from a distance*, and the word *telegraph*, which literally means *writing from a distance*. The etymology of telemedicine, however, tells us very little about the actual practice of telemedicine. The additional problem in obtaining an adequate understanding of telemedicine is that no universally accepted operational definition of telemedicine has been adopted.

Despite agreement on basic principles, what is called telemedicine today is not a monolithic entity or a single unified and well-defined system. Whereas telemedical practice is proliferating in the United States and world-wide, a concept has yet to be universally accepted, and clear distinctions have yet to be made between categorical clinical or diagnostic services rendered remotely through telecommunications and comprehensive telemedicine or telehealth services (Bashshur, Sanders et al. 1997: 6)

One common view of telemedicine, for example, makes telemedicine synonymous with two-way audio-video systems that allow for interactive consults between patients and healthcare providers. However, other definitions of telemedicine are equally common and may include the use of information and communication technologies (e.g., computers) that capture, store, manipulate, and display medical data but not include the use of interactive communications between patients and healthcare providers. Consequently, a fax machine used to transmit patient medical information and the telemonitoring of a cardiac patient would not count as telemedicine under the first

definition whereas they would under the second definition of telemedicine (Denton 1993; Preston 1994).

Although no universal agreement exists among telemedicine experts on the scope of telemedicine and what distinguishes it from alternative forms of healthcare, they do agree that any definition of telemedicine must include three elements. These elements are (1) the use of information and communication technologies, (2) geographic distance between the participants, and (3) health or medical uses. On the basis of these three characteristics, the Institute of Medicine (IOM) defines telemedicine in the following manner:

Telemedicine is the use of telecommunications and information technologies to share and to maintain patient health information and to provide clinical care and health education to patients and professionals when distance separates the participants” (Field 1996: 27)

Like the IOM, the American Telemedicine Association (ATA) has adopted a similar definition of telemedicine that does not overly restrict and specify the kind of medical information that is transmitted, the manner in which it is transmitted, and how the information is used. The ATA definition of telemedicine is as follows:

Telemedicine is the use of medical information exchange from one site to another via electronic communications for the health and education of the patient or healthcare provider and for the purpose of improving patient care (Linkous 1998: 6)

The broad definitions of telemedicine given by the IOM and the ATA can be made more specific, however, depending on whether (a) emphasis is given to a particular application of telemedicine (e.g., video conferencing or Internet) (b) a distinction is made between clinical and non-clinical applications, and (c) whether telemedicine is conceived

of as an integrated system of healthcare delivery rather than a collection of electronic tools.

Non-clinical applications of telemedicine typically include professional education, healthcare administrative duties, management meetings, research, and the aggregation of health data, but they usually exclude medical treatments and decisions for specific patients. Clinical applications of telemedicine involve patient care and include medical decisions, diagnostics, and treatments for particular patients. It is important to note, however, that the non-clinical-clinical distinction can be difficult to maintain in some applications of telemedicine because many of the new information and communication technologies being used allow for a greater convergence of tasks and activities, for example, when e-mail communications between patients and providers are automatically stored in a computerized record system.

There are a number of ways in which clinical telemedicine can be subdivided. One way is to classify clinical telemedicine applications by the point of service or the patient's location, for example, rural telemedicine, correctional telemedicine, and home-based telemedicine. Another classificatory scheme common to clinical telemedicine is to organize services by medical specialization, for example, telepsychiatry, telecardiology, teledermatology, teleradiology, and telepathology (Perednia and Allen 1995; Perednia and Brown 1995). A third approach is simply to categorize telemedical services in terms of present and future healthcare reimbursement policies, for example, emergency care, follow-up care, consultation, and the transmission of diagnostic images (Grigsby and Kaehny 1993).

The IOM's and ATA's tripartite definitions of telemedicine--geography, telecommunications, and medicine—can be also expanded upon when telemedicine is conceived as a system of healthcare rather than as the discrete use of particular telecommunication technologies in isolated medical settings. According to one view, a *telemedicine system* can be defined as follows:

A telemedicine system is an integrated, typically regional, health care network offering comprehensive health service to a defined population through the use of telecommunications and computer technology (Bashshur, Sanders et al. 1997: 9)

When telemedicine is defined as a system of healthcare, the distributive and integrative strengths of information and communication technologies to form a seamless healthcare network are highlighted. This broader definition allows telemedicine to be seen for what it is, namely, an organized system that uses technologic, economic, and human resources to provide a variety of healthcare services. Moreover, this definition of telemedicine, because it highlights the systemic nature of telemedicine, helps to illuminate many of the social and ethical aspects of telemedicine not readily visible in more basic definitions.

Efforts to define the scope of telemedicine have moved in new directions in the past couple of years as a wider group of healthcare professionals have become involved with telemedicine and as more sophisticated communication and information technologies, such as the Internet and interactive software, have emerged. For instance, the more inclusive term, *telehealth*, is becoming fairly common in the healthcare literature. This term is reflective of the broader social and political changes affecting medicine today, namely, a greater emphasis on the role of non-physicians in providing healthcare services and on the importance of *caring* for patients when they cannot be

cured. Telehealth is also being used to express a broader range of patient care activities and healthcare services that include healthcare administration and education (Allen 2000).

Another neologism that has rapidly entered the healthcare lexicon is the term *ehealth*. This term specifically refers to Internet-based healthcare services and can be included as a subset of either telemedicine or telehealth practices. The most notable aspect of ehealth is that it is not profession-centric, but driven by the concerns and needs of patients, consumers, and businesses. Also, as the uses for the Internet and computers have expanded in healthcare, a new discipline known as *medical informatics* has emerged. As with the new field of telemedicine, there is no universal agreement on the scope and definition of medical informatics. In fact, there is debate within the medical informatics literature whether telemedicine should be classified as a subset of medical informatics (Allen 2000).

Indicative of these terminological shifts, the Department of Health and Human Services recently established the Office for the Advancement of Telehealth (OAT). The OAT was created to conduct research and “to promote the wider adoption of effective telecommunication and information technologies in providing health care services to the nation’s underserved people.” The OAT defines telehealth as follows:

The use of telecommunications and information technologies to share information, and to provide clinical care, health professions education, consumer health education, and public health and administrative services at a distance (OAT 1999).

Whether telemedicine is a form of medical informatics remains in dispute. What is not in dispute, however, is that telemedicine is gradually being viewed as a subset of telehealth. Unlike the term *telehealth*, the term *telemedicine* is being reserved for

specific medicine-oriented applications such as telesurgery, teleradiology, and tele dermatology. The telehealth-telemedicine distinction is useful because it helps to eliminate some of the confusion over whether telemedicine should be narrowly or broadly defined. As discussed above, clinical and non-clinical applications of telemedicine are often difficult to distinguish in practice. The concept, *telehealth*, effectively covers both kinds of applications and denotes their interconnectedness in actual practice. Additionally, the term *ehealth* allows for more specificity about the communication technology being used to deliver healthcare services and information.

1.2 A Brief History of Telemedicine

If we include healthcare professionals' early use of the telegraph, telephone, radio, and television, telemedicine is not a new phenomenon. The first public telegraph system in the United States was established in 1844 and linked Baltimore with Washington, D.C. It is well documented that during the American Civil War telegraph services were used extensively by the military to order medical supplies, transmit casualty lists, and to conduct medical consultations. With the invention of the telephone in 1876 by Alexander Graham Bell, simultaneous two-way electronic speech transmissions across great distances became possible and extended the ability of healthcare professionals to consult with each other and their patients. Later, the advent of radio and television broadcasting allowed information to be transmitted without the use of wires or cables. This, in turn, permitted healthcare professionals to provide healthcare information and services across greater distances and to even more remote regions of the world (Field 1996).

It was not until 1950 that the first explicit reference to telemedicine was made in the medical literature. Under discussion was the 26-mile transfer of radiological images by telephone line between Philadelphia and West Chester, Pennsylvania, which had taken place in 1948 (Zundel 1996). Later, the first documented medical use of two-way interactive television (IATV) in the United States occurred in 1959 when the University of Nebraska transmitted patient neurological examinations to medical students across its campus. In 1962, the Nebraska Psychiatric Institute in Omaha established a wireless microwave link with Norfolk State Hospital, 112 miles away, for telepsychiatry consultations with patients and for distance-education for healthcare professionals. This system remained in operation for nearly six years and demonstrated the technological efficacy of long-distance interactive video (Perednia and Allen 1995).

In a very short period of time, telemedicine would become a global enterprise. In 1964, Dr. DeBakey performed open-heart surgery at Houston's Methodist Hospital. What is significant about this particular operation was that the surgical procedure was transmitted in real time via satellite and transatlantic phone line to an audience attending the World Health Organization meeting in Geneva, Switzerland. Although there were minor transmission difficulties, this was the first demonstration of its kind of international telemedicine (Armstrong 1998).

In recent years, the United States armed services have become instrumental in developing and implementing international telemedicine projects to reduce the geographic and temporal barriers to healthcare. In 1994, the United States military established the Department of Defense Telemedicine "Test Bed." Reminiscent of the U.S. military's use of the telegraph systems during the American Civil War, the armed

services are increasingly using sophisticated telecommunication and information technologies to provide medical services to remote locations around the world. By means of satellite and other communications technologies, telemedical services have been provided to troops in remote and war-torn regions such as Somalia, Bosnia, and Burundi. In the very near future, the U.S. Army will have a telemedicine network that will link every Army medical center in the world (Grigsby and Kaehny 1993; Edwards and Motta 1997).

1.3 First-Generation Telemedicine

After the success of many of the small-scale telemedicine projects in the late 1950s and early 1960s, a number of large-scale clinical telemedicine programs were initiated throughout the United States and Canada. Collectively, these watershed programs are often described as the *first generation* of telemedicine. The primary goal of first-generation telemedicine was to demonstrate the technological feasibility of extending scarce medical resources across distances by means of audio and video transmissions. The majority of these pilot programs used some form of video to supplement the telephone, which was the basic telemedicine tool at that time.

For the most part, first-generation programs achieved their goals but did not make telemedicine a common and accepted means for healthcare delivery (Barrett and Brecht 1998). There are a number of reasons for this. In many cases, the potential of first-generation telemedicine technologies was not realized because many of the healthcare professionals who used these systems were poorly trained in the efficient use of telemedicine technology. This, in turn, negatively affected healthcare professionals'

acceptance of telemedicine as a mode of healthcare delivery. Another contributing factor in the demise of these early programs is that not enough attention was given to comparing the quality of telemedical care with traditional in-person services. Finally, economic independence and cost-effectiveness were not priorities of first-generation telemedicine demonstration projects. Most of them were entirely funded by federal grants and when the flow of federal money ended so did the majority of these telemedicine projects.

Although there were many first-generation telemedicine pilot projects, a few programs in particular illustrate the scope and diversity of telemedicine at that time. One successful telemedical system linked Massachusetts General Hospital with the medical station at Boston's Logan International Airport. This program began in 1967 and continued until the mid-1980s. As a way to bypass long delays in medical care caused by congested highways, this telemedicine system provided occupational health services to airport employees and emergency services to airline passengers by means of an interactive audio-visual microwave connection. The medical station was staffed 24 hours a day by nurses. Typical services provided by the station include teledermatology, telecardiology, teleradiology, and telepsychiatry. During its operation, this telemedicine program circumvented Boston's traffic to treat over 1,600 patients (Armstrong 1998).

Unlike Boston's innovative telemedicine project, many first-generation telemedicine projects were closely connected to advances in satellite communications technology and space exploration. For example, much of the telemetry technology initially developed and used by NASA for tracking satellites and for monitoring the vital functions of the Mercury astronauts was used in these early telemedicine programs. In 1971, the National Library of Medicine and National Aeronautics and Space

Administration (NASA) initiated the Alaska Applied Technology Satellite Biomedical Demonstration Project. The purpose of this project was to evaluate the effectiveness of satellite video consultations to improve the quality of rural healthcare at 25 sites in Alaska. The results of the study concluded that the satellite system was effective in all locations and for all medical problems except emergency care (Bashshur and Lovett 1977).

Another noteworthy first-generation telemedicine program also involved NASA. In 1972, NASA joined forces with the Department of Health and Human Services and the Indian Health Services to sponsor the Space Technology Applied to Rural Papago Advanced Health Care (STARPAHC). This unique telemedicine program used satellites and other telecommunication technologies to provide medical services. This federally sponsored project had the dual function of monitoring the physiological conditions of astronauts while in space and of providing ground-based medical services to the residents of Papago, an isolated Indian reservation in Arizona. This innovative telemedicine project helped to demonstrate the capacity of telemedicine to provide healthcare to remote regions, on and off the planet Earth, and continued for almost 20 years in various incarnations (Bashshur and Lovett 1977).

1.4 Second-Generation Telemedicine

The *second generation* of telemedicine began to emerge in the late 1980s and coincided with the further miniaturization and portability of computer technology, home computing, the Internet, multimedia browsers, and electronic mail. By the early-to-mid-90s, electronic commerce also began to expand exponentially and healthcare

professionals and patients alike were making ever-greater use of private and governmental online resources to obtain health information and to communicate with each other (i.e., Internet and World Wide Web).

A less visible but more important catalyst in the evolution of second-generation telemedicine was the development of digital and compression technologies (Barrett and Brecht 1998). Earlier telemedicine technology relied on analog signals to transmit audio and video data. An analog signal is a continuous electrical wave signal that varies as the source of information varies. Unlike an analog signal, a digital signal consists of non-fluctuating bits or units of information that can be more easily compressed than analog signals. The compression of a digital signal allows for the transmission of more data using less bandwidth. In the field of telecommunications, bandwidth is a measure of the information carrying capacity of a communications channel and is a practical limit to the size, costs, and capability of a telemedicine service (Field 1996).

Thus, unlike the analog-based technologies of first generation telemedicine, the new compression and digital technologies employed by second-generation telemedicine programs made possible the transmission of greater amounts of medical data in less time and at significantly lower costs. In addition, digitization and computerization have made telemedicine equipment smaller and, subsequently, readily available to healthcare professionals and patients in the form of user-friendly teleconferencing equipment and desktop workstations.

As a result of the evolution of information and communication technologies during the late 1980s and early 1990s, telemedicine programs began to multiply and diversify. In 1989, for example, Texas initiated both the Texas Telemedicine Project and

the Med-Net program located at Texas Tech University Health Sciences Center. Both of these programs are rural telemedicine networks and are designed to improve the accessibility and availability of healthcare services to persons who live in geographically remote areas. In 1991, the Medical College of Georgia established a similar rural telemedicine program that has grown into a statewide network with over 60 interconnecting sites.

Many rural and urban areas in the United States are designated as Health Profession Shortage Areas (HPSAs), which means that these areas lack trained medical specialists or medical personnel altogether. The advent of rural telemedicine is significant because it allows healthcare professionals to electronically provide healthcare to small rural hospitals and clinics that are inadequately staffed by physicians and other healthcare workers. By means of low-cost and efficient telecommunication technologies, many rural residents in Texas and Georgia have been able to improve their access to healthcare resources. In addition, these rural telemedicine systems have permitted both patients and providers to reduce the cost and time associated with long-distance travel and time off from work.

Prison-based telemedicine programs also experienced moderate growth during the second-generation phase of telemedicine. During this period, three noteworthy programs were established and are currently operating in Texas, Ohio, and North Carolina. The University of Texas Medical Branch in Galveston is working with the Texas Department of Criminal Justice, the Ohio State University Medical Center has a correctional telemedicine project, and East Carolina University is operating the Central Prison Program. All three of these telemedicine programs have successfully completed

thousands of video-mediated consultations. Common telemedical services at these sites include optometry, dermatology, and psychiatry. Because prison-based teleconsults reduce the need for transporting prisoners to and from medical centers, the costs associated with prison healthcare have declined without reducing access. Moreover, the chance for escape, especially by violent offenders, has been reduced because there are fewer opportunities to do so.

1.5 Third-Generation Telemedicine

The *third generation* of telemedicine began approximately in the mid-1990s and includes present-day telemedicine activities. As in earlier stages of development, advancements and refinements in information and communication technologies continue to shape the evolution of telemedicine. Unlike earlier generations, however, third-generation telemedicine is being shaped by a flurry of federal legislation and policy initiatives and by newly constituted professional telemedicine organizations.

In an effort to remedy the lack of universal access to telecommunications in the United States, Congress passed the Telecommunications Act of 1996 (U.S. Congress 1996). This legislation is important for the advancement and viability of telemedicine because it mandates the establishment of a consistent and uniform national telecommunications infrastructure. In particular, this means national standards that guarantee the interoperability of various telecommunication technologies must be put into place. It also means that analog services will eventually be replaced by integrated services digital networks (ISDNs), which are necessary for high volume video, voice, data, and compressed video traffic. Until the technical gaps within the national

telecommunications infrastructure are eliminated, a nation-wide telemedicine network will be difficult to achieve in the United States.

Another important feature of the Telecommunications Act of 1996 is the bill's provision for universal service (Report II, Section 254). The universal service provision stipulates, first, that rural and underserved communities have a right to advanced telecommunication services for healthcare. The provision also mandates that the rates underserved, isolated, and low-income persons pay for new telecommunications services must be comparable to the rates for services in urban and suburban areas. Finally, the provision requires individual states, the federal government, and telecommunication providers to establish specific and predictable technologic and economic support mechanisms that promote the equitable and nondiscriminatory advancement and preservation of universal telecommunication services. As a whole, the universal service provision is designed to provide an ethico-legal framework for the fair distribution of telecommunications technology with the aim of eventually bridging the digital divide.

In addition to congressional action on the 1996 Telecommunications Act, the Joint Working Group on Telemedicine (JWGT) has invested millions of dollars in telemedicine programs (JWGT 1997). The JWGT is a large collaboration of federal agencies that are engaged in telemedicine activities and research. Agencies currently participating in the JWGT include the Department of Defense, the Department of Agriculture, which is home to the Rural Utility Service, the Department of Commerce, which is home to the National Telecommunications and Information Administration; the Department of Justice, the National Aeronautics and Space Administration, the Office of Management and Budget, the Department of Veterans Affairs, and the Department of

Health and Human Services, which is home to a number of other organizations that are deeply involved in telemedicine research. These organizations include the National Institutes of Health, the Agency for Health Care Policy and Research, the Food and Drug Administration, the Health Care Financing Administration, the National Library of Medicine, and the Office of Rural Health Policy.

In 1996, the National Library of Medicine, under the direction of the National Institutes of Health, provided \$42 million to fund 19 highly diverse telemedicine projects. These 19 multi-year projects are located in 13 states and the District of Columbia. The primary goal of these third-generation projects is to determine whether telemedicine can become a regular and common mode of healthcare delivery in the United States. To this end, these new programs are systematically evaluating telemedicine's impact on the accessibility, availability, quality, and cost of healthcare, as well as identifying the factors that inhibit or enhance provider and patient acceptance of telemedicine. Moreover, the majority of these telemedicine demonstration projects are required to develop business plans and eventually become economically self-sustaining enterprises. As mentioned above, earlier telemedicine projects failed to become economically self-sustaining and were terminated when federal grant money dried up.

Another significant development for third-generation telemedicine is the Next Generation Internet initiative (NGI), which began in 1997. The White House National Science and Technology Council's Committee on Technology coordinates this multi-agency project, which include, for example, the National Science Foundation, the Computer Science and Telecommunications Board, the National Library of Medicine, and the National Institute of Standards and Technology. The purpose of the NGI

initiative is to develop and evaluate advanced networking technologies and new Internet applications for education, business, and healthcare that are 100 to 1000 times faster than today's Internet. Investment in NGI research and development is rather large, totaling approximately \$200 million for fiscal years 1998 and 1999 (NLM 1999).

Telemedicine has traditionally consisted of stand-alone and point-to-point technologies that allow for interactive audio/video communication and store-and-forward functions. The NGI initiative and the exponential growth of ehealth applications significantly transform telemedicine because they allow for the development of a fully integrated healthcare system that includes, for example, e-mail, multimedia healthcare websites that provide health information and services, online pharmacies, and computerized patient records. Overall, the Internet allows for greater connectivity and flexibility in the delivery of health-related information and services and is probably the single greatest technological development to affect telemedicine.

Third-generation telemedicine has also witnessed the rapid establishment of professional telemedicine organizations such as the American Telemedicine Association (ATA), the Association of Telemedicine Services Providers (ATSP), and the American Medical Informatics Association (AMIA). A leader in telemedicine issues, the ATA was founded in 1993, initiated the *Telemedicine Journal* in 1995, and by 1996 held its first professional national meeting (DeBakey 1995). Telemedicine organizations like the ATA are playing a pivotal role in the development and acceptance of telemedicine by guiding telemedicine policy and by addressing the technical, legal, and economic barriers to the wide-scale implementation of telemedicine. Specific telemedical issues being addressed by these organizations include (1) reimbursement for telemedicine services, (2)

provider liability, (3) patient privacy, and (4) interstate licensing and credentialing (Sanders and Bashshur 1995).

The unwillingness of insurance providers to reimburse for telemedicine services is a major obstacle to the expansion of telemedicine. Historically, reimbursements for medical consultations over the telephone have not been allowed. According to the guidelines set by the Health Care Financing Administration (HCFA), medical consultations must be face-to-face or occur in the same room to be reimbursable. What this means is that healthcare providers cannot be paid for the vast majority of advice, clinical information, and medical services they provide electronically, for example, in e-mail communications with patients. There are some exceptions to the HCFA guidelines that allow diagnostic services such as telepathology and teleradiology to be reimbursed. But, until insurers cover a broader range of clinical telemedicine services, healthcare providers will be reluctant to adopt telemedicine.

Second, telemedicine organizations have been working to establish clear legal liability standards for the remote consultation with patients and other healthcare providers. One issue in particular concerns the safety and reliability of telemedicine technology itself. Does the use of telemedicine technology meet community practice standards? Does telemedicine increase the chances for error in clinical observation and in reporting of signs and symptoms? Is the quality of medical information reduced when electronically transmitted? Moreover, who is legally responsible when telemedicine technologies fail or do not provide adequate information?

Another aspect of legal liability that telemedicine organizations are focused on concerns the process of litigation itself. For example, it is less than clear how current

legal guidelines for medical malfeasance apply to healthcare providers who have at-a-distance relations with patients. Moreover, it is not yet evident when, if at all, provider-patient relationships are established online. Until these issues are resolved with the development of clear legal guidelines, many healthcare providers and medical institutions will remain reluctant to adopt telemedicine and e-healthcare.

Third, threats to patient privacy and confidentiality are also barriers to the full development and acceptance of telemedicine. The primary concern is that electronically gathered, stored, and transmitted patient data are at greater risk of being accessed or altered by unauthorized persons. The privacy of patient electronic information is a fundamental prerequisite for the success of telemedicine. Without patient and provider confidence in the security and reliability of patient medical information, it is unlikely that telemedicine will be widely accepted by the public. This recognition has led organizations like the ATA to encourage the adoption of encryption technology and the passage of laws that help to protect patient information.

Fourth, telemedicine proponents argue that the lack of an interstate medical licensing system for healthcare providers is a major obstacle to telemedicine development in the United States. As they correctly point out, the unique strength of telemedicine is its ability to overcome the barriers of geography and time. Conducting telemedicine across state lines, however, is problematic because there is no uniform medical licensure requirement for all states. Currently, the United States has a state-based medical licensure system that makes medical reciprocity and telemedicine practice across state lines highly cumbersome.

To make matters worse, some states have enacted laws to keep out healthcare providers licensed in other states. Although not explicitly stated, the purpose of these restrictive state laws is, at least partly, to protect the economic interests of healthcare professionals living within those states. In response, telemedicine organizations have been vocal advocates of a national or universal medical licensure system that permits reciprocity between the states. Until such a system is in place, the full potential of telemedicine is likely to remain unrealized.

Finally, the advent of telemedicine raises questions about whether telemedicine is simply a new set of tools or an entirely new area of specialization in which physicians and other healthcare providers should be trained and credentialed. For example, should physicians be required to master the basics of medical informatics and other information and communication systems before using these technologies to provide healthcare to their patients? In other words, how much knowledge, if any, should telemedicine providers have about the tools they use? At this time, there is no consensus among telemedicine organizations whether credentialing and special training is needed or even desirable.

1.6 Home-Based Telemedicine

Home-based telemedicine experienced some growth in the early 1990s. As with rural and prison telemedicine systems, new developments in information and communication technologies, especially the lower transmission costs of digitization, made home-based telemedicine economically practicable. The home-care market has great potential for telemedicine growth, but the healthcare industry is only beginning to make use of information and communication technologies when compared to business

and education. However, as information and communication technologies become cost effective and user friendly and as demographic and economic pressures increase, there is a developing trend in healthcare to employ these technologies to help care for patients in their homes.

Even before the advent of home-based telemedicine, traditional home care has been seen as a partial solution to America's healthcare-related economic problems. The reasoning is that if patients are kept out of expensive hospitals, then costs can be cut and patients can remain in the comfort of their own homes. This is not a bad idea, if it works. Currently, more than 20,000 home care providers in the United States deliver traditional home care services to individuals who suffer from acute illness, long-term health conditions, permanent disability, or terminal illness (*National Association of Home Care 1999, www.nahc.org/*). According to recent estimates, there are a half-billion home-health visits by nurses per year in the USA (Golberg 1995). In 1997, annual expenditures for home care were \$40 billion.

Traditional home care may prove to be less expensive than hospitals and nursing homes, but home care is still expensive and will only become more so as larger numbers of baby boomers age and continue to live longer, but not necessarily healthy lives. As we enter the 21st century, healthcare utilization and costs are projected to climb even higher as the number of elderly and chronically ill increase. This in turn is likely to lead to greater efforts to control exploding hospital costs by reducing further hospital in-patient days and/or keeping patients out of hospitals and nursing homes altogether. Thus, traditional home care can be at best only a temporary solution to our healthcare economic crisis. If nothing else is done, America's home care demands of the future will surely outstrip her economic and human resources (Little 1992; Laboratories 1996).

In response to strengthening economic and demographic pressures in American healthcare, government agencies and private home care organizations are funding and evaluating more home-based telemedicine pilot programs. Home-based telemedicine allows healthcare professionals to diagnose, treat, and monitor remotely patients who are in their homes by means of information and telecommunication systems. Also, in conjunction with the Internet, home-based telemedicine allows patients and family caregivers access to a multitude of online healthcare services and information. Outcome data are limited, but researchers are generally optimistic about home-based telemedicine's potential to reduce costs and extend services. For example, Blue Cross Blue Shield of Minnesota has reported a 45% reduction in patient visits, an 86% patient acceptance rate, and a reduction in cost from \$65 down to \$12 per contract. In addition, it has been estimated that in Kansas alone that electronic home care would save the state nearly \$1.5 billion per year (Barrett and Brecht 1998).

Home-based telemedicine is frequently thought to be identical with expensive and cumbersome high-tech medical equipment linked to whirring and buzzing communication systems that are frightful in their complexities. This, however, is not always the reality of contemporary home-based telemedicine. Home-based telemedicine can be divided into four elements: (1) *technology*, which includes such things as telemedicine work stations and telemetry-capable medical devices (also known as peripherals); (2) *telecommunications links*, such as telephone lines, the Internet, and satellites; (3) *healthcare professionals and patients*; and (4) *policies and protocols* (Coiera 1997).

Typical technologies and telecommunication links used in home-based telemedicine include the Internet, the common telephone, fax machine, video conferencing equipment, home computers, and interactive software, all which can be purchased off the shelf at home-electronic stores. The majority of these low-cost technologies generally depend on standard phone lines for the electronic transmission of health data, but other means of electronic transmission are rapidly being adopted and used by the general population (e.g., fiber optics, ISDN, DSL, and satellite) (Jerant and Epperly 1997).

When linked to telecommunication delivery systems and specialized telemedicine work stations, telemetry-capable medical devices make it possible for healthcare providers to remotely monitor the operation of medical equipment and analyze the physiological and psychological functions of their in-home patients. By means of information and communication technologies, electronic medical data, such as high-resolution images, sounds, live video, and patient records, can move at the speed of light between patients' homes and central tracking stations. Telemetry-capable devices commonly used in home-based telemedicine include electronic blood pressure cuffs, stethoscopes, glucometers, oximeters, and videophones.

Home-based telemedicine services can be divided into two broad categories: (1) electronic or virtual house calls and (2) healthcare call centers. Electronic house calls are typically initiated by a healthcare professional and may include either a simple asynchronous e-mail communication or a more complex synchronous interactive video system linked with telemetry-capable medical devices and the Internet. Unlike electronic house calls, the functions of healthcare call centers primarily consist of medical telemetry

designed to monitor a patient's vital functions. Interactions with healthcare professionals may not occur, but, if they do, patients in an emergency usually initiate them. Although home-based telemedicine can be divided into two broad categories, in practice, however, the combined use of electronic house calls and call centers is not uncommon.

Typical home-based telemedicine services include telemedicine-enabled echocardiography, stroke evaluation, and dermatology. Also, as mentioned above, Internet access at home allows patients direct access to a growing number of multimedia healthcare websites that provide healthcare services and information. Moreover, rapid developments in the electronic patient record (EPR), sophisticated interactive software, as well as wireless and hand-held technologies may soon allow healthcare professionals and patients even easier access to healthcare information and medical records (Kinsella 1997; Ostbye and Hurlen 1997).

Supporters of home-based telemedicine see a number of potential benefits. First, home-based telemedicine could reduce the cost of providing services to patients distributed over large geographical areas. Some home care patients only require limited interactions, information, and emotional support that could be achieved over various communication and telemetry links rather than in person by a home care worker. Because home telemedicine is less dependent on the physical presence of healthcare professionals, geography or the "friction of distance" is less of an impediment to the delivery of home care services. Less travel time means fewer healthcare professionals could provide more care to more people at lower costs. At the same time, home-based telemedicine could also mean that time-strapped healthcare professionals could see their in-home patients sooner and more often.

For patients and family caregivers, telemonitoring and immediate videophone access to healthcare professionals could mean better access to healthcare professionals and a decrease in their fears and anxieties associated with high-tech home care (e.g., infusion pumps and ventilators). This is especially so for elderly frail and chronically ill patients who live in remote areas and/or lack transportation. Telemedicine could allow them to circumvent the burdens of finding transportation and traveling long distances in poor health to and from outpatient clinics and regional hospitals. It could also mean that patients could leave the hospital sooner or stay at home longer before being institutionalized. Patients and family caregivers could also gain more control over their daily schedules by reducing the number of intrusions into their homes by healthcare workers and thereby protect the intimate sphere of the home (Winslade 1995).

Take as an example the wife of an elderly man who suffers from congestive heart failure, diabetes, and early-stage dementia. She can take some comfort in knowing that her husband's cardiac condition is being remotely monitored and that she can access health information, virtual support groups, and home care staff at any time of the day. If her husband should suffer complications with his heart, this information would be immediately and automatically transmitted to a central tracking station that would dispatch emergency personnel to the patient's home.

With traditional home care services, patients and family caregivers would have to wait for medical and home care workers to drive to their homes just to confirm whether the patient did in fact suffer a serious cardiac event. In some remote regions, home care workers must drive fifty miles one way to a patient's home. False alarms are not only common in home healthcare they are expensive, too. By means of home-based

telemedicine, many of the economic, physical and psychological burdens of home care can be minimized and the benefits of home maximized for patients, providers, and taxpayers. Unlike many technologic innovations in healthcare, information and communications technologies, when carefully applied, could reduce costs and maintain, if not improve, the standard of care of home care services. Patients and their families may chose to have more in-person visits than televisits from healthcare professionals, but home-based telemedicine would give them options that don't readily exist in our in our healthcare system.

Home-based telemedicine is likely to produce many benefits; nonetheless, the advent of home-based telemedicine raises, or ought to raise, a number of ethical concerns that have been inadequately addressed within the telemedicine and the medical ethics literature (Bauer 2001a). In the chapters that follow, an attempt is made to identify and to explore the ethical issues at the intersection of medicine, telecommunications, and our homes.

CHAPTER 2

PROVIDER-PATIENT RELATIONSHIPS

2.1 Introduction

When provider-patient relationships move from the face-to-face to the electronic mode, they are frequently transformed. The in-home use of telemetry-capable medical devices, diagnostic software, electronic mail, interactive video, computerized patient records as well as online medical sites and support groups introduces new interpersonal and social dynamics. Provider-patient relationships that were confined to specific situations are now no longer geographically confined, but can take place anywhere.

In some cases, home telemedicine patients and healthcare providers will interact and communicate by means of e-mail and interactive video. In other cases, healthcare workers and in-home patients will lack all personal interactions and communications with each other, whether face-to-face or electronically mediated. In these situations, healthcare providers will simply interact with abstract and digitized patient data sets, which have been automatically transmitted through electronic networks from a patient's home and stored in an electronic medical record. As a result of these and similar electronically mediated interactions and communications, home-based telemedicine has the potential to redefine the roles and responsibilities of patients and healthcare professionals and, thereby, has the potential to increase some of the benefits and burdens of provider-patient relationships and to decrease others.

Because the findings from empirical research on home-based telemedicine are, at best, limited and mixed, there is no consensus on how, if at all, electronically mediated

provider-patient interactions and communications benefit or harm provider-patient relationships and, ultimately, patient health outcomes. Furthermore, to determine whether home-based telemedicine undermines or enhances provider-patient relationships, some normative standard of what constitutes an ethically ideal provider-patient relationship must be included as a basis for evaluative judgment.

But, what characteristics make the provider-patient relationships of home-based telemedicine ethically appropriate or inappropriate, good or bad? The features we think ought to constitute the provider-patient relationships of home-based telemedicine will influence how this question is answered. This, in turn, will require reflection on various ethical and legal conceptions of the provider-patient relationship and identification of the values, goals, and virtues that are central to the practice of healthcare. First, however, we turn to an examination of the culture of *modernity* and its effects on the provider-patient relationships of home-based telemedicine.

2.2 Modernity and Provider-Patient Relationships

Although a myriad of social, economic, and technological forces have continuously reshaped the provider-patient relationship since the days of Hippocrates, the provider-patient relationship has undergone exceptionally rapid and dramatic changes in the latter half of the twentieth century. Until relatively recently in medicine's history, the provider-patient relationship has been characterized by a substantial imbalance of power between patients and healthcare providers. Within the traditional provider-patient relationship, healthcare professionals, especially doctors, have had more control and authority than their patients have. In simple terms, healthcare providers have had a

dominant and active role while patients have had a subordinate and passive role in healthcare decisionmaking. This unequal distribution of power within the traditional provider-patient relationship is predominately a consequence of the medical expertise that healthcare providers have but patients lack and need in order to get well and to feel better. Of course, imbalances in medical knowledge and power still exist within contemporary provider-patient relationships, but they are considerably less pronounced as they once were.

For some social theorists, medical anthropologists and bioethicists, the gradual realignment of power within the traditional paternal provider-patient relationship is, and continues to be, the result of *modernity*, which consist of convergent social, economic, and technological forces associated with the process of industrialization. The changes taking place within the provider-patient relationships of home-based telemedicine can also be understood in terms of these broad cultural and social forces. Concerning modernity and the provider-patient relationship, Cockerham has the following to say:

Modernity promotes social relations that span the globe, moves social life away from traditional practices, and features the progressive use of knowledge to organize and transform society. In this context, medical science becomes increasingly accessible to laypersons. This situation, along with the desire of modern individuals to be in control of their lives, points towards a modification in the physician-patient [provider-patient] relationship in the direction of greater equality between the two parties (Cockerham 1993: 48).

The net effect of modernity for the provider-patient relationship is that the power and prestige of healthcare professionals, especially physicians, have been incrementally cut away, producing more equal interactions between patient and healthcare providers. The author does not explicitly mention telemedicine, nevertheless, the phenomenal growth in telecommunication technology and recent developments in home-based

telemedicine can be construed as an elaboration of modernism that continue to modify traditional provider-patient interactions and, subsequently, our understanding of what constitutes ethically appropriate provider-patient relationships. As will be discussed below, the technology of home-based telemedicine has the dual potential to either increase and/or decrease this power differential.

With this in mind, what specific modernist trends have transformed the traditional provider-patient relationship, and how is home-based telemedicine an elaboration of these trends? According to Giddens, four related trends of late modernism have contributed to the transformation of the traditional provider-patient relationship. These trends include (1) the commodification of healthcare associated with a growing consumerism, (2) an increase in scientific knowledge and its dissemination, (3) mounting healthcare costs associated with new medical technologies and (4) exponential growth in chronic diseases resulting from an extended life span (Giddens 1990; Giddens 1991).

First, expanding economic markets and a growing consumerism have gradually led to the commodification of healthcare services. Consumerism, in turn, has increased the public's understanding of healthcare services as something to be negotiated or contracted. Thus, whatever one thinks of the commodification of healthcare services, the consumerist trend in healthcare has made patients into better "shoppers," of which active, rather than passive, participation by the patient is considered a key element. At the same time, the consumerist trend has restricted the power of healthcare providers by forcing them to compete and to deliver a better healthcare "product" or "service."

In the context of home-based telemedicine, the use of commercially supported online medical services allow in-home patients access to more information about diseases,

treatments and specific healthcare providers than ever before. In many instances, in-home patients have access to the same medical information that providers do. Although too much medical information that is poorly understood can be as dangerous as having too little or inaccurate medical information, more accurate medical information often produces better informed patients and families, giving them more power in the selection of healthcare providers and healthcare decisionmaking.

In addition, on-line support groups and e-mail afford home health patients the opportunity to share their experiences of which treatments worked and failed and of which healthcare providers they liked and disliked. Here, home telemedicine patients can engage in real “consumer reports” of their healthcare services and healthcare providers. By giving in-home patients more leverage and negotiating power in provider-patient relationships, the tools of home-based telemedicine continue the modernist trend of consumerism in healthcare.

Second, as a result of a more informed public and an unprecedented increase in medical knowledge over the past few decades, there is greater skepticism toward those who are in positions of power and authority (Starr 1982). Healthcare professionals have not been exempted from this skepticism associated with late modernism. Through education and the mass media, scientific knowledge, medical practices and the reality of healthcare culture have been demystified. In turn, patients have increasingly desired more control over their healthcare and have become more active participants in the provider-patient relationship.

At the same time, today’s healthcare professionals must master more medical information than their predecessors had to do. But since there is more medical

information available, their mastery of new medical information covers less of the total expanse of medical knowledge. This, in turn, has required healthcare professionals to specialize and to practice in narrower and narrower sub-fields because there is simply too much medical information for any one healthcare professional to comprehend, much less read. With that said, healthcare professions still remain powerful vis-à-vis patients because a diminution in the power resulting from specialization does not necessarily mean that patients will know as much as healthcare professionals.

Nonetheless, home-based telemedicine continues the trend of demystifying healthcare by giving in-home patients greater access to healthcare information and resources. Also, as home-based telemedicine makes it possible to carry out a greater number of medical procedures within the homes of patients rather than in hospitals and in medical clinics, healthcare culture is imported into the homes of patients. Thus, patients are likely to gain a better understanding of medical technology and medical procedures as they take on more significant roles in managing their illnesses. This process may have its downside, as I will explain in a moment, but as patients and their families become more familiar with the language, procedures and norms of medicine, and as their private home life is increasingly altered by telecommunications technologies, it is unlikely that patients will wish to remain passive recipients of care.

Third, as a means of controlling healthcare costs, managed healthcare organizations have limited the power and authority of healthcare providers. Subsequently, healthcare providers must now make treatment decisions in light of cost-conscious guidelines and restrictions established by managed healthcare organizations. Although this trend does not always translate into greater patient autonomy over

healthcare services, this trend has undercut the authority and power of healthcare providers. This modernist trend is now being expressed in the growth of home-based telemedicine programs. As previously discussed, home-based telemedicine is viewed by insurance companies, managed care organizations as well as by state and federal government as a potential means to reducing overall healthcare costs by minimizing hospital stays and by reducing personnel and travel costs associated with traditional home healthcare.

Fourth, late modernity is also associated with increased rates of chronic diseases that follow from extended life spans. Because of longer life spans, medicine and healthcare policy are becoming less focused on cure and becoming more focused on wellness and the prevention of further decline by patients with chronic diseases. This, in turn, has begun to modify the way patients and healthcare providers interact with each other. In a healthcare system increasingly populated by chronically ill patients that cannot be cured, treatment often involves control of symptoms by medication and changes in lifestyles and habits. Under these circumstances, patients need to be persuaded by healthcare providers of the need for lifestyle changes and better selfcare practices. As a result, healthcare providers now have less control in managing their patients' illnesses, whereas patients have more control and more selfcare responsibilities.

Increased life span and the corresponding rise in chronic diseases have also affected the growth of home-based telemedicine. As discussed previously, most demonstration projects evaluating home-based telemedicine have focused on patients who suffer from chronic illnesses such as diabetes and congestive heart failure. Because the site of patient care is in the home, and because healthcare providers in many instances

will not be physically present with their patients, home-based telemedicine extends the selfcare trend. As a result, as patients and family caregivers take on more selfcare responsibilities associated with chronic illnesses, it is very likely that healthcare providers will have even less influence over their home telemedicine patients.

Finally, the overall synergistic effect of these modernist trends on the provider-patient relationship has been a transition from provider paternalism to greater equality between patients and healthcare providers. Moreover, the advent and development of home-based telemedicine and associated technologies can be easily situated within the modernist framework. Thus, from broad cultural and sociological perspectives, home-based telemedicine can be conceptualized as an additional refinement of modernism that is continuing to reshape traditional provider-patient relationships, healthcare social practices and healthcare delivery modes.

2.3 Normative Conceptions of the Provider-Patient Relationship

For many patients and healthcare providers, the provider-patient relationship is still considered the moral core of the healthcare experience. What the moral core of this relationship is, or should be, remains a philosophically disputed issue. Clear evidence of this dispute can be found in the many different conceptions of provider-patient relationships that have been formulated over the past five decades. Some conceptions are normative, others descriptive, while others yet have both normative and descriptive functions.

In the early 1950s, Von Gebattel developed a dynamic model of the provider-patient relationship that included three stages: (1) the stage of responsive fellowship, (2)

the stage of detachment, and (3) the stage of personal communication. According to Eric Cassell and Mark Siegler, “the first and third stages deal essentially with the ethics of interhuman communications in medical care,” whereas “the third stage deals with the relationship of patient and physician as persons in all the complexity of individual metaphysics and the dialectical tensions of partnership” (Cassell and Siegler 1979: 112-113).

Because the Von Gebattel dynamic model distinguishes between the ethics of being technically competent and the ethics of relationship and interpersonal communication, this model is useful when reflecting on the provider-patient interactions that occur in home-based telemedicine. On the basis of this model, for example, telemedicine providers could deliver superior technical care, but simultaneously fail to develop ethically appropriate communications and relationships with their in-home patients.

There are, however, limitations associated with the Von Gebattel model. First, what counts as ethically appropriate provider-patient communications and relationships on this model is less than evident. Second, the dynamic model is very traditional in that it minimizes the patient perspective and emphasizes the provider perspective on the process and experience of communicating, providing information, and developing a provider-patient relationship.

In the mid 1950s, Szasz and Hollender articulated three provider-patient relationship models that rely on the severity and stage of a person’s illness and the personality and preferences of both patients and healthcare providers (Szasz and Hollander 1956; Reichman 1981). The models are (1) the active-passive, (2) the

guidance-cooperation and (3) the mutual participation. Not only are these models more sensitive than the Von Gebattel model to the preferences and expectations of patients and to the different possible levels of participation in the provider-patient relationship by both patients and providers, these models also provide more specifics about the relational and communicative aspects of provider-patient relationships. Also, unlike the Von Gebattel model of provider-patient relationships, Szasz and Hollander's three models more easily serve as a foundation for an increasing number of more sophisticated models of the provider-patient relationship.

Built on the early work of Von Gebattel, Szasz, and Hollander, five models that articulate the ethical ideals, expectations and behaviors of provider-patient relationships have received significant attention in the medical ethics literature in the past three decades. These five models are (1) the paternalistic or priestly model, (2) the engineering or informative model, (3) the collegial, interpretive or deliberative model, (4) the contractual model, and (5) the conscience model. All of these models have both normative and descriptive functions and, as will be discussed, are in different ways applicable to the provider-patient relationships of home-based telemedicine (Veatch 1988; Emmanuel and Emmanuel 1995).

The *paternalistic or priestly model* of the provider-patient relationship is similar to Szasz and Hollander's active-passive model and is primarily guided by the ethical principle of beneficence. In short, this is the *doctor knows best* model. As a normative model of provider-patient interaction, this model directs healthcare providers to promote the health and well being of their patients and to do no harm. Under this model of interaction, the broad scope of medical paternalism is justified on grounds that the

medical expertise and power of healthcare providers is used to further the best interests and well being of patients. This is deemed permissible because criteria for determining what is best for patients are considered objective are shared and because patients would come to the same answers as providers if they made their own healthcare decisions.

The paternalistic model assumes that there are shared objective criteria for determining what is best. Hence, the physician can discern what is in the patient's best interests with limited patient participation. Ultimately, it is assumed that the patient will be thankful for the decisions made by the physician even if he or she would not agree to them at the time. In the tension between patient's autonomy and well being, between choice and health, the paternalistic physician's main emphasis is toward the latter (Emmanuel and Emmanuel 1995: 67).

There are, however, problems with the priestly or paternalistic model of the provider-patient relationship. First, although it is assumed that patients would make the same decisions as healthcare providers, this model of the provider-patient relationship gives ultimate decision-making authority and power to healthcare providers, not to patients. Not only is this empirically false, as patients frequently make very different healthcare decisions than their providers, healthcare providers are construed to be active agents of the relationship while patients are construed to be passive objects.

Second, the problem of assuming the reality of shared objective criteria is that it erroneously presupposes, at a deeper level, a necessary (i.e., non-contingent) fact-value distinction that is unaffected by historical, cultural and psychological forces. Some versions of this view deny that there is any distinction between medical fact and ethical choice; rather, there are only "medical indications" for choices. This assumption, however, can and does lead to confusion between *medical expertise* and *moral expertise* by both patients and providers. This conflation of moral and medical expertise can undermine patient self-determination and, ultimately, run contrary to the very goal of the

paternalistic model, which is to promote the moral dignity and well being of patients. According to Veatch, the problem can be summed up as “one of a generalization of expertise: transferring expertise in the technical aspects of a subject to expertise in moral advice” (Veatch 1991: 12).

Thus, it is one thing for healthcare providers to have expertise in medical matters, but it does not follow that healthcare providers will possess expert knowledge of their patients’ values about what counts as a good life for their individual patients. Healthcare providers may understand, for example, that particular medical treatments will have no medical benefit for their patients (i.e., medical futility), but regardless of the medical futility of a treatment, patients may nonetheless see value and usefulness in them. A medical futile treatment may not only provide patients a feeling of hope, but also allow them, for example, to reconcile with estranged family members, to say goodbye to loved ones, and to prepare emotionally and spiritually for death. In the vast majority of cases it will be the patients themselves who will have expertise in their values and, in the end, should have decisional authority over healthcare treatment options that directly affect them. As will be discussed subsequently, some aspects of home-based telemedicine fit this particular model.

The *engineering or informative model* assumes that there is a clear distinction between medical facts and values that is shared by patients and providers. Unlike the paternalism model, which may inadvertently grant providers moral and priest-like authority over their patients, the engineering/informative model conceives of healthcare providers as technicians who are only responsible for making medical diagnoses, providing therapeutic options, and for delivering accurate and relevant

healthcare information to their patients. Under this model, the values and preferences of healthcare providers are not to be factors in the provider-patient relationship. Medical paternalism is negligible and the autonomy of patients is considerably stronger (Veatch 1988).

Like the aforementioned model, the engineering/informative model of the provider-patient relationship also suffers from the problems that arise from the false belief in a clear distinction between medical facts and medical values. Furthermore, this model (1) assumes that patients have thought about and understand their values regarding healthcare matters, (2) discounts the moral standing (i.e., the preferences, values, and interests) of healthcare providers, and (3) minimizes the emotional or affective aspects of the provider-patient relationship. Thus, for critics, the engineering/informative model of the provider-patient relationship is not really about relationships at all. Rather, this model simply emphasizes the supreme importance of making available scientific facts and medical information to patients.

The engineering/informative may not be the optimal framework for all provider-patient relationships. But, the reality of our current healthcare environment already makes it very difficult for many patients and healthcare providers to maintain, if not establish, ongoing relationships. More and more, providers and patient are and remain strangers to each other. This is especially true for those persons who are uninsured or live in health profession shortage areas. In yet other instances, patients simply want convenient, timely, and accurate health information; they do not want emotional connections with their providers (Bauer 2001b).

Home-based telemedicine could increase the number of anonymous contacts between patients and providers by reducing the opportunities for patients and providers to get to know each other on a personal level. But it could also provide patients with more health information and allow healthcare professionals and patients to communicate more efficiently, if not compassionately. Given the economic reality of healthcare, the high rate of medical errors, and the unreliability of much of the information on the Internet, an informative/engineering model of the provider-patient relationship, as a normative framework, could be an improvement for home-based telemedicine, not a manifestation of an unwanted technological fix at the expense of what is truly human (Bero, 1997; Eng and Gustafson 1999).

In the *collegial, interpretive or deliberative model* of the provider-patient relationship some of the excesses of the previous models are circumvented. Here, healthcare providers and patients are conceived of as colleagues, collaborators, or even friends with the shared goal of treating or curing the patient's illness and elucidating the patient's values about different medical interventions and the possible risks and benefits of those interventions. In Veatch's collegial model, the provider and patient are colleagues. In the Emmanuels' interpretive and deliberative models, even though both have a significant degree of paternalism, the provider takes on the role of being a counselor, teacher, or friend to the patient.

Unlike the engineering or informative model, healthcare providers under this group of models help patients to identify their values, to select treatment options, and in many instances to adopt new values. In these models, unlike the paternalistic or priestly model, the autonomy and moral standing of providers is respected, but, at the same time,

the patient has the final authority in determining which treatment options he or she wants to pursue. This, in turn, produces equilibrium between the technical and value aspects inherent in the provider-patient relationship.

The central problem with the collegial, interpretive or deliberative model is that it assumes patients and healthcare providers have the same interests or that healthcare providers can understand and work with their patients' range of interests. This assumption of convergent interests, however, does not always match the current healthcare reality because it ignores the many real conflicts of interests that arise between patients and healthcare professionals. As discussed above, similar objections plague the paternalistic/priestly model of provider-patient relationships. Moreover, even if we assume that patients and providers share a set of common interests, the rankings and priorities assigned to them may be very different. For example, although reasonable to believe that healthcare providers have an interest in the health and well-being of their patients, some providers also have an interest in urging one form of treatment over others because it corresponds to their research interests, because they own stock in a particular pharmaceutical company, or just because it fits with their specialty—a surgical remedy may be the first thing that occurs to a surgeon, whereas an internist may first think of a drug treatment. Also, with the increasing power of provider-owned managed healthcare organizations, healthcare providers may have financial incentives to restrict certain treatment options for their patients and to reduce healthcare expenditures.

Veatch is very critical of the collegial model:

But social realism makes us ask the embarrassing question: Is there, in fact, any real basis for the assumption of mutual loyalty and goals, of common interests, that would permit this model to apply to the physician-patient relationship? There is some proleptic sign of such community in

some elements of the radical health movement and free clinics, but for the most part we have to admit that ethnic, class, economic, and value differences make the assumption of common interest, which is necessary for the collegial model to function, a mere pipedream (Veatch 1991: 13).

Home-based telemedicine is not exempt for these possible conflicts of interests between patients and their healthcare providers. For example, there is an expanding chorus of critics who question the motives and priorities of those healthcare providers who practice over the Internet, claiming that their goal appears to be more about profit and less about the well-being of patients (Anderson 1999).

The *contractual model* of the provider-patient relationship shows more promise than the other models. As both a descriptive and normative model of the provider-patient relationship, this model is not to be understood in legal terms, but rather in terms of a traditional marriage or religious covenant in which there are explicit ethical, social, and personal responsibilities and benefits for providers and patients. According to Veatch, “only in the contractual model can there be a true sharing of ethical authority and responsibility” (Veatch 1991: 14).

In the modern healthcare environment, the contractual model is more likely to be successful than previous models because no assumptions are made about the existence of either (1) a distinction between medical facts and medical values or (2) shared goals between patients and providers. Also, (3) differences in power, knowledge, and goals are made explicit, and (4) the autonomy and well being of patients and providers is respected. As a consequence, patients and providers are more likely (a) to share decisionmaking authority, (b) to maintain their moral integrity, and (c) to avoid a conflation of technical and ethical expertise.

In addition, according to Veatch, the reality of healthcare in advanced industrialized society makes other provider-patient relationship models difficult to employ. The reason for this is that the institutional settings where healthcare is delivered makes it very cumbersome for patients and providers to maintain, if not establish, ongoing relationships. Because providers and patients are more likely to be strangers to each other in today's healthcare environment than in the past, a contractual model in which patients and providers negotiate the provision of healthcare services and the moral ground rules for the provider-patient relationship is preferable. On this point, Veatch states the following:

The stranger/physician relationship is the norm in urban clinic and hospital outpatient services, student health services, military and veteran's hospitals, as well as tertiary care settings and specialists referrals. Some sense of the growing importance of anonymous contacts can be gleaned from the national and local data (Veatch 1991: 39).

Given the problems of the aforementioned models and the rise of "anonymous contacts," in which there is an absence of shared values between patients and providers, or in which the respective parties' values are simply unknown to each other, Veatch's support of a contractual model as a means to avoid both the defects of the other models and to supply an ethical framework for contemporary provider-patient relationships has merit. Additionally, the contractual model is readily applicable to the new field of home-based telemedicine where patients and providers now find themselves geographically and temporally separated from each other, possibly making provider-patient relationships even more difficult to establish and to maintain. Veatch underscores the significance of selecting an appropriate ethical framework for provider-patient relationships in which the participants are likely to be moral strangers:

Whether the context is an exotic one or nothing more complicated medically than a routine physical exam, the selection of a model for the moral relationship between the professional and the lay communities will be decisive. This is the real framework for medical ethics in a revolutionary age (Veatch 1991: 15).

Veatch is correct about the estrangement of providers and patients in today's healthcare environment and the need for an appropriate ethical framework. But, it is possible that some applications of home-based telemedicine can make it easier, rather than more difficult, for patients and providers to establish and to maintain on-going relationships and for patients to make healthcare decisions? If this proves to be the case, then home-based telemedicine has as much potential of making moral acquaintances of in-home patients and providers as it does of making them moral strangers. With that said, it needs to be pointed out that, according to Agency for Health Care Policy Research, "no information is available to date, however, on the effects of patient decision-making informatics tools on patient-clinician communication" (Hersey, Matheson et al. 1997).

2.4 The Conscience Model

The contractual model is attractive as both a descriptive and ethical framework for the provider-patient relationships of home-based telemedicine. However, like all the models discussed in this chapter, the contractual model neglects elements that are of central importance to both a descriptive and normative account of provider-patient relationships in general and of telemedical relationships in particular.

One inadequacy of the other models, including the contractual model, is their failure to recognize the influence of technology in shaping provider-patient relationships.

In failing to do so, the previous models ignore important human factors within provider-patient relationships that are affected by various technologies. In the case of the informative/engineering model, these human factors are completely irrelevant.

Subsequently, these models are also limited in their capacity to prescribe the role that medical technology should have within provider-patient relationships. David Thomasma echoes this view:

Medical technology has its own economic and moral system, requiring more attention to human values once taken for granted in the physician-patient relationship. Medical technology introduces a fourth party—the machine and its technician—into the physician-patient-insurance triangle. The patient often has more contact with the technician, especially in serious illnesses, than with the physician. Because of the pervasiveness of technology, many moral problems are resolved by technologic solutions, although we are not yet sure whether technology has a true social good. In effect, we simply postpone the moral question until it becomes unavoidable—when, for example, we most propose criteria for selecting patients for exotic treatment. Finally, the unforeseen consequences of technology often leaves the feeling that the future of medicine will take rational control out of human decision making (Thomasma 1983: 243-244).

And later:

The problems associated with technology in medicine show the need to pay more attention to the human factor in the medical relationship. In my opinion, this factor is ignored in the models being proposed for modern medicine (Thomasma 1983: 244).

For Thomasma, an adequate conception of provider-patient relationships will need explicitly to address and counteract the growing “technologic imperative” in healthcare, whereby moral problems are increasingly being “resolved” by technologic solutions, rather than by patients and healthcare professionals engaged in joint ethical decision-making. Although unlikely that Thomasma had information and communication technologies in mind, his concerns about the rise of technologic imperatives in healthcare

and the decline of ethical decision-making are relevant to the practice of home-based telemedicine. More about this relevance will be discussed below.

A second inadequacy of the other models is their overemphasis on either provider paternalism or patient autonomy. For Thomasma, these models are extreme. They distort the reality of provider-patient relationships and contribute to the power of technologic imperatives by undermining the ethical decision-making of patients and healthcare professionals.

According to Thomasma, patient autonomy models are inadequate because (1) they rely on atomistic conceptions of individuals that neglect the reality of human relatedness; (2) they underestimate how disease can undermine personal integrity and autonomy; (3) they minimize the importance of other moral principles, such as beneficence, and possible conflicts among them; and (4) they presumes an adversarial relationship to exist between patients and providers. Similarly, Thomasma argues that most paternalism models of provider-patient relationships are inadequate because (1) they fail to respect persons by violating their autonomy and civil rights, (2) ignore other moral values and the importance of context in ethical decision-making, and (3) impose relative values on patients as if they were absolute values (Thomasma 1983).

In order to overcome the limitations of the autonomy and paternalism models, especially their tendency to undermine joint ethical decision-making by patients and providers and to strengthen the technologic imperative, Thomasma proposes *the conscience model*:

Given the shortcomings of both the patient autonomy and medical paternalism models of medical practice, is there an alternate that is not reductionistic or does not unduly stress one or the other model? I suggest there is. I call it the physician's conscience model. If space permitted, this

model would be balanced with a comparable model of patient conscience as well; the complexity of the physician-patient relationship can never be adequately described in a single model (Thomasma 1983: 246).

For Thomasma, the “conscience of the physician” is synonymous with prudential judgment (i.e., *phronesis*), which is essential for ethical decision-making and antithetical to the blind forces of technologic imperatives. Unfortunately, patient autonomy models limit providers in exercising their prudential judgement in the best interests of their patients. Thomasma does not develop a model of patient’s conscience, but we can assume that Thomasma would also define the “conscience of the patient” as “prudential judgment” and see medical paternalism models as limiting the ethical decision-making of patients and creating an ethical vacuum that will be filled with ethical conflict and technologic fixes.

Thomasma posits six features of the conscience model that he believes would do a better job of describing provider-patient relationships than the other models and that should be used as a normative guide for medical practice (Thomasma 1983):

1. Beneficence or care for the patient should influence the degree of autonomy and paternalism involved in the provider-patient relationship.
2. The existential condition of the patient, not professional codes, should guide provider interactions with patients.
3. Values should not be identified and ranked a priori or in abstraction from individual provider-patient relationships.
4. Consensus should be the goal of patients, providers, and healthcare teams.

5. The goal of a consensus-driven relationship should be a pragmatic moral object, which is the resolution of ethical problems in the treatment of patients that preserve as many values as possible.

The sixth element of the conscience model identified by Thomasma consists of five explicit moral axioms (Thomasma 1983):

- a. Providers and patients must be free to make informed decisions.
- b. Providers are morally required to pay increased attention to patient vulnerability.
- c. Providers must use their power responsibly to care for the patient.
- d. Providers must have integrity.
- e. Providers should have a healthy respect for moral ambiguity.

The conscience model is not perfect and like the other provider-patient relationship models has limitations. For one thing, it is not always evident whose conscience should be honored—the patient’s or the provider’s—and what the outcome of conflicts between them should be. This limitation, however, is not unique to the conscience model and, as Thomasma recognizes, moral ambiguity and conflict are sometimes inescapable in healthcare (see axiom e above).

Respect for ambiguity is difficult, especially when by training and disposition physicians aim for clinical closure and problem solving. But in the model of physician’s conscience there is no single answer to the dilemmas a physician will face with patients. Respect for ambiguity would permit a physician to rationally discuss alternatives without the pitfalls.... (Thomasma 1983: 247).

For Thomasma, the pitfalls of not respecting moral ambiguity within provider-patient relationships are evident in the other models of provider-patient relationships, including an exaggerated emphasis on patient autonomy and provider paternalism,

attempts to “resolve” moral ambiguities and conflicts a priori, reliance on technologic fixes, and, ultimately, truncated moral decision-making responsibility by healthcare providers and patients.

Thomasma proposes that ethical problems within provider-patient relationships be addressed by means of consensus-building procedures (see features 5 and 6 above) that not only respect moral ambiguity, but also respect the values and integrity of patients and healthcare professionals.

Admittedly, a consensus model takes time and energy but it also wards off many agonizing hours of conflict later in the course of serious illness. In fact, one of the temptations of the autonomy and paternalism models derives from the comparative ease of decision making: either the physician makes all the decisions, or the patient is always thought to be right. Both models abandon the rewards and trials of mutual exchange between doctor and patient (Thomasma 1983: 247).

How, then, is the conscience model relevant to the provider-patient relationships of home-based telemedicine and how could it do a better job than the other models in both describing the provider-patient relationships of home-based telemedicine and in addressing the ethical issues that may arise within these relationship?

First, the conscience model would do a better job in helping patients and providers to identify and to assess specific benefits and burdens associated with home-based telemedicine. Because the conscience model recognizes the importance of context and depends on consensus-building procedures to resolve conflicts between patients and providers, rather than on a priori solutions, the conscience model makes it less likely that preconceived notions about the nature of provider-patient relationships would be imposed on the growing number of provider-patient relationships of home-based telemedicine. Consequently, since the conscience model avoids easy algorithm-like solutions to

conflicts, artificial and premature *resolution* is avoided and connections are maintained to those who provide and receive telemedical services.

Second and related to the first point, because the conscience model does not unduly stress the importance of patient autonomy and provider paternalism, it is less likely that the provider-patient relationships of home-based telemedicine will be judged *en masse* by how they either maximize provider paternalism or maximize patient autonomy. Instead, the conscience model allows patients and providers to determine jointly what an acceptable provider-patient relationship is in the context of home-based telemedicine. This sort of flexibility for the provider-patient relationships of home-based telemedicine is important, given that patients and providers will more often be physically separated, that the point of care is within patients' homes, and that relatively little is understood about this treatment modality at this time.

Third, since the conscience model requires medical decision-making to be a consensus between patients and healthcare providers, it is more likely that potential disagreements and conflicts in the decision to adopt, modify, continue, or discontinue home-based telemedicine activities will be identified and addressed by patients and providers. In doing so, the conscience model is more likely than the other models to prevent home-based telemedicine from becoming another technologic fix in our modern and complex healthcare system.

2.5 The Goals and Values of Healthcare

Related to the choice of a model, three overlapping healthcare goals and values are central to an ethical evaluation of the provider-patient relationships of home-based telemedicine and can be distilled from the previously discussed models of the provider-patient relationship. These goals and values are (1) to achieve the best quality of patient care, (2) to balance the art of healthcare with the science of healthcare, and (3) to balance patient autonomy with professional autonomy (Hanson and Callahan 1999; Kaplan 2000).

The differences among the five provider-patient models discussed above can be understood in terms of the aforementioned matrix of healthcare goals and values. For example, the paternalistic or priestly model places more importance on the quality of patient care and on provider autonomy (i.e., paternalism), but minimizes the importance of patient autonomy. The informative or engineering model gives more importance to patient autonomy and the science of healthcare, but minimizes the importance of provider autonomy and the art of healthcare. Thomasma's conscience model, without exaggerating the role of autonomy and paternalism, attempts to include all these elements by configuring the provider-patient relationship to the unique condition of each provider-patient relationship.

The expression of these goals and values in different conceptions of the provider-patient relationship can facilitate an ethical evaluation of the interactions between patients and healthcare professionals in the context of home telemedicine. For example, it is possible that various information and communication technologies (e.g., interactive video, e-mail, and on-line support groups) will advance or retard any one of the three

aforementioned healthcare goals. This, in turn, will determine which model of the provider-patient relationship best describes the relationships of home-based telemedicine as well as which model of the provider-patient relationship, as an ethical ideal, is being violated or undermined by the use of a particular information or communication technology.

First, *quality of patient care* refers to the ability of a new medical technology to improve patient care and health outcomes. Sometimes, however, acceptance of a new medical technology by healthcare providers has more to do with their belief in it than whether it can be demonstrated to improve the quality of patient care. This initially was the case with CT scanning, in which wide-scale adoption and satisfaction with this medical device surpassed adequate scientific evaluation and other technology that may have been as beneficial (Kaplan 2000). Today, home-based telemedicine presents a similar challenge to healthcare professionals. For some, the technology of home-based telemedicine represents a threat to the provider-patient relationship; to others, it is no threat at all. The reality is that until home-based telemedicine has been adequately evaluated, we are left with competing speculations. Nevertheless, the belief that a new medical technology either harms or benefits the quality of patient care and the provider-patient relationship will play a large role in whether a new technology is accepted. The information and communication technology of home-based telemedicine is no exception.

Second, *healthcare as both an art and science* has an extensive history and is closely connected to the quality of patient care. On the one hand, *the science of healthcare* refers to standardized clinical practice guidelines, automated procedures, scientific evidence, and the employment of medical technology. As is the case with

science generally, the science of healthcare is always changing as new discoveries are made and better techniques emerge. On the other hand, *the art of healthcare* refers to the individual clinical judgements and intuitions of healthcare providers. The art of healthcare also refers to the affective or emotional dimension of the provider-patient relationship. When the art of healthcare is practiced well, healthcare providers are able to genuinely feel and express empathy and compassion for their sick and vulnerable patients.

Unlike the science of healthcare, the art of healthcare encompasses what is likely a universal and unchanging aspect of the human condition—the experience of being ill, being vulnerable, being dependent, and being healed. The art of healthcare, unlike the science of healthcare, requires a deep moral sensitivity to the experience of illness.

Concerning this experience, Edmund Pellegrino states the following:

It [illness] is only in part defined medically as a concrete organic or psychological aberration. It is the perception of the change in existential states that forms the central experience of illness---the perception of impairment and the need to be made whole again---to be cured, healed, or cared for (Pellegrino 1981: 71).

If Pellegrino is correct, then both the art and science of healthcare are desirable and necessary for the provision of technically sound healthcare services and the formation of ethically appropriate healthcare relationships.

Since Hippocrates' day, however, there have been tensions between the science and art of healthcare. Efforts to strike a balance between the two are not new and will likely be interminable, given the ceaseless march of scientific discovery and technological innovation. How the art and science of healthcare are balanced will influence whether a new medical technology is accepted or rejected and, subsequently,

will shape provider-patient relationships. According to Pellegrino and Thomasma, our healthcare system is characterized by an imbalance in which technology and the science of healthcare dominate the provider-patient relationship:

The temptation to employ technology rather than to give oneself as a person in the process of healing is a “technological fix.” The technological fix is much easier to conceptualize and to implement than the more difficult process of a truly human engagement. The training and the skills of modern health professionals overwhelmingly foster the use of technological fixes. By instinct and proclivity, all persons in modern civilization are tempted by technical rather than personal solutions to problems (Pellegrino and Thomasma 1993: 124).

At this time, some applications of home-based telemedicine have proven to be easier and cheaper. Although the verdict is out on whether home-based telemedicine is simply an instance of modern man’s proclivity for easy technical solutions to complex human problems, Pellegrino believe that overemphasis placed on technology and technical competence in medical education gives us good reasons to be concerned:

Physicians seem to be moving toward a restricted sense of the promise [of healing], emphasizing technical competence while patients seeks technical competence plus compassionate help with the experience of illness as an assault on the person. This gap promises to widen as specialization increases and the demands of competence become more urgent. The wider it becomes the further it moves from what is required of a genuine healing relationship grounded in the experience of illness (Pellegrino 1981: 75).

As discussed earlier, Thomasma’s conscience model, unlike autonomy and paternalism models of the provider-patient relationship, could minimize the impact of relying exclusively on technological solutions in healthcare. The conscience model is more likely to allow for mutual exchanges between patients and providers, to encourage joint healthcare decisionmaking between providers and patients, lead to consensus on healthcare goals, and, in the end, to reduce the possibility of technological fixes.

Presently, there is no consensus on how the gap between technical competence and compassionate help is to be, or even should be, closed. For example, because some telemedicine providers and patients believe that healthcare is more art than science, automated computers, telemetry-capable medical devices, and disembodied and remote patient care is less attractive to them. Some take a middle ground and believe that telemedicine technology can be used to enhance and to extend the art of healthcare. Yet, others believe that more and better medical information and techniques, alone, are more important than and override the art of healthcare. From this perspective, Pellegrino and Thomasma's concern about technological fixes may simply reflect the values and worries of a bygone era in healthcare.

In light of the wide spectrum of viewpoints on the possible roles of telemedicine and its effects on provider-patient relationships, a conscience model would be useful in the context of home-based telemedicine, as it would allow individual patients and providers through a consensus-building process to determine what they consider an appropriate balance of telemedical art and telemedical science.

Third, *professional autonomy* is another healthcare goal/value basic to the acceptance of new medical technology and the provider-patient relationship. Specialization and the increasing use of computer decision support systems, clinical practice guidelines, and research protocols give, in many instances, more weight to the science of healthcare and less weight to the expertise and autonomous judgments of individual healthcare professionals about patient care. This is already the case in most healthcare settings where a team of healthcare providers is more likely to care for a single patient. As members of a healthcare team, professional autonomy is restricted and

unilateral decisionmaking must give way to consensus building and shared decisionmaking with those providers who are on the patient's healthcare team. The introduction of telemedicine into the homes of patients may intensify this trend.

According to Douglas Walton:

The Hippocratic treatises are quite right to cite excellence of craftsmanship as a central ethic of competence for medical treatment. But in modern terms this competence must be understood to entail a sharing of scientific knowledge. Hence a corporate and institutional notion of technology as the coordination of a team effort is necessary. It is futile to try to go back altogether to the model of the caring family doctor as the bringer of treatment (Walton 1985: 60).

Moreover, if home-based telemedicine programs evolve and expand, it is possible that increasing numbers of patients and their family caregivers will take on more healthcare responsibilities, limiting the role that healthcare providers have in direct patient care. As more patients selfcare with the aid of computers and telemetry-capable medical devices, healthcare providers may work in virtual teams that are geographically and temporally decentralized, lacking, in many instances, any face-to-face interactions with their colleagues. Because patients and providers are no longer geographically and temporally centralized, more efforts at coordinating patient care will need to be made. This is likely to place new restrictions on the professional autonomy of providers vis-à-vis other providers. Nevertheless, home-based telemedicine may enhance the professional autonomy of some healthcare providers by affording them greater access to remote in-home patients.

Some combination of these three healthcare values are basic to most conceptions of provider-patient relationships and interactions, each value having a different level of importance in the various provider-patient relationship models examined earlier. That is,

depending on the normative model of the provider-patient relationship that is adopted, professional and patient autonomy, the art and science of healthcare, and the quality of patient care will be ranked and treated differently. This, in turn, will shape one's perspective on whether home-based telemedicine is harmful or beneficial to provider-patient relationships and thereby ethically appropriate or inappropriate. However, given the lack of general consensus on the appropriate uses for home-based telemedicine and its consequences for provider-patient relationships, a conscience model, because of its flexibility, would allow telemedicine providers and patients to reach their own consensus on these matters.

2.6 Medical Technology

Concern about the impact of medical technology on the provider-patient relationship and patient care is not new nor the result of high-tech medical devices only, for example, dialysis machines, cardiac pumps, and complexly integrated intensive care units. In fact, alarm over the increasing use of medical instruments in patient-provider interactions has a long history that includes the introduction of low-tech medical instruments such as the now commonly used stethoscope, thermometer, and the sphygmomanometer (i.e., blood pressure cuff). When first introduced these medical tools were considered controversial because of their possible negative implications for patient care and the provider-patient relationship. On this point, Evans discusses the threat of medical technology to dehumanize the provider-patient relationship:

Many chroniclers claim that high-tech medicine has evolved at the expense of the doctor-patient relationship, that machines have created a cold and impersonal chasm between the healer and the patient. In their

minds the doctor has become a mere technician, a “body mechanic,” who can treat disease but not the person (Evans 1993: 82).

For Evans, however, “high-tech” healthcare does not have to be synonymous with an impersonal provider-patient relationship; in many instances it can also be associated with a personal and “high-touch” provider-patient relationship.

This is possible because Evans is not advocating some form of technological determinism or technological fix in which medical technology is singularly responsible for the changes, good or bad, which have occurred within the provider-patient relationship. Nor does he suggest that the impact of a new medical technology is tantamount to an endless stream of interpretations and rootless meanings. Rather, he is opting for a middle course, suggesting that the meanings assigned to a new medical technology is as important as the technology itself in altering the provider-patient relationship. That is, ideal notions of the provider-patient relationship, cultural and institutional contexts, and the values held by healthcare providers and patients play a significant role in either the adoption or rejection of a new medical device. This is evident in the changing attitudes toward the thermometer, sphygmomanometer and stethoscope, which are now taken for granted as basic and reliable tools of healthcare professionals. Unlike earlier generations, very few of today’s patients and healthcare providers would consider these tools to be impediments to an effective provider-patient relationship. In fact, the failure of healthcare providers to employ these highly effective instruments would raise doubts about their professional competence (Turkle 1984; Schement and Curtis 1995).

For good or bad, however, the introduction of new medical devices into the provider-patient relationship can have a substantial influence on the way patients and

healthcare providers interact with each other and, consequently, on the provider-patient relationship. This was what happened with the thermometer, sphygmomanometer and stethoscope. First, healthcare providers gained more power because, unlike the vast majority of their patients, they understood how these new medical tools functioned. Second, these new tools modified provider-patient interactions by facilitating the creation of an objective scientific nosology (i.e., classificatory scheme) that allowed healthcare providers to diagnose the patient's disease independent of the patient's subjective reports. Third, because of an objective nosology and the relatively simple and universal manner in which these new tools were used, doctors were able to delegate time-consuming activities to nurses and support staff, making doctors less directly involved in basic patient care.

Keeping in mind that one's culture and beliefs about the provider-patient relationship will influence judgments about new medical tools, the cumulative effect of the thermometer, sphygmomanometer and stethoscope was a substantial alteration in the provider-patient relationship. According to Evans:

With medical instruments, doctors [healthcare providers] could subject patients and their symptoms to objective scrutiny. As doctors gained more data from instruments, the quality of the information related by the patient seemed less important. Doctor and patient shared less knowledge; there was less common ground between them. A medical instrument acted as a lens through which the doctor could see the disease unfiltered by the patient's interpretations. Instruments thus altered the doctor-patient relationship, making the patient's experience of illness less important (Evans 1993: 90).

The impact of medical technology in minimizing the patient's subjective experience of illness can be found in the *symptoms-signs* distinction routinely employed in the taking of a patient's medical history.

The medical history furnishes the *chronology* and *symptoms*. Symptoms are the variations from normal sensations and behavior that enter the

patient's consciousness. They are *subjective*; they form the basis of complaints, offered spontaneously or in response to questions. The physical examination discloses *physical signs*; these are *objective* manifestations of disease perceived by the examiner. Laboratory tests provide *findings*; x-ray examinations furnish *radiologic signs* (DeGowin and DeGowin 1976: 2).

It should be noted that the *symptoms-signs* distinction is not simply a product of modern medical instruments, but has a history at least as old as the practice of medicine. Modern medical technology, however, has made it possible for objective signs and provider diagnostic skill to play a larger role than patients' subjective reports of symptoms.

The emphasis on objective signs over subjective symptoms should not lead one to conclude healthcare providers and patients have different attitudes toward medical instruments and medical technology in general. As Evans points out in his analysis of the effects of medical technology on provider-patient relationships, "the appeal of efficiency, accuracy, and precision was felt by all Americans---not just doctors. Patients, too, shared a faith in these qualities as symbols of progress" (Evans 1993: 91).

2.7 Telecommunications Technology

Questions about the possible risks and benefits of medical technology for the provider-patient relationship have not been limited to medical instruments narrowly understood, but have also focused on the possible risks and benefits of information and communication technology. According to Joyce Lashof of the OTA, *medical technology* includes "the drugs, devices, and medical and surgical procedures used in medical care and the organization and support systems within which such care is provided" (Lashof 1981: 36-37). On the basis of the OTA's definition, the information and communication technology employed in home-based telemedicine can be subsumed under "support

systems within which such care is provided” and, therefore, counts as medical technology.

As it turns out, questions about the possible risks and benefits of information and communication for the provider-patient relationship also have a long history. As early as the 1880s, for example, some physicians were lamenting the use of the telephone as a means of communicating with their patients. They were concerned that geographical distance and the lack of a hands-on approach with patients would undermine their ability to care for their patients. Before the telephone, the telegraph was subjected to the same kind of criticism.

Now, with the advent of home-based telemedicine, similar themes and questions about possible risks and benefits have emerged. As with the telephone and the telegraph, contemporary healthcare providers and patients are apprehensive about the possible consequences new communication and information technologies will have on the balance between the art and science of healthcare, professional autonomy, the quality of patient care, and, ultimately, provider-patient relationships (Sanders and Bashshur 1995; Wooton and Darkins 1997).

First, some speculate that as home-based telemedicine becomes more commonplace in the treatment, if not the diagnosis, of in-home patients, healthcare providers will be less adept at understanding their patients’ experiences of living with and dying from disease. One particular concern is that physical separation and electronically mediated communication may make the establishment of emotional connections between patients and healthcare providers more difficult.

On the patient side, confidence, trust and dependence on his or her healthcare provider may be diminished as in-home patients increasingly obtain their medical information from websites, receive emotional support from on-line support groups, and electronically communicate with healthcare providers by means of e-mail and interactive video. If this turns out to be the case, an engineering or informational model of the provider-patient relationship would be operative, at least descriptively, in home-based telemedicine. At a normative level, this would simply be an undesirable technological fix for some theorists (Bero and Jadad 1997; Eng and Gustafson 1999).

The concern, however, is that these telemedicine technologies may diminish provider-patient interactions and deleteriously affect the quality of patient care. In support of these worries, a number of studies using randomized controlled trials have demonstrated that the quality of clinical communication is related to positive health outcomes. In other words, the more cumbersome and awkward provider-patient communication, the more likely patients will not get well (Kaplan, Greenfield et al. 1989).

Second, although some applications of home-based telemedicine have the capacity to enhance patient autonomy and well-being, they also have the capacity to undermine patient autonomy and well-being especially when, for example, the telemedical tools are limited to automated telemetry-capable medical devices and computerized patient records (Beasley and Graber 1984; Howe 2001). The reason for this is that healthcare providers will have little or no physical contact with their patients, interacting only with abstract patient data sets that have been transmitted through electronic networks and stored as computerized patient records. On this point, George

Marckmann argues that under these conditions healthcare providers may (1) fail to include patients in decisionmaking about the patient's care and (2) inadvertently dehumanize their patients. He writes the following:

Without the physical presence of the patient there will be an increasing probability of unilateral decisions by physicians, thus conflicting with the ideal of a shared decision-making between physician and patient (Marckmann 1999: 60).

And later:

If the personal consultation of specialists is replaced by teleconsultations, there will be an increasing risk that not the individual patient but just the digital data set--the gnostic analogue of the patient---becomes the object of diagnosis and treatment. Electronic patient records must be considered as a highly abstract, possible erroneous "artifact" which should not get a life of its own: not the data set but the patient needs treatment (Marckmann 1999: 60).

Third, if Marckmann is correct about the behavior of healthcare providers involved in teleconsultations, then, on the patient side, home-based telemedicine may further minimize the subjective experiences of in-home patients in favor of greater amounts of quantifiable and objective physiologic data. If this is the case, then home-based telemedicine, by depending more on abstract information about patients and less on communication with them, may modify the level of *interconnectedness* that exists between patients and healthcare providers and, thereby, transform the provider-patient relationship.

At the descriptive level, engineering or paternalistic models of the provider-patient relationship are applicable. Whether this is an unacceptable technological fix or an infringement on patient autonomy will depend on the provider-patient relationship model one adopts. If, for example, one's normative conception of the provider-patient relationship is governed by an engineering model, in which the art of healthcare is given

a lower priority than the science of healthcare, a technological fix could be viewed as a desirable healthcare goal. Empathy and compassion may be less valued than timely and accurate healthcare services and information.

According to Jorge Reina Schement and Terry Curtis, the concept of *interconnectedness* can be understood in terms of micro, meso, and macro levels that describe the effects of information and communication technology on social relationships. Interconnectedness at the micro level has particular relevance to the provider-patient relationships of home-based telemedicine.

At the micro level, individuals experience interconnectedness as change in the nature of their social relationships. For most people, this means an increase in the number of relationships, but a decrease in their depth. That is, we are in regular-if not frequent contact with more people, but we don't know many of them very well (Schement and Curtis 1995: 47).

Similar notions about the quality of social relationships are expressed in the *theory of social presence*. According to this theory, *social presence* is the feeling one has that other persons are involved in a communication exchange. The degree of social presence in an interaction is hypothesized to be determined by the communication medium: the fewer channels or codes available within a medium, the less attention that will be given by the user to the presence of other social participants. As social presence declines, messages become more impersonal and task oriented (Walther 1995).

Assuming that the concept of interconnectedness and the theory of social presence are descriptively accurate, the primary goal of many electronically mediated relationships may turn out to be neither the person nor the relationship, but the information. Of course, the accurate and timely exchange of information between patients and healthcare providers has great benefits in the diagnosing and treatment of patients and in the cost-

effective management of healthcare organizations. Moreover, easy access to health information and healthcare workers via telemedicine technology may enhance the autonomy of patients and families, reduce their anxiety, and provide for an overall better quality of life for them. However, by the normative standards of some provider-patient relationship models, an effective and ethically appropriate provider-patient relationship ought to include more than the efficient accumulation of patient data, for example, a patient-centered relationship governed by empathetic communication and an awareness of the patient's existential state in the midst of illness. This, as was discussed, is more likely to be achieved by the conscience model of provider-patient relationships.

If home-based telemedicine turns out to be a tool used more for information gathering rather than communication and relationship building, then certain types of provider-patient relationships may not be possible in home-based telemedicine. This may be perfectly acceptable in many situations; but an emphasis on information over persons and relationships may be ethically problematic in the context of home-based telemedicine and healthcare generally, depending on one's normative conception of what the provider-patient relationship should be. As stated previously, findings from empirical research on home-based telemedicine are, at best, limited and mixed. There is, however, a growing body of empirical research that lends support to the theory of social presence and the notion of interconnectedness.

Electronic Mail

Very little is scientifically understood about how e-mail use in home-based telemedicine affects the quality of provider-patient relationships. As a result of this dearth of scientific knowledge, provider-patient e-mail is undergoing its first randomized,

controlled trial at the University of Michigan (Carrington 1999). Until this and similar research is completed we can only speculate about the harms and benefits, if any, of e-mail communications between patients and healthcare professionals.

On the basis of anecdotal evidence, however, e-mail appears to have a number of potential benefits for home-based telemedicine patients and providers. E-mail may allow patients and healthcare providers to transmit very detailed and specific medical information to each other that is difficult to do verbally, whether face-to-face or over the telephone. Also, the use of e-mail may allow healthcare providers to reduce the time spent on the phone with in-home patients and to more easily document interactions in the patient record.

In addition, as more healthcare services are provided in the home, the need to transmit more information increases while the opportunities for face-to-face communication decreases. E-mail creates the means for providers to give social support to in-home patients and for patients and providers to keep each other informed of treatment progress and complications. More information may lead to patient treatment compliance. Finally, by providing in-home patients with medical information and social support, e-mail has the potential to enhance their overall quality of life by promoting their autonomy and well being (Mandel, Kohane et al. 1998).

Nonetheless, e-mail may prove to be restrictive for home-based telemedicine patients and providers. First, by concealing the subtle emotive cues expressed in both the patient and provider's tone of voice, e-mail may turn out to be overly mechanical and impersonal when compared to interactive video and face-to-face communication. Thus, e-mail may be a poor means for developing or maintaining empathetic communication

between patients and providers. In other words, this may be a case in which the science or technology of healthcare overrides the art of healthcare. Also, unless healthcare providers regularly check their e-mail on at least a daily basis, e-mail may be inadequate for time-sensitive information that is crucial to the health of in-home patients. Overall, if provider-patient communication is limited by e-mail, some standards for the provider-patient relationship may not be met and the quality of patient care may decline.

On-line Support Groups and Medical Websites

What are the possible implications of on-line support groups and medical websites for the provider-patient relationships of home-based telemedicine? In light of the exponential growth in these Internet applications, this is an important question. According to one estimate, there approximately 17,000 biomedical Internet sites currently in existence (McClung, Murray et al. 1998). Moreover, a 1998 report from the National Library of Medicine states that the Medline website processed 350,000 searches per day in the month of March alone. Furthermore, 30% of the Medline searches during that period were conducted by non-clinicians (i.e., consumers and patients) (NLM 1998).

The likely benefits of on-line support groups and medical websites for home-based telemedicine patients include improved access to medical information, social support, and anonymity, which collectively can improve the autonomy and well being of patients. In fact, regardless of the results, the very use of healthcare websites by patients is in and of itself an exercise of their autonomy. But, access to these on-line healthcare services by home telemedicine patients may lead some patients to question the authority and expertise of healthcare providers. In some cases, assuming the accuracy of the information, in-home patients will have more knowledge than their healthcare providers

will about specific healthcare conditions and new treatments. The following from Eng nicely states the possible implications of these online services for the provider-patient relationship:

Information and advice from other information sources, such as online publications reporting new research, or anecdotal sources, such as online chat groups, can be used to challenge---or “second guess”---clinicians. These factors, the sheer volume of biomedical information produced everyday, and the increasing ease of access to health information, create an environment in which the public’s perception about authorities for health information is changing. Physicians and other traditional health professionals may come to be perceived as one of many sources of authoritative medical knowledge, and clinicians may become one of several types of professionals that individuals rely on to help solve a health problem. In some cases, patients may have greater access to information about their conditions than their health care providers (Eng and Gustafson 1999: 21-22).

Although information and communication technologies make it possible for patients to obtain greater information about their health conditions, whether patients will ever have more information than healthcare professionals will depend on a number of factors, including their willingness and ability to use medical websites and adequate access to the appropriate technology. Moreover, assuming patients can, want, and do make use of websites, healthcare professionals will likely have easier access to computers, the Internet, and, subsequently, to more websites than their patients.

Interactive Video

Although not as common as the Internet applications discussed above, interactive video is likely to play a larger role in home-based telemedicine in the future. Like the Internet, the use of interactive video presents both potential harms and benefits to the provider-patient relationships of home-based telemedicine.

The limitations of interactive video are well established. The possible harms and benefits of interactive video on the provider-patient relationships of home-based telemedicine are less clear. General research has found interpersonal asymmetries within video-mediated communication that are not found in face-to-face interaction and other kinds of technologically mediated communication such as telephone calls (Sellen 1995; Doherty-Sneddon, O'Malley et al. 1997).

The asymmetries of video-mediated interaction can interfere with and distort certain forms of visual conduct within the provider-patient relationship. Patients and providers will have visual access to each other, but some non-verbal cues, bodily gestures, and movements that facilitate communication and relationship building between participants will be undermined because video technology can alter the temporal and spatial organization of a movement. For example, subtle glances between healthcare providers and patients designed to elicit the gaze of the other are transformed when they appear on a video screen. In other words, the movement or gesture produced by one participant is not the movement or gesture received by the other participant. According to Christian Heath and Paul Luff:

The relatively subtle glances through which individuals can ordinarily re-establish mutual engagement, even gross attempts to attract the attention of another, can be undermined by the medium through they are performed. So, on the one hand, video-mediated presence provides individuals with the ability to mutually monitor each other's visual appearance and conduct, but, on the other hand, fails to provide a reliable medium for the production and recognition of non-vocal actions and activities. The technology appears to interfere with the local sequential significance of a range of visual actions, revealing an alternating imbalance between the participants as they shift between the roles of speaker and hearer (Heath and Luff 1993: 48).

What this could mean for the provider-patient relationships of home-based telemedicine is healthcare providers and in-home patients will have visual access to each other but the quality of those video-mediated communications will possibly be inferior to face-to-face communications.

A growing number of studies specifically designed to evaluate the use of videoconferencing equipment in home healthcare continue to support the technical, financial, and ergonomic viability of using this technology in the homes of patients. Furthermore, this technology has successfully been employed for a wide variety of chronically ill patient populations, who need medical treatment and support with activities of daily living.

However, the effect of video-mediated communication on the provider-patient relationships of home-based telemedicine remains unclear. In addition, other aspects of video-mediated communication for home telemedicine are poorly understood at this time: (1) the level of training required for providers and in-home patients in the use of interactive video, (2) the conditions under which video-mediated communication is clinically appropriate, and (3) the acceptable tradeoffs between convenience, economics, and patient care. (Takano, Nakamura et al. 1995; Hornick and Kline 1997).

Despite the possible limitations of e-mail and interactive video, an expanding body of research consistently shows that patients are generally satisfied with video-mediated and other electronic communications with their healthcare providers (Tang and Isaacs 1993). For example, in a recent pilot study of home telemedicine by the Mayo Clinic in Jacksonville, Florida, researchers assessed the attitudes of 20 patients of a retirement community for a period of eight weeks in 1998 (Mayo Clinic 2000).

Of the 20 participants, 18 completed the survey on the project and 11 of them were comfortable operating a home-based telemedicine work unit that included telemetry-capable medical devices and e-mail. More importantly, this study found that 17 of the 18 patients thought that computer-mediated interaction with their healthcare provider did not harm their provider-patient relationship. Moreover, 11 of the 18 patients stated that computer-mediated communication enhanced their relationship with their healthcare provider.

One of the most significant findings was that 17 (94%) of the 18 participants reported the computer system did not have a negative impact on their relationship with the physician and 11 (61%) actually thought the system has a positive effect. This is in contrast to many perceived beliefs that telehealthcare may harm the doctor-patient relationship (Mayo Clinic 2000).

Specifically how the provider-patient relationship was enhanced needs to be fleshed out in future research on home-based telemedicine. Nevertheless, these findings by the Mayo Clinic, limited as they are, suggest that electronically mediated communications in the context of home-based telemedicine may not be as harmful to the provider-patient relationship as some have speculated.

2.8 Legal Issues

Electronic interaction between in-home telemedicine patients and healthcare providers also raises new and interesting questions about the legal status of the provider-patient relationship. Because telemedicine technology permits in-home patients to interact more easily with their healthcare providers, for healthcare providers to access more easily patient health data and records, and for healthcare providers to collaborate more easily with each other, the traditional boundaries of the provider-patient relationship

are altered and stretched, making uncertain the standard of care. Consequently, the training required to practice home telemedicine, the scope of provider liability for equipment failure, and the threshold for medical malpractice are all in a state of flux (Darkins 1996; Stanberry 1998).

A central concern is the jurisdictional or licensure status of home telemedicine consultations. It is not always evident whether a particular telemedicine encounter constitutes a provider-patient relationship and the practice of medicine under various state laws. This proves to be especially problematic for those home healthcare agencies that operate home-based telemedicine programs across state lines (Short and Saindon 1998). In addition, unlike traditional face-to-face relationships that typically include discrete episodes of hands-on care from identified healthcare professionals, telemedical relationships often preclude a hands-on examination by the consulting provider and may include multiple consultants that may simultaneously or at different times review electronically stored patient information. As a result of the geographical distance between patients and providers, patient care is less likely to be characterized by tightly circumscribed episodes of hands-on care from identifiable healthcare professionals who know, and who are known by, the home telemedicine patient.

These new electronic relationships have advantages for patients and providers, such as lower costs and convenient access to services, but the duty to care on the part of providers and the standard of care for telemedicine encounters are greatly complicated because legal precedent for medical malpractice cases fail adequately to guide the provider-patient relationships of home-based telemedicine. Concerning these developments, Patricia Kuszler, a physician and healthcare lawyer, states the following:

In the traditional malpractice case, the alleged negligence occurs firmly within the temporal boundaries of an episode of care delivered by an identified physician. Specialty consultations occur in a sequential pattern, each occupying a distinct quantum of patient and provider time. However, in a telemedicine intervention, the temporal boundaries are more fluid. Moreover, the intervention may involve multiple physicians and consultants simultaneously, or involve store-and-forward images and data that are reviewed by the provider or secondary providers at a later, undefined time. Thus, telemedicine presents the opportunity for the courts to recast the provider-patient relationship, and the duty that flows from it, in a more elastic fashion (Kuszler 1999: 4).

According to Kuszler, the courts will likely look at two kinds of cases to help guide the provider-patient relationships of telemedicine. The first involves cases in which the telephone has been used to establish a provider-patient relationship and in which harm occurred. The second kind of case includes situations in which negligent patient care resulted, in whole or in part, from a consulting physician's advice.

In the cases involving telephone communications, a provider-patient relationship and associated provider duties are not established until the following occur. First, the healthcare provider must agree to care for the patient. This consent to care for the patient may be either direct or indirect. Second, the provider must perform, at a minimum, a simple evaluation of the patient. Third, the patient must depend on and act on the physician's evaluation and diagnosis. When these three criteria are met, case law supports the position that a provider-patient relationship can be established by means of the telephone. Thus, by extension, if the electronic interactions of home-based telemedicine meet these criteria, a provider-patient relationship and the duties that attend it may also be established. This, for example, might occur when providers and patients communicate by e-mail or when in-home patients make use of online psychiatric and medical services.

In those cases that involve consultations, two kinds of consultation, formal and informal are recognized. First, with formal consultations, healthcare providers must have access to the patient's medical record and must give advice to the attending healthcare provider about the diagnosis and treatment of a specific patient. In situations like this, the consulting healthcare provider not only bills the patient for services rendered but also has a relationship with the patient and a legal duty to provide competent medical advice and treatment to the patient.

Second, there are informal "curbside" consultations in which the consulting and attending healthcare providers informally talk about a patient's medical history and condition, but in which the patient's identity may be unknown to the consulting healthcare provider and no fees are charged. In situations like this, no legally established provider-patient relationship exists between the patient and consulting provider and, thereby, no duties of care are legally binding.

The problem, however, is that the advent of home-based telemedicine and telemedical services in general may further obscure an already less than clear distinction between formal and informal medical consultations and could either lower or raise the legal threshold for the establishment of provider-patient relationships between consulting healthcare providers and patients. On this point Kuszler has this to say:

Telemedicine will exponentially increase the opportunity for both the informal and formal categories of consultations. Moreover, the distinction between the informal consultation, where no physician-patient relationship is formed, and the more substantive consultations will be increasingly difficult to draw. With the enhanced ability to transmit records and diagnostic images and to engage in interactive video-conferencing, barriers of time and distance will be removed. This will facilitate easy transmission of more information to consultants, prompting more formal consultations and the decreasing likelihood of the casual, informal "curbside consult" (Kuszler 1999: 13).

Concerns about when a provider-patient relationship and legal liability are established in the context of home-based telemedicine may be overblown and unnecessary. In terms of the quality of care, a reduction in informal consults is likely to be an improvement. Instead of incomplete and sketchy patient histories, the consultant can look at all the patient's data.

Also, in an effort to clarify when a teleconsultation can receive reimbursement from Medicare and Medicaid, the HCFA and the AMA's Current Procedure Terminology state that a teleconsultation, in order to count as a formal consult, must meet three criteria. It must (1) include two-way, real-time (synchronous) interactive audio-video that allows communication among the patient, the referring provider, and the consulting provider; (2) the patient must be present during consultation; and (3) the technology must, if needed, permit the consulting healthcare provider to medically examine the patient.

Given the above three criteria for a formal teleconsultation, the legal threshold to establish a provider-patient relationship and legal liability in the context of home-based telemedicine would be very high. Thus, the distinction between formal and informal medical teleconsultations would simply be made differently; it would neither collapse nor be as difficult to discern as Kuszler hypothesizes (Millman and Kiesel 1999).

2.9 The Case of Cybertherapy

One particular application of home-based telemedicine that challenges legal and ethical notions of the provider-patient relationship can be found in the rapidly growing area of cybertherapy, Internet/computer-aided psychotherapy. By means of videoconferencing tools, e-mail, on-line support groups, and medical websites, mental health and home healthcare services are now being brought together in the form of home-based cybertherapy. In addition to convenience, the potential benefits of on-line mental healthcare services are that (1) healthcare providers can screen for persons who may benefit from in-person mental health services, (2) patients can have more time for thoughtful communications with their providers through asynchronous e-mail communication, and (3) the depth of disclosure can be improved by patients who feel inhibited in face-to-face situations (Zarr 1994).

According to Scott Sleek, cybertherapy and other “online services raise the distinction between therapy and advice giving” (Sleek 1999). For many mental healthcare professionals, cybertherapy is not really therapy at all, but only advice giving. However, if cybertherapy is therapy, not advice giving, it should only be used as a supplement to regular face-to-face psychological counseling and limited to persons who suffer from less complicated psychological problems. Thus, on-line services should not be used to make a formal diagnosis of mental and emotional disorders. In some instances, cybertherapy (e.g., e-mail) may be counter productive for patients who are working in therapy to develop better interpersonal skills, who tend to objectify others, or who feel emotionally isolated from others. In other instances, however, cybertherapy may be an appropriate medium and treatment modality (Maheu 2000).

The less than a solid distinction between therapy and advice giving raises questions about the motives of healthcare professionals who provide mental healthcare services over the Internet without ever seeing or examining a patient. According to James Anderson, “this has major implications for the traditional doctor-patient relationship since it makes the new arrangement monumentally impersonal” (Anderson 1999: 25). If only advice, not therapy, one would hope that the advice given would be of a personal nature, especially when it involves one’s mental health.

A more basic issue related to the fluid nature of the advice-therapy distinction is whether on-line encounters for mental healthcare services can ever constitute a provider-patient relationship. John Grohol does not think so. He states the following about on-line mental healthcare services and computer-aided psychotherapy, what he terms “e-therapy”:

E-therapy is not psychotherapy, nor is it psychological counseling. Since it does not presume to diagnose or treat mental or medical disorders, and because it does not limit who may be appropriate to provide e-therapy services, it would be inappropriate to compare it to traditional face-to-face psychotherapy, assessment, or counseling services. Like other types of therapy (occupational therapy, bibliotherapy, physical therapy), e-therapy helps a person address issues of concern to them in their lives under the guidance of a professional. E-therapy does not diagnose disorders, nor does it treat diagnosed mental or medical disorders. E-therapy is similar to the idea of “coaching,” helping a person address specific concerns with specific skills. But e-therapy is flexible enough to also address more philosophical issues as well, if an individual so desires (Grohol 2000).

The problem with the aforementioned is that the author does not raise and answer a number of important questions: What are the professional and ethical responsibilities of e-therapists to their on-line patients? What constitutes appropriate training for coaches? What ethical obligations and responsibilities do the so-called coaches have for their so-called players if their “coaching” unexpectedly produces horrible consequences for their

players? What sorts of legal remedies should be available to those who are inadequately coached?

Moreover, just because e-therapists do not diagnose or treat those who have already been diagnosed with a mental/emotional disorder, it does not follow necessarily that the provider-patient relationship is simply and automatically transformed into a coach-player relationship and that the ethical standards of their respective health professions no longer apply. For example, even when “advisees” are adequately informed about the coach-player rules for on-line mental healthcare services, it would still be easy for a rational person to assume that a therapeutic relationship had been “indirectly” established after a series electronic communications with an e-therapist. In fact, a therapeutic relationship may be a natural by-product of communicating intimate information about oneself to another person. This is even more likely to occur when the “advisee” suffers from a serious psychological disturbance. The coach-player metaphor may help to exempt on-line mental healthcare providers from legal liability, but it fails to exempt them fully from ethical responsibility (Shapiro and Schulman 1996).

Nevertheless, even if on-line providers of mental healthcare services can be discharged of all ethical responsibility for their patients, and even if e-therapy can be successfully distinguished from psychotherapy, viewed as a form of supplemental advising, electronically mediated communications between home telemedicine patients and e-therapists still present communication and relationship risks. As stated earlier, the use of e-mail and videoconferencing tools have been demonstrated in some studies to lead to the distortion or the complete loss of particular visual and auditory cues that occur in typical face-to-face communications. In the healthcare context, additional empirical

research will be needed to either confirm or disconfirm that non-verbal cues are or are not crucial to good patient care and satisfying provider-patient relationships.

For mental healthcare professionals, their ability to “read” the non-verbal communications of their patients is, in the vast majority of cases, vitally necessary for making accurate patient diagnoses and the formulation of effective treatment strategies. Moreover, without non-verbal cues, it is less likely that on-line mental healthcare providers will feel and be able to convey empathy toward their geographically remote in-home patients. As a result, physical separation may involve emotional separation between patients and providers. In the most extreme scenario, not only will cybertherapists be unable to empathize with their “patients,” they may be unable to ascertain their identity when online psychotherapeutic interventions are limited to text-based e-mail.

2.10 Conclusion

To date, empirical research on the effects of information and communication technologies on provider-patient relationships is limited. More research will be needed before any firm conclusions can be drawn about the relative benefits and burdens of home-based telemedicine for provider-patient relationships. Therefore, in addition to telemedicine research that examines technical and economic feasibility, future telemedicine research should include more detailed analyses of how specific information and communication technologies affect the provider-patient relationships of home healthcare.

Empirical evaluations of home-based telemedicine's impact on provider-patient relationships are not enough. To fully appreciate the effect of home-based telemedicine on the provider-patient relationship, an examination of the broader cultural forces and the values and goals of healthcare will need to be considered by researchers as well. More importantly, in order to assess how, if at all, home-based telemedicine technology enhances and undermines provider-patient relationships, it will be necessary to have in mind some ideal standard or normative model of the provider-patient relationship.

Finally, of the models discussed, the conscience model articulated by Thomasma has the most promise as both a descriptive and normative framework for the provider-patient relationships of home-based telemedicine. For one thing, the conscience model does not exaggerate the roles of patient autonomy and medical paternalism in provider-patient relationships, which can undercut the ethical decisionmaking responsibilities of patients and providers. Additionally, because the conscience model is sensitive to the impact of technology on provider-patient relationships and employs consensus-seeking procedures, the conscience model would be better suited to deal with conflicts that might arise when providers and patients are considering home-based telemedicine as a treatment option. In doing so, threats of technological fixes and future conflicts between patients and providers are likely to be minimized under the conscience model.

CHAPTER 3

PRIVACY & CONFIDENTIALITY

3.1 Introduction

Concerns over the privacy and confidentiality of identifiable health information and health-related communications are not new. Evidence of this can be easily found in the vast literature devoted to the philosophical, legal, and policy aspects of privacy and confidentiality in healthcare. However, the continued adoption of computerized patient records and the expanding use of the Internet by patients and healthcare professionals, especially websites and e-mail, as a place to post, find, store, and transit health-related information have only led to even greater concerns about the integrity of healthcare privacy and confidentiality and who should have access to health-related information. In light of these developments, this chapter first examines the concepts of privacy and confidentiality and then looks at specific technological and policy developments in e-health, evaluating their implications for privacy and confidentiality within home-based telemedicine.

3.2 The Concept of Privacy

Defining *privacy* and privacy-related concepts such as *confidentiality* is not a simple task, as there is no universally accepted definition, theory, or justification for privacy within the philosophical, legal, and public policy literature. Because of this lack of agreement on the scope of privacy, identification and analysis of important privacy issues within home-based telemedicine and other healthcare activities can be difficult, if not entirely overlooked. Despite this limitation, however, privacy has often been

analyzed in terms of (1) the nature of privacy, (2) the coherence and distinctiveness of privacy, (3) the contingency or cultural relativity of privacy, and (4) the normative status of privacy (Schoeman 1984). These elements of privacy are important in understanding what is meant by *privacy* and why and how privacy is ethically significant in the context of home-based telemedicine.

The Nature of Privacy

Questions about the nature of privacy typically center on (a) examining competing definitions of privacy and (b) determining whether privacy is a right. Three definitions are common (Schoeman 1984). First, privacy can be defined as a *moral right* or *entitlement* that individuals have to determine what personal information may be disclosed or communicated to others.¹ Second, privacy can be defined as the *control* persons have over (a) personal information, (b) intimacies of personal identity, or (c) who has sensory access to them. Third, privacy can be defined as the *state or condition of limited access by others to a person's* (a) information, (b) thoughts, and/or (c) body.

All three definitions of privacy have their limitations and are subject to objections. First, defining privacy as a moral right or entitlement assumes that privacy is morally significant, but fails to identify what is morally significant about privacy. To make this determination requires an understanding of why privacy is important to persons and should be accepted as a moral right. One could argue that knowledge of the right to privacy is a matter of intuition and that some persons simply do not have this sort of intuitive knowledge. This, of course, is an epistemologically legitimate position to hold.

¹ Rights to privacy are not limited to individuals, but have been assigned to corporations, organizations, and institutions. The notion of rights, especially corporate rights, remains controversial.

The problem with this position, however, is in adjudicating among conflicting intuitions and in deciding on an agreed criterion to resolve such conflicts.

Second, to make privacy synonymous with control over (a) personal information, (b) intimacies personal identity, or (c) who has sensory access to us, does specify what is morally significant about privacy and avoids the problem of simply stipulating that privacy is an individual moral. Yet, the problem with defining privacy in terms of control is that there are clear cases in which persons can have privacy without having control and other cases in which persons can have control without having privacy. In the first instance, a person lost in a forest or stranded alone on a desert island has privacy, but does not have control over personal information and who has sensory access to himself. In the second instance, persons can freely disclose to others their most intimate thoughts. Here, persons have control over the intimate thoughts they divulge to others, but they no longer have privacy (Rachels 1984; Schoeman 1984). Divulging personal information to another person is a prerequisite for confidentiality. I will say more about this later.

Third, to define privacy as the state or condition of limited access that others have to a person's (a) information, (b) thoughts, and/or (c) body, is superior to other definitions of privacy because it allows us to remain agnostic about privacy's status as a moral right and to evaluate infringements of privacy independent of a person's control. Under this definition, persons have privacy to the extent that others have limited access to them.

But, a central problem in remaining agnostic about privacy's status as a moral right and in defining privacy in terms of the states and conditions of limited access is in reaching a consensus on what will count as the states and conditions of limited access by

others. For example, there is ongoing debate about the extent to which persons should expect privacy within their homes and under what conditions the state (i.e., police) can violate such privacy. This debate also includes the workplace, as illustrated by more recent discussions about the privacy of employee communications and documents that are stored and rely on employer supplied computers. The difficulty in determining the states and conditions of limited access by others may be blunted if privacy considerations are restricted to a particular profession or tightly circumscribed context like home-based telemedicine (Allen 1995). By doing so, general agreement on the states and conditions of privacy is more likely.

The Coherence and Distinctiveness of Privacy

Thus far, it has been assumed that privacy is both a coherent and distinctive moral value that can be identified in widely different privacy claims and issues. The *coherence thesis of privacy* holds that diverse privacy claims and issues have in common the fundamental moral value of privacy (Schoeman 1984). The *distinctiveness thesis of privacy* holds that there are moral values and principles distinct from privacy that can be used to defend privacy claims (Schoeman 1984). For theorists who favor these two views, privacy as a coherent and distinct moral value unites seemingly disparate privacy issues and reflects a unique and diverse social reality that other values, such as *autonomy* and *respect for persons*, fail to do.

There are, however, theorists who reject both of the aforementioned theses of privacy. Their general argument is that the coherence thesis should be rejected because different privacy claims or issues actually reflect different and unrelated moral values (e.g., autonomy, the right to property), which very often do not cohere with each other.

In addition, because of this lack of coherence, some theorists argue that the distinctiveness thesis ought to be rejected because privacy can be reduced to other more basic legal and moral values and principles. Following this line of reasoning, instead of talking about a person's right to privacy, it would simply be better to understand privacy and its violations in terms of the more basic values of autonomy and respect for persons and the better established rights of property.²

The Historical Relativity of Privacy

Arguments for and against the cultural and historical relativity of privacy typically involve two theses: (1) *the thesis of historical variation*, which includes the consideration of whether any notion of privacy is recognized, and (2) *the thesis of the privacy criterion* (Schoeman 1984).

The first thesis centers on determining whether all cultures and societies throughout history have valued privacy. To the chagrin of some theorists, evidence of privacy's cultural and historical contingency is fairly well established. In fact, before Warren and Brandeis penned their famous 1890 law review article on privacy, the legal right to privacy remained undifferentiated from the right to property and was not a central concern for American society (Warren and Brandeis 1984). Regarding this point, Amitai Etzioni writes that "American society only had a vague social concept of privacy, albeit one that was not embedded in a distinct legal doctrine or constitutional right" (Etzioni 1999: 189).

An explicit concern for privacy only emerged as a result of the political, social, and technological changes that were sweeping across America during the late nineteenth

² A good example of questions about privacy's distinctiveness can be found in the debates over decisional privacy. This topic is addressed below with a discussion of informational, physical, and decisional privacy.

and early twentieth centuries. From the cultural and historical relativity of privacy, however, it does not follow necessarily that there are no aspects of life that are inherently private; rather, it may mean that some cultures and societies, including our own at some periods in our history, have failed to recognize privacy's inherent value.

The thesis of the privacy criterion centers on determining whether there are items, conditions, and aspects of personal and social life that are inherently, rather than conventionally, private. It must be emphasized that the second thesis is not so much concerned with how cultures, past and present, deal with privacy, for a brief examination of history reveals that what counts as private in one place and time may not count as private at another place and time. Instead, this second thesis reflects a different goal: to identify or establish a criterion to judge what *ought* to be private.

One problem with this approach is that any criterion of privacy is subject to revision and modification. For example, we could take as the criterion of privacy to be those areas of one's life that are of no consequence to the interests of others (e.g., medical information, one's home). However, as soon as one's personal medical information and home is deemed to affect the interests of others in some significant way (e.g., public health, medical research, and child abuse prevention) they cease to be inherently private. Another problem of the second thesis is that any criterion of the private may be itself historically and culturally relative, a contingent rather than a necessary marker of the private.

The Normative Nature of Privacy

The fourth issue of privacy concerns its ethical or moral status. In the majority of the telemedicine literature on privacy, a particular definition of privacy is usually

stipulated and simply functions to empirically describe what information and spaces are to be protected and secured. This, of course, is very important to the success of home-based telemedicine. What is frequently missing from these descriptive definitions and accounts of privacy are normative considerations of what counts as the ethically appropriate and ethically inappropriate items, conditions, and means of securing privacy.

At issue, then, is not merely whether there are barriers that block visibility and audibility, but also which barriers are legitimate and which are not. The concept of privacy implicitly denotes the existence of *legitimate* barriers; illegitimate barriers are seen as fostering concealment or secrecy, terms that imply illicit, if not illegal behavior. That is, both the scope of privacy and the nature of the specific acts that are encompassed by definitions of privacy (e.g., sexual behavior, voting) rather than excluded (e.g., office mail, including e-mail, the private lives of public figures) reflect a society's particular values (Etzioni 1999: 197).

If Etzioni is correct, then what persons (e.g., telemedicine policymaker and legislators) consider as private automatically privileges some values, subordinates others, and possibly overlooks other values altogether. Here, privacy is a social category. As such, notions of privacy not only describe various social relations, practices, and norms, but also have normative functions that prescribe (usually implicitly) what social relations, practices, and norms are ethically appropriate and permissible (Benn and Gaus 1983).

What are the possible implications of the cultural and historical contingency of privacy? One consequence is that there is no natural or absolute right to privacy and that definitions of privacy, the values they reflect, and what counts as public and private are plastic and subject to regular modification. Another possible consequence of the above view is that even if we believe that the "content" of the right to privacy is culturally, historically, and individually contingent, it does not follow necessarily that the right to privacy is itself contingent.

Normative Theory: Ethical Justifications for Privacy and Confidentiality

Granting the normative function of privacy and confidentiality, there are a number of ways in which privacy, confidentiality, and their exceptions can be justified in terms of consequentialist and deontological considerations that characterize them as personal and/or social goods requiring preservation and protection. There are, of course, other ethical theories, but these two ethical systems provide useful architectonics for evaluating privacy issues in general and in telemedicine in particular.

From a consequentialist point of view (e.g., utilitarianism), privacy and confidentiality have instrumental value because they promote and serve other more important social and personal goals, such as the enhancement of individuality and self-determination. Without privacy and confidentiality, a realm where individuals can cultivate intimate and loving relationships that are free from the pressures and demands of public life and government is not likely. Moreover, without a clear demarcation between public and private domains, the autonomous individuals, families, voluntary associations, and homes that constitute liberal democracies would not be possible (Habermas 1989).

Consequentialist justifications for privacy and confidentiality in healthcare usually address specific values and disvalues that include, but are not limited to, the promotion and protection of the patient's social status and the provider-patient relationship. In regard to social status, privacy and confidentiality help to protect patient health information that, if known by an unauthorized third party, could seriously harm the reputation, social standing and economic opportunities of patients. The ethical significance of protecting health information privacy is most evident when the health information being protected carries social stigma and social penalties, for example, HIV-infection, alcoholism, and mental

illness. Without health privacy and confidentiality, the autonomy and well-being of patients are at risk (Allen 1995).

In regard to the provider-patient relationship, privacy and confidentiality promote trust and openness of communication among patients and providers. Without a commitment to privacy and confidentiality on the part of healthcare professionals, there is a concern that patients would not seek treatment and disclose intimate physical and psychological details about themselves. A lack of privacy and confidentiality would not only have deleterious health consequences for patients; it would also undermine society's trust in medicine and healthcare institutions.

From a deontological point of view, privacy and confidentiality are rooted in a respect for persons, which is grounded in the more fundamental principle of autonomy or self-determination. According to Immanuel Kant, persons are rational, self-legislating moral agents and, therefore, are ends in themselves rather than simply means or things to be used by others. In other words, persons have inherent worth and dignity, intrinsic value, not simply extrinsic or instrumental value. Thus, privacy/confidentiality and claims against unauthorized access are ethically justified on deontological grounds by reference to the intrinsic value and dignity of autonomous persons, not in terms of the instrumental value of privacy and confidentiality or the ends they serve. In doing so, privacy and confidentiality function to acknowledge the moral agency of persons and their choices to live their lives as they choose (Benn and Gaus 1983; Allen 1995).

To date, the majority of telemedicine literature acknowledges the significance of privacy and confidentiality, but remains normatively a-theoretical, thereby making no explicit ethical commitments concerning privacy and confidentiality. Although not

explicitly designated as such, telemedicine practitioners and policy makers nonetheless regularly engage in moral decisionmaking and ethical justifications when, for example, they weigh the respective harms and benefits to personal privacy in home-based telemedicine. In most cases, a mixture of consequentialist and deontological justifications are employed.

3.3 The Concept of Confidentiality

Confidentiality is similar to privacy to the extent that both concepts generally refer to limiting the access that others have to one's body, thoughts, feelings, documents, and living spaces. Confidentiality is also like privacy in that both concepts generally refer to what is out of the public domain. It is these shared characteristics that explain why privacy and confidentiality are sometimes confused and used interchangeably. These two notions, however, are very different from each other.

First, privacy, broadly construed, pertains to the bodies, thoughts, feelings, documents, information, and living spaces of persons, while confidentiality is best understood as a complex of moral, social, and legal practices for protecting privacy. Second, confidentiality requires at least one person to give up his or her personal privacy to another person in the context of a trust- and promise-based relationship. Disclosure may occur, for example, in professional relationships among healthcare providers and their patients, among lawyers and their clients, or in the informal and non-professional relationships existing among friends and intimates. Thus, unlike privacy, confidentiality is always relational and must include at least two persons or agents, one of whom discloses private information to the other with the expectation that the disclosed information will remain confidential.

In home-based telemedicine, disclosures may not always directly involve two persons. This occurs, for example, when patients complete online health forms or give health information to online interactive software designed to diagnose depression and anxiety. According to the Science Panel on Interactive Communication and Health, these sorts of health disclosures will become more common:

In the near future, personal health information will be generated during clinical and nonclinical encounters in disparate settings, such as schools, mobile immunization clinics, public places, and the home. In fact, many health encounters may not even involve a health professional or a person, but rather, an intelligent software agent may be the intermediary (Eng and Gustafson 1999: 86).

Therefore, as long as these patients have good reasons to expect their disclosures to remain confidential, confidentiality, strictly speaking, does not require two persons. Persons can freely disclose their private health information in circumstances where no special relationship, trust, or contract is established, as when a public figure discloses this information to the media. If this is done, however, the recipient of disclosed information is not obligated to keep the information confidential because there is no reasonable expectation to do so (Winslade 1982; Winslade 1995).

Breaching Confidentiality

According to the Hippocratic Oath, healthcare professionals have a moral obligation or duty to protect patient confidences:

What I may see or hear in the course of treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about (Edelstein 1943: 3).

However, unlike Hippocrates and the vast majority of western medicine's history, the duty of patient confidentiality in contemporary healthcare is not thought of as a sacred obligation or absolute rule:

The principle of confidentiality was deemed sacred, and the possibility of breaching this trust was diminished by the limited record-keeping practices of the early 20th century: the typical health record was simply a small ledger card with entries showing the dates of the patient's visits, treatment prescribed, and service fees (Bruce 1984: 2).

Change in confidentiality's status is due to a number of converging social and technological factors which include increased medical knowledge, professional specialization, the need for greater specificity of information to improve public health and medical research, as well as advances in information and communication technologies. What have been the results of these changes in confidentiality's status?

First, when patients disclose private health information today, the expectation of confidentiality is weaker because it is likely that many more authorized parties will have access to patient information, which makes it more difficult to determine who is responsible for subsequent disclosures. This will likely be true for home-based telemedicine, which will rely on the electronic transmission of more patient health information and involve more persons and institutions in patient care.

Second, medical confidentiality is today generally viewed as a *prima facie* moral rule that allows for exceptions when other moral values or social goods, such as public health, are at stake. For home-based telemedicine, this means that even though there are potentially greater risks to the privacy and confidentiality interests of individuals, they will need to be balanced against other medical goals and the common good.

Disagreements remain over the finer points of when it is morally permissible to breach confidentiality with patients, but a general consensus has emerged that healthcare professionals should keep in confidence all information about their patients unless (Edwards and Graber 1988):

1. The patient has given authorization to his/her healthcare provider or medical institution to disclose his/her medical information to a third party;
2. The healthcare provider is required by law to do so as in cases of communicable diseases, child abuse, and gunshot victims;
3. There is a specific clear and present danger to the life of the patient and/or other persons;
4. There is a likely threat of serious bodily or psychological harm to the patient and/or other persons.

In addition to the above, healthcare professionals should *ethically justify* exceptions to medical confidentiality by evaluating the respective harms and benefits of keeping and breaching confidentiality in specific cases. In doing so, healthcare professionals ought to (Edwards and Graber 1988):

1. Consider all other less drastic means of promoting and protecting competing moral values;
2. Reasonably believe that a violation of patient confidentiality or trust will actually promote or protect competing values;
3. Reasonably believe that the combined values of breaking confidentiality will trump the combined disvalues of maintaining confidentiality.

The aforementioned principles and professional guidelines for confidentiality have received judicial acknowledgment and support in *Tarasoff v. Regents of the University of California*, 17 Cal.3d 425, 131 Cal.Rptr. 14, 551 P.2d 334 (1976) (Furrow, Greany et al. 1997). This case dealt with a psychotherapist at the University of California whose patient, Podder, had explicitly threatened to harm his former girlfriend during sessions. No one,

including the therapist, attempted to warn the woman, Tarasoff, and Podder eventually killed her.

Most health professions and healthcare institutions promise to protect patient confidentiality, but *Tarasoff* established legal precedent for the protection of third parties by requiring disclosure of patient information by healthcare professionals and healthcare institutions to identified third parties when they have information about a patient's intent to harm that third party (i.e., someone outside the traditional provider-patient relationship). As discussed above, confidentiality had been historically treated as inviolate feature of the provider-patient relationship and had been considered to be in the best interest of the patient. Moreover, disclosure of patient information to third parties by healthcare professionals exposes them to legal liability and is avoided for reasons of self-protection. Under *Tarasoff*, however, physicians and other healthcare professionals now have an affirmative legal duty to protect identified third parties by warning them of the likely harmful actions of their patients. Now, if they fail to disclose such information to third parties when there is a credible threat of harm, they could be subject to liability (Furrow, Greany et al. 1997).³

3.4 Implications for Home-Based Telemedicine

What are the practical and ethical implications for home-based telemedicine? In general, exceptions to privacy and the need to consider specific harms and benefits when breaching or risking confidentiality should apply to home-based telemedicine as it does in other areas of healthcare (Kongehl 1999; Wilson 1999). In particular, however, should

³ Although there is a general consensus among healthcare professionals and others about what counts as "harm," there remain variations among healthcare professionals' judgments about the "likelihood" of any particular harm occurring. The individuality of each patient and knowledge of patients will influence healthcare professionals' determinations of whether their patients will harm a third party.

we conclude that no single item or condition of non-access is intrinsically private and confidential and that the value assigned to a particular item or condition of non-access explains how that item or condition comes to be categorized as private and confidential? If the answer is yes on both counts, then the prospect of identifying necessary and sufficient conditions for privacy and confidentiality that are universally applicable to diverse settings is unlikely.

But complete agreement on the conditions of privacy and confidentiality and universal application are not required for home-based telemedicine. Instead, a useful approach might be to develop *procedural criteria* to determine what ought to remain private and confidential in the context of home-based telemedicine, for example, by letting individual patients decide what they want kept private and confidential. This approach is consistent with a view that defines privacy and confidentiality as the state or condition of limited access that others have to a person's information, thoughts, and/or body. The strength of this approach is that it not only respects the and autonomy of patients (consistent with the law), but is also practicable, allowing for considerable latitude in determining what should be private and confidential in home-based telemedicine (Wasserstrom 1984).

Assuming that telemedicine providers and policy makers adopt a procedural approach that allows patients and family caregivers to decide, it will still be necessary to avoid a simplistic understanding of privacy and confidentiality that oversimplifies or overlooks competing moral values, interests, and social goods. The following statement underscores this concern and provides useful guidance for attaining a consensus on the nature and scope of privacy and confidentiality in home-based telemedicine:

We agree that the flexibility native to the concept of privacy makes it desirable to provide a tighter meaning. This objective is particularly germane for policies regarding which forms of access to which persons will constitute losses that are violations of privacy. We are, however, reluctant to castrate the concept to make it serviceable for policy. Instead, we recommend that those who propose policies carefully specify conditions of restricted access that will and will not count as a loss or violation of privacy. The policy should accurately define the zones that are considered private and not to be invaded, and it should also state interests that may legitimately be balanced against privacy interests. Often the focus will be informational privacy and restricting modes of access to information about persons; but in other cases policies will govern privacy in making decisions, in intimate relationships, and the like (Beauchamp and Childress 1994: 408).

Therefore, before home-based telemedicine can even be evaluated as either an ethically appropriate or an ethically inappropriate mode of healthcare, before useful procedural criteria can be adopted, the scope and meaning of privacy and confidentiality must be guided by and should reflect the concrete conditions and norms that are unique to providing telemedical care to in-home patients.

This will require, first, useful categories of privacy for home-based telemedicine, which are *informational privacy*, *physical privacy*, and *decisional privacy*. Second, the impact of specific information and communication technologies on these three types of privacy, the need for tradeoffs, and their implications for confidentiality must then be evaluated comparatively against incursions inherent in healthcare generally and hospital care in particular.

3.5 Physical, Informational, and Decisional Privacy

Physical privacy generally refers to the restricted access that others have to our bodies, relationships, and living spaces. Physical privacy is ethically significant because it allows for intimacy, solitude, personal control, and peace of mind (Allen 1995). In

contrast both to prior forms of home care and also to in-hospital care, home-based telemedicine is significant for physical privacy because it has the potential to reduce the number of unwanted in-person intrusions by healthcare workers. As teleconsultation and telemonitoring increasingly substitute for in-home visits, it may be possible for patients and family caregivers to gain more control over their homes, personal relationships, and daily schedules.

Overall, the greater physical privacy afforded by home-based telemedicine has the potential to protect the intimate and non-public sphere of the home and to enhance the autonomy and well-being of patients and families at a time when much in their lives is out of control. In the future, patients and their families may chose to have more in-person visits than televisits, willingly sacrificing a measure of privacy for security and greater social interaction, but home-based telemedicine might give them options to enhance their physical privacy that don't currently exist in hospital settings.

Informational privacy in healthcare refers to the *confidentiality* and *security* of identifiable patient health information and clinical data found in patient records and in communications among healthcare professionals and patients (Allen 1995). In brief, *confidentiality* is the protection of private information, once it has been disclosed by a patient (e.g., during a medical examination or taking of a medical history by a healthcare professional), from being shared with others within or outside healthcare settings not directly involved in the patient's care. Confidentiality restricts who can see and use that information.

The *security* of patient health information, which includes considerations of its *accuracy*, *reliability*, and *quality*, refers to the human, legal, and technical means of

preventing the unauthorized or accidental disclosure of confidential health information. Common technological mechanisms include the use of electronic passwords, firewalls, digital signatures and time stamps, and data encryption software that allow health information to be encoding and decoded for transmission and storage (Collmann and Silvestre 1988; Jenett 1996).

Decisional Privacy is closely related to the two prior forms of privacy, but can be distinguished from them, applying generally to those situations in which persons have secure environments to discuss matters, weigh options, and reach decisions without undue influence by healthcare professionals. For some theorists, however, decisional privacy is not really privacy at all, but rather an aspect of autonomy, freedom, or liberty that has been poorly defined (Allen 1995). Although the exact status of decisional privacy continues to be debated, as a practical matter decisional privacy has gained general acceptance within the legal system of the United States (See section 2.1 on the distinctiveness of privacy).

Home-based telemedicine's use of computerized patient records, electronic mail, medical websites, online support groups, and video conferencing tools create new threats and opportunities for the informational, physical, and decisional privacy of patients and family caregivers. Although security violations are relatively uncommon, the potential for harm is great for telemedicine patients and their families, especially when the security of socially stigmatizing health information is breached. Patients and families may not only lose their privacy, they may be subject to social ostracism, job discrimination, loss of insurance, and social control in the form of blackmail (Shea 1994).

Total informational, physical, and decisional privacy is not realistic in home-based telemedicine and healthcare generally. First, other goods like medical research and public health require that limits be placed on the privacy of health information. Second, in order to treat and cure their patients, healthcare professionals must sometimes compromise or enter the informational, physical, and decisional privacy of their patients. Healthcare professionals must be able to touch their patients and obtain information about the intimate details of their patients' lifestyles and personal habits. In many instances of home healthcare and telemedicine, this requires healthcare professionals to enter the homes of their patients. Hence, patients must give up some informational, physical, and decisional privacy to achieve the benefits of medical expertise. Depending on the site or point of care (e.g., hospitals, ambulatory clinics, and patients' homes), patients and families will have more or less informational, physical, and decisional privacy.

Failing to Distinguish among Informational, Physical, and Decisional Privacy

Unfortunately, much of the telemedicine literature on privacy simply fails to distinguish among informational, physical, and decisional privacy. A lack of adequate distinctions should not be construed as a simple semantic problem, lacking policy and legislative implications for telemedical home care. If such distinctions are not recognized, many of the privacy issues that should be considered when formulating privacy laws and guidelines that affect home-based telemedicine will be overlooked.

Furthermore, even when distinctions among physical, informational, and decisional privacy are acknowledged in the telemedicine policy literature, the focus often remains entirely on informational privacy and the confidentiality of identifiable health information. A good example of this can be seen in the Institute of Medicine's

Telemedicine: A Guide to Assessing Telecommunications in Health Care. Initially, the IOM distinguishes between and physical and informational privacy, but focuses on informational privacy in its assessment of telecommunications in healthcare. Although recognized by the IOM, physical privacy is not explored in any depth and there is no discussion of the potential impact of telemedicine on the decisional privacy of patients (Field 1996: 101).

The current emphasis on informational privacy over both physical and decisional privacy is problematic when it comes to assessing the benefits and harms of home-based telemedicine and for educating patients about the need for potential tradeoffs among these types of privacy. Electronic mail and video conferencing, for example, can enhance the physical and decisional privacy of patients by reducing the number of in-person visits from healthcare professionals.⁴ Yet, these same patients may increase risks to their informational privacy as their physiological data and electronic communications stream through standard phone lines to be shared with other clinicians and/or researcher and to be stored in electronic patient records. If the distinctions among physical, informational, and decisional privacy are overlooked or deemed unimportant, then ethically significant conflicts between these kinds of privacy and the need for possible compromises will be missed and remain unarticulated in policies and laws affecting home-based telemedicine.

⁴ Videoconferencing, however, might compromise physical privacy by inadvertently showing patients and family members in compromising situations, which they do not realize will be picked up by the camera. I deal with this issue later.

3.6 Common Tools of Home-Based Telemedicine

The tools of home-based telemedicine are transforming the way in which health information is acquired, used, disclosed, transmitted, and stored. As a means to facilitate information sharing and cost reduction, managed care organizations, hospitals, insurance companies, and individual healthcare professionals are increasingly employing more sophisticated telecommunication systems for data management and clinical services within the home. As a result, personally identifiable health information about individuals is increasingly available in electronic form through electronic patient records, electronic mail, digital video recordings, the Internet, and through online networks that link insurance companies, hospitals, individual providers, and patients (NRC 1997).

As mentioned earlier, the use of telecommunication technology in the home presents significant benefits for healthcare professionals and patients, including enhanced patient physical privacy, autonomy, improved access, reduced costs, better clinical treatment, and advances in epidemiological research for public health. However, the increasing ability of healthcare institutions and individuals to electronically record, transfer, and store a combination of identifiable patient information raises serious ethical concerns about the privacy of home-based telemedicine. In what follows, key tools of home-based telemedicine are evaluated in terms of their impact on the informational, physical, and decisional privacy of patients and family caregivers.

The Computerized Patient Record

The electronic patient record (EPR) is one tool of home-based telemedicine and has many advantages. First, the EPR makes it technically feasible for in-home telemedical patients to access, amend, and correct their medical records from their home computers.

Whether clinicians will allow this to happen remains to be seen. This development could enhance patient autonomy and could afford patients a more active role in their healthcare, allowing them to make better and more informed decisions about their health plans, providers, and treatments (Gostin 1995). Second, because the EPR could allow for a more efficient management, organization, and dissemination of large amounts of medical data, it is likely that the clinical care of home-based telemedicine patients would be improved. For example, the EPR makes possible faster and more accurate diagnoses, increased checks on medical procedures, prevention of adverse drug events, and the dissemination of expert medical information to the homes of patients that are geographically separated from the EPR and medical workers (Fitzmaurice 1995).

Despite offering significant benefits, the use of the EPR for home-based telemedicine also threatens the informational privacy of patients and healthcare professionals. The EPR makes it much easier for electronic-based health information to be more easily accessed, changed, viewed, copied, disclosed, or deleted by more authorized and unauthorized people than traditional paper-based records. Moreover, unlike paper records and depending on how the system is set up, some electronic patient records could be anonymously accessed and viewed remotely in a short period of time from many different computer terminals. This kind of quick and anonymous access is less likely to occur when patient records are stored in paper form in a chartroom (Marr 1994; Barrows and Clayton 1996).

Electronic Mail

The use of the Internet and electronic mail in healthcare are growing rapidly and increasingly becoming indispensable tools for home-based telemedicine. In *The Future of the Internet in Health Care*, the Institute for the Future states the following:

By 2005, more than half of U.S. consumers will have high household incomes, some college education, and access to a computer at home or at work. Health care consumers of the future will be more actively involved in making decisions about the care that they receive. They will expect high levels of choice, control, customer service, interaction with their health care providers, and access to information. They will use the Internet to help meet those expectations (Mittman and Cain 1999: 1).

Electronic mail (e-mail) can be a highly effective healthcare communication tool that can increase the physical and decisional privacy of patients. First, e-mail can circulate health information more efficiently, especially when linked to EPRs. Second, e-mail can make communication among providers and patients more flexible and convenient. For example, it can help reduce the time that time-strapped healthcare professionals spend answering questions on the phone. Third, it can enhance the quality of medical records by allowing messages to be saved in paper form or as part of the patient's EPR. Fourth, e-mail by means of hyperlinks can directly connect patients to healthcare websites and online support groups. Fifth, effective e-mail communication between patients and healthcare providers has the potential to prevent unnecessary and expensive office visits. Finally, e-mail can facilitate the scheduling of appointments and allow healthcare providers to leave patient appointment reminders (Neill 1994; Mittman and Cain 1999).

But, e-mail also raises informational privacy concerns for home-based telemedicine patients and healthcare professionals. First, the informational privacy of both patients and providers is at risk because unauthorized third parties can intercept unsecured e-mail in

transmission. Second, anyone with access to a healthcare provider's e-mail account can access, alter, and respond to patient e-mail with the illusion of authority. Thus, the accuracy of e-mail may be in question. Third, technical complications may prevent the transmittal of important e-mail information at critical times.

In response to these risks to e-mail privacy, reliability, accuracy, and security, the American Medical Informatics Association has developed privacy guidelines for provider-patient e-mail. These guidelines recommend that healthcare providers should (a) obtain informed consent from patients before using e-mail for direct correspondence, (b) explain and use security mechanisms, (c) prohibit the forwarding of patient e-mail without express authorization, (d) inform patients about those having access to their messages and whether their messages will become part of their medical records, (e) respond to messages responsibly and professionally, and (f) avoid references to third parties (Neill 1994; Kane and Sands 1998).

Online Health Networks

Another feature of the Internet and the World Wide Web is the availability of online health networks. In 1997 it was estimated that nearly 43 percent of adult Internet users searched for health information and services online (Mittman and Cain 1999: 24). For home telemedicine patients and family caregivers, online health networks allow for easy and inexpensive access to (1) health information websites and (2) online support groups.

Older public health information databases such as the National Library of Medicine's MEDLINE and newer commercial websites such as www.webmd.com and www.medicconsult.com allow in-home patients to research specific medical conditions, treatments, journal articles, and healthcare providers with the click of a button. From the

comfort of their homes, patients can have immediate access to medical information from every corner of the world. Moreover, Internet searches for health information continue to be made easier by means of ever more sophisticated search engines that allow patients to find even the most obscure medical article or research data (Wolf 1997; Manners 2000).

The merit of online support groups is that they provide chronically ill patients and their time- and energy-strapped family caregivers with virtual meeting places where they can commiserate and share personal experiences and information anytime of the day or night in the privacy of their homes. Online support groups have the potential to reduce social isolation, improve treatment compliance, reduce costs, and ultimately, enhance patient and family well-being by giving them psychosocial support and greater control over the management of their illnesses. Evidence of this can be found as far back as 1987, when the University of Wisconsin initiated its Comprehensive Health Enhancement Support System (CHESS). CHESS is a computer-based support system designed to help patients access health information and to provide social support by means of a computer in the home to people living with HIV/AIDS (Borberg 1995).

As online support groups and health information databases proliferate and are increasingly used by home-based telemedicine patients, they raise a number of informational privacy concerns. First, current technology permits website developers and sponsors to track the Internet addresses and use-patterns of its users by surreptitiously placing “cookies” on users’ computers when visiting online servers. Cookies are pieces of digital information that online servers send to home computers, which are then sent back to the online servers (Eng and Gustafson 1999: 86). Cookies may include electronic identification tags that allow others to access databases containing information about a user.

This potential lack of anonymity may be especially problematic for home telemedicine patients who access the Internet for medical information and who suffer from socially stigmatizing conditions such as HIV/AIDS.

Furthermore, some online servers forward their cookies to other online servers. This means that it is possible for more unauthorized persons to mine and merge health data about home telemedicine patients who visit medical websites and online support groups. With basic information about a person, it is possible that detailed medical profiles of individuals can be assembled by means of cookies generated by online servers. This is fine, as long as patients give informed consent and the data compiled is used for ethically legitimate purposes such as epidemiological research for improved public health (Gotterbarn 1999). This, however, is not presently the norm in the online world.

Second, medical websites and online support groups present serious problems related to the accuracy and quality of medical information. First, anyone can hang a shingle on the Internet and claim to be a doctor. Also, it is possible to get potentially hazardous drugs from online pharmacies without ever seeing a doctor. Third, reputable medical websites can lead to bad sites, which may give self-caring in-home patients a false security about the accuracy of the information they are collecting. Fourth, advice from online support groups and chat rooms is likely to be anecdotal and possibly worthless, if not life threatening. Fifth, some Internet healthcare sites require patients to pay for information or are dedicated to selling a product. However, most useful medical information on the Internet is provided for free (Fisher 2000; Shaw 2000).

But, even if all of the health information retrieved from online support groups and medical websites were accurate, patients and family caregivers can become overwhelmed

with too much medical information. Also, because patients and family caregivers are usually untrained in scientific research methods and statistics, it can be very difficult for them to decipher and compare the results of medical research. This is not surprising, considering that many healthcare professionals even find it difficult to stay abreast of the latest and best evidence-based medical research in their areas of specialization.

Video Conferencing, Telemetry-Capable Devices and Home Telemedicine Units

Video conferencing equipment and various telemetry-capable medical devices are also common tools in home-based telemedicine. In recent years, videophones, computers, and telemetry-capable medical devices have been centralized in user-friendly telemedicine units or systems. American Telecare, for example, now manufactures the Personal Telemedicine System or PTS, which is a video communications system for the home that uses standard phone lines for its transmissions (AMA 1996).

The employment of PTS and similar devices let healthcare workers monitor patient physiological data and visually inspect the overall physical and psychological functioning of in-home patients from a distance. The PTS consists of a patient unit for transmitting and a nursing unit for receiving. The patient unit has a control panel and videophone that can be used for assessing the patient's mental status (i.e., mood, alertness, and general neurological functioning) and for viewing wounds and dermatological problems. Also included in the patient unit are a speakerphone, an electronic blood pressure cuff, and a telephonic stethoscope, which transmits real time sounds of the heart and lungs (Allen 1996).

There are benefits in using video conferencing equipment and telemetry-capable medical devices in the homes of patients. In addition to cost reduction, telemonitoring can reduce the number of in-person visits by healthcare workers and allow patients and families

greater physical privacy, peace of mind, flexibility, and intimacy in their home life. This is a worthwhile goal, when one considers the rising cost of traditional home health services and that it has been estimated that “as many as 50% of home care nursing visits simply do not require “hands on” care” (Allen 1996). Moreover, for those patients who are socially and geographically isolated, video communication systems like PTS can supplement in-person visits by home-care workers and provide additional psychosocial support (Takano, Nakamura et al. 1995; Hornick and Kline 1997).

Like many of the other tools of home-based telemedicine, the use of video conferencing equipment and telemetry-capable medical devices in the home raise some privacy concerns. First, video consultations allow for the clear identification of specific patients who can be associated with specific health information and specific healthcare professionals. When video consults are broadcast over the airwaves or transmitted through the Internet and unsecured phone lines, this can be especially risky to the informational privacy of patients and providers. These risks apply equally to telemetry-capable medical devices when they transmit patient data (Norton, Lindborg et al. 1993).

Second, in two-way interactive video conferencing, the angle and scope of the video camera will likely limit a home telemedicine patient’s field of vision. In some cases, video consults may be more involved and require the physical presence of non-medical technical staff, an engineer, for example, thereby increasing the number of persons who will be privy to sensitive patient health information. In other cases, the video consult may be unidirectional, allowing only the healthcare provider to see and to hear the in-home patient. As a means of protecting their privacy and confidentiality, these patients should be informed

of any additional personnel who may be in the room with the consulting provider during both interactive and non-interactive video consults (Preston 1994).

3.7 The Development of Ethical Codes

Because of the privacy problems associated with maintaining the confidentiality and accuracy of medical data and identifiable patient health information, it has been suggested that the Information Super Highway should be renamed the Information Snooper Highway (Gotterbarn 1999). Whether we adopt this suggestion, there is little disagreement that the Internet and the electronic transmission and storage of health information has fundamentally and dramatically altered privacy and confidentiality concerns. In response to these concerns, legislative, technical, and ethical standards have been implemented or are currently under consideration.

In a recent report on Internet privacy and security, the National Research Council recommended that the federal government should take additional steps to include new technical features that will better protect the privacy and anonymity of Internet users. In its report, the National Research Council stated:

The features include mechanism to protect the anonymity of Internet users, to keep patient information secure, to validate the identities of users participating in confidential online transactions, and to track users of databases (Kiernan 2000).

Efforts are also underway to make medical websites more reliable and safe by establishing ethical guidelines for them. These guidelines would address issues such as privacy, advertising, and online pharmacies. Recently, the American Medical Association (AMA) proposed guidelines for AMA medical and health information sites on the Internet consisting of four principles that govern (1) content, (2) advertising and sponsorship, (3)

privacy and confidentiality, and (4) e-commerce. These guidelines were prompted by the launch of a for-profit site, Medem, by the AMA and six other doctors' groups. The site offers health information and allows patients to correspond with doctors online (Shanz and Cepelwicz 1999; Winker 2000: 4).

Some medical websites already provide the *HON Code of Conduct* insignia, which is supported by the Health on the Net Foundation (<http://www.hon.ch/>). Medical websites, such as MEDLINE, that display the insignia have adopted an ethical code that guarantees such things as user anonymity and information reliability (Shaw 2000). Two other Internet health organizations have also developed ethical conduct codes for e-health websites. The Hi-Ethics/Health Internet Ethics (<http://www.hiethics.com/>) and the Internet Healthcare Coalition's e-Health Ethics Initiative (<http://www.ihealthcoalition.org/ethics/ethics.html>) have each developed separate codes aimed at the developers of e-health sites. The goal of these organizations is to give consumers the opportunity to make informed decisions about e-health sites by allowing them to compare security and privacy statements of e-health sites using universal descriptions (Baur and Deering 2000).

More recently, the not-for-profit URAC, formerly the American Accreditation Health Care Commission, issued a list of accreditation standards for online health sites designed to help the online health industry to regulate itself, to help consumers assess health information, and to provide a forum for reporting misinformation, privacy violations and other complaints. The URAC standards include over 50 criteria that e-health sites will be required to meet before receiving the URAC seal of approval.

Accredited sites will have the seal on their home pages, linked to URAC's Web site, allowing consumers to register complaints (Landro 2000).

Finally, DHHS has established a gateway to sites that have been reviewed for quality and reliability (<http://www.healthfinder.gov>). Taking this review process to the next level, the World Health Organization has proposed the creation of a “.health” domain to join other Internet top-level domains such as “.com” and “.org” that would help persons to locate accurate and reliable health information (<http://www.who.int/>) (WHO 2001). In conjunction with technical safeguards, ethical guidelines, the creation of a “.health” domain is not only likely to improve healthcare on the Internet, it would be a step toward making home-based telemedicine a safe and ethically appropriate healthcare option for patients, families, and healthcare professionals.

3.8 Privacy Legislation and Policies

As stated, the kinds of privacy most relevant to an ethical evaluation of home-based telemedicine are *physical privacy*, *informational privacy*, and *decisional privacy*. Because of the unique threats and opportunities that home-based telemedicine presents for privacy and confidentiality, tradeoffs will be necessary. Without adequate legal and regulatory safeguards for health privacy and confidentiality, it is more likely that the practice of home-based telemedicine will remain problematic. Unfortunately, much of the enacted health privacy legislation affecting home-based telemedicine is either (1) fragmented (i.e., limited to individual states and governmental agencies), (2) inapplicable

to electronic health information, and/or (3) fails to distinguish fully among the different types of privacy.⁵

Legal protections for health privacy in the United States have been a mishmash of federal and state laws (Gostin 1997). The U.S. Constitution provides some protection for the privacy interests of its citizens; however, there is no explicit right to privacy under the Constitution. In fact, the word *privacy* does not appear in the Constitution. Instead, constitutional privacy protections are derived from case law (Leibowitz 2000).

The First Amendment, which protects free speech, and the Fourth Amendment, which prohibits government from unjustified searches and seizures of private property are frequently cited as the basis for health privacy protections. Moreover, constitutional privacy protections are restricted to governmental activities, which means these health privacy protections do not apply, for example, to private sector hospitals and managed care organizations where a large amount of health information is exchanged. Overall, the Constitution's position on privacy is open to a good deal of interpretation, making constitutionally based privacy protections in healthcare subject to considerable confusion and modification over time (Schwartz and Reidenberg 1996).

In addition to limited constitutional protection, certain federal regulations do provide some protection for patient health privacy. As with constitutional protections for privacy, all federal privacy regulations only apply to public or governmental institutions. In 1973 the U.S Department of Health, Education and Welfare (HEW), the predecessor of the Department of Health and Human Services, drafted the *Code of Fair Information Practices*.

⁵ However, adequate professional guidelines could help to mitigate this problem. More about this is discussed later.

This privacy legislation includes the following principles (Cavoukin and Tapscott 1997: 36; Marr 1994: 215).

1. There must be no personal data record keeping whose existence is a secret;
2. There must be a way for people to find out what information about them is in a record and how it is being used;
3. There must be a way for people to prevent personal information obtained for one purpose from being used for other purposes;
4. There must be a way for people to correct or amend a record of themselves;
5. Any organization creating, maintaining, using or disseminating records for identifiable personal data must assure the reliability of that data for their intended use and must take precautions to prevent misuse of data.

As a result of the 1973 *Code of Fair Information Practices*, the *Federal Privacy Act of 1974* was passed to regulate the transmission of government-held health data and to protect the public from nonconsensual governmental disclosure of confidential information by federally operated healthcare and research institutions that maintain medical records (Cavoukin and Tapscott 1997; Marr 1994). Later, the *Freedom of Information Act* was passed. It permits, but does not require, the exclusion of certain medical information from its disclosure requirements, usually medical information to which social stigma is attached, for example, mental illness and HIV-infection. Under this Act, however, federal agencies retain full discretion to disclose health information without individual consent (Cavoukin and Tapscott 1997; Marr 1994).

Other federal regulations affecting health privacy include *The Americans with Disabilities Act*, the *Provisions of the Public Health Service Act*, and the *Medicare Conditions of Participation*. Each of these federal regulations respectively mandates that all federally-supported healthcare institutions maintain separate files for employee health-

related information, protect drug and alcohol treatment records, and ensure the confidentiality of patient records (Gostin 1995; Gostin 1997).

At the state level, each state has its own privacy laws governing the use and disclosure of health information, resulting in significant differences among the states in health privacy protection (See Georgetown University's Center for Health Privacy for a state-by-state listing of privacy statutes: <http://www.healthprivacy.org>). To complicate matters, there is usually no one law or statute regulating health privacy in individual states. Constitutional and federal privacy guidelines do help, but individual states have enormous flexibility in determining how these privacy protections should be balanced against competing healthcare interests or social goods such as improving clinical care, facilitating medical research, reducing healthcare costs, and maximizing overall public health (Hodge 1998).

The historical absence of universal privacy protections in the U.S. at the federal level combined with disparate privacy laws at the state level has made both the intrastate and interstate protection of health privacy an almost impossible task. Furthermore, most of these laws have limited applicability to electronic health information and thereby limited application to the practice of home-based telemedicine. This, however, is not the case in Europe. For example, the Council of Europe and the European Union have articulated stronger and more uniform guidelines that “set out principles of fair privacy practice for users and Internet service providers” and that are recommended for inclusion in codes of conduct (<http://www.coe.fr/cm/ta/rec/1999/99r5.htm>) (Council of Europe 1999).

3.9 HIPAA: Federal Regulation Protecting Electronic Health Information

In 1999, DHHS published proposed regulations to guarantee patients new rights and protections against the misuse or disclosure of their health records. After an extended comment and revision period, the *Health Insurance Portability and Accountability Act (HIPAA)* took effect on April 14, 2001 (<http://www/hhs.gov/ocr/hipaa>). Full implementation of HIPAA for covered entities will take approximately two years. Under HIPAA, it is expected that greater legal, organizational, and technical protections will be provided for both the electronic and non-electronic collection, transmission, and storage of individually identifiable health information (Collmann 1999; Shanz and Cepelwicz 1999; HHS 2001).

Under HIPAA, *identifiable health information* is defined as follows:

Health information means any information, whether oral or recorded in any form or medium, that:

1. Is created or received by a health care provider, health plan, public health authority, employer, life insurer, school or university, or health care clearinghouse; and
2. Relates to the past, present, or future physical or mental condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an individual.

The HIPAA definition of *identifiable health information* is broader than earlier definitions because it now covers electronically stored and transmitted health information and new types of health information generated by, for example, two-way interactive video systems.

HIPAA includes five key principles for protecting and governing medical records and health information that is electronically stored and transmitted. These HIPAA principles generally seek to protect electronic health information by guaranteeing persons rights of

access, copying, amendment, and knowledge of disclosures to third parties (Shanz and Cepelwicz 1999; HHS 2001):

1. *Boundaries or Limitation on Use*---healthcare information would be disclosed for health purposes only with limited exceptions. Using health information for non-health purposes such as hiring and firing would be prohibited by institutions covered by HIPAA.
2. *Security*---with limited exceptions, health information would not be distributed without patient authorization. Those who receive such information must safeguard it. Healthcare organizations covered by HIPAA must take steps to protect electronic health information against accidental and deliberate disclosure.
3. *Patient Control*---persons would have a legal right to access and amend their health records and to be informed of the purposes for which it is used or disclosed to third parties.
4. *Accountability*---those who improperly handle health information would be criminally punished and subject to civil and monetary penalties.
5. *Public Responsibility*---individual privacy interests would not override national priorities of public health, medical research, preventing health care fraud, and law enforcement.

HIPAA is revolutionary in its attempt to expand the current scope of federal and state privacy protections by comprehensively regulating electronic health information. HIPAA, however, is not revolutionary in its attempt to protect the privacy and confidentiality of identifiable patient health information. In fact, HIPAA principles are very

similar to the five principles articulated in HEW's 1973 *Code of Fair Information Practices*. In many respects, HIPAA simply applies earlier privacy regulations and principles to meet the new challenges produced by digitization and the broader application of telecommunication technologies in healthcare.

3.10 HIPAA and Home-Based Telemedicine

HIPAA regulation generally applies to health information and is not specifically designed for telemedicine. However, if implemented in its current form, HIPAA does raise a number of privacy questions about much of the electronically transmitted, recorded and stored patient identifiable health information common to home-based telemedicine. According to the Office for the Advancement of Telemedicine (OAT), telemedicine policy makers and practitioners need to consider HIPAA's ramifications for (1) interactive information, (2) store and forward digital information, (3) provider training, and (4) legal issues (OAT 1999).

First, it is not clear whether a taped or digitally recorded interactive video consultation in home-based telemedicine should be treated as protected health information under HIPAA. Furthermore, if recorded interactive video is construed as protected health information, current HIPAA guidelines do not specify whether this should be part of, or remain distinct from, the patient's record. If recorded interactive video is not part of the patient record, questions of how long the video should be stored and how it should be destroyed still need to be answered. HIPAA does not give determinate answers to these questions. But, according to the OAT, the Interagency Committee for Medical Records of the General Services Administration does not consider videotapes to be part of the patient

medical record and may provide some guidance to telemedicine policy makers and practitioners.

Second, it is unclear how the storage and forwarding of materials of home-based telemedicine (e.g., still video, radiological images, e-mail, and physiological and psychological data in the form of medical telemetry) should be identified or coded to protect patient privacy and confidentiality under HIPAA. There is some concern that removing identifying patient information and replacing it with an anonymous patient code may create more confusion in the management, transmission, and protection of patient health information.

Third, in its current form HIPAA standards are “scalable,” which means they are designed to accommodate diverse medical settings. This avoids the “one size fits all” problem. As such, home-based telemedicine programs will need to train their employees about privacy and confidentiality issues unique to their programs and technology. Who and what should be included in this training and, more importantly, what counts as a secure teleconsultation or electronic transmission of patient information must yet be determined for home-based telemedicine. HIPAA provides a general framework, but home-based telemedicine programs will be left to work out the details of its implementation.

Fourth, HIPAA raises legal questions about the practice of home-based telemedicine. For example, what kind of legal contracts are required for healthcare and non-healthcare providers of telemedical services? Under what conditions would healthcare and non-healthcare personnel be subject to malpractice in home-based telemedicine? Also and related to the issue of legal responsibility, consent protocols or guidelines for home-based telemedicine will need to be addressed under HIPAA. As a prerequisite, telemedicine

policy makers must understand the specific privacy risks and benefits of, and conflicts between, informational, physical, and decisional privacy.

3.11 Authorized Abuse and Individualism in HIPAA

There are some potential problems with using legislation to protect the privacy and confidentiality interests of home-based telemedicine patients. As discussed earlier, there is a clear genealogy of privacy legislation from the 1973 Code of Fair Information Practices through HIPAA, which means that the defects of earlier privacy legislation are likely to have been inherited by HIPAA. Two potential problems that stand out are (1) the problem of authorized abuse, and (2) the problem of individualism.

First, cases of unauthorized access to medical information tend to be isolated acts, often carried out by one person. Most instances of violations of medical privacy and confidentiality result from persons who have authorized and legal access to another's medical information. Etzioni calls this *authorized abuse*.

Most violations of privacy of medical records are the result of the legally sanctioned--or at least tolerated--unconcealed, systematic flow of medical information from the orbit the physician-patient-health insurer and health management corporation to other non-health care parties, including employers, marketers, and the press. I refer here not to the occasional slip-up or mischief of a rogue employee, cases that often violate ethical codes or laws, but to authorized abuse---the daily, continuous, and very numerous disclosures and uses that are legal but of highly questionable moral standing (Etzioni 1999: 144).

Unlike traditional medical settings, it is very likely that more electronic health information will be recorded and transmitted in home-based telemedicine in the form of video consults, e-mail, and the steady flow of physiological data. HIPAA legislation, if passed, will have implications for the regulation of electronic health information that is

generated during telemedicine encounters. If Etzioni is correct, this means there could be more opportunities for authorized abuse “that are legal but morally questionable in home-based telemedicine.

Second, most privacy legislation and regulation, according to Etzioni, reflect individualism and after-the-fact punitive measures for privacy violations rather than a policy of prevention. If this is the case then these policies have the potential to undermine the common good by thwarting other healthcare goals of quality control, cost control, and medical research. On this point, Etzioni states the following:

The prevailing suggestions for dealing with the tension between privacy and health care goals and a major source of that tension are based on the same legal-ethical doctrine, that of informed consent. This notion is based on legal, philosophical, and moral individualistic assumptions (Etzioni 1999: 155).

For example, HIPAA includes the *principle of patient control*, which holds that persons have a legal right to access and amend their health records and to be informed of the purposes for which it is used or disclosed to third parties. From Etzioni’s perspective, this HIPAA principle could be seen as an instance of individualism overriding equally important healthcare goals. For example, if voluntary informed consent for each and every disclosure of patient health information were the norm, the mere mechanics of getting informed consent from patients could require an enormous expenditure of human and financial resources that would, in turn, retard the pursuit and actualization of other medical goals. Also, a legal right for patients to access and amend their records could give them more autonomy, but it could also burden clinicians by requiring them to avoid using technical language in their record keeping that would confuse the average patient. This, in turn, could have a deleterious effect on healthcare efficiency.

As a means of combating authorized abuse and individualism, Etzioni argues for a new communitarian conception of privacy that avoids the extremes of an individualistic conception of privacy by balancing the interests of individuals with the common good. HIPAA, however, does acknowledge the ethical tension between personal privacy interests and competing social goods, such as public health and medical research. This is expressed in the *principle of public responsibility*, which holds that individual privacy interests ought not to override national priorities of public health, medical research, preventing health care fraud, and law enforcement.

This does not mean that concerns about authorized abuse and individualism are groundless, but they can be managed by means of appropriate technological, social, and organizational measures. First, in addition to obtaining a patient's consent for various categories of disclosures to third parties in advance, EPRs could be configured to send an automatic notice to patients via e-mail, with the transmission of their record to third parties. Second, the development of professional guidelines and codes of ethics for health professions could prove useful in mitigating some legal abuses of privacy (Baker, Caplan et al. 1999).

The American Medical Association and the American Medical Informatics Association have already developed practice guidelines for governing e-mail communications with patients (Kane and Sands 1998; Spielberg 1998). Similarly, the American Telemedicine Association has formulated general guidelines that address the use of medical web sites (ATA 1999). In some instances, these new professional guidelines for telemedicine and other e-health applications are more stringent than the laws and regulations designed to protect patients and consumers.

When healthcare professionals responsibly use their autonomy to self regulate by setting high standards for e-health and other telemedicine practices, the public benefits. Moreover, if healthcare professionals want to remain autonomous and to maintain the trust of the public, it is in their best interest to set the highest standards. If they do not do this, it is likely that they will gradually lose their professional autonomy as more laws and regulations are required to do what they failed to do.

3.12 The 1997 Telemedicine Report to Congress

As part of the 1996 Telecommunications Reform Act (Congress 1996), Congress mandated that the Federal interagency Joint Working Group on Telemedicine (JWGT) be formed to evaluate economic, technical, medical, and legal issues in telemedicine.

Unlike HIPAA, the JWGT focused exclusively on telemedicine. After a period of 18 months, the JWGT delivered the *1997 Telemedicine Report to Congress*. The JWGT report identifies four privacy concerns associated with telemedicine (JWGT 1997):

1. A lack of uniform confidentiality and privacy legislation at the state level in terms of the transfer of health information in telemedicine encounters (just as there is with respect to health information generally). Since telemedicine consultations can take place over state lines, the potential for confusion over which state's standards should be employed arises.
2. A long-distance telemedicine consultation typically involves a clinician-patient session that can be videotaped in its entirety. Thus, the health professional may face his/her own privacy issues under these circumstances. For example, unlike standard medical record documentation in which the practitioner has the discretion to selectively record his or her findings, most interactive telemedicine consultations are recorded in toto. This record is maintained as part of the documentation of the consultation. As a result, practitioners have less discretion to remove sensitive items that they might not otherwise record. From the patient perspective, the patient may not be able to "see" who else is viewing the session along with the clinician on the other side of the long distance consultation.

3. The use of telemedicine equipment usually adds additional personnel to the typical provider-patient encounter. For instance, a technical outsider, like an engineer, may be privy to the consultation.
4. From a technical standpoint, there is a higher volume of data and complexity involved in the various communication mediums used during the typical telemedicine consultation. That could make securing data more problematic.

The four privacy issues identified in the JWGT *1997 Telemedicine Report to Congress* parallel the privacy issues identified in the OAT's evaluation of HIPAA. There is, however, a significant difference between the OAT and the JWGT. Item (2) from the *1997 Telemedicine Report to Congress* would be less problematic if videotaped consultations are not considered as part of the medical record, as the OAT and the Interagency Committee for Medical Records of the General Services Administration suggest. Nevertheless, problems of patient consent and the storage and destruction of taped material would remain unresolved.

Overall, HIPAA, the OAT, and the JWGT identify many privacy and confidentiality issues that are of importance to the practice of home-based telemedicine, but there are a number of problems. First, *privacy* is narrowly understood in terms of *information*. Although there are instances when the OAT, JWGT, and HIPAA glimpse that the concept of *privacy* refers to more than just *information*, none explicitly say so. This means, unfortunately, that other kinds of privacy common to home-based telemedicine, physical privacy and decisional privacy, are poorly conceptualized or overlooked.

For example, the *1997 Telemedicine Report to Congress* only refers explicitly to informational privacy. No explicit mention is made of physical and decisional privacy issues. At one point, the JWGT does state that “telemedicine technology brings with it

concerns about privacy, security, and confidentiality that go beyond those associated with protecting medical records. Identifying those specific concerns is just now beginning” (JWGT 1997). Here, the JWGT may be referring to physical privacy or to other kinds of informational privacy associated with e-mail and the Internet. In either case, it is not clear which kind of privacy is being alluded to because no clear distinctions are made among informational, decisional, and physical privacy. At best, then, the *Telemedicine Report* obliquely suggests that physical and decisional privacy are relevant in the formulation of telemedicine policy and regulation.

Second, after restricting privacy to informational privacy, the JWGT states that information privacy is “the ability of an individual to control the use and dissemination of information that relates to himself or herself” (JWGT 1997). Likewise, according to the OAT and HIPAA, “privacy is an individual’s claim to control the use and disclosure of personal information” (OAT 1999). Although it is reasonable to conclude that some kinds of privacy pertain to information and one’s control over it, a definition of privacy as “individual control over information” is too restrictive to fully appreciate the privacy issues of home-based telemedicine. Also, it should be remembered that confidentiality presupposes that persons give up some control over private information.

Furthermore, as discussed earlier, the OAT’s view of privacy is fairly common and problematic, because persons can have physical, informational, and decisional privacy without having control over others and the conditions of their privacy. This happens, for example, when home-care patients are ignored or go unnoticed by healthcare professionals or when an authorized employee of a large telemedicine program or managed care organization accidentally deletes portions of a patient’s electronic medical

record. In these examples, patients lack control over persons, the conditions, and the items of their privacy, but still have, strictly speaking, physical, informational, and decisional privacy (Beauchamp and Childress 1994: 408).

As discussed above, the effective practice of medicine and healthcare confidentiality require patients to give up some of their privacy by relinquishing control over private health information and others who have access to it. Thus, in addition to control, patients must *trust* that their health information will remain confidential. Control over information and what others do with it is important, but there is no reason to believe that the dominant conception of privacy should be understood in terms of one's *control over information*. This is especially true in healthcare where patients must give up control to receive the benefits of medicine.

3.13 Conclusion

Before telemedicine policymakers, researchers, and legislators can determine what is and ought to be private in home-based telemedicine, the meaning and scope of privacy must be appropriately defined. Without a clear understanding of privacy issues in home-based telemedicine, effective and ethically appropriate telemedicine laws and policies are unlikely.

Unfortunately, much of the enacted and proposed health privacy legislation and guidelines affecting home-based telemedicine is inadequate because it (1) is fragmented, (2) fails to distinguish fully among informational, physical, and decisional privacy, (3) is potentially subject to authorized abuse, or (4) potentially neglects other medical and social goals in favor of individual autonomy. To make matters worse, it is unlikely that a

univocal understanding of privacy will be reached regarding (1) the nature of privacy, (2) the coherence and distinctiveness of privacy, (3) the contingency or cultural relativity of privacy, and (4) the normative status of privacy.

Consequently, it is important that the privacy and confidentiality needs of telemedicine patients are determined by the concrete conditions of providing telemedical care to in-home patients. This requires useful conceptions of privacy for evaluating the electronic tools of home-based telemedicine, in particular, *informational, physical, and decisional privacy*. Without these distinctions, many of the privacy and confidentiality issues that should be considered when formulating laws and guidelines for home-based telemedicine could be overlooked. In addition, procedural privacy criteria for patients, family caregivers, and healthcare professionals should be developed in terms of these three kinds of privacy. Finally, procedural criteria and clear distinctions among different types of privacy will be important, as compromises will be needed among confidentiality, as well as informational, physical, and decisional privacy.

CHAPTER 4

DISTRIBUTIVE AND FAMILY JUSTICE

4.1 Introduction

In this chapter, justice issues associated with home-based telemedicine are examined on two different levels. The first level of analysis looks at the Internet and telemedical applications from a distributive justice perspective, which deals with questions about access and the fair distribution of healthcare benefits and burdens among populations, non-intimates, and strangers. Joseph Fletcher puts it this way:

It seems that the heart of the problem of distributive justice is how we are to allocate our resources; for example, as between rural and urban patients; or between preventative and curative care; or between care by physicians and care by auxiliary and paramedical personnel; or between high-cost specialties and low-cost care (Fletcher 1976: 102).

When understood in this way, home-based telemedicine clearly raises questions about distributive justice. Although useful in evaluating many aspects of home-based telemedicine, the objective categories of distributive justice are inadequate when evaluating the implications of home-based telemedicine among intimates. Therefore, the second half of this chapter examines the notion of *family justice* and what should count as a fair distribution of benefits and burdens within families with regard to telemedicine.

4.2 Distributive Justice in Healthcare

Over the past few decades, debates over healthcare justice in the United States have focused on the lack of access to healthcare services, inadequate health insurance coverage, and health profession shortage areas. There are good reasons for why debate has emphasized

these issues. First, as of 1999, approximately 42 million persons were uninsured at some time in the United States (Schroeder 2001). Second, although more physicians are practicing in the United States today than in the past, the number of rural and inner city areas lacking access to basic healthcare services continues to increase. It has recently been estimated that there are approximately 700,000 physicians practicing in the United States, meaning there are approximately 275 physicians for every 100,000 persons. However, even with this doctor-to-patient ratio, when we look at rural areas where 20% of the U.S. population lives, only 9% of physicians practice there (Marwick 2000).

Thus, even when persons in rural areas have health insurance coverage, it remains very difficult, if not impossible, for many of them to gain access to basic healthcare services without excessive burdens. This is problematic from public health and ethics perspectives because, as numerous empirical studies have demonstrated and common sense suggests, there is a strong link between health outcomes and access to healthcare services (Davis 1991).

But, what does distributive justice in healthcare generally require and what roles can the Internet and telemedicine play? In general, distributive justice in healthcare requires the application of *fair* or *equitable* standards that make *quality* healthcare both *available* and *accessible* to persons in an *efficient* manner. A healthcare system is *fair* or *equitable* when (1) persons are not denied healthcare services on the basis of *prima facie* morally irrelevant criteria, such as class, race, gender, and geography; and when (2) persons can secure an adequate level of care without excessive burdens (President's Commission 1983).

The Internet and telemedicine technologies now make it easier to provide healthcare information and services over long distances, thereby greatly minimizing many of the

obstacles of geography. For example, a single 68 year-old man who is unable to get to the doctor to monitor his congestive heart failure and diabetes can now have his heart function and glucose levels remotely monitored and transmitted to his healthcare providers. In addition, because this patient is forgetful and at times non-compliant, an automated e-mail and phone systems can now remind him and his family caregivers to take specific medications in specific quantities at specific times.

Second, *quality* in the distribution of healthcare means not only that services should be delivered with an eye towards avoiding errors, but should also be provided in a competent, compassionate, and respectful manner as well (IOM 2001). As discussed previously, the use of the Internet and telemedicine technologies in the home raises concerns about privacy and the quality of electronically mediated clinician-patient relationships. Also, it is not yet clear under what clinical circumstances information and communication technologies should be employed and when, if at all, they should supplement or replace face-to-face interactions between patients and healthcare professionals. Consequently, standards of care for various telemedicine services and questions of whether telemedicine improves or decreases the quality of healthcare services provided in the home remains to be answered. These quality issues ought to be addressed when home-based telemedicine is being considered.

Third, the importance of *availability* and *accessibility* in healthcare justice is that both individuals and populations should receive services when they need it without undue burden. In some cases, healthcare services may be available within a community or geographical region but remain inaccessible by some persons because of inadequate transportation. Telemedicine and the Internet now make it possible to deliver some

healthcare services and information to persons who live in geographically remote and/or underserved areas who would otherwise need to travel long distances. Consequently, telemedicine technology in the home has the potential to reduce the burdens associated with getting healthcare services. However, as with healthcare in general, a lack of financial resources in the context of telemedicine will be a problem for many home care patients if they are required to purchase computers and telemedical devices. In the most unfortunate circumstances, some patients will be unable to afford telephone and electrical services on which most home-based telemedical services depend (See section 4.4 on the digital divide).

Finally, *efficiency* is also an important variable in the distributive healthcare justice equation. Because of limited healthcare resources and the high demand for them, inefficiencies such as duplicated services, waste, and errors should be minimized to the greatest extent possible by healthcare professionals, patients, and family caregivers (VHA 1999). The Internet and allied technologies have the potential to reduce healthcare costs, minimize errors, and to facilitate the storage and transmission of healthcare information and patient records. For example, rather than replicating expensive healthcare services and technologies at different sites, a telemedicine network could electronically link multiple remote sites to a centralized healthcare center where patients' records are stored.

Efficiency, along with fairness, quality, accessibility, and availability, are the core elements of a general conception of distributive justice and important to an ethical assessment of home-based telemedicine. If distributive justice in healthcare is to be a reality, no one of the aforementioned element of distributive justice should be pursued to the exclusion of the others. An inherent and interminable problem with this goal, however, is that the elements of distributive justice frequently come into conflict with each other. For

example, improvements in the *quality* of some healthcare services may require placing limitations on the *availability* of other healthcare services because they lead to an unacceptable increase in the aggregate cost of healthcare and produce an unfair allocation of limited healthcare dollars.

These sorts of conflicts among the elements of distributive justice have implications for home-based telemedicine, such as when tradeoffs between quality and access must be made. For example, telemedicine and the Internet are likely to increase access to medical services, clinicians, and healthcare information, but the quality and confidentiality of electronically delivered medical services and clinician-patient interactions might not meet current standards of care established for traditional face-to-face medical encounters. Moreover, although patients now have access to a plethora of online health information, the quality and reliability of much of this information is in question. However, given the option of no, or limited, access to healthcare services and information, telemedicine services, even if of lower quality, may be preferable.

4.3 Theory, Wide Reflective Equilibrium, and Equality of Opportunity

If decisions about tradeoffs among the elements of distributive justice are to be justified rather than being arbitrary, a method of ethical justification and the use of higher-level action-guiding principles will be needed. This, however, does not mean that a commitment to a particular theory of justice is needed. According to James Sterba, different conceptions of justice have the same practical consequences in that they all require the same rights to welfare and equal opportunity.

Assuming that it is possible to show that libertarian, welfare liberal, socialist, communitarian, and feminist conceptions of justice have the same practical

requirements as a right to welfare and a right to equal opportunity, then in order to determine the morally appropriate level of healthcare, it would be necessary to determine what provision of health care would be required by these rights. Since a right to welfare and a right to equal opportunity are usually associated with a welfare liberal conception of justice, it would seem reasonable to use John Rawls' original decision procedure—a procedure favored by welfare liberals—to determine what level of healthcare would be required by a right to welfare and a right to equal opportunity (Sterba 1995: 1313).

Sterba's claim that different theories of justice lead to similar ethical principles and similar practical consequences is not incompatible with the method of *wide reflective equilibrium* first advanced by John Rawls as a coherentist method of ethical justification (Rawls 1974). For Rawls, the method of wide reflective equilibrium is a theoretical account of justification in ethics that can help us to revise our pre-theoretic judgments in light of theoretical considerations. For our purpose, what is significant about wide reflective equilibrium is that even though it is a theoretical account of justification in ethics, it is not itself a normative theory or theory of justice. Regarding this point, Norman Daniels writes:

Seeking wide reflective equilibrium is thus the process of bringing to bear the broadest evidence and critical scrutiny we can, drawing on all the different moral and nonmoral beliefs and theories that arguably are relevant to our selection of principles or adherence to our moral judgments. Wide reflective equilibrium is thus a theoretical account of justification in ethics and a process that is relevant to helping us solve moral problems at various levels of theory and practice (Daniels 1996: 1-2).

Granting the correctness of wide reflective equilibrium as a method of ethical justification and a means of selecting moral principles, as well as accepting Sterba's claim that different theories of justice yield similar action-guiding principles and practical consequences, the goal here is not to argue for a particular theory of justice. The goal, instead, is to examine the *principle of equality of opportunity*, which is derivative of

different theories of justice and can provide guidance when making distributive justice decisions or policies for home-based telemedicine.

As Sterba points out above, John Rawls advances the most widely accepted version of the concept of equal opportunity in the *principle of fair equality of opportunity*. According to Rawls, this principle holds that it is unjust for social institutions to base persons' entitlements to goods on their possession of natural advantages. How particular benefits and burdens in society are to be allocated is determined, for Rawls, by imagining people behind a veil of ignorance, which precludes them from knowing their age, class, race, and gender. While behind this imaginary veil, these people, who will not know their station in life until the veil is dropped, determine the distribution of social goods, resources and services to all member of society. Assuming these persons are rational (i.e., self-interested) agents, they will select an allocation scheme that encourages among other things equality of opportunity (Rawls 1971).

Norman Daniels has appropriated Rawls' original position decision procedure and the principle of equal opportunity for specific use within his theory of just healthcare (Daniels 1993). According to Daniels, the principle of equal opportunity requires that efforts be made to create a level playing field within the healthcare system by removing barriers to opportunity that are due to departures from normal species functioning, which are generally beyond a person's control (i.e., diseases). On Daniels' view, then, a just healthcare system will require society to provide medical treatments and preventative services to counteract those natural inequalities that constitute diseases and, limit equal opportunity. In the context of home-based telemedicine, the principle of equal opportunity might require the regulation of the market as a way to equitably disseminate computers and telemedical equipment to

patients who need them most. Questions about fairness, accessibility, availability, and efficiency would be regulated by this action-guiding principle and ethically justified by engaging in a process of wide reflective equilibrium.

There are, however, disagreements on how the principle of equal opportunity should be interpreted and applied (i.e., on what counts as a “level playing field” in healthcare). Three major interpretations of equal opportunity have been identified (Buchanan, Brock et al. 2000). The first and most restrictive version of equal opportunity (EO1) only requires the elimination of formal legal barriers to similar prospects for persons of similar talents and abilities. The second version of this principle (EO2) is broader in that not only are formal legal barriers to be eliminated, extra-legal or informal barriers (e.g., racial, ethnic, gender, class, sexual preference, and religious discrimination) must also be eliminated. The broadest and most controversial interpretation of the equality of opportunity principle (EO3) goes beyond EO2 by also requiring that efforts be made to eliminate the *effects* of bad luck in the social lottery (i.e., one’s social starting place, such as class and family).

All three versions of the principle of equal opportunity can be ethically justified by the method of wide reflective equilibrium and applied to home-based telemedicine. First, given that telemedicine has and continues to be employed as a means to overcome geographical barriers in the provision of healthcare services, EO1 would be important in shaping telemedicine policies and telecommunication regulations. Beyond this application, however, EO1 appears to have limited applicability to home-based telemedicine and telemedicine generally.

In the case of EO2 and EO3, the informal barriers of healthcare discrimination typically do not include geography but could be expanded to include explicitly the role of

geography. This makes some sense, considering that ethnically and economically disadvantage persons tend to live in particular geographical locations (e.g., poor, elderly whites in rural areas and poor black in urban areas). Therefore, if it can be determined that a particular geographical region is an informal barrier to healthcare that, in turn, deleteriously affects the opportunities of those persons who live in those areas, it seems reasonable to conclude that remedies to overcome this barrier would be ethically required of society. How this is achieved is open to debate, but a possible solution could include the use of telemedicine technologies in the home.

4.4 Telemedicine in Rural Healthcare Settings

Although telemedicine technologies are now being introduced into urban health profession shortage areas, telemedicine technologies have historically been used as a way to deliver healthcare services to geographically remote areas. From a healthcare justice perspective, the Internet and telemedicine are important to rural healthcare because they can reduce disparities in primary and specialized care, minimize the burdens of traveling long distances, and can constrain healthcare costs.

In one study of real-time interactive teleconferencing conducted by the Brody School of Medicine at East Carolina University, it was determined that patients whose demographics restricted care were able to increase their accessibility to medical care by using telemedicine and were generally satisfied with their interactions with healthcare professionals (Gustke, Balch et al. 2000). In one example, an internist in a rural community had a young boy examined by a pediatric cardiologist 70 miles away. Because the boy's father, a Hispanic migrant worker, lacked transportation, the boy and the father were

examined by telemedicine consultation using an electronic stethoscope. By means of telemedical technology, it was confirmed that the boy did in fact have a heart defect that required surgery.

In another study conducted by the Telemedicine Department at the University of Tennessee Medical Center in Knoxville, telemedicine was shown to be effective for dermatology consultation in new patients referred from rural communities (Burgiss, Julius et al. 1997). Without teledermatology services, many rural patients in East Tennessee who develop skin disorders often do not receive specialty care because of the lack of both transportation and economic factors. In this study, the costs of care for conditions diagnosed by telemedicine were less expensive than in-person visits with a dermatologist and patients and clinicians were generally satisfied with telemedical services. In both the aforementioned studies, rural patients who would not have normally had access to healthcare services were able to obtain quality care in a cost-effective manner without the additional out-of-pocket costs associated with travel.

In these studies of telemedicine there were no obvious conflicts among the elements of healthcare justice. Nevertheless, the potential for conflict remains. For example, increased access to healthcare services by means of telemedicine could also increase the amount of money spent by hospitals and particular healthcare systems. Subsequently, telemedicine services might not be a long-term solution because they could have the unintended consequence of making healthcare services more expensive by bringing more people into the healthcare system and by increasing the rate of utilization. That is, even if per capita healthcare services were to drop, there is the danger that aggregate healthcare cost could increase. If this turns out to be the case, telemedicine may not be an economically

viable option. And, of course, one must balance economic considerations against other aspects of justice.

The two studies above are of hospital- and clinic-based telemedicine programs, in which small rural hospitals and clinics are linked to larger medical centers, which are usually located in urban areas. Unfortunately, it is often the case that persons who live in geographically remote areas are not even able to access rural clinics and community hospitals that offer telemedical services because of economic and transportation difficulties. In addition, during the 1980s and early 1990s, the closure rate for rural hospitals and clinics doubled compared to earlier decades to 10 percent (AHA 1989; AHA 1992). This trend appears to be worsening as more rural hospitals struggle to survive. In California, for example, one in five rural hospitals have closed or filed for bankruptcy since 1996 and almost 75% of the remaining rural hospitals in that state have lost money (Trousens 2001).

So, even when rural patients and their families have transportation, community and regional healthcare services may not exist. This is particularly worrisome because, as younger persons have migrated to the cities and suburbs for jobs, there are now a disproportionate number of elderly poor who are living in rural areas, many of whom suffer chronic health conditions (Capalbo and Heggem 1999). Although not a completely satisfactory solution, home-based telemedicine is seen as one way to provide some healthcare services to the worst off underserved rural populations, namely, the elderly poor who are have chronic health conditions (Redford and Parkins 1997). Persons within this population without electricity are even worse off, but telemedicine can do very little for them (See section 5.4 on the digital divide).

A few studies have evaluated home-based telemedicine. One such study is a 3-year federally funded demonstration project of a home telemedicine program in Grainger County, Tennessee. The University of Tennessee Home Care Services and the University of Tennessee Medical Center Telemedicine Network in Knoxville conducted this project (Dimmick, Mustaleski et al. 2000). In this study, nearly 500 televisits were made for health conditions including, for example, congestive heart failure, diabetes management, and hospice services for lung and breast cancers. For most patients, a video camera, a video monitor, and a speakerphone linked to a standard phone line were installed in the homes of participants. In addition, hand-held digital monitors and telemetry-capable medical devices including a glucometer, sphygmomanometer, pulse oximeter, spirometer, scale, and thermometer were used in the homes of patients and families.

This study shows that home-based telemedicine can be very useful in efficiently providing quality healthcare services in a cost-effective manner to chronically ill persons in underserved rural areas (Dimmick, Mustaleski et al. 2000). Patients, family caregivers, and healthcare professionals generally found the telemedicine technology easy to use and were satisfied with the services provided. In many instances, patients and family caregivers avoided burdensome trips to the University of Tennessee Medical Center, which requires a round trip of over 100 miles for some patients and family caregivers. In general, home care patients and their family caregivers found home-based telemedicine services to be convenient and comforting. From the provider's perspective, the time and distance spent driving to and from patients' homes was reduced, the number of home bound patients seen by home care workers per day was increased, and the costs for home visits were lowered.

4.5 The Digital Divide

As more healthcare information goes online and as more telemedical services are made available to the public, the digital divide (i.e., the unavailability or inaccessibility to information and communication technology) has become a healthcare justice concern. The digital divide is relevant to questions about healthcare justice and telemedicine because persons who lack access to information technology or the skills needed to operate the same technology may also have greater burdens obtaining healthcare information and telemedical services compared to persons who have training and access to the Internet and computers (AMIA 1997).

Substantial gains have been made at digital inclusion in the United States in the past few years. For example, more rural households now have Internet access—up 75% from 1998. For home-based telemedicine, expanded Internet access means greater potential for access to health information and medical services in the home. This, in turn, means that patients who are cared for at home are more likely to have better health outcomes. The healthcare justice problem that remains, however, is that persons with disabilities are half as likely to have Internet access (21.6%) as those without disabilities (42.1%) (Department of Commerce 2000). Therefore, those who are the least well off—disabled elderly persons who live in rural areas—will have greater burdens in obtaining online health information and home telemedical services that rely on the Internet. Access to home computers and the Internet could improve the continuity of services, the reach of healthcare professionals, and the quality of life and health status of the homebound chronically ill and frail elderly (Department of Commerce 2000). But, until this gap in digital services is filled for the rural elderly poor, home-based telemedicine services will remain limited for this population.

Assuming that digital inclusion becomes a reality in the near future for health profession shortage areas, there remain additional distributive justice concerns that telemedical services will be of a lower quality when compared to in-persons healthcare services. The question this raises is, When, if at all, should home telemedicine replace in-person home care services? Or, instead of worrying about greater digital inclusion and the establishment of telemedical services, maybe healthcare justice requires more effort and financial resources be devoted to supplying rural HPSAs with physicians and other healthcare professionals. From a distributive justice perspective, issues such as this will require a determination of what sorts of tradeoffs between quality, access, and efficiency are ethically permissible (AMIA 1997). As discussed above, these kinds of decisions can be facilitated by the application of some version of the principle of equality of opportunity and do not necessarily require commitment to a particular theory of justice.

To date, home-based telemedicine appears to overcome some of the problems associated with healthcare accessibility and availability, and appears to provide a cost-effective and efficient means of delivering some healthcare services without a substantial loss in the quality. Moreover, patients, more than healthcare professionals, are generally satisfied with telemedical services (Borberg 1995; Ostbye and Hurlen 1997; Mayo Clinic 2000; Dimmick, Mustaleski et al. 2000). Thus, in light of the need to control healthcare expenditures, rural hospital closures, the practical difficulties in getting healthcare professionals to relocate to health profession shortage areas, that some healthcare services are better than no healthcare services, and growing acceptance by patients, home-based telemedicine may prove to be a practical and ethically acceptable solution for underserved rural areas. However, whether home-based telemedicine becomes a practical and ethically

acceptable solution is itself contingent on the establishment of an adequate telecommunications infrastructure for rural areas that can bridge the remaining digital divide.

4.6 Justice within and for Families

Reflection on the potential benefits and burdens of home-based telemedicine also raises questions about justice within families. A distributive justice approach is adequate when considering the allocation of healthcare services among strangers. But when the focus is on the distribution of benefits and burdens within the intimate context of families, justice involves complex, if not unique, ethical considerations that can be difficult to identify and to manage within a traditional distributive justice framework.

Specifying the justice issues associated with family caregiving in the home is partly complicated by the fact that the concepts, *family* and *caregiving*, lack common and distinct meanings. For some, the meaning of *family* is defined in terms of one's membership in a group whose members are biologically related. The limitation of this definition is that it ignores the importance of emotional and psychological ties between persons. It is often the case that non-biologically related persons have better communications and are more intimately involved in the day-to-day lives of each other than biologically related persons. Likewise, biologically related persons are often emotional and psychological estranged from each other (Ross 1998; Blustein 1982).

A satisfactory conception of family would recognize the significance of emotional and psychological bonds and include persons who are not biologically related (Nelson and Nelson 1995a; Nelson and Nelson 1995b). This broader conception of what it means

to be a member of a family is reflected in the definition of *family* adopted by the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO). According to the JCAHO, *family* consists of the following:

The person(s) who plays a significant role in the patient's life. This may include an individual(s) not legally related to the patient. This person(s) is often referred to as a surrogate decision-maker if authorized to make care decisions for a patient should the patient lose decision-making capacity.

Similarly, what is meant by *caregiving* does not always match the reality of caregiving within families. For example, *caregiving* often means the support that one family member gives to another during the course of regular and ordinary interactions. However, the reality of contemporary family caregiving is that it increasingly includes skills that go beyond the bounds of normal care. This is sometimes the case with chronically ill persons who often require family caregivers to provide great amounts of their time and energy. With this in mind, family caregiving within the home would be better understood as *the provision of ordinary and/or extraordinary care by biological relatives, spouses, and close friends for limited and extended periods of time*. This definition avoids the narrowness of a biologically oriented conception of the family and incorporates the realities that persons face when caring for chronically ill family members.

Throughout the 1980s and 1990s, more attention was given to the role that family caregivers play in providing healthcare services for family members who became dependent as a consequence of chronic physical and mental illnesses. This interest in family caregivers over the past twenty years was largely a byproduct of changes within the American healthcare system. These changes include a continuing demographic shift in which a larger percentage of the American population is defined as elderly, a corresponding increase in the

utilization of expensive high-tech medicine, exploding healthcare costs, and a growing number of uninsured Americans.

One approach to reduce healthcare expenditures and to redirect economic resources to other healthcare needs has been to discharge patients from hospitals sooner and to send them home to be cared for by family caregivers. It has been argued that if family caregivers were unavailable, the American healthcare system would be overwhelmed and unable to supply the demand for healthcare services (Biegel, Sales et al. 1991). Of course, home healthcare is not new. In fact, until the post WWII era, a vast majority of the healthcare people received was delivered in the home and provided by family caregivers. However, beginning in the late 1940s and continuing through the late 1970s, more people began to receive more of their high-tech healthcare services from medical professionals outside their homes. With that said, it likely remains the case that most people, rather than seeking professional help, continue to cope with less severe illnesses on their own by means of home remedies and over-the-counter medications (Graber, Beasley et al. 1985).

Some of evidence of this realignment within the American healthcare system can be found in the dramatic increase in hospital construction expenditures from the late 1940s until the late 1970s. However, because of skyrocketing healthcare costs associated demographic shifts, new medical technologies, and hospital-based services, interest in home healthcare increased as well. This trend can be clearly seen in the American healthcare system's more recent redirection of its expenditures from hospital-based services to home-based services. For example, in 1970, hospital expenditures exceeded home healthcare by a margin of 279 to 1. But, by 1991, this margin had fallen to 29 to 1 (Arno, Bonuck et al. 1994).

4.7 The Burdens of Traditional Home Healthcare

Home healthcare may save the healthcare industry money and provide some benefits to patients and family caregivers, but it is not without its problems (Levine 1998). One problem is that many families are less likely to be geographically centralized and, therefore, unavailable to assist sick family members in the management of home care services. Thomasma and Graber echo this view in the following:

But nowadays the resources of the extended family are not readily available. This is an irony. At the time the technological environment created by massive advances in medicine cries out for the family's support as a corrective, the family itself no longer can provide that support because it has weakened in our society (Thomasma and Graber 1990: 96)

But even when family caregivers are available to provide support to sick loved ones, they are often poorly equipped and poorly trained to provide adequate support. This issues is addressed in a recent report addressing the training and support given to family caregivers who provide home care services in New York City.

The report found that 60% of family caregivers surveyed received no training from healthcare professionals for essential care responsibilities in the home (Rigoglioso 2000). For example, a fifth of family caregivers who were surveyed reported they did not receive instructions on how to operate home medical equipment; 16 percent were not instructed on how to manage a patient's prescription medication schedule; and 85% of respondents had not arranged for hired help in the home for lack of trust or lack of financial resources.

The authors of the New York City study recommended that hospitals, healthcare providers, and home care agencies establish services to meet the reality of increased burdens for family caregivers that include the provision of adequate caregiver education and emotional support. Efforts to do this are now underway by the Department of Health and

Human Services, which recently announced \$113 million in grants to states to provide support and education for families that care for the elderly at home under the National Family Caregiver Support Program (Rigoglioso 2000).

As part of the effort to alleviate the burdens faced by patients and family caregivers, home-based telemedicine and allied technologies are also being recognized as a way to reduce the burdens placed on family caregivers who care for loved ones in their homes, usually elderly parents. Of course, family caregivers do not need to live with their sick family member to benefit from these new technologies. For example, elderly parents who live in their own homes are often forced to move into nursing homes or assisted living communities even when they are medically stable. The primary reason for this is that adult children become anxious and worried about their parents because they are unable to check on them regularly. This, in turn, creates pressure on family caregivers to move elderly and frail parents into nursing homes or assisted-living communities.

The Internet, telemedical devices, and the development of “smart homes” may help to prevent this. Smart homes, for example, employ tracking and monitoring systems that provide digital information about a person’s level of activity and vital signs. This information can then be transmitted to family caregivers via the Internet. Smart homes also include memory aids and decision-support systems that prompt patients to take their medication, which can be stored in smart boxes that signal family caregivers when opened by the patient. Although smart homes and many home telemedicine systems are experimental at this time, they may help to reduce family caregivers’ anxiety, allow some elderly patients to remain in the comfort of their home, and reduce costs associated with institutional care (Eisenberg 2001).

There are, of course, potential burdens for patients and family caregivers in using these technologies. For example, to what extent, if at all, will the intimate sphere of personal and family life be subjected to greater public intrusion as more information and communication technologies are introduced into the home? Will home-based telemedicine, the Internet, and smart homes dissolve the thin membrane that separates the public from the private sphere? Moreover, will greater connectivity by means of telemetry-capable medical tools and biosensors lead to an inadvertent medicalization of patient and family caregiver homes? Less privacy and greater medicalization of the home might be acceptable if the alternatives are to send ill loved ones to nursing homes or assisted living communities. These sorts of healthcare justice concerns should be addressed before home-based telemedicine and allied technologies are adopted.

4.8 A Moral Framework for Families

Healthcare justice within families also raises conceptual problems that have implications for home-based telemedicine. Historically, a patient-centered framework in which the interest of patients is given primary importance has governed healthcare. In general, the needs and wants of families have been normally considered to be factors that are external to the clinician-patient relationship. According to one widely accepted view, an “*external factor* in medicine refers to any result of a clinical decision that can constitute a benefit or a burden to some party other than the patient about whom the decision is made” (Jonsen, Siegler et al. 1982).

Healthcare professionals have and do consider the needs of family caregivers, but, as “external factors,” they are usually and rightly secondary to the patient’s. This makes good

sense because it is the patient's body, well being, and interests that are at stake. However, because home-based telemedicine and home healthcare in general can have profound consequences for the life style, financial status, and emotional and psychological well being of family caregivers, creating additional burdens and conflicts of interests normally not found in institutional medical settings, fuller consideration should be given to the interests of family caregivers. That is, as more healthcare services move into the homes of patients and their families, the interests of family members should be given greater moral weight. A similar point has been made regarding seriously ill newborns. Since it is the parents who will shoulder the burdens of caring for the baby, they ought to have a significant say in how aggressively the rescue efforts are to be for the baby (Hauerwas 1981; Ruddick 1988; Nelson and Nelson 1995b).

Therefore, a decision to adopt home-based telemedicine should be made within a moral framework that is applicable to the home environment and family caregivers. Given that more healthcare services are being provided in the home by family caregivers and that telemedical services could facilitate this trend, it make ethical sense to consider the interests of family caregivers (Arras 1995; Rigoglioso 2000). Therefore, when home-based telemedicine is an option, a *family-centered moral framework* that promotes *justice within families* should supplement, if not replace, the more traditional patient-centered model of decisionmaking. Unlike the impersonal standards of distributive justice, family justice deals with allocation of benefits and burdens among intimates. According to Thomasma and Graber, the distinction between distributive and family justice is important because:

The distribution of benefits and burdens within the family might not satisfy objective standards of fairness; but, if not, any departure from impersonal principles of justice ought to be negotiated openly and freely within the

family on the basis of both mutual respect and mutual affection/love/compassion (Thomasma and Graber 1990: 97)

According to John Hardwig, family caregivers whose interests (e.g., emotional, financial, or lifestyle) will be affected by the choice of a treatment option (i.e., have a stake in the decision) should have a say in determining the treatment options that are eventually selected for the ill family member. For Hardwig, the authority to make such decisions ought not reside with the patient alone, but also include the legitimate moral claims of family caregivers.

The prevalent ethic of patient autonomy ignores family interests in medical treatment decisions. Acknowledging these interests as legitimate forces basic changes in ethical theory and the moral practice of medicine (Hardwig 1990: 5).

According to Hardwig, the current medical ethos shifts the burdens and responsibilities of care to family caregivers, but fails to recognize their rights. If justice is going to be realized for family caregivers, medical practices and theories will need to change.

In fact, I would argue that we must build our theory of medical ethics on the presumption of equality: the interests of patients and family members are morally to be weighed equally; medical and nonmedical interests of the same magnitude deserve equal consideration in making treatment decisions (Hardwig 1990: 7).

For Hardwig, the rejection of the patient as the ultimate moral agent and the inclusion of family interests in medical decisionmaking are justified in terms of a theory of individual rights, autonomy, equality, and fairness. However, healthcare justice within families on Hardwig's view is not without its problems and could have implications for some families when deciding on home-based telemedicine as a mode of treatment.

According to Jeffery Blustein, we can agree with Hardwig about the shortsightedness of any view that ignores the legitimate claims of families and fails to balance the rights and responsibilities of all stakeholders. However, Blustein believes that Hardwig underestimates the limitations that illness place on the autonomy of patients and overlooks the threats from hateful, resentful, or manipulative family members who may coerce patients to go along with their decisions through guilt or fear.

Hardwig's proposal for greater family involvement in medical decisionmaking, however, runs up against the problem of patient vulnerability: joint family decisionmaking provides too many opportunities for the exploitation of patient vulnerability. Serious constraints on patient autonomy, such as anxiety, depression, fear, and denial, are inherent in the state of being ill (Blustein 1993: 7).

James and Hilde Nelson advance a view of the family similar to Hardwig's. According to them, the interests of family caregivers or intimates need to be given greater moral consideration than they currently receive. However, they note that extending the moral umbrella to cover family caregivers is likely to make treatment decision more difficult rather than easier.

Medical decisionmaking would be a messier but better thing if it honored what is morally valuable about patients' families. The concerns of intimates have a legitimate call upon us even when we are ill (Nelson 1992: 6).

Although Hardwig and the Nelsons hold similar views, the Nelsons do not justify, at least not explicitly, greater family involvement in terms of individual rights, autonomy, equality, and fairness. Rather, the Nelsons justify greater moral consideration for the family by viewing the family as an organic unity in which the interests of patients and families ought not to be separated. The Nelsons' position is similar to some of the communitarian theories of the family that reject the individual rights-based approach advanced in Hardwig's analysis of the family. From a communitarian perspective, the patient and family members

are not isolated and distinct moral agents with their rights and responsibilities; rather, the identities of patients and family members are constituted within the family by means of a mutual understanding of shared ends and goals (Blustein 1993).

Mark Kuczewski, who champions communitarianism and believes that a rights-based approach in medical ethics makes impossible an adequate discussion of the role of the family in medical decisionmaking, argues that Hardwig's and the Nelson's views are more or less the same. For Kuczewski, the Nelsons may give more moral authority to family members than does Hardwig, but like him, they ultimately conclude that greater moral weight should be given to the preferences of patients in the majority of conflicts surrounding medical decisionmaking within families.

Hardwig's position can be interpreted as virtually identical with the Nelson's. These arguments are framed in terms of conflict between interests of the patient and those of the family. With some exceptions, most conflicts must be settled in favor of the patient (Kuczewski 1996: 31).

Kuczewski's conclusion is misguided on two counts. First, the Nelson's go out of their way to point out that they are rejecting traditional theoretical ethics, at least in the context of analyzing the role of families in medical decisionmaking, because it fails to capture adequately the intimate nature of family life and ignores how family member's interests are "complexly entwined." On this point, the Nelsons state the following:

Yet there is increasingly reason to believe that this intensity of focus on patient interests—considered as the interests of splendidly isolated individuals—reflects a kind of moral obtuseness, and that we would do better to design a system of medical decisionmaking sensitive to a broader range of values (Nelson 1992: 7).

Given the Nelsons' position, it is difficult to see how Kuczewski can draw the conclusion that Hardwig and the Nelsons have "virtually identical" views about the family. Rather, it

seems that the Nelsons' position has more in common with Kuczewski's own communitarianism than Hardwig's rights-oriented individualism.

A second objection to Kuczewski's communitarian position is his interpretation of what it means to have individual rights within the family.¹ For Kuczewski, families should not be viewed as being constituted by rights-bearing individuals because "the profundity of the links and bonds between family members is hidden from view in these legalistic discussions of interests and rights" (Kuczewski 1996: 31). The problem with Kuczewski's interpretation of individualism and a rights-oriented approach is that talk about community and intimacy does not eliminate all disagreements about ends and conflicts of interests that might arise within families. More importantly, individuals and rights are not only necessary elements of families, but appear to be what is most important about families. Concerning this issue, Neera Badhwar states the following:

An ideal family or friendship may wipe out all differences of ends, both final and intermediate, but it cannot wipe out "the separateness of life and experience." *Au contraire*, it would seem that it is precisely ideal family love and friendship that will appreciate the "distinction of persons," recognizing the interest of each individual in *pursuing* a shared good, and her right to do so within the constraints of justice (Badhwar 1993).

From the foregoing it is obvious that there is a general agreement that families should have a larger role in medical decisions that affect them, and, therefore, that something along the lines of a family-centered moral framework, rather than a patient-centered moral framework, would be better in addressing healthcare justice issues that are likely to arise within home-based telemedicine and home healthcare generally. Despite this agreement on the importance of family, there remains disagreement on how greater family involvement should be theoretically justified.

¹ This objection also applies to the Nelsons.

Therefore, with the above in mind, the adoption of a family-centered moral framework for home-based telemedicine that promotes justice within families does not automatically mean either the rejection of a rights-oriented approach or the acceptance of a communitarian approach. However, given that our legal and constitutional systems are rooted in a theory of rights and that families, whether functional or dysfunctional, consist of individuals, a family-centered moral framework for home-based telemedicine would seem best justified in terms of the rights and responsibilities of individuals. There is, of course, the objection that a rights-based justification for greater family involvement in medical decisionmaking overlooks the threat of selfish family members and vulnerabilities that illness places on patient autonomy. However, a rights-based, unlike a communitarian, justification for a family-centered moral framework for home-based telemedicine is also more likely to recognize and to protect the interests of vulnerable patients because it better recognizes and appreciates the distinction of persons.

Although imperfect, a rights-based justification of a family-centered moral framework is more likely to cohere with what will actually take place within families who are considering home-based telemedicine. It would do so, for example, by respecting the autonomy of patients to decide how, where, and by whom they will be medically cared for, on the one hand, and recognizing how telemedicine will affect the individual lives of family members, on the other hand. It is true that a rights-based approach could lead to more conflict within families, but it would do so as a result of taking seriously the distinction between persons and the possible differences of opinion within families about the adoption of home-based telemedicine.

4.9 Conclusion

Justice within families will not only require a family-centered moral framework, it will require society to determine what are and should be reasonable expectations of families when caring for sick family members at home. In some cases, the emotional, physical, and financial burdens of home-based telemedicine on family caregivers could be so great that families ought to have the right to refuse home care technologies and select other options that are less burdensome. The need for appropriate limits on familial duties in the context of home-based telemedicine is especially evident when we consider that it will likely be female family members in the majority of cases that will care for sick loved ones at home. If justice within families is going to be achieved, patients and their families may need to have viable alternatives to home-based telemedicine services, such as nursing home care, that allow them to manage the burdens of caring for sick family members.

However, if it happens that specific applications of home-based telemedicine increase access to healthcare services, are of good quality, and reduce healthcare expenditures, they should be made the standard of care for specific medical conditions. In doing so, it may turn out that what is deemed a just healthcare system for society will sometimes conflict with what has been deemed just within and for some families. As with conflicts among the different elements of distributive justice, appeal to action-guiding principles, such as the principle of equality of opportunity, and the method of wide reflective equilibrium can help to decide and to justify the distribution of benefits and burdens between society and families.

CHAPTER 5

INFORMED CONSENT

5.1 A Brief Medical History of Informed Consent

If patients and families are technically, medically, and emotionally naïve about the potential benefits and burdens of home-based telemedicine, they could be unable to make adequately informed decisions about its use or non-use. As a means of promoting their well being and autonomy, potential home telemedicine patients and family caregivers should be adequately informed about the potential benefits and harms of home-based telemedicine compared to traditional home healthcare treatment modalities.

In order to appreciate the informed consent issues that are unique to home-based telemedicine, it is useful to have a general understanding of both the medical and legal history of informed consent and the relatively new emphasis given to it by medical professionals, legal scholars, and philosophers. For most of medicine's history, the idea that healthcare professionals had ethical or legal obligations to provide information to and receive consent from their patients, not to mention families, was simply lacking. It was not until the second half of the twentieth century that ethical and legal requirements for patient informed consent were explicitly established.

The minor role played by informed consent in the historical drama of the physician-patient relationship is evident as far back as the Hippocratic Oath, one of the earliest classical documents of western medicine to address the ethical duties of physicians. In addition to stipulating that physicians should commit to life long learning and honor the profession of medicine, the Hippocratic Oath urged ancient physicians to

adopt paternalistic relationships with their patients. Although the terms “paternalism,” “beneficence” and “non-maleficence” are not explicitly used in the Hippocratic Oath, they are central in understanding the roles of patients and physicians in classical times.

I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice (Edwards and Graber 1988: 40)

Nowhere in the Hippocratic Oath are the health values, preferences, and judgments of patients mentioned. There is no mention in the Hippocratic Oath that physicians should promote their patients’ autonomy by receiving patient consent, educating patients about their medical condition, and disclosing to them the likely harms and benefits associated with various treatments options and medical procedures. As a consequence, classical physicians who followed in the Hippocratic tradition were only required to promote the well being of their patients and to avoid harming them. However, what constituted a patient’s well being and the avoidance of harm was left entirely to the professional judgment of individual physicians. Such judgments were not to be arbitrary, but rather to be directed by the physician’s medical knowledge and a paternalistic concern for patients.

In addition to protecting medical secrets, it was thought by the ancient physician that the less their patients knew about their medical conditions and about possible treatments and interventions, the less likely they would worry and, subsequently, suffer additional psychological and physical harms. Thus, ancient physicians were not only exempt from informing their patients, these physicians could deceive their patients if they thought doing so would promote their patients’ overall good.

The purpose of medicine as expressed in the Hippocratic oath was to benefit the sick and keep them from harm and injustice. Managing

information in interactions with patients was portrayed as a matter of prudence and discretion. The Hippocratic writings did not hint even at obligations of veracity (Beauchamp and Faden 1995a: 1232).

By the dawn of the nineteenth century very little had changed with respect to informed consent. In his 1803 book, *Medical Ethics*, Dr. Thomas Percival made only a small modification to Hippocratic paternalism by arguing that patients should be informed about their illnesses and treatments when “absolutely necessary” (Percival 1927; Katz 1995). During Percival’s day this was an improvement over the received Hippocratic doctrine. But the occasions when patients were informed remained very limited and these occasions were difficult to identify because Percival provided little in the way of objective criteria for those “absolutely necessary” occasions when patients should be informed about their illnesses and treatments. Consequently, how, when, and the conditions under which patients were informed about their illnesses and treatments effectively remained ill defined and under physician control at the advent of the nineteenth century. As will be discussed subsequently, similar questions have arisen in connection with establishing informed consent guidelines for home-based telemedicine.

In 1847, the American Medical Association (AMA), the largest medical association in America and a leader in establishing ethical standards for professional conduct, published its *Code of Medical Ethics*. This work was revolutionary in that it helped to establish medicine as a profession and provided guidelines for physician-physician interactions. Unfortunately, the AMA’s new code had a less substantial impact on the way physicians actually related to their patients. To a great extent, the AMA’s new Code simply reproduced Percival’s position on patient informed consent, a position

which itself was barely distinguishable from the twenty-four hundred year old Hippocratic Oath (Baker, Caplan et al. 1999; AMA 2000).

A physician should not be forward to make gloomy prognostications,But he should not fail, on proper occasions, to give to the friends of the patient timely notice of danger, when it really occurs; and even to the patient himself, if absolutely necessary. This office, however, is so peculiarly alarming when executed by him, that it ought to be declined whenever it can be assigned to any other person of sufficient judgment and delicacy. For, the physician should be the minister of hope and comfort to the sick; that, by such cordials to the drooping spirit, he may smooth the bed of death, revive expiring life, and counteract the depressing influence of those maladies which often disturb the tranquility of the most resigned, in their last moments. The life of the sick person can be shortened not only by the acts, but also by the words or the manner of a physician. It is, therefore, a sacred duty to guard himself carefully in this respect, and to avoid all things which have a tendency to discourage the patient and to depress his spirits” (Baker, Caplan et al. 1999: 325).

Subsequent revisions of the Principles of Medical Ethics in 1903 and 1912 gradually modified the AMA’s position on patient informed consent. But, as the following excerpts demonstrate, these changes are woefully inadequate by today’s standards.

In a section titled “Honesty and Wisdom in Prognosis,” the 1903 version of the Code states:

Ordinarily, the physician should not be forward to make gloomy prognostications, but should not fail, on proper occasions, to give timely notice of dangerous manifestations to the friends of the patient; and even to the patient, if absolutely necessary (Baker, Caplan et al. 1999: 336).

In a section titled “Prognosis, the 1912 version of the Code states:

A physician should give timely notice of dangerous manifestations of the disease to the friends of the patient. He should neither exaggerate nor minimize the gravity of the patient’s condition. He should assure himself that the patient or his friends will have such knowledge of the patient’s condition as will serve the best interests of the patient and the family (Baker, Caplan et al. 1999: 347).

It was not until 1957 that the AMA significantly revised its code of ethics and took the first steps toward giving patient informed consent a larger role in patient care (Katz 1995). Two point points need to be made about the AMA's recognition of the ethical and clinical importance of receiving informed consent from patients.

First, the AMA's 1957 position on informed consent did not apply universally to all healthcare contexts and forms of patient care. Rather, the requirement of informed consent was circumscribed to persons involved in medical research and experimental studies; informed consent had not attained the status of an ethical duty owed to patients undergoing established treatment procedures (Morin 1998).

Second, because the AMA's 1957 Code coincided with the articulation of a legal doctrine of informed consent, modifications in informed consent requirements may have had more to do with circumventing possible malpractice charges than with the advancement of patient well-being and self-determination (Baker, Caplan et al. 1999).

The most recent edition of the AMA's *Code of Medical Ethics* is even more explicit about the importance of informing patients, going as far as stating that informed consent is a right of patients and a duty of physicians (AMA 2000). For example, Principle IV of the AMA's *Principles of Medical Ethics* states that "a physician shall respect the rights of patients", while Principle V states that physicians are required to "make relevant information available to patients." The AMA Code of Medical Ethics also includes the *Fundamental Elements of the Patient-Physician Relationship* that specifies the rights of patients. The phrase "informed consent" is never mentioned, but Elements 1 and 2 are unambiguous about a patient's right to informed consent. Element 1 deals primarily with the informational aspects of informed consent:

The patient has a right to receive information from physicians and to discuss the benefits, risks, and costs of appropriate treatment alternatives. Patients should receive guidance from their physicians as to the optimal course of action. Patients are also entitled to obtain copies or summaries of their medical records, to have questions answered, to be advised of potential conflicts of interest that their physicians might have, and to receive independent professional opinions (xv).

Unlike Element 1, Element 2 of the physician-patient relationship deals with the decisional authority aspect of informed consent and the importance of respecting the autonomy of patients to make treatment decisions based on the information provided by their physicians. Like Element 1, Element 2 makes no explicit mention of informed consent or patient autonomy.

The patient has the right to make decisions regarding health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended treatment (xv).

The American College of Physicians (ACP) also recognizes that physicians have both a legal and ethical duty to disclose relevant personal health related information to their patients and to the greatest extent possible make sure that patients understand disclosed information before giving consent (ACP 1998). Unlike the AMA, the ACP's *Ethics Manual* explicitly mentions a patient's right to informed consent:

The physician is obligated to ensure that the patient or surrogate is adequately informed about the nature of the patient's medical condition and the objectives of, alternatives to, possible outcomes of, and risks involved with proposed treatment (579).

5.2 A Brief Legal History of Informed Consent

Although the AMA, ACP, and many other prominent medical associations in the United States now recognize the ethical importance of informed consent, the field of medicine, given its long history, has been characterized as slow and reactive in its

recognition of informed consent. The legal history of informed consent, on the other hand, has been characterized as rapid and proactive, at least in the latter half of the twentieth century, and primarily responsible for introducing the medical community to the doctrine of informed consent. Concerning this point, Jay Katz draws two conclusions from his analysis of the history of informed consent:

“Informed consent” is a creature of the law and not a medical prescription... When judges were confronted with claims of lack of informed consent...physicians were ill-prepared to shape judges’ notions on informed consent with thoughtful and systematic positions of their own (Katz 1995: 88).

The term *informed consent* was first introduced into United States case law in 1957 (*Salgo v. Stanford University*), the year that the AMA overhauled its *Code of Medical Ethics*, as a means to clarify the legal duties that physicians have to inform their patients of likely harms and benefits of specific diagnostic procedures and treatment alternatives, including the option of no treatment (Katz 1995). Concerning the development of the legal doctrine of informed consent, Beauchamp and Faden state the following:

During the 1950s and 1960s, the traditional [legal] duty to obtain consent evolved into a new, explicit duty to disclose certain types of information and then to obtain consent. This development needed a new term; and so “informed” was added onto “consent,” creating the expression “informed consent”...(Beauchamp and Faden 1995a: 1234).

Thus, the decision by the *Salgo* court is significant because, not only were patients required to give their *consent* to treatment, they were now required to be *adequately informed* about the risks and benefits of proposed and alternative treatments. The legal doctrine of informed consent was further developed in the 1960 Kansas Supreme Court case of *Natanson v. Kline*. In this groundbreaking case, the court decided

that an inadequate provision of information to a patient by a healthcare provider about his or her medical condition and the potential harms and benefits of both proposed and alternative treatments could constitute grounds for the legal charge of negligence (Beauchamp and Faden 1995a).

The establishment of a legal foundation for informed consent in the 1950s and 1960s requiring healthcare providers both to inform and to receive voluntary consent from their patients was an important milestone in advancing patient well being and autonomy. Throughout most of this period, however, ethico-legal arguments tended to justify the developing doctrine of informed consent in terms of beneficence and non-maleficence, not in terms of patient autonomy (Beauchamp and Faden 1995a). The central problem with a beneficence-based justification for informed consent is that it does not guarantee that competent patients (or their surrogates) have a legal or ethical right to be informed and to determine what is in their healthcare interest. Hence, decisional power over treatment was effectively left in the hands of healthcare providers, not in the hands of patients (Meisel and Kuczewski 1996).

Beginning in the early 1970s and continuing through the 1980s, a series of court cases on informed consent (i.e., *Canterbury v. Spence*, *Cobbs v. Grant*, and *Wilkinson v. Vesey*) considered whether patients and their surrogates comprehended the information they received during the process of informed consent. In doing so, the ethical principle of patient self-determination became a key issue for legal scholars. One result of the new emphasis on patient self-determination was that the principle of informed consent not only required healthcare professionals to *inform* their patients and for patients to give

consent to treatment, competent patients were now required to *understand* the information they were provided as a prerequisite for exercising their autonomy.

Finally, the 1980s saw the transformation of informed consent as a legal requirement into an ethical requirement rooted in patient autonomy. To a large extent, a report on informed consent included in the 1982 *U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioral Research* (1982) was responsible for this transformation. According to Beauchamp and Faden (Beauchamp and Faden 1995a):

The commission argued that although informed consent has emerged primarily from a history in law, its requirements are essentially moral and policy oriented...The principle of self-determination was described as the “bedrock” of the commission’s viewpoint (1237).

5.3 The Elements of Informed Consent and Disclosure Standards

As a result of court cases, governmental commissions, and philosophical analyses, there now exists a broad interdisciplinary consensus among medical, legal, and philosophical perspectives on the core elements of informed consent in medicine. In his book, *Deciding Together: Bioethics and Moral Consensus*, Jonathan Moreno claims that the broad consensus on informed consent is simply an expression of our more deeply held liberal democratic values (Moreno 1995):

In classical liberal terms, respect for individual self-determination is the very condition for civil society, for entrance into the social contract. The bioethical consensus that has grown up around the doctrine of informed consent in health care is really a reflexive confirmation of our society’s essential philosophy: the answer to the “who should decide?” problem is that everyone should decide for himself or herself, under conditions of freedom and quality (26).

The core elements of informed consent on which a consensus has been reached include the following (Meisel and Roth 1981; Beauchamp and Childress 1994; Beauchamp and Faden 1995b):

1. *Competence* of the patient
2. *Disclosure* to the patient about the likely risks and benefits of treatment options
3. *Understanding* by the patient of disclosed information
4. *Voluntary* participation by the patient (i.e., free from coercion)
5. Consent to treatment by the patient

Despite the broad consensus on the core elements of informed consent, there remain disagreements over the meaning and scope of these individual elements. For example, what counts as an adequate level of patient competence and understanding for a given medical intervention? What in particular constitutes patient coercion? When should patient consent to treatment be explicit rather than implicit? Is patient implied consent ever morally permissible? And, if so, under what conditions?

As discussed above, various legal cases (i.e., *Salgo v. Stanford*, *Natanson v. Kline*, *Canterbury v. Spence*, and *Cobbs v. Grant*, *Wilkinson v. Vesey*) have assigned importance to patient self-determination. This, in turn, has raised questions about what and how much information should be disclosed to patients in order that they can make adequately informed healthcare decisions. Answers to these questions lead to competing disclosure standards for informed consent. To date, three standards of disclosure have received the most attention by the courts and medical ethicists: the professional practice standard, the reasonable person standard, and the subjective standard (Faden and Beauchamp 1986).

The *professional practice standard* for disclosure is based on what is “customary” or “normal” to a community of healthcare providers. According to this standard, the welfare and best interests of patients are best served by complete reliance on the medical knowledge and technical expertise of healthcare professionals. This standard is typically justified in terms of patient beneficence and non-maleficence and is easy for healthcare professionals to use.

The problem with the professional practice standard is that healthcare decisions are not only medical and technical decisions, but also include value decisions by patients and families about the importance and desirability of various medical interventions and treatment modalities. By conflating medical expertise and ethical expertise, the professional practice standard overlooks the non-medical aspects of healthcare and fails to provide patients and families with sufficient information to permit them to make healthcare decisions in light of their values. As a result, patient autonomy and family integrity is at risk of being undermined (Faden and Beauchamp 1986; Beauchamp and Faden 1995b).

The *reasonable person standard* for disclosure overcomes the limitations of the professional practice standard by being more patient-centered. The amount of information required for disclosure is determined by reference to what a “reasonable person” would want to know in order to make an informed healthcare decision. The merit of this approach is that since the autonomy of patients and families are given greater consideration, their values are less likely to be obscured by the medical and technical expertise of healthcare professionals.

The reasonable person standard has its flaws, however. First, the reasonable person standard is based on what an “average person” would want to know about his or her health. But, since the “average person” is an abstraction that does not refer to any one individual, as a practical matter, it is difficult for healthcare providers to determine what information is relevant and should be disclosed to patients. Second, because individual healthcare providers must imagine what a reasonable person would want to know, the reasonable person standard is in danger of collapsing into a “subjective provider standard,” which reflects the idealized, if not the idiosyncratic, views of individual healthcare providers about their patients (Faden and Beauchamp 1986).

In the *subjective standard*, the values and unique informational needs of individual patients determine the amount and type of information they receive from their healthcare providers. The merit of the subjective standard, unlike the professional practice and reasonable person standards, is that it respects the autonomy of patients and is practicable for clinical settings. Two related problems, however, are associated with this standard. First, patients may have only an inadequate understanding of their own values and preferences, making a determination of what information to disclose to these patients very difficult. Second, it is unclear on the subjective standard what and how much healthcare providers must know about their patients values, character, and background as a basis for determining what information to disclose to them (Beauchamp and Faden 1995b).

Although there remain philosophical and legal disagreements over how much and what kinds of health information healthcare providers should give to their patients, the reasonable person standard for disclosure has become widely accepted. Consequently,

healthcare professionals are generally considered legally negligent if the following criteria are met:

1. A patient-physician relationship existed.
2. The physician had a duty to disclose certain risk information.
3. The physician failed to provide this information and the failure to do so does not fall under any excusing conditions.
4. If the physician had disclosed the patient with the undisclosed information, the patient would not have consented to treatment.
5. The physician's failure to disclose this information was the proximate cause of the plaintiff's injury and the damages claimed.

It should be emphasized that a legal determination of negligence to obtain informed consent from patients requires more than knowledge of what information ought to be disclosed to patients under various circumstances and for various medical treatments. A legal determination of negligence also depends on some conception of the provider-patient relationship, the duties that healthcare providers have to their patients, and of what counts as an "proximate cause" of a patient's injury. Finally, how negligence is defined will depend on the *standards of care* unique to different areas or specialties of medical practice ((Morin 1998; Stanberry 1998).

5.4 Informed Consent and a Standard of Care for Home-Based Telemedicine

Standards of care are criteria by which a healthcare professional's conduct toward a patient is evaluated and judged and are essential in court cases that deal with malpractice negligence lawsuits. The problem, however, of determining when patients

and family caregivers have been informed adequately in the context of home telemedicine is that a standard of care does not exist for any version of telemedicine. The reasons for this are that the use of information and communication technologies in direct patient care is not commonplace and no precedent-setting legal cases for telemedicine have occurred.

There is no clarity with respect to the standards of care in telemedicine practice. This is not surprising because the widespread use of communications technology to provide or to support healthcare over distances is relatively new, and there has been little opportunity for the development of standards of care. Additionally, no legal case has yet been put forth as sufficiently precedent-setting or influential to establish standards of care for telemedicine practice, a situation that may persist for some time (Viegas and Dunn 1998: 53).

Unlike the above, some have argued that no special or unique standard of care is required for home-based telemedicine or any other application of telemedicine because telemedicine is not a new area of specialized medical practice. On this view, home-based telemedicine is simply a collection new tools that can be used to deliver traditional medical services to patients (Darkins 1996). But, even if this view is accepted, the present reality of home-based telemedicine is that provider-patient relationships are less well defined in the law, family caregiver interests play a larger decision-making role, and there is a less than optimal knowledge of the harms and benefits of home-based telemedicine. These knowledge gaps, alone, make it difficult to determine when a telemedicine provider is legally negligent of failing to inform his telemedicine patients (Millman and Kiesel 1999).

Therefore, home-based telemedicine may or may not constitute a distinct area of medical practice that requires its own standard of care. What is evident is that guidelines of some kind are needed to guide healthcare professionals in determining what counts as

relevant information and when this information should be shared with home telemedicine patients and their family caregivers. As has been the case in previously emerging fields of medicine, practice guidelines for informed consent in home-based telemedicine will likely develop out of necessity and through a process of trial and error. This was the case for telephone consultations. It has not always been the case that physicians can be held legally negligent when they fail to return their patients' phone calls in a timely manner (Rosoff 1999).

As a general rule, however, healthcare professionals who provide telemedical services should not accept lower standards for patient informed consent than they would for in-person care. A key consideration in clarifying what home telemedicine patients and family caregivers should know is to ensure that they do not encounter preventable harms that would undermine their autonomy and well being. If there are concerns that the risks of home-based telemedicine are greater than the risks of traditional home care, patients need to be informed of these risks. A standard of care or guidelines for informed consent for home-based telemedicine would help to specify what counts as relevant information that should be disclosed to patients and family caregivers (Grande 1997).

5.5 Informed Consent in Home-Based Telemedicine

As discussed in previous chapters, home telemedicine patients and family caregivers should be informed about the specific benefits and burdens of different information and communication technologies for (1) informational, decisional, and physical privacy, (2) medical confidentiality, (3) provider-patient relationships, and (4) family justice issues. In addition, (5) patients and family caregivers will need to be

trained in the operation of various telemedical devices. However, because empirical research on these aspects of home-based telemedicine is limited, more empirical investigation is required to determine what patients and families specifically need to know and what methods and procedures are most effective in informing patients and their caregivers about the benefits and burdens of home-based telemedicine. Therefore, future research on informed consent in home-based telemedicine should attempt to answer the following questions:

1. Should informed consent be a process or an event? Given the long-term implications of home-based telemedicine for chronic illness, how should the training and informing of patients/families occur?
2. What are the risks and benefits of specific communication and information technologies (e.g., e-mail, electronic patient records, and video-conferencing)?
3. What information and communication technologies best facilitate informed consent and on-going education for patients and families?
4. To what do patients and their family caregivers give consent when deciding about a system of care rather than an isolated event or telemedical device?
5. When evaluating a system of care before and during use, what constitutes denial/withdrawal of consent? For example, when does rejecting a portion of a proposed telemedicine treatment plan constitute rejecting the whole? How can patients/families negotiate with providers about the components as well as the whole of a treatment plan?

6. Given the responsibility of patients/families for multiple clinical and technical tasks associated with home-based telemedicine, who should be responsible for obtaining informed consent? From whom must consent be sought? If families are to have responsibilities, what right, if any, do they have to reject telemedicine? What role should clinicians have in helping families exercise that right?
7. What obligations do healthcare providers have in proactively initiating reconsideration of the decision to proceed with home care and telemedicine? When are healthcare providers negligent?

5.6 Informed Consent: Process or Event?

Should informed consent be an *event* or a *process* in home-based telemedicine?

An event model of informed consent is desirable because it allows for an easy application of specific rules for informed consent at designated times. An event model of informed consent is especially useful in one-time clinical encounters or at those times when therapy is going to be initiated, terminated, or modified. According to one view, because informed consent in these settings is a discrete event, rather than an ongoing process, the core elements of informed consent are more likely to be met; meaning that the moral values and goods that the doctrine of informed consent is supposed to advance are also achieved (Wear 1993).

However, given the nature of human understanding in learning and applying new information and that patients and families are often under emotional strain, a process model of informed consent could better satisfy the ethical goals of informed consent. A

process model of informed consent, for example, could be especially useful for medical cases where patient care is carried out over an extended period of time, as with patients who suffer from chronic health conditions. One advantage of a process model of informed consent is that it recognizes that patients may not fully and immediately understand information about their diagnoses and treatment options.

A second advantage of the process model is that patients have an opportunity to reflect on treatment options in light of their values. If patients have a poor understanding of their own values, a process model gives them the time to reflect on their values and reevaluate their choice of treatment. Because an event model of informed consent is based on a discrete and time-limited format, there is concern that patients will be less likely to assess treatment options in light of their values and thereby make adequately informed decisions about their care.

A third strength of a process model of informed consent is that it allows patients and healthcare providers more time and opportunities to reach agreement when there are differences of opinion about the optimal courses of action. This is especially important in an era where patients and healthcare providers are often strangers to each other and/or where a team of healthcare professionals, rather than a single healthcare provider, has the responsibility of caring for the patient.

How does this event-process distinction affect the choice to use or to reject home-based telemedicine? For one thing, we should keep in mind that the doctrine of informed consent was originally formulated to be used with acutely ill patients with discrete health care needs for which there is a specific course of healthcare treatment (Haddad and Kapp 1991). Therefore, conceptualizing informed consent as an ongoing process, rather than

an isolated and discrete event, in the context of home-based telemedicine, is appealing for a number of reasons.

First, most pilot programs evaluating home-based telemedicine are being used with patients who suffer chronic health conditions that extend over a longer period of time and involve multiple procedures, treatments, and technologies. Thus, obtaining consent for the implementation of home-based telemedicine is likely to be less well defined than with acutely ill patients receiving outpatient healthcare services. Unlike an event model, a process model would allow healthcare professionals more time to learn more about their patients' values, preferences, and lifestyles and to educate them about the pros and cons of home-based telemedicine (Shaul 2000).

This is especially important when one considers that the implications of illness or injury are usually not felt in the hospital environment. Most social, emotional, and environmental adjustments by patients and family caregivers occur after discharge from the hospital and when the patient returns home to face the reality of daily living (Haddad 1987). Thus, if we grant that patients and families will only gradually become aware of the implications of home-based telemedicine over a period of time, it is unrealistic to assume that healthcare professionals will know how individual patients and their families will adjust before the introduction of telemedicine.

Second, because home-based telemedicine is likely to take place within homes where family caregivers live, a decision to use telemedicine will have lifestyle implications for family caregivers as well. Therefore, a process of informed consent that occurs over an extended period of time will be more likely than an event model of

informed consent to identify and to give expression to the interests of patient and family caregivers.

Although the event-process distinction for informed consent is a useful analytic distinction, these two approaches to informed consent need not be mutually exclusive in the practice of home-based telemedicine. A process of informed consent can consist of discrete times or events when telemedicine patients, families, and healthcare providers regularly meet to discuss diagnoses, treatment options, and the emerging benefits and burdens of telemedical care in the home. Nonetheless, a one-time informed consent event, which may be sufficient for acute outpatient medical services, is likely to be inadequate in the context of home-based telemedicine. That is, given the realities of chronic health conditions, adjustments to life at home, and the interests of family members, an event model of informed consent is necessary, but is likely to be insufficient in the context of home-based telemedicine.

5.7 Using Telemedicine Technology to Inform Patients and Families

In addition to informing patients and family caregivers about the potential benefits and burdens of home-based telemedicine, the use of telecommunication technologies and interactive multimedia systems can be the means by which home telemedicine patients and family caregivers are informed and give their consent to different elements of home-based telemedicine. If the range of patient autonomy is shaped by the context where care is given and the technology employed, patients and families should control to the greatest degree possible when, where, how and in what formats they are educated and informed about home-based telemedicine and other

options (Beasley and Graber 1984). This position is not only consistent with a process view of informed consent, but given the possible implications of home-based telemedicine on the lives of patients and their families, this would afford home telemedicine patients and families greater control over their living spaces and the medical services they receive (Peifer, Hopper et al. 1998; Shaul 2000).

Ideally, telemedicine patients and other users of an interactive multimedia system should be able to interact with the system and have the greatest possible control over the presentation of information. Interactive multimedia is a collection of multiple media such as text, graphics, audio, video and animation in a synchronized fashion, where one media element is used to support another. Consistent with the autonomy and well being, patients and family caregivers should be able to look up information when needed from the convenience of their homes and have significant control over its presentation. Online support tools that combine decision support software, e-mail, and video-conferencing are typical interactive multimedia technologies that can facilitate the informed consent of home telemedicine patients and family caregivers (Jimison, Sher et al. 1998; Eysenbach, Diepgen et al. 1999). With these online support tools, a patient can, for example, review a digital video about a particular medical procedure or medication located on a physician's web site at any time and as many times as desired. If the patient has questions, he then can e-mail his healthcare providers for clarification. In some cases, a videoconference, possibly involving other patients who are undergoing similar telemedicine procedures, could be arranged to field questions after the patient has watched the online video.

Currently, the Internet can't make any guarantees about the rate and speed that it will deliver data to a given destination, making many real-time multimedia applications difficult or impossible. With the high-speed capabilities of the Next Generation Internet (NGI), it is likely that as NGI becomes more commonplace home telemedicine patients will be able to take full advantage of multimedia systems that integrate text, video, animation and audio contents. The potential capabilities of NGI to support interactive multimedia applications in home-based telemedicine may make it significantly easier for patients and family caregivers to stay educated and to make informed decisions about traditional and home telemedicine services.

Studies have shown that combining more than one type of media and allowing the patients to interact with the system to carry out learning activities increases the long-term retention of the educational material. Research has also shown that we remember 10% of what we read and 20% of what we hear. However, we retain up to 90% of what we learn through active participation (Bandura 1977). For instance, video conferencing technologies that rely on the Internet and standard phone lines are now being used in greater numbers by home-based telemedicine programs. As Internet bandwidth and speed increase, it is likely that in the near future videoconferencing technologies in conjunction with other media will become a common feature of home-based telemedicine.

Moreover, a plethora of research has documented that when a partnership between patients and healthcare providers exists, patients are more likely to be compliant in their treatment and more likely to have better health outcomes (Towle 2000). Thus, if better informed and more involved patients can produce these outcomes, and the information and communication technology of home-based telemedicine makes it possible for

patients to be more informed and more involved, there are very good reasons to use this technology in the process of informed consent. But, even if this were not the case, the ethical imperative of patient autonomy should allow the patient ultimate decisional authority.

It is likely that NGI may make it easier for home telemedicine patients to (1) participate in interactive video-based chat rooms with other home telemedicine patients; (2) participate in interactive video-based chat with physicians, nurses, and social workers; (3) engage in on-line educational seminars over the Internet; (4) access their medical charts; and (5) watch educational movies about telemedicine in general and their procedures specifically. However, in order to design multimedia systems that facilitate informed consent by accommodating learning differences associated with gender, socioeconomic status, and physical abilities and disabilities, these multimedia systems must be flexible. To this end, it is very important to identify the users' needs and to match them to appropriate systems before the design of the system. The design of many of today's multimedia systems is based on the perspective of the designers and may or may not match the user's interests or capabilities (Ferguson 2000).

Given the long-term implications of home care for chronic illness, home telemedicine patients and their families should be provided with in-home training and education. Ideally, online educational materials should be readily available and permit patients and family members the opportunity to look up medical and technical information as needed or at their leisure from the convenience of their own homes. The Next Generation Internet potentially offers unique capabilities for supporting home telemedicine patients and families by enhancing and facilitating the on-going process of

informed consent. By allowing users greater control over access and presentation of materials, it is likely that patients and their families will be better educated about home-based telemedicine, be better prepared to self-manage illnesses in the home, and be a more active partner in the informed consent process with healthcare providers. This movement toward greater patient involvement in and control of their own healthcare is part of a larger consumerist trend in the United States (Jimison, Sher et al. 1998;Gawande and Bates 2000).

For example, an NGI educational tool known as “HelpBot” is under development by Project Phoenix, a telemedicine hemodialysis project at Georgetown University Medical Center funded by the National Library of Medicine. HelpBot is an online support system that enables home telemedicine patients and family members to explore the project’s approach to data security as deeply and as often as individually required simply by clicking through various levels of the tool. Four basic levels exist, including a homepage that introduces the whole project, a level that explains the telemedicine network, a level that explains the risks to data security, and a level explaining the project’s risk management plan (Collmann 1999).

By means of HelpBot, home telemedicine patients and family caregivers can migrate through the tool in a great many ways depending on their own need to know and personal approach to learning. For example, if a patient wants to go straight from the beginning to the end, he or she can proceed horizontally from the introduction to the risk management plan. If a family member wants vertically to explore a particular component of the system, the telemedicine unit for example, he or she can click on the telemedicine unit, then click on the risks in the telemedicine unit and finally click on how the risks are

being handled. At any point, a user can change the search pattern, return to the beginning or exit. In relevant sections, a user can activate links to other sections within the website or to other websites. Home telemedicine patients and their families may thus obtain as detailed an explanation as possible of the project's approach to data security while individually determining the level of detail actually searched.

5.8 Informed Consent for E-mail and Video Conferencing

Although e-mail, video conferencing and other telecommunication technologies may be useful tools that can inform and empower home telemedicine patients and family caregivers in illness work, the information and communication technologies of home-based telemedicine also pose risks that patients and families should be aware. Although HIPAA legislation is in the process of being implemented, no laws to date have been enacted that specifically require healthcare professionals to inform patients and family caregivers of the potential harms and benefits of home telemedicine. This, as discussed above, is because there is no standard of care for telemedicine and a dearth of scientific data on the level of harms and benefits associated with home-based telemedicine in general.

There is, however, a growing body of knowledge on the potential risks and benefits of using particular information and communication technologies to provide home-based healthcare services. As these risk and benefits are better understood, informed consent guidelines for specific information and communication technologies are being proposed. The two technologies that have received the most attention thus far are e-mail and video conferencing.

Informed Consent Guidelines for E-mail

The American Medical Informatics Association has proposed e-mail consent guidelines (Kane and Sands 1998). Considering the increasing number of patients and healthcare providers who use e-mail to communicate with each other, informed consent guidelines for e-mail, if adopted, will directly affect the practice of home-based telemedicine. E-mail is an interactive medium in which the healthcare provider and patient's own words may be stored as part of the patient's electronic medical record. In addition, other medical professionals and payers may be able to view stored e-mail messages for administrative and billing purposes. Thus, it is important that patients and family caregivers are educated about the potential ramifications of e-mail before consenting to or rejecting it as a form of provider-patient communication in the context of home-based telemedicine.

In a particular, informed consent guidelines for e-mail use in home-based telemedicine should inform potential patients and family caregivers of the following (Spielberg 1998;:

1. Who will have access to their telemedicine providers' e-mail accounts.
2. Whether the patient's e-mail will ever be forwarded to third parties.
3. Whether the patient's e-mails will become part of their official medical record.
4. The potential risks to e-mail privacy and security.

In addition to the informational elements of informed consent listed above, informed consent for e-mail communications in the context of home-based telemedicine should:

1. Allow patients to prohibit telemedicine providers from including identifiable, medical related information from appearing in provider-patient e-mail communications to both patients and to third parties.
2. Give patients and family caregivers alternatives to communicating by e-mail. For example, telemedicine providers should also be accessible by phone or be available to meet in person with home telemedicine patients.
3. Finally, consent to e-mail communications in home-based telemedicine (a) must be in the form of full written consent and (b) must be subject to revision at the request of the patient and/or family caregivers.

Informed Consent Guidelines for Video Conferencing

Although not as common for technical and economic reasons, video conferencing is becoming more commonplace in home-based telemedicine. Like e-mail, a decision by home telemedicine patients and family caregivers to use or to reject video conferencing technologies should be informed. Therefore, home telemedicine patients and family caregivers should be educated about the potential benefits and harms of using video conferencing technology in the home. In many ways, threats to the privacy and confidentiality of patients and family caregivers mirrors those involved with the use e-mail. Nevertheless, the use of video conferencing technology in home-based telemedicine raises additional concerns about privacy and confidentiality of which home telemedicine patients and their caregivers need to be aware.

First, medical and technical personnel at the telemedicine center may see the images and personal medical details of home telemedicine patients. In some cases, technical staff may be managing equipment or providing support to the attending

healthcare provider. In other cases, medical, nursing, radiology, social work, engineering, and even medical ethics students, who are in training, may be in the studio and observing the attending healthcare provider during a video consult. Second, because the video consults involves the home, it is possible that the images of family caregivers may also appear on video and be recorded as well. Third, as with all electronically transmitted data, there is always a risk that personal medical information, which in this case is linked with patient images, could be intentionally or unintentionally intercepted during a video consult (Burton and Huston 1998).

Therefore, as part of the informational content of the informed consent process for video conferencing technology, home telemedicine patients and family caregivers need to understand the following (Norton, 1993; Hornick, 1997):

1. Details of medical history and examinations may be discussed with other medical professionals and viewed by various personnel for administrative and training purposes.
2. Non-medical technical staff may be in the studio but off-screen to aid in the video transmission.
3. Other medical personnel may in the studio be but off-screen as observers for educational purposes.
4. That all efforts will be taken to protect the privacy and confidentiality of electronically transmitted and stored materials, but that security is not absolute. For example, technical personnel should be instructed that they ought not to watch the screen except insofar as they need to in order to monitor transmission quality. In addition, security measures for storing tapes

and digital images should be developed, as well as guidelines for who can use them and when.

In addition to the aforementioned informational aspects of informed consent, home telemedicine patients and family caregivers should understand that they have authority to (Norton, 1993; Hornick, 1997):

1. Request that personally sensitive information be removed from the video record.
2. Limit the scope of any physical examination suggested by the healthcare provider during a video consult.
3. At anytime ask that all medical and non-medical staff not directly involved with the video consult leave the studio.
4. Stop the video consult at anytime and for any reason.
5. As with e-mail, the informed consent or refusal of video conferencing by home telemedicine patients and family caregivers should be in writing.

5.9 Conclusion

The introduction of information and communication technologies into the intimate sphere of the home to support telemedicine services also introduces new ethical and practical considerations regarding informed consent. On the one hand, these technologies may enhance the well being and autonomy of home telemedicine patients and family caregivers by providing them access to multimedia information and decision-support systems that facilitate a process of informed consent. On the other hand, these

same information and communication technologies pose potential risks to the well being and autonomy of home telemedicine patients and family caregivers.

Consequently, patients and family caregivers should be informed of the potential benefits and hazards of home-based telemedicine when considering it. Depending on the nature of the patient's illness, and the level of family support, potential home telemedicine patients and family caregivers will need to be informed about (1) the operation of various telemedical devices and the (2) potential consequences of these devices for their (a) privacy, (b) confidentiality, (c) provider-patient relationships, and (d) the distribution of benefits and burdens in the home among family members.

In addition to the above and more specifically, patients and family caregivers (3) should be made aware of differences in the modality of documenting their consent (e.g., paper form vs. a verbal consent on audio or videotape, (4) the persons from whom consent will be sought, especially if the of privacy of family members is at stake and their cooperation in carrying out telemedicine procedures is required, (5) the potential for subtle coercion introduced by the impersonality of an authority figure speaking, for example, from the television monitor, and (6) risks/benefits of telemetry monitoring, for example, the freedom from remaining in the hospital versus the possibility of less prompt capability of healthcare providers to respond to a medical emergency.

However, the specific details that home telemedicine patients and caregivers should know about, for example, privacy and confidentiality, will depend on the technology being employed. As discussed above, the specific risks to privacy and confidentiality are slightly different for e-mail and videoconferencing. Therefore, in light of the many types of telemedicine technologies, the variation in patient and family

preferences and abilities, and the absence of a standard of care, an on-going process of informed consent for the use of specific information and communication technologies by patients and family caregivers, rather than a single blanket consent for home-based telemedicine, is preferable at this stage of home-telemedicine's development.

Chapter 6

Case Analysis of Telemedicine-Supported Home Peritoneal Dialysis

6.1 Introduction

Approximately 17% of the end-stage renal disease (ESRD) population in the United States use peritoneal dialysis (PD). Growth in the number of peritoneal dialysis patients world wide has stopped while the number of patients having home peritoneal dialysis (HPD) remains about the same as 10 years ago (20% per year) (Churchill 1997). The primary reason for this lack of growth in PD is the risk of developing peritonitis, the most likely complication and the leading cause of dropout from HPD. In most cases, high infection rates develop because of patients' difficulties in maintaining in their homes the strict aseptic techniques learned during PD training. Second, lack of growth in the use of PD may be due to limitations in the efficiency of PD, including patients' failure to perform scheduled cycles of PD and to deliver prescribed volumes of peritoneal fluid. Other factors may include malfunctions of automated cyclers and patient failure to set the cycler to deliver the correct prescription.

There is a growing body of telemedicine research that examines home applications of PD. Until recently, however, none of this research has neither specifically examined home peritoneal dialysis nor looked at the ethical implications of using telemedicine with this patient population. This chapter examines the ethical aspects of telemedicine-supported peritoneal dialysis, relying on interview data collected when this author worked as a Research Associate on *Project Phoenix: Scrutinizing a Telemedicine Testbed*, a National

Library of Medicine funded contract with the Renal Dialysis Patient Management Program at the Georgetown University Medical Center (NLM 2000).

The overall aim of *Project Phoenix: Scrutinizing a Telemedicine Testbed* was to determine whether patient management and monitoring via telemedicine would result in better outcomes and higher utilization of HPD in the ESRD population. Patient compliance and early recognition of complications are central to their success in the self-management of their illness and in maintaining their health. A specific goal of this pilot project on HPD was to evaluate the technical and economic feasibility of various telemetry-capable medical tools and information technologies. Another goal of this project was to conduct an ethical analysis of the experiences of patients and their families who used telemedicine-supported peritoneal dialysis.

6.2 Technology Used and Operational Protocol

Patients in this pilot project visited the clinic once a month. Although able to contact their doctor or nurse over the telephone, patients had little confidence in actually making contact with healthcare providers between clinic visits. When problems with aseptic technique or equipment go undiagnosed, PD patients are at elevated risk of infection, equipment failures, and loss of confidence in the technique. Improving patient competence in aseptic techniques and compliance with dialysis prescriptions by means of telemedicine could potentially overcome these limitations in HPD and improve the health outcomes and quality of life for patients and their family caregivers. With improvements in medical and communications technology, it is now possible (1) to provide more reliable communications

between patients and their care team and (2) to ensure that HPD patients are carrying out the proper procedures at home.

First, Baxter International provided patients with an automated and telemetry-capable peritoneal dialysis device, the HomeChoice Pro. A database and online interface was also established between the Baxter's PD database and Georgetown's Renal Dialysis Patient Management Network.

Second, a website was established to provide personalized information to patients about the project. In addition, patient data could be displayed at the request of the patient. This data included PD prescriptions, lab values, appointment reminders, tests, and other elements. This website also included educational information for patients and family caregivers about nutrition and exercise, as well as capabilities for e-mail with healthcare professionals and other study participants. Overall, patients and healthcare providers had better access to each other and to relevant information using the telemedicine system in comparison to face-to-face and paper systems. The privacy and confidentiality of patient health information and communications was maintained.

Third, the project had initially planned on using interactive video conferencing technology, but owing to logistical, technical, and economic complications this technology was not used. As a result, the use of telemedicine technology was limited to basic telemetry and access to the Internet. However, as discussed subsequently in more detail, these basic telemedicine tools have the potential to greatly affect the various benefits and burdens that HPD patients and family caregivers may encounter.

Three HomeChoice Pro devices were installed for three different patients. New telephone lines were installed in their homes so that the HomeChoice Pro and Internet

access would not interfere with their normal telephone use. The patients conducted their individual sessions as follows. Before starting each dialysis session, the HomeChoice Pro device would prompt them to enter their pre-dialysis weight and blood pressure. Once the dialysis session was completed, they would disconnect themselves from the device and set the device to “Modem Connecting” mode. A member of the healthcare team would then dial in from a remote location and download patient data and PD parameters.

The first two patients who received the HomeChoice Pro device were very cooperative and compliant. They were patient with the installation of the phone lines and devices. They used the device daily and remembered to put the machine into auto-answer mode on most occasions. The third patient was less understanding about the special circumstances involved with participating in a research project. She used the device for three weeks and then decided to remove herself from the project. There were problems with the installation of the telephone lines and the configuration of her machine. She was unable to deal with the uncertainty and additional effort required using the device.

For the two remaining patients, 13 weeks of data for one patient and 8 weeks of data for the other were collected. The second patient was removed from the HomeChoice Pro device when he developed peritonitis and it was determined that performing manual exchanges of dialysis fluid would be better in a clinical setting.

It was determined that the electronic capture of peritoneal dialysis data using a telemetry-capable device like the HomeChoice Pro and the remote access to collected data is feasible and not perceived as intrusive by patients and caregivers. The online access to patient data and PD parameters was very useful to the healthcare teams. The healthcare

teams used the website several times a week to check on their patients, allowing the healthcare team to easily observe trends in their patient's data.

It was hoped that 5-10 patients would be on the website by the end of the project, but unfortunately the number of patients never progressed beyond 3. A delay in the installation of phone lines in patients' homes was not anticipated. Also, the 2 patients who stayed on the project for the 2-3 month period did not take full advantage of the information on the website. One possible reason for this is that the site was still under development when they were first given the HomeChoice pro device. We provided a one-on-one training session for them after a couple of weeks, but they did not provide much feedback to us. Overall, however, the pilot project was a significant step in introducing healthcare providers and patients to telemedicine technology to manage ESRD and PD in the home.

6.3 Ethical Aspects of Telemedicine-Supported HPD

The goals of studying the ethical aspects of telemedicine-supported home peritoneal dialysis (HPD) in this project were: (1) to determine the specific burdens and benefits of using HPD, (2) to assess how telemedicine-supported HPD affects the distribution of burdens and benefits for patients and their family caregivers in managing HPD, and ultimately (3) to develop ethical guidelines for HPD. In this project we analyzed patients' and spouses' experiences with telemedicine-supported HPD as a basis for developing ethical guidelines to protect and enhance the autonomy and well being of participants. Particular attention was given to privacy, confidentiality, informed consent, and the fair distribution of benefits and burdens within families.

The study employed a structured, open-ended interview instrument with an established set of questions to discuss with patients and spouses their experiences with telemedicine-supported HPD. In general, patients' and spouses' perceptions of the benefits and burdens were evaluated to determine whether their autonomy, well being, level of understanding remained enhanced, unchanged, or diminished as a result of telemedicine technology. We expected these values to vary over time, in response to the complexities of their illness, and as a result of their interaction with telemedicine devices.

Two patients (Mrs. Gains and Mr. Moore) and their spouses were interviewed two times, including a baseline questionnaire that focused on the history of the patient's illness and a follow-up questionnaire one month later designed to assess their experiences with telemedicine-supported HPD (See Appendices 1 and 2). Interview data revealed that home-based peritoneal dialysis has benefits over traditional hemodialysis in a clinical setting for our sample of patients and family caregivers. In general, HPD enhanced the autonomy and well being of dialysis patients and family caregivers by affording them more independence in activities of daily living and the management of dialysis treatment. Given the short duration of patient experiences with telemedicine-supported HPD, these results are preliminary. Nonetheless, these findings suggest that telemedicine adds no new burdens to the HPD process and potentially reduces documentation burdens. Telemedicine appears to have no impact on physical burdens such as weight of effluent bags.

6.4 Informed Consent

HPD patients signed a consent form granting researchers permission to conduct interviews with them about their experiences with telemedicine-supported HPD (See

Appendix 3). Prior to this, HPD patients also gave their informed consent to participate in the telemedicine project. It was hypothesized that, when properly informed about the institution's policies and procedures for collecting, transmitting, and maintaining the confidentiality of their electronic health information and medical records, patients would agree to use the telemedicine system. All patients received an overview of the telemedicine procedures, the risks involved in storing and transmitting confidential patient information electronically, and the steps taken to protect their data. It was concluded that the possible risks to data security and medical privacy were trumped by the utility of increased access to patient information by patients and healthcare providers. It was also recognized that consent, especially among the chronically ill who are receiving care in their homes, must function as a continuous process that expects potential changes in the patients' need and desire for information and changes in their illness.

6.5 Specific Benefits

One benefit of the Home Choice Pro device is that it permitted the patient's healthcare team to dial into the modem and to retrieve stored patient data and PD parameters. Once collected, this information was then downloaded to the Baxter database. Nurses were able to collect patient data and PD parameters via modem anytime within an eight-hour period. Consequently, patients and family caregivers were not required to coordinate with their healthcare team to transfer information. This gave patients, spouses, and the healthcare teams greater flexibility, facilitated the detection of errors, and improved the overall continuity of care delivery to patients.

A second benefit of using a telemetry-capable device such as HomeChoice Pro over standard dialysis devices is that it automatically recorded and electronically stored patient data and PD parameters from each dialysis session. Standard dialyzers require patients to maintain a paper log of each session, including tracking their pre-dialysis weight and blood pressure. With the new telemetry-capable technology, patients no longer needed to track these variables or remember to bring this information to their physician during clinic visits. The healthcare team only had to access the electronic database to retrieve the information. Moreover, this simple telemedical service has the potential to reduce errors and improve the timeliness of care for patients. This, in turn, made the illness work of patients and families less burdensome and reduced their worries of inaccurately recording health data by hand.

Third, the two interviewed patients reported that with HPD they were able to be more involved with their own care and escape the traditional patient role as a passive object of treatment as in traditional outpatient hemodialysis. For example, Mrs. Gains and her husband discussed their satisfaction with being better able to adjust HPD treatment in a timelier manner because they had easier and more reliable access to their treatment data from earlier PD treatment sessions that had been electronically registered in the HomeChoice Pro device and placed on the website.

The Gains also stated that hemodialysis, unlike HPD, subjected them to the demands and routines of a clinical schedule that regularly interrupted their home life and privacy, diminishing their autonomy and well being. Moreover, Mrs. Gains and her husband both found the hemodialysis a “morbid” environment that depressed them and made them feel powerless over the management of Mrs. Gains’ ESRD. Telemedicine-supported HPD has reduced these sorts of stresses by increasing their opportunities to engage in self-care

routines while reducing the possibility of error and peritonitis. This, in turn, has increased the hope the Gains have about their future and has allowed them to maintain a more positive conception of themselves as a couple in control of their daily routines and illness management.

To a large extent, Mr. and Mrs. Moore's experiences with telemedicine-supported peritoneal dialysis mirrored the Gains'. Mr. Moore reported that after only one month of hemodialysis he had "no life" because it took the whole day, when travel time was factored in. In addition, Mr. Moore stated that he often felt alienated while at the hemodialysis clinic because the clinic regularly employed different technicians and healthcare staff, all of whom failed to get to know him well. Given the alternatives, Mr. Moore preferred to have as little interaction with clinic and medical providers.

Fourth, when compared to traditional hemodialysis, patients and their spouses reported that HPD was less physically demanding and time consuming, permitting them more time to engage in desirable activities at work and at home. In Mrs. Gains' case, she was able to resume her teaching at a nursing school. Also, until her knees began to cause her problems, she was able to spend time tending the family garden, cleaning her home, preparing meals. In Mr. Moore's case, HPD has given him and his wife greater flexibility to travel, to spend more time with their grandchildren, to garden, and to carry out a household renovation project. With traditional hemodialysis, patients and spouses had less time to devote to enjoyable activities.

6.6 Specific Burdens

Compared to traditional hemodialysis, HPD has many benefits. Moreover, when telemedicine is used, potential risks are reduced. Nonetheless, HPD presented its own illness-related challenges for patients and their spouses; some but not all might change with telemedicine. Preliminary data suggest that HPD poses important physical burdens related to the management of equipment, namely the lifting of effluent bags, transportation of the dialysis device, and the manipulation of the mechanical features of the device. The significance of these burdens, however, varied with the phase of each patient's illness and the availability of caregivers other than the spouse to assume these burdens when the patient was incapable of doing so.

Chronic illness states develop trajectories over time: stable, unstable, improving, and declining. Many conditions affect a patient's illness trajectory, such as the biological progression of the disease, the patient's access to care, and conditions in other areas of the patient's life such as work. With respect to understanding the impact of home care technology, as patients move from one phase to another phase of their illness, the effect of a particular home care device or system might also change. For example, if a device such as a home dialysis machine requires the lifting of heavy effluent bags of fluid, a patient moving from a stable to an unstable phase of illness may lose the ability to physically manage the work associated with such a device. This, in turn, may require changes in how work gets accomplished and in household routines. Thus, simply because telemedicine technology is cost effective and can reduce the possibility of patients developing peritonitis in HPD, this does not mean that it is always a benefit to patients and their families. Other factors will

need to be taken into consideration in deciding to employ telemedicine-supported peritoneal dialysis in the home.

The use of HPD had a direct effect on the workloads and the division of labor within the households of interviewed families. When interviews were conducted, Mrs. Gains was in a stable phase of her illness and awaiting a kidney transplant. Because of undetermined comorbidities, Mr. Moore in contrast was suffering a decline in his illness trajectory. So whereas Mrs. Gains and her husband had established a routine and acceptable division of labor, Mr. and Mrs. Moore were renegotiating the implications of telemedicine-supported HPD for their lives and associated responsibilities.

In Mrs. Gains' case, ESRD and her knee problems eventually compromised her ability to perform most household chores, producing greater dependence on her husband, other family members, and neighbors to perform household tasks. For example, Mrs. and Mr. Gains reported that she was no longer able to perform most of the work related to HPD, such as changing effluent bags and maintaining the functions of the HPD device. The additional workload has required Mr. Gains to retire early from his career and willingly take on added responsibilities connected to his wife's illness. Mr. Gains, however, has been able to distribute his new burden and to maintain some of his enjoyable activities and hobbies by training other family members and neighbors to help Mrs. Gains manage her illness when he needs a break or is unavailable to help his wife.

Like Mr. and Mrs. Gains, the Moores have also experienced significant alterations in their daily workloads associated with Mr. Moore's ESRD, HPD, and other "illness work." Unlike the Gains, however, Mrs. Moore continues to work a full-time job outside the home and is unavailable to her husband for most of the day. In addition, the Moores did not report

that they received any support from family members and neighbors in the management of Mr. Moore's ESRD and HPD. As mentioned above, Mr. Moore was capable of gardening, watching his grandchildren, and slowly working on a home renovation project while his wife was at work. But recently, Mr. Moore entered a new destabilized phase of his illness that has made these activities difficult, if not impossible, to carry out.

Furthermore, Mr. Moore cannot safely drive because he now unexpectedly and frequently falls asleep and suffers periods of forgetfulness. This has left him incapable of doing many household chores such as shopping. Consequently, there are even greater workload responsibilities and less independence for his wife, who is already overburdened. In addition to these new divisions of labor caused by HPD and Mr. Moore's recent physical and mental decompensation, the social life of the Moores has been greatly restricted. For example, their frequent excursions to shopping malls have sharply waned and nights out to dinner and vacations have become increasingly rare for them. According to Mrs. Moore, the elimination of enjoyable shared activities has caused them great distress. At this time, their life together is undergoing a fundamental and possibly irreversible change as they assume more burdens associated with Mr. Moore's illness and illness-related work.

6.7 Conclusion

These interviews strongly suggest that illness trajectory, familial support, and the matrix of personal values are more basic in shaping the relative benefits and burdens of telemedicine-supported HPD than the properties of the technology itself. At the simplest level, a telemedicine device that an engineer finds simple might intimidate a patient with its complexity. Or, a telemedicine device that seems simple enough when a patient feels good

and leads a more or less normal life might become overly burdensome when there is a decline in their condition. Alternatively, as a patient's illness trajectory improves, the feasibility of a particular home care medical device might increase. The data in this study supports this assumption for HPD technology use, including telemedicine-supported HPD. Therefore, understanding the conditions that shape the effect that a home care telemedical device might have on patients and family caregivers might help to produce protocols for evaluating the feasibility and appropriateness of these devices in particular cases.

With this in mind, future research on telemedicine-supported peritoneal dialysis as well as other applications of home-based telemedicine should do the following:

1. Work to develop clear ethical and clinical guidelines for assessing the choice of home-based telemedicine for particular populations. It is likely that clinical and ethical guidelines can assist in evaluating the appropriateness of home telemedicine in individual cases. In particular, ethical and clinical guidelines should include an identification of the most likely benefits and burdens of home-based telemedicine for patients and families, likely threats to privacy and confidentiality, and the likely impact of information and communication technologies on provider-patient relationships.
2. Investigate the conditions, processes and consequences of tailoring the type, amount and manner of presenting information to patients and families about home telemedicine services, products and technologies. This will likely require that the process of informed consent will need to be redesigned as new telemedicine devices are used to support home care in order to provide patients and their family caregivers with information.

3. Empirically investigate further the likely errors, adverse events, and unintended consequences of integrating medical and telemedical devices, and into the home environment. This is important because telemedicine support potentially eases the burdens and improves management of errors, adverse events and unintended consequences in using complex home care technology.

Appendix 1

Home Peritoneal Dialysis Baseline Questionnaire

History of Managing Illness and Therapy

1. When and how did you first notice you were becoming ill?
2. How were you diagnosed?
3. What kinds of therapy did you initially try?
 - a. Did you ever attempt HPD?
 - b. If so, please tell us about your experiences
 - c. Did you try therapies recommended by someone other than your doctor?
4. What kinds of work did you/your spouse/other family members have to do to manage your illness and therapy?
 - a. How did you decide who would do what tasks?
 - b. Have you changed who is responsible for the various tasks since then?
 - c. How did this work affect your spouse/your family members?
 - d. Has this caused conflict in your household?
5. How have the illness and associated work affected your ability to hold a job and develop your career?
 - a. Did you lose or have to change jobs as a result of your illness?
 - b. If so, what did you do to find new work?
 - c. If you are unemployed, how are you supporting yourself?
6. How have the illness and associated work affected your life at home?
 - a. Did you have to change how you and your family performed house chores such as cleaning and cooking?
 - b. How has this experience affected the feelings your family members have for you and each other?
7. How has being ill changed your hopes for yourself?

Expectations for Home Peritoneal Dialysis (HPD)

1. What concerns do you have about HPD?
 - a. What do you think about the possibility of infection?
 - b. Do you think the telemedicine might help you?
 - c. Do you think you can manage the system?
2. What hopes do you have for HPD?
3. Do you think this will change the work you must do to manage your illness?
 - a. If so, how do you think the work will change?
 - b. Will it change who has to do the work to manage your illness?
4. Do you think this will change your ability to perform your job or your job opportunities?
 - a. If so, how do you expect it to change?
 - b. Do you expect to work more or less easily?
 - c. Do you expect to be able to acquire or return to a better job?
5. Do you expect this to change life around your household?
 - a. For example, do you expect this to change responsibility for doing housework and how?
 - b. How will you arrange any changes you and you family might make?
6. Do you think HPD will lessen or heighten conflict in your home concerning your illness?
7. Do you think HPD will enhance opportunities for your life?

Appendix 2

Home Peritoneal Dialysis Follow-Up Questionnaire

I. Work Related to HPD

1. I am going to ask you some questions to help me understand how comfortable you are with the home dialysis you are currently using.

- a. Please tell me the most serious problem you have had, if any, setting up your dialysis equipment.
- b. Please tell me the most serious problem you have had, if any, operating your dialysis equipment.
- c. Did the home dialysis training you received prepare you to resolve problems setting up your dialysis equipment?
- d. Did the home dialysis training you received prepare you to resolve problems operating your dialysis equipment?
- e. Considering both setting up and operating your dialysis equipment, have you made adjustments to using the dialysis equipment that are different from what you were taught?
- f. In spite of training and adjustments you might have made, sometimes-unexpected things can happen. Have you experienced any unexpected events or mishaps with your dialysis equipment?

2. Now I am going to ask you some questions about telemedicine and your home dialysis treatment.

- a. Has working with a nurse by telemedicine helped you in operating your dialysis equipment?

{IF 2a is “Yes” ASK 2b; OTHERWISE GO TO 2c}

- b. What specific things has the nurse helped you with?
- c. Do you think that you still need to consult with the nurse regularly on how to use the HPD equipment?
- d. Compared normal dialysis treatment, has telemedicine added new tasks to your care that you would prefer not to do?

{IF 2d is “Yes” ASK 2e; OTHERWISE GO TO 2f}

- e. Please tell me about the new task that you would most prefer not to do.
- f. Compared normal dialysis treatment, has telemedicine added new burdens to your care that you would prefer not to deal with?

{IF 2f is “Yes” ASK 2g; OTHERWISE GO TO 2h}

- g. Please tell me about the greatest burden that you would most prefer not to deal with.
- h. Do you think that you can manage all the tasks associated with telemedicine supported HPD or are they too much work?
- i. If telemedicine were not available to help you with your dialysis treatment, would this be a burden for you?

{IF 2i is “Yes” ASK 2j; OTHERWISE GO TO QUESTION 3}

- j. Please tell me what your greatest burden would be if telemedicine were unavailable to you.

3. Home dialysis with telemedicine support is different from regular dialysis treatment and may involve differences in how you and your family manage your treatment. Now, I am going to ask you some questions about how you and your family manage your treatment.

- a. Do other family members help you manage the tasks related to your dialysis treatment and telemedicine support?

{IF 3a is “Yes” ASK 3b; OTHERWISE GO TO SECTION II, QUESTION 4}

- b. Has your dialysis treatment created new tasks for your family that they did not anticipate?

{IF 3b is “Yes” ASK 3c; OTHERWISE GO TO SECTION II, QUESTION 4}

- c. Please tell me about the most important of these new family tasks.
- d. How did you decide who would do what tasks?
- e. Have performing these new tasks created conflicts in your family?
- f. If so, how are you managing them?
- g. Do you think your family can manage all these tasks or are they too much work?

II. Consequences of HPD for Everyday Life

4. Now I am going to ask you some questions about how home dialysis and telemedicine have affected the everyday life of you and your family.

- a. Has home dialysis and telemedicine affected your everyday life in any way, positively or negatively. For example, has your dialysis treatment given you more time to pursue other activities?

{IF 4a is “Yes” ASK 4b; OTHERWISE GO TO SECTION III, QUESTION 5}

- b. Has home dialysis created changes in your daily schedule compared to before you started this treatment?

DO YOU WANT A FOLLOW-UP HERE (e.g. “How has your schedule changed?”)

- c. Has home dialysis changed how you and your family perform house chores such as cleaning and cooking?

{IF 4c is “Yes” ASK 4d; OTHERWISE GO TO QUESTION 4e}

- d. Please tell me about the most important changes you and your family have made concerning household chores.
- e. Telemedicine and home dialysis may affect your ability to manage your everyday schedule of activities. Has telemedicine helped you manage your daily activities or has it made managing your daily activities more difficult?

{IF 4e is “Yes” ASK 4f; OTHERWISE GO TO QUESTION 4g}

- f. How has telemedicine HELPED/HURT your ability manage your daily activities?"
- g. Telemedicine and home dialysis might affect your ability to work and manage your career. Has telemedicine helped or hurt you in your work life?

{IF 4g is “Yes” ASK 4h; OTHERWISE GO TO SECTION III, QUESTION 5}

- h. Please tell me how telemedicine has HELPED/HURT you in your work life.

Appendix 3

I.R.B. NO: _____

This form is for use when the research will involve non-therapeutic procedures.

Georgetown University
Consent to Participate in Research

1. Project Name: Ethical Analysis of Telemedicine-Supported Home Peritoneal Dialysis
2. Project Director: Jeff Collman, Ph.D. Telephone: 202-784-3433
3. Purpose of this research:

You are participating in a research project evaluating the assistance that telemedicine might contribute to the process of peritoneal dialysis in your home (HPD). You are being invited, as part of that study, to discuss the impact of telemedicine-supported HPD upon the work you do everyday to care for your illness and manage your everyday life. You will be invited particularly to discuss such issues as whether you feel you understand how telemedicine and home dialysis equipment work and whether you feel comfortable operating the equipment. You will also have the opportunity to discuss how telemedicine-supported peritoneal dialysis in your home affects your relationships with family, friends, and work.

4. The general plan of the research:

You will be interviewed two or three times (depending on the time available) about your experiences as a patient with end stage renal disease and with dialysis therapies, including hemodialysis and peritoneal dialysis. The first interview will explore your experience prior to receiving telemedicine-supported peritoneal dialysis. The second and third (if it occurs) will explore your experiences with telemedicine-supported peritoneal dialysis at home. Depending upon your preference and schedule, two investigators will interview you at your home, the dialysis center or other location of your choice. The interviews will last approximately one hour.

5. The following procedures will be performed on those who participate in this research:

No procedures will be performed on you doing this evaluation.

6. Those who participate in this research will be asked to do the following things:

If you agree to participate in this evaluation, you will take the following steps:

1. You will agree to be interviewed by the investigators in a location of your choice.
 2. The entire interview should last no longer than one (1) hour.
 3. You may refuse to answer any question during the interview or end the interview at any time.
7. This research may result in the following discomforts:

You should experience no discomforts beyond those of a normal conversation during these interviews.

8. Participation in this research may involve the following risks:

You should experience no risks in these interviews beyond those of normal conversation.

9. Compensation (amount and schedule of payment):

You will receive no monetary compensation for participating in these interviews.

10. The investigators will do everything possible to prevent or reduce discomfort and risk, but it is not possible to predict everything that might occur. If a participant has unexpected discomfort or thinks something unusual or unexpected is occurring he/she should contact the Office of the Medical Director, Georgetown University Hospital at 202-784-3011.

While every effort will be made to maintain the confidentiality of these study records, on occasion the Food and Drug Administration (FDA) may wish to review these.

In the event of any injury resulting from this research, acute medical care will be provided at the usual charge, but no Federal, District of Columbia Government or Georgetown University funds will be available for compensation. Additional information on this subject may be obtained from the Office of the Medical Director, Georgetown University Hospital at 202-784-3011.

If you agree to participate in this research, you may change your mind at any time. Refusal to participate or to continue to participate will not harm your relationship with the investigators, your physicians, the hospital or the university.

I have read the above description of the research project (it was read to me by: _____). Anything I did not understand was explained to me by: _____ and I had all my questions answered to my satisfaction. I agree to participate in this research.

I acknowledge I have received a personal copy of this signed consent form.

(Signed) _____
(Participant or Legal Representative) Date

(Signed) _____
(Assent of child if under 18 years of age) Date

(Signed) _____
(Witness) Date

(Signed) _____
Date

Chapter 7

The Future of Home-Based Telemedicine: Knowledge Gaps, Barriers, and Policy and Ethics Recommendations

7.1 Introduction

Online shopping, telebanking, and a host of other e-commerce services have been helping individuals, ill and healthy, to buy products and to manage their financial affairs for some time. Although trailing the business community, the healthcare industry has now become a central participant in the information revolution. This is evident in the growth of degree-granting medical informatics programs, public and private investments in telemedicine demonstration projects, medical privacy legislation, a plethora of new journals, and rapid adoption of neologisms, such as *e-health*, *cybermedicine*, and *telehealthcare*.

Advances in information and communication technologies, such as the Internet, e-mail, medical websites, and video conferencing, are now making it possible for patients and consumers to access a broad range of healthcare services and information from their homes and to communicate more easily with healthcare professionals. Some home health agencies are already employing miniaturized biosensors and telemetry-capable medical devices to monitor unobtrusively and remotely the health status of their patients. In addition, home care services of the future are likely to be supported by an electronic patient record that reflects a comprehensive history and supports continuity of patient care. Today's electronic patient record is increasingly integrating text and images, but still does not capture much of the narrative that is critical in medicine. However,

technology is rapidly moving ahead with voice recognition and other software to capture the “patient’s story” and is likely to become integrated into a seamless information system.

At the present rate of development of increasingly low cost, user friendly and interactive technologies, it is reasonable to think that the home could become the largest entry point into the healthcare system in the not-to-distant future. If this happens, home-based telemedicine could enable a better integration of environment, community, and home to support independent living in one’s home, which is a key goal for most older and disabled individuals. This would be a significant achievement since the long-term health and well-being of ill, disabled, and dying individuals, as well as their family members, is often dependent on their ability to access healthcare professionals and services and to remain connected to their community and loved ones.

In the present healthcare system, however, barriers within and outside the home often undermine patients’ efforts to avoid social isolation, to access healthcare services, and, ultimately, to maintain independent lives. But, by means of the Internet, e-mail, chat rooms, listservs, video conferencing systems, and other telemedical technologies, it is now possible to increase patient access to healthcare services and to reduce social isolation by bringing people together virtually in their homes at the flip of a switch. At the same time, without adequate precautions, these same technologies could provide inferior healthcare information and services, exacerbate social isolation if used as a substitute, rather than as a supplement, for human contact, threaten privacy and confidentiality, place additional burdens on family caregivers, and undermine provider-patient relationships.

There are good reasons to be optimistic about the potential of home-based telemedicine. The problem is that there is scant research on home-based telemedicine. Moreover, of the studies that have been conducted, investigators have focused on the technical, economical, and clinical aspects of home-based telemedicine. These are important considerations and should be thoroughly evaluated before home-based telemedicine is implemented on a larger scale. However, what is missing from many of the studies is adequate attention to ethical issues.

This study has identified and explored some of the key ethical issues that should be considered by researchers, healthcare professionals, patients, and family caregivers who want to implement and to use home-based telemedicine services. The ethical issues selected for examination in this study included home-based telemedicine impact on (1) provider-patient relationships, (2) privacy and confidentiality, (3) informed consent, and (4) the distribution of benefits and burdens for society and within families.

Unfortunately, technology initiatives in healthcare have often been developed without adequate consideration of the unintended consequences and the range of barriers and knowledge gaps that could hinder implementation. A thorough analysis of knowledge gaps and barriers as well as options for addressing them is invaluable in the successful implementation of such initiatives and for the avoidance of so-called “technological fixes” in healthcare. Therefore, it is important to identify knowledge gaps and to understand better the legal, economic, social, and regulatory barriers to effective deployment of home-based telemedicine technologies, and to explore the options for reducing or eliminating them.

7.2 Remaining Knowledge Gaps in Home-Based Telemedicine Research

1. *Which clinical services are appropriately and effectively delivered in the home via telemedicine technologies versus in person?*

If we fail to answer this question, we run the risk of: (1) substituting technology too often or inappropriately for in-person care, thereby compromising the quality of services received; or (2) substituting technology too little, thereby losing the opportunity to gain efficiencies in our health care system, or missing an opportunity to more effectively monitor patients, thereby compromising the quality of services that might be available to individuals.

For example, there is concern about the consequences of unregulated healthcare delivered through the Internet and consumer-oriented computer technology, but very little data. The related problem is that we have no data on the relative risks posed by more traditional alternatives, which may entail delayed or restricted access and/or hurried or incompetent practitioners. Before home-based telemedicine can be adequately evaluated, there needs to be a consensus on what counts as quality home-based telemedicine services and who should measure it and how.

The National Library of Medicine (NLM) and other federal agencies have supported comprehensive studies of the clinical and cost effectiveness of telemedicine, including some home-based telemedicine projects (Gostin 1995). These studies constitute a foundation for extending inquiry into the conditions under which home-based telemedicine may or may not be clinically and financially appropriate. The NLM studies also constitute models for how future studies should be designed, requiring the examination of the entire system of home healthcare, not just the individual impact of a range of devices.

Corbin and Strauss emphasize how stable and unstable phases of a chronic illness affect everyday life in the home (Corbin and Struass 1988). Stable phases yield differing burdens and outcomes than unstable or declining phases. A central question for home-based telemedicine is who bears the costs and other burdens as care migrates from the hospital to the home. It is likely that costs saved for the hospital will migrate to the home in new unanticipated forms. Additionally, creating acceptable systems of home healthcare will undoubtedly create new costs in technology and staff for patients as well as providers. Defining what constitutes a “cost” or a “cost savings” poses a challenge to the assessment of the benefits and burdens of home-based telemedicine.

2. *Which types of data are important for clinical decisionmaking and which data are worth monitoring in home-based telemedicine?*

Given advances in engineering, computers, and miniaturization, it is now possible to monitor a myriad of bodily functions and collect endless patient data from home health patients. Such monitoring and data collection can create an information overload for healthcare providers. Answering the question above will require us to determine what parameters and clinical information is significant to measuring health status and quality of life in the home telemedicine context.

3. *Lack of knowledge about likely errors, adverse events, and unintended consequences of integrating multiple devices, drugs and technologies in the home environment.*

Clinical pharmacologists increasingly appreciate the importance of assessing drug-drug interactions as well as a drug’s specific action in a patient’s care. When considering home-based telemedicine, one may generalize the point to highlight how drugs, devices and supporting technologies interact to create complex, emergent

circumstances with potentially harmful and/or beneficial consequences for the patient and family.

Corbin and Strauss emphasize how families articulate different tasks to accomplish the work necessary for home care (Corbin and Struass 1988). The possibility for errors, adverse events and unintended harmful consequences increases with the complexity of the tasks and the difficulty of integrating them into a manageable work process. As they stress, disruptions in illness-related work hold the potential for destabilizing the rest of life and thus negatively affecting the overall illness trajectory itself. Rochlin adds to this analysis that introducing computers into skilled labor such as hospital or home-based health care potentially generates new, unanticipated kinds of errors as users depend upon computer output to inform them (Rochlin 1998). Thus, computerized monitors, telecommunications devices and other home care devices might potentially reduce instead of improve effectiveness of communication between patients, families and healthcare providers.

Many studies of telemedicine affirm its positive impact on patient-provider interaction. Indeed, preliminary data suggests video conferencing and other communication devices can enhance patients' overall ability to manage their illnesses. The question still remains how a comprehensive treatment network that includes diagnostic, therapeutic and communication devices might alter their individual performance and the ability of patients, families, and providers to use them successfully.

4. *What are sufficient methods for tailoring the type, amount and manner of presenting information to patients and families to enable them to make informed decisions about home-based telemedicine services, products and technologies?*

Retooling homes to support home-based telemedicine will require (re)training of patients and families. Although such training will have to meet minimum standards of medical care and will encounter current problems with conventional informed consent, home-based telemedicine poses new problems for informed consent itself (Arras 1994). New research should address the following questions: To what do patients and families give consent when deciding about home-based telemedicine? What constitutes denial/withdrawal of consent? For example, when does rejecting a portion of a proposed treatment plan constitute rejecting the whole? How can patients/families negotiate with providers about the components as well as the whole of a treatment plan involving telemedicine? Given the responsibilities of patients and families for multiple clinical and technical tasks in home care, who should be responsible for giving, obtaining and reaffirming informed consent? Given the possibility of failure, what obligations do providers have in proactively initiating reconsideration of the decision to proceed with home-based telemedicine?

5. *How do telemedicine technologies influence the structure of the health care system?*

Information and communication technology has the potential to increase the efficiency and effectiveness of how we deliver health services. To date, however, the introduction of computers, the Internet, and other technologies have not significantly changed the paradigm of how we organize healthcare services.

6. *How can we assure equitable distribution of technology that is required for home-based telemedicine?*

America continues to experience a mal-distribution of health resources, with urban and rural poor or geographically isolated populations continuing to be underserved. In the absence of public policies, there is no reason to believe that underserved populations will achieve any greater access to home-based telemedicine services than they have for other health services. Thus, we might expect those with financial means to be maintained in the comfort of their homes, irrespective of their disabilities, and those without means to be warehoused in largely publicly-funded institutions, at significant monetary and social cost to patients, families, and to our nation.

7.3 Barriers to Telemedicine

In addition to the aforementioned knowledge gaps, there are barriers to home-based telemedicine that must be removed if wide-scale implementation and adoption is to be achieved.

1. *Payment structures and reimbursement mechanisms do not fully support home-based telemedicine services.*

The long-term sustainability of any health service depends on the development of a stable revenue stream. Some low-cost home telemedicine technologies may thrive simply on private out-of-pocket payments, but the successful integration of these technologies into mainstream home health care will depend on coverage by third-party payers. To date, Medicare, the largest single third-party payer, provides only limited reimbursement for teleconsultation and payment for home-based telemedicine services.

2. *Nascent communication standards for medical devices need to be developed, promulgated, and accepted widely before the integration of telemedicine into the healthcare system can proceed efficiently.*

The lack of standards in the field is a major impediment to telemedicine technologies reaching their full potential. Healthcare professionals and administrators are reluctant to make large investments in telemedicine technologies today that will become out-dated tomorrow. In the long run, uniform standards will facilitate rather than impede technology development. The challenge is to develop technical standards and effective procedures for updating these standards without stifling innovation.

3. *Resistance from healthcare professionals to use home-based telemedicine.*

It is often difficult to get healthcare professionals to accept home-based telemedicine technologies, especially those that promote greater patient self-care. In addition to limited reimbursement and discomfort with unproven technologies, many of the new communication and information technologies challenge healthcare professionals' traditional roles and positions of control and power.

4. *Lack of public confidence in the security and confidentiality of computer-based patient health records, medical websites, and electronic transmission of health information undermines trust in using automated information systems to support home health care.*

The debate about medical information security tends to polarize into two broad perspectives. On the one hand, easy trafficking in medical information poses grave risks to patients' privacy and confidentiality, a situation that electronic patient records, medical websites, e-mail, and the Internet will only exacerbate. On the other hand, the entire progress of health reform, including improvements in maintaining patients' privacy and confidentiality, could depend upon adopting telemedicine and e-health technologies. Congress and the Department of Health and Human Services have

attempted to address both concerns with recently enacted HIPAA guidelines. As with all such guidelines, healthcare providers will have to interpret and possibly go well beyond the legal requirements in order to meet their obligations to both their patients and themselves. How should healthcare providers act and what should patients understand about how providers protect their information?

Providers' actions and patients' trust are linked. Although surveys reaffirm that Americans doubt that large organizations adequately protect sensitive, individually identifiable information, they do trust particular organizations under certain circumstances. When Americans observe an organization diligently seeking to protect sensitive information, they provide necessary information about themselves and trust the organization will adequately guard it. Implementing home-based telemedicine will require, therefore, good security practices on behalf of providers coupled with comprehensive, accessible materials informing patients about the security efforts underway.

5. Lack of access to telecommunications services maintains the digital divide.

The lack of affordable or reliable telecommunications services in some rural and urban communities limits access to the infrastructure necessary to support certain home-based telemedicine technologies. But, in terms of home healthcare, relatively simple telecommunications services, such as telephone lines, can support many home telemedicine applications. More often, limitations are related to lack of experience, familiarity, expertise, training, and comfort with home telemedicine technologies.

6. *Healthcare providers face information liability.*

A healthcare provider who receives information directly from a home or patient may receive low-quality data and may be liable for failures to detect or anticipate adverse outcomes implied by such data. Liability has not been a major impediment so far to the telemedicine field. However, as the field grows, insurers anticipate increasing concerns in this area. One key issue is who is liable: the healthcare provider or the telecommunications company?

7. *The lack of interstate licensure slows telemedicine's development.*

Within the United States, healthcare professionals are licensed within the state in which they practice. If they wish to practice in more than one state, they must receive a separate license for each state in which they practice. Also, many states require home health agencies to have a state license. Therefore, if a home health agency has multiple facilities located across several states, each may be required to comply with state licensure laws in the state where it is located. The potential penalties for practicing without a license may include civil fines and even criminal prosecution. The lack of interstate licensure poses a significant impediment to home-based telemedicine programs that operate across state lines and undermines its greatest strength—the ability to overcome the barriers of geography.

7.4 Policy Recommendations

1. *Support large-scale demonstration projects that seek to incorporate and evaluate home-based telemedicine's integration into current healthcare practice and health information systems.*

Currently, there are many small-scale demonstrations that purport to demonstrate the cost-effectiveness of the technologies under study. What is needed, however, are large-scale test-bed studies that specifically examine how different telemedicine technologies, such as the Internet, can be effectively deployed in a variety of home health settings. Without such studies, it is unlikely that home care agencies and third-party payers will heavily invest in these technologies.

2. *Support consumer and professional education, training, and retraining in the use of information and communication technologies.*

Too often we invest in technology without adequately considering the investment required for developing the human interface for supporting the effective use of the technology. By considering the training process early in the design of telemedicine technologies will help to motivate technology developers to produce user-friendly systems in the first place. More importantly, effective education and training is likely to lead to a greater acceptance of telemedicine technology by healthcare professionals.

3. *Develop and promote standards and protocols for exchanging and archiving information that address the fluid environment created by home-based telemedicine.*

In an increasingly mobile society, we need standards that promote the exchange of information regarding the care of an individual that cut across sectors of the healthcare field. Such standards would enable rapid exchange of information regarding individuals, no matter where they received health-related services. At the same time, these standards

must reflect concerns that the privacy, confidentiality, security, and integrity of data are maintained (e.g., HIPAA).

4. *Pass and implement legislation that ensures universal, affordable access to the Internet, including households, healthcare providers, and social service providers.*

Provisions to assure universal, affordable access to basic telecommunications services were included in the Telecommunications Reform Act of 1996. Unfortunately, the implementation of the provisions leaves much to be desired. In today's world, access to the Internet has become as essential as access to the telephone was 50 years ago. We need a strong national program to ensure that all households and healthcare and social service providers have affordable access to this basic service. It is unclear whether this objective can be achieved without additional legislation, explicitly outlining a national program for universal Internet access.

In addition, designs for home-based telemedicine should allow patients and families to adapt telemedicine technologies to the demands of their homes and self-care activities, not just force patient and families to adapt to the technologies. This has readily apparent implications for disabled individuals, but should also underlie how we think about telemedicine technologies for all patients and families. Thus, in addition to investigating ways to connect remote and low-income families to the Internet, federal agencies should encourage construction of information-ready homes. Embedding advanced information and communication technology in housing designs would complement the context-sensitive design of many telemedical devices yielding living spaces engineered for maximum support of home healthcare.

5. *Reimbursement policies should not discriminate against home-based telemedicine products and services.*

Reimbursement for patient care should be provided on a site-neutral basis. If reimbursement for healthcare services, information, and products are provided in settings such as hospitals, a long-term care facilities or hospice, reimbursement for the same services, information, and products should not be denied simply because they were provided in a patient's home by means of telemedicine technologies.

6. *Adopt interstate licensure for telemedicine providers.*

Under the premise that patients deserve access to site-neutral care, patients should also have access to the provider of their choice regardless of geographic location. In order to encourage the use of home-based telemedicine services, federal guidelines should be promoted to allow qualified practitioners to legally administer medical care or advice over distance, without respect to state boundaries.

7. *Promote public debate and understanding about the clinical and ethical conditions for appropriate telemedical care in the home.*

As Arras makes clear, home healthcare does not meet the needs of all patients or their families (Arras 1995). As the pressures grow to move patients earlier from the hospital to other locations of care, patients and families face difficult choices with few options and little understanding. If home-based telemedicine is deemed to be cost-effective, these pressures on patients and families may increase. Presently, few affordable alternatives to home care exist for the population as a whole. Innovative assisted-living or graduated care communities frequently cost more than many families can afford.

Depending on the clinical and family situation, even practical and skilled nursing for home healthcare may be unaffordable. No consideration of home-based telemedicine should avoid the broader policy discussion about developing viable alternatives. Also, patients and family caregivers do not always understand or assess in advance the burdens and benefits of home care. Therefore, social policy should promote an open discussion of the complexities, costs and potential benefits of home-based telemedicine.

7.5 Establishing Ethical Guidelines for Home-Based Telemedicine

In 1998, the American Telemedicine Association (ATA) formulated clinical guidelines for medical websites and home-based telemedicine that set criteria for patients, providers and technologies (ATA 1998; ATA 1999). The ATA guidelines are a big step in the right direction. The problem that remains, however, is that there still are no widely accepted ethical guidelines for the practice of home-based telemedicine. What is required?

In general, ethical guidelines for home-based telemedicine should identify the *benefits* and *burdens* of home-based telemedicine in a way that considers and advances the *autonomy* and *well-being* of patients and family caregivers. Home-based telemedicine should also be evaluated in terms of its ability to promote *fairness*, *availability*, *access*, and *quality* in healthcare (Beauchamp and Childress 1994). As barriers are eliminated and more knowledge about home-based telemedicine is gained through research, our understanding of specific benefits and burdens of home-based telemedicine will likely improve. Until that time and in light of limited information

about home-based telemedicine, the following issues ought to be considered when establishing ethical guidelines for home-based telemedicine: (1) provider-patient relationships, (2) privacy and confidentiality, (3) distributive and family justice, and (4) informed consent.

Provider-Patient Relationships

Ethics guidelines should consider the impact of home-based telemedicine on provider-patient relationships. In particular, do telemedicine technologies impede the development of empathy and compassion between patients and healthcare professionals and ultimately harm patient care and health outcomes (Belas, Jaffrey et al. 1997)?

Although not the case for all normative models of the provider-patient relationship, good character and virtue are central to the moral practice of medicine and the lack of appropriate emotional ties between patients and providers can be construed as an unacceptable moral vice in clinical medicine (Pellegrino and Thomasma 1993). This is so from the perspective of Thomasma's *conscience model*. As discussed in Chapter Two, the conscience model appears to be the best candidate for both describing and ethically evaluating the provider-patient relationships of home-based telemedicine (Thomasma 1983).

Privacy and Confidentiality

Ethics guidelines for home-based telemedicine will need to consider how various telemedicine technologies affect the privacy and confidentiality of home health patients, family caregivers, and providers. Thus far, the telemedicine literature and most legislation and regulation have focused on the potential benefits and harms to informational privacy (Bruce 1984). This is important, but in the context of home-based

telemedicine, attention will also need to be given to how telemedicine technology affects both physical and decisional privacy of patients, family caregivers, and providers (Allen 1995). In some cases, different types of privacy will be in conflict and compromises between, for example, informational privacy and physical privacy will be required.

Distributive and Family Justice

Ethics guidelines for home-based telemedicine will also need to consider distributive and family justice issues. From the point of view of distributive justice, it will be important to know how home-based telemedicine, at a societal level, affects the allocation of healthcare resources and associated benefits and burdens. At the aggregate level, how, if at all, will home-based telemedicine improve or harm healthcare access, availability, quality, and efficiency (Sterba 1995; Daniels 1996)? From a family justice perspective, what is an ethically appropriate distribution of benefits and burdens within families when employing home-based telemedicine? Moreover, conflicts of interests normally not found in traditional medical settings, in which healthcare is governed by a patient-centered moral framework, are likely to arise in the home (Brody 1983).

As with home healthcare generally, home-based telemedicine will introduce new benefits and burdens for family caregivers. Hence, a family-centered moral framework that includes and assigns significantly more weight to the interests of family caregivers will be required to assess whether home-based telemedicine an ethically appropriate mode of healthcare for particular families.

Informed Consent

Finally, ethics guidelines for home-based telemedicine will require an on-going informed consent process for patients and their families (Wear 1993). If families and

patients are technically, medically, and emotionally naïve about home-based telemedicine, it is highly unlikely that they will be able to make informed decisions about it. Related to the issue of informed consent, is the need for viable options to home-based telemedicine (Arras 1995). For example, under what condition should home-based telemedicine be used as a replacement instead as a supplement for face-to-face healthcare services? What if patients and family caregivers do not want telemedical services in their home? Informed consent to home-based telemedicine will require that patients and their families have real alternatives. If no options to home-based telemedicine services are present, then consent is an empty formality for patients and their families no matter how informed they are about home-based telemedicine.

7.6 Conclusion

Home-based telemedicine is a new and ethically complex phenomenon in healthcare. As the site of healthcare delivery continues to move from hospitals to private homes, the ethical implications of home-based telemedicine should be thoroughly considered, and clear ethical guidelines should be established for its use. This is easier said than done, but we must remember that knowledge, whether scientific, technical, or clinical ultimately should be used to promote human flourishing and to reduce human suffering. If society adopts home-based telemedicine on a large scale, it will be important to identify in advance rather than after the fact the ethical issues and values at stake. By doing so, we are more likely to create a more rational and humane healthcare system and avoid the undesirable and unintended consequences of new technologies that are so characteristic of modern healthcare.

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