Special Section: Cyberethics:
The Internet and Allied Technologies

# *Home-Based Telemedicine: A Survey of Ethical Issues*

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In the past decade, digital technology, fiber optics, cellular phones, satellite television, home computers, and the Internet have substantially transformed business, education, and leisure practices. These technologies are becoming so integrated into our daily routines that their ubiquity often goes unnoticed. We are, nonetheless, in the midst of a telecommunications revolution, and the healthcare industry is becoming a major player. The burgeoning field of home-based telemedicine is evidence of this.[1]

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 that are vital to the success of home-based telemedicine. However, the problem with these assessments is that they neither identify the moral values involved in home-based telemedicine nor address its possible ethical implications. Given that the economic and technologic viability of home-based telemedicine is not identical with its ethical appropriateness and justification, this is a serious oversight. Therefore, as the site of healthcare delivery incrementally moves from hospitals to homes in the form of home-based telemedicine, a better understanding of it is required.

## Defining Home-Based Telemedicine

The literal meaning of *telemedicine* is *medicine from a distance*. This, of course, tells us very little about the actual practice of telemedicine. For a more practical definition, telemedicine can be defined as *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*.[2] In the case of home-based telemedicine, the point of care is moved directly into the patient's home and refers to the in-home delivery of healthcare services by means of telecommunications to patients who have already been diagnosed in a standard medical setting.[3]

The informatics literature often reserves the word *telemedicine* for specific medicine-oriented applications such as telesurgery, teleradiology, and teledermatology, whereas *telehealthcare*, *telecare*, and *telehomecare* generally refer to broader healthcare services such as those provided in the home. I do not make use of these terminological distinctions in this paper. However, it is important to note that the manner in which telemedicine services are eventually defined, categorized, and conceptualized will have implications for the future of provider-training, credentialing, reimbursement, and a host of other telehealth policy

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issues. There currently is no consensus on whether telemedicine and home-based telemedicine activities constitute entirely new medical disciplines or simply new electronic tools for healthcare providers.

For those who are unfamiliar with telemedicine, the word *telemedicine* often produces images of expensive and cumbersome high-tech medical equipment linked to whirring and buzzing communication systems that are frightful in their complexities. This, however, is not the reality of contemporary telemedicine. Typical communication and information technologies used in home-based telemedicine include the common telephone, fax machine, video-conferencing equipment, home computers, and interactive software that can be purchased off the shelf at home-electronic stores such as Radio Shack and Sears. 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 (e.g., the Internet, fiber optics, and satellite).[4]

When linked to these telecommunication delivery systems, telemetry-capable devices make it possible for healthcare providers to monitor remotely 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 (e.g., 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, and oximeters. Already in use, videophones will soon make the "virtual house call" commonplace in home healthcare. Moreover, rapid developments in the computerized patient record and in sophisticated interactive software will soon allow both providers and patients easy and comprehensive access to medical information from their desktop computers.[5]

## Demographic and Economic Trends in Healthcare

Home-based telemedicine has great potential, 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 care for in-home patients.

Even before the advent of home-based telemedicine, traditional homecare has been thought by some to be a partial solution to America's healthcare-related economic problems. Their reasoning is that if patients are kept out of expensive hospitals, then costs can be cut while patients remain in the comfort of their own homes. This is not a bad idea—if it works. Currently, more than 20,000 homecare providers in the United States deliver traditional homecare 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 United States. In 1997 annual expenditures for homecare were $40 billion.[6]

Traditional homecare may prove to be less expensive than hospitals and nursing homes, but homecare is still expensive and will only become more so

as larger numbers of baby boomers age and continue to live longer but not necessarily healthier lives. As we enter the twenty-first century, healthcare utilization and costs are projected to climb even higher as the number of elderly and chronically ill increases. This in turn will 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 homecare can be at best only a temporary solution to our healthcare economic crisis. If nothing else is done, America's homecare demands of the future will surely outstrip her economic and human resources.[7]

Something is being done. In response to strengthening economic and demographic pressures in American healthcare, research on home-based telemedicine is multiplying exponentially. The National Library of Medicine, the Health Care Financing Administration, the National Science Foundation, the U.S. Department of Health and Human Services, and other governmental and private sector agencies are now funding and evaluating the economic, technical, and clinical viability of home-based telemedicine pilot programs. Outcome data are limited, but researchers are generally optimistic about home-based telemedicine's potential.[8]

## Potential Benefits of Home-Based Telemedicine

What are the likely benefits of home-based telemedicine? First, homecare agencies can reduce the costs of providing services to patients distributed over large geographical areas. Some homecare patients only require limited interactions, information, and emotional support that can be achieved over various communication and telemetry links rather than in person by a homecare worker. Because home-based telemedicine is less dependent on the physical presence of healthcare providers, geographical inaccessibility decreases as an impediment to the delivery of homecare services. Less travel time means that fewer healthcare workers can provide more care to more people at lower costs. Unlike many technologic innovations in medicine, information and communications technologies when carefully applied are likely to reduce costs and maintain, if not improve, the standard of care of homecare services.

Second, from a healthcare justice perspective, home-based telemedicine technologies can increase healthcare access and make possible a more equitable distribution of healthcare resources.[9] With a home computer and an Internet connection, patients can access a plethora of healthcare information and services from both non- and for-profit web sites such as DrKoop.com, Intelihealth, WebMD, Mediconsult, Healtheon, and Medline. These and many other cyberspace medical resources address every conceivable medical topic and condition. Additionally, patients who live in remote areas and/or lack transportation can receive televisits from healthcare specialists and circumvent the burdens of finding transportation and traveling long distances in poor health to and from outpatient clinics and regional hospitals.[10]

Third, as homecare workers substitute televisits, teleconsults, and telemonitoring for unnecessary in-home visits, patients and family caregivers will gain more physical privacy and control over their daily schedules. Physical privacy is ethically significant because it enables patients and their families to maintain comfortable routines at a time when much in their lives is out of their control. For many patients and their families, the information and communication tech-

nologies of home-based telemedicine might reduce the number of intrusions into their homes by healthcare workers and thereby protect the intimate sphere of the home.[11] Patients and their families may choose to have more in-person visits than televisits from healthcare professionals, but home-based telemedicine will give them options that do not currently exist.

Fourth, it is possible that many of the fears and anxieties associated with high-tech homecare (e.g., infusion pumps and ventilators) can be reduced and patient and family well-being increased because of telemonitoring and immediate videophone access to healthcare workers. Internet support groups can also provide comfort and information to patients and families at any time. 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 homecare staff at anytime 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 homecare services, patients and family caregivers would have to wait for medical and homecare workers to drive to their homes just to confirm whether the patient did in fact suffer a serious cardiac event. In some remote regions, homecare workers must drive 50 miles one way to a patient's home. False alarms are not only common in homecare, they are expensive, too. By means of home-based telemedicine, the economic, physical, and psychological burdens of homecare can be minimized and the benefits of home maximized for patients, providers, and taxpayers.

Finally, home-based telemedicine has the potential to alter our current healthcare paradigm of rescue and cure because it promotes wellness, prevention, and greater self-management of illness. Given that many home visits do not require direct physical care by healthcare providers, limited economic and human resources can be conserved for the worst off and those who truly need in-person visits.[12]

## Ethical Issues in Home-Based Telemedicine

Whether a particular homecare technology is ethically appropriate will depend on a variety of context-specific elements, including the kind of telecommunication systems and medical devices used, the complexity of treatment, the level of family support, and the benefit-to-burden ratio acceptable to both patients and caregivers.[13] Nonetheless, there are identifiable ethical issues generally associated with the use of home-based telemedicine that require ethical reflection.[14]

First, home-based telemedicine, as an auxiliary to homecare, may further medicalize the home environment.[15] As mentioned earlier, hospitals are under pressure to cut costs and are sending sicker patients home sooner to be cared for by family members. Naturally, home-based telemedicine is increasingly viewed as a cost-effective alternative to in-hospital care and as a means to support the care of patients in their homes.[16]

The problem with this approach is that the private domain of the home becomes a highly porous, public node where medical information and communication technologies merge. In other words, home-based telemedicine has the

potential to dissolve the thin membrane that separates our public and private lives. Telemetry-capable medical tools and biosensors can electronically link patients and healthcare workers. However, a potential downside of home-based medical telemetry is that the homes of patients and family caregivers may become medicalized or, in extreme cases, de facto ICUs (intensive care units). At the very least, home-based telemedicine raises questions about the meaning and purpose of our homes, our families, and our bodies. Therefore, before we rush blindly into a wide-scale adoption of home-based telemedicine, we need to have a better understanding of the capacity of information and communication technologies to transform our private living environments, our families, and our bodies. Once we have done this, we can then decide whether home-based telemedicine is something we want.[17]

Second, a traditional approach to healthcare justice is more than adequate when macroallocation issues are at stake or when the interests of individual patients are being evaluated in connection to large and impersonal institutions such as hospitals and the federal government. But, when we begin to speak of justice within the small and intimate context of families, justice takes on new and more complex characteristics. In a hospital setting, healthcare is governed by a *patient-centered framework* in which the patient's interests are usually of primary importance. Healthcare providers do consider the needs of family members, but they are usually and rightly considered secondary to the patient's. This makes good sense because it is the patient's well-being and interests that are at stake.

However, as more healthcare services move into the homes of patients and their families, the interests of family members should be given greater moral weight. This should be done because home-based telemedicine may increase the already heavy burdens on family caregivers and create conflicts of interests not normally found in traditional medical settings, where a patient-centered framework is the norm. In those cases, for example, where a sick loved one is chronically ill, home-based telemedicine may have profound and lasting implications for the lifestyle, financial status, and emotional and psychological well-being of family members who care for him or her.

Thus, home-based telemedicine will require the adoption of a moral framework that is applicable to the home environment and multiple stakeholders. In short, a *family-centered moral framework* that promotes *justice within families* will need to replace the more traditional patient-centered model.[18] Because a family-centered moral framework requires that the interests of families be given greater moral consideration than they would be given in a patient-centered moral framework, the fiduciary relationship of the patient-centered moral framework is decentered. Within a family-centered moral framework, families, whatever their configuration, have interests that uniquely distinguish them from individuals and society. This, of course, profoundly transforms the traditional provider-patient relationship in which the interests of individual patients are primary and balanced against the interests of the larger society.

Furthermore, justice within families will require families 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 may be so great that families may refuse home-based telemedicine services and select options they believe to be less burdensome. The need for appropriate limits on familial duties is especially evident when we consider the affect of home-based tele-

medicine on women. If history is prologue, it will likely be female family members in the majority of cases that will care for sick loved ones. If justice within families is going to be achieved, patients and their families will need to have viable alternatives to home-based telemedicine services that allow them to manage the burdens of caring for sick family members. This means home-based telemedicine should be viewed as a supplement to traditional homecare and hospital-based medicine in the majority of cases, not as a complete replacement of them.

A third and centrally important ethical issue in home-based telemedicine is in determining what constitutes informed consent.[19] If decisions to use home-based telemedicine are not adequately informed, then the autonomy and well-being of patients and families cannot truly be promoted and protected. In general, healthcare workers will need to educate patients and their families about the unique benefits and burdens associated with home-based telemedicine. Concerning the burdens, patients and their families need to be aware of possible complications with equipment, costs, and the roles of family caregivers in the use of the technology. This process should also include discussions about possible threats to privacy and the confidentiality of medical information.

Also, the informed consent of patients and their families should be an ongoing and open-ended process. The reason for this is that some patients and families may eventually change their minds as they have more experiences with home-based telemedicine. Consequently, patients and family caregivers will need adequate information on an ongoing basis about the burdens and limitations of home-based telemedicine, the patient's medical condition, and the technical operations of homecare technologies. If family caregivers and patients are technically naive, it is highly unlikely that they will be able to make informed decisions and give informed consent about the initiation of home-based telemedicine. Patients and family caregivers can always refuse to consent to home-based telemedicine, but the availability of alternatives to home-based telemedicine would make it easier for families, whatever their reasons, to decline telemedical services.

Fourth, the philosophical literature on technology is replete with examples of how technology can atomize and dehumanize human experience and task performances.[20] Along these lines, it is argued that mass computerization is leading to a greater impersonalization of society where people live in physical isolation from each other. What we need to know, and what we do not know at this time, is how home-based telemedicine affects the task performances of patients and providers. That is, will home-based telemedicine transform healthcare providers into mere informaticians—technicians of health information and data—as more of their day-to-day job activities revolve around information and communication technologies and as patients and families take on more patient-care responsibilities?

More specifically, what are the implications of home-based telemedicine for the provider-patient relationship? As stated above, home-based telemedicine requires a family-centered moral framework. Is this a diminution of medical paternalism or simply do-it-yourself healthcare? Do the multiple fiduciary obligations of a family-centered moral framework effectively make impossible anything like an actual provider-patient relationship?[21]

Additionally, how are trust, empathy, and overall patient outcomes affected by machine- and electronic-mediated relationships as found in electronic mail

and interactive video? Because patients are often vulnerable and frail, the necessity of provider empathy and compassion takes on added importance. These qualities are basic to good medical practice. Moreover, because good character and *virtue* are central to the moral practice of medicine, a lack of appropriate emotional ties between patients and providers can be construed as an unacceptable *moral vice* in clinical medicine.[22] Thus, before home-based telemedicine is widely adopted, we must consider whether home-based telehealth technologies impede the development of emotional connections between patients and healthcare providers and affect patient health outcome.[23]

When answering the aforementioned questions, we must not forget that medicine is a profession dedicated to the healing and comforting of sick and vulnerable persons. As such, it is governed by moral ideals and ethical principles designed to protect the interests of patients and to guide the provider-patient relationship. Second, healthcare is not synonymous with the management of medical data nor is it simply a commodity. Rather, health and healthcare services are special and basic goods that are integral to who we are as persons; that is, they are necessary prerequisites for human well-being and flourishing. Thus, future demonstration projects should consider how home-based telemedicine affects traditional healthcare values and practice norms. To date, completed outcome studies on home-based telemedicine have emphasized technologic and economic efficiency and have provided mixed and limited answers to these questions of value.[24]

Fifth, as stated earlier, home-based telemedicine might lead to a more equitable distribution of healthcare resources by increasing healthcare access for patients who are homebound and/or live in remote regions. However, home-based telemedicine's potential for the social stratification of healthcare resources should not be underestimated.[25] The well off and educated will have access to medical information and services that the poor and uneducated will not. Moreover, what if home-based telemedicine proves to be superior to traditional homecare services? What obligations, if any, would we have to "wire" the information and communication disadvantaged? An ethical evaluation of home-based telemedicine will need to include considerations of equity in the distribution of information and communication services.[26]

Sixth, as discussed previously, home-based telemedicine might enhance the *physical privacy* of patients and their families. However, the *informational privacy* of patients and providers is at greater risk with home-based telemedicine. E-mail and telemetry transmissions generally use less-than-secure standard phone lines. Wireless transmissions may prove to be even more problematic.[27] Also, electronic patient records can be easily centralized and replicated, and they would include all video and audio communications that can be instantly disseminated across the globe to many people, either intentionally or unintentionally.[28] Concerns about the privacy, confidentiality, and security of medical records and data are not new. What are new are the means, the context, and the extent to which they can be compromised. Encryption technology will help, but to meet these challenges directly, deep-rooted organizational and social changes will be necessary.[29] For example, the establishment of universal protocols as well as training and credentialing standards for home-based telemedicine information management are currently under consideration. We may also need to decide on an "acceptable" trade-off between informational privacy and improved healthcare quality and access.

Seventh, home-based telemedicine will likely include Internet access to a wide variety of healthcare information and services for patients and their families. An abundance of healthcare information that is readily accessible to patients in their homes can be desirable and useful. The downside is that patients and families may suffer from an overload of healthcare information. Too much information, especially when one is seriously ill, can be as bad as not having any information at all. A related problem for patients and their caregivers will be in distinguishing the accurate and reliable healthcare information sources on the Internet from dubious sources. At present, it is almost impossible to distinguish the two.

Until there are better means for determining which medical online services are legitimate and which ones are not, patients, families, and the healthcare profession will be at greater risk of harm from the online quackery of snake oil salesmen. If home-based telemedicine is going to be effective and safe, healthcare services and information provided through the Internet will need to meet scientific standards for accuracy and reliability and be certified by an authoritative medical body. More importantly, patients and family caregivers will need to become more knowledgeable and sophisticated about medical research and scientific methodology.

Finally, current home-based telemedicine research is supposed to assess patient quality of life by informing us about how it compares to traditional home healthcare.[30] By determining whether patients are at least as well off with home-based telemedicine as with traditional approaches, a standard of care is maintained. The problem is that home-based telemedicine is slowly being adopted at the same time that it is being tested and evaluated. Thus, by the time enough data have been gathered to show whether home-based telemedicine meets already accepted standards of care, it will be a widespread and permanent fixture of American healthcare. For example, it is unclear when home-based telemedicine should be a supplement rather than a substitute for traditional homecare. Before we can know this, evidenced-based practice guidelines that are rooted in scientifically sound outcome studies must be developed. Unfortunately, the application of home-based telemedicine may be another instance where new and experimental technology outstrips our understanding of its ethical implications.[31]

## Conclusion

The adoption of home-based telemedicine is often justified in economic and technological terms that minimize the ethical dimensions of medically treating patients in their homes. We want home-based telemedicine to be medically appropriate, cost effective, and technologically efficient, but we should also want it and related health policy to be governed by ethical guidelines that reflect both a minimum standard of justice and the moral ideals of medicine. An ethical assessment of home-based telemedicine will help us to identify likely shortcomings and plan for future improvements in the employment of these technologies in the home.

In general, the formulation of ethical guidelines for home-based telemedicine should help patients, families, and providers determine an acceptable ratio of benefits to burdens when deciding to use home-based telemedicine. If the burdens are too many for patients and their families, then home-based tele-

medicine should be rejected. More precisely, an ethical framework for home-based telemedicine will need to: (1) guide clinical standards for provider-patient communications, (2) provide for an ongoing process of informed consent, (3) protect informational privacy, and (4) include a standard of justice that is applicable within and across families.

We must remember that home-based telemedicine is an exercise in healthcare, not electronics. Communication and information technologies are means to an end. Before embracing these new means, we need to know whether home-based telemedicine encourages responsible self-care or unnecessarily burdens patients and families with do-it-yourself homecare. Given the increased responsibilities and risk of error, we need to determine the specific information and skills that patients and their families require before their consent to home-based telemedicine can be considered informed. When possible, the availability of traditional homecare services can function as either an alternative or a supplement to home-based telemedicine and afford families flexibility in caring for sick loved ones at home. Finally, because the dignity and well-being of patients and their families are at stake, ethical guidelines that are rooted in the ethical and social realities of home-based telemedicine should be formulated.

## Notes


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