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Special Section: The Newest Frontier: Ethical Landscapes in Electronic Healthcare

Ethical Challenges of Telemedicine and Telehealth

BONNIE KAPLAN and SERGIO LITEWKA

As healthcare institutions expand and vertically integrate, healthcare delivery is less constrained by geography, nationality, or even by institutional boundaries. As part of this trend, some aspects of the healthcare process are shifted from medical centers back into the home and communities. Telehealth applications intended for health promotion, social services, and other activities—for the healthy as well as for the ill—provide services outside clinical settings in homes, schools, libraries, and other governmental and community sites. Such developments include health information web sites, on-line support groups, automated telephone counseling, interactive health promotion programs, and electronic mail exchanges. Concomitant with these developments is the growth of consumer health informatics, in which individuals seeking medical care or information are able to find various health information resources that take advantage of new information technologies.

These shifts are motivated by a sense that it is better for people to be able to stay in familiar and friendly environments and have more control over their lives and health. However, as the population ages, it seems that the demands for home care will outpace the economic and human resources to meet those demands. The rapid growth of these applications is, therefore, also fueled by the growth in the information technology industry and encouraged through governmental initiatives under the assumption that telecare home services might be less expensive than institution-based alternatives.

Often a distinction is made between telehealth and telemedicine. Telemedicine has a clinician as at least one of the participants, whereas telehealth is any use of information technology for health purposes.[1] Both involve using electronic information and communication technologies for healthcare when distance separates the participants. They span a spectrum of applications, from the relatively simple—like linking telephone, video, facsimile, home computers, and other low-cost technologies to various devices so that health-related information can be sent to clinicians from individuals' homes—to clinical consultations conducted at sites remote from each other and, therefore, convenient to both clinicians and patients, to complicated procedures, such as telesurgery, performed remotely. Rather than the cumbersome phrase "telehealth and telemedicine," sometimes we will use one of these terms to stand for both of them. We also may

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use the broader term "e-health," more common in the United Kingdom, which refers to "the emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies,"[2] though we mean this to include mainly consultation, communication, and intervention.[3]

Potential benefits of telehealth and telemedicine include greater availability of services and access to healthcare providers (including specialty services that may not be located near to those needing them), reduced disparities in healthcare accessibility, less travel time for both patient and clinician, lower costs, and quality improvements presumed to derive from access to more timely and accurate data and improved information flow available any time or any place.[4] These improvements also could lead to changes in infrastructure that would provide seamless and continuous care available on a more equitable basis by allowing interorganizational cooperation and ready flow of information between wherever patients and providers may be.[5]

These new developments seem to provide what people want: personalized relationships with providers, information targeted to their concerns and needs, and interactive tools for health and disease management.[6] It is thought that patients and others needing healthcare services will benefit from use of these technologies in several ways commonly considered "empowering." First, they would be able to stay in their own homes rather than be institutionalized, with fewer intrusions by healthcare workers and more control over their privacy, health management, schedule, and activities. Individuals may even obtain care from providers from whom they are physically distant and whom they may not have met in person. Moreover, knowing that patients' conditions are being monitored could offer some reassurance for both patients and their loved ones. Further, the power differential between patients and clinicians would be reduced through patients' access to health-related information and by providing a means for the like-minded to connect, possibly set up their own healthcare organizations, and thereby leading to increased democratization.[7] It is thought likely that the care paradigm would shift from crisis intervention to promoting wellness, prevention, and self-management.[8]

Using these new technologies, then, has the potential for great good. Although neither their clinical nor cost effectiveness has been well established,[9] it, therefore, is likely that governments and healthcare institutions will provide more and more healthcare services using these new tele-technologies. We, too, are enthusiastic. Mixed with our enthusiasm is our recognition that these advantages come combined with ethical tensions. E-health is not only a technological improvement, but a reengineering of healthcare processes requiring consideration of sociotechnical aspects of their design and development. It is meant to broaden the scope of healthcare delivery, place citizens at the center of services, and provide them increased interaction with health professionals who look after their health needs.[10] This, it is believed, could lead to improving healthcare not only locally, but also worldwide, through global thinking and information technology.[11] The Internet is seen to "ha[ve] the greatest potential to promote health and prevent disease for individuals and communities throughout the world" and "seems uniquely suited for health education and promotion because it can be used as a tool within our existing models and frameworks without sacrificing our principals[sic] and values."[12]

But what principles and values are those? Some question whether this new model of medical attention is clinically effective and provides positive outcomes for the users. Both the effectiveness and ethics of such services still are under discussion.[13] It is now eight years since Iverson warned that little time was left to avoid adoption before thinking through moral implications.[14] Bauer, too, pointed out that home-based telemedicine is being driven by economic and technological criteria, with little attention to its ethical appropriateness or justification.[15] They, and others, called for frameworks and guidelines so that comparisons with standards of home care and other alternatives, as well as reasoned discussion, occur before the technology becomes too entrenched to be able to effect changes.

This paper explores some of the hopes, concerns, and ethical tensions surrounding these new technologies, particularly in industrialized countries. Although privacy, security, confidentiality, and information accuracy are common ethical concerns, we think additional issues also need addressing. We begin by discussing design issues. This leads us into considering evaluation issues in telehealth and clinical research. We then focus on the individuals using the technologies, looking at informed consent, autonomy, and empowerment. Next we shift to relationships among various individuals involved, such as patients, providers, caregivers, and people within a patient's family. We then move on to societal and policy issues.

Our discussion is by no means exhaustive. We hope, instead, to both broaden and deepen understanding of how to use these and other technologies that have so much to offer for improving both health and overall well-being. To this end, we conclude by pointing out the need for evaluation of these technologies that addresses their ethical and social aspects, thereby adding to the thoughtful considerations and colleagues' calls for finding ways to use the new technologies to benefit patients and practitioners while avoiding potential pitfalls.

Ethical Issues Concerning Design

Telehealth, as Layman interestingly notes, has raised problems stemming from conflicts between various aspects of technology usage and such ethical principles as abridgement of privacy (including combining and mining data), inaccurate and obsolete data, and security breaches.[16] Other frequently discussed issues pertaining to design include information overload; usability and user-friendliness; data standards and integration for linking patient and personal information to achieve interoperability for individual records, personal health management, and public health; and how new applications fit with changes in healthcare delivery and health information infrastructure. The quality and accuracy of online information also is of deep concern, which various honor codes and vetting mechanisms have evolved to help ensure.[17]

Rarely does the literature address additional design issues that also seem important to us. Among them is whether individuals would use the technology and whether or not it is "usable" or "obtrusive." Going beyond dimensions of usability and obtrusiveness identified in Hensel et al.'s excellent review[18] are how what constitutes usability or obtrusiveness, as well as other concerns, may differ for different use sites (e.g., home, community center) or different populations of

people intended to use the technology (e.g., people with the same diagnosis or of the same socioeconomic status or with a particular disability). In addition, how much are actual users involved in user-centered and use-friendly design approaches to telehealth applications?[18a]

Also important are problems deriving from disciplines involved in creating, deploying, and using the new technologies. Bioengineers, computer experts, software technicians, web programmers, insurance providers, physicians, and nurses are some of the participating actors. Each group has its own economic, professional, and social orientations and differences in knowledge and know-how concerning telecare and, hence, its own interests in e-health developments. Moreover, e-health is promoted as "not only a technical development, but also a state-of-mind [sic], a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology."[19]

Design and deployment decisions are necessarily influenced by these kinds of values and intentions for how and why the technologies should be used. In the process, patients might not be the ones to decide whether conventional medicine or telehealth fits their needs better or just how their concerns are incorporated into the technologies they are expected to use. And to make things even more complicated, sometimes, those needs may be hard for them to identify if they become confused by disguised marketing initiatives, as when web sites mix information and advertising to sell medical services. Consequently, ethical problems may arise related to the intentions of those who develop these systems, the goals that they seek, and the final outcome of those new procedures.[20] That designs may benefit clinicians more than the ill or elderly or, in fact, produce effects opposite to what had been expected has led to laudable attempts to articulate more ethical design principles.[21] Among the issues we think important are the following: How provider- or patient-centric is the technology? Does the shift to remote services promote rationality and efficiency at the expense of values traditionally at the heart of caregiving? How does the design affect home life and family dynamics? To what extent should technology usage involve attempts to manipulate users into different behaviors? How might the replacement of human contact by new technologies be ameliorated? To what extent is the deployment of technology an end in itself, aimed not toward the improvement of health or well-being, but to create market needs? How do we identify the boundaries between genuine solutions and futility in light of technologies that may shift them? How can those who design technology become more cognizant of and sensitive to "the human condition and all its complexity," a mark of the move toward "holistic engineering"?[22]

Lastly, different individuals attribute different meanings to the same technology. For example, some users considered a telephone-based diet and exercise telephone counseling system as a way for the provider organization to reduce costs and contact with practitioners, whereas others viewed it as a friendly and empowering alternative to depending upon a human counselor.[23] Further, what is acceptable in a particular country or region may not be acceptable in another, so the same design or technological approach may lead to different results in different user communities or different cultures. These differences need to be considered during design and implementation so that the technology is received and used as beneficially intended.

Telehealth, Clinical Research, and Evaluation

Telemedicine and telehealth evaluations, like evaluations of other healthcare interventions, are affected not only by the changing context of healthcare, but also by what evaluation questions are being addressed. These questions rarely include ones pertaining to values or to how the technology is deployed and used in situ, nor other ethical issues such as those we raise in this paper.

Most evaluations of medical and health informatics applications are based on positivist, rationalist, or rational choice theoretical perspectives and study designs, whereas technology assessment, similarly dominated by quantitative experimental designs (based on randomized controlled trials) and cost/benefit analysis, also has developed over the past 30 years to emphasize safety, efficacy, and economic impacts. The dominant evaluation focus, then, including evaluations of telemedicine, has been medical and technical, especially examining feasibility, safety, technologic and economic efficiency, and clinical outcomes, with frequent study of physician behavior or reactions rather than those of other actors. Thus, evaluations mirror the values of scientific rationality and efficiency often motivating the systems being evaluated. Studies generally have not included social or ethical concerns and may not be useful for policy making.[24]

Telemedicine evaluations are scarce or of problematic design.[25] Yet, evaluations in related areas suggest that well-established communication and status patterns shift and that information concerning a patient is decontextualized. Both these changes may lead to poorer quality care. For example, in a breakthrough providing accessibility to remote communities or solutions to overcrowded or understaffed hospitals, a radiologist distant from a patient imaging site reads an image. However, if this radiologist is overwhelmed by a flood of images from a network of institutions, misdiagnosis may occur. Besides, clinicians lack information when they interpret images in the absence of direct knowledge of the patient. The remote radiologist is not able to benefit from in-person radiology conferences with the treating physician, and the treating physician may not be able to assess the radiology report in light of direct knowledge of the radiologist. This disconnect, too, may lead to misdiagnosis.[26] Another example is the need for clinicians to review data from in-home devices that monitor physiological signs. Clinicians are both legally and morally obligated to consider all the data they receive, including the new stream of data from these devices. Physicians or nurses responsible for reviewing this influx must handle voluminous data, far more than they used to consider when caring for patients at home. The overwhelming amount of decontextualized data, changes in their work routines, and redistribution of clinical tasks all may contribute to errors. Even with baseline measures, it may not be obvious in the mass of frequent readings what to consider a normal fluctuation and what to consider alarming. Determining the boundaries between what is significant and what is not adds more burden. Further, trust in electronic information may interfere with recognizing that these wonderful tools and state-of-the-art data transmission might also increase the likelihood of hurting patients. It is especially questionable morally if a telehealth service substitutes for a traditional human medical service because it is a cheaper alternative reserved for those socially disadvantaged.

Also, it is not always clear just whose responsibility it is to detect and respond to potential problems. Already there is some evidence that telemedicine changes

work routines and redistributes responsibilities by shifting clinical tasks to nonmedical personnel or to the technologies involved.[27]

As these examples suggest, efficacy, economy, and technical correctness, then, need to be considered in light of other values and findings from studies that address broader evaluation questions. Ethical and social considerations lead some researchers to advocate moving beyond the traditional focus on clinical effectiveness and patient outcomes to include ethical components and the kinds of study designs to address them.[28] As a mirror of the change in medicine and nursing toward understanding illness in social as well as medical and technical terms, there have been calls for evaluating treatment and clinical practice beyond what is possible through randomized controlled clinical trials and economic criteria so as to include, for example, patients' interests and experiences.[29] Telehealth applications also may be evaluated not only as therapies, but also as information technologies embedded in organizational or institutional contexts and as information services embedded in personal, societal, or community contexts.[30] We, too, consider it an ethical imperative to conduct evaluations and to develop and use different evaluation research approaches and questions so as to address significant ethical issues. The challenge is to assess interventions not only on technical correctness but also moral appropriateness.[31]

Informed Consent

Informed consent also is identified frequently as an ethical challenge associated with telehealth technologies.[32] We consider "informed consent" in telehealth to go beyond what usually is discussed either for clinical trials or healthcare decisionmaking and explore what constitutes "informed." Bauer questions what "informed" means when new technologies require education about benefits and burdens associated with their use. He would like to enable individuals to change consent as they gain information and experience with the technologies and weigh them against other available alternatives.[33] Like others, he enumerates potential issues that could add to the benefits and burdens of which those giving consent may wish to be aware, and we present still more.

It seems to us that being informed involves being aware of these benefits and burdens. This is commonly understood in drug trials, where adverse events that might occur generally fall into well-understood categories. New technologies, though, may involve new kinds of risks, so consent implies consenting to risk impossible to anticipate. It seems ethical that those giving consent also should be aware of this.

As an example of one such unanticipated consequence—albeit a rather mild one—of using a new telehealth technology that raises consent issues, consider reactions people had to using a voice-response intelligent telephone counseling system for diet and exercise behavior. Some described the voice they heard on the phone as "the doctor," "a friend," "a mentor," or someone who really cared about them as a member of their family would. Some even looked forward to "his" saying "good morning" to them and to meeting "him," or missed "him" enough to keep calling after the end of the study. On the other hand, others told interviewers that the "disembodied voice from on high" made them feel guilty and talked down to them as their mothers did when they were children.[34]

When one of us reported this study, she indicated that both sets of reactions involved participants' forming personal relationships with the telephone system and projecting personalities onto it. No one had anticipated that people would form personal relationships with the voice they heard for about five minutes per week, that people would speak of "him" in ways the researcher interpreted as their falling in love with "him," or, alternatively, would feel guilty during the study. Should people be advised that they may have unanticipated, and perhaps troubling, emotional or psychological responses to new technologies they are being asked to use? Just what is needed to ensure that informed consent is informed? Another ethical concern from this study is whether it is right to induce guilt in order to achieve improved health. This concern leads us to consider empowerment and autonomy, both related to questions of what constitutes being informed.

Empowerment and Autonomy

Empowerment or Manipulation?

Automated diet and exercise counseling raises considerations over what has been called "persuasive technology"—using technologies to invoke changes in behavior, not well addressed by ethical principles already proposed.[35] Individuals knew that the automated counseling system was intended to help them improve their diet and exercise behavior and consented to that. Even so, feeling demeaned was not an intended part of the counseling, nor were people informed that this might happen. Even if individuals had hoped to change their behaviors in just the ways intended, is it right to use emotional reactions deliberately in order to push them into changing? How manipulative is this, with or without consent, and, if manipulative, is it unethical?

Are such uses of new technologies part of the on-going shift from paternalism to shared decisionmaking that has occurred over recent decades in light of pressures toward self-determination, autonomy, and patients' rights,[36] or the old paternalism in a new guise? Are individuals using this technology being empowered to make wiser decisions or being manipulated into behaviors considered better for them by others? The issues may be compounded when economic interests of providers and institutions mix with healthcare information on web sites discussing (or is it promoting?) services or treatments.

Autonomy, Independence, and Social Interaction

Social support, friendships, and other human relationships contribute to health and well-being. Interdependency among individuals is nurtured by reciprocal relationships throughout their lives. Reaching old age may be possible because of social networks, yet social and support networks tend to decrease as individuals age, with negative health consequences.[37] Therefore, growing older implies the reconstruction of interdependency because of restrictions in mobility, lack of family ties, and financial constraints. People necessarily are forced to find creative ways to live independently while maintaining some sort of interdependency with society. Although they prefer support from family, friends, and community, they turn, when necessary, to alternatives provided through using

healthcare or other services that replace informal support with support in formal settings.[38] There is a trade-off between independence and social support.

One argument commonly made in favor of home care technologies and monitoring devices is that they enable more freedom and comfort. The frail or elderly can continue living in their homes, and people with chronic illnesses can travel. An individual's condition can be monitored remotely so that help may be provided when and where needed. This may promote not only peace of mind for the person and family involved, but also obviate the need for the added attention previously available only at a healthcare facility. Nevertheless, such technologies also may have just the opposite effects.[39] They might increase isolation. Perhaps children who used to visit elderly or ill parents may feel reassured enough not to stop by or telephone as frequently. Caregivers no longer need to be in direct contact with their charges, reducing those people's opportunities for the social interaction and physical contact that is part of a caregiver visit. A person remaining at home may be deprived of the ready-made community and accessible activities and services provided by such places as assisted living facilities.

On the other hand, e-communications could provide ways for people to maintain their independence while also interacting with healthcare providers and rebuilding or preserving social networks. Someone socially isolated can better communicate with remote people more easily with the help of video hook-ups and web services and perhaps even meet new people or gain valuable information and social support through Internet support groups. Providing means for people to create and control ways in which they connect may then enhance independence. Will telehealth or telemedicine contribute to social cohesion or to isolation and exclusion?[40] And perhaps it may do either differentially, as women are more likely than men to seek and provide communication and support online, and the better educated and more well-off are more likely than others to use such services.[41]

Perhaps even newer technologies will occasion new and different ways to develop social and emotional attachment. Research shows that people unavoidably treat computers as social beings.[42] Weizenbaum famously decried the way in which people shared emotional and psychological confidences with his ELIZA program, which simulated the kind of dialog one might have with a Rogerian therapist.[43] Visiting nurses report that when they enable a home monitoring device's "talk" feature, patients say they become accustomed to the voice as though there is another person in the household. If people formed personal relationships with the telephone counseling system mentioned above and thought "he" cared about them, robots and other computer-based technologies deliberately designed to be sociable will do this all the more. Already there is an extensive literature on how to increase people's trust in web sites,[44] and research is underway to make computer applications and robots exhibit human-like emotional and social responses.[45] Machines designed to engage in sociable behaviors give people the feeling that they are dealing with sentient beings who care about them. Turkle argues that with philosophical assumptions concerning meanings of emotions, aliveness, and what makes a person a person embedded in these technologies, radically different views about authenticity are at stake.[46] This seems to us to necessitate far more thoughtfulness about how telehealth, telemedicine, and home healthcare technologies are used and encouraged, and

whether whomever gives consent for their use understands these consequences as well.

We fully support an individual's desire to remain at home and be cared for there or to prefer the company of robots to alternatives, but we recognize that new technologies may not clearly be autonomy enhancing. How autonomous or empowering is a choice when one is so lonely as to prefer robotic company to no company or is pressured by one's children or healthcare providers into accepting either home care technologies or being forced to live in a nursing home, for example? (We understand that similar issues may arise in the absence of technology, with the "choice" between accepting a home health aide or nurse as one alternative and a nursing home as the other.) Whether or not bonding with sociable technologies is inevitable, would it be wiser to find human ways to remedy or prevent the kind of loneliness and helplessness many ill, frail, incapacitated, homebound, or elderly people experience? On the other hand, technologies that enable people to connect and link to each other without considerations of location or personal status may well offer welcome social opportunities and interpersonal connections not available any other way.

These issues may be exacerbated by other ethical concerns connected with placing such technologies in the home or using them in healthcare facilities. Smart environments such as the MavHome, the Gator Tech Smart House, the iDorm, the Georgia Tech Award Home, the Adaptive Home, the Home Depot Smart Home, and PathFinder projects all acquire information about a place and its residents with the goal of improving quality of life in that environment.[47] Intel's Proactive Health Research, for example, is using ubiquitous computing for proactive systems that anticipate needs and foster independence of people in their homes and daily activities.[48] Projects such as this, in the words of MIT's AgeLab web page, are based on the assumption that "[q]uality living is independent living."[49] (Some, perhaps, as indicated above, might consider living interdependently with others as quality living.) Such technologies track and monitor our activities, routines, whereabouts, and even our social interactions and our diets by placing sensors both in homes and outdoors as well as monitoring various shopping and purchase preferences and physiological and health measures. They transmit reminders to the residents and information to their children, caregivers, healthcare practitioners, researchers, and perhaps (unknown) others. Privacy of all kinds (e.g., physical, informational) clearly is compromised, and what had been private space and private behavior now is becoming public. This change in boundaries between public and private spheres is well recognized, as is the concomitant medicalization of the home environment and social phenomena.[50] Some laud these privacy changes as new opportunities for more openness.[51] Others question assumptions of improved quality of life, empowerment, and autonomy. Especially in a time of increased surveillance for law enforcement and counterterrorism, we, too, think deeper understanding is needed of how such technologies may be used and what changes may occur.

Changing Relationships

Commentators point to ways using new technologies affects relationships between patients and healthcare providers or caregivers. Tele-applications may change the balance between provider and patient by moving us toward "educated consent" or

"informed autonomy," in which patients' access to information and social support aids them in making healthcare decisions in line with their values and their therapeutic goals.[52] The use of these applications also may facilitate by-passing the patients' family doctor, as clinical and fiduciary relationships develop between patient and telecenter personnel, or by patients and those close to them becoming more involved in their healthcare decisions based on encouragement and information provided through online support groups.[53]

In addition, information technologies often are promoted as freeing providers to provide better and more personalized care,[54] yet others raise the question of whether telemedicine or telehealth technologies depersonalize both provider and patient. Either may become alienated if care and service become more decontextualized and less personalized.[54a] As has happened in different settings, new technologies and technological savvy are replacing expertise based on personal interactions, subtle cues, and deep intuitive knowledge gained through long experience.[55] Introducing new technologies may affect how providers, caregivers, and patients view vulnerability and frailness. Their use can change the empathic or emotional connection between the different individuals involved, even through so seemingly insignificant a change as when clinicians pause during patient encounters to use computer technology.[56] With care provided remotely, human touch and other forms of nonverbal communication are lacking, and that, too, may affect the way in which both clinical understanding and personal relationships develop, or do not.[57] Clinicians may miss important visual cues; they may be reluctant to rely on intermediaries rather than seeing for themselves; they may miss offering comfort by touching the person they are treating.[58] When multidimensional cues are lost as telecommunications technologies replace face-to-face encounters, clinicians and patients interact in different ways.[59] Replacing real patients by virtual ones creates representations potentially divorced from the actual people involved.[60] Already, physicians viewing patient images may consider the image more real than the actual patient.[61] Living, breathing patients as sources of information could be replaced by subsets of data in data warehouses and clinical data repositories.[62]

Prudence is needed in the use of telehealth. However, those determining selection criteria for remote management—be they governmental policy bodies, insurance companies, venture capitalists, healthcare organizations, patient advocates, or any other interest—may have different criteria for "prudence" than others do, ranging from empowering patients, caregivers, and clinicians or even provider organizations to instead, entailing means of control, standardization, and cost-cutting.[63]

Similar considerations also lead to concerns over just who will be affected by these technologies and whether others should be giving consent in addition to the patient. Family and living arrangements change when a person becomes ill, and previously personal concerns become subject to expert intervention and the commodification of expertise to handle situations that people used to handle on their own.[64] More thought should be given to how to take into account family members', close friends', and caregivers' interests, lifestyle, financial status, emotional and psychological well-being, and ability to provide or make decisions concerning caregiving. This should be done with sensitivity to the possibility that patient needs lose their centrality, which, in turn, would further change relationships among patients, providers, and caregivers.[65]

Societal Issues

Though it is difficult to totally divorce individual and societal issues, we now move from ethical issues primarily on an individual level to more clearly societal, structural, and policy issues and dilemmas. One such dilemma is balancing concern for privacy and security of data against the desirability of linking disparate sources of information about an individual that could be helpful for personal, actuarial, epidemiological, and biosurveillance purposes.

Another dilemma concerns equity in access to both health information and healthcare services. This may involve whether technological "solutions" for the poor or those who live in remote areas substitute for more personalized care through direct human contact or whether, instead, new technological developments will benefit only those able to afford them. In the United States, gender and education, as well as income, affect Internet use (though all these variables may not hold true for other information sources such as doctors or newspapers[66]) resulting not only in a digital divide but also what has come to be called the "information gap." These divides and gaps can occur between socioeconomic and ethnic groups in the same country and also among nations. Therefore, attention needs to be given not only to suitable ways of providing access but also to how various health information is produced, developed, and disseminated.[67] Decisions concerning net neutrality and other network infrastructure issues, placement of community communication centers, and just who is involved in all these decisions and on what grounds the decisions are made likely will affect both the digital divide and e-health developments. Institutional and governmental policy decisions about access and equity, then, involve whether it is best to expend scarce resources on technological developments or other ways of improving health and healthcare in the most humanitarian ways. Is the commitment to networked, global thinking among the wisest uses of resources to improve worldwide health? Will social stratification and marginalization be exacerbated or abated as telehealth and telemedicine services are used more widely?[68]

Another set of concerns centers on structural changes in healthcare delivery, institutional and professional roles, and relationships, employment, and job satisfaction.[69] Status differences between centralized specialist services and local physicians may be reinforced. As their role changes, physicians may be delighted by more informed and questioning patients[70] or by being able to hand off difficult cases to remote specialists, or they may be uneasy about losing control over decisionmaking and medical activities that are both legally and morally their responsibility.[71] Changes in relationships, status, control, legal responsibility, and "geography" of healthcare, then, have unexplored implications both for quality of care and for social policy.[72]

E-health can involve other new ways of working. Salary and reward structures may be affected, as those with long experience caring for the ill may see themselves being replaced by the higher-salaried technologically adept or by lower-salaried less skilled workers backed up by "intelligent" machines and telecommunications. Often these concerns are couched in terms of deskilling of healthcare professionals, mirroring the earlier debate over deskilling due to automation in other areas. We suspect that, just as resulted then, the outcomes will be a complex mix of deskilling in some areas and reskilling and improving

status in others, depending on how the technology is used and the environment into which it is introduced.[73] Although family doctors may be less involved in patient management, others are becoming more skilled. The few studies done in this area indicate that telehealth and telemedicine services involve delegating clinical tasks to nonmedical personnel. This "upskilling" requires tele-practitioners to perform more complex tasks requiring clinical knowledge. It also motivates them to develop new work practices in order to maintain usual status and role differences between healthcare providers and align the new division of labor with legal and organizational constraints. Despite this additional work and knowledge, these changes generally are recognized neither professionally, legally, nor economically.[74]

A further related concern not often discussed is effects on patient employment and satisfaction and possibly even life-styles. With increased home monitoring, for example, will it be easier to detect malingering or, perhaps, will a flood of information and ready availability of home testing induce hypochondria or even illness or, on the contrary, provide reassurance to the worried? With the promotion of disease management and increased gathering of personal health data by employers and insurers, how will patients' jobs and ability to obtain insurance be affected? If it becomes easier to detect when patients do not follow medical advice, such as by not taking medications or keeping dietary restrictions, will it also become easier to deny services (as can happen in the controversial West Virginia Medicaid reforms) or employment or to assess differential health insurance costs (as may happen to smokers) to those whose health behaviors are suspect in any regard or to intervene in ways patients may find intrusive?[75] This goes beyond issues of personal autonomy into broader policy issues.

Conclusions

We have detailed a number of ethical, social, and policy issues we think need more attention in light of new technological developments and how they are being used for telemedicine, telehealth, and home care. We, unfortunately, are in good company in the group Goodman faults for posing a series of questions without answering them.[76]

First, our primary goal is to broaden the discussion so that the great potentials of the new technologies will be realized as humanely and beneficially as possible. We would like to see discussion of ethical issues expanded beyond the frequently considered constellation of privacy, security, confidentiality, liability, and so forth. We have mentioned a variety of other concerns and raised questions requiring empirical study to answer, but these are only some of the many potential issues that need attention. We sincerely hope that others will join us in attempting to develop thoughtful analyses to address the concerns and resolve the dilemmas and keep vigilant for additional considerations.

Cross-cutting the specific concerns we raise are several broad themes. As we have suggested, there also deep philosophical issues and consequences for how what we consider appropriate is related to what we mean by "human" and "humane" and how the meanings of these concepts themselves are shifting. Second, we need to take into account that there may be different consequences in different situations, even when involving the same technology. The various contingencies need to be identified and factored into the discussion. They also

need empirical study on which to base ethical analysis. Lastly, in addition to thoughtfulness in deploying new technologies, we join in the calls for care in avoiding exaggerating either potential benefits or pitfalls when promoting technologies. The future will show whether e-health meets the high hopes reflected in the sometimes utopian rhetoric and mindset of its promoters or at least contributes to better alternatives for more people.

Consequently, we, too, advocate evaluation that helps identify multifaceted and complex influences surrounding introducing new technologies. Among the numerous reasons for evaluation is our conviction that new technologies have the potential for tremendous benefit. We think people need to understand the various considerations so that they can make more informed decisions and make wiser choices about how to use new technologies. Evaluation can help illuminate important ethical, social, and policy issues for deeper consideration. Evaluation, therefore, needs to include not only technological and economic assessments, but also long-term effects on personal well-being, structure of healthcare provision, professional roles, substitution of care—in short, ethical and social aspects of the new technologies.[77] Consequently, we need to refine evaluation approaches to take account of both new technologies and changes in healthcare delivery and to add to the evaluation research repertoire methods for studying computer-mediated communication and healthcare at a distance.[78]

We conclude by suggesting that our considerations do not apply only to those who are disabled, frail, or otherwise receiving or providing care. As some of our examples indicate, healthy individuals also may use home care, telehealth, or telemedicine technologies. While ethical concerns are starker when someone is ill or otherwise vulnerable, when discussing patients, we also mean our discussion to apply to the hale and hearty.

Further, we do not mean our remarks to apply solely to new telehealth, telemedicine, and home care technologies. They apply to other uses of technology as well. Technology, we think, should complement clinical and care decisions based on values fundamental to the practice of healthcare, values like compassion, care, humaneness, and the connection of all people, and not be pursued as an end in itself. We hope to stimulate more education, discussion, and ethical analysis centering, not only on tele-technologies, but on other uses of information and computer technologies that can surely help improve healthcare, health, and general well-being.

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