section one

Introduction and overview to pervasive healthcare

chapter one

Overview of healthcare, disease, and disability

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1.1 Introduction

This chapter summarizes the impact of current trends in disease and disability on the delivery of healthcare using pervasive technology. We review the remarkable demographic shifts of the past century that have been driven by increases in life expectancy as a result of advances in public health as well as in medical technology. The impact of these trends is further discussed with regard to the need to focus healthcare not only on its traditional core (providing point of care diagnosis and acute intervention) but also increasingly on managing growing numbers of people aging with chronic disease outside of traditional hospital or clinic settings. In this context we review how a broad range of technologies using pervasive computing may provide important new approaches to improve the provision of healthcare. How these technologies may affect diagnosis and treatment in specific settings such as the home or doctor's office or as a hospitalized patient or resident of a continuing care facility are considered in turn with special emphasis given in conclusion to the power of pervasive computing to effectively integrate and blur the boundaries of these conventionally isolated healthcare settings. Finally, we conclude with a consideration of what these new technologies will require to become widely adopted such as standardization and adequately powered clinical trials demonstrating efficacy and safety.

1.2 Demographics, disease, and disability

Healthcare is an endeavor that constantly looks forward while forever being judged by what has just passed. In part, this is the result of the perception that medicine and health sciences are driven by rationally designed breakthroughs rather than by changes in small increments, which are often the result of discovery in unsuspected corners. Although conceptually tied to cures and revolutions in care, the concept of "improvement" in health nevertheless operates on a playing field where improvement is measured not by an absolute sea of change, but in small waves of change relative to recent standards of care. With time, the weight of evidence, balanced by cost and social norms, leads to the new standard of the day. This transition has been most evident when one observes the unprecedented growth in health and well-being marked by the striking gain in life expectancy of almost forty years during the twentieth century.[1] This remarkable increase (in developed countries, at least) is often attributed to advances in medicine and healthcare technology, when in fact the major advances are likely to be more closely linked to advances in fields not typically considered "medical." Advances in areas such as sanitation, food sources, and workplace safety have probably played a much greater role in this growth in life expectancy than inventions of medical devices or pharmaceuticals, save for vaccines.

Such advances have led to a dramatic demographic shift of increased survival to increasingly advanced ages. The young are and remain healthier, resulting in more elderly in successive generations. Also, as populations have aged in most developed countries, birth rates have declined, leading to a decline in the relative number of young while the older group continues to grow (see Figure 1.1). Baby boomers are now transitioning from a middle-aged to an older-aged cohort. As the baby boomers represent large percentages of the U.S. and Canadian populations, the focus of healthcare

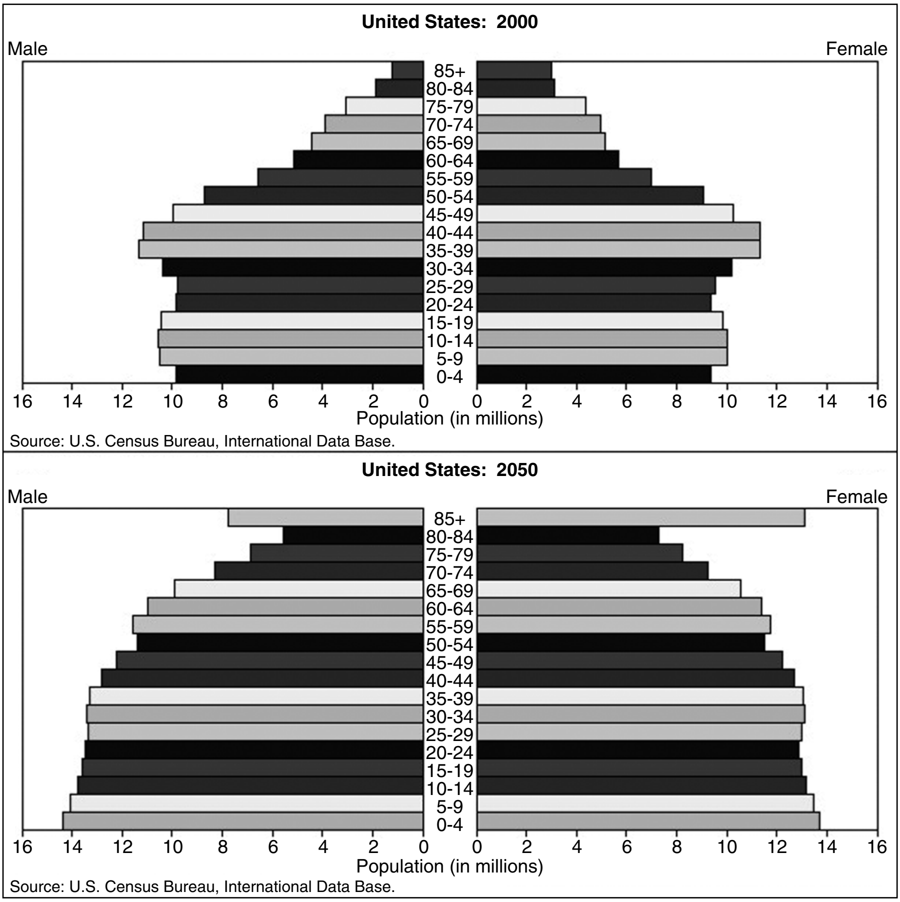

Figure 1.1 Distribution of U.S. population by age and gender: 2000 and 2050. Source: U.S. Census Bureau, Population Division, International Programs Center. International Data Base Population Pyramids at http://www.census.gov/ipc/www/idbpyr.html.

in North America is perceptibly shifting to accommodate this aging cohort's needs. Additionally, those in the "sandwich generation" are balancing the demands of caring for elderly parents at the same time as they are raising young children.

1.2.1 Consequences of the demographic shift

Along with this increasingly aged population, the profile of those at risk for disease and disability has accordingly shifted. The fastest-growing threats to public health are currently age related. People now survive the once-fatal illnesses and diseases of youth and live on to experience chronic and debilitating conditions of advanced age. In 1900, the leading causes of death in the United States were pneumonia, tuberculosis, and gastrointestinal diseases. Now, people succumb most often to heart disease, cancer, and cerebrovascular disease.[2] Accordingly, populations experiencing these demographic changes now face causes of mortality and morbidity that are strongly age associated. Age, rather than infectious agents, is the greatest risk factor for the current top causes of mortality.

1.2.2 Burden of disability and care needs

The impact of the demographic shift is apparent in causes of morbidity as well as mortality. Americans over sixty-five are more likely to incur medical expenses than younger Americans and their average cost per expense is higher: $6,140 as compared with $2,127 for those under sixty-five.[3] Chronic conditions, especially loss of mobility and cognitive function, not only fuel healthcare costs but also prevent the elderly from living independently in their homes. Changes leading to the loss of independence may be subtle and slow to develop, such as loss of mobility due to arthritis, a visual impairment, or a cognitive decline. According to Centers for Disease Control and Prevention statistics, 80 percent of adults over sixty-five report having at least one chronic illness, while 50 percent have at least two.[2] Predominant causes of disability and impairment in adults over sixty-five include arthritis, heart disease, diabetes, vision loss, and hearing loss. The prevalence of these conditions is presented by age group in Figure 1.2.[2] On the other hand, loss of independence may be precipitated by more acute events, such as strokes, accidental injuries like falls, medication errors, or acute systemic illness. These events frequently result in the need for alternate care situations, such as relocation to a nursing home or a rehabilitation facility.

Together, these acute and chronic conditions form a major target for the technological interventions and remediations that are discussed in detail in

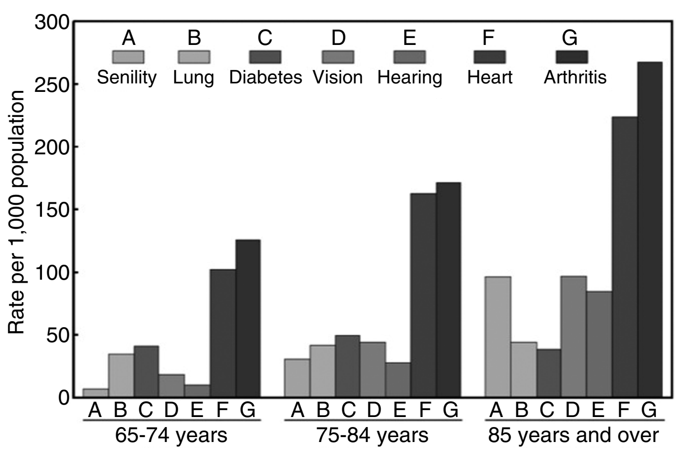

Figure 1.2 Chronic conditions causing limitation of activity, 2002–2003. Source: National Center for Health Statistics, United States, 2005.[2] Figure 20. Accessed via http://www.cdc.gov/nchs/hus.htm.

the following chapters. Technological advances in healthcare may yield a considerable return on investment, not just in terms of saving healthcare dollars, but more importantly and perhaps more certainly in longer independent living and improved quality of life. A recent economic report from the New Millennium Research Council provides just one impressive example from the communication technology field. It estimates that current use of broadband technology will yield up to $927 billion in savings and benefits for Americans over sixty-five or for those living with a disability, with an additional $532 billion to $847 billion saved with targeted dissemination of these services.[4]

All of these trends create unique needs and challenges for care that are specific to the age group affected. In general, the penetration of technology into the lives of the current elderly is quantitatively and qualitatively different from that of their children (the "boomers") as well as their grandchildren, who may be more familiar and comfortable with using such technology. These differences have practical implications. Emphasis in healthcare systems is appropriately placed on the elderly as the consumers with the greatest needs for healthcare. Technology designed for elders may need to be fundamentally altered to adjust to their needs. The concept of universal technical solutions should be inclusive in trying to accommodate seniors who may not use a cell phone or computer as well as teenagers who habitually use instant messaging and video games. Ironically, the technology culture of the younger generation may contribute in part to poorer health as they age. The current intense media culture that is highly embedded with messages designed to promote fast food and a sedentary lifestyle is largely responsible for the epidemic of obesity in the United States.[5]

1.2.3 Disparately burdened groups: Socioeconomic status and gender

Other challenges extend beyond the age-based continuum outlined above. Aside from age, the different strata of society and cultural backgrounds from which people originate or reside play an important role in the impact of technology on health. Those coming from lower socioeconomic groups are likely to have less technology experience or access while simultaneously having above average needs for healthcare. Among those over sixty-five, women and poorer Americans on average experience a heavier burden of chronic conditions. Research with health-related quality-of-life data from the Centers for Disease Control and Prevention found that the number of unhealthy days per month reported by adults over age sixty-five varied significantly with socioeconomic status and gender. Women consistently reported more unhealthy days per month than men of the same age, regardless of socioeconomic status. Similarly, those with lower socioeconomic status also reported more unhealthy days than those with higher status.[6]

Although this chapter refers primarily to U.S. and comparable populations, the goals and principles of pervasive computing technologies applied to healthcare are highly relevant throughout the world. Aging of populations, accidental injuries, war and violence, automobile crashes, chronic diseases, and many factors contribute to the rise in disabilities worldwide. There are approximately six hundred million people worldwide living with disabilities. Of those six hundred million, 80 percent live in poor countries where access to basic and rehabilitation services are limited or unavailable.[7] The World Health Organization Assembly has established a resolution to assist member states in developing policies on disability and rehabilitation, especially for those who are poor.[8] It has become a global priority to develop technologies for early disease detection, improved treatment, and high-quality assistive living.

While a limited standard of living in developing countries is a huge barrier to technological investment and development, making a wireless leap is easier in some ways. For example, most developing countries have few or no hard-wired telephone systems. Rather than investing in a network of landlines, these countries have gone straight to using mobile technology. As such, mobile service in some developing countries may actually be more available and reliable than in some developed countries. The challenge of making phones widely available to the general public should improve with time as the cost of this technology continues to decrease. The actual cost of the phone itself is small relative to building and maintaining communication networks. Nevertheless, it is likely that mobile, wireless phones, rather than personal computers, hold the promise of boosting entrepreneurship and economic development in poor countries.[9] Where economic development is increased, better public health will follow.

1.3 The healthcare model: Transforming with technology

There are many ways to review and discuss the interaction of technology with healthcare: by persons involved (patients, caregivers, clinicians), by the technologies and methods employed, by time of use (acute versus chronic care), and by locus of care. We have chosen to organize this review by locus of care for two reasons. First, presenting technologies by locus of care cuts across most domains, such as disease or condition requiring care or category of technology that might be used by a patient or clinician. Second, it allows us to describe major challenges and opportunities in a manner that reflects the sequence and location of care that an individual might experience when challenged with a health problem over time. Although our organizing principle here is locus of care, the reader should keep in mind that the ultimate goal of the ideal healthcare system is to ensure optimal functioning and quality of life of patients. Implicit in this assumption is that most individuals would choose to maintain their health in their own residences; if they require care outside of the home, most individuals would also choose to minimize their time in institutional facilities. Thus, the ultimate health system is "homeless" and able to provide care and ensure health regardless of location. This is the promise of pervasive healthcare.

1.3.1 Home- and community-based health

The vast majority (84 percent) of Americans over sixty-five live independently in single-family homes or apartments.[10] They arguably spend most of their time in the home, including approximately 364 minutes (just over six hours) spent sleeping or at least in bed at night.[11] The home environment is usually where the realization that someone is sick first occurs, as well as where most acute and chronic illnesses are managed. This means that among the most important classes of technology that may be brought to bear in this setting is in the realm of monitoring. Many homes may have a few simple health monitoring technologies such as thermometers, scales, or blood pressure machines. Some health conditions or concerns lead to specialized home devices or kits, such as home blood glucose monitors for diabetes, CPAP machines for obstructive sleep apnea, and nebulizers for asthma treatment. By and large the general penetration of technology into the home setting for healthcare so far has been rather rudimentary, reactive, and underdeveloped, particularly for devices aimed at self-diagnosis or decision making (as to whether more specialized help is needed).

The initial point of care at home is most likely the telephone, as the conduit for determining the need to leave the home for testing, consultation, and treatment. It is suspected, although not proven, that most initial outside medical advice received in the home is provided by informal contact with relatives and friends through phone calls. Growth of the Internet and home computer use has resulted in a greater opportunity for individuals to access multiple sources of healthcare advice. As of September 2005, 30 percent of adults over sixty-five reported having Internet access,[12] up from 15 percent in 2000.[13] In recent surveys of Internet users, 80 percent state they have used the Internet to obtain health or medical information, while 6 percent state that they had done so "yesterday."[14] However, Internet access is less accessible for those with lower incomes. Only 54 percent of households with annual incomes below $30,000 have access to the Internet, compared to 78 percent of those with annual incomes of $30,000–$49,999, and at least 87 percent of those with $50,000 or greater report being online.[12]

There is a huge variety of health-related sites available through Internet or Web portals ranging from those that are disease specific to more general or comprehensive medical sites. A major challenge for the consumer is to determine the validity of the information provided. It has been pointed out that the consumer's risk of accessing an inadequate site is a function of both the amount of inadequate information on the Web and the ability of the individual to determine the quality of the information. This has made it difficult to objectively determine the impact of the over six thousand (and growing) health-related Web sites or Web pages available.[15]

Many nonprofit disease-oriented lay organizations (e.g., National Cancer Society, American Heart Association, the Alzheimer's Association, etc.), as well as governmental agencies (e.g., NIH, FDA, VA) occupy this Web space, and their Web sites are generally considered more reliable and less biased. Yet the fact that these Web sites are nonprofit or governmentally sponsored does not guarantee that the information is unbiased or useful or that the user will interpret the data appropriately.

A growing number of informational sites are offered through the healthcare system that an individual belongs to and a few even offer the opportunity to e-mail a clinician with a question, such as the Kaiser health plans or the Department of Veterans Affairs (My Health eVet). This type of interactive capability appears, at least on the surface, to offer an efficient procedure with no "phone tag" and allows for fully documented and enhanced communication among stakeholders (as others involved in the individual's care could be automatically notified). How this online interactive capability will develop is uncertain. Major forces that will impede or enhance the development of these Internet systems include policy development regarding reimbursement for providing these services[16] as well as liability concerns around providing care advice without a direct examination. More discussion of disease management through electronic media is discussed in Section 1.3.3 on hospital-based care.

Determining patient needs in the face of symptoms is a reactive approach to healthcare that is embedded in current U.S. care models. In these models, reimbursements are highest for acute care medicine. Aside from the sometimes convoluted economics that drive our care models, to some degree the institutional or clinic-based care model also is a product of the need to bring the person to a place where the tools and technologies for diagnosis and treatment reside rather than to provide these capacities at home. This is a tremendous opportunity for technology innovation and creativity, both from the standpoint of bringing these tools to bear in the home, and perhaps more important, for providing systems of care that are proactive in detecting a problem before it leads to major disability.

Proactive healthcare through home monitoring is not new. Pervasive or minimally obtrusive systems for home monitoring have been described for over a decade[17] and are further discussed in Chapter 5. In the home healthcare arena there has been a natural convergence of technologies and systems for monitoring and assisting people with special needs (e.g., low vision, hearing loss, limited mobility). In general, these systems consist of a few common elements, such as control devices for the automated modulation of the environment, health monitoring devices for disease management, and motion sensors for assessing general activity. Unfortunately, these integrated systems have yet to "catch on" for a number of reasons including cost and lack of reimbursement, complexity, and scalability. Most important, the vast majority of these systems have not been tested in rigorous clinical trials, therefore there is a lack of evidence that they are effective (and will not cause harm) in a generalized setting.

As the clinical efficacy of home-based monitoring and intervention systems is tested and refined, there will be certain areas that may especially benefit from these technologies. One such area is medication taking. Medication errors in the home usually occur when patients take the wrong drug, take the incorrect dose, misunderstand instructions, or are not made aware of potential drug interactions.[18] Medication errors are a particular threat to safety to all but are a special challenge for older patients, as they take more medications and are at greater risk for memory problems that may lead to adherence problems.[19] Pervasive technologies can provide checks for correct drug administration or reminders to take medications. For example, smart medicine cabinets equipped with radio frequency identification (RFID) capabilities can help ensure the correct medication is chosen from the shelf, personal digital assistants can provide timely reminders when medications are due, and pill boxes that record dose administrations can provide a record of medication compliance.[20,21]

Despite the current challenges of proactive home monitoring, the principle has strong face validity that is grounded in the power of preventive medicine and early detection. There are obvious advantages to detecting illness at an early stage or identifying patients at risk rather than managing advanced illnesses or patients in crisis. Home-based systems are growing in use and offer promising potential for facilitating wide-scale proactive monitoring of diagnosed diseases. The use of various technologies for disease management with an identified medical problem is generally called telemedicine. Although the practice of telemedicine focuses on the home, it depends on an outside clinical monitoring support system. Because telemedicine applications depend on having received a diagnosis or recognized treatable medical condition, outpatients are prime candidates for telemedicine systems, as we discuss in the Section 1.3.2 on outpatient care.

The integration of these formal telemedicine systems with more individually driven, clinician-independent home health monitoring programs is an important area for future development. Such integration may more effectively address the knowledge gap between professionally driven programs and well meaning but could potentially be harmful with unsupervised, informal home care. The blurring of professional with personalized lines of healthcare may require a new social contract with regard to responsibility for health outcomes. This inevitably will be followed by new regulations to apportion diagnostic and treatment responsibilities. Chapter 9 looks at some ways to assess and regulate pervasive healthcare, such as telemedicine.

1.3.2 Outpatient care

With the maturing of home-based systems, as well as evidence that diagnosis and treatment can be safely and efficiently augmented or provided through home-based care, one can envision that traditional clinic- or office-based care will evolve accordingly. This will be true for both primary care as well as specialty care.

Once the decision is made that a person needs medical attention beyond self-care, the current model is to seek an appointment with a clinician for an assessment. The location of this assessment is by and large an office or a clinic; therefore these constitute the center of outpatient diagnosis and treatment initiation. One of the first major challenges for outpatient care is the transfer of the information needed to conduct the medical interview and provide appropriate treatments. As medical history is the keystone to a diagnosis, the front end of each outpatient clinical encounter is in essence a data-gathering operation. Unfortunately, in current office practice much of this information gathering is time-inefficient, with most of the time taken up by reviewing with the patient what they can best recall of their symptoms, medical history, and relevant medications. Because patients may not seek care except when they feel unwell, they are often not at their best in terms of being prepared for the visit or remembering important information. Efficiently obtaining accurate information about a sick patient at the point of care is at a minimum a potent time saver. It also has important implications for quickly reaching the correct diagnosis and initiating proper treatments, ranging from ensuring that a logical sequence of diagnostic tests is pursued to prescribing treatments that are the most successful and safe. The latter issue of safety is not only a matter of advising an appropriate treatment, but also about avoiding lost time from ineffective treatments and preventing frank medical errors.

These challenges should diminish as electronic health records (EHRs) and information transfer systems mature. However, unless they are part of an integrated health system (such as those used within the Veterans Administration or Kaiser health systems), EHR systems are still rather scattered and not able to seamlessly transfer information. Outside of an integrated health system, EHRs rarely extend beyond the confines of the medical office to include accurate pharmacy or laboratory data. Nevertheless, even fully integrated EHR systems will only improve the information flow between the traditional office or laboratory settings. A truly integrated and pervasive health information system would expand a patient's health records to include information acquired daily at home when the patient feels healthy and is going about his or her daily routines. One can clearly see the advantage of marrying the home-based monitoring information noted above with the office visit. A clinician would have a better idea of a patient's overall health by including information obtained from the patient when in their typical environment and could also more accurately monitor the progress of any therapy instituted after the clinical visit.

Remote care capabilities are continually increasing as new technologies and systems are implemented. The remote monitoring and management of health is currently accomplished through a number of channels (e.g., phone, Internet, interactive video). This form of health delivery, now usually subsumed under the category of telemedicine, has received much attention during the last decade. Unfortunately, despite many applications being proposed and reported on, there is currently little systematic evidence for the efficacy of these programs.[22,23] Among home-based applications, the most highly studied area has been monitoring of blood sugar in patients with diabetes mellitus. Other applications have been pursued for a number of chronic disease management areas ranging from blood pressure to mental health. By and large these studies have been too small and of limited duration and thus statistically underpowered to provide definitive conclusions as to how effective and generalizable they are compared to conventional procedures. Despite the lack of clinical trials for most of these applications, there are a growing number of companies that offer commercially available remote care products, complete with online monitoring of data of many types in the users' homes (e.g., weight, blood pressure, temperature, pulse and cardiac rhythm, oxygenation or pulse oximetry, blood glucose, lung capacity). Examples of products that are currently available include HomMed (Honeywell), ViTel Care, and MedStar (CybernetMedical). Key to such developments is not simply attempting to optimize remote data acquisition, but also supporting the effective integration of the data, the inference of the individual's health state, and the ability to differentiate between salient outcomes.

In addition to applying telemedicine to home health, there is also increasing use of telemedicine approaches in the interface between office- and hospital-based medical practice. In this arena, most studies have suggested the benefits of teleradiology or the transmission and interpretation of images. Other related areas have been applied to patient interviewing or examinations, such as teledermatology. Obviously, the prefix "tele" can and will be added to any specialty using this technology. Again, as with the home-based telemedicine applications, the efficacy of telemedicine methods for office- and hospital-based practices has yet to be proven. Compared to pure clinical efficacy, there is even less evidence that telemedicine is cost-effective.[24] In part, this lack of evidence is the result of too few systematic studies. However, this also raises the important need to establish common standards or benchmarks to measure efficacy and assess costs in this field.

1.3.3 Hospitals

Although many, if not most, illnesses can be managed at home or in the outpatient setting, there are clearly medical conditions that require more intensive care and treatment in a hospital. Generally, patients are either brought to an emergency or urgent care department for acute diagnosis and management or a nonurgent procedure is scheduled weeks or months in advance at the outpatient office. These latter procedures are not necessarily acutely time-sensitive but require the diagnostic and operating facilities and technology only afforded in the hospital or surgical care unit. Contemporary hospitals have an exceptional variety and density of technologies. These range from the information systems needed to operate the facility to the medical devices required to diagnose, monitor, and intervene in acute medical illnesses. It is notable that most of the technologies within this array of systems and devices are stand-alone and are not integrated with one another. In part, this is the result of the institutions themselves. Hospitals are built and continually renovated or expanded in a piece-meal fashion. Additionally, their organizational structure typically results in semiautonomous departments and services that are not coordinated in terms of long-range planning or purchasing.

On average, today's hospitals spend approximately 2.5 percent of their operating budgets on technology, while hospitals investing in more advanced clinical information systems spend 3 to 5 percent or more.[25] A comprehensive review of all the technologies in hospitals and related facilities is beyond the scope of this chapter, but selected examples of technologies and their functions are presented in Table 1.1. Within this wealth of technology, it is worth emphasizing the crucial and dramatic changes in the hospital setting resulting from the huge prevalence of information technology (IT).

IT pervades the entire health institutional ecosystem from the moment of entry (e.g., registration, health record creation, or update), to traditional testing (e.g., laboratory and diagnostic procedures), treatment (e.g., medical or surgical procedures), and discharge from the hospital. In the best of settings these activities are tightly integrated with work flow and allow clinicians to instantly tap into the chain of events to retrieve any information needed at the point of care. This information-rich chain creates the opportunity for expert or intelligent ("machine") agents to facilitate not only the process, but the actual care provided as well. This ranges from tasks such as the appropriate interpretation of diagnostic results to the proper institution of medications and therapies. However, this ideal has yet to be achieved, mostly because hospital systems tend to operate separately. One only needs to observe the work of a typical hospital-based nurse or attending physician for a few hours to conclude that the practice of medicine has absorbed pieces of technology, such as computerized order entry or reference to drugs on a PDA carried in a pocket, but rarely achieves the full power of information integration that more pervasive healthcare technologies could deliver.

Table 1.1 Examples of Technology Applications in the Institutional Healthcare Setting

Function	Examples
Core information technology services	Patient registration, accounting, facilities management
Clinician documentation	Electronic health record, computerized order entry, ASR transcription
Patient safety	Bar coding, "smart" beds, alarm and monitoring systems
Digital imaging and diagnostics	PACS (picture archiving and communication system), advanced imaging, personal medicine
Computer-aided medicine	Computer-aided diagnostics, computer-aided surgery, robotics
Health research	Evidence-based medicine, quality assurance, virtual or simulated surgery
Telemedicine	Remote monitoring, patient–health system networking, education

Improved healthcare through new technologies or better application of existing systems has been slow to develop. For example, the Institute of Medicine issued its landmark report, *To Err Is Human: Building a Safer Health System*, in 2000, yet it is sobering that since that time there has been disappointing progress in the area of patient safety.[26] For instance, medication errors can lead to adverse drug events, causing unnecessary hospital admissions and deaths. An estimated one out of 854 inpatient deaths can be attributed to medication errors.[27] While not all medication errors cause direct harm to patients, they cost healthcare consumers and provider systems millions every year. Standard healthcare delivery systems present many opportunities for errors to occur. The most common hospital-related medication errors are the prescriptions of an incorrect dose, prescriptions of a drug that will adversely interact with an existing prescription in the patient regimen, administrations of an incorrect dose, and administrations of an incorrect medication. EHR systems are capable of providing warning alerts that identify potential medication errors before they happen by requiring the verification of prescribed doses and calling attention to possible contraindications. Bar-coding strategies have been developed to ensure the correct medications are administered to the correct patients, where the bar code on hospital patients' admission wristbands must match the bar code on the prescription bottle.

The slow adoption of patient safety-related measures is certainly not to be blamed solely on technology. However, technologies have a great deal of unmet opportunities to improve healthcare in the hospital environment. Although computerized order entry systems may reduce errors, they nevertheless have not been proven to reduce preventable injuries.[28–30] This highlights the need to consider the application of technology interventions as any other treatment: unproven until rigorously tested and benchmarked by meaningful outcomes. Additionally, while the cost of implementing such systems may quickly be regained in prevented events and admissions, a lack of start-up resources can be a significant barrier.[31]

Despite these challenges, the healthcare delivery system recognizes the promise and power of more effective technology solutions such as wireless connectivity and intelligent agents. Through 2010, IT spending among U.S. healthcare providers is projected to experience a 7.4 percent five-year compound annual growth rate.[32] When applied to a critical issue like medication errors, effective pervasive computing technologies would be a tremendous force for data consolidation, clinician coordination, and error prevention, thus avoiding unnecessary morbidity, mortality, and healthcare costs. Current and future trends in pervasive technology within the hospital are presented in Chapter 3.

1.3.4 Assisted-care communities and institutions

Unless individuals return to their homes, patients leave the hospital or acute care venue to enter an alternate care setting. This transition to institutional care takes many forms, specific to each person's needs. In general, the choice of an alternative living situation is related to the level of assistance or dependent care needed. In the best of situations these transitions are temporary and after a period of rehabilitation, the person returns home. However, returning to prior levels of independent living may not always be possible. Thus an individual may come to reside permanently in assisted living, adult foster care, or a nursing home. According to the National Center for Health Statistics for 1999, 4.3 percent of adults over sixty-five live in nursing facilities, with such facilities operating at 87 percent capacity.[33] Increasingly, people approaching the certainties of disability with advancing age have chosen to live in continuing care retirement communities (CCRCs) that provide the full spectrum of care in an integrated living environment. The precise number of elders residing in CCRCs is not readily available, as residents living independently within the communities are reported as living in single-family homes.

From the perspective of pervasive healthcare technology, these living situations run the spectrum of applications and opportunities already outlined in Section 1.3.1 on home-based care and Section 1.3.3 on hospital care. CCRCs and assisted living facilities more closely mirror the needs of a person living freely in the community, while facilities with a greater emphasis on skilled nursing care or rehabilitation reflect the types of technology applied in the hospital setting. Because the focus of people in any of these residences is to optimize independence, this emphasis has appropriately transferred to a focus on the design and use of assistive technology. These assistive technologies range from mobility-assistive devices to speech synthesizers and automated cognitive remediation. Current and future trends in pervasive assistive technology are discussed in greater detail in Chapter 8.

As in both the home and hospital environments, there has yet to be a seamless integration of technology to its full potential in assisted living environments. This is likely to change as the care industry is increasingly implementing and relying on technological solutions for common care problems. For example, many nursing homes have commercially available ubiquitous alarm or warning systems to protect residents who are at risk of wandering and becoming lost. One notable assistive living residence, Oatfield Estates in Milwaukie, Oregon, has gone farther than most in integrating pervasive technology for monitoring and care of elderly residents. In this model, bed and chair sensors track residents' sleep habits, weight, and daily movement. RFID badges track patient location continuously, including night-time behavior. Residents who are prone to wandering are discouraged from leaving the grounds by a motion-activated in-ground sprinkler system, rather than by locks or alarms on entrance or exit doors. The system is used not only to assess the status of the resident, but also as a way to determine the effectiveness of the staff. Recently, a "family portal" was added to the system to enable family members to log on to a secure Web site and check on the status of their loved one.

1.4 Conclusions

This overview of healthcare, disease, and disability has outlined several dominant themes relevant to pervasive computing in healthcare. In the coming years, the burden of disease in developed as well as developing countries will be driven by the demographics of an aging population. There will be a continuous shift toward chronic conditions and age-related illness as the dominant forces driving both care needs and financial obligations. Although older populations may dominate healthcare from a population perspective, obviously there will continue to be younger individuals in need of care as well. Many of the technical principles developed for the application of care to seniors will be applicable to children as well.

Small, nonrandomized studies of isolated devices or methods of care using technology have been conducted. These suggest that the power of technology and pervasive computing to assist in facilitating diagnosis and treatment while easing the burden of care appears to be real, but in many areas has yet to be proven. In part, this is the result of the strong need for adequately powered, replicated clinical efficacy and outcomes studies. One barrier to conducting these needed research studies is cost. Large-scale studies of cutting-edge technologies being used in typical clinical settings come with large price tags. However, the issue is not simply cost. There is not yet a research infrastructure designed to carry out these kinds of ecologically valid clinical studies. As a result of issues such as these, current research does not usually progress past small feasibility studies, where a few subjects are observed for a brief period of time. Larger, more in-depth studies with multiple subjects in realistic settings must be conducted with new technologies to ensure that the technologies are reliable, safe, and useful.

In addition to more substantial testing, there is a critical need to create standards and metrics so that measured outcomes using new technologies are valid, reliable, and comparable across individuals and populations. Additionally, most pervasive computing technologies inherently can collect continuous, real-time data. This results in a different frame of reference for health assessments than the episodic, data-poor measures available in current practice. Standardized methods must be developed to incorporate and compare conventional measures to new ones. As recently stated in an Institute of Medicine report, ultimately there is a need for a comprehensive and universal system for measuring and reporting healthcare quality.[34] Pervasive computing and new healthcare technology benchmarks must be integrated into the fabric of these developing measurement and reporting systems.

These are some of the challenges that face a transition from today's care methods to more technologically rich and pervasive ones. People's well-being and their lives are at risk when healthcare is mismanaged. Therefore pervasive care solutions must be robust, reliable, and proven. As such, the development and implementation of these systems can be slow and the cost high. Nonetheless, pervasive technology offers a promising method of augmenting care across the healthcare spectrum.

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