

Chapter 6

Preserving Life, Destroying Privacy: PICT and the Elderly

Cynthia M. Jones

6.1 Introduction

Without doubt, technology has substantially increased both the length and the quality of human life in the last century, but our reliance upon technology is greater than ever and growing by the day. As the Baby Boomers age, a substantial proportion of Americans and Europeans will be increasingly reliant upon technology. As their health declines and their ability to live on their own decreases, they will be prime candidates for assistive technology and pervasive information and communication technologies (PICT) in their residences. The benefits to the elderly deriving from increases in health outcomes, autonomy of place and of movement (i.e., being able to choose to live safely in one's own home longer than would otherwise be possible, given declining health and mobility), and potentially longer lives must be weighed against the costs of decreased privacy, decreased general autonomy, and the potential for harm arising from fear or mistrust of technology and the dehumanizing aspects of pervasive technology.

Other chapters in this volume explore significant moral concerns for PICT, such as the issues surrounding the collection of public health data, the problems involved in the sheer magnitude of information about people that is continuously collected and stored, and the ease of deception arising from applications of PICT. Some of these issues are also particularly troubling when considering the situation of the elderly in the U.S., many of whom are wary or fearful of technology and many of whom may have decreased capacities for fully understanding the consequences of technology in their homes and in their lives.

This chapter will evaluate the relationship between privacy, competency, paternalism, coercion, and PICT in the elderly – a group that will likely be the first

C.M. Jones, Ph.D. (✉)

Pan American Collaboration for Ethics in the Professions (PACE), The University of Texas – Pan American, Edinburg, TX, USA

e-mail: jonesc@utpa.edu

to have pervasive technology invade their residences. In addition, I will discuss certain issues that are in some ways unique to the elderly, such as living wills and vulnerabilities arising from diminishing capacities. The chapter concludes with an examination of the fear and mistrust of technology often experienced by the elderly, the potential for deception and dehumanization in PICT and elderly citizens, and suggestions for best practices for minimizing harm in dealing with PICT and the elderly. The goals for this chapter are thus to weigh the positive aspects of PICT in residences of elderly individuals against the negative aspects, and to suggest ways to avoid or to mitigate as many of these negative aspects as possible.

6.1.1 Key Terms

For the purposes of this chapter, I offer the following definitions.

Privacy refers to the moral and legal right to be left alone in one's own sphere of influence or to control information about oneself.

Competency refers to the ability to make reasonable or rational decisions and can be either situation-specific (an individual can be competent to make decisions about some things but not others) or general (a generally competent individual should be allowed to make life-or-death decisions, for example, even if her physician or family disagree with her decisions).

Autonomy refers to the ability to be self-determining or to make decisions free from external influences or coercion, and it is typically considered to be the moral basis for privacy rights.

Paternalism refers to acting in the perceived best interests of another individual or group of people, with or without their consent. Respecting an individual's autonomy in health care decision making can often be at odds with acting paternalistically towards that individual, as people do not always make decisions that health care providers would deem to be in their best medical interests. In recent decades in the U.S., the health care system has moved away from health care providers acting paternalistically towards patients and making decisions for them, and towards respect for patient autonomy and informed consent and allowing patients to make decisions for themselves, given the relevant information, whether or not those decisions are in their best medical interests.

Advance directives are intended to specify the wishes of an individual when he is no longer able to express them personally, due to diminished capacities or declining health. Advance directives include living wills, do-not-resuscitate (DNR) orders, and giving another person durable power of attorney over health care decision making. Recent trends in advance directives also represent a less paternalistic approach to end-of-life decision making and demonstrate a greater emphasis on individual autonomy.

Aging in place refers to elderly individuals remaining in their own residences rather than moving to a nursing home, an assisted living facility, or a health care facility.

6.2 Privacy, Competency, Autonomy, and Paternalism in Dealing with the Elderly

The potential benefits from integrating assistive technology into homes occupied primarily by elderly individuals are significant. Robotic assistants and computer technologies that offer reminders to take medications, suggest healthful food choices, and call for outside help in case of an emergency are already in place in the homes of some elders. Studies suggest pervasive technology in the homes of elderly individuals can increase health outcomes, increase satisfaction with care, and potentially increase longevity. Aging in place can thus be facilitated, despite decreasing health and physical abilities, by PICT. Given that many individuals prefer to stay in their own residences as they reach the last period of their lives, pervasive technologies in homes of the elderly offer many the opportunity to remain in their homes longer than they could otherwise, likely leading to a substantial increase in happiness and positive self-image. Of course, there are obvious advantages for elders who leave their homes for the easily-accessible health care assistance available in nursing homes and assisted living facilities, but PICT offers elderly individuals the opportunity to maintain autonomy by providing the ability to monitor vital statistics in a reasonably non-invasive manner and instantly call for help when needed. However, the tradeoff for this kind of autonomy seems to be a decrease in other types of autonomy, such as the ability to control personal privacy and the sharing of personal health data.

Consider the following example.

Linda, an elderly Alzheimer's patient, is living at home with her husband, Chris, who has no signs of dementia although he has had a heart attack and a subsequent angioplasty. Their adult children have installed monitoring devices in Linda and Chris's home so they know if there is a medical emergency. While the couple knows the technology is present, they do not know the extent of the monitoring capability, which allows their children to know when they get up, when they take their medications, and whether their vital signs change significantly. Linda and Chris have maintained a sexual relationship and the first time they are sexually active after the monitoring technology is installed, paramedics rush to their house, at their children's request, as their vital signs changed significantly and they haven't answered the phone. Linda and Chris are both embarrassed and annoyed by the situation. Their children suggest that Linda and Chris notify them first whenever they plan to be sexually active so they don't call the paramedics again.

Given that privacy rights are often construed as the ability to be left alone within one's own sphere of control, the tradeoff for autonomy of place for the elderly with PICT in their residences is decreased control over personal health information, and perhaps other kinds of information, as the above example illustrates. But such concerns may be addressable to some extent. The simplest way to mitigate such concerns over privacy and autonomy for the elderly in their residences would be to fully disclose to the affected individuals what type of data is being collected and for what purposes, as well as the identity of the recipients of such data, and allow the affected individuals (or their family members if competency to consent is an issue) to consent or not. Another worry, however, is that many elderly in these situations will likely

face the inherently coercive “choice” between consenting to PICT in their homes or being forced to move to a nursing home or assistive care facility. Unless other viable options are available, the coerciveness of this choice may be unavoidable.

Issues of privacy are undeniably central moral concerns in PICT, as many aspects of individual privacy seem to be unavoidable casualties of the ubiquity of technology in our lives and in our homes. However, the situation is acute for the elderly, for whom privacy tends to decrease along with competency and autonomy. As a result, ethical concerns regarding infringement upon privacy seem less significant in end-of-life situations and in elderly individuals with decreased competency. When privacy is pitted against health, privacy is likely to lose. On the other hand, it may be argued that diminishing capacities make the elderly as a group more vulnerable to coercion and we should thus be more careful to protect their autonomy. What is clear is that decreased autonomy of movement and potentially decreasing mental faculties render many elderly more vulnerable to manipulation and harm. It is far too easy to project incapacity onto elders when the key issue is actually the convenience of caregivers. The consequences of vulnerability will be explored in more detail in the next section, but for now it is important to note that privacy, competency, and autonomy are tied together and can be serious issues for many elderly individuals, given the prevalence and scope of different kinds of senile dementia and the declining physical abilities many elderly experience. In examining the costs and benefits of PICT in homes of the elderly with diminishing mental capacities, the cost/benefit analysis may need to be frequently adjusted to correspond with changes in situation or declining mental or physical health, as designers and monitors of PICT in homes of elderly individuals are surely aware.

As some elderly experience diminished reasoning capacities that threaten their competency to make appropriate decisions for their health, paternalism requires that others make decisions for them, assuming they have left no advance directives for health care. Before turning to a discussion of issues that can arise regarding advance directives and living wills for elderly individuals with pervasive technologies in their residences, it should be mentioned that paternalism may suggest installing technologies without the consent or knowledge of the elderly resident. Obviously, it is preferable to have the fully informed consent of the affected individuals when PICT is concerned, but this may not be possible in many situations. It might be questioned whether PICT applications that are minimally invasive and thus virtually undetectable are morally problematic in general (for all residences) and specifically in homes of elderly individuals who are likely more vulnerable to external abuses if others control the technology in their homes. But such reasoning fails to consider privacy, autonomy, and respect for individuals. Just because data is easy to collect and because such collection is virtually undetectable, it does not follow that data collection without informed consent is morally permissible. This issue is addressed in other chapters in this volume in greater detail, but the significance of privacy and autonomy in considering the application of PICT in residences of elderly individuals requires that the designers and implementers of PICT are conscious of the unique situation present in residences of the elderly, given the potential mental and physical health challenges of the occupants.

The interconnectedness of privacy, competency, autonomy, and acting in the best interests of the elderly should be considered when making decisions regarding installing and monitoring pervasive technologies in residences. In the preliminary stages, a cost/benefit analysis weighing perceived benefits against expected harms would be prudent. Even though the potential benefit from PICT in residences of the elderly seems in general to be greater than the possible harms, minimizing the potential harm is key. It does not seem prudent to place elderly individuals in virtual fishbowls, where they are monitored “for their best interests”, even if they are unaware of the monitoring, as the undermining of privacy in general seems problematic on a societal level. Section 6.5 of this chapter will expand on this theme, but the unique challenges arising from end-of-life concerns and vulnerability issues in the elderly require addressing first.

6.3 Autonomy, Competency, Advance Directives, and Vulnerable Populations

Two central moral topics in the sphere of ethics and aging are end-of-life concerns and vulnerability issues. End-of-life concerns include advance directives like living wills whereas vulnerability issues center on the increase in vulnerability and the potential for coercion that often accompany a decrease in competency. These topics are significant enough in ethics and aging that they require consideration in an evaluation of PICT in the homes of elderly individuals.

Given the recent trend in health care of recognizing the rights of patients to make decisions that fit with their life narratives (even if those decisions are not, strictly speaking, in the best interests medically of the patients), it is important to recognize what a person would have wanted, if competent, as many people feel revulsion at the idea that they may end up as a “vegetable” in a PVS (persistent vegetative state) or, perhaps even worse, as a conscious but significantly mentally compromised individual.

The relationship between autonomy, competency, and advance directives is worth discussing here as the desire to avoid a lack of autonomy is often a compelling factor for individuals who enact advance directives. There is a significant psychological component to privacy and autonomy, as embarrassment and the desire to control personal data and private information have much to do with self-image. It may be that a person with compromised psychological competency is less vulnerable to the psychological harm of privacy violations; however, friends and family members may well suffer such harm on the elderly person’s behalf, even if the elder herself cannot completely experience embarrassment. And again, such worries often drive people to enact advance directives.

A colleague once relayed a compelling story about a good friend and former mentor who had been a well-known researcher but who was reduced by senile dementia to the equivalent of a 5-year-old playing with a top at the senior center

that cared for him. As he told the story of his former mentor, he was visibly shaken as he described the once-brilliant man's embarrassing state and went on to detail all of the important publications and theories for which his friend was responsible. Clearly, the embarrassment he felt for his friend was significant, even though his friend could feel no embarrassment for himself. This is the kind of experience that reminds us of the importance Western culture places on autonomy, as the thought of being in such a state ourselves in the future drives many people to consider specifying what kinds of treatment in certain circumstances they want to avoid. This story also illustrates that the kind of autonomy most of us desperately wish to retain is related to the autonomy we can easily lose as the pervasiveness of technology becomes all-encompassing.

Even though the percentage of people with living wills in the U.S. is still quite low (studies report between 25 and 40 %¹), there are a growing number of people who wish to specify the types of medical treatment they want employed and the types of medical treatment they want to avoid in certain situations when they are unable to speak for themselves. Again, most people who enact living wills or DNR (Do Not Resuscitate) orders are attempting to avoid being in a compromised situation like existing in a hospital in a PVS while hooked up to machines to stay alive. Several questions might be asked in dealing with elderly individuals who have living wills and who have PICT in their residences. Should the technology be modified such that outside assistance is only summoned under certain circumstances? Consider a hypothetical situation:

James has a living will stating that no extraordinary measures during or after a health crisis, such as a stroke or heart attack, should be taken to preserve his life if there is a significant chance of brain damage. His health is monitored by a number of devices in his home that are able to detect such events and make a reasonably confident assessment of his condition. James wants the technology in his home to be programmed to not issue a call for help if the probability of resuscitation is low or if the probability of brain damage is high.

Should PICT in homes of elderly individuals be making life and death "decisions" for the occupants? If so, who has the power to change such programming? In situations of diminished decision making capacities with elderly patients, family members typically make decisions if the patient cannot. As a safeguard, should PICT in the residences of elders be required to ask a designated family member or guardian to make the decision before alerting health care providers or calling for assistance?

Fears regarding technologies in our homes making euthanasia decisions for us may seem a bit far-fetched, but considering worst-case scenarios for use and misuse of technologies in the homes of elderly individuals is nonetheless a worthwhile

¹The Pew Research Center for the People & the Press reported in 2006 that 29 % of those surveyed had living wills. <http://www.people-press.org/2006/01/05/strong-public-support-for-right-to-die/>. (Accessed 8.19.12). Another source reports a range between 25 and 40 %, depending upon the survey. <http://www.freelegaladvicehelp.com/trust/wills/Statistics-On-Living-Wills.html>. (Accessed 8.19.12)

exercise from a moral standpoint. Understanding how technologies may be misused before they are operational can help avoid future problems. Many further questions can be asked in considering advance directives. For example, can PICT be a category of medical treatment that an individual can decide for or against in designing an advance directive? Perhaps another important safeguard for PICT in the homes of the elderly is to educate those who are enacting advance directives for themselves in the current technology trends so they can understand the costs/benefits of PICT while they are able to understand the implications and consequences.

Turning specifically to vulnerability issues in dealing with the elderly, it is worth noting that vulnerability arising from diminished capacities can and does exist in many elderly individuals and this vulnerability may be further compounded by a fear of or by mistrust of technology. In health care ethics, labeling a group of people as a “vulnerable population” entails recognizing that the group is more likely to be subject to problematic coercion and thus more likely to have their autonomy violated. Even though it seems that the reduced competency of some elderly individuals might allow employing technologies without their consent, designers and implementers of PICT should be wary of categorizing all elderly individuals on this basis. Indeed, the history of health care ethics demonstrates that protecting the autonomy and safety of vulnerable populations is important for respecting autonomy generally. Two infamous examples of violating the autonomy of medical research subjects or their families are the Tuskegee Syphilis Study and the Willowbrook Hepatitis Experiments.² Both Tuskegee and Willowbrook are significant for highlighting the moral issues inherent in using vulnerable groups in research, but the lessons learned from these studies are also directly relevant to employing technology on vulnerable populations. Populations such as children, the poor, the imprisoned, and the mentally challenged (including those suffering from senile dementia or diminished reasoning capacities) require extra consideration and consent procedures because their ability to freely and fully consent is questionable or diminished.

²The Tuskegee Institute in Alabama was the site of a U.S. Public Health Service observational study of a population of poor and mostly illiterate African-American sharecroppers. The study began in the mid-1930s and examined the long-term effects of syphilis, for which there was no standard treatment when the study was initiated. The study’s major ethical issues include deception: The subjects were told they were being treated when they were not, and they were not informed that they were part of a study, making it impossible for them to consent to the study. About fifteen years after the study began, penicillin became the standard treatment for syphilis, but subjects were not treated with it. The study was finally terminated in the mid-1970s.

The Willowbrook experiment is significant for applied and biomedical ethics for similar reasons, primarily because it involved using mentally challenged, institutionalized children in non-therapeutic research (research from which they did not stand to directly benefit medically). The children at the Willowbrook State School for the Retarded were intentionally infected with hepatitis (which admittedly was endemic to the institution) for the study and the consent obtained from their families was arguably incomplete and coercive.

Synopses of these and other cases can be found in (Rothman 2003).

6.4 “Forced” Ubiquity, Fear, Deception, and Misunderstanding of Technology

There are well-documented generational differences in adaptation to new technology.³ Elderly individuals are generally more reluctant to employ and to adapt to new technology and generally are more mistrustful and fearful of technology in their homes. There have, however, been great strides in anthropomorphizing certain kinds of assistive technology, although the jury is still out on the kinds of traits that older individuals find most appealing. For example, it was thought that more “human” qualities in assistive technology would lead to greater acceptance by users, but this has not been the case across the board – more “humanlike” appearances for robots do not necessarily result in greater acceptance of the technology. Some anthropomorphized characteristics may even result in rejection by users.⁴ It is clear from the literature on assistive technology in the homes of the elderly that preliminary screening on a case-by-case basis is a good way to match technology with the user. For example, many elderly express preferences for small, female-sounding, non-threatening robots that are perceived as “not too autonomous.”⁵ And some studies have demonstrated that matching needs of the elderly (such as reminders to take medications or perform daily tasks, help with mobility, help with hearing or vision, etc.) with technology that directly addresses their needs increases acceptance. In other words, it is possible to have some idea in advance of the characteristics of technology to which an individual will respond positively (Broadbent et al. 2009). In integrating PICT into residences of the elderly, the highest rate of acceptance and success requires some individual preliminary evaluation. Alternatively, it might be effective to explain the limitations and abilities of particular technologies and allow potential users to make some choices on appearances and abilities.

Returning to issues of competency and informed consent procedures for PICT in residences of elderly individuals, the coercive and forced aspects often associated with health care and the elderly can be compounded by a mistrust or fear of technology. Given the previous discussion of the relationship between privacy and competency, a serious concern for PICT and the elderly arises from the potential to “force” elderly individuals to accept the presence of pervasive technologies in their

³For a review of literature on responses to robots and technology in health care settings, including home health care, and differences between older and younger generations, see Broadbent et al. (2009). In addition to documented differences in acceptance of technology arising from age and generational differences, it has been demonstrated that culture, gender, and possibly education all have an impact on technology acceptance and thus should be considered as well when installing PICT in elders’ homes.

⁴Masahiro Mori’s “Uncanny Valley” hypothesis, and the subsequent research it spawned, is the most obvious example. See (Misselhorn 2009) for a discussion.

⁵A small cat-bot was determined to be more popular with the elderly than with younger individuals (Libin and Libin 2004, cited in Broadbent et al. 2009).

residences. It was suggested earlier that acting in the best perceived interests of some elderly clients could allow installation and use of PICT in their residences without their consent, without their knowledge, or even against their expressed wishes, if the potential benefit is great enough and if the “invisibility” of the technology is high. Such “forced ubiquity” is generally frowned upon in the general population, but some may consider it permissible if the user’s competency is compromised, which may be the case in residences of the elderly. It should be recognized, however, that elderly individuals are more likely, as a group, to have health decisions foisted upon them, whether or not they possess the competency to make such choices for themselves. Many elderly who do not experience competency challenges are treated paternalistically merely based on their age, although doing so is a clear infringement on their autonomy and thus detrimental. Again, those who design and employ PICT in residences of the elderly need to be cognizant that many of the users do not suffer from diminished competency, and this should figure into design and implementation.

6.5 “Dehumanizing” Aspects of PICT

Aside from the standard concerns over privacy, autonomy, and deception and their detrimental effects on the elderly, and the specific concerns regarding competency, living wills, and mistrust of technology that are directly relevant to the elderly, the pervasiveness of technology raises moral concerns regarding *dehumanization*, or treating individuals as less than people by treating them in a manner that deprives them of certain characteristics like freedom or empathy that many take to be essential to rational human beings.

Dystopian novels like Yevgeny Zamyatin’s *We*, Aldous Huxley’s *Brave New World*, and George Orwell’s *1984* warn of a future filled with technology that has stripped individuals of central aspects of humanity like autonomous decision making, individuality, and free thinking. *1984* in particular illustrates how pervasive and fully integrated technology can be used by a state to oppress its citizens by stripping away privacy and by aiding in deceiving citizens into believing everything the state tells them. *Brave New World* suggests that the apathy arising from having more information than anyone could process would result in the inability to distinguish useful information from irrelevant information. Although many of the central themes of these dystopian novels are social/political in nature, the implications of pervasive technology for privacy, autonomy, and “humanity” that they portray is relevant to this discussion – pervasive technology has the potential to undermine or minimize significant characteristics of what it means to be a rational human being.

Other chapters in this volume mention two significant moral concerns of PICT: a significant decrease in privacy for those involved and a significant increase in the ability to deceive people. The pervasiveness of technology has the potential to destroy traditionally-conceived privacy rights as well as the potential to deceive

its intended subjects, for example, by enabling them to think they are not being monitored and manipulated, when they in fact are constantly monitored and manipulated. Although dystopian novels are works of fiction, they illustrate a clear potential for misuse of technology in people's homes and lives. In dealing with elderly citizens, this situation is exacerbated, given the already dehumanizing aspects present in end-of-life care. Of course autonomy of place and aging in place can go a long way to maintain dignity and self-respect in elderly individuals, and this is a definite benefit of PICT in residences of the elderly, but it is important to be cognizant that we do not trade one kind of dehumanization (condemning the elderly to sterile hospitals or nursing homes with uncaring attendants) for another kind of dehumanization (condemning the elderly to virtually transparent environments where they are monitored and observed without their consent).

In addition to the general "dehumanizing" aspects of technology, PICT in homes of the elderly has the significant potential to decrease the amount of human contact for affected individuals. A recent conversation with the head of a home health care agency, who proudly reported an increase in the agency's "efficiency" rate thanks to the decreasing number of nursing visits to clients' homes, left me with concerns for the clients involved. Recently installed technology that monitors medications and food intake had significantly decreased the need for nursing visits to clients' homes. This increase in technology in clients' homes resulted in cost savings and more "efficient" use of resources, but also resulted in significantly fewer hours of human contact for clients, most of whom are elderly and most of whom are sorely lacking in human contact in general. Although pervasive technology in the homes of elderly individuals has the potential to increase their quality of life in many ways, it also has the potential to isolate them from society by making their homes so efficient that outside human contact is virtually unnecessary until a serious problem arises that requires outside intervention.

6.6 Conclusion

Previous sections in this chapter have suggested that those designing, installing, and monitoring PICT in homes of elderly individuals should be cognizant of the possible harms that the technologies may cause. Even though PICT in homes of elderly individuals seems to offer the potential for greater benefit than harm, recognizing potential harms is an important step in preventing or mitigating these harms. Other chapters in this volume discuss transparency, disclosure, and effective communication as tools for minimizing harm from PICT. These are useful tactics for minimizing potential harm from the combination of PICT and the elderly as well. Educating affected individuals and obtaining informed consent should be added to this list of tactics, to the extent that informed consent can be obtained from the individuals in question or from their families. Even if individuals cannot fully understand the implications and consequences of PICT, respect for human dignity and autonomy requires that they be informed as best as possible, assuming that the

discussion itself is not harmful. Another alternative is to inform and obtain consent from family members or medical decision makers, if consent from the individuals affected is not possible. Perhaps the best advice that can be offered at this point is that designers and implementers of PICT in residences of the elderly should be cognizant of the history of abuse in health care and research ethics in dealing with vulnerable populations. Making decisions in the best interests of others is always an endeavor filled with potential landmines, and implementing PICT in residences of the elderly should be approached with equal caution to using vulnerable populations in research, even if it seems to be in their best interests.

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