Autonomy in Assistive Technology for The Elderly: Not as Simple as "Plug N Play"

A Research Paper submitted to the Department of Engineering and Society

Presented to the Faculty of the School of Engineering and Applied Science
University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree
Bachelor of Science, School of Engineering

James O'Connell
March 29, 2024

On my honor as a University Student, I have neither given nor received
unauthorized aid on this assignment as defined by the Honor Guidelines
for Thesis-Related Assignments

ADVISORS
Kent Wayland, Department of Engineering and Society

I. Introduction

THERE IS NO DOUBT that the global elderly population is steadily growing. In fact, the global population of people aged sixty and over is growing by 3.26% per year (Daoudi et al). A larger elderly population is predicted to induce sweeping social and economic changes to the structure of global society. The most pressing economic issue that these changes present is the increased demand for employees and resources from healthcare systems. To address this issue, many engineers have been designing systems that employ various sensor technologies to assist human actors in providing healthcare. These systems will henceforth be referred to as assistive technologies (AT) (Bechtold, 157).

The development of AT systems establishes a seemingly straightforward connection between a social problem and a technical solution. However, no two elderly care facilities operate the same; each possesses a unique physical structure, chain of command, and resource capability. These conditions create unique relationships between the patients, care workers, and managers that are maintained through listening to and meeting the needs of the patient. Introducing AT into elderly care facilities disrupts this fragile network of relationships by threatening patient autonomy, creating an issue to which general technical requirements provide no remedy. The technical devices in AT systems possess neither reason nor will; they serve the technical purpose of preserving the patient's health, but do not understand the patient's needs as they change. Nonetheless, the *data* that they provide is interpreted and used by a care worker who can understand the patient on a human level. This situation creates a danger of technology blocking the patient's true needs from the full awareness of care workers, thereby reducing patient autonomy. This also shifts massive power to engineers, who now have an impact on healthcare decisions by shaping both the nature and representation of AT system data.

From a technical standpoint, it is critical for engineers to design these systems so that they do not make any errors in fact. These assistive technologies are designed to perform very high stakes duties. Events such as falls and heart attacks that occur suddenly and randomly *must* be handled appropriately by assistive technologies; lives are at stake. Furthermore, it is critical that AT systems be designed with *relational* requirements as well as technical requirements (Sánchez-Criado, 695). Relational requirements are created by rigorously defining the patient's profile, their expressed needs, and their apprehensions. The goal of these requirements is to design AT technical devices to be intermediaries between the patient and care worker that foster positive relationships that respect patient autonomy. But how do we create these requirements through defining "the patient," and what specific kinds of AT satisfy these requirements? That question is the object to which the efforts of this inquiry are directed.

II. Background and Context

Until a few years ago, personalized care for the elderly in their homes was designed to be completed by humans only. No technology was used to monitor the daily life of patients, nor to administer care initiatives. Today, several types of AT systems exist, and many more are being developed with a greater emphasis on technological control. A common function of these systems is to use infrared and visual sensing to gather data on patients, constructing good routines and preventing danger in the home by alerting professionals. Others provide data on an interface to care workers, helping them decide correctly in care conflicts. If the patient has family or others that visit them, these individuals often also play a role in the AT system asynchronously by receiving status updates. Regarding such AT systems from a consumer perspective, the design choices seem simple and logical, as if the patient, care workers, family, and sensor technology were all positioned to but put together like pieces of a puzzle.

Unfortunately, sociotechnical systems do not usually come together so simply. Indeed, AT systems represent an *instauration*, or a system that requires understanding of contractual and relational requirements along with technical requirements (Sánchez-Criado, 698). Instead of traditional technical design requirements that aim to satisfy a measurable goal, instaurations place emphasis on maintaining beneficial stakeholder relationships, along with being cognizant of social structures, customs, and obligations. From a developer perspective, it is critical to consider the power that each stakeholder possesses in an instauration. The relationships therein must be appropriately balanced using this power dynamic. In addition, the context in an instauration is highly important, as it reveals the specific cultural and structural requirements for a particular system environment.

In this inquiry, the concept of patient autonomy will be explored in the context of the instauration of AT systems. To determine how much autonomy the system affords to the patient, it is easiest to divide the technologies into two principal groups, active intervention, and passive intervention. The former comprise systems that seek to form habits among the elderly through structured routines such as medicine schedules, and to reinforce them through alarms and reminders. Moreover, any systems that handle or sense emergencies in the home are also categorized as active intervention. On the other hand, passive intervention systems comprise sensory inputs that are compiled to form reports about activities. Issues of autonomy with active intervention AT arise when the systems encourage care habits that do not satisfy the desires of the patients. While passive intervention AT do not usually compromise autonomy directly, they may violate the scope of the patient's desired privacy or may produce data that leverages professionals' interests over patient interests.

The concept of AT sensor systems for the elderly is widely regarded by the academic community as a complex sociotechnical system with numerous stakeholders. Each stakeholder group devises their own “imagined future” by inscribing their experiences and values into the new technology. Not surprisingly, imagined futures are almost always heavily biased, and are rarely fully manifested. Nevertheless, the “diversity of futures” imagined by stakeholder groups is usually either a catalyst of productive innovation, or an object of contention and inaction. The outcome depends upon both the intrinsic concordance of the futures together and the productivity of stakeholder discussions about them. Gaps in knowledge and experience can serve to reinforce each other, but can also create fear and distrust (Bechtold, 160).

STS scholars posit that three groups within society have vastly different imagined futures for these ambient and assistive technologies. The three groups are academic experts, direct stakeholders (patients, care workers), and the general population. The first group, experts from different fields, imagine the ethical challenges that will arise from using identification and wireless technologies with stakeholders. They consider the value, the robustness, and the plausibility of the system to the stakeholders, concepts that are far removed from the vision of the stakeholders themselves. Although experts often have ideas that are well formed from a large knowledge basis, they often overlook the unique identity of the patient in the face of attractive general qualifiers. The second group of direct stakeholders (the patients, their families, and care workers) are more concerned with the political decisions and societal behavior that affects the quality of care provided by the technology. Stakeholders combine their personal user stories with this to develop their own imagined futures. The stakeholders have an excellent sense of patient autonomy, but often forget about contextual limits of a system by making unreasonable demands (Bechtold, 163).

Finally, the imagined futures of the general population are best measured by gathering data on their perspectives on healthcare issues when answering research questions. Group brainstorming and discussions about how citizens would like to live when they get older can serve as valuable input to these imagined futures. Unfortunately, the general population has developed their "imagined futures" from a very deterministic perspective. The prospect of improving people's lives to help them live longer and be happier has caused lots of discussion over new technologies and capabilities. However, the societal influences and the social effects of AT on patients are not yet well developed, a crucial error when introducing a completely new sociotechnical system (Bechtold, 163).

Another important consideration within the sociotechnical system of AT systems is the interactions between patients and care workers, the principal stakeholders in the system. These interactions are important to the patients because of the social development and connection that they foster. Similarly, it is important to care for workers in making their job meaningful. In the face of long hours and high stress, it is essential to ensure that care workers and mentally positive and excited about working. It has been shown that when care workers are mentally sound, they are better able to communicate with their patients (Hirohashi, 891).

Another present danger that arises in AT is the tendency of technology to leave patients "out of the loop" thereby removing their autonomy. Normally, "the loop" comprises the professional and the patient that receive feedback from each other to form an effective healthcare plan. Now, there is a third technical actor, and its power must be balanced against its good effects. This will be studied through cases in the evidence section (Mort, 256).

III. Methods

In short, evidence collection covered issues of patient autonomy across various implementations of AT with both active intervention and passive intervention elements. The evidence focused on the patient's opinion on their autonomy relative to other stakeholders. The IEEE scholarly journals were used heavily, as they have many different system proposals that explain the desired effect of the chosen technology. Additionally, HCI (human computer interaction) databases were consulted to collect evidence about implementations that concern the care workers' and patients' interactions with the active and passive elements. To ensure that the information here is not biased, sources were vetted for interests that concern electronics vendors or other lobby groups. The evidence collection constituted a case review, with the goal of analyzing active and passive AT present in many different system devices, to better understand issues of patient autonomy in all systems.

IV. Evidence and Discussion

A. Literature Review: Development of "The Patient"

Before the autonomy of patients across different forms of AT can be properly treated, it is important to develop a few core characteristics of the patient. Who is the patient? What does the patient want, and how do the patients' actions reflect these desires? Moreover, creating an identity for patients allows an accurate assessment of whether their autonomy is being respected, either through actual implemented systems or discourse, research, and development of systems by others.

In the past, the concept of a "patient" was often constructed with very strict and basic technical requirements: "The marketization of health care during the 1980s in the United

Kingdom led to an uneasy settlement of citizen as consumer, one whose responsibilities for self-care are emphasized alongside accompanying rights" (Mort, 13). The patient was assumed to have little knowledge to directly control their situation without receiving input from the medical professional. More recently, explorations into relational requirements between patients and care workers have caused optimism for a more "informed" and "resourceful" patient who has much more responsibility to manage their own care. Ideally, the patient would be capable of easily indicating their desires and feedback to care workers despite new care methods that use sensor technology and data. In this spirit, proposals of AT systems have often assumed that the patient will acquire additional technical or medical knowledge to actively shape their AT experience.

Despite these ideas, research has shown the opposite: "Rather than assuming a greater role, the patients (in the case above, the frail elderly) are cast very much as passive players being monitored, yet with the ostensibly enhanced autonomy of being at home" (Mort, 13). This finding represents a gap in "imagined" futures from experts and actual futures as discussed earlier, and further supports the idea of AT as an instauration. The concept of "user" for AT systems is usually associated with the patient, as if the patient always has access to directly control or interact with the technical devices. This proves very often not to be the case and supports the view that associating stakeholders directly with technology without an awareness for other stakeholder relationships is unwise. Creating this perceived knowledge can falsely delegate power to certain stakeholders. In the case of patients in a healthcare system, the patient stakeholders are imagined controlling their destiny through knowledge of the system. Of course, it is usually the care workers that operate the technology, and this misconception presumes patient power, resulting in AT systems that compromise patient autonomy by ignoring their needs.

Nevertheless, the first important consideration about patients of AT is that the patients' role in controlling these systems is inherently *passive*. This is not to say that AT always plays a passive role in the patient's life, or that the patient has no input whatsoever, but the patient is *being monitored* or *assisted* through a system that is almost always set up and operated by a care worker (Hirohashi, 891).

The attitudes of both the academic community and the public toward the patients in AT systems have shaped the concept of the principal stakeholders. However, ongoing research and most specifically evaluative knowledge production has also mischaracterized the idea of the patient. "Despite some evidence of increasing patient involvement through organized participation, engagement in the process of knowledge production is completely absent in the case of telehealth care, where patients have been largely ghettoized within the legitimizing device of the patient satisfaction survey" (Mort, 18). Surveys that ask about general satisfaction and safety do not accurately reflect the needs and issues of the patient that arise from very specific AT contexts. Often, researchers assume that if the AT system performs its duties according to the technical design requirements and is safe for the patient, the patient must be satisfied, and their needs must be fulfilled.

This view once again reflects the propensity of researchers and academics to overlook relational requirements when treating AT as a sociotechnical system. More dangerously, it directs others to judge a system based on strict usability principles instead of context-specific satisfaction, creating knowledge biased against finding the needs of the patient. The current state of knowledge discovery about AT is again shifting autonomy away from the patients. It is assuming social complacency with technical results. In other cases, researchers judge the validity of a patient's feedback based on their ability to use the system. For example, here is a statement from a consultant with respect to a telehealth care trial:

> I think it does work a little bit the other way round, they are looking for people who might be quite good in it, because I have overheard once a comment, "he'd be good for the trial," if they think somebody is quite good and would be quite keen, "let's do this patient," so this is an interesting learning point that we need to get past fairly quickly (Mort, 20).

Research techniques such as these compromise the autonomy of the patient by creating a patient "control" group who has all the desired skills to best operate the AT system, and who is generally satisfied with the role AT plays in their life. Developing knowledge about how to best serve the patient while removing the social uniqueness of the patient from the process almost never achieves the original goal. Therefore, in this inquiry, the "patient" will be characterized by specific and distinct skills, needs, and attitudes with respect to the AT system that they use.

A clearer definition of the "patient" in AT systems allows a more detailed exploration of different patients' needs and expectations from AT. Foremost, the elderly are more prone to serious injuries due to falls and accidents in the home. Most forms of AT that monitor these conditions are *passive* in the sense that they monitor living conditions, and *active* when they act on them if there is an emergency. Another major aspect of elderly life that AT addresses is daily routines. Again, sensors that collect data about routines without acting are passive, and those that directly influence behavior such as alarms are active. The elderly also use AT to engage socially, usually with their family or friends. A good understanding of how the elderly rank these needs is important to exploring the relationship between the specific functions of the AT and patient autonomy. A study conducted on elderly individuals in the Philippines reveals a snapshot of this concept. Over 100 subjects were asked to rank "perceived need" categories for AT on a scale from 1 (strongly disagree) to 6 (strongly agree). The results are shown in Table 1 (Albina, 4).

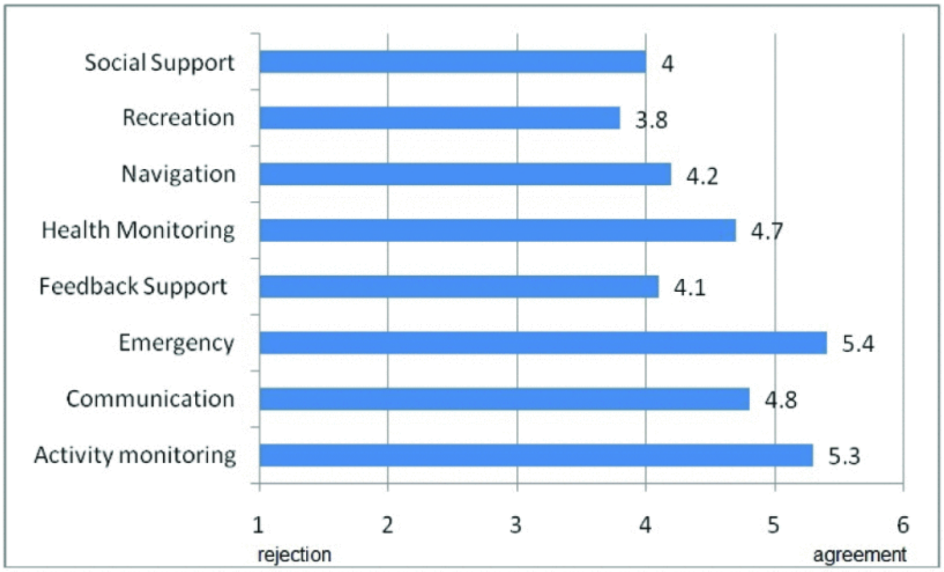

Table 1: Elderly Ranking of Needs of AT

The results clearly indicate that the elderly patients value AT systems that directly monitor their health for dangerous conditions the most. Three of the top four category responses involve health issues or monitoring daily activities to promote good health habits. On the other hand, the results suggest elderly patients do not see as much of a need for assistance with activities that they have done their entire life. From these two trends, it is reasonable to conclude that the patients do not trust the technology; they are significantly more comfortable with AT performing duties that are vital to their well-being than they are with AT assisting them with actions they are fully capable of performing, such as recreation and navigation. This behavior of elderly people can be explained by a concept called *culture lag* (Albina, 6), which occurs when technology induces trends that change social norms much faster than those of certain groups in society. In this case, very recently developed navigation technology is widely used by young adults, as they have no other navigation basis to rely on. On the other hand, most elderly people lived their lives memorizing directions and maps. This knowledge basis causes resistance to AT that seems untrustworthy and useless to the elderly (Albina). The same study conducted in the Philippines also analyzed the perceived benefits and barriers of AT for elderly patients.

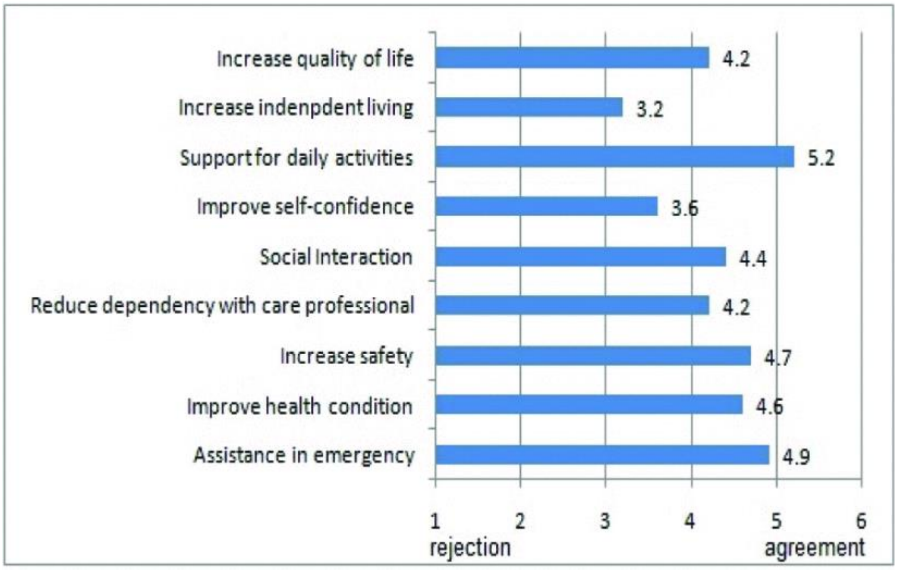

Table 2: Elderly Ranking of Benefits of AT

Most elderly patients value their health and safety and see this as the principal benefit of AT. On the other hand, the primary barriers that elderly patients worry about are invasion of privacy and threats to autonomy, as lots of AT systems use sensor arrays that collect sensitive data. The results of the study are summarized in Tables 2 and 3 (Albina, 4).

The results in Table 2 show a very strong desire of the elderly for support with monitoring health and safety. The top four choices are all related to improving the living condition of the patient. However, the patients clearly indicated that they do not see independence or confidence as a net benefit of AT systems. As mentioned before, most elderly people have established lives in which they feel confident from past successes or experiences. The reluctance of elderly patients to indicate independence and confidence as a benefit might draw from their social condition. However, it also could indicate an intrinsic fear of AT systems possibly overtaking tasks with which elderly patients need neither assistance nor confidence.

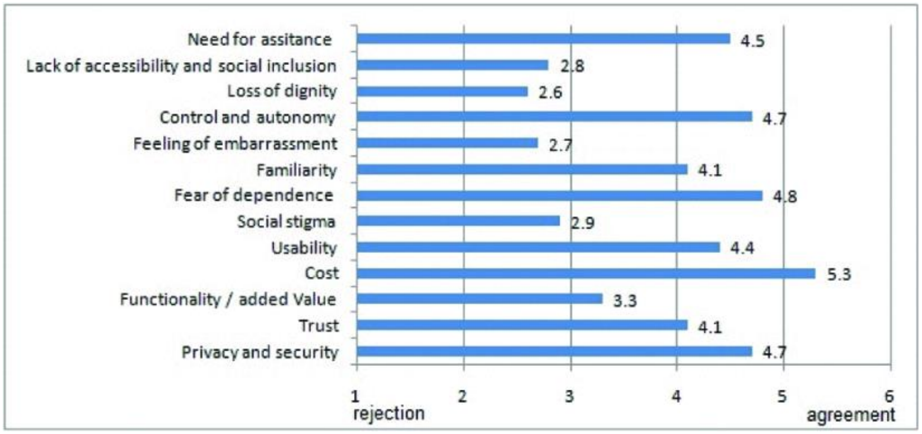

Table 3: Elderly Ranking of Barriers of AT

The results from Table 3 (Albina, 4) are the most revealing of the patients' perspective on their autonomy. Four of the top five choices for barriers reflected both the patients' fear of not understanding how AT systems operate and process their data, and their fear of AT systems creating a cycle of dependence for simple tasks, thereby removing their autonomy. On the surface, the results from the needs, benefits, and barriers do not fit together well. Why would patients see so many benefits in *active* facets of AT such as emergency handling and activity monitoring, while also fearing that the AT will take too much control of their lives and compromise their sensitive data? The answer becomes more complicated. It seems that patients are willing to surrender some of their privacy and autonomy to AT functionalities if the end is to preserve their well-being, especially in critical situations. The conclusion of this analysis is that the patients first value their health and safety, and then their control. Moreover, the analysis highlights the importance of considering the relational requirements of the system in design. This study provides a model of the "patient" that can be used by technical designs (Albina).

B. Case Study: “Sensor-Floors”

The efforts of this inquiry so far have afforded a tangible definition for the “patients” that use AT systems, as well as their most important values with respect to these technologies. To continue investigating the concept of the patient’s autonomy, a specific system will be examined in a case study. The study is focused on a “sensor-floor” technology that is implemented in a Danish residential care center (Grosen, 254). According to the manufacturer, the goal of sensor-floors is to make patient-care worker interactions more efficient:

> [A sensor-floor] helps the right nurses to be at the right place at the right time. Routine checks are reduced to save limited resources and improve the privacy of the residents. Quality of life is hugely improved having the constant assurance that help is always available when needed: 24/7, 365 days a year (Grosen, 260).

The sensor-floor technology aims to preserve the autonomy of the patient by restricting the number of visits from care workers to only when necessary, allowing the patient to spend more time alone. The sensor arrays collect data and notify care workers if there is abnormal activity in daily habits or movements. Sensor-floors are considered a unique form of AT because of their capability to administer care from a large distance.

The patient profile of the study is elderly adults who are very weak and can no longer live at home. The residential care center also includes a multitude of nurses and health care aides to assist the patients. The technical design of the sensor-floors comprises heat sensors that detect motions and send notifications to care workers when there is an important change of status for the patient. The study used observations to collect evidence and conducted interviews to capture the attitudes of both care workers and patients. One statement from the manager of the facility reflects the employees' belief in increased patient autonomy from their own experiences:

> …present with our care at the time that it's needed, by way of the technology. This means that, instead of having like a plan of: "First I'll go there, then I'll go there, then I'll go there…"—well, you have to modify that and think: "I'll go when the residents themselves let me know" (…) when they themselves, by way of the technology, say: "I'm awake now, and I need help now" (Grosen, 259).

This sentiment shows that care workers can tell when they are compromising the autonomy of a patient. Constant visits and "making rounds" that could result in unnecessary disturbances and intrusions into the patients' life can leverage pressure against the patient to ask for help when they really don't need it, simply to feel like they've satisfied the purpose of the care worker's random visit. With sensor-floors, the patient knows that the care workers will only visit when there is a real problem that needs assistance, offering them greater independence to accomplish other tasks that they can perform on their own. The lack of unexpected visits also affords the patient more tranquility and reduces the mental dependence on random visits (Grosen).

The core value of efficiency that drives sensor-floors does seem to afford the patient more autonomy from less intrusive visits. However, the floors collect lots of data to which care workers have complete access. When the data reviewed by care workers conflicts with the interests of the patient, there is a new threat to autonomy. For example, here is a documented situation that occurred in the study between a care worker and a patient:

> Hans (a resident) has complained to the staff that he cannot sleep at night, and has asked for sleeping pills. Lise (care worker) decides to check the floor-log of his apartment on the

> computer. Opening the log, she comments to the observer, that looking in the log like this is a bit of a grey area [privacy wise]. She checks the last five nights between 1 am and 8 am, and sees that there have been no movements on Hans' floor. She comments that during these nights he has gone neither to the bathroom nor to his armchair, where he usually smokes. Lise concludes that then he must have been sleeping, and therefore does not need sleeping pills. She discusses this with a nurse; they agree on the conclusion and note it in Hans' record (Grosen, 268).

The patient knows what he desires and has his independent will to get proper care by taking sleeping pills. The care worker, however, views the data as a form of the patient's will to get care, as it does not indicate a need for sleeping pills. In this case, allowing technology to speak the needs of the patient goes against their needs, reducing autonomy. From this case study, it is concluded that *passive* instruments of AT (those in sensor floors) can serve to both enhance and reduce patient autonomy. The outcome is largely context dependent and is heavily influenced by other actors that interpret both the input of the patient and the technology (Hirohashi).

V. Conclusion

This analysis concludes that although the patient generally has well defined needs, AT systems must be designed with *relational* requirements in mind specific to the actor network context to fully satisfy the patient's autonomy. The findings confirm the hypothesis that AT represents an instauration; there is no simple solution that combines the patients with the technological elements seamlessly. To design an AT system that properly treats patient autonomy, the following must be followed. First, the "patient profile" must be created to reflect the patients' abilities, needs, and expectations of the system. Next, any intermediaries (care workers) must be informed of the patient profile and must not be placed in a position to contradict patient desires by means of the technology. Finally, the technology must be designed to only engage *actively* with the patient if it is explicitly desired, or in an emergency. As healthcare technology continues to effectively perform more and more human duties, it has never been more important to design AT systems around relationships that are created and maintained to preserve user autonomy.

References

A, B. B., Kannimuthu, S., & Hussain, D. M. (2023). An in-depth analysis of Automated Health Monitoring Systems for elderly care. *2023 Second International Conference on Augmented Intelligence and Sustainable Systems (ICAISS)*. https://doi.org/10.1109/icaiss58487.2023.10250731

Albina, E. M., & Hernandez, A. A. (2018). Assessment of the elderly on perceived needs, benefits and barriers: Inputs for the design of Intelligent Assistive Technology. *2018 16th International Conference on ICT and Knowledge Engineering (ICT&KE)*. https://doi.org/10.1109/ictke.2018.8612447

Grosen, S. L., & Hansen, A. M. (2021). Sensor-floors: Changing Work and Values in Care for Frail Older Persons. Science, Technology, & Human Values, 46(2), 254-274. https://doi-org.proxy1.library.virginia.edu/10.1177/0162243920911959

Hirohashi, Y., Oyama-Higa, M., & Lee, S. (2011). Study of relations between the elderly and the care workers in the welfare facilities for the elderly, using non linear analysis of Finger Plethysmograms. *2011 IEEE International Conference on Systems, Man, and Cybernetics*. https://doi.org/10.1109/icsmc.2011.6083764

Mort, M., Finch, T., & May, C. (2009). Making and Unmaking Telepatients: Identity and Governance in New Health Technologies. Science, Technology, & Human Values, 34(1), 9-33. https://doi.org/10.1177/0162243907311274

Sánchez-Criado, T., López, D., Roberts, C., & Domènech, M. (2014). Installing Telecare, Installing Users: Felicity Conditions for the Instauration of Usership. Science, Technology, & Human Values, 39(5), 694-719. https://doi.org/10.1177/0162243913517011

Ulrike Bechtold, Leo Capari & Niklas Gudowsky (2017) Futures of ageing and technology – comparing different actors' prospective views, Journal of Responsible Innovation, 4:2, 157-176, DOI: 10.1080/23299460.2017.1360721

Yang, Y. (2012). Patient Autonomy Investigation Under the Technology-Based Health Care System. Bulletin of Science, Technology & Society, 32(2), 163-170. https://doi.org/10.1177/0270467612455750