

Ethical frontiers of ICT and older users: cultural, pragmatic and ethical issues

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Abstract The reality of an ageing Europe has called attention to the importance of e-inclusion for a growing population of senior citizens. For some, this may mean closing the digital divide by providing access and support to technologies that increase citizen participation; for others, e-inclusion means access to assistive technologies to facilitate and extend their living independently. These initiatives address a social need and provide economic opportunities for European industry. While undoubtedly desirable, and supported by European Union initiatives, several cultural assumptions or issues related to the initiatives could benefit from fuller examination, as could their practical and ethical implications. This paper begins to consider these theoretical and practical concerns. The first part of the paper examines cultural issues and assumptions relevant to adopting e-technologies, and the ethical principles applied to them. These include (1) the persistence of ageism, even in e-inclusion; (2) different approaches to, and implications of independent living; and

(3) the values associated with different ethical principles, given their implications for accountability to older users. The paper then discusses practical issues and ethical concerns that have been raised by the use of smart home and monitoring technologies with older persons. Understanding these assumptions and their implications will allow for more informed choices in promoting ethical application of e-solutions for older persons.

Keywords E-inclusion · Senior citizens · Ethics · Ageism · Cultural assumptions · Views on independent living · Western views of ethics · Smart home and monitoring technologies

Introduction

The ageing of European society has stimulated EU initiatives for promoting e-inclusion of its senior citizens and discussions concerning the ethical issues this would entail (Mordini et al. 2009). The European Union 7th Framework Programme for Research and Development in ICT (Information and Computer Technology) defines ICT for Independent Living and Inclusion as a major challenge (Valin n.d.). This was part of a larger EU strategy, initially established by the Lisbon (EU Reform) Treaty, directed at eradicating poverty and social exclusion of marginalized populations, including older people, by 2010. Beyond the ethical concern to extend the benefits of ICT, there is also an economic impetus for these initiatives to cut the costs of an aging population. By 2020 one-fourth of the EU population will be over 65, with proportionally fewer younger workers to support them. One of six older people already live in poverty and 28% of persons over 70 reside alone. The current trend for older workers to retire early (47% of

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men and 65% of women aged 55–64) adds further concern about the premature spending needed for pensions, in addition to health and long term care (Wright 2008: 2). The economic impacts might be reduced if older people remained economically productive and active for a longer period of time. In an Information Age only 10% of EU persons over 65 are literate in Internet usage. The EU initiative for e-Inclusion is an effort to bring into the Information society older persons who might otherwise be excluded from its benefits. ICT is seen as contributing to the well-being of older persons in European society by re-engaging them to contribute to the economy, enabling them to expand their social and communicative networks, and facilitating their living independently with the help of assistive technologies (AT).

Historically, however, the problems and needs of older persons and solutions to address them have been defined by persons other than the elders themselves. Even when elders have clearly acknowledged a particular problem, they have rarely been involved in crafting a solution to it. Nursing homes in the United States during the 1950s, for example, were devised as a response to problems perceived by stakeholders other than those for whom they were devised—hospital administrators overwhelmed by growing numbers of chronic patients, families needing assistance with elder care, and policy makers seeking efficient solutions to the demographic challenge of housing a growing older population (Vladeck 2003, 2004); however, they were not the solution that older persons themselves would have selected, as ongoing objections attest (Kane 1996). As a result, the history of nursing homes over the past six decades has been one consumed by efforts to re-conceptualize elder housing needs and the assumptions that guided the development of nursing homes. This has led to ongoing and costly correctives to past solutions that continue to fall short of elders' wishes (Kane and West 2005). As Europe moves to embrace strategies for the e-inclusion of older people, it risks repeating this pattern of having stakeholders (in this case, researchers, industrial leaders and policy makers) other than the elders themselves decide what elders need and what solutions should be developed. The initiative of e-inclusion for elders has assumed a status of inevitability for improving social equality in the modern world. However, as Zwijsen et al. (2011: 424) assert, the use of assistive technologies “should never be a goal in and of itself”. Thus the givenness of this solution should not be taken for granted if Europe hopes to produce truly inclusive approaches for improving the lives of its older citizens.

As with the selection of the nursing home solution in previous decades, the information solution was embraced to correct demographic pressures of an ageing population. As the press release for the European Action Plan for “Ageing Well in the Information Society” states, “These

new EU initiatives will contribute to allowing older Europeans to stay active for longer and live independently. Together they promise a triple win for Europe: improved quality of life and social participation for older people in Europe, new business opportunities for Europe's industries and more efficient and more personalised health and social services.”¹ Older Europeans here are identified as key stakeholders, along with business and government, but the e-solution, as with that of nursing homes, is an *imposed* solution to which older Europeans are expected to adjust, even if they do not wish to do so. Liisa Ero, Director-General of Communications in the Finnish Ministry of Transport and Communications, brought light to the severity of this demand on more timid senior citizens when she noted that they “must be provided with training and guidance so that they have the *courage* [italics added] to use electronic media”.² A recent study in the UK confirmed that 43% of adults who lack internet access would choose to remain unconnected even if given a free computer and free connection (Wright 2009: 82). Given the difficulty many older persons already have in navigating their world, it is perhaps not surprising that ICT would be perceived as yet an additional challenge. This underlines the importance of attending to their own preferences in developing policies for them. While the e-solution may be suitable for much of the older population, those who are not so inclined must accept it, even if their own preferences are ignored. Since they are the ones most affected by these policies, it is vital that their preferences for possible alternatives should also be taken seriously in helping to shape future policies. Meanwhile, as Europe moves forward with the e-solution, it is vital to maximally involve older stakeholders in ongoing developments.

The challenges introduced by ICT and smart home technologies to promote independent living for older persons brings us to new ethical frontiers that to date have been inadequately explored; thus their implications for users remain unclear (Zwijsen et al. 2011). These ethical challenges, however, cannot be addressed in a vacuum. Therefore it is worthwhile examining some of the cultural assumptions and relevant theoretical issues associated with this new direction before considering some pragmatic and ethical issues related to its implementation. Toward that end this paper will critically examine several cultural issues and assumptions related to improving elders' quality of life through e-inclusion. These include: (1) continuing challenges of ageism in spite of the assumption that e-inclusion will eliminate it; (2) three perspectives on independent

¹ €1bn in digital technologies for Europeans to age well. Brussels, 14 June 2007. http://ec.europa.eu/information_society/newsroom/cf/itemlongdetail.cfm?item_id=3457.

² Cited in Wright (2008, p. 18).

living with contrasting implications for improving quality of life; and (3) the cultural values that have shaped dominant ethical principles (e.g., autonomy and rights vs. dignity) given their implications for accountability to older users. Understanding these issues and their implications will allow for better informed choices in promoting ethical application of e-solutions for older persons. Drawing from my and other research on ICT with older users, the paper will then consider practical and ethical concerns that have emerged with the use of smart home and monitoring technologies with older users. It will conclude with a brief discussion of some of the implications of these issues and considerations for the future.

Cultural issues impacting e-inclusion

This section identifies key cultural issues relevant to e-inclusion, including the enduring challenge of ageism and three alternative views about the meaning of “independent living.” It then makes the case for a binary ethics of e-inclusion and the judicious choice of ethical principles to ensure accountability to older users.

Challenges of ageism

In his book, *What are Old People For?* geriatrician Thomas (2004), gets to the heart of what is at stake in an ageing society, namely: “How should we define the value of older people in a changing society?” In an information age, I would also ask, “Does ICT change the perceived value and relevance of elders?”

EU Commission initiatives on e-policy and its related action plan³ were motivated by justice concerns⁴ for remedying e-exclusion, a desire to reduce health and social care costs, and the economic advantage of creating an industrial basis in Europe for ICT and ageing (Wright 2008: 11). This e-policy has encouraged “active” living, beneficial to many elders, but not necessarily desired by all of them. Might there not be alternative possibilities for a vision of ageing that could equally handle the demographic challenge without this insistence on “active” living?

Thomas’s deliberately instrumental question, “What are old people for?” pushes us to consider this question further. In a Europe struggling to accommodate the multiple needs

of all its citizens, both those who are contributing to an economy, and those who are not, those who are independent, and those who are not, there is a strong incentive to encourage continued economic contributions from all citizens and to minimize their dependence and drain on resources. Within this context, a pragmatic response to Thomas’s question might be that old people are good for their economic contributions and ability to function independently with little or no help from others—a view associated with the now controversial concept of “successful ageing” (Rowe and Kahn 1997). As Minkler and Holstein critically observe, “If the choice is between being “burdens” and “contributors,” the message is clear (2008: 197). Once these contributions cease, old people effectively lose their value, unless it is replaced by non-economic values. In a non-secular, pre-Information age, they provided an important social role as holders of social memory, but in a secularized Information Society, where knowledge is extensive and accessible through other means, their value may be perceived as having run its course.⁵ We cannot afford to disregard the stark moral implications of this interpretation.

In addition, by placing pressure on older people to become more socially “acceptable, and less economically burdensome” through their integration into the information world, policies promoting ICT with older persons may divert attention from structural inequalities and ageist processes of social exclusion, and inadvertently blame the elders as victims. In following EU initiatives for ICT with older users, it is essential to acknowledge the variation that exists among them, as with the population in general.⁶ Although age alone is an inadequate basis for distinguishing among users, young and old, it offers some clues for correcting different kinds of injustices with regard to needs and availability of ICT and smart technologies. Still there is a covert danger in deliberately distinguishing groups in terms of technologies used to promote active social engagement versus those designed for supportive care services for older people. Advancing technologies that can only be accessed by the more cognitively, physically, and economically advantaged persons risks widening the gap between those at the extreme poles of ageing (Cowan and Turner-Smith 1999), or other people for that matter. On the other hand, advancing technologies that promote a desired autonomy by more frail persons can help close this gap. The key may lie in the extent to which any technology supports an improvement in quality of life as experienced

³ European Commission, Ageing well in the Information Society, Action Plan on Information and Communication Technologies and Ageing, An i2010 Initiative, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, COM(2007) 332 final, Brussels, 14 June 2007. <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52007DC0332:EN:NOT>.

⁴ See Mordini et al. (2009) for an elaboration about justice issues.

⁵ As discussed at the Socio-Anthropological Workshop on ICT and Ageing, SENIOR, Brussels, 2 June 2008.

⁶ For an excellent discussion of the theoretical issues involved in differentiating the old from the young, and among different groups of older persons, and their implications for different uses of ICT, see Mordini et al. (2009).

by the person her/himself. Nonetheless, noble efforts to challenge ageism by distinguishing among elders' different needs may paradoxically draw attention to differences resulting from age, and inadvertently reinforce it.

The problem of bi-polar ageism

Bi-polar ageism is a dilemma with which gerontologists have long struggled (McHugh 2003; Bytheway 1995, 2000; Cole 1983, 1992). Gerontologists find themselves accused of being ageist if they depict negative images of ageing, ageist if they emphasize only positive views, and ageist even if they embrace "ageless" views (Andrews 1999).⁷ Focusing on the negative pole of ageing encourages ageism because it highlights attributions such as frailty, dependence, inactivity, incompetence and high resource consumption. This negative emphasis ignores enduring capabilities, and can serve to encourage exclusionary practices. On the other hand, promoting an exclusively positive image of healthy or "successful" ageing (cf. Rowe and Kahn 1997) and agelessness is both ethically and politically problematic (Cole 1983: 39) because it masks the reality experienced by many frail elders (Featherstone and Hepworth 1991: 371–89). It also fuels policy decisions that restrict services to those in need, thus further marginalizing the more frail from the more fortunate members of their cohort. As Cole eloquently puts it, "the Scylla of prejudice is not far from the Charybdis of denial of human differences" (Cole 1983: 34).

Cole posits that the way around this is to deny neither the positive nor the negative pole of ageing, but to acknowledge the full range of variation—from vitality to frailty—that exists among older people, like the variation of any person over his/her life course. It also requires embracing the fundamental mortal nature shared by human beings—which unites both young and old—and considering what that means as they approach death. This is a significant challenge to face in a rationalizing secular society. Yet, it may be core to some of the issues that must be addressed.

The problem of ageism is deeply cultural, value-laden and tenacious and has surfaced, as Cole has illustrated, in various "keys" over the course of modernity. During the Victorian period, moralists used it to blame unfortunate elders for their own fate. Misery and early death were seen as just rewards for living an immoral, sacrilegious, non-productive, life; a good old age was the presumed product

⁷ The same homogenizing thinking, that underlies agelessness, in attempting to defy ageism by rejecting negative images associated with ageing may also have stimulated the promotion of "design-for-all" or "universal design" principles in some cases, especially for purposes of marketing. See Diemel et al. (2004: 224–238) for further discussion.

of accumulated just deeds and hard work. In its contemporary secularized key, where the self and self-value have become somaticized in what Nikolas Rose calls a body-obsessed culture (Rose 2001: 18), the quality of old age again is associated with actions directed at reconstructing the self through a focus on the body. Here, what Rose calls an "ethopolitics" of self-governance directs the self and way of life through discourses on diet, exercise and life style. In both cases, a focus on the responsible autonomous individual links "freedom to choose" the quality of one's life, health and longevity with self-disciplined practices or moral actions. Human value becomes defined in somatic terms of measurable changes. But as Cole incisively warns, all of us are ultimately "destined to fail in a society in which health has been transformed from a 'means of living well into an end in itself'" (Cole 1992: 238–9), and where inevitable decline and death are denied. What is lost in this no-win endgame is the meaning of life itself (Blaikie 1999; Mollenkopf 2003: 213). This sobering recognition puts into perspective the genuine limitations not only of e-solutions, but of any solutions for addressing human frailty and inevitable decline.

Perspectives on independent living

Recognizing our ultimate mortality, however, should not inhibit aspirations to maximize human life span and quality and to minimize disability and frailty; rather, it should accept these as temporary, but useful solutions (Rose 1999: 55). Opportunities for promoting healthy living, continued social engagement and contributions, and ongoing personal growth should be encouraged, particularly when sought by the elder him/herself. Since older frail persons face physical and mental decline, reduced mobility and autonomy and possible institutionalization, a principle goal of e-inclusion of older senior citizens (typically, those over 80), who are more statistically likely to be frail than younger persons, has been containment of frailty and support for independent living.⁸ The threat to independence, however, stems not only from *individual* functional impairments, but also from challenges of the built environment (Tinker et al. 2004: 9), the social environment and opportunities or restrictions for social inclusion. Thus technical solutions alone are necessarily limited in their capacity to support independent living.

Nonetheless, facilitating independent living through assistive technologies has been a goal of many initiatives involving ICT and older persons. In spite of its central importance in policy however, the actual meaning of

⁸ See, for example, Ethics of e-Inclusion of older people. Discussion paper for the workshop on Ethics and e-Inclusion. SENIOR Project, Bled, 12 May 2008.

“independent living” has not been examined adequately. I will therefore identify three perspectives—functional, normative, and relational—and briefly consider their assumptions and implications for older persons expected to live independently.

The functional view

A dominant view of independent living is the *functional* definition held by the World Health Organization (WHO). Under this definition, independent living is “the ability to perform functions related to daily living—i.e., the capacity of living independently in the community with no and/or little help from others”.⁹ In keeping with the WHO’s “active ageing” perspective adopted in the late 1990s, the functional view attempts to move from a “needs-based” approach of passivity to a proactive “rights-based” approach that encourages participation and “equality of opportunity and treatment.” The emphasis on “active” aging places a premium on functional capacity and engagement in social and productive activities throughout the life course, with prevention of disability and maintenance of independence as key goals. These are the very elements associated with “successful aging” (Rowe and Kahn 1997), which has become synonymous with “active engagement” (Holstein and Minkler 2003: 789). Those elders who fail to remain actively engaged, and are less functionally independent, risk being deemed “unsuccessful” or “dysfunctional,” and hence marginalized from the more successful. As the concept of “successful aging” has received greater scrutiny, several writers have drawn attention to the neoliberal principles underlying the promotion of active engagement and independent functioning and to state policies that impose increasing responsibilities on elders, while withdrawing resources from them (Katz 2000; Minkler and Holstein 2008; Rozanova 2010). Indeed, the emphasis of reducing the economic burden to the state by promoting higher functioning,¹⁰ risks shifting the emphasis from “opportunity” and “rights” to individual “responsibility” and pressure to function at a higher level, even when that is difficult or not desired by the elder. This is consistent with a rights framework, which is grounded in the liberal philosophical tradition which emphasizes the rational autonomous individual and his/her moral responsibility. Nonetheless, the emphasis on functional capacity and the moral autonomy with which it is associated, again threaten to polarize older people who under these terms are functioning well as competent autonomous beings from those who are not (e.g., those with dementia).

⁹ WHO (2002: 11).

¹⁰ Mordini et al. (2009) also recognized a hint of this within EU policies of e-inclusion.

This specifically functional definition of independent living is uncritically adopted by much research on assistive technology, which places emphasis on a person’s ability to perform ADLs (Activities of Daily Living) alone, independently without help. However, this is not achievable by assistive technologies in many cases. Nor, as Joy Hammel observes, is it the way many older adults and others who are ageing with disabilities would define the goal of independence (Hammel 2004: 128).

The normative approach

In contrast to this more prescriptive functional and self-reliant view of independence, which has assumed a status of normativity in research and policy circles (cf. Holstein and Minkler 2003: 787), I posit an alternative *normative* approach that presents a more relativist and subjective understanding of independent living by the elder herself. As stated by Paddy Nixon, former Director of the Irish based Technology Research for Independent Living Centre (TRIL),¹¹ “Independence is not about being alone, but about living a normal life, whatever that means to you. It’s about being able to do what you want to do [and, I might add, *not do*] in your daily life—having the freedom of choice to be able to visit friends, go for a walk, make a cup of tea, work in the garden. As we age, those everyday activities become more difficult, and we can lose the ability to control our everyday destiny.”¹² The emphasis here is on control and self-determination.

Thus this approach moves away from the *externally* imposed demand that one *must* be self-reliant and independent; instead, it focuses on the important subjective point of view and preferences of the person herself, whatever that preference may be, *even if it is to do nothing*. Rather than placing emphasis on functioning alone, the normative approach to independence shifts the emphasis to “freedom and choice in deciding what, how, when and with whom” (Hammel 2004: 128) to do whatever one chooses, including using ICT. This is a view more akin to the self-empowerment perspective adopted by many older people with disabilities—a view that would encourage using ICT to support community residence over institutionalization (where one risks losing control over one’s life), and to facilitate social engagement, communication and inclusion (Hammel 2004: 128). Although the values of active engagement and functionality, which *necessarily* define functional independence, may be similarly embraced

¹¹ For information about the TRIL Centre, see <http://www.trilcentre.org/>.

¹² Cited in Aging Options: An article about Independent Living. *TRIL News*. 25 February 2008. http://www.trilcentre.org/news/ageing_options:_an_article_about_independent_living.397.573.news.html.

within the normative view of independent living, what distinguishes the latter is its emphasis on self-determination by the person herself.

The relational view of independence

In contrast to these two perspectives, bioethicist George Agich challenges the very idea of independent living, positing instead a *relational* understanding of living. All people, whether healthy or unhealthy, are fundamentally *inter-dependent* on others (Agich 2003). According to Agich, there is no absolute independence. Even our relations with technology are possible only through systems that involve other people. Given our interdependence on each other, a critical life or health event can shift our balance by disrupting existing social relations; likewise, it can activate the social support necessary to regain our bearings (Comyn et al. 2006: 40–41). Furthermore, each of us is “inherently” more or less temporally dependent on others over different periods of our life course (Zwijzen et al. 2011: 425), inescapably requiring us to call upon our relations with others for sheer survival, let alone nurturance and pleasure. A relational view of independence brings attention to our fundamental social nature that is supported *within* relationships, and challenges as artificial the idea of complete independence outside of them.

The current obsession with personal responsibility to maintain a strong healthy highly functioning body (Nikolas Rose’s ethopolitics) encourages an ideology of independence that leads to unnecessary suffering and a sense of failure in many older persons. Functional and, to a lesser extent, normative views of independence that place a premium on autonomy and functioning may be somewhat easier to grasp and measure—and thus offer pragmatic advantages for a systematized rationalized economy. But they restrict our understanding of what ageing “independently” actually entails for social beings; such views may also lead to narrowly prescribed solutions that promote make it difficult to avoid bi-polar ageing. Unless we critically examine our assumptions, we may wonder whether non-ageist thinking is even “fathomable or culturally possible” (McHugh 2003: 181). More to point, we risk promoting solutions for independence that ignore the realities of our needs as social creatures, and even work against satisfying those needs.

It is thus useful for stakeholders to be attentive to what “independent living” means for different elders, and how this may change during different points in their lives. Whether independent living means active functioning, a self-defined normative independence, a resolutely relational inter-dependence, or even a blend of these approaches, their assumptions and implications should be kept in mind in designing solutions to assist elders to live as they

wish. It is equally important for policy makers to attend to the implicit economic motivations that may drive certain policies that may not always be in the best interest of those they serve, and to be willing to adjust those accordingly.

Toward an ethics of e-inclusion, and the judicious selection of ethical principles

“The difficulty of defining senior citizens as a homogeneous class of persons in need of protection without making reference to context and personal conditions has consequences for the implementation of e-inclusion policies. In particular, it has consequences for the forging of an ethics capable of guiding, protecting and promoting the participation of senior citizens, as well as people in general, to the functioning of their (information and communication) society. The categorisation of senior citizens, as a result of socio-cultural determinism, emerges critically as one proceeds to identify and overcome the obstacles and satisfy the needs of senior citizens for ICT.”¹³

As captured above, the varying and changing needs within the older population (*context*)—for protection, access, or both—and for any given person over his/her life course (*personal conditions*), will necessitate different ethical requirements at different times. As a result, a uniform principle-based ethic is unsatisfactory for addressing their ethical requirements. Categorizing senior citizens, as also suggested above, is bound to prove inadequate, as any individual is likely to have changing needs over time. What may be more in order is an examination of these varied needs and consideration of the type of ethics they demand. It is also essential to be cautious in assuming the universal constructiveness of all ethical principles, as some (e.g., moral autonomy) may be counterproductive to the task.

A twofold ethical charge

In spite of the promise of ICT, there has been a keen recognition that approaches must be developed to address the potential ethical and privacy risks ICT may pose for older users. The recently published “Dialogue Roadmap” (Wright 2009) provides an excellent discussion of the complexities at stake, and offers nuanced practice based guidance, grounded in the need to involve all key stakeholders. I agree with the direction of that important work, and do not intend to duplicate it here. Rather, I wish to point out that one way of looking at these ethical issues is to see them as two-pronged, with quite different charges and implications, and to address the caution that must be

¹³ Ethics of e-Inclusion of older people. Discussion paper for the workshop on Ethics and e-Inclusion, p. 13. SENIOR Project, Bled, 12 May, 2008 and in Mordini et al. (2009).

exercised when selecting those most relevant to particular situations.

One prong, directed at expanding the reach and benefits of e-inclusion, necessitates a *positive* rights based *ethics* aimed at creating justice through fuller, more equitable, access. At the other prong, a *negative ethics* must also be developed to oppose violations of privacy of people through e-access, and also against potential abuse or misuse of monitoring technologies and the data gained from them. Ethical guidelines must accommodate the different ethical requirements necessitated by this double charge and any related issues these may entail (cf. Christakis 1992: 1089).¹⁴

A human rights approach, following the Charter of Fundamental Rights of the European Union¹⁵ as guide, should well serve the positive ethical prong, e.g., promoting a citizen's right to access, the justice of making ICT available and accessible, and the equality this demands. In this case, the Charter's principles of dignity, freedom, equality, solidarity, citizen's rights, and justice can be applied without undue complication.

However, for the negative prong, directed at protecting against potential abuse¹⁶ and invasion of privacy, particularly of vulnerable people, special attention should be given to the principal of *dignity*, given its historical roots in preserving the integrity of all persons. The principal of dignity derives from a Kantian appreciation that people have an ultimate worth in and of themselves, not as an instrumental means to another end (Novak 2001: 33). Kant states, "What has a price can equally be replaced by something else of an equivalent value. What is superior to any price, however, and what, therefore, has no equivalent is what has dignity."¹⁷ In spite of actual limitations of his original conception,¹⁸ his comments argued convincingly against a *utilitarian* view of personhood and rights that define human worthiness in terms of instrumentality or economic productivity. They favoured instead a humanistic perspective that includes all human beings as persons, regardless of their cognitive limitations, by virtue of their dignity. In contrast, liberal ethical principals such as moral autonomy, widely embraced by both biomedical ethics and rights discourse, restrict personhood only to those deemed competent (and hence

responsible).¹⁹ Such interpretations retain a "hypercognitive" bias (Post 2000: 245) that endangers the rights of those who are less fortunate. Thus in employing the negative prong of ethics, it is crucial to remain vigilant to ethical principles that may inadvertently threaten the personhood and rights of the most vulnerable elders.

As Nicholas Christakis argues, culture shapes the very content and values of ethical principles, such as the emphasis on individual rights, autonomy, privacy, and self-determination that permeate Western value systems (Christakis 1992: 1086). However, even within Western philosophical traditions ethical principles are by no means uniform and restricted to solely individualist approaches (McLean 2007: 42; Christakis 1992: 1088). As ethical systems develop, Christakis cautions, they must be seen as tools not for regulating behaviour, but rather for helping to interpret it. As an ethics of e-inclusion evolves by means of concrete deliberations and evaluations by key stakeholders examining mounting cases (SENIOR's Dialogue Roadmap) (cf. Wright 2009) and situations, the goal will be to optimize future interpretations for expanding, not restricting, opportunities for older persons.

Practical and ethical issues raised by smart and monitoring technologies

Drawing from examples from the literature and from my own ethnographic research conducted in Ireland between August 2007 and July 2008 to explore older users' experiences and perceptions of ICT, I shall now address issues raised by the application of smart home and monitoring technologies with older persons.

Smart home technologies

Smart homes and smart technologies have become one means for promoting independent living for seniors. Smart homes refer to living spaces that have been deliberately designed to accommodate a variety of interactive technologies, such as appliances controlled by touchscreens anywhere in the house, or security systems that simulate user habits (like opening shades or turning on lights) when the user is out. Smart home technologies integrate "technology and services through home networking" to improve quality of life²⁰ within existing homes. Of all age groups, people over 55 typically have shown the least interest in residing in smart homes due to insecurity or distrust in their operations (Pragnell et al.

¹⁴ The need to avoid "single instrumental thinking" and to embrace a broad approach to protecting human rights was also addressed in the Bled workshop paper, p. 26. Fn 46.

¹⁵ http://www.europarl.europa.eu/charter/pdf/text_en.pdf.

¹⁶ Abused could include, e.g., using older persons as instruments to test new technologies. See caveat in Mordini et al. (2009).

¹⁷ Quoted in Bernard (2001: 58).

¹⁸ As a product of the Enlightenment, Kant reserved the attribution of pricelessness only for those people he deemed rational.

¹⁹ For further discussion on how this occurred, see McLean (2007: 43–44).

²⁰ According to the Smart Homes Association. Soprano (2007: 7).

2000). This is why there has been a call for “intelligently designed” interfaces based on a thorough understanding of the perceptions of older users (SOPRANO 2007: 16–18), including embedded designs not requiring their direct engagement.

Older users who have lived in smart homes, have appreciated their safety and convenience features (Meyer and Mollenkopf 2003), while at the same time having preferred an option to manually operate its systems.²¹ This option would be especially valuable in their later years, when they might more easily manage the traditional technologies to which they had become accustomed in their youth, but which remain deeply imprinted. This is because memory for spaces is established early in adulthood, when design structures are strongly entrenched (Marshall 2005: 282), like those called POTS (plain old telephone service).²² Thus familiarity with technologies learned in young adulthood is most likely to endure. Thus an optimal time to preserve benefits of smart home features might be very early in the ageing process, to reinforce memory of their operations. This notion of a cognitive-environmental symbiosis provides an important clue for designers that could inform prospective anticipatory designing to extend the period of time that older people can negotiate their environments independently. It might also be valuable in smart home designs in assisted living or even intentionally designed nursing homes, such as Green Houses (c.f., Thomas 2004: 232).

From smart homes, to adapting homes smartly

New developments with wireless networks have produced more affordable and more widely accessible alternatives to smart homes by embedding technologies within people’s own homes (Tinker et al. 2004). Smart home technologies can equip the home to respond to the changing needs of its occupants, such as physical, sensorial and cognitive fluctuations in performance (SOPRANO 2007: 7, 16), possibly even more responsively than by a human caregiver. In addition, such technologies enable someone to remain in a familiar and emotionally satisfying environment with the added advantage of person-environment adaptation acquired over a lifetime. This is *especially true for those who had resided in the home since early adulthood*, as Mary Marshall indicates (2005: 282). Even in cases where a person suffers from physical and cognitive impairments, familiarity with an unchanged environment may enable the person to remain at home by extending his or her ability to function through reduced environmental stress and heightened navigational ability. For example, I observed a

93-year-old woman with advanced dementia who effectively used a walker to seamlessly move around, and up and down the staircase of the three-story home in which she had resided for over 60 years. The home had remained unchanged structurally and in decoration throughout that period, reinforcing its imprint on her. Smart technologies can unobtrusively reinforce such environmental-person interactions to promote independence, however it is defined.

Disadvantages and unintended consequences of smart home technologies

While smart home technologies can facilitate mobility and independence, reducing dependence on caregivers, little is known about their long-term advantages and disadvantages. The short term convenience of making purchases using computers, for example, may discourage social contact and the benefits of face-to-face relationship on the long run (Mollenkopf 2004). And yet a disabled person may gain unique access and satisfaction unavailable without such technologies, such as daily communication with friends and bloggers. Still a study of older community dwellers revealed that in addition to ICT, “*actual engagement in the material and social neighbourhood is essential to well-being and self-identity*” (Peace et al. 2006: 75). Indeed, social contact is believed to be beneficial for the health (Peace et al. 2006; Lund et al. 2004; Litwin 1998; Greaves and Farbus 2006), cognition (Ybarra et al. 2008), and quality of life of older people (Garcia et al. 2005; Bowling et al. 2003), even if the reasons or mechanisms are not fully understood. By obviating the need for someone to initiate social contact, do we risk adversely impacting that person’s physical and cognitive health?

In addition, unforeseen outcomes, such as new dependencies and anxieties (e.g., about Information system failure) and the weakening of existing strengths, like note-taking (Mollenkopf 2003: 207–212; Morrow 2003: 292) may pose yet further threats, particularly when dementia is already in process.²³ For such reasons Mollenkopf argues that “function” should not be the definitive measure of these technologies’ success (Mollenkopf 2003: 207–210). Finally, as technologies become ever more sophisticated, the skills needed to handle them may create even larger digital divides in the future between the more and less capable users, including those who are competent today (Morris et al. 2007: 53). Such unforeseen consequences should be anticipated in designing and assessing the value of new technologies and ubiquitous computing systems.

²¹ van Berlo (2005), cited in Steg et al. (2006).

²² This is an acronym used by designers at the TRIL Centre, Dublin.

²³ There are strategies, however, that might minimize losses. See Morris (2005: 31–33) and Morris et al. (2003: 232).

Monitoring

While the safety and convenience measures of smart technologies are appealing, their broad monitoring capabilities and access to personal information create privacy concerns; reluctance against being monitored is thus understandable. Submitting to monitoring may depend on such factors as its purpose and perceived necessity, the sense of security gained, and mutuality and user control, tempered by personal and cultural factors. These issues will be discussed, together with speculations on current and future issues concerning tagging and research involving monitored data.

Purpose and perceived necessity: medical versus behavioural monitoring

Many older persons appreciate having information about their physical states (like blood pressure or glucose levels) monitored and sent to medical professionals. Automating this process relieves them of having to worry about seeing the medical professional in person, or having to ‘bother’ the professional by calling them to report their results (Pols 2010). However, sharing this information with their family, especially with their children, depends on the nature of their relationship. Some older persons demand total privacy and control over their health data, while others are accustomed to asking their children to communicate with medical staff and monitor their health. However, there is greater reluctance in sharing with family members data related to their monitored behaviour because they experience such data as less necessary and more intrusive and do not want to needlessly worry their children with information not directly related to their health.²⁴ Those who have agreed to being monitored, however, often want feedback, preferably in written form, for their own records.²⁵

The sense of security: a false assurance?

Privacy concerns are heightened by the visibility of sensors, which can be seen as a public marker of disability and the need for surveillance. While this may deter some users, others see this as a price to pay for greater security: “I’d wear a brick if it could save me,” said a woman who had suffered falls from blackouts and feared she might not survive another undetected occurrence.²⁶

²⁴ Andy Cochrane, TRIL project, personal communication, May 2008.

²⁵ Cahill, Suzanne (2008). Conference paper, The Subjective Experience of New Patients and their Primary Caregivers attending a first appointment at a Memory Clinic. Presented at 18th Alzheimer Europe Conference, Oslo, Norway, 23 May 2008.

²⁶ Bailey, TRIL project, personal communication, October 2007.

However, some specialized medical devices may work beautifully for their intended purpose (e.g., alerting medical staff to specific data), and yet miss other vital, even life-threatening, information. A device used with terminally ill cancer patients in the Netherlands, for example, sends a daily list of specialized questions for patients to answer regarding their symptoms, overall psychosocial condition, and even spiritual state (Pols 2010). The answers are reviewed by a nurse and followed up with a phone call in case of any potentially alarming responses that are flagged. When one nurse called her patient after being alerted by a flagged response, she was shocked to learn that the woman was shivering with the flu—a problem not part of the questions routinely asked: “*My god, I did not know...*” The patient also regretted not having called the nurse to inform her since, “*She does not see that through the device! And she couldn’t know from the questions.*”²⁷ In this case relying strictly on the device impeded care because it trained the patient to depend on the nurse to initiate contact.

The *Presence Lamp* is a device which uses an unobtrusive lamp in each of two homes to monitor movements it lights up in one home to signal when someone is home in the other. It provides particular comfort to adult children and helps relieve guilt and worry. It might, however, lend false assurances about the parent’s subjective well-being, resulting in less frequent face to face contact. It also begs the question, “For whom and for what purposes are monitoring technologies designed?”

French sociologist and philosopher Henri Lefebvre would have regarded this modern usage of “presence” as contradictory and misleading (Lefebvre 2004: 22). His writing offers trenchant commentary about such simulations. “Presence,” he argues, “is *here* (and not up there or over there)” and requires “dialogue, the use of time, speech and action.” In contrast, the “present simulates presence...” “With the present, which is *there*, there is only exchange ...of the displacement (of the *self* and the *other*) by a product. “A skillfully utilized and technicised form of mythification (simplification), it resembles the real and presence as a photo of photographed people: it resembles but it has neither depth, nor breath, nor flesh” (Lefebvre 2004: 47).

Mutuality and user control

Nonetheless, the bi-directional feature of the Presence Lamp enhances its acceptability to older users because they experience it as mutual communication rather than as monitoring (Morris et al. 2004: 1153). On the other hand,

²⁷ Quoted in Pols (2010).

an apparently innocuous device like a mobile phone may be regarded as a monitoring device by a person who feels pressured to be “on call” by others. Several participants in our study felt distrustful of the mobile phones their children had bought them. They either abandoned them, or adopted them only gradually after becoming personally persuaded of their value.

“I don’t want to have my daughter keep checking on me,” one man frankly stated. “She’ll never leave me alone; she’ll torture me!” Several participants “couldn’t remember” where they had placed their mobile phones or they used them only for specific purposes, and then abandoned them. One man, for example, had found his mobile phone to be quite useful when he was volunteering as a driver for a social service organization. After an injury ended his volunteer service, he abandoned the phone and later was unable to locate it. In an extreme case, one woman angrily threw her new gift phone across the room, protesting her threatened loss of privacy. After several months, however, she learned how to use it to keep track of her busy schedule. Once she assumed ownership over the device, she no longer perceived it as a personal invasion.

Current debates: tagging

The use of Radio Frequency Identification (RFID), or “tagging”²⁸ of confused elderly persons at risk of wandering away from home evokes contradictory responses. On one hand, it seems like the ideal solution for reducing the person’s risk, while gaining a measure of freedom. On the other hand, subjecting the person to constant surveillance becomes an ethical issue that cannot be taken lightly. Many professionals are enthusiastic about tagging, and regard the ethical discussion something to get “out of the way” so that policy makers can finally institute the practice. This works, however, to block discussion, rather than encouraging an examination of the nuances and complexities raised by tagging. As Nicholas Christakis argues, “ethical systems... do not exist in order to eliminate ethical discourse....they provide a frame for such discourse...” (Christakis 1992: 1089). He adds, “in the thick of ethical differences, the goal should be to *engage* rather than *abolish* ethical conflict.”

Geriatrician Julian Hughes²⁹ tells the story of a man with dementia who was informed that he would be moving to a nursing home—something he dreaded—because of his tendency to wander away from home. Later that evening he

again wandered away from his house and he was later found dead. Hughes found it notable that when he shares this story with professionals, most of them express relief that the man escaped an unwanted fate, even though they continue to privilege soma over spirit in their work with vulnerable seniors.

The tagging debate will not be settled easily because it forces us to confront competing tendencies between the will to freedom and the impulse to protect, both of which define us as human (Glass et al. 1986: 117–12; Lichtenberg, and Strezpek 1990). This is messy terrain, but to ignore our differences, Christakis argues, is to “delude ourselves into thinking there is more commonality of belief than really exists” (Christakis 1992:1089). Competing commentaries, he adds, will illuminate “what the other obscures” (Christakis 1992:1090). To move the ethical debate forward, it would be useful to develop a catalogue of test cases on tagging and other kinds of monitoring as these case studies unfold, and to trace how the deliberations and solutions have been worked out, both positively and negatively over time for those involved.³⁰ Universal principles that do not allow for messiness will be less useful for informing a developing body of knowledge about best ethical practices (Wright 2009).

Future considerations: emergent ethical questions in monitoring research

Research involving the longitudinal monitoring of behaviour may also raise new questions and new ethical challenges. One research project, for example, is seeking to establish unobtrusively monitored behavioural biomarkers for early detection of cognitive impairment. The study participants, seen as the main stakeholders and recipients of feedback, were informed that they would not be receiving feedback about their future cognitive status, given the uncertainty of the findings and length of time to complete the research. Most participants indicated that they did not want this information even if it were to become available. Now if the research eventually reveals confident biomarkers of future cognitive decline, would the researchers’ ethical responsibilities change? Would they now be obligated ethically to inform study participants of their risk, even though the participants did not want this information? Would they be obligated to forward this information to the family or clinicians for referral? (Hammel 2004: 128–129). Doing so would violate the person’s wishes for confidentiality. However, under liberal ethical principles that prioritize reason, might the participant’s potentially changed cognitive status (toward incompetence) free the researchers

²⁸ Communication on Radio-frequency identification (RFID) in Europe: steps towards a policy framework. COM (2007) 96, Brussels, 15 March 2007. http://ec.europa.eu/information_society/policy/rfid/doc/rfid_en.pdf, cited in Ethics of e-Inclusion of older people, Senior Discussion Paper No. 2008/01, April 2008.

²⁹ Julian Hughes, personal communication, 21 April 2008.

³⁰ See SENIOR’s recommendation to “promulgate the use of good practice case studies.” Wright (2009: 77).

to share this information with others, even against the participant's wishes? Given such unforeseeable circumstances, researchers might seek to protect confidentiality by obtaining advanced directives³¹ from study participants while they are still clearly competent, in order to know how to proceed with revealing such information in the future, should the research participants' cognitive status change.

Discussion: Is monitoring a threat or protection against loss of privacy?

At its extreme, the uneasiness experienced with being monitored reflects a genuine societal threat—particularly for more vulnerable persons—of infringements not only on their privacy, but on their very right to self-determination (Mollenkopf 2003: 209–210). A person who is regarded as cognitively impaired becomes extremely vulnerable to losing self-determination. Even persons who are not so impaired, but whose behaviour is nonstandard can be subject to professional control and lose personal freedoms (Culliton 2008:1).³² In an age where civil servants must handle excessive case loads and quickly dispose of cases (Rhodes 1991), their decisions regarding such serious matters as institutional placement may have drastic consequences for that person. As some social critics have reminded us, preventive practices in a risk-averse society can lead to expulsion of those deemed less fit and to a collapse of consent into compulsion (Rose 2001: 3). In the wrong hands, without precautions in place, access to tracked behavioural data might similarly be misused.

On the other hand, as Eric Dishman convincingly argues, IT monitoring creates new possibilities to maximize a person's ability to delay or even completely avoid institutionalization, where loss of privacy is almost certainly guaranteed.³³ The challenge for those who decide is to be ever vigilant of practices and structures that impede the promotion of capacity and freedom. This requires diligently finding ways to maximize protections of persons, no matter how impaired, while minimizing invasion of their privacy. The difficulty of this task is a testimony to its complexity.

³¹ These directives, though by no means a perfect solution, could be similar to those designed for disclosing a disease. See Keeting et al. (2005).

³² See also Mordini et al. (2009) on limited guarantees of informed consent.

³³ See MacMillan (2006) for interview with Dishman. See also Dishman (2004).

Self-monitoring and information seeking: the more insidious threat?

As monitoring technologies become increasingly available, the dilemmas they produce will offer us clues for evaluating their relative value versus privacy invasion factor. In the meantime, it is worth noting that whatever is being monitored provides only a partial view about the person (Lefebvre 2004: 77) and that caution must be exercised when deriving inferences.

There is evidence that as people grow older they become more interested in exploring their inner life and spiritual values than being concerned with privacy invasion.³⁴ Perhaps a more insidious threat, then, is not from external surveillance at all. As one older woman in our study shared, “computers are a terrible time waster; they keep me away from things that I value more.” It may be that our own culturally shaped pursuit of information and our regular self-monitoring of body, brain and behaviour (Rose 2001) will regrettably divert us from attending to the very meaning of life as we face its final chapter.

Concluding remarks

Policy solutions directed at addressing problems of ageing have too often been driven by the interests of the most powerful stakeholders over the wishes of the vulnerable persons who are most directly affected by the solutions. Such was the fate of millions of older persons in the United States who since the 1950s were destined to live out their lives in institutions, given the absence of other choices. Today, the e-solution that has been embraced to promote digital access and independent living of older persons has similarly been crafted mainly by stakeholders in positions of power (policymakers concerned with promoting e-inclusion, cutting costs, and developing jobs, and researchers and business leaders hoping to expand the e-sector and expand profits). Despite the enormous potential of this approach, it should not exclude alternative options that some elders might prefer. Policy makers must find ways to address these preferences, while cautiously moving ahead to implement their current programme.

Toward that end, this paper has sought to encourage more equitable and better informed decision making by urging those in charge to carefully examine the assumptions that have driven past solutions beyond any of the more pragmatic interests of the stakeholders. It has also

³⁴ Nohr, Oyvind. Conference paper, “The competent seniors: Ageing and the use of digital media—conflict or happiness.” Presented at the Socio-Anthropological Workshop on ICT and Ageing, Brussels, 2 June 2008.

encouraged careful examination of the ways in which certain ethical principles (e.g., those emphasizing moral autonomy and responsibility versus others emphasizing human dignity) can actually be damaging to vulnerable persons (cf. Holstein and Minkler 2003). A greater understanding of these issues will extend our capacity to be help older citizens, especially the most frail among them.

Even elders who are afraid of using information technologies (cf. Mordini 2007) may very well benefit from their application within their home environment, e.g., invisibly embedded sensors that may assist them in remaining at home. Still uneasiness persists among many older persons with regard to e-technologies. It may be that some of them fear these technologies will replace warm human contact (Zwijssen et al. 2011: 419). Others may have an unsettling fear that ICT will obviate their need for other persons ... while never quite filling the void. Perhaps even more disturbing is the awareness that ICT, like genetics, may be changing our fundamental human nature. As Nicholas Rose observed in relation to the genetics revolution, “*The philosophical status...the very ontology—of human beings is being reshaped through the decisions of entrepreneurs... geneticists ... clinicians...*” (Rose 2001: 20).

Poignantly, the same can be said of ICT today through the investments of researchers, clinicians, engineers and designers, government agents, and entrepreneurs. As sensors are being implanted into human beings, “and directly connected to their nerve cells,” the distinction between *natural* and *technological* will become blurred and our ontology will come into question (Rose 2001: 20). The distinction “between the *individual* as subject, with his or her own body and identity, and *technology* as object” that is neutral and separate from the individual (Mollenkopf 2003: 212) is no longer tenable in the digital world. As Donna Haraway has long argued, “We are all cyborgs” (1995). The erosion of boundaries—between the organic and inorganic, the subjective and objective, and the human and inhuman—stirs our imaginations, forcing us to question the very make-up of our alterable material being, and compels us to uncomfortably confront uncharted territories and challenging ethical frontiers. As we consider the future and the challenges it will bring, it is worth speculating about the directions toward which we intend to move, the assumptions that will help us define them, the values that will guide us, and the means by which we should proceed.³⁵ The following question may help spark our imaginings.³⁵

- What kind of future do we envision as entrepreneurs, scientists, clinicians and citizens?
- How do we wish to see older people in it?

- How can future visions of ageing maximize the benefits of ICT, but not be driven by it?
- How can key stakeholders control the shape and integration of home technologies?
- Finally, as we face life’s last chapters, how might ICT contribute to our understanding of what it means to be human, while not diverting us from achieving that understanding?

Our ultimate challenge will be to handle demographic pressures by using rational technological solutions for needed care, without losing sight that they can take us just so far.

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