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Home-Based Care, Technology, and the Maintenance of Selves

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Abstract In this paper, I will argue that there is a deep connection between home-based care, technology, and the self. Providing the means for persons (especially older persons) to receive care at home is not merely a kindness that respects their preference to be at home: it is an important means of extending their selfhood and respecting the unique selves that they are. Home-based technologies like telemedicine and robotic care may certainly be useful tools in providing care for persons at home, but they also have important implications for sustaining selfhood in ways that are of value to individuals and those who care for them. I will argue, by appealing to Hilde Lindemann's notion of "holding" persons' identities in place, that technological interventions are not only useful tools for improving and sustaining health and good care at home, but that they may also help to extend our personal identities and relational capacities in ways that are practically and ethically good. Because of these important goods, I will claim that there is a *prima facie* moral duty to do this "holding" work and that it is best done by family members and loved ones who are well suited to the job because of their history and relationship with the individual that needs to be "held" in place.

Keywords Home-based care · Assistive technology · Feminist ethics · Aging · Cognitive decline

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Introduction

My goal in this paper is not to morally evaluate specific technologies for use in home-based care, as several authors have already done well (Dittmar et al. 2004; Hicks 2013; Bauer 2001; Zwijsen et al. 2011), but to consider how those technologies may positively relate to our identities and our personal spaces. As I will argue, home-based technologies can serve the moral good of extending an individual's opportunity to remain at home,[1] a space that is imbued with her memories, that is familiar in its contours and configurations, and that may sustain her very sense of self.[2] As more technologies are developed for use at home (including telehealth technologies that monitor a person's vital signs and technologies that serve as a memory for the individual—e.g., to remind her whether or not she has taken her pills; where she has placed objects; when she has appointments; and so on),[3] such an analysis of home-based technology and the self becomes smore urgent.

In what follows, I will argue that there is a deep connection between home-based care, technology, and identity. Providing the means for persons (especially older persons) to receive care at home is not merely a kindness that respects their preference to be at home: it is an important means to extending their cognitive capacity and respecting the unique selves that they are. Home-based technologies like telemedicine and robotic care may certainly be useful tools in providing care for persons at home, but they also have important implications for sustaining selfhood in ways that are of value to the individuals and those who care for (and about) them. Offering home-based technologies may result in better processes of informed consent in health care decision-making, since it allows individuals to make medical decisions or to reflect on options in the familiarity of their homes, where there are unique cues, practices, and configurations of objects and furniture that allow for more complete and authentic decision-making. I will argue by appealing to Hilde

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[1] The term "home" may have a variety of meanings, but for the purposes of this paper it will denote the space where an individual primarily resides that is deeply personalized and meaningful. Home is the place where one is most authentically herself, and where she feels most comfortable. By this definition, a nursing home or long term care facility could also be "home" if the space is personalized and deeply meaningful to the individual. Note, however, that what matters is whether the individual in question views her space as being "home," not how her adult children or others view it.

[2] For the sake of simplicity, and given that the majority of elderly persons receiving care at home are women, I will use the terms "she" and "her" throughout this paper when referring to an elderly individual.

[3] The kinds of technologies that are relevant to my discussion in this paper are home based technologies that run the gamut of assisting the individual resident with everyday tasks (remembering to take her pills, using telemedical technology to contact care providers, or automatically turning off burners if they are accidentally left on) to collecting data so caregivers can monitor the health and function of elderly patients at home (for example, by using advanced technologies like "SHIMMER" which is a body-worn sensor that tracks information about a patient's gait, stride length, or tremors to determine if there are any negative changes taking place; or the magic carpet, which can detect and map an individual's walking patterns, thus allowing physicians to detect even a small deterioration in a person's walking patterns that might not be evident to a caregiver or family member. For more on these technologies, see http://www.gizmag.com/magic-carpet-detects-falls/23979/ and http://www.shimmersensing.com/research-and-education/applications/#applications-tab).

Lindemann's (2009) notion of "holding" persons' identities in place that technological interventions are not only useful tools for improving and sustaining health and good care at home, but that they may also help to extend our relational capacities in ways that are practically and ethically good. Because of these important goods, I will claim that there is a *prima facie* moral duty to do this "holding" work and that it is best done by family members and loved ones who are well suited to the job because of their history and relationship with the individual that needs to be "held" in place.

New telemedical and assistive technologies now make it possible for individuals to safely remain in their homes long past the time they would have been able to do so prior to the technologies' inception. In many cases such technologies also extend individuals' relational and communicative capacities so that they are able to maintain their familial and other social relationships. Philosopher of geography Ed Casey notes that the ability to remain at home for an extended period of time is significant in that home is the site of one's identity and one's memories. As he states,

> …more than comfort is at issue in the elective affinity between houses and bodies: our very identity is at stake. For we tend to identify ourselves by—and with—the places in which we reside. Since a significant part of our personal identity depends on our exact bodily configuration, it is only to be expected that dwelling places, themselves physical in structure, will resemble our own material bodies in certain quite basic respects (1993, p. 120).

The use of technology to allow individuals to be cared for at home, then, is no less than an issue of identity maintenance: we are unique selves in large part because of the spaces we inhabit, and because of our interactions with, and ability to interact with, others. Without this capacity, who we once were may become lost, sometimes irrevocably. In the next section, I will address this issue in more detail to develop the connection between our selves and our homes.

Why Home Matters

Iris Marion Young has pointed out that "house" and "home" is the space where our identities are maintained, and where meaning-making activity can take place. She encapsulates the deep meanings with which we associate home, homemaking, and family life as follows:

> Home is the space where I keep and use the material belongings of my life. They are mine—or ours, when I live together with others—because I/we have chosen or made them, and they thus reflect my needs and tastes. Or they have found their way into my home as inheritance or gifts or perhaps even by accident, but then I have appropriated them. The home is not simply the things, however, but their arrangement in space in a way that supports the body habits and routines of those who dwell there. The arrangement of furniture in space provides pathways for habits—the reading lamp placed just

> here, the television just here, the particular spices on the rack placed just so in relation to this persons' taste and cooking habits" (1997, p. 150).

No small wonder, then, that despite the onset of physical and sometimes cognitive loss, home maintains a special meaning and enables continued function, even when one's increasingly limited capacities might indicate that one should no longer be able to function there. The intuitive arrangement of things in one's home, as Young eloquently phrases it, "supports the body habits and routines of those who dwell there." In a very real sense one's home is an extension of one's self, since it provides "pathways for habits" that become deeply ingrained. The placement of things, and one's habits within home, make it deeply familiar and thus second nature to negotiate in a way that is unique to that space alone. Having a home and being cared for at home also serves to mark an individual (especially an individual of advanced age) as a unique self, someone with a unique history who deserves respect.[4]

These observations regarding the way one's habits and routines in the home support memory and sense of self are not mere philosophical musings, but are supported in literature that addresses memory and dementia. A number of sociological, gerontological, and physical therapy studies are showing a positive correlation for individuals with dementia between familiar spaces, routines, or memories of pastimes once enjoyed and the extension of their cognitive capacities.[5] Indeed, certain actions may become so deeply ingrained in an individual's memory and/or muscle memory that she is capable of continuing those actions even when working memory begins to fail. To take the activity of cooking as just one example, one study suggests that "actions involved in preparing food are activities that use procedural memory of habitual activities learned in the past," and as such, they serve as stimuli that promote reminiscence and cognitive function (Nawate et al. 2008). Receiving simple instructional cues or technological support at home may be sufficient to remind individuals in earlier stages of dementia about when and how to complete the activities of daily living, such as completing their morning bathroom routine, dressing, or setting the table (Lancioni et al. 2009). As Diane Jokinen and her colleagues note in their report from the National Task Group on Intellectual Disabilities and Dementia Practices, when dementia is diagnosed, the emphasis should be switched from skill acquisition to skill maintenance; routines in the home should be standardized "so the person is able to manage their own day and living situation to the greatest extent possible (e.g., meal, activity, exercise, bathing, bed and wake times)"; and personally valued activities should be redesigned so that they are "failure-free" and emphasize involvement with things already known rather than acquiring new learning (Jokinen et al. 2013, pp. 9–12). All these studies lend

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[4] It is especially important for older individuals to be viewed and respected as unique persons, since institution-based care takes them completely out of context. Especially in cases where an individual is experiencing some degree of cognitive decline, she may be easily seen as a body to take care of or a mouth to feed, rather than as an individual with a history, a home, and a unique set of interests (Parks 2003).

[5] As examples, see Jokinen et al. (2013), Lancioni et al (2009) and Nawate et al (2008).

credence to Young's claim that, with some accommodations for dementia, home supports the body habits and routines of its inhabitants.

Given the depth of meaning associated with home, and the degree to which one's very identity is constituted by that space, there is a *prima facie* obligation to maintain older persons in their homes because so much is at stake for them. Choosing the place and manner in which one lives and the kinds of relationships in which one wishes to engage are some of the most important choices one can make, and they seriously impact one's life meaning and enjoyment. However, this obligation is not absolute, since the elderly individual may be too confused, frail or ill to remain at home. At the very least, I argue that an older individual should be allowed and even encouraged to remain at home as long as possible, taking measures that will extend her ability to remain there. This is not because I assert that the principle of autonomy should reign supreme, but rather because such a decision speaks directly to an individual's identity and self-understandings.[6]

Furthermore, the meaning of home, being home, and feeling at home are not things that one can achieve independently. To achieve these goods requires the help and support of others—in some cases technological help and support, too—and not only for old persons or individuals with dementia, but for all of us. Feminist philosopher Hilde Lindemann argues that others have a significant impact on our "self-constituting" narratives. Indeed, others may "hold" us in our identities when we are no longer able to do so ourselves (for example, when we are ill or suffering memory loss). By how they interact with us, our loved ones can remind us of who we are (2009, p. 419) or remind others who we are, holding us in a state of identity preservation as determined by their narrative framing of our life history (2009, p. 418).

So far I have argued that home and family can "hold" our identities in place: but how do assistive and telemedical technologies fit into this picture of holding? I am arguing that at certain times and in certain applications, these technologies truly can *assist* in allowing persons to remain at home by collecting health data and monitoring health, as well as providing the cues, reminders, and warnings necessary to persons who may be experiencing deficits in memory and cognition. Assistive technology that has been designed to remind individuals that it is time to take their medications (or that they have already taken their medications) may also serve to extend the time those individuals can remain safely at home. And the increasing use of telemedicine is allowing persons with more complex health care needs—who would otherwise need to be placed in long term assisted living—to have their health monitored at home.[7] Thus, these sorts of technologies can assist in allowing individuals to remain in their own homes for the maximal period of time, meaning

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[6] Indeed, my account of the self is not rooted in a traditional notion of autonomy which sees the individual as an independent, self-sufficient, rights-bearing entity, but rather it is rooted in a relational conception of the self in which our identities come out of, and are sustained within, a community of caring others (see Mackenzie and Stoljar 2000; Nelson and Nelson 1995; Kittay 1999; Lindemann 2009).

[7] For a primer on telemedicine, please see the American Telemedicine Association at http://www.americantelemed.org/about-telemedicine/what-is-telemedicine#.VOez_fnF8gk. The rise in the use of telemedicine has been addressed by Frist (2014), Freudenheim (2010) and Worth (2014).

that the individual's identity and connection to others, as well as her psychic and physical comfort and health, is maintained.[8]

By incorporating assistive and telemedical technologies into care plans to help sustain persons at home, then, I argue that a family may be enacting what Lindemann would call "good holding" because the purpose is to maintain the individual's relationships and narrative, and to allow for continued residence at home, all aided by home-based technologies. Lindemann distinguishes "good holding" from "bad holding" in terms of the holder's adherence to stories or actions that represent "something actual about the person" (2009, p. 419), rather than how the holder *wishes* to see the individual. By using technology to help shore up the individual's physical health and cognitive capacity, one practices good holding; but in using technology to assist in holding a person to a false identity, or to place family convenience above all else, one is practicing bad holding.[9]

When considering links between identity, family, home, and technology, one can appreciate the complexity of assessing how home and technology should come together to "hold" persons in place. Consider, for example, a woman, Marjorie, who has gone through life as a mean, bitter, or hurtful person. Should her family members hold Marjorie in place by remembering and helping her to carry on those traits? If Marjorie has been significantly influenced by harsh life events (poverty, domestic abuse), it would seem cruel to keep reminding her of these personality-forming events later in her life, or even to maintain her in spaces where such events took place, when she may no longer have the memory or desire to remain there. Emphasizing happier, though less identity-constructing life events might be better for both Marjorie and her loved ones; and moving her to an assisted living facility may remove her from a home setting where she may not be or feel "at home." While this may risk creating a fiction[10] rather than actually maintaining Marjorie's previous identity, the purpose of holding persons in place is not to *mercilessly* and *inflexibly* hold them to identities that they once had. As the example of Marjorie suggests, then, whether one is "holding" others well or poorly is not determined by an appeal to a universal, abstract standard: rather, it can only be determined in a particular context based on the motivations of the holders, the ability of the person

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[8] Notice that, just as families and loved ones "hold" one another *of all ages* in memory and identity so, too, do technologies like those mentioned above "hold" us all in place. For example, while some of the technologies I mention are particularly useful to older persons who may be experiencing some cognitive decline, they are also useful to individuals in general, helping us to locate items, remember appointments, and so on.

[9] I do not think it is always wrong for families to decide to place their elderly family members in assisted living or nursing home institutions. In cases where the care needs of their loved one would place an extreme burden on family members (especially female family members, who are mostly expected to complete the care work), the family members also have a major stake in the decision to provide care at home. The goal is not to keep individuals in their homes *at any and all costs*, but to do so in a way that balances the goods that will be achieved over the negative aspects of doing so. I believe that incorporating some home-based technologies can help families to achieve these goods for their loved ones by reducing some of the care demands they might otherwise face. This issue will be discussed in more detail later in this essay.

[10] Note, however, that all memory is narrative and fictive: the stories that we tell about ourselves and others are by their very nature open to interpretation and selective telling and re-telling. See Margaret Urban Walker (2007) and Nelson (2001) for more on narrative and selfhood.

with cognitive deficits to be held in place, and the resources available to ensure good "holding."[11]

Implementing Home-Based Technologies

I have suggested thus far that: (1) insofar as it is possible, there is *a prima facie* moral obligation to assist persons to remain at home because "home" is a space that serves to shore up and extend one's sense of self and to maintain one's self-constituting relationships; and (2) technology can function as a way of allowing persons to achieve this good of staying at home. Not only can technology support the physical care of older persons at home, but it can also serve to help "hold" persons in place in the way Lindemann discusses.

Furthermore, technology can allow caregivers and loved ones better access to the content of an individual's health status, cognition, and memory, which can serve various useful ends. For example, during clinical appointments with their primary care physicians, older persons with cognitive decline may be unable to report how they were feeling weeks or even days before the check-up: technology may assist by offering a history of vitals (heart rate, blood sugars, etc.), a log of how the individual has been feeling, any activities in which she has engaged, or other relevant information. Such information, largely available to the minds of persons without cognitive decline, would be lost for the elderly individual with memory loss were it not housed externally in the technology.[12] But even better, by receiving care and completing medical checks at home telemedically, where the setting and cues are conducive to an individual remembering things better, she is more likely to receive more accurate, effective health care. As Bryan Kibbe notes in his work on technology and the self:

> It is then a function of home-based telemedical systems that they can firmly place/situate some aspects of medical decision-making and chronic disease management back within the home, that is, within a secure and practiced place that sometimes serves as the material scaffolding for a range of cognitive processes utilized for autonomous decision-making. Telemedicine does not simply allow patients and healthcare professionals to communicate about and coordinate medical care at a distance from one another but, rather, it positions people inside of highly particularized environments that have a functional role

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[11] While I do not have the space to consider this issue in detail, more work needs to be done on good and bad "holding." Family relationships can be loving, supportive, and edifying; but they can also be hateful, abusive, and destructive. Not all family members—or families—are good "holders," and not all individuals are in a state where they are able to be held in place. As dementia deepens, and home is no longer a meaningful space, such "holding" may be an impossible task for both families and those they care for.

[12] I say "largely" here because, as I have repeatedly noted, even younger persons without cognitive decline use assistive technology to remember things and to extend their cognition outside of the brain. We are all "extended minds" (Clark 1997) in the sense that all human beings use technology in various ways to hold memories. For example, without my Google calendar I would not remember what I did many months or years in the past; I can open the calendar online and access activities from five years ago, which my mind is not capable of doing.

> in the way that they think and carry out decision-making processes. Thus, where decision-making in the clinic can sometimes remove patients from the practiced places of their homes replete with cognitively significant technologies, telemedical technologies are part of the effort to repair that broken relationship between a patient and various objects by putting the patient back into lived relationship with those objects amidst the task of medical decision-making (2014, p. 254).

Telemedical technology may further advance the good health of the patient by allowing her to receive more care at home, a "practiced place" where her memories are housed, where she can avoid the need to seek transportation to face-to-face meetings in clinics, and where she may thus avoid unnecessary exposure to accidents or illnesses.

Consider one example of how home-based technology may serve this goal of maintaining an elderly or disabled person in his home. As Kibbe has highlighted in his recent work, the Veteran Health Administration's (VHA) telehealth program is geared toward allowing individuals to remain at home in cases where they would otherwise be placed in long-term residential care (Kibbe 2014). As a separate health care system, the VHA maintains 152 hospitals and 882 clinics nation-wide that annually provides care for 5.6 million veterans (Naditz 2008; Darkins et al. 2008 as cited by Kibbe 2014). This system has implemented a comprehensive telehealth program entitled "Care Coordination/Home Telehealth" that, in 2012, served 119,535 veterans and which saved $1999 dollars per veteran (Kvedar et al. 2014, as cited by Kibbe 2014).

Much like an intake evaluation to receive home health services, veterans entering the CCHT program have their care needs assessed by a care coordinator, who then determines which telemedical technologies are needed to support the individual at home. The technologies that may be incorporated into the care plan include "videophones, messaging devices, biometric devices, digital cameras, and telemonitoring devices….Biometric devices record and monitor vital sign data. Videophones and video telemonitors support audio–video consultations into the home that replicate face-to-face examinations" (Darkins et al. 2008, 1120 as cited by Kibbe 2014). As Kibbe indicates, care coordinators are in charge of monitoring the stream of patient data, identifying patients who may be at risk, and working with patients to manage their medical conditions. The use of messaging technologies that ask patients a series of questions highlight knowledge deficits, adverse symptoms, and harmful health related behaviors so that care coordinators can intervene immediately and help the patients to avoid unnecessary hospitalizations (2014, pp. 242–243).

Such an initiative by the VHA not only allows veterans to remain at home, but also serves the ends of significant cost-savings and confronts the reality of the growing caregiving shortage. Estimates suggest that by 2025, there will be shortfall of 124,000 physicians (Dill and Salsberg 2008), given the rising need for health care services and the projected number of medical school graduates. Add to this mix the predicted "age boom"—estimates are that the number of people over the age of 65 will double by the year 2050, and individuals will live longer, with more significant chronic care needs (Institute of Medicine 2008)—and one can appreciate why the development of home-based technologies, like robotic care and telemedical care, are worthy of support. There are thus economic and demographic reasons for backing these home-based technologies that go hand-in-hand with the moral reasons I have cited for supporting them.

Home-based technology involves more than just telemedical technology like that developed by the VHA, however. Increasingly, robotic care is being implemented at home to ensure the safety of persons, even older persons experiencing some degree of cognitive decline. Robots may assist with a variety of needs, including washing, tracking vital signs, monitoring the safety of the individual, reminding the individual to take medicines, and other "cognitive prostheses" that serve to support the individual at home.[13] As a recent study on what caregivers desire in home-based robotic care indicates:

> The function of the robot most demanded by the caregivers is the cognitive stimulation programme that primarily can meet the needs of the person with cognitive impairment. As a consequence of the inability to remember, the patients may forget an appointment or to take medicine correctly. Thus, the robot serving the function of cognitive prosthesis (cognitive stimulation programme, drug intake reminder and appointments reminder) that can help the elder compensate for his/her impairment is welcomed by the caregivers. The robot should serve as a cognitive orthotic, providing the elderly with reminders about their daily activities. In fact, for over a decade, efforts at designing cognitive orthotics have enabled reminders to be provided using the telephone, personal digital assistance and pager (Faucounau et al. 2009).

The Challenges Faced by Home-Based Technology Use

Although, as I have been arguing, there are a variety of moral, economic, health, and demographic reasons for supporting the advancement of home-based technology use, there are also significant moral issues that it raises. First, one might question the use of the technology itself, and the potential violations or invasions of privacy that are associated with it. For example, when data is shared, transferred electronically, or stored on computer, that information is arguably more vulnerable than a written medical file that is physically located in a medical clinic rather than being stored in a cloud. A breach of privacy for electronic medical records is greater in scale and impact than one that occurs with physical records, given the number of persons who might have access in such a breach, so one may counter that telemedicine presents heightened likelihood of privacy violations. While I do not have the space to address this concern in great detail, it is worth noting that such information requires special protection to ensure it is properly encrypted and that it is retrievable in the case of a system failure.[14] The new challenges posed by home-based technology should not

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[13] See Faucounau et al. (2009) and Heerink et al. (2006) for more on robot care technology.

[14] In his work, Kibbe (2014) details the importance of creating technologies that are transparent, user-friendly, and repairable so that they can do their valuable work of sustaining selves in personhood.

automatically count against more fully incorporating these practices into at-home care.

Countering such a privacy objection is the argument I have been constructing in this paper: that telemedical technologies may actually be an important means to achieving *better* informed consent and more effective health care, since it allows individuals to make medical decisions or reflect on options in the familiarity of their homes, where there are unique cues, practices, and configuration of objects and furniture that allow for more complete and authentic decision-making (Kibbe 2014, p. 256). This is, as I have noted, especially important in cases where patients are experiencing some memory loss, since thinking and relating from the familiar space of home can buttress their cognitive capacities.

A second challenge to the use of home-based technology concerns the possibility that its implementation may have the ironic result of limiting older persons' relationships and community by serving to further isolate them in their homes. Those who defend the use of home-based technology like robotic or telemedical care do so on the grounds that they are not meant to replace human care and touch, but only to assist with or supplement it. Yet, given the looming shortage of caregivers mentioned earlier in this paper, and the strain put on family members to be present 24/7 for their loved ones, it is difficult to see how the use of such technology will not have the effect of limiting human contact. Allowing machines or remote medical care to replace hands-on caretaking may result in a lost opportunity for individuals who remain at home to engage in conversation and human touch, something that is already woefully lacking for many of our elderly citizens.

Thus, I argue that extreme care is required to ensure that in cases where telemedical or robotic care is implemented in the home that it does not serve to *replace* rather than *assist* human caretaking. This is particularly the case where robotic care may be replacing the human touch and the mundane but meaningful human interactions that occur between caregivers and those receiving care. Solutions to home-based care that cement the alienation of citizens from one another should be viewed as morally problematic. One principle by which we can determine the value of a caretaking technology is by asking if it enables an individual to function without at the same time further alienating her from other human beings.

As I have argued thus far, there may be rich relational goods associated with the development of home-based technology, but such goods are cancelled out if they result in older citizens, who may already be at risk of experiencing loneliness and solitude, being cut off from their loved ones and/or their communities. Any evaluations of home-based technology should outright reject mere cost-cutting substitutions of human caretakers through the use of "assistive" technology. While there may sometimes be a fine line between "assisting" and "replacing," in a capitalist system such as the United States in which health care is driven by profits, one can presume that cost-cutting may become the ultimate goal.

A third concern relating to the further advancement of home-based technological care concerns the claim that we should give moral weight to an individual's preference to remain in her own home. If older individuals are to receive care at home then such an arrangement requires a workforce of home caregivers to provide the hands-on care that is required to help make this happen, even if assistive and telemedical technologies are available. As many bioethicists writing on aging and long term care have pointed out, this requirement falls heavily and almost exclusively on women, as both family and paid formal caregivers (see Parks 2003; Holstein 1999; Lai 2012). While caregiving can be fulfilling and rewarding (Nelson and Nelson 1995), it also has detrimental effects in terms of caregiver injury and care "burnout" (Parks 2003, Maslach 2003; Lombardo and Eyre 2011); and it also serves to support the very notion that home may be a "natural" space where women belong. Thus, the desire for at-home care is fraught with gender-based concerns that must be taken into account if such a mode of caregiving is to not unfairly burden women.

Perhaps most importantly, the work of "holding" persons in place may tend to fall primarily on women such that holding work itself may carry unintended gender expectations. Women tend to have responsibility for holding their loved ones' identities in place given the gender role socialization that trains women to be sensitive to the needs of others and to advocate for others (especially their children and elderly parents). If "holding" persons in identity at home is an obligation that arises out of the deep connection between home, self, and family, then such holding work will need to be shared equally by men and women alike. Being a "holder" (which requires frequent contact, repeating stories over and over, and constantly advocating for the one that is being held in place) is exhausting, even if there is only one elder in one's life at a time. Someone working as a "holder" for multiple relatives or friends can be run ragged—and their efforts may be further strained by their own experiences of worry, loss, and heartache as their loved ones slip away. The goal of keeping seniors at home may significantly add to the burden of care on loved ones, and for this reason it is a duty that must be shared equally within families, and assisted by service agencies and governments.

Any proposal to advance home-based technological care, then, must address the gendered care expectations that are built into our system of providing care and doing "holding" work at home. Ideally, since all citizens are the beneficiaries of care and holding by loved ones, the responsibility for such work should be divided evenly among the population. This is of moral concern when one considers that "Many families caring for terminally ill older adults report making major life changes and personal sacrifices to care for their relative. Furthermore, caregiver burden has been identified as a risk factor for worsening caregiver physical and psychological health, worsening health-related quality of life, compromised immunity and mortality" (Garlo et al. 2010, p. 2315).

While various assistive home-based technologies may offer female caregivers some relief (by, for example, eliminating the need to do some of the back breaking work of bathing or transferring persons from bed to wheelchair), and telemedical technologies may improve oversight of a loved one's care via electronic record-keeping, human caregivers are still required to take on much of the hands-on care, to oversee the technology that is being used at home, and to do the essential work of holding identities in place that I have addressed previously in this paper. Thus, no amount of technology is going to eliminate the need for human caregivers (nor, as noted above, should it, since such an outcome would be a significant loss to many care recipients whose only human interactions are via their routines of daily care). Given the devastating effects that the burden of home care often entails for family caregivers, any caring society should make this issue a national concern.[15] Providing home-based care for citizens and holding their identities in place is thus a social and political project in which we must *all* engage: it must not be viewed as merely a private individual family's "problem" to be solved as best they can (Parks 2003). It is to society's role in providing home-based technological care that I will now turn.

Society's Role in "Holding" Persons in Identity

So far I have identified the need for technology in home-based care to serve the end of "holding" individuals in place—maintaining their capacity to sustain relationships and identities, and to make effective medical decisions. This holding is of moral value because it serves to maximize the cognitive function that is still available, thus allowing one's continued opportunity to relate to friends and loved ones in meaningful ways, while simultaneously allowing one to remain at home, where one's memory and self is deeply rooted.

Who should be held responsible for "holding" persons in place, however, is not a settled issue. In the United States and other countries, families are largely responsible for providing the kind of care necessary to keep their elders at home, and for holding their identities in place. Indeed, given the account by Lindemann it is difficult not to take the family to be largely responsible for such "holding" work, since (in many, if not most, cases) our families know us best and it is our families upon which we most often confer authority to speak for us when we are no longer capable of doing so. This is especially so in times of illness or injury, where we become estranged from ourselves. However, this work of holding our loved ones in place is in part a social obligation, and should not be read as simply a private one. As already noted, the work of holding others in place has tended to fall almost exclusively on women (as wives, daughters, daughters-in-law, sisters, and friends) which has had the undesirable effect of subjecting women in particular to such difficult (though, often rewarding) emotional work. Relying too heavily on women to do the work of holding on to one another may only serve to tear asunder the family unit as the demands of care start to wear on them. Home care and holding work is privatized by understanding it as a problem for individual families and by having the work done almost entirely by female family members. This will continue to be the case as long as gender role socialization emphasizes women's relational qualities, while minimizing its importance for men. Clearly, if we are to hold on to one another in any meaningful way, it will require assistance from all family members (not just women), and help outside the family unit, in order to be able to

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[15] Of course, this moral "ought" is an ideal that some nations cannot possibly meet due to a weak economic, political, and social infrastructure.

do it well. There is a *social* obligation to hold on to one another that must be recognized if holding is going to work. As Lindemann states,

> …societies, too, have a role to play in helping us hold on to one another. If the familiar places and objects of home importantly hold us, it is better for us, all things being equal, to stay in our homes as long as we possibly can. However, when home care for people with progressive dementia is left to family members almost entirely, the familial capacity for care may be exhausted well before the benefits to the demented person of living at home have come to an end. In the United States, a nursing home then becomes the only option for many people….This state of affairs is not inevitable….Eventually, nothing will keep selves of progressively demented people from coming completely undone, but until then, they and their caregivers need the rest of us to hold them—if not as well as we can, then at least better than we do (2009, p. 423).

Conclusion

This essay has highlighted the ways in which home-based assistive and telemedical technologies can support the continuation of selves at home, a space of deep personal meaning. I argue that insofar as being at home allows individuals suffering physical and mental decline to extend their cognitive capacities, there is a *prima facie* obligation to maintain them there. Living the "good life" in one's later years seldom, by anyone's account, includes living one's remaining years in a nursing home or other care institution; and this is not mere prejudice against institution-based care. As Iris Young has pointed out, one need only think of the difference between staying at a hotel—even a nice hotel—and being at home. Though hotel rooms provide for all one's needs, offering hot water, heat, a comfortable bed and so on, there is, as she states, "nothing of one's self, one's life habits and history, that one sees displayed around the room. The arrangement is anonymous and neutral, for anyone and no one in particular" (1997, p. 149). By contrast, being at home means feeling at home, even where one's home may be small or simple.[16]

The good that can be done by home-based technologies, then, requires wider assistance in order for the individual with illness or physical/cognitive decline to benefit from them. At minimum, it requires a family of women *and* men[17] that can maintain the individual's history and narrative to help hold that individual in her identity. But more than this, it requires broader support structures that make it

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[16] In stating this, I do not assume that everyone feels safe, comfortable, or loved in her home space. I recognize that some homes are the sight of abuse, violence, and unspeakable harm, and that some homes are in no condition to be inhabited by families, despite the fact that families live in them. I would venture to say that all persons should have the opportunity to have a home where they do feel safe, comfortable, and loved; our job, then, is to do what we can to allow individuals to stay at home, where that is desired by the individual, or to help individuals who do not have such a place to find one.

[17] This is not to say that men do not do the kinds of "holding" work mentioned in this essay. However, as Carol Gilligan noted over 30 years ago (Gilligan 1982), we need to ensure that men and women develop equally within themselves orientations towards both justice and care so that we can all be balanced, fully flourishing selves.

possible for families to do the good work of holding their loved ones in place.[18] And on this score, as Hilde Lindemann has noted, we can always do better.

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[18] These support structures might include a variety of strategies such as funded respite care so familial caregivers can take breaks from care demands; state supported implementation of home based technologies to relieve families of the cost for their implementation; or flexible work schedules that permit caregivers to check on family members during the day. An excellent argument in favor of providing care for caregivers can be found in Eva Kittay's work, *Love's Labor: Essays on Women, Equality, and Dependency* (1999).

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