The Uncertain Bodies and Spaces of Aging in Place

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Abstract
In the United States, "aging in place" has been established as the preferred method of aging. This article examines the work, processes, and tensions involved in aging in place in the southwest US, focusing on the experiences of chronically ill older adults receiving Medicare-reimbursed home health care. Based on an in depth ethnography, it examines the resources and work that go into aging in place amid uncertainty, and highlights how processes related to the integration of person and place are negotiated and contested between older adults, family members, and home health nurses. Drawing on definitions of place from geography, I argue that aging in place should be understood using a processual lens to highlight the ways that health regimes aimed at facilitating aging in place can, at times, reinforce and introduce sense of bodily risk, shift embodiment and daily practice, and require negotiations among household members. I also point to the difficulties people face in maintaining aging in place when supports are lacking and futures uncertain.

Keywords: place, home care, medicalization, United States

In the United States since the 1980s, there has been a growing political and social imperative for "aging in place." However, the value, experience, and processes involved in remaining at home for the elderly have not been sufficiently investigated, particularly in this time of economic insecurity, scale backs in social services, and uncertainty about entitlement reform. Aging in place is a period of change and the work, adaptations, and resources required to support and enable remaining at home can be fraught with complications.

Home health (HH) care often provides bridging care for persons with chronic illness. Following acute health problems, frequently involving hospital and or rehabilitation stays, HH professionals assist patients in their home on a short-term, intermittent basis. Receipt of increasingly high-technology care in the home allows an otherwise relatively immobile, ill person to remain at home. While these processes can lend a sense of assurance in the face of uncertainty, they also must be negotiated among household members and can involve individuals in new ways of experiencing and acting upon their bodies, and inhabiting their homes. When HH necessarily ends, people are often left to do the work of chronic illness and manage uncertain futures in an environment of few known supports and threats to benefit programs.

Background

Aging in Place

Throughout the 1900s, the percentage of older adults institutionalized within nursing homes grew steadily (Estes and Harrington 1981). Within the US, this trend was facilitated by gains in longevity, rise in chronic disease, medicalization of aging, changing family residence patterns, specialization of hospitals, increasing

government support for these facilities, and development of the nursing home industry within a medical model (Johnson 1987).

The idea of "aging in place" gained broad prominence in the 1980s along with positive development theories of aging (e.g., Atchley's continuity theory, concept of "successful aging"). These theories purport that frail older adults can remain more independent and enjoy a better quality of life, as well as avoid the trauma of relocation, by residing at home. They contend that especially for the elderly, an attachment to place is adaptive (Rowles 1993). Advocacy for aging in place took place amid broad social and economic shifts, such as deinstitutionalization efforts, concerns about nursing home quality and safety, and reforms in hospital reimbursement. Advocates argued against previous age-segregation approaches to the problem of aging and for more inclusive, integrated solutions. Policy makers facing fiscal crisis, were concerned about the high costs of health care and the expense of handling aging issues within facility-based medical models (Estes and Harrington 1981). They were also subject to lobbying efforts of the health care industry and providers of community health services. Providing care in the home and community became viewed as a more cost-efficient means for caring for older adults in their later years. Thus, advocacy takes into consideration both humanistic and economic concerns (Estes and Harrington 1981; Wiles 2005).

Elements of Place

The construction of place is a lifelong process. Homes as places are multifaceted, subjective and objective, as well as dynamic. They are sites for the weaving of social relationships and practices, and the production of narratives of self (Dyck et al. 2005). As such, place must be analyzed in relation to its physical and relational contexts (Wahl and Lang 2004). One such relationship is that between person and place.

While home is often conceptualized in a bounded way, as a personal and private space standing outside public life, it is better thought of as a permeable space, at times more or less accessible to the outside world. Homes are permeable both physically (e.g., through the introduction and exit of people, materials, and equipment) and ideologically (e.g., social values), and thus affected by broader conditions, supports, and demands. Because the home is not fixed or bounded, Moss (1997) has suggested the concept of home be pushed in a relational sense, to be "home environment." In the context of the elderly, particularly those with chronic conditions, understanding the relationship between the home and the outside world becomes important in understanding how aging in place is accomplished.

The imperative to age in place draws on cultural understandings of place and home. Within the US, the successful acquisition and maintenance of a home has become a sign of adulthood, competency, and independence. Home is often taken for granted as a safe and therapeutic landscape, a site where control and dignity can be maintained. In the context of aging, this stands opposed to hospitals and nursing homes (Fairhurst and Vilkko 2005; Wiles 2005). These institutional settings segregate residents, disrupt normal social relationships, limit residents' control over their space and time, and reinforce associations between old age and dependence (Hugman 1999; Johnson 1987). They evoke many negative emotions and are sometimes perceived as sites where one waits to die (Wiles 2005).

By contrast, living alone can signify mastery, control, and competence (Rubinstein, Nagy, and Kilbride 1992; Sixsmith and Sixsmith 2008). Definitions of place often stress a "rootedness" or "centeredness," and senses of belonging and purpose (Williams 2002). Aging at home is represented as providing opportunities for individuals to construct their daily activities and networks of support in ways that are individually meaningful and coherent (Rubinstein, Nagy, and Kilbride 1992), and giving a sense of comfort, security, and privacy (Sixsmith and Sixsmith 2008). It is also described as ensuring continuity in environment, independence, and social ties (Barrett, Hale, and Gauld 2011), and generally a better quality of life.

The discourses that take aging in place as the ideal have linked old age as a problem of place, and made it imperative that the domestic sphere be the "arena for aging" (Fairhurst and Vilkko 2005:2). Successful aging is realized whence one is able to continue in place, when one is able to "stay put." However, despite homes' positive associations and the comfort they can provide, homes are not always safe or comforting places, especially when supports and resources are scarce (Sixsmith and Sixsmith 2008). Lack of access to safe, accessible and affordable housing and transportation have been identified as barriers to aging in place (Farber et al. 2011). While there are broad rhetorical supports for aging in place as both a humanitarian and financial good, acknowledgement of the social and material supports needed for its realization are lacking.

Aging Bodies in Places

The materiality of a place is dynamic, changing with the composition of people and things within it and the resources available . When person-environment fit, place contributes to well-being and is thus therapeutic (Williams 2002). The fitness of places and people are in constant flux, as both people and environments change. People actively create their homes and surrounding environments toward certain ends, arranging materials such that activity and pursuit of interests are facilitated (Rosel 2003). The process of place integration is a lifelong one (Cutchin 2003), however for older adults with chronic illness, particular shifts are highlighted. While discourses attempt to present a more positive representation of the process of getting older through the ideal of aging in place, aging in itself remains a highly marked endeavor, inscribed at every corner with risk. Perils such as loss of senses, falling, dementia, dependence, abuse, and being forced from one's home are socially salient and associated, at a societal level, with the conception of aging.

The medicalization of aging emerged in the twentieth century with changing family patterns, the marginalization of older adults, the rise of gerontology as a discipline, and, ultimately, the construction of "old age" as a problem (Arluke and Peterson 1981; Estes 1979; Estes and Binney 1989). Narratives within medicine identify the aging body as physiologically distinct, which helps to legitimize the surveillance of older adults for signs of deviancy. Such signs are then medicalized and intervened upon (Powell and Longino 2001). Tools such as geriatric assessments are used to uncover abnormalities and extend the medical gaze from the person into his or her behavior, social system, and environment (Kaufman 1994). As medical institutions' processes define, manage, and treat within the narrow medical model, the potential increases for the management of the elderly (Estes and Binney 1989), particularly within the home.

As functional status declines, items in the home can become barriers, with adaptations necessary for best fit and practical utility. Once mundane objects can become hazards. These new dangers reinforce and make more visible the riskiness of the bodies associated with them, and by extension, the vulnerability of being old (Barrett, Hale, and Gauld 2011; Fairhurst and Vilkko 2005). As one's space is conceived of as a place of potential risk and harm to the self, it can in turn affect the embodiment and practices of the older person within a once known and familiar space (Sixsmith and Sixsmith 2008), and enhance the sense of uncertainty.

The inscription of bodies and spaces with risk provokes attempts to control those dangers with therapeutic checking and treatment practices (e.g., medical assessments and monitoring, medications, exercise) and material adjustments (e.g., assistive devices). These changes generally aim to bring person-environment back into better fit, however they might have unintended consequences (e.g., create new hazards) and be resisted by household members because of what they symbolize or how they change existing home practices (Sixsmith and Sixsmith 2008). Throughout these processes, there is a tension between risk, uncertainty, and control.

As efforts are made to help people age in place, new care practices and materials enter the home space from the medical sphere. As yet, there is little literature on how the home becomes site for new caregiving regimes (Wiles 2005) and how this affects bodies within spaces. Below, I examine the dynamic nature of aging place within the context of home health care.

Mediating through Home Health Care

Medicare, the US insurance program for people older than 65 years of age and/or disabled, has a home health (HH) care benefit. HH is one of the few home-based supports for which Medicare reimburses. Persons deemed to be homebound, with intermittent (acute) skilled need can have HH ordered by a medical doctor, if their condition is expected to improve under that care. Care is provided by non- and for-profit Medicare-certified HH agencies.

Depending upon needs determined by a standardized assessment, HH services may include skilled nursing care, physical and occupational therapies, social services, and HH aide help. There is no limit on number of visits for a beneficiary during a care episode. Persons with Original Medicare plans (i.e., administered by the government) are given 60 day care episodes which are reimbursed according to assessed needs; HH agencies decide how many visits to allot during that period and/or whether additional care episodes are needed. Persons with Medicare Advantage plans (i.e., administered by private insurers contracted with the government) are often authorized for a handful of visits at a time, though this depends on the nature of the plan (e.g., HMO, PPO); HH agencies can request additional visits as needed.

The strictures of Medicare HH benefit, which stand as a model for other US private insurers, lock the provision of care in a medical framework (Cabin 2007; Hood 2001). While nursing care in the home has traditionally been

more custodial in nature, the Medicare benefit was always intended for acute not chronic care (Cabin 2007). Thus, the acute, intermittent limitations placed onto the benefit affect how patients are assessed and treated. Because care takes place in private homes, provision brings health care field logics and practices into the home (Exley and Allen 2007), where they interact with existing practices (Angus et al. 2005; Martin et al. 2005).

HH, in the form of nurses, routines, medications, can be welcomed and needed. At the same time its treatment processes can be contested as they meet conflicting desires and practices of patients and their families (Exley and Allen 2007). Home care often affects the existing modes of activity and manners of engaging with the space, posing a threat to privacy and sense of identity (Dyck et al. 2005). All of these impact and structure sense of embodiment and lifestyle to varying degrees as will be discussed below.

In examining the complexity of this encounter, we can begin to deconstruct the static notions of place that seem to adhere to "aging in place." Much of the existing literature takes aging in place as an objective, something to attain, without examining aging in place as a complex material and social process (Wiles 2005). Taking the concept of place from humanistic geographers, we can start to understand home in a relational sense, as a site of social relations, and one's perspective shifts to the processual and formative nature of aging in place.

It is too simplistic to think of "aging in place" as something that just happens. Following the work of Cutchin (2003) and Stafford (2009), I argue for understanding aging in place as a process that is not without tradeoffs. People work with available material and social supports to adapt bodies and spaces amid changing circumstances. During times of economic crisis, this work can be especially tenuous and fraught. I also follow Kearns and Joseph (1993) in examining the processes involved in health care, illness, and caregiving, and the impact those have on the experience and meaning of bodies and homes. As the provision of HH is aimed at preventing the institutionalization of older adults, as bodies and needs change, the flows of resources into the home and the practices and relationships within the home shift. HH care is a support that helps bridge institutional and community-based care, assisting in the reintegration of acutely ill persons back into the community and preventing future facility-based care. HH nurses accomplish some of this work by identifying bodies and spaces as risky, and introducing new devices, spatial arrangements, and practices. Patients and their lay caregivers are critical to these efforts, particularly given the private nature of the space. People manage these experiences and practices in a variety of sometimes contradictory ways, such as through active participation, tolerance, and resistance that vary according to circumstances.

In this article, I explore the experience of aging in place and how it is mediated by HH care. Using ethnographic data, I flesh out issues identified in medical geography, nursing, and sociological literatures, providing a picture of the nuances of the experience of aging in place through the mediation of HH care. I do so by first asking how the experience of and practices within the home shift with ill health. Within that context, through what methods does HH care intervene and affect aging in place? Finally, how do people experience, contest, embrace, and regulate these interventions?

Methods

Data for this paper have been principally derived from 12 months of ethnographic fieldwork in a metropolitan area in the Southwest US (November 2009 to November 2010). The study was approved and conducted in accordance with the University of Arizona IRB.

This paper rests heavily on observations gathered during job shadowing of nine HH nurses from two Medicare-certified, for-profit HH agencies. Job shadows were also utilized to recruit patients into the study. Patients aged 65 and over, with Medicare or Medicare Advantage Plan paid HH episodes, were eligible to participate. I asked nurses to recommend participants with chronic illnesses and at risk for future hospitalizations or acute health crises. Twenty-two patients (10 men and 12 women) initially agreed to participate in three interviews over the course of five months. Patients ranged in age from 65 to 94, with a median age of about 82. All patients were white. The older adults had a range of formal and informal support arrangements: 41% (n=9) had a child caregiver, 36% (n=8) had a spouse caregiver, 9% (n=2) had a friend or other type of informal caregiver, and 41% (n=9) had a paid caregiver of some type. Housing also varied: 45% (n=10) lived in freestanding homes, 27% (n=6) in age-restricted manufactured home parks, 18% (n=4) in apartments, and 9% (n=2) in independent living facilities. Patients occupied a range of socioeconomic situations, from low income and living off government assistance, to middle income and mostly living off Social Security and some additional retirement assets, to high income.

Many were being treated for pressure ulcers or open wounds, while others were recovering from and being monitored following strokes or falls. However, their situations were generally complicated by chronic conditions such as heart and other circulatory issues, pulmonary diseases, as well as diabetes and various cancers. Their episodes of care varied dramatically, from a handful of visits spread over the course of a few weeks to six months or more of biweekly visits.

I conducted 55 semi-structured interviews with patients. While I attempted to interview each informant three times, given patients' health problems, scheduling follow-up interviews proved difficult. Fifteen patients participated in all three interviews, one declined participation after the first interview, two had health problems that precluded participation after two interviews, and four could not be reached after one or two interviews. Interviews with patients lasted between 40 minutes and three hours (averaging about an hour). Interviews covered a wide range of topics, including patients' experience receiving HH and aging, thoughts and feelings about their homes, and hopes and fears for the future.

Nine nurses (all women and white) were each shadowed through the course of a standard work week. I spent between one to four days shadowing each nurse, for a total of 23 days. During the 77 patient visits I observed, I made deeply descriptive notes on setting and interactions between nurses, patients, and caregivers. This allowed for the documentation of mediation of HH care in real time. In between visits, I rode with the nurses in their cars and conducted informal, unstructured interviews.

Nine current HH nurses (four of whom also participated in job shadowing; seven women and two men) and six women with previous nursing and HH experience (n=15), also participated in semi-structured interviews of about an hour in length. Approximately 73% were white (n=11), 7% were Asian (n=1), 7% were Native American (n=1), and 13% were of indeterminate racial or ethnic background (n=2). Interviews centered on their experience being a HH nurse and their practice. Additional interviews (n=29) were conducted with family and other direct caregivers to provide additional perspectives and insights into the experience of HH care specifically, and aging at home more generally.

Audio and detailed notes were taken at all interviews, and audio from the interviews were partially transcribed. Interview, observational, and other fieldnotes were uploaded into an Atlas.ti database and coded. Codes were constructed based on original research questions, themes drawn from the literature, and emergent topics from fieldwork.

Bodies out of Places/Spaces

Many patients are provided HH care following an acute health problem and stay in a facility, such as a hospital or rehabilitation center. The time away from home for treatment took people out of their daily lives and familiar contexts, reduced their access to privacy, and limited their control of space and activity. Most patients and their caregivers were happy to return home, but their experiences were sometimes conflicted and often marked by uncertainty. While homes were sources of comfort and stability for patients, continued ill health and social isolation could contribute to their feelings of discomfort, fear, sense of risk, and boredom.

For the most part, patients described returning home as an opportunity to relax into a known and more controllable environment. Being in a personal space, amid customary sounds and smells, with family and pets, and part of household rhythms lent to a sense of being rooted in place and grounded in a personal history (see also Stafford 2009). Evocative objects in the home, such as photos and memorabilia from travel, contributed to this. Donald, a 93 year old, described returning home as "a little breath of heaven." For other informants, the sensation of relief was palpable but difficult to articulate.

People found consolation in plush chairs, stretchy clothes, and supportive beds, and pleasure in sitting in the sun, reminiscing or receiving affection from pets. However, they described the tiresome monotony of being housebound, where days might feel "endless" or, as one described, like a series of transfers from bed, to living room, bathroom, and back again. Doctors' appointments were sometimes welcome opportunities to leave the home but were also exhausting. With limited mobility and assistive devices, trips outside the home required time, effort, and planning. In general, many of the people I met at least initially had their days structured by previously mundane activities, such as getting out of bed, taking medications, and watching television shows. These became new orienting points that set both a comforting and sometimes tiresome tempo to their days.

While returning home was a hopeful time for many, marking a step toward possible wellness (Cartier 2003), it was also a liminal period. With hospitals releasing patients "quicker and sicker," a large percentage of patients were

quite ill and waited in dread for the next health crisis. Some with few social and economic supports also worried about obtaining help. Andrew, an 85 year old man, said, "I felt that I was being discharged [from rehab] and I was on my own. I had no idea that we were going to get any help after my discharge." His 91 year old wife added, "We were both very scared. Scared, insecure. Alone, NO help of any kind." Many faced similar uncertain futures, not knowing their needs, insurance benefits, or where to begin to find help, and dealing with living as an at-risk person.

Physical constitution and mobility were affected by a range of factors, such as weeks of being relatively bed bound, medications (and their synergies), infections, broken bones, and changes in blood flow. Embodiment also changed, with one woman saying that after she returned home from the nursing home, on water pills, with constant diarrhea, and nearly bed bound, she felt like a "wet noodle." Others provided anecdotes about their bodies acting in unexpected and perplexing ways. These changes could leave one feeling at-risk, particularly for falling.

Falls presented logistical difficulties for caregivers, and were a particularly salient social and physical signifier of vulnerability and dependence. Those with a history of falling articulated a fear of falling and a sense of embodied risk. Abe, an 87 year old, described these sentiments to me during a friendly afternoon visit:

> I worry about falling. This "whole mess" started when I fell and broke my hip. Now when I fall, because my wife can't get me up and my leg strength is so diminished, we have to call 911. One day, before going out, my wife left me in her bathroom. I fell and was stuck, because her bathroom doesn't have grab bars like mine. I crawled out into the bedroom and fell asleep on the floor. When my wife came home, she thought I was dead. She was very upset. We called the firemen to get me up. It really does something to your ego to be in such a situation and to see your physical capacities diminishing. I have this swelling in my legs that I don't know what to do about. I can't find a position that is comfortable and that will allow me to still do things. And I'm worried about my wife, she does so much for me, I don't want her to break.
> (from fieldnotes, Abe, older adult)

This conversation illustrates the emotional complexity and sense of lingering vulnerability involved in falling that was echoed by other informants. Abe expressed a sense of embarrassment, shame, frustration, and guilt at his circumstance that he felt more generally in day-to-day life, but that was brought to acute awareness in the event of falls.

Fall risk also brought to focus how mundane objects in the home, such as stairs and rugs, could be transformed into hazards and barriers to action (Williams and Wood 1988). To negotiate, people described adapting their behaviors in their spaces in order to accomplish tasks and practices, and reduce embodied risk. They might only shower when they knew someone else was in the home, walk around the edges of rooms to use walls as support, and avoid spaces with rugs.

Regulating Flows and Surveillance

The opening of the home, a domestic and private space, to the unfamiliar nurses has the potential to change the meaning of home (Milligan and Power 2009). Nurses, generally, enter patients' private spaces as strangers, their presence and authority legitimized through their occupation (Fairhurst and Vilkko 2005). Through surveillance of the patients' lifeworlds, nurses suggest physical and behavioral changes to enhance patient (re) adaptation to their condition and environment, and prevent patient displacement to facilities.

HH care personnel and practices were not always warmly embraced by patients. As noted, transitioning home can be a scary and overwhelming time for patients and their caregivers. Often patients were not able to clearly articulate how HH came about. For many, HH referral most likely occurred during discharge from a hospital or rehab facility, a time many described as rushed, emotion-filled, and confusing. Informants described varying levels of activity in managing their use of HH. Some accepted HH because doing so allowed them to leave a facility, others did so at family members' urging. Many were uncertain who would pay for HH or whether taking HH would erode their Medicare benefits and negatively impact their access to other health care. It was not surprising that many informants returned home without a clear sense of what would transpire.

Despite the potential power of nurses to intervene, almost everyone I spoke with in doing fieldwork (e.g., patients, nurses, community providers) constructed HH, as opposed to facility-based care, as empowering to patients. Nurses continually positioned the home as the purview of patients and highlighted patients' freedom of choice in complying with treatment. However, given the fragile states of many of the patients, it was often evident that informants did not have many practical choices.

In some cases, nurses' presence in the home was limited to a handful of visits and only a minor disruption. Episodes which lasted longer might be integrated into the normal rhythm of the home. For patients and caregivers who spent most days at home, these visits could be an opportunity to talk to someone new, vent frustrations, get practical tips, share a laugh, and find sympathy. However, at other times, I found interactions stilted and uncomfortable. Some patients complained of nurses who had been unprofessional or were inconsistent in their visits. No matter how much the nurses were liked, depending on the frequency of the visits, the number of HH people involved, the patient's condition, comfort level, and support from caregivers, the visits could also be exhausting and disorienting. However, patients and caregivers' complaints were often slight and most expressed gratitude towards HH as a useful support to their condition and home life.

With the entrance of nurses and other HH personnel into the home, the medical gaze extends into the normally private space of the home and lifeworld. The surveillance can be difficult for patients who might feel at their worst and for caregivers who might perceive they are being judged. But being overseen by medical professionals was also a source of comfort, especially in a context of uncertainty about health and desires to regain wellness.

Surveillance in patients' homes allows experienced nurses to identify potential problems. They can spot possibly risky behavioral practices or noncompliance which might be effectively hidden in other medical settings. Nurses valued this because patients were often viewed as unreliable sources for information. Nurses explained that patients might not fully disclose to them to avoid shame or because they do not know or fully understand their health history and why certain pieces of information might be relevant.

Surveillance was a negotiated process. Patients attempted to collaborate with, limit, and shape HH professionals surveillance through management strategies. They might define spatial boundaries for the visits (e.g., not give access to certain parts of the home), clean spaces before visits (e.g., throw out bottles of alcohol), and physically present themselves in particular ways during those visits (e.g., bathed and dressed, feet elevated) to garner more or fewer interventions. Nurses likewise chose where to and not to intervene. I observed nurses opting to attend to and follow up on, or to ignore cues suggesting home life difficulties. Nurses were sometimes caught in the middle of conflicts between their patients and their families, which could be difficult to navigate. In several instances I observed nurses trying to change the course of conversations when patients started to discuss family problems, even in cases where the issues might point to abuse or neglect.

Measuring was essential to surveillance efforts, as well as in reinforcing and mediating informants' embodied risk. Informants' bodies were already marked by diagnosis, physical condition, and roles when they entered HH, and each visit their bodies were further highlighted as they were scanned visually and tested with instruments for signs of improvement or ill health. Urine clarity and odor, consistency of feces, blood pressure, wound drainage color and texture, and smell of bile were all potential fodder for evaluation. Body relations during the act of measuring and treatment were frequently intimate. Nurses kneel and bend by, and come into bodily contact with their patients. Expressions of pain could be audible, but also palpable in gripped tables and chairs, grimaces, and quivering limbs. While instruments (e.g., pulse oximeters) were routinely used to obtain precise measures to document, nurses relied heavily on their sensory observations and conversations with patients. They looked beyond the physical body for signs like poor grooming or tense social relationships that might suggest abuse or neglect. Identification of signs that were perceived as problematic for treatment opened up opportunities for intervention (e.g., occupational therapy, social work, Adult Protective Services) to ensure best fit and reduce risk.

Informants became habituated to being objects of surveillance and topics of intimate discussion, and were called upon to engage in self-measurement. I frequently spotted blood pressure monitors and glucose meters in dining rooms and kitchens. For informants, the measures became new frames in how they viewed their bodies and cues for assessing their health. Often this was a continuation of a practice they had been socialized into in facilities and doctors offices. They showed varying interest in the measures. Some would become visibly anxious if the measures differed from what was normal or would show relief when the scores had not changed. The act of measuring reinforced the construction of the body as at risk and socialized informants to new relationships with their bodies and home practices, while also providing a sense of control.

Embodiment was further affected by prescribed changes to bodily comportment, such sitting and walking. Nurses and other health professionals worked to reset informants' expectations for their bodies, encouraging them to pay attention to their feelings and to rest when

feeling tired, and dissuading them from thinking about what they could no longer do. Many were prescribed physical therapy exercises that could be difficult, draining, and discouraging. Some of those with histories of falls expressed fear about having to do these exercises. For example, 88 year old Beatrix refused physical therapy when it was offered because the therapist wanted her to practice walking on the road by her home. Throughout our interviews, she expressed generalized anxiety about her condition and lack of social supports, but a very particular fear of falling that contributed to a reluctance to leave her home. By contrast, other informants were diligent in their exercise, described it as their personal responsibility to perform, proudly demonstrated to me what they were able to do, and seemed to hold out hope that they would continue to see improvement in their conditions if they maintained their exercise practice.

While there were certain formalities and obvious surveillance activities, HH nurses often adopted informal approaches to interacting with and gaining information from patients and their caregivers. This helped them negotiate the control issues that came with practicing in home spaces. By gaining access to patients' places, nurses had access to a broader perspective of patients' contexts, allowing a more patient-centered intervention, tailored to addressing the fit between patients and their environments, thereby reducing risk and, hopefully, supporting aging in place. These practices also worked, however, to create a representation of informants' bodies, and in a less direct way aging bodies, as risky and needing of monitoring and control. Combined with factors such as physical condition upon returning home and other particular circumstances, this also shifted informants' embodied experience and involved them in new, medically oriented practices.

Changing Spaces

The penetration of intimate space occurs through increased gaze on informants' bodies, as well as in the reconfiguration of spaces and activities. Assistive devices were integral in helping to improve body-environment fit to lessen perceived risk. They also helped people improve their range of activity and independence of action, in some cases reducing what they felt was a burden on their caregivers. During the course of HH, nurses might suggest using preventive materials and other durable medical equipment, such as cushions, air mattresses, and motorized wheelchairs.

The homes I visited were populated with such artifacts. The introduction of aids changed spaces both materially and practically (Fairhurst and Vilkko 2005). I often navigated walkers and scooters when visiting informants, and frequently found myself surprised when I encountered hospital beds in living and dining rooms. Materials not only changed spatial arrangements and flows, they also brought in new smells and sounds, like the sucks and hums of an oxygen concentrator.

For many, devices and equipment were constant companions. Emma, a 76 year old with Multiple Sclerosis who had received HH for a pressure wound, was sitting on a gel cushion on her couch, with her feet propped up on her motorized scooter, next to her hospital bed, as she explained the equipment that meant most to her:

> "The bed, the scooter, the bathtub bench, things that make me feel…comfortable, I can take a shower without anybody's help. I feel like I'm independent that way. And this cushion I'm sitting on, I couldn't sit on the couch by itself, because that would make pressure points on my behind. [Chuckles] […] Right now, I don't feel like I need anything. I feel pretty well in control of my life."
> (Emma, HH patient)

These materials were enabling for her, assisting her in having independence and the ability to direct her life. Even though she spent most of her time in the privacy of her home, the devices were likewise important to her in her social sense of self. During a previous visit she had explained that her cushion enabled her to get out of bed and, even though largely housebound, to sit up and, as she put it, "feel like I'm part of society."

However, people expressed fears about adopting and adapting to assistive devices. Emma, who above described the instrumental qualities of these materials, later talked about how difficult it had been to decide to get her first motorized scooter:

> "it tired me out to walk around. [Pause] It really hurt my legs […] And when I got on the scooter I felt, oh! So relieved. I didn't like givin' up- I didn't, you know, I don't know if I gave up. I gave up walkin' because it was more comfortable to drive around, it hurt my legs to walk around."
> (Emma, HH patient)

As Emma describes, adopting an assistive device could be experienced as a sort of defeat, giving up on certain capacities. However, taken practically, devices could provide much relief, make one better fit in their environment, and increase functioning.

While assistive devices were generally enabling and lent a sense of security, they could also be limiting, even risky, and fit awkwardly into existing life. Devices could become burdens and challenges to navigate both physically and socially. Spatial challenges might include maneuvering a walker through a narrow doorframe, while practical maintenance issues could mean figuring out how to replace spent oxygen tanks. These could be difficult even when family members were available to help. In addition, sometimes it took time, effort, and bumps and bruises to acquire the body knowledge to use a new device. People described abandoning devices because they were frustrating or otherwise did not fit into their life.

Equipment often had to be negotiated and sometimes interfered with engaging in meaningful activities. For Marsha, while large oxygen concentrators provided her body with oxygen, they could be social barriers:

> "My two best friends […] do things together. I'm never invited any more. I'm left out. Because they'd have to take my walker and take my oxygen and be, they're afraid that I will fall again and get hurt. So my social life is zero." (Marsha, HH patient)

Thus, her perceived riskiness, proven by her falls and health problems, and symbolized in the materiality of the devices, as well as the logistics of moving with the devices, disrupted her normal social life.

Informants and family members varied in the degree to which they were willing, and able, to change the environment and behaviors. Seventy-six year old Celia explained that her home was not the same as it was before her stroke. She said, "I like my house but it's a prison for me now." She walked me around her home, showing me the paint and drapes she had put up when she moved in. When we arrived to her bedroom, she pointed to her handmade bed and gestured to the commode next to it. She explained, "My bedroom used to be a very welcome place, but now I'm almost afraid of it. I don't sleep that well." While Celia had many things going on in her life that left her quite unhappy and frustrated (including lack of familial support), the aesthetic disruption of the home she had so carefully nurtured seemed to be an irritant and reminder of her changed state. She struggled to accept the changes, much as she worked to negotiate her new sense of embodiment.

Many homes were family spaces and changes had to be negotiated with other household members who might not be supportive. Theodore explained that the rugs layering his home's floors, while functionally a hazard to him and his sometimes dragging leg, were kept at his wife's insistence. He felt for the sake of the relationship that he had to support her wishes and as a prompt to pick up his leg. However, during my next visit, I found him shaken after tripping on a rug. Coffee still stained the kitchen floor where he had fallen, vomited, and lain for five minutes waiting for the dizziness to subside. While in talking to me Theodore transformed the rugs from objects of risk to objects of pleasure and body-helpful challenges, they were still obstacles that at least periodically reminded him of his changed physical state.

As noted above, home routine was altered for persons receiving home care. People's altered movements within and without their homes were to a degree structured by new assistive devices, medicinal regimens, and treatment. In a context where aging is stigmatized, these new objects and behaviors sometimes evoked negative emotions and a sense of heading down a road of increasing dependence (Wahl and Lang 2004) and restricted social life. They could be symbolic reminders of reduced capacities and, often, a feared future that might include increased dependence and institutionalization, which were markers of the end of life.

The Other Side of the Bridge

Many patients and caregivers look forward to discharge from HH. Technically, discharge occurs when there is an end to a skilled need, when the specific problem has been resolved, or no further improvement is expected. Discharge is a signpost for the end of an ordeal, a closure, a successful refit into environment, and a return to "normal life."

In practice, vestiges of one's experience and the mediating role of HH linger. These can be physical, such as in scars from a wound, indentation in a bone from a fall, "glue" stuck on skin from a dressing, or a new wheelchair. Or they can be practical, such as adjusting to new devices, technologies, and medication regimes, and dealing with medical bills. They can also be behavioral, as in continued participation in therapeutic exercise or self surveillance. Many informants were discharged whilst resetting themselves to a new normal and described a future of a "long down slope" with constant renegotiation of fit with home environment. As 81 year old Paul said, "the longer time goes on, the more I realize I'm never gonna get to the point of where I think I used to be."

During our last meeting, Marsha expressed similar sentiments. With a very limited income, some insurance

coverage, and her daughters' help, she had managed to continue physical therapy for about a month after her HH episode. However, she could not continue that and was frustrated to see how her assistive accoutrements and physical difficulties affected her life:

> "And it'll never get better, that's, THAT'S what really bugs me. If I thought I could have this [oxygen concentrator] on for a month and then it'd be gone, I wouldn't mind it at all, I wouldn't mind tripping over it and stuff like that. I'm just NOW, all this time, I'm just now coming to the (Slight pause) realization that I'll be this way forever. And I think that's hard." (Marsha, HH patient)

For Paul, Marsha, and others, their embodiment had shifted in the course of their chronic illnesses and the future provided an unknowable, uncertain, and new landscape. In some cases, the end of HH and the future of aging at home were ambiguous and the sense of uncertainty, reinforced and constructed during HH, persisted. This appeared most commonly among persons with newly identified or problematic chronic illnesses and short episodes of care (e.g., a handful of visits over the course of a couple weeks). Discharge could occur abruptly and unexpectedly, either at the behest of insurers, nurses, or patients and their caregivers.

Those with access to caregivers (whether informal or paid) might be able to continue care regimes within the home, often on a more limited basis, which provided some assurance and sense of control. In some cases, family members seemed confident in taking up these roles. Others seemed more overwhelmed with the tasks at hand, especially when other social supports were lacking. Stu, a 90 year old, was discharged under ambiguous circumstances. Blanche, his wife and sole caregiver, seemed overwhelmed and confused. She explained that she had liked the nurse very much, but had not been adequately trained in how to care for Stu and his breathing machine. She felt that she had cared for their nurse on a personal and material level, and suggested she expected the nurse to reciprocate in kind. This relates more broadly to the emotional and ethical landscape of care. HH occurs within intimate space and the personal-professional lines between patients and HH staff can be blurry.

I saw many informants and family caregivers grappling with their conditions, needs, and available supports. In some cases, HH nurses could help by offering limited social work assistance. However, community resources were scarce and many informants failed to qualify for them. To varying degrees, nurses could also try to help by extending the HH episode if they could document need and the insurer authorized it. While these extra bridges could be helpful, they were not available to everyone or for the long term. This left those with continued long-term needs, with limited economic and social resources in a lurch.

As such, the situation upon exit might be tenuous, at times frustrating, and lead to a cycling between home and facilities with new health crises. Such relocations are disruptive and, in part because of poor coordination of services, make management of chronic care difficult and require a negotiation of a web of different service providers (see Cartier 2003). Several informants contemplated movement into an assisted living facility or nursing home, sometimes at the suggestion of HH nurses. Dyck (1995) described residential movement as an active strategy women in her study chose in order to maximize independence and fulfill social roles. Often relocation was described as something necessary because of an inability to maintain a larger home and reluctance, or inability, to ask family members for assistance. In a sense, they were choosing a different type of mediated aging experience given a range of possible, usually limited, options.

The policy imperative to age in place in some cases might represent a trap (Fairhurst and Vilkko 2005), providing for few options and supports outside of the home. As Martin (2005) noted, home is often reified as necessarily therapeutic, but that is not always the case. I encountered a handful of cases in which informants described themselves as being stranded, unable to access possible family caregivers who lived in other parts of the country, because their conditions (physical and economic) made movement impossible. In some cases, the amount of care available might be insufficient and around the clock, supportive nursing care in a facility might be a more positive option (Bamji 2010; Flynn 2007).

Conclusion

This article documents how aging in place is a process that for chronically ill older adults is frequently an uncertain and marked endeavor, often involving physical, behavioral, and social adaptations. HH mediates this experience by helping control risky bodies and environments, while helping maintain person-place integration and quality of life, whilst also taking advantage of the healing qualities of place. However, its introduction is experienced, negotiated, and contested in multiple ways. It works to reinforce and at times introduces a sense of bodily risk,

and helps to shift embodiment and daily practice.
I discussed how patients were socialized into being the objects of the gaze of health professionals through repeated and varied interactions with the health care system (e.g., doctor's visits, nursing home stays). I observed and nurses described ways patients attempted to shape how they were evaluated and receive fewer or more interventions. Future research could examine these processes in more depth, with focus on the efforts employed, for what purpose, and to what success or failure.

While HH care can assist a person to refit changed body conditions into home practices, the lack of availability of long-term supports for many older adults makes aging at home complex and uncertain, and perhaps marked by multiple hospitalizations and acute health crises. The older adults I met were very worried about the stability of their own financial resources, concerned about burdening adult children (many of whom were unemployed or at risk of becoming so, or embroiled in other health or social issues), and had no idea what services were available or where to go to look for help.

In a time of economic crisis, government cutbacks to programs such as Medicaid, and concerns about Medicare reforms, despite intentions for older adults to remain in the community, some were concerned they would be forced to be institutionalized in facilities of uncertain quality. While many were not aware of services offered by various agencies, such as meals, transportation, and friendly visiting services, community providers consistently told me these services were restricted and limited. For certain individuals, such as those who expressed feeling isolated and at risk because of lack of physical, social, and economic resources, longer term community supports would make aging in place more easily and reliably attainable.

Remaining at home is a complex experience for people and not wholly positive. This does not mean that people, in general, see institutional settings as a better option, but neither are they and their family members satisfied with the limited range of options and opportunities for at home support. However, making home-based long-term care more accessible is only part of the solution. Disparities experienced across a lifespan contribute to individual aging experiences. Addressing broader political, social, and economic disparities, and exploring how these manifest in peoples attempts to age at home is an area for future research.

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