

MIND THE GAP: THE DYNAMICS AND WORK OF AGING AND CARING AT HOME

by

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ABSTRACT

In the United States, a growing proportion of the population is aged 65 and older. Associated with this demographic transition is a rise in the number of people who are aging with chronic disease. While there is a cultural ideal for older adults to remain in the community and out of institutional settings (“aging in place”), there is little recognition of the work and experience of trying to accomplish this. In the following papers, I draw on 12 months of ethnographic research in the Southwest US to describe the work of “aging in place.”

As a starting point, I use Medicare-funded home health care (HHC), which stands at the crossroads of acute-based institutional care and custodial, long-term care. In the first paper, using definitions of place from cultural geography, I explore the work of aging from the perspective of chronically ill older adult HHC users. I illustrate how bodies, practices, and places shift as processes of disease and medicalization inscribe them with risk, and the ways in which people accept, resist, and negotiate these changes. The second paper extends the work on audit culture to describe how Medicare’s audit system has structured the organization and practice of HHC, and how this has reinforced the commodification of patients. I note how HHC nurses can draw on personal and professional logics in their documentation practices as a means of resisting rationalizing forces and opening up eligibility for care. The third paper uses case studies to push the literature on family caregiver burden to include the fraught, yet highly meaning-filled experience of caregiving. The cases show the difficulties and ambivalence in providing care to a chronically ill family member.

Throughout these articles, underlying the tensions, uncertainties, and gaps I explore questions about what type of care is needed, who is worthy of care, and how responsibilities are distributed. I focus on how people’s worlds and work are structured by larger scale social,

cultural, and economic forces, and attend to the ways in which they reproduce, contend, and negotiate these forces from their unique positions, in effort to protect what they value.

CHAPTER 1

In the last 30 years in the United States, as researchers and policy makers have anticipated a growing aged population, concerns have arisen about who is responsible for providing and what is the best way to provide care for functionally impaired and/or chronically ill older adults. The broad consensus from older adults, families, social service and health professionals, and policy makers is that the ideal is to “age in place.” This is partly a rejection of models of institutionalized aging or “warehousing” older adults in nursing homes. However, there is disagreement about what is needed, who is worthy of care, how responsibilities should be distributed, and the work required for people to realize aging in place.

This project examined the experiences, systems, relationships, and work involved in aging in place. I take as my starting point home health care (HHC), which stands at the interstices of acute-based, formal models and more custodial, informal models of long term care. As a sort of in-between time, it offers a site for exploring a variety of tensions and uncertainties, and through those the work of culture and other forces.

My project has attempted to elucidate and speak to a variety of contemporary social phenomena through the particular experiences and narratives around aging with chronic illness. Following Corbin and Strauss (1985), I have approached this study with the understanding that living with and managing chronic illness requires much work. This work does not just involve the person who is chronically ill, but necessarily involves the networks of people, places, organizations, and conditions in which the person is embedded. The labor involved is shaped, limited, resistant to, and made possible by these interrelationships.

As such, I have taken aging with chronic disease as fundamentally processual in nature. At different points along people’s life trajectories, they interact with a variety of people and

institutions. These relationships are structured and sometimes filled with tensions, with positive and negative aspects for those involved.

Thinking then about more abstract and social ways of framing this experience, I was interested in the ways in which older adults become increasingly enrolled in the biomedical system as a way to manage their aging experience. Following the literature on the medicalization of aging, I was interested in how biomedical projects, narratives, ideologies, and practices could help (re)structure identity, goals, and one's life world.

I was also interested in how bureaucratic structures and methods that undergird contemporary health care systems define who is eligible for care and structure the type of care that is provided. In particular, I wondered how efforts to define need and limit or open up health care benefits affected both users and their families, and health care professionals and organizations. In particular, how were these strictures negotiated in everyday practice and interactions?

The narratives surrounding the threat of high costs of health care for the elderly (particularly at the end of life), concerns about the allocation of scarce resources, and "generational equity" debates (Cassel and Neugarten 1991; Minkler 1986; Robertson 1990) are also important to consider. The continued positioning of the aged as a threat to the economic security of the state is in the background of more local and individual debates about eligibility for care and determining where responsibilities lie.

Two main chapters and three appended papers comprise this dissertation. This chapter provides an introduction to this project and its place within existing scholarship. A second chapter provides details on the project's methodology, a brief overview of the results, and key conclusions from the research. The three appended papers, which have been submitted for

publication, provide an in-depth exploration of some of the key issues that emerged from this work.

In this chapter I briefly review some of the major issues and literatures that helped frame my understanding and work. I begin by reviewing some of the demographic trends and shifts that have helped shine light on older adults in policy, academic, and lay fields. Within this I discuss critical social theory work that deconstruct and problematize the framing of the problem of aging and the ways in which care is structured and disbursed.

Following this review, I describe how I approached this research, the questions I asked, and my goals. I then discuss my research design and methods, and how those adjusted as issues emerged in the field. I close the introduction with a brief description of the three articles drawn from the data collected during this project.

Anthropology of Aging

As a universal human experience, aging occurs over the life course as a biological, social, and cultural phenomenon. By examining aging cross-culturally, we can see how the scripts and spaces for, and experiences of growing old are remarkably varied (Fry 1999; Jay Sokolovsky 2009).

Although consideration of age in the anthropological literature have figured prominently since the early days of ethnography, often in descriptions of kinship and life cycle systems, it was not until the middle of the 20th century that age became a distinct object of study (Fry 1999). Since that time, anthropologists have explored aging and culture from a number of perspectives. For example, they have examined how age is defined, how people move through different life stages, the different expectations and statuses ascribed to stages, and the relationship between generations. Often this work also takes into account how non-age structural

positioning, such as gender (e.g., Kerns and Brown 1992; Lamb 1997; Lock 1993), socioeconomic status (e.g., Hendricks and Leedham 1992), ethnicity (e.g., Hegland 2009; Myerhoff 1978; Sokolovsky 1985), and geography (e.g., Laws 1995; Lipman 1970; Zhang 2009) might affect how individuals and subgroups experience aging.

The following work builds upon the anthropology of aging tradition in that I explore the experience of aging as a context-dependent, complex affair that is embedded within place, history, social relations, and sign systems. I study these issues by attending to the processes at work in the experience of aging in place with chronic disease in the US during the early twenty-first century. For this work, age is figured as a key structuring condition, particularly as it impacts the social and political situations of the people I studied, but it is taken up as the central object of concern. Instead, I look at processes at play, such as those in contemporary bureaucratic health systems and the relationships between people and places, and concern myself with systems and the experience of those within them.

Aging in the United States: Demographic Transition and Policy

In the US, the older adult share of the total population increased dramatically over the course of the 20th century. In 1900, older adults aged 65 and above accounted for just four percent of the population (Werner 2011). By contrast, in 2010, 13 percent of the US population was aged 65 and older, a number expected to jump to 17 percent by 2020 with aging Baby Boomers (Anderson and Hussey 2000). More significantly, the greatest gains in relative population size have been seen among the oldest old, those 85 and older (Werner 2011).

Worldwide, there has been a distinct “demographic transition” toward aging populations due largely to growths in life expectancy. In the US, in 2008, the average life expectancy for females was about 81 years and for males 76 years (Arias 2012). These gains have occurred in

part because of better control and treatment of communicable diseases, particularly during childhood (World Health Organization and U.S. National Institute of Aging 2011). Along with a reduction in childhood mortality, this transition has also been accompanied by declines in fertility. Across the globe, the timing, size, and implications of these population age shifts vary,¹ but they have provoked international discussions related to concerns about aging, dependent populations, equitable distribution of resources, and protecting vulnerable populations (e.g., McCarthy 2001; Restrepo and Rozental 1994).

The economic and political situation of older adults in the US has also shifted during this transition. Economically, older adults have seen declines in rates of poverty, especially since the 1960s, due in part to the increasing prevalence of private and public pensions (e.g., Social Security), assistance programs (e.g., through the Older Americans Act), and federal health care programs such as Medicare and Medicaid (Schulz 2001). However, disparities exist along urban-rural lines, and by gender, ethnicity, and region (Administration on Aging 2011). In addition, measures of poverty are somewhat problematic, especially if one takes into account the greater expenditures older adults make on health care. For example, in 2011, the US Census used a new Supplemental Poverty Measure that took into account additional factors, such as out of pocket medical expenses, and it found just under 16% of older adults live in poverty, compared to the official poverty rate of 9% (Administration on Aging 2011).

The policies and programs aimed at older adults have also helped to institutionalize the older adult identity into a formative and distinct subject group. In academic and policy literature, as well as popular accounts, a supposed “gray lobby” has been described as a powerful network of groups, like the AARP, that influences policy-making and resource allocation in the interest of

¹For example, in the US, as compared to, for example, Europe and many developing nations, the demographic shift

older adults (cf. Pratt 1993). Because they are no longer always viewed as a marginalized group, their legitimacy as deserving beneficiaries of scarce social funding has eroded, though cutting aid to age-related programs is difficult because of their institutional clout (Hudson 1999), such as age-related programs (e.g., Medicare), lobbying groups, and industries. Beyond the politics, the interests and experiences of older adults are diverse and the narrative of an entitled, powerful older adult population is at odds with other depictions of the elderly as needy and at risk.

Disease and Aging: Processes of Medicalization

As part of the demographic transition, the overall disease burden has shifted from communicable diseases to chronic diseases like heart disease, cancer, and stroke. A nationally representative survey found that among older adults in the US in 2008, 92% reported having at least one chronic disease, with an increasing number reporting multiple chronic disease diagnoses (Hung et al. 2011). In addition, about a quarter reported having a disability in at least one activity of daily living (e.g., toileting, dressing) or instrumental activity of daily living (e.g., shopping, finance management). Polypharmacy is also prevalent among older adults, with a variety of surveys showing that on average, community-dwelling older adults take two to nine prescription drugs each day (Hajjar, Cafiero, and Hanlon 2007).

The depiction of older adults as diseased and decrepit helps to establish old age as a problem in need of correction and control. Social scientists have drawn on critiques of processes of medicalization and the extension of medical authority (Cassel and Neugarten 1991; Foucault 1990; Lupton 1997) to point out how old age has become synonymous with disease and the experience and management of it increasingly under the purview of biomedicine.

The institution of medicine plays a dominant role in contemporary experiences of aging in the US (Kaufman 1994). Estes and Binney (1989) have identified two aspects of the

biomedicalization of aging. The first is the social construction of aging as a medical problem and old age as synonymous with disease (Arluke and Peterson 1981). This process has been facilitated by ageism (Estes 1979; Sankar 1984) and the blurry boundaries between what is considered normal physiological aging and disease processes (Kaufman 1994). It also has roots in the establishment of gerontology in the late 1930s (Estes and Binney 1989), which helped to define aging as a period of life that requires special attention. This work opens the door for the definition, management, and treatment of the elderly within the medical model.

The second aspect of biomedicalization involves the practice of aging as a medical problem. Estes and Binney (1989) identify at least four spheres of praxis: the public (e.g., perceptions and consequences), the professional, the scientific, and policy. This conceptualization pushes traditional critiques of medicalization beyond narrow focus on the expansion of medical professional dominance, to point to, as Light (2000) has suggested, a complex of “countervailing powers.” Each of these forces has its own interests, cultures, and goals that can be aligned or at odds with other stakeholders.

Processes of medicalization have important implications for the experience of aging. Elderly persons can become almost completely defined through medical diagnoses, which suffuse their existence with concerns of illness and health. The paradigm that diagnoses provide can create frameworks for understanding experience and structuring subjectivity. Associated medical technologies provide means of objectifying and quantifying individuals (Chatterji 1998), allowing derivations of deviation that legitimate intervention by different specialists and encouraging dependency on health care professionals. This reinforces power relationships within the health care setting, as well as fosters demand for products and services that claim to delay, prevent, or reverse aging. Treatment regimens and doctor appointments can also impose central

structures onto everyday life. For example, complex medication regimens often require engagement in specific daily or weekly practices, such as counting and organizing pills, eating at specific times with medication, dietary changes, and surveying one's self for signs of iatrogenic effects.

However, not all diagnoses necessarily result in medical intervention. Both "senility" (Lyman 1989) and "disability" (Sanders, Donovan, and Dieppe 2002) have been found to be understood as normal components of aging. By naturalizing certain diagnoses as "just old age," physicians can deny medicalization and entitlement to services (Kaufman 1994), as well as manage ambiguous situations that carry expectations counter to biomedical goals (e.g., cure, prolong life) (Sankar 1984). However, as disorders are increasingly created or reclassified as deviant and hence treatable, they can become subject to intervention.

Lay persons are not passive within these processes, as they have complex, dynamic, and critical feelings about medicine (Williams and Calnan 1996). People, including older adults, are often ambivalent about the risks and benefits of modern medicine, and skeptical of medical professional's advice on health and lifestyle. They may set their own goals for recovery based on their own values and practices (Becker and Kaufman 1995). At the same time, medicalization is one of the primary avenues through which older adults gain access to entitlements (such as Medicare), making self-medicalization an important strategy in garnering resources (Nichter 1998).

Similarly, for informal (i.e., nonpaid) caregivers, medicalization provides a means for caregivers to legitimize entitlement to services (e.g., formal caregiver services, respite care) and, by naturalizing problems, it may help them escape interpretations of the older adult's behavior that might otherwise stigmatize the family (cf. Cohen 1995). Medicalization can also provide a

narrative framework that provides a degree or semblance of control, predictability, or knowledge base to help guide action (Lyman 1989). However, caregivers can also be subject to the gaze of medicine, enrolled in care management projects, and participate as a primary care provider (Hasselkus 1992). At other times, caregivers contribute to domains of care traditionally controlled by physicians, such as diagnosis, interpretation of symptoms, and treatment recommendations. In private, caregivers often act as the primary care provider (Hasselkus 1992). These roles affect relationships within families, as well as increasingly situate kinwork within the context of medicine (cf. Kaufman, Shim, and Russ 2004).

Chronic Disease and Disability: Long Term Care and the Public Health Problem

It is within these broader processes that frame old age as synonymous with disease and in need of treatment that chronic disease is placed. As a result of the demographic trends described above (aging population, more chronic disease), there has been increased focus on the provision of long term care (LTC). LTC refers to a broad array of services aimed at supporting persons with chronic illness or disability.

The LTC system in the U.S. is comprised of (1) informal care (i.e., non-remunerated), (2) formal home and community-based care (e.g., home health care, home care, congregate meals, transportation services), and (3) institutional care (e.g., nursing homes) (Clark 1996). While described as a system, in reality it is a patchwork of different people, groups, networks, and philosophies to which individuals have varying access and from which they draw upon as different needs and circumstances arise. Within this compendium of care, since the 1980s, out of both respect for people's wishes to "age in place" (i.e., remain at home) and concerns about ballooning costs, there has been an emphasis away from expensive facility-based LTC (e.g., nursing homes) and towards home- and community-based provisioning of care (though not

necessarily more dollars being transferred to that field). New technologies and treatments have also made it more possible to manage conditions in community rather than institutional settings.

The expansion of health care services and products described above are both supported and constrained by managed care and public health care funders (i.e., Medicare), who increasingly set the limits of what types of treatment (and to what extent) are approved for reimbursement (Conrad 2005). In the 1970s, expanding the health care service market was seen as an important economic strategy, as well as a means of solving social problems (e.g., the aged) (Binney, Estes, and Ingman 1990; Estes 1979). However, chronic disease poses an issue for standard medical practices which are acute problem and cure-oriented. In an era in which there is widespread concerns about national debt, public outlays to entitlement programs, and an aging population, there exist push-pulls toward medicalization and expensive health care resource use as a means of managing aging, and privatizing the responsibility and work of aging.

In the US, LTC is financed through a range of sources. As of 2004, about a third of the formal (paid) LTC for older adults was financed out of pocket (Congressional Budget Office 2004). The other major payers were Medicaid (35%), the federal-state insurance program for persons of low-income, and Medicare (25%), the federal insurance program for persons 65 and older and/or disabled. It is expected that the numbers of people requiring LTC will only grow, with the older adult population, in the future, creating greater demands on already fragmented and limited care, and possibly more responsibility onto informal, nonpaid sources.

While 93% of older adults have health insurance coverage through Medicare (Administration on Aging 2011), this does not cover most of their long term care needs. Notably, and to the surprise of many, Medicare coverage, while providing about a quarter of LTC dollars, does not include LTC coverage. Medicare will reimburse for short-term, acute condition care

provided by organizations that would be classified as LTC providers. This includes skilled nursing facilities or home health agencies that might provide short-term post-hospitalization rehabilitation and care. Many community-dwelling older adults who have chronic illness will periodically have acute health problems (e.g., stroke, hip fracture, pressure ulcer) which might result in a stay in a facility like a hospital and/or skilled nursing facility. As part of their post-acute care and as a means of transitioning back into the community, they may receive short-term, skilled home health care (HHC).²

Medicare Home Health Care

In the US, the federally funded health care program for the elderly, Medicare, is the largest payer source for HHC. Over the last 20 years, with the growing prominence of managed care and demographic changes, Medicare has undergone a number of revisions. Recently, there have been moves to privatize Medicare,³ which fundamentally changes the relationship between older adults and the State. Increasingly, the state has ceded obligations to ensure the welfare of citizens to the construction of citizens into consumers. As consumers, individuals have personal responsibility to participate in markets and lifestyle practices to secure their well-being. As noted above, there are also heightened concerns with rationing of services, with both imperatives and disincentives for medicalization (a disease-based model), which acts as a legitimating force in

² Though it is somewhat problematic, I differentiate HHC from more custodial types of home care. I do so in order to below discuss HHC as the specific manifestation of Medicare-funded home care services. In practice, paid in-home services range from highly technical tasks (e.g., skilled nursing, physical therapy) performed by credentialed professionals, to general social or supportive services (homemaker, respite care), and everything in between. Many of the Medicare-certified agencies I encountered during fieldwork maintained an additional home care or “staffing” office that provided more general, custodial home care services, often paid for out of pocket by individuals and families or through contracts with Medicaid.

³ As an alternative to the traditional fee-for-service Medicare program, Medicare beneficiaries may enroll in the Medicare Advantage (MA) program. This consists of an array of plans offered by private insurers. The proposed benefit to enrollees is the flexibility of choosing a plan that best fits their individual needs and circumstances, particularly for prescription drug coverage. At the time of fieldwork, there were two main types of MA plans: fee-for-service and coordinated care plans (including health maintenance organizations and preferred provider organizations) (MedPAC 2011). Enrollment in MA has steadily increased since they have been offered. In 2010, 24 percent of Medicare beneficiaries were enrolled in an MA plan (MedPAC 2011).

allocating Medicare resources (cf. Conrad 2005). In this context, little is known about the ways that older adults and/or their health care professionals may actively seek medicalization in order to argue for entitlements and services. Also, how in this time of economic downturn, discourses about entitlement programs have become heightened, providing insight on how different groups represent themselves and argue for rights to resources.

To understand how these processes play out in HHC, it is useful to understand how the industry and service use have shifted with policy changes. Important to these policy changes has been the longstanding construction of the HHC industry as ripe with fraud and poor quality care (e.g., U.S. Department of Health and Human Services. Office of the Inspector General 2012; U.S. Government Accountability Office 2009). High profile HHC fraud cases (e.g., The Associated Press 2009; Cloherty and Jones 2009; Cohn 2012) have reinforced the representation of the HHC industry as untrustworthy and helped to legitimate the cycle of stepped complexity in Medicare rules (e.g., Dey et al. 2011; CMS 2011).

HHC developed from small, charitable visiting caregiver associations in the 19th century, into a field of diversified, (inter)national, corporate chains employing a range of skilled professionals and complex technologies.⁴ HHC condensed from more general home care⁵ amid shifts in social demographics (e.g., gains in life expectancy, changing family patterns) and epidemiology (e.g., less communicable disease, more chronic disease), infusions of public and private dollars (e.g., insurance benefits), the rise of biomedicine (e.g., medicalization), and changes in patterns of governance. Its trajectory, growths and declines, specializations and

⁴ The history of the home health industry is necessarily glossed here, but can be found in more detail elsewhere (e.g., Buhler-Wilkerson 1991, 2001, 2007; Davitt and Choi 2008; Dieckman 2008).

⁵ I differentiate HHC from other types of home caregiving. By contrast to custodial (e.g., bathing, cleaning) and long-term care provided by paraprofessional caregivers, HHC is generally a short-term intervention utilizing credentialed and “skilled” staff. I recognize this distinction is imperfect.

diversifications have been non-linear and impacted by changes in public policy and the logics of capitalism and managed care.

The passage of Medicare in 1965 created a HHC benefit for intermittent at-home skilled nursing, under orders of a doctor.⁶ The benefit was imagined as a short-term, post-hospital intervention for people with acute health problems. Reimbursement was limited to HHC agencies certified through a survey process. Participation in Medicare opened new revenue sources for agencies, but also required investments in staff and infrastructure to handle billing and regulatory requirements, as well as a practical reorientation toward acute health interventions.

The benefit has changed and been reinterpreted through the years in ways that grew or constrained access to care (e.g., Bishop and Skwara 1993).⁷ In both the 1970s and 1980s, HHC was expanded as policy makers attempted to constrain more expensive facility-based care (Zawadski 1984). The loosening of restrictions allowed for and incentivized private HHC agencies to enter the market, and led to a more pronounced business orientation in HHC (Davitt and Choi 2008; Szasz 1990). With industry growth and associated costs to Medicare, however, came concerns about fraud and abuse of the benefit, and quality of care (Davitt and Choi 2008; U.S. General Accounting Office 1982, 1986). These cost discussions were entangled in disputes about the proper scope of the benefit (e.g., acute illness vs. chronic care) and the type of person deserving of care. Agencies felt increasing pressure to check costs by limiting nonreimbursable services and orienting toward market rationalization (Szasz 1990).

⁶ Initially, payment to agencies was made based on a fee-for-service model and, in some cases, beneficiaries had deductibles and copayments, and there were limitations on the number of visits per year (Buck 2004; Davitt and Choi 2008; Murkofsky and Alston 2009).

⁷ These shifts cannot be completely understood without reference to changes in use and governance of other aspects of the health care system (e.g., hospitals, managed care), or the lobbying efforts of professional and industry groups. This was beyond the scope of the current study and not detailed here.

Legislation in the late 1980s required the development of standardized tools for assessing outcomes of persons utilizing HHC care services to, in part, address concerns about increases in spending, access problems, growing complexities of HHC patient conditions, and questions about quality (Kane and Kane 1994). The costs of the Medicare HHC program continued to grow⁸ before the program was re-formed with the Balanced Budget Act of 1997. This eliminated the previous fee-for-service model (which allowed agencies to recoup aggregate or reasonable costs) and introduced a new prospective payment system (PPS).

The new system was based on a standardized assessment tool called the Outcome and Assessment Information Set (OASIS). The tool was created to generate data for the assessment of payment rates and quality, and to use as a coding and reporting standard that is readable and auditable by those reimbursing for and regulating services. The processes of documentation this system captures and records information, as well as creates certain ways of seeing patients and structuring care, according to the demands of the Medicare program. However, how this works out in practice, is not always as intended.

Since 1999, Medicare HHC agencies have been required to integrate OASIS into their existing assessment practices. With few exceptions, the assessment must be conducted on every Traditional Medicare, Medicare Advantage, and Medicaid patient at the start of care, every 60 days afterwards, and/or upon discharge. At the time of fieldwork in 2009, the dataset was comprised of 114 items categorized within 16 domains (e.g., clinical record, living arrangement, sensory status, activities of daily living, medications). For beneficiaries with Traditional Medicare coverage, items on OASIS provide the basis payment. Rates take into account clinical and functional severity, expected service utilization, as well as other factors such as geographic

⁸ Between 1990 and 1997, Medicare expenditures on HH rose from 3.3 to 18 billion dollars (CMS 2003).

wage indexes (Dey et al. 2011; Grimaldi 2000). Beneficiaries are allowed to continue accessing HHC, in these 60-day episodes, so long as they demonstrate positive change in relevant outcome measures, and continue to be homebound and be deemed by their doctor to require medical care at home. If not, the care will be assumed to be completed, and lingering issues deemed chronic or treatable in a community setting, and the patient discharged.

HHC offers an interesting site for exploring a number of different issues. In its practice, nurses must negotiate between contemporary management technologies that frame care within economic structures and “objective” knowledge (Campbell 2001) and more individualized and context-specific patient goals (Fraser and Strang 2004). Ageism and cultural ideas of what “old age” means can also impact the degree of medical and rehabilitative services deemed appropriate by, for example, establishing what degree of functioning is possible and “normal” (Becker and Kaufman 1988; Kvittek et al. 1986; Sankar 1984). Patients must position themselves in different socially intelligible ways to meet certain goals, such as arguing for more or less care, in relation to the requirements set forth by Medicare, the specificities of OASIS, and ideas of old age (cf. Olaison and Cedersund 2006). By examining how patients are assessed and how services are negotiated within HHC, this study sheds light on power relations, service utilization, and nursing practice. Additionally, study findings fill gaps in the literature on medicalization by showing the ways that “ageism” interacts with and mediates processes of medicalization (cf. Vincent 2008) and service provision (Sanders, Donovan, and Dieppe 2002).

Home care can also serve as a useful venue for studying issues in aging, embodiment, and identity. As mentioned above, Medicare HHC utilizes a biomedical framework that, in general, constructs the elderly as diseased, decrepit, and dependent. This is at odds with U.S. social ideals (e.g., independent, competent, vital), plus moral imperatives for retirement (“busy

ethic” (Ekerdt 1986; Katz 2000)) and newer purportedly more positive models of aging, such as “active aging” or “successful aging” (Luborsky 1995). One of the touted benefits of HHC is it can help recipients remain independent. However, for older adults, to maintain a sense of self as an autonomous individual, “independence” must be reframed within a context that requires that one is dependent (cf. Soodeen, Gregory, and Bond 2007). Compounding this is the disruption that illness experiences can have on one’s sense of self (Becker 1993; Kaufman 1988; Sanders, Donovan, and Dieppe 2002). Thus active negotiation and integration is required for a person to construct a sense of independence and self within this context. Researchers have found that older adults sometimes negotiate their identity by differentiating between a “true,” “inner” self and an outer, physically aging body (Clarke 2001; Kaufman 1986), constructing for themselves specific spaces and terms of existence (Kontos 1998), and, perhaps, redefining what it means to be independent (Neysmith and MacAdam 1999). How these negotiations occur within the web of relations discussed above can add to the anthropological and sociological theory of aging and identity within contemporary culture. An anthropological perspective in turn will help to situate aging issues within the practice and perspectives of older adults.

Caring Labor: Informal and Paraprofessional Care

While under Medicare reimbursed HHC, the focus is on “skilled” care provided by professionals like nurses and therapists, when looking at formal (i.e., paid) home care, most of the direct care is performed by paraprofessional home care workers (HCWs). This includes personal assistants, homemakers, and home health aides (the latter of which may be covered by Medicare HHC). These workers assist in supporting elderly care recipients in their homes through services such as housekeeping, everyday personal care services, instruction and psychological support, and routine medical checks.

Data from 2000 show that this is a demographically distinct workforce: 92% of home care aides were female, 50% were from a minority ethnic group, 25% were foreign born, 31% had less than a high school education, and 47% lived in or near poverty (Montgomery 2005). Although discussed in the literature as the “backbone” of the HHC industry (Gilbert 1991), agencies have great difficulties recruiting and retaining staff due to low job status, poor pay, little training, and difficult working conditions (Bell 2001; Benjamin and Matthias 2004; Yamada 2002). While they are often structurally disadvantaged compared to their clients, in the context of disablement, home care provides a unique intersection of multiple vulnerabilities and perspectives on the side of both caregiver and care recipient.

Home care work is an essentially decentralized activity that occurs behind closed doors in private homes, with both the worker and their client vulnerable to abuse and adverse events. While some have discussed these HCWs as an exploited labor force, others have analyzed HCWs in terms of domestic labor, particularly the use of immigrant female labor to fill roles in wealthy countries that used to be filled by female kin (Lan 2003). These authors point to how the diminishing size of families and increasing employment of women outside of the home in Europe and North America have created a demand for female migrant women to fill caregiving roles (Lyon 2006). This ties HCWs into transnational flows of labor and expands analysis of HCWs beyond the confines of local, regional, and national issues to highlight how caring labor is (and has been) gendered, classed, and marked by ethnicity and nationality (Lyon 2006; Neysmith and Aronson 1997; Panayiotopoulos 2005).

While many feminist and Marxist-leaning researchers have discussed the increasing transformation of care into managed workforces, government policies, and markets, informal (or non-paid) caregivers continue to provide the bulk of care. Much of the literature on informal

caregivers of older adults centers on caregiving burden (e.g., Starrels et al. 1997; cf. Walker, Pratt, and Eddy 1995 for critique). Formal home care is often discussed as a remedy to this burden, but the effects of home care on informal caregivers is mixed (Zarit 1999) and there is evidence that informal caregivers do not relinquish the care giving role when publicly paid home care becomes available (Li 2005).

Some family members take up management roles in relation to their older family member's health and have periodic or daily contact with paid home care providers and home care recipients. Interactions that occur within home care are governed by social values and norms, structural factors (e.g., policies' governing client-caregiver relationships, social isolation of the homebound elderly, and degree of homogeneity in terms of gender, race, age), as well as parties' personalities, motives, spatial location, and personal preferences (Meisenheimer 1991; Piercy 2000; Ward-Griffin and McKeever 2000). However, to date, little is known about the multifaceted nature of these interactions (Dalton 2005). By studying the complex exchanges that occur between these parties utilizing anthropological methods, such as participant observation and in-depth interviews, this study will fill in gaps in the literature on how older adults and their families negotiate and manage the need for home care, as well as coordinate that care amongst a variety of individuals who may have different goals and expectations. This will additionally provide insight into contemporary family norms and practices, expanding from the mainstream focus on burden to understand it in its complexity.

Research Questions

Given this background, I approached this study with several broad questions. How do older adults, their families, and health care providers negotiate and manage the fragmented long term care system in the United States? What can the fragmentation of this system and the ways

that people navigate its gaps tell us about contemporary cultural beliefs about aging, gender, ethnicity, race, family relationships, and independence, as well as power relationships and the broader political economy?

With these in mind, I set out with a handful of interrelated goals.

1. To document the historical allocation of home health care under Medicare through Medicare policy analysis and examination of the articulation points between federal, state, and local agencies. Of particular importance is an analysis of how cultural, social, economic, and demographic changes have impacted allocation and regulation of Medicare home health care over the past 15 years.
2. To understand the power relations involved in how home health agencies negotiate federal and state requirements for Medicare certification in nursing practice (e.g., allocation of services). This is accomplished through analysis of interviews and job shadowing.
3. To examine the gendered, classed, ethnic, and racial marking of the home care workforce. This involves study of home care workers' motivations for entering caregiving, training, their work practice, career trajectories, and their discussions of their work and their relationships with clients and their families. Data is drawn from ethnographic interviews and job shadowing.
4. To explore interactions between home health nurses, home care workers, and care recipients and their families, paying special attention to stereotypes (e.g., related to who perceived to be appropriate caregivers), expectations for caregivers, coordination of care, and the role that gender plays in these interactions. Here attention is given to data drawn from extensive participant observation to identify

how different understandings and interpretations are negotiated to coordinate and provision care.

5. To understand how older adults and their families negotiate and manage the need for home care both during and following the provision of Medicare home health services. This involves information gathered during repeated interviews with participants (during, at the end of, and some time after receipt of home health care). I examine how older adults experience care and old age, as well as their strategies for constructing an identity with available cultural resources.

As described in the methods section below, accessibility issues, as well as the discovery of emergent issues required adjustments to my original plans during the course of fieldwork. In particular, my access to paraprofessional home care workers was limited. However, I was afforded much more time with HHC nurses than I anticipated and this provided new opportunities for exploring the ways in which HHC has evolved and the ways that eligibility for care are shaped during practices.

In the next chapter, I discuss the methods used and data gathered to study these questions. Following this, I provide overviews of the appended papers' theoretical frames and results. I close that chapter with some general conclusions and suggestions for future work.

CHAPTER 2

This chapter provides a summary of the methods, results, and conclusions of this research. Specific explorations of findings can be found in the appended papers. The chapter closes with general conclusions that can be drawn from this work. I begin, though, with a brief description of the study site, design, and data.

Setting

This research took place in a metropolitan area in the southern part of Arizona, US. The area's major city sprawls between five mountain ranges, amid blonde arid dirt, saguaros, mesquite, javelinas, sidewinders, lizards, and a surprisingly abundance of other plant and wildlife. More than a million people call the metro area home. A major highway bisects the city center and an extensive grid of streets spread in all directions throughout the city's 227 square mile expanse.

The area lies in the Sonoran Desert. This unique region extends from southern Arizona and California, down into the northwestern parts of Mexico. Often characterized as boasting a "dry heat," the metropolitan area frequently reaches temperatures above 100 degrees Fahrenheit in summer months and more comfortable highs in the 60s during the temperate winter. While as a desert ecosystem annual rainfall is quite low, averaging about 12 inches a year, there are distinct rainy seasons in the winter and summer.

In the county, which encompasses the metro area, the majority of the population is white not of Hispanic origins (55%) (U.S. Census Bureau: State and County QuickFacts 2013a). However, more than a third of the population claims Hispanic heritage (35%), and smaller shares of the population are made up by Native Americans (4%), African Americans (4%), and Asians (3%).

Economically, Arizona provides a mixed and disparate picture. The area once was heavily impacted by mining, though today major industries in the area tend more toward education, health care, defense, and tourism. It is home to a major university, an air force base, and several large manufacturers. Between 2008 and 2010, the state had the second highest rate of income inequality in the nation (Persad 2012b). The metro region is one of the poorest in the nation, and has been characterized by slow economic growth, high unemployment, and widespread poverty (Persad 2012a). The economic landscape was especially negatively impacted by the Great Recession from 2007-2009, and has been slow to recover, in part, because of the economic reliance on the housing market and construction industry (Rothschild et al. 2012). In the county in 2010, compared to the rest of the nation, there were elevated rates of poverty for children (25% locally versus 22% nationally) and adults (18% versus 14%), while slightly lower rates for older adults (8% versus 9%).

Thanks in part to its warm climate, low tax rate, and low cost of living, Arizona is home to a very large and growing older adult population. In 2010, older adults made up nearly 14% of the population, which is a bit higher than the national average of 13% (Werner 2011). The numerical growth rate of older adults in Arizona was the fifth highest in the nation (Werner 2011). Looking at state averages, though, ignores unique seasonal variations and geographic clustering. The state plays host to a sizable population of retired winter residents or visitors, more colloquially known as “snowbirds.” These individuals spend winter months in desert environments, and travel or reside in cooler climates during the warmer months (May through September). While many of these people seasonally migrate to the state and stay in mobile home and RV/travel trailer parks, others reside in single family homes, condos, hotels, and other accommodations. The last state-wide study estimated that at least 300,000 people spent the

winter of 2002-03 in Arizona and had a significant economic impact (Hogan, Happel, and Walls 2003). Indeed, winter visitors are considered important contributors to the study area's tourist season (Chihak 2013).

The presence of large retirement and continuing care communities, as well as other infrastructure and services aimed at an older adult population, also has helped create clusters of large populations of older adults in the state. For example, to the south of the study's major city, a census designated place is essentially an unincorporated grouping of retirement communities. Here the older adults make up 72% of the population (U.S. Census Bureau: State and County QuickFacts 2013b). To the north, over a quarter of another town's population was comprised of older adults (U.S. Census Bureau: State and County QuickFacts 2013c).

Design

This project began slowly and somewhat organically. In the spring of 2007, I began informally exploring issues related to aging and home care. I began by spending a few days in a local retirement community where I talked with residents and their caregivers, getting my first glimpse into the important issues and topics involved in aging.

I also started spending several weeks a year with my 90-year old grandmother in southern California. I found this time both personally and intellectually rewarding. It placed me within the daily life of my grandmother as she negotiated her new widowhood, diminishing capacities and mobility, and fears of being taken from her home. I learned how she structured her days, took part in self-care regimes, and found joys in seemingly mundane things. I still treasure the hours I would sit with her on her back patio in the sun, reading and periodically discussing the neighborhood cats. Staying with her also allowed me to observe her relationships with her

daughters and son-in-laws and, as time progressed, the delicate, and not so delicate, balancing of blurred roles, responsibilities, and relationships.

As my own research plans firmed and I acquired funding through a National Science Foundation Doctoral Dissertation Improvement Grant, I began talking to experts and providers in the study community, and informally job shadowed two home health nurses. I learned about the patched network of long term service providers and got a much better understanding of the work of home health nurses and their relationships with their patients.

After approval for design and methods was obtained by the University of Arizona Human Subjects Protection Program, formal fieldwork began in November 2009 and ceased in November of 2010. The project was designed in two phases. The first phase was to last two months, allowing me to make stronger contacts in the community, particularly in the home health field, interview long term care service providers, participate and observe community events related to aging, and generally situate myself. While the first phase would allow me to survey and map the community and long term care system in general, the second phase would involve work more specifically directed to answering my research questions. I would principally engage in job shadowing, interviews people involved in home care, and short-term follow-up with older adults receiving home health care.

Overall, I recruited 91 individuals who were involved in or knowledgeable about the care of chronically ill older adults to participate in at least one semi-structured interview. These included older adult recipients of HHC (n=22), their informal caregivers (n=16), home health nurses (n=9), home health administrators (n=5), paraprofessional home care workers (n=14), and a variety of other service providers and health professionals (n=25). In addition, I conducted job shadowing with nine home health nurses from two for-profit Medicare-certified home health

agencies. This included observing 77 visits with patients. I also engaged in a variety of volunteer positions and variously participated in community events related to aging. Throughout these activities I tried to get a sense of the experience of aging with chronic disease, the ways in which aging was conceptualized and managed, the long term care landscape, and sites of tension and discord. Interview guides were prepared for semi-structured interviews.

Phase 1

The first phase involved three key activities: home health administrator and manager interviews, stakeholder interviews, and participant observation. For the home health administrator and manager interviews, the goal was to purposively sample 10 directors of nursing or managers among the county's 24 Medicare-certified home health agencies. In the end, after making calls to most of these agencies, representatives from five of these agencies agreed to participate in semi-structured interviews. An additional director of nursing agreed to speak with me as a professional and not an agency representative, but only so long as the material went into fieldnotes and was not recorded as a formal interview. The interview guide focused on issues related to aging, home care, service provision, and policy issues including recent and anticipated shifts in funding as entitlement programs are reviewed and subject to reform by a new presidential administration. Interviews ranged from short, phone conversations lasting 15 minutes to face-to-face discussions lasting close to two hours. All of the participants were women and most had nursing experience and long careers in HHC.

Stakeholders became a catch-all category for persons knowledgeable about long-term care and/or home care but who did not fit any of the specific categories of people being interviewed. Twenty-five people were interviewed as stakeholders, four were men and 21 were women. They included social workers (n=7), case managers (n=4), older adults receiving care

(n=3), nurses (n=2), a physician (n=1), an ombudsman (n=1), and people variously involved in aging-related services (n=6). Interviews ranged from guided conversations to semi-structured, and often lasted about an hour. During the interviews I asked them about their experiences in their jobs, the community needs they encountered, and the landscape of the broader local long term care system. Notably, these interviews took place throughout the study period as I met people at events, was referred to knowledgeable individuals, or found out about different programs and services.

Participant observation during the first phase of the project was somewhat difficult (see below). I attended public meetings and events related to aging, such as a Medicare Update conference, events for caregivers, and health-educational sessions provided by a local hospital. I continued to participate and attend similar events throughout the study period. Here I had opportunities to identify what aging-related topics were highlighted in public discourse and how these were talked about, as well as meet people and interact informally with participants at these events.

I also began volunteering at a senior center and with a non-profit that provided many senior services to persons residing in a sector of the study area. While I discontinued volunteering at the senior center by December 2009, I continued volunteering with the non-profit and later became a hospice volunteer and a volunteer at a group home. These volunteering activities first provided me with an opportunity to familiarize myself with the community and community-dwelling older adults, as well as begin to identify the different types of care giving relationships that exist. During the first phase it also served as initial exploratory research to help identify themes and significant issues for further investigation (Schensul, Schensul, and

LeCompte 1999). Over time, it provided me the opportunity to interact more informally with people and develop relationships that were not necessarily research-related.

Phase 2

There was not a clear demarcation between phase one and two of the project except that phase two commenced with the start of job shadowing with home health nurses. From this home health care recipients and caregivers were identified and recruited to participate in interviews. Initially focus groups and written surveys of home health agencies were planned, but this was scrapped after recruitment challenges were encountered (see below). The second phase was critical to the project, though the first phase involved activities that were essential to accomplishing my research goals.

While interviewing home health managers and directors of nursing I asked whether their agencies might be willing to allow me to job shadow several of their employees, specifically home health aides. For the most part, these requests were met with extreme skepticism. Several indicated upper management or corporate would never allow it, others cited concerns for company and patient privacy. Despite the negative reception overall, two managers enthusiastically agreed to allow me to job shadow some of their nurses. Given nurses function quite differently than home health aides (who I learned are now mostly used to help patients bathe) and provide much more “skilled” medical care, this meant a rather large departure from my initial goals of studying the blurry line between formal and informal domestic labor. However, because nurses are care managers within HHC, the change provided me with a better opportunity to explore the different forces that shape care, particularly bureaucratic and auditing practices.

Scheduling the job shadowing, however, was somewhat difficult. While I had the support of two people in management, the reception was not so warm when I was handed off to people lower on the chain of command who were charged with arranging the job shadow placements. My interaction with them was limited and their understanding of what I was doing was incomplete, and details were lost in the communication between myself, my contacts in management, and those charged with assisting me. For example, there was much miscommunication about how many nurses I wanted to shadow and for what length of time. Initially, because I wanted to study interactions between providers and patients of different ethnic backgrounds, I had planned on sampling by ethnicity and where people were born. However, from my observations, both agencies had rather racially homogeneous nurses and I was told that the agencies could not fulfill my request. In one agency, I was explicitly told I was being placed with their best nurses so that I could see home health done the “right way.” While the home health office staff that I interacted with seemed willing to help, their engagement with the project was small and their list of things to do long, and I was not a priority.

Both Agency A and Agency B are Medicare-certified home health agencies, however their structures and scopes of operations differed. Agency A was one of the larger and well known home health agencies in town. It is run by a nationwide, privately owned company that operates home health offices in about a third of the states in the U.S. It was founded in the 1970s and had been locally Medicare certified since the late 1990s. The branding of this agency was much more pronounced than with Agency B. Agency B is a home care and medical staffing franchise, with independent franchises operating in localities in almost every state in the U.S. as well as one foreign country. The corporation had been involved in home health since the 1960s and the local franchise had been Medicare certified since the late 1970s. At the time of fieldwork

the local office was undergoing a management change and a manager from another office was commuting to Tucson to oversee the transition. They had hired a new clinical supervisor and new nurses. Unbeknownst to me at the time, the agency was also in the process of firing a handful of nurses. Observations showed that there was much tension in the workplace and at least one nurse expressed concern for her job safety.

When I began job shadowing in winter 2009-10, both agencies were experiencing an uncharacteristically low patient population. People with both agencies speculated that there were fewer “snowbirds” because of the poor economy. This meant that nurses saw fewer patients than usual when I was shadowing with them, which made for shorter days and weeks.

In terms of assigning me to nurses, Agency A fit me into existing student nurse practicum channels. For the most part, I was placed with nurses who had been pre-approved to be preceptors for students training to become nurses. I found this led to nurses being less than thrilled to be asked to allow me to shadow them because, as I learned, having student nurses is seen as a burden to some of the home health nurses. Some nurses later told me that they had been less than eager to have me shadow them and I presume that this was one of the reasons I never heard from at least two nurses to whom I was assigned. With Agency B, as I noted above, I was placed with the nurses the clinical supervisor thought were model nurses. Thus there were various selection biases at work in terms of who I job shadowed that have necessarily affected the interactions I was able to observe. At the same time, the nurses I shadowed showed a great range of experience in home health, relationships with their patients, and also attitudes about the field.

Job shadowing commenced in fits and starts. It was continually delayed because nurses did not contact me when they said they would, nurses’ plans changed at the last minute (e.g.,

patient discharged, patient in hospital) and they could no longer take me out at the planned time, etc. In the end I spent time with nine nurses for periods of up to one day and one patient visit, to four days and up to eight visits per day. In total, I job shadowed nurses for 22 days and 77 patient visits. All of the nurses were white and female ranging in age from their late 20s to late 50s.

Generally I would meet the nurses at the agency office and ride with them in their cars to patients' homes. When things went as planned, it was a tremendously valuable experience not just because it allowed me to recruit recipients of care into the project, but because I could speak with nurses at length about their work during the car rides, observe their practice and interactions with patients and caregivers, and otherwise get a feel for the tempo and workings of home health care. It also allowed me to develop an understanding of the explicit and tacit aspects of the culture of aging and health care at work (DeWalt, Dewalt, and Wayland 1998). Gaining an understanding of tacit parts of culture is a particularly important, as tacit culture is something that generally lies outside of people's awareness and thus is not likely to be articulated in conversations or interviews with participants.

While job shadowing with nurses I asked them to identify patients who met my study criteria, namely persons 65 years and older, non-demented, who (a) have an underlying chronic condition and (b) would be at high risk for acute crisis or home care services upon termination of Medicare HHC. Because of HIPPA concerns, I never asked nurses for specific confidential patient health or other history, just whether they thought the person would be appropriate for the study. In cases where the person was deemed appropriate, typically at the end of the visit I would talk to the person about what I was doing and ask whether he or she would be willing to participate in the study. (Toward the end of job shadowing, when I found that I was having difficulty scheduling shadows and meeting patients (in part because of the low enrollment

numbers) I expanded eligibility criteria to include older adults identified by other home care workers. These individuals privately paid for home care and were at risk for acute health problems. Notably only one person was recruited using those expanded criteria.

Patient participants were invited to participate in a series of three interviews. The first was to take place while they were receiving HHC, the second would be about two weeks after discharge from HHC, and the third would be three months after the second. Soon after starting to interview people, however I found this scheme overly complicated and problematic. In the first case, some of the individuals I met were just about or in the process of being discharged. Sometimes this meant that, in part because I might have been dedicated to job shadowing that week, I did not get an opportunity to interview them until after their home health episode was over. In addition, I found that two weeks after discharge was difficult to keep track of for those people with whom I had sporadic contact and sometimes it meant too little time between interviews. Three months between the second and third interviews proved to negatively affect the building of rapport and was often too great a period of time for people to remember what had happened. Thus within a few months into the research I changed the scheme to have the interviews spaced about four to six weeks between each other. Although this seemed straightforward and flexible, it was also difficult to maintain because often it was hard to make contact with people as they had other things going on (e.g., new health problems, visitors).

Initially I had hoped to have a large enough pool of potential participants from which to sample 15 women and 10 men. In the end, I was able to recruit 22 individuals, 12 females and 10 males. 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.

Their experiences receiving HHC varied and later made comparing across situations quite difficult. 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.

With older adult patients, I conducted a total of 55 interviews, all of which took place in their current residence. 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). I prepared semi-structured interview guides to use with participants for each of the three interviews, with each interview taking up a different topic or theme. The first interview focused on the person's background and life history, the circumstances surrounding receipt of HHC, and experiences with HHC. The second interview collected information about how the person's condition had changed since the first interview, how HHC had ended (if it had), current service use, the

individuals' relationship with their home, and plans for the future. The final interview again asked questions about current condition and service use, but also delved into broad questions about aging experiences. In conducting interviews, however, I found that they often took on unanticipated forms. In some cases, participants appeared to have no interest in answering my prepared questions, seemed to lack the capacity to discuss the issues in depth, or had other things they wanted to talk about. I found it was best to discuss what they wanted to as it helped to build rapport and also gave me insight into the issues that meant most to them. I was able to insert most of my topics and questions as related issues came up in our conversations.

Principally through my relationships with patients, but also through job shadowing experiences and meeting people at events, I recruited 16 informal (i.e., non-paid) caregivers to participate in semi-structured interviews with me. (Eleven of them were caring for someone who also participated in the study) Three were men and 13 were women. All were white and ranged in age from 43 to 92. While most had occupied or were occupying multiple caregiving roles, and in some cases were care receivers, for the purposes of the interviews I asked them about specific caregiving relationships in which they were an identified caregiver. Eight were caring for a spouse (6 were wives, 2 were husbands), six were caring for a parent (5 were daughters, 1 was a son), one for an aunt, and one for a friend. At the time of our first meeting, 10 were residing with, four lived within an hour's drive of, and two lived in a different state from their care recipient.

Interviews averaged about an hour and a half (45 minutes to three hours). Caregivers chose the sites for the interviews. Most of the interviews took place in their or their care recipients' homes. The interview guide contained items related to their caregiving experience, home health care, and aging in general. Questions and prompts such as those provided

touchstones for conversation and emergent follow-up questions based on caregivers' unique experiences.

After completing most of the job shadowing, I began recruiting home health nurses for semi-structured interviews. I had hoped to interview 15 home health nurses, however after much effort, I was able to secure interviews with nine nurses. Of the nine, four had also participated in job shadowing. Seven of the nurses were women and two were male, and two were foreign born. Six were white, one was Asian, one was Native American, and one was of unspecified decent. All except one was a registered nurse (she was a licensed practicing nurse) and were currently employed by a Medicare-certified home health agency.

Interviews took place at a place of their choosing, which most often was a café, and lasted about an hour and a half. Interviews centered on their experience working HH and their practices, particularly how it has changed with the introduction of new policies and documentation. For the four nurses who I had job shadowed, the interviews allowed me to follow up on issues that had come up during the job shadowing, as well as explore other issues I had laid out for interviews. In truth, many of my interview questions were covered during the job shadowing as well as during interviews with home health managers or administrators with nursing experience, so I have data from about seven additional nurses on many of the topics covered during the interviews.

As noted above, I was initially very interested in the experiences of paraprofessional home care workers, such as paid home health aides, but had difficulty meeting and recruiting them through my work with home health agencies. Through a variety of avenues, including older adults and their families, home health nurses, training centers, and participation in caregiving events, I was able to recruit and interview 14 paraprofessional caregivers (9 women and 5 men).

(Six were caring for an older adult who participated in the study.) They ranged in age from 19 to mid-60s. Seven were white, four were white of Hispanic decent, two were black, and one was of Asian heritage. Of these, eight were privately employed by the person or people that they cared for, while six were employed by a home care agency and assigned to cases. Their experiences within the field were varied, ranging from a person who had taken a part-time job as a caregiver with no training and as a way to make money while going to college, to a person with a master's in social work and training as a certified nursing assistant. A handful also currently worked at or had experience working as aides within skilled nursing facilities.

Interviews took place at sites of their choosing, which most often were fast food establishments or cafes, and lasted about an hour. Interview questions centered on their experiences working as home care workers, their job trajectories, and their relationships with their care recipients. Compared to the other groups I interviewed, my interactions with paraprofessionals was more limited and formal.

Notably, this project involved a range of different types of people who were involved in care of older adults. Many of the people I interviewed and informally talked to throughout fieldwork had experiences with multiple roles. For example, many of the older adults, nurses, and service providers shared experiences of informally caring for their own spouses or parents. Many others were also able to speak to the experience of aging and managing chronic illness. Thus, the categories in which I have placed people does not adequately express the breadth and depth of experiences that were shared with me. Ethnographic data has been supplemented with agency reports, newspaper articles, and other relevant policy literature. To protect the anonymity of those participating in the project all names and certain pieces of identifying information have been changed.

Data Management and Analysis

When possible (which was in most cases), audio recordings were taken during interviews. I also took detailed written notes while conducting interviews. Following interviews, thorough ethnographic notes regarding how the person was recruited into the project, the setting of the interview, contextual details of the interaction (e.g., physical description, rapport), and major themes and observations were typed up. Later, notes from the interview were typed based on the written notes taken during the interaction, as well as summaries and spot transcripts from listening to the audio recording. Each person who participated in interviews was assigned a unique identifying number which was used in place of their name in all notes about them. Later, each person was also assigned a pseudonym to be used in publications.

Written notes were taken during all job shadowing experiences. I paid particular attention to physical interactions between nurses and patients, topics of conversation (e.g., jokes, shared personal interests, family, education), the roles that informal caregivers played, and practices of assessment. Notes were also taken during my informal conversations with nurses during car rides between patient visits. These notes were generally typed up, based on written notes, within a week of the experience.

Fieldnotes were also taken throughout the study period. These included detailed notes of events I attended (e.g., caregiver conferences, public aging lectures), informal interactions with people I met, observations based on my volunteering experiences, problems or changes in study design, reflections on my position as a researcher, and early, emergent themes from the research.

All these typed documents were uploaded and managed within an Atlas.ti (qualitative analysis software) database. I constructed a code book based on research and interview questions, as well as emergent themes from research. Codes ranged from those that helped point

me back to particular, descriptive information (e.g., interaction between nurse and patient, descriptions of homes, information about how HHC started, work history), to those that referred to specific objects or practices of interest (e.g., medications, falls, narratives about families, referral processes, Medicare), to more abstract themes (e.g., emotion, gray areas, moral identity). Code reports based on these themes were then used as a basis for collecting similar information in one place for reflection, analysis, and writing. This was an iterative and ongoing process, as all parts (e.g., listening to audio, typing notes, reading notes and coding) elicited questions, reflection, re-readings, new codes, and synthesis of ideas.

Results

I recall heading into my first, unofficial job shadowing experience with thoughts of bureaucratic systems, medicalized aged bodies, and exploited female caregivers dancing in my head. However, I quickly learned that HHC is an immediate and, for lack of a better word, fleshy experience. In people's homes, my senses were greeted with smells, sounds, and nakedness. There were frail limbs, gaping wounds, and expressions of pain and grief. It was an intimate experience and I was discomfited by my place in it as an outsider and observer. However, I quickly found that there was also a lot of laughter and warmth in these interactions. The conviviality, the ways that people helped and cared for one another were affirming and welcoming for me.

While I went into this project unprepared for the sensorial and emotional nature of my intended study, I found that those experiences gave complexity and texture to my understanding. It also provided a foil to the more abstract forces and concepts that I found myself tracing in the day-to-day interactions and relationships. The feelings I encountered and empathetically

witnessed were sometimes difficult for me to handle, but they were also the most meaningful and memorable parts of this work.

As I sat down to write, I struggled to find the right frames and language to capture the depth and breadth of these experiences. The metaphor of the gap emerged again, but post-fieldwork it took on new meaning. It did not just index the fragmentation of the LTC system or the gulf between the experiences of the people involved in it, but it also spoke to the uncertainty as people negotiated their various positions within the systems and relationships that they were embedded. I saw that at stake in the jockeying around the gap were things that people valued and that different structuring forces and conflicting responsibilities could pose threats to holding onto those things.

Using different theoretical lenses, I decided to focus the three papers that follow on the work of older adults using HHC, home health nurses, and family caregivers. To varying degrees in each of the papers I discuss what was at stake for the different groups in the phenomena of aging in place. I placed the work they did around this within the context of the complex systems that made up their world, attending to the ways that they experienced, negotiated, reproduced, and contested them.

In the first paper (Appendix A), “The Uncertain Bodies and Spaces of Aging in Place,” I focus on the experiences of chronically ill older adults receiving Medicare-reimbursed HHC. I frame this within a critique of simplistic notions of “aging in place” by drawing on definitions of place from geography and the medicalization literature described above. In this paper, I highlight the resources and work that go into aging in place amid uncertainty, and how processes related to the integration of person and place are negotiated, contested, and regulated. Following Wiles (2005) I argue that aging in place needs to be viewed as a social and material process.

Using ethnographic examples, I illustrate how HHC is a mediating force in these experiences and has immediate impacts on the experience of self and place. I note how 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 thus make the argument that the processes of aging in place come with tradeoffs. In addition, that lack of LTC supports (e.g., availability of informal caregivers, access to services) can make the work of aging in place extremely difficult and, in the end, impossible for some people.

My second paper (Appendix B), “Documenting the Way to Care,” takes off from the idea of barriers to access to care to look at the forces that work to define what types of care are available to older adults with chronic illness. However, the frame shifts upstream to Medicare, to mid-level for-profit health care organizations, and to front-line health care providers. In this paper, I predominantly draw on the lens of governmentality and the work that Michael Power (1999) has done on audit culture.

In this paper, I describe the ways in which audit culture has suffused the Medicare system and created complex rules and systems as a means of making durable certain ways of organizing, seeing, and knowing in health care. Underlying this is a drive to control costs and threats to the Medicare system, such as HHC fraud and abuse. However, these have effects, some of which are unintended, in the organization of HHC agencies, day-to-day practices of home health nurses, and, ultimately, the ways that beneficiaries are represented as worthy (or not worthy) of care.

I focus on the ways that documentation is critical to these practices. I argue for the need to view documentation and the data that makes up these audit systems as produced through social interactions which may follow different logics than those embedded in the audit technologies (e.g., assessment tools). I trace these practices, and how they are bent, through the

mundane, micropractices of agency and nurse practice, noting particularly sites of tension where several logics and imperatives conflict. I also indicate how these processes feed into privatization, in which complex care work around aging with chronic disease is handed off to individuals and their families.

The third paper (Appendix C) moves the lens back into the private sphere and into the experiences of informal caregivers. As noted above, informal caregivers provide the brunt of the labor in LTC. Existing literature highlights the costs and burdens borne by unpaid caregivers, particularly women. However, there has been less examination of understanding caregiving in a broader, more complex, more meaning-filled way.

Through four case studies of family caregivers, I explore the complexity of feeling and meaning constitutive of caring relationships, by stressing the interactional and socially embedded nature of the caregiving position (Abel 1990; O'Connor 2007). I highlight the shifts in relationships and identities as people confront the tensions wrought by the uncertainties and ambiguities of aging in place with chronic illnesses and disabilities. With a focus on what is at stake for each of them (Kleinman 1999), I illustrate how informal caregivers construct their moral identity and how they establish and maintain a sense of what is important to them.

Conclusions

As this study highlights, tensions and uncertainties ran through the experiences of those trying to achieve “aging in place.” I showed how the ideal of aging in place is not a state, but a process that is structured by larger scale social, cultural, political, and economic forces. The appended articles point out how questions of what type of care, who is deserving of care, and how care responsibilities are distributed play out within the lives of chronically ill older adults and the people who help them.

This study contributes to the existing aging literature by showing that aging is more than a biological given. It is an experience and process that is fundamentally mediated by personal history, as well as sociocultural and political economic forces. By using an anthropological lens, I was able to look at aging in place as a whole system. I presented my results through three theoretically distinct papers in order to show how the different pieces of the complex puzzle of aging in place fit, and sometimes do not fit, together. Doing so also allowed me to shine a light upon how these different pieces (e.g., aging at home with chronic illness, caring for an aging family member, home health nursing, and Medicare policy) are nested together as a means of fleshing out the complexity of the experience of aging. Seen together in this dissertation, these papers show what anthropology, as a discipline that emphasizes holistic, ethnographic research, has to offer for better understanding the processes involved in aging.

As emphasized here, in the US, as people age, they are enrolled into the health care system as a means for managing their aging experience. However, the health care system is fragmented, disorganized, and ill-suited for chronic care needs. Lay people as well as professionals are thus left trying to make the best of the situation.

Complexity and ambiguity permeated older adults and their family members' experiences of aging at home. During the periods in which I met people, following or in the midst of acute care crises, conditions were constantly shifting and the future was unknown. People worked to adjust their outlooks, practices, and settings to respond to changes in identity and physiological condition. In doing so, they drew on biomedical practices and narratives of risk to organize their world. This was reinforced by some of the practices in HHC, such as measuring and checking (e.g., blood pressure), care regimes (e.g., medications, wound care), and rehabilitative exercises.

However, while people were surrounded by a host of structuring forces, they were not completely subject to them.

As noted in all three papers, control battles could emerge during the process of aging in place. Within the home, differing values and imperatives were held between nurses, patients, family members, and formal caregivers, not to mention other people involved in care, such as doctors, social workers, and others. These tensions complicate static notions of aging in place, as there exist a host of differing ideas about what aging in place should entail and, indeed, whether it is something worth pursuing.

Part of the ambivalence noted above was driven by the opacity of the medical system in which people were immersed. Older adults and their caregivers were often relied upon to communicate information between health care professionals, and were sometimes confused and exhausted by complicated care regimes, appointments, and testing. At the same time, health care professionals were often looked to to help make sense of situations, provide support amid uncertainty, and as sources of hope for healing. As noted in paper 2, nurses were actively involved in transmitting knowledge to lay caregivers, as well as patients. Through educational efforts, theoretically, they would help people remain in their homes without skilled involvement. Thus nurses, and home health agencies, could sometimes act as cultural brokers by providing education and tips to older adults and their families in navigating the complex system and remain at home.

For many people, Medicare funded HHC worked as intended: to treat and resolve acute health problems. While this meets the needs of some beneficiaries, others who are dealing with multiple, chronic conditions can find themselves needing to find longer term home help options or soon face another acute health crisis (which could require hospitalization and/or another

episode of home health care). However, finding assistance amidst the varied and limited community options can be extremely difficult, especially if one does not qualify for the public long term care program for persons with low income and limited assets, Medicaid.

In general, many individuals and families were left wondering where to go for help. As one director of a home health agency, Carol, laughingly noted when I asked her about the long term care system:

“there is none. [no long-term care system] (Laughs) There is none, there is none. Um, yeah, we’re just not ready for the elderly, who are alive longer than they used to. [...] there’s just nothing in the health care system is really set-up for getting these chronic, long-term health problems and functional decline that they have, so um (Pause) yeah, it’s really very sad. (Pause) And it’s because the whole health care system is acute care based, it solves problems, prevention isn’t, you know, at all in our (Slight pause) incentivized by, by any means.”

While I encountered some very good local, centralized resources (e.g., the county’s Area Agency on Aging) and met a handful of people who had positive interactions with them, not everyone was aware of such those resources. Many services were not accessible. Many local service providers had limited (and not always stable) resources, and often had geographic and income eligibility requirements. Many people I met were frustrated and discouraged when they found possible resources, but then were unable to access them.

At the time of fieldwork, the impacts of the Great Recession were being felt by community service providers who were witnessing increased need in the community at the same time that program funds were being cut. Some community providers voiced concerns about cuts to already fragmented and meager programs providing support to community-dwelling older

adults. While home health can help stabilize a frail older adult after a hospitalization or acute crisis, questions remain about how to ensure maintenance and support once home health comes to an end. In a time of government cut backs to programs such as Medicaid (for which some of the participants in the study tried and failed to qualify for), despite intentions for older adults to remain in the community, some were concerned that they would be forced to be institutionalized in facilities of uncertain quality.

In addition, the issue of “frequent fliers” to hospitals (i.e., chronically ill persons with frequent hospitalizations) seemed to point to the lack of stable supports for people living in the community. One hospital social worker explained that some of those people were entering the hospital because their caregivers needed a break, others came because the hospital was better than what they had back at home.

Increasingly, there are private individuals and groups who provide care management and personal advocacy services, which help people navigate the fragmented system and access resources. However this has to be paid for out of pocket and many of the people I met were unaware of these services and probably would be unable to afford them. The complexities of and privatization in care management enhance disparities.

Given these complexities and difficulties, for most of the frail, chronically ill people I met, it was essential they had informal support. In talking to me about the tasks she could no longer do around the house that her son, who lived with her, had taken up, Emma reflected: “I’m glad I have him around to do these things for me. If he wasn’t here, I don’t know what I would do. I’d have to go to a nursing home and nobody wants that. [...] I would be really lost.”

Adjusting to anticipations of long-term disability or ill health looked different for those lacking

social support and the means to buy in-home support. The future looked uneasy and the options scarce.

Informal caregivers do not simply substitute for formal caregivers, though. Often, the presence of informal caregivers to do caregiving duties when formal caregivers are not there is a condition of providing service. HH nurses are not allowed to do daily visits to patients, so there must be someone to do needed caregiving in their absence. Otherwise, the individual might be designated as someone requiring institutional care. When needs are high and professional caregivers ability to be in the home limited (either practically or because of insurer stipulations), informal caregivers help make it possible for the person to remain at home (Frederiks et al. 1990).

Many informal caregivers end up taking on an increasingly involved caregiving role over time. Crisis often precipitates people exploring options for care within the public sector. However, as noted above, long term care is decentralized, fragmented, and variably accessible. Many caregivers find this landscape confusing and overwhelming. The complexity and ambiguity provide some incentive for caregivers to take on more responsibility for care (Wiles 2005).

Identity politics were also at play at a much broader level. Over the course of the 20th century, a handful of major policies (e.g., The New Deal, Medicare, Social Security Income) were enacted to address widespread poverty among the elderly. In doing so they helped to reinforce the conceptualization of old age a separate and distinct social problem, which helped to legitimate age segregated approaches (Estes and Harrington 1981). These policies and the programs they created helped to institutionalize old age, or more accurately retirement, into a socially, economically, and politically powerful group and self-identity around which people

could organize (Hudson 1999). During the time of fieldwork, as narratives constructed an image of a growing older adult population and dwindling public funds, there were widespread public conversations about reforms to some of these age-segregationalist programs, particularly Social Security and Medicare. Through these reform discourses and their critiques, the federal systems for supporting older adults were constructed at threat, and by implication (explicitly and implicitly) older adults were also at risk.

This work has several messages for policy makers. Medicare and other insurers could help relieve a lot of confusion and angst for members and their families if benefits were described in clearer language and programs were structured in more straightforward and integrated ways. Insurers could also provide more coverage for supportive services and acknowledge the cultural brokering services that some nurses provide.

I noted the availability of social work services was very limited in the agencies I became familiar with. For example, I met one HHC social worker that worked part time at multiple agencies and was the sole social worker at each of those agencies. While some of the nurses I met were aware of resources in the community that they could refer patients to, social workers would be better trained and knowledgeable about different care options and resources available for patients and their families.

However, social workers can only point patients to resources that are available. Many social service providers, as well as others, described the lack of availability of home-based services. While transportation and meal services were generally available (though probably not to the degree they were needed), in-home homemaker or aide services was hard to find. The Medicaid long-term care program (in Arizona known as ALTCS) covered some of this care, but I was told by providers and users that it had been scaled back and was not sufficient for many of

the recipients. For those did not qualify for Medicaid, there were limited very community-based assistance programs, but those were experiencing funding cuts and waiting lists during the study period. Thus most of the people I met who were using home care services of this kind were doing so out of pocket. Some of the older adults and families who were unable to afford it, expressed interest in being able to hire someone to help out a little.

Many of the older adults I met were clear that they did not want to move in with their adult children should they find themselves having trouble living in their own homes. While many explained they would not want to be a burden on their children, some articulated a concern about having to alter their lifestyle and sense of identity. What was important here was that although most clearly preferred to stay in their current homes, some were willing to explore other options should they not feel safe or not want to live in their homes anymore. Unfortunately, many were not aware of alternative possibilities and unable to access them.

A handful of the older adults I met expressed interest in moving into independent living facilities where they would live with peers, but in their own apartments with assistance from staff. Such settings are often well designed to allow for accessibility, offer a host of different activities for people, and provide opportunities for socializing and conviviality. However, they are not cheap (and indeed are often advertised as being resort-like) and are not covered by public assistance programs like Medicaid, and thus were not feasible for many of the older adults I met. Adult care homes was another option that some people I met explored and utilized. These and other alternative housing options might be a way to support older adults in living comfortable and independently.

Another example from the community was organization within neighborhoods, often in conjunction with neighborhood churches, to provide assistance to older adult residents. The first

one in the area was organized during the late 1990s as a non-profit (cf. Old Fort Lowell Live-At-Home Program, n.d.). With a handful of grants, donations, and volunteers, it offered an array of free services, including transportation to doctor's appointments, group walks, minor home maintenance, and trips to art exhibits. While not all neighborhoods would be able to provide such services and it was unclear to me how well these worked in practice, I thought this was an interesting way to possibly foster a sense of community, help people remain in place, and not create age-segregated communities.

If the health care system were better coordinated and integrated, and primary and chronic care models strengthened, it would leave individuals and their families with fewer strings to hold. It could also make for a more fulfilling experience for health care providers, such as the HHC nurses I met, who want to provide holistic, person-centered care to the people they serve.

More fundamentally, we might also rethink whether the medical system is the place for aging and chronic disease management. Are there other ways we can think about aging? Are there better approaches that would not take "old age" as a discrete category to be handled separately and instead thought about health as a broad public good?

I am reminded that Estes and Harrington (1981) who said that the aging "problem" we see in society is socially constructed. What is not recognized is that the chronic conditions we see as physiological inevitable corollaries of aging are often generated by structural issues. This is not to say that we do not need more and better accessibility to (coordinated, person-centered) social and medical supports for older adults. We should also start thinking about how different social positions, not just in terms of race or ethnicity or gender or SES, but also geography, work history, and built environment lead to different and unequal aging experiences.

My research was limited by several factors. Problems with accessibility followed me throughout fieldwork, which was unsurprising given the private, often hidden nature of my object of study. I was lucky to find three home health agencies that were willing to help me by allowing me to follow their nurses and meet their clients. While there were certainly privacy concerns and bureaucratic issues, I also had trouble communicating to home health administrators and nurses what I was doing and how that had any relevance or benefit for them. If I were to do it over, I would spend more time developing a partnership with agencies and designing components into my work that might have been valuable or concrete interest to them (e.g., follow-up patient satisfaction surveys).

Accessibility could have also been helped by pursuing, earlier in the process, other avenues of meeting people with home health experience so that I was not so reliant upon what access I was granted by agencies. Toward the end of fieldwork I started meeting more paraprofessional home care workers and family caregivers, and this provided a way of meeting people with experience, albeit sometimes in the past, home health experience. While it was valuable to meet people while they were receiving home health care, it was a trying time for some of those patients and their family members. I could have increased the range of perspectives and experiences by recruiting from other places, such as senior centers, support groups, churches, and other sources.

Exploring more ways of meeting and enrolling patients might have also helped me develop a more racially and ethnically diverse sample. As noted, my HHC user participants were all white. Thus the results and conclusions I make are drawn from the experiences of a very particular subsection of the older adult population, which limits the generalizability of my findings.

These limitations, however, provide areas for future research. Work could be done to examine whether older adults of different racial and ethnic backgrounds might experience HHC differently, and whether there are different factors at play in mediating their experience of aging in place.

The issues described in the second paper could be explored in more depth by gaining more HHC agency access. It would be interesting to look more closely and systematically at how agencies are, or are not, implementing quality assurance initiatives. Questions include: What is their process and reasons for self-auditing? How do they use OASIS data internally? How are nurses and other employees involved? How does this impact nursing practice?

Future work could also be done to examine what if any disparities exist in both the experience of HHC. None of the nurses I job shadowed were bilingual, yet there was a very large Hispanic population within the study area. During job shadowing, I observed some of the nurses interact with Spanish-only and English as a second language-speaking families. Communicative practices, experiences, and outcomes would be important to study in these cases. Similarly, disparities in the transition out of HHC and to long term, community-based chronic care should be studied. As noted above, much of the long-term care financing must come out of pocket. How do differing financial and other resources (e.g., savvy caregiver, accessible home) affect this experience and what people have access to? These disparities might help address some of the repeat hospitalization concerns that are increasingly a focus within the Medicare system.

While paraprofessional home care workers were an initial focus for this study, because I was unable to access them through the home health agencies, this strand of research was largely unfinished. Within the study area, groups of paraprofessionals were trying to organize themselves into a recognized body. Some of these efforts, such as professionalization moves,

were directed toward improving working conditions. However, in talking to the organizers, I found many were frustrated because it was very hard work and it was difficult for them to get buy-in from fellow workers. The efforts, politics, and experiences involved in these organizing efforts would be a fruitful site for further study. Important questions include who is involved and left out, who resists them, how to they fit within existing norms and practices, and what is at stake.

I was able to meet and speak with a diverse group of paraprofessional home care workers. The ways in which they spoke about their work and the people they serve would provide a fruitful area for future research on the divide between the disabilities rights movement and aging advocacy (Jonson and Larsson [2009] discuss this in the context of Sweden). What does this tell us about how people identify and organize? What does this tell us about how we define age? How does this impact the experiences of long-term care for different groups of people?

There are also many areas for future research into the experiences of informal, family caregivers. One trend is to simultaneously provide support for the caregiver and enhance formal and technical support by formalizing or training the heretofore informal caregiver (see Sadler and McKeivitt 2013). While I met caregivers who had taken on technical caregiving tasks, none had formal training or were receiving compensation from the state for the care they provided. An area for future research includes how such developments affect family caregivers' moral identity constructions, sense of obligation, and their assignment of responsibility.

This has potential to shift the identity of family caregivers, as noted in paper 3. These changes in sense of identity and practices are produced through their sociality with the people they care for. As caregivers engage in labor that is more or less formalized and involved with clinical practices (e.g., biomedical care management, patient advocacy, treatment), this can also

work to shift the relationship with their loved one. In cases where their caregiving is complicit in more institutional treatment efforts, this can create tensions and complications in relationships (Wool and Messinger 2012). Examining this in more depth could provide insight into these caregiving relationships in particular and social relationships more generally.

Since the time of fieldwork, there have been a number of developments in the policy landscape. The changes and the discussions that have followed them offer fruitful areas for follow-up research. I note here some of the more (potentially) significant shifts that might affect the situations of chronically ill older adults and specific questions that might be addressed in future studies.

In the fall of 2012, following a settlement of a class action lawsuit (c.f. Center for Medicare Advocacy, 2011), the Department of Health and Human Services said that it would revise language about HHC to extend benefits to persons whose conditions would be expected to be maintained, or further deterioration prevented or delayed, by the receipt of home health care (Pear 2012). This is a significant departure from the previous interpretation that a person would need to be deemed likely to expect improvement from a care episode to be eligible for Medicare reimbursed HHC (see Paper 2).

The Patient Protection and Affordable Care Act, also known as the Affordable Care Act (ACA) or “Obamacare,” was signed into law during the middle of fieldwork in 2010. Even at the time of writing in 2013, the implementation of the law and rules, and its effects on programs like Medicare is something of a moving target. The negotiations that have followed have dovetailed with other conversations about entitlement reforms that have direct implications for Medicare and home health care.

One example is the issue of rehospitalization rate. The ACA led to the implementation of financial penalties to hospitals with high patient readmission rates. Starting in October 2012, hospitals could see their Medicare reimbursement rates slashed up to one percent should they have high patient readmission rates within 30 days of treatment for certain conditions. These penalties are partly intended to incentivize providers to engage in better coordinated care, long noted to be a critical problem in the care of older adults in community settings. It is unknown how this will work out in practice, but provides an extremely interesting area for examining how (private) health care organizations do and do not network and leverage resources to address a problem wrought, in part, by the fragmentation of the health care system.

Health care organizations are not the only ones being asked to help share costs. Following ACA, the Centers for Medicare and Medicaid Services (CMS) proposed several rule changes. One of these proposals involved limiting Medicare Advantage plans ability to impose cost-sharing, like copayments, on home health benefits. In early 2011, the congressional agency Medicare Payment Advisory Commission (MedPAC) responded very critically to this proposal, arguing that singling out home health cost sharing was illogical and that creating such a prohibition would limit private insurer plans' ability to ensure "appropriate and effective use" of the home health benefit (MedPAC 2011:1). Instead of limiting private plan copayments, MedPAC recommended that a copayment for home health services be created for beneficiaries with Traditional Medicare coverage. They suggested \$150 copayment applied per episode of care, which amounted to about five percent of the average costs for episodes of care (Alonso-Zaldivar 2011; Christman 2011). In 2013, President Obama's budget proposal included \$100 home health copayments for new Medicare enrollees, whose episode of care lasted at least five visits and did not follow a hospital or post-acute care (e.g., rehabilitation facility) stay (The

Associated Press 2013; Kaiser Family Foundation 2013). The proposal, unsurprisingly, was strongly opposed by industry groups for placing additional burdens on vulnerable patient groups and providers, and for not significantly producing long term health care savings (Partnership for Quality Home Healthcare 2013).

Although home health fraud is usually discussed as being perpetrated by agencies/providers, in this case the argument was made to use copayments as a means of tempering consumer/beneficiary demand and thus limiting growth in outlays to home health. According to the argument, “beneficiary choice” would help prevent ballooning costs (Christman 2011:10). This would ostensibly place responsibility for determining the adequacy of the need (i.e., is the condition serious enough for them to want to pay some money for home health care) for home health benefits on the shoulders of seniors and their families. It would also serve as a further roadblock to using Medicare home health care as a long term care service. While Medicaid would pick up the copayments of lower income dual eligibles, it would place additional strains on already financially strapped individuals. In such cases, decisions to forgo home health care might be more a case of necessity than choice.

These conversations about beneficiary copayments raise many issues for future research and conversation. The institution of beneficiary cost sharing for home health can be viewed as parcel of the ongoing tit for tat game in which Medicare home health care access is opened and closed. While this has always taken place within the larger conversation about Medicare expenditures, the home health benefit has interestingly become a central part of the broader conversation about health care in the U.S. and politics of responsibility. Future explorations of these issues can tell us much about the complex processes involved in aging in place our society.

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APPENDIX A – THE UNCERTAIN BODIES AND SPACES OF AGING IN PLACE

Paper is pending publication in *Anthropology and Aging Quarterly*.

ABSTRACT: In the United States, “aging in place” has been established as the preferred method for 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, the paper 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.

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 as individuals become frailer in older age, they can remain more independent and enjoy a better quality of life, as well as avoid the trauma of relocation, by residing at home. They assume 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 Vilkkko 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 Vilkkko 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 places is dynamic, changing with the composition of people and things within them and the resources available to them. 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 Vilkkko 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 Cutchin (2003), 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 paper, 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 meet and 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.

Results/Discussion

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. 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 console 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 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 Vilkkko 2005). Through surveillance of the patients' lifeworlds, they

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 it or whether taking it would erode their 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 their 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 goodness of 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 Vilkkio 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 was 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 a 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 Vilkkio 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 paper 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 sense of bodily risk and helps to shift embodiment and daily practice.

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 meal, 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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APPENDIX B – DOCUMENTING THE WAY TO CARE: AUDITS, ELIGIBILITY, AND
THE MICROPRACTICES OF HOME HEALTH CARE

Paper was prepared to submit to *Social Science and Medicine*.

ABSTRACT: This is a case study into how governmentality, through the techniques associated with audit culture (Power, 1999), infiltrates and structures Medicare-certified home health care (HHC). The processes that audit culture engenders, seemingly, make durable certain ways of organizing, seeing, and knowing in health care. These processes define what types of care are legitimately actionable and what types of bodies are eligible for care. Through processes of documentation, practices and people are made auditable. However documentation is produced through social interactions or following logics that may differ from those deployed in audit technologies. In this article, based on ethnographic fieldwork in the United States from November 2009 to November 2010, I describe how Medicare-funded HHC has been impacted by the regulatory and auditing practices of the Medicare system. I trace these practices and how they are bent through the mundane, micropractices of HHC agency and nurse practice, noting particular sites of tension where several logics and imperatives conflict. I highlight the ways that embedded incentives within the related payment system reinforce the commodification of patients and care, and shape the ways that eligibility is constructed.

Since the 1980s, auditing has become increasingly dominant as an organizing principle within public and private policy to account for social actions in which resources are exchanged (Power, 1999). Auditing provides a formal, technical means for checking performance and an assurance against fraud, abuse, and waste. In the social science literature, the rise of audit culture

is tied to the rise of neoliberalism (c.f., Harvey 2005), new forms of management practices (Power, 1999; Shore & Wright, 1999), and increasing senses of mistrust and doubt (Brown 2010; Power 1999).

The practice of auditing, for example in case reviews, has a long history within health care, but has morphed and elaborated under these influences, with a number of intended and unintended effects (Power, 1999). In the United States, Medicare, the federal insurance program for persons 65 and older and/or disabled, audit practices tend to focus on “cost effectiveness” and “quality.” Amid concerns about providers abusing and committing fraud against the system, as well as ballooning costs, Medicare has changed the way it reimburses for care (e.g., Newhouse, 2001; Vladeck, 1984), created privatized insurer-administered Medicare Advantage plans, and instituted programs to ensure care quality. These changes, and their associated audit processes, directly impact the industries, companies, and health care professionals providing care under Medicare, the care that is provided, and beneficiaries and their families who are objects of that care. This paper offers a case study of how the idea of audit has become a central organizing point within home health care (HHC), an important Medicare benefit.

This paper asks several questions. First, how have Medicare HHC benefit regulations affected the home health industry? What logics play out in documentation practices? What kinds of knowledge and subjects are created through nurse documentation micropractices? I show how HHC documents, as well as representations of patients and eligibility for care, are products of social processes of documentation and caregiving by for-profit agencies and HHC nurses. Documentation is an objectifying practice, through which a tidy, material artifact and textual account, discursively and ideologically divorced of its constitutive social relations is produced to represent a patient.

This account is then used to categorize the patient in particular, meaningful ways: as eligible or not. Eligibility for care is thus a relational effect, in part, of interactions between nurses, patients, assessment technologies, HHC agencies, and auditors. Claims for legitimacy of caring for patients, and payment for care, are constructed through particular documentation practices. By attending to the mundane practices of HHC nurses I show how they are generative of eligibility for care and different types of patients.

I argue that auditing and documentation are strategies used within a complex of government and insurer networks to instantiate and make more durable the system for producing who is and is not worthy of care (cf. Goldade, 2009; Horton & Barker, 2009; Rivkin-Fish, 2011; Willen, 2012). The logics embedded within the benefit system reinforce existing logics in society and biomedicine, and renders some things visible and actionable in the purveyance of HHC care. In particular, it reinforces a medical model in which chronic and custodial care are seen as the realm of the private and not legitimated for reimbursement or government assistance. Before engaging with ethnographic examples, I explain some of the policy background.

Home Health Development: Role of Audit

HHC developed from small, charitable visiting caregiver associations in the 19th century, into a field of diversified, (inter)national, corporate chains employing a range of skilled professionals and complex technologies. HHC was constructed amid shifts in social demographics (e.g., gains in life expectancy, changing family patterns) and epidemiology (e.g., less communicable disease, more chronic disease), infusions of public and private dollars (e.g., insurance benefits), the rise of biomedicine (e.g., medicalization), and changes in patterns of governance (c.f., Buhler-Wilkerson 1991, 2001, 2007; Davitt and Choi 2008; Dieckman 2008). Under Medicare, the HHC benefit was originally imagined, and is still largely interpreted today,

as a short-term, post-hospital intervention for people with acute health problems requiring “skilled” care. It is explicitly not for maintenance treatment for chronic conditions. Since 1965, revisions to the benefit have expanded and limited access, as well as incentivized private HHC agencies to enter the market, increased the business orientation and rationalization in the field, and limited nonreimbursable services (Davitt & Choi, 2008; Szasz, 1990).

The stepped complexity of the Medicare HHC audit system is legitimated by the widespread representation of the HHC industry as untrustworthy, and possibly riddled with providers that commit fraud and supply care of uncertain quality (e.g., U.S. Department of Health and Human Services. Office of the Inspector General 2012; U.S. Government Accountability Office 2009), and who earn very large profits (Christman, 2011). This representation has been reinforced by high profile HHC fraud cases (e.g., The Associated Press 2009; Cloherty and Jones 2009; Cohn 2012).

To account for and track HHC performance, Medicare has created an evolving, opaque network of mostly privately contracted actors to pay, educate, and police program providers. These entities are employed to normalize inefficiencies (e.g., financial waste) and vulnerabilities (e.g., fraud), and hold accountable health care providers and others who make up the Medicare system. Contractors increasingly screen HHC data using predictive analytic technologies that survey, label and discipline the riskiness of providers, claims data, and, more generally, Medicare (CMS 2011a). These technologies rely on statistical models and representations of normal behavior, as well as real-time model adjustments, to target and make audit processes more efficient. However, it is within these audits that abnormalities are constructed and made visible.

Reimbursement Framework

Legislation mandating that patient outcomes be tracked (Kane and Kane 1994) and tremendous growths in payments (i.e., expenditures) and use (c.f., CMS 2003) helped usher in HHC program reforms in 1997. The Balanced Budget Act of 1997 eliminated the previous fee-for-service model (which allowed agencies to recoup costs) and introduced a new prospective payment system (PPS). This system and the technologies, relationships, and processes it engenders, provides a structure for an expansive auditing program.

The HHC PPS is based on a standardized assessment tool called the Outcome and Assessment Information Set (OASIS). The tool was created as a coding and reporting standard that generates data for the appraisal of payment rates and quality, data that is auditable by those reimbursing for and regulating services. HHC agencies must integrate the 114 items on the OASIS into their patient assessment protocols. With few exceptions, the assessment must be conducted on every patient at the start of care, every 60 days afterwards, and/or upon discharge. The items cover a wide range of domains, such as clinical record, living arrangement, sensory status, and activities of daily living (see example in Figure 1).

For beneficiaries with Traditional Medicare coverage, OASIS items provide the basis for deriving payment rates for 60 day episodes of care. Based on OASIS scores, beneficiaries are classified into one of 153 HHC resource groups (HHRGs) (which are similar to hospital diagnosis-related groups [DRGs]). These groups take into account clinical and functional severity, as well as expected service utilization (see Figure 1) (Dey, Johnson, Pajerowski, Tanamor, & Ward, 2011; Grimaldi, 2000). The payment rate is calculated using a complex algorithm that take into account additional factors (e.g., wage index, whether there were five or more visits provided). In general, if at the end of 60 days, a follow-up OASIS shows patients have experienced positive change in relevant outcome measures, and continue to be homebound

and be deemed by their doctor to require medical care at home, patients can be recertified for additional 60-day care episodes. If not, the care is assumed completed and the patient discharged. OASIS assessments, which are constructed amid microsocial processes and interactions in and out of patients' homes (see below), are critical in the construction of seemingly durable knowledge for making claims about patients and care in forms that are measured, readable, and auditable by Medicare contractors (c.f., Power 1999).

Fieldwork

This paper is based on 12 months of ethnographic fieldwork in the Southwest US, completed between November 2009 and November 2010. During my fieldwork I job shadowed nine HHC nurses from two for-profit Medicare-certified HHC agencies. The nine nurses (all White women) were each shadowed for a standard work week, for a total of 23 days and 77 patient visits. During our visits with patients, I made deeply descriptive notes on setting and interactions between nurses, patients, and caregivers. This allowed me to document the relationships between people, places, and things that made up a HHC visit. In between visits, I rode with the nurses in their cars and conducted informal, unstructured interviews.

I also conducted semi-structured interviews (n=20) with nine current HHC nurses (four of whom also participated in job shadowing; seven women and two men), five women currently working in HHC management (many previously were HHC nurses), and six women with HHC work experience (e.g., nurses, social workers, aides, marketers). Of this group, 13 were White non-Hispanic, one was White-Hispanic, one was Asian, one was Native American, and four were of unspecified ethnic background. Interviews centered on participants' experience working in HHC and how their practices changed with the introduction of new policies and documentation associated with HHC payment reform in the late 1990s. For example, I asked participants about

the impact of OASIS, and its various updated versions, on the operation of their agencies and the nurses' care for patients.

Notably, in job shadowing and interviews participants emphasized the uniqueness of HHC nurses. The decentralized and unpredictable nature of the job demanded that nurses be independent, confident, and flexible, and possess a broad array of skills. They described nurses going into homes not knowing what to expect, not being able to control anything, without the support of coworkers or equipment, and with expectations that they will do everything. Most of the nurses I met had some hospital-based nursing experience and were generally sharp, observant, and sensitive to their patients' needs. They expressed liking their jobs because it afforded them independence and the ability to provide more personal, holistic care. The nurses were also extremely busy, with multiple demands from work (e.g., paperwork, patient management, productivity pressures) and life (e.g., childcare, money issues, health problems), which lent them an aura of no-nonsense.

I also conducted extensive interviews and fieldwork with older adult patients, family members, service providers, and other direct caregivers (cf. Penney 2013a; Penney 2013b). I interviewed patients and their families over the course of a year. These interviews and other informal interactions with those groups contributed to my understanding of the relationships comprising the lived reality of the HHC system.

Detailed notes and transcripts were taken throughout fieldwork and uploaded into an Atlas.ti database for analysis. Codes were constructed based on original research questions, themes drawn from the literature, and emergent topics from fieldwork. I used these code reports to help answer research questions, such as those outlined above, and as a basis for papers such as this one.

Assessment Practices and Durable Knowledge

The processes of documentation that HHC caregivers must follow create certain ways of seeing patients, and structuring care according to the demands of the Medicare program. However, how this works in practice is not always as intended or in a manner as standard as it is represented. During job shadowing, I witnessed nurses administer OASIS assessments on several occasions. These were lengthy procedures, often lasting between an hour and an hour and a half. They frequently were embarked upon with audible and visible displeasure by nurses, patients, and their families.

The following vignette describes a portion of a follow-up assessment, a nurse, Olga, conducted with a patient, Roger. During this assessment, which took about an hour and was conducted in the Roger's living room, Olga sat in a kitchen chair next to Roger's easy chair with a handful of documents in her lap. Roger's wife sat next to him in another easy chair and frequently attempted to foster conversation. Olga mostly deflected these invitations to conviviality by ignoring them and staring at and shuffling through her paperwork.

Olga launched into the items, directing most of the questions to Roger's wife. She went through each of the prescription drugs she had previously recorded Roger taking, verifying dosage and frequency, and making necessary changes in her documents if there had been adjustments. Several times she tripped over the pronunciation of official names of drugs and discrepancies with generic drug names. Roger stared blankly ahead during most of this, while Olga and his wife went back and forth, referring to prescription drug bottles and lists of medications his wife kept. In passing, his wife mentioned Roger was taking an antibiotic. Olga had been unaware of this, asked her the name of it, and wrote it down. Roger's wife also mentioned Roger was cold all the time, which she supposed was because he was taking a blood

thinner. However, it meant the heat was always on in the house and it made her feel smothered. Olga recommended she take a walk outside when that happened and then asked about Roger's "peeing" and "pooping."

The tenor of the interactions during assessments varied, with paperwork providing points of orientation for nurses, patients, and informal caregivers. Another nurse, Sonja, said she would scribble notes on the patient face sheet, which contained some admissions information, and try to spend most of the first visit making connections rather than shuffling through paperwork. She stressed nurses each had his or her own approach to assessing patients. Her portrayal resisted notions that assessments could be standardized and nurses easily replaced as assessors.

I noted in other cases, particularly when the nurse was newer to HHC, there was a preoccupation with documentation during the assessment (e.g., assessment forms, doctors' notes). However most, like Sonja, did not fill out the paperwork while with the patient, but jotted notes on scratch paper (especially specific measures like temperature) and committed other details to memory. Invariably, even when nurses tried to lead patients through the items from start to finish, question asking was messy and often involved family caregivers, conflicting or erroneous information, and tangential and circular narratives.

Frequently question asking elicited information that did not fit the standard response choices, in part because patients and their family members were not necessarily aware of how they were supposed to answer. Nurses responded to these seeming irrelevant details by ignoring, interrupting, re-asking questions, or moving to other items. In some cases they fostered chit chat and inserted patient education, which they would later describe as important in relationship and trust-building.

Beyond patients and their caregivers, who were often viewed as unreliable yet critical sources of information, other actants (Latour, 1987) were involved in producing knowledge during the assessments. These included physical materials like blood pressure cuffs, thermometers, prescription bottles, and medication reference books. Nurses also used their senses to acquire information about patients and use in their question asking. For example, a nurse smelled smoke and noted ash trays in the home of a patient with an oxygen tank, which posed a serious hazard, which prompted her to ask about smoking practices.

Outside of the patient visit, paperwork had to be practically managed before it was transmitted. During the work day, I observed it managed in nurses' mobile offices (i.e., cars), sometimes loose in the passenger seat, other times in color coded folders in plastic file tubs. For most nurses I met, they told me the bulk of official documentation occurred after work hours, at home, sometimes while watching TV, based on notes they had taken during the patient visit and filled in by their memories.

All of these processes (e.g., question asking, observing, filing, documenting) and actors and actants (e.g., OASIS forms, nurses, caregivers, blood pressure cuffs) interacted to create the assessment process and the translation of the patient into a representation. While standardized in some way by the items on the form, the enactment itself was variable according to its individual constituent parts. By contrast, the knowledge it produced, as documented on the assessment form, was decontextualized from the social relations in which it was produced. It was made to seem rational, standard, and durable (cf. Hadders, 2009).

In both agencies in which I job shadowed, nurses filled out paper copies that were later translated into electronic form by office staff (staff who, according to one nurse I interviewed, were not educated in health care and often did not understand the material they were handling).

In one agency, data was next processed and internally audited by a separate office for errors (e.g., omitted data, improbable values). An administrator with that company told me that the physical separateness of that office allowed reviewers to examine the “broad picture” that emerged from OASIS. She implied that reviews of coding practices were valid, in part, because they were completely removed from context.

While shadowing nurses, I observed that office staff sometimes phoned nurses with questions or problems around documentation. For example, I was driving with Sonja when a staff member from her office called to ask about an assessment that was missing a blood pressure value. Sonja had not taken the patient’s blood pressure because it was normally only taken once a week and the patient had just gotten it done at the doctor’s office. The new software the company was using would not allow the staff member to leave a value blank and the staff member recommended Sonja just choose a number that they could input into the system. After some hesitation Sonja told the staff member to input a value that was typical for the patient. Once off the phone she told me that she would not have made up a number if she thought the patient’s blood pressure was clinically significant. In this case, the demands of the system required the generation of a number that could be recorded and communicated. It forced a performance on the part of Sonja and the staff member that was only tangentially tied to the body it was supposed to represent.

Eligibility for Care: Seeking and Constructing Patients

Representations of patients were key to many of the practices I observed in HHC, including eligibility for care. The complex computations that are used to determine HHC reimbursement rates have created unintended economic incentives for enrolling certain types of patients and for engaging in certain types of coding practices. For example, the case mix

adjustment to the payment rate, which is derived from the HHRGs (see Figure 1), differentially values diagnoses, functional limitations, and expected duration of care. While the values, which are frequently adjusted, are supposed to match the average or expected costs of caring for that condition, some conditions' values or patient characteristics can be perceived as more likely to yield a profit. This creates incentives for agencies to recruit patients with these characteristics or to construct them through coding practices.

A director of nursing noted that especially as there were moves toward paying agencies based on patient outcomes, acute patients were more highly valued than those with chronic conditions because there was better chance of showing improvement (which is read as "quality" care in audit practices) among the former. Patients with Traditional Medicare coverage were also preferred to those with private-insurer run plans. While initially I hypothesized that it would be the opposite, I quickly learned that PPS was valued both because payment rates were viewed as (generally) more generous and the 60 day episodes of care allowed some flexibility in disbursing care. By contrast, private insurers were often portrayed as stingy with both reimbursement and authorization of visits. Nurses described having to "fight" for authorizations to provide care to patients, a process that was frustrating and taxing. An agency director indicated that revenue gains from PPS payments helped to offset losses incurred through private insurers.

Industry literature urges using complex metrics to determine the "attractiveness" of different patient populations and discusses patients in terms of their differential market value and effect on margins. For example, in one article (Chesney and Orsini 2009), agencies are told to identify the market shares of different diagnostic-related groups and the different patient "fiscal characteristics" (434). I quickly learned that agencies employed a range of strategies to get patient referrals (e.g., agency marketers) and that those practices sometimes sought very specific

types of patients. Embedded incentives appeared to lead to some forms of niche marketing (e.g., direct advertisement to patients with certain conditions), strategic access practices, or forming formal and informal relationships with referral sources such as managed care plans, hospital discharge planners, and rehabilitation facilities. These practices reinforce the commodification of patients and care, and help to shape the nature of eligibility for HHC for patients. It also established economic incentives for maintaining Medicare certification and compliance.

Incentives have also resulted in changes in coding practices, which according to CMS have resulted in “nominally” increasing the average clinical and functional severity, and resource use of HHC patients over time. Several nurses described employers who had instructed them to “upcode” (i.e., documenting excess need) on the initial patient assessment. One nurse explained that in doing so they could “prove” both an increased payment rate and that their care resulted in “good stuff” (i.e., better outcomes) for the patient. She indicates that how they represented the patient on the assessments legitimated their service and supported their claims of enacting quality care.

This points to how accounting systems can produce new motivational structures which can come into tension with actors’ other motivations (cf. James, 2012), such as profit motive. Actors can perform in ways that have the appearance of compliance, while also maintaining some autonomy through employing other rationalities (Power, 1999). This inclination to perform to particular directives and outcomes may result in focus on form over content (Shore & Wright, 1999). They also create incentives to “game” the system (Brown 2010).

Both the practices of looking for and constructing certain types of patients through documentation respond to the PPS’ embedded incentives as a way to capture resources. However, by identifying and highlighting the ways that HHC agencies make use of these through

abusive and fraudulent practices, and creating ever more complex policies and audit technologies, CMS seeks to neutralize these advantages and bring the system back into order.

Reorienting Internal Processes and Conceptualization of Quality Care

Within agencies I observed evidence of steps to standardize and rationalize practice. HHC managers described innovations, such as tablet computers used by nurses to make documentation more efficient, standardized disease management programs, telehealth programs to enhance patient management, and partnerships with hospitals to reduce patient hospitalizations, in effort to reduce costs and improve quality of care. Some of these steps could enhance patient care, such as more coordinated care and streamlined documentation. These changes were also consistent with policy changes enacted to compel providers to restructure their care to cut costs and enhance quality. However, the impetus for these changes, for both policy makers and agencies, was related to cost.

As with other audit technologies (c.f. Shore and Wright 1999), OASIS is couched in self-actualizing, positive language, and sold as a tool for controlling and improving quality. For HHC agencies, Medicare qualifications, certified by state survey agents, construct and signify the agencies' claims of competency and trustworthiness (Power, 1999). However, the incentives embedded in the system enlist agencies to perform self-surveillance and service rationalization. Items on the OASIS provide an orienting point for internal quality management and help to reproduce systems of control to make the CMS regulatory system, seemingly, more durable. Auditing processes rely on partnerships and leveraging multiple stakeholders, while also placing an apparent focus on transparency (Power, 1999). However, the meta-accounts of auditing practices often do not match what they actually do. Indeed the scope and meaning of audits are often vague, an "essential obscurity," that lends it power (Power, 1999, p. 10).

One of the ways agencies are ostensibly held accountable is through the public reporting of 12 of the OASIS outcome measures (e.g., hospitalization rate, percentage of patients who get better at ambulation after receiving care) on the Home Health Compare Website. Each agency's listing shows their rate and compares it to the state and national HHC agency average. While this website is posed as an empowering tool for rational consumers, it also provides an aura of transparency while cloaking the complex processes through which these figures are derived. Notably, almost no one I spoke with beyond those in HHC management was aware of the website. The measures and their display seemed to provide an orienting point for internal agency reform to fit the program's definition of "quality."

In both the conversations I had with people working in HHC and in the literature (e.g., Fortinsky et al. 2012; Jencks, Williams, and Coleman 2009), agency hospitalization rate (percentage of patients admitted to hospital while receiving HHC care) was frequently cited as a major cost and indicator of poor quality care. Carol, an agency director, brought it up when I asked her about the website. She said she did not think a lot of patients looked at the website. However, she thought "the good agencies" did care about their scores. For her company, the hospitalization rate was important. Like all HHC agencies, they received that rate along with the other outcome measures in a report from their state survey office. They compared their hospitalization rate to other offices within their company as well as the national average.

It's a tool that helps us get better. A lot of the home healths will not, don't have the resources [...] to track that stuff, so [the outcome reports] may be the only way they're getting the info on [Pause] truly what the rehospitalization rate is [...] [I] really think rehospitalization and urgent care are going to be the two biggest indicators of quality. Because, yeah, somebody may have more medicines and still need help when they're discharged, whether that means we

did our job or not- ahhh, there's too many variables. But the hospitalization truly does [tell you whether you did your job].

Carol's comments reinforce the dominant construction of hospitalization rate as a key signifier of care quality and reify the notion that the standardized assessment tool allows them to get to the Truth of their practices. However, she also indexes the complexity of assessing their care when a variety of other factors, of which they had no control (e.g., patients' broader access to care), impacted outcomes. The messiness of reality is erased within and in tension with the figure of the hospitalization rate.

Setting Boundaries for Care

The changes described above helped to highlight costs and form the basis for setting limits to what was possible for care. They also worked as a frame for making certain things about patients visible and invisible (Ceci, 2006). A director of nursing, Dolly, said that PPS and other new rules had shifted focus from treatment based on what the nurse determined was best to costs. She likened the HHRGs to working with a budget when shopping; nurses needed to stay in the budget set by their payment rate, which as shown above, was determined and manipulated through documentation practices.

Nurses varied in the ways they talked about how the focus on costs affected their care for patients. Several discussed how cuts to reimbursement had led to increased productivity demands from their agencies. Time spent on patient visits was a particular area for concern, monitoring, and feedback. Some nurses described being asked to finish completing paperwork during visits, which would ostensibly ensure that visits would orient more around the paperwork and not around things deemed irrelevant to care. However, most nurses expressed that filling out paperwork during visits was a distraction from attending to patients and performing quality care.

Angela was the most explicit in discussing how agency economic imperatives structured her practice. She described three things she had to do with a patient with Traditional Medicare insurance coverage. She had to make sure the patient was not hospitalized (to avoid financial penalty), she had to make more than four visits (to be reimbursed at a higher rate), and she had to recertify the patient for another episode of care if they lost money during the first episode of care.

Importantly, these imperatives were not necessarily made explicit by the agencies in which she worked, but were implied and reconstructed based on critical feedback she received about her management of patients. For example, if Angela had a patient whose functional score was low (i.e., not reimbursed at a high rate or possibly not eligible for care), it would trigger a phone call from her office and she would be asked to legitimate her continued care. This would place her in a difficult situation because there were pressures to keep the patient on service: the patient had been recruited through agency marketing and Angela, as a per diem nurse, needed the visit. She indicated that she could resolve these difficulties posed by economies of performance (Fisher & Owen, 2008) by changing the patient's functional scores so as to reflect more need.

When questioned about the affect of OASIS on their practice, nurses frequently rolled their eyes, sighed, and complained about the paperwork burden. Systems of accountability can engender frustration and cynicism among those called to perform in the evaluations, particularly if those performances are viewed as in conflict or competition with activities that would contribute to meeting goals (Brodwin, 2011; Kipnis, 2008). Similar to Brown's (2010) finding that incentives to game the system could breed cynicism, nurses expressed frustrations with the documentation game playing and nitpicking, as well as the opacity of the system that affected their care but was not seen as relevant to it. Many articulated sentiments similar to Christina, a

nurse, who asserted that program rule makers “don’t know anything about nursing.” Many denied the legitimacy of the experts who created OASIS, the ways in which the reimbursement system codified virtue (e.g., who deserved care, what quality care looked like), and recast OASIS as irrelevant (see also Brown and Calnan 2011).

While nurses might have downplayed how the assessment affected their knowing and care of patients, the act of completing the paperwork and acquiring information through it created a frame through which they oriented toward a patient. As one administrator, Stephanie, explained, sometimes they could lose sight of the goal of HHC, “patient independence,” in the “rigmarole” of OASIS (which, ironically, is supposed to facilitate acquiring and tracking information to get the patient independent). She noted that the frame of OASIS was restricted and not as encompassing as a (good) nurse would need. Indeed, the definition of Medicare HHC, as intermittent, problem-focused, and standardized, and the rationalizing logics embedded in the documentation, contrasted sharply with the construction of (good) HHC care articulated by the people I met. For example, Carol described HHC as a holistic practice, centered on a “personal care” model, and flexible and adaptable in the face of rapidly changing and very complex patient situations.

Ecologies of Practice

The rationalizing of care worked in ways to sometimes subtly reform nurse practice into a technical form that was auditable, while also devaluing their expert knowledge. However, nurses described OASIS and the norms it represents as, in the words of Power (1999), decoupled from their practice. There was a vagueness in their understanding of the specific technologies involved in auditing and indeed how insurance worked. Thus while nurses are required to enact policies and logics through their documentation practice, they do not always understand or approve of the

goals embedded within them. Their performances are driven by a host of other logics that at times come into tension with dominant forms. The complexity of the logics nurses used and their adaptability helped them to resist the normalization pressures from auditing practices (see Power 1999).

Above, Dolly described how care provision was framed within the limits of the HHRGs. By contrast, Carol emphasized that her corporation, as opposed to others who were “bottom-line, bottom-line, bottom-line,” strongly discouraged managing patient care according to the reimbursement rate. Nurses were encouraged to do what they thought best for patients and that on balance, the company would make money.

Nurses, while expected to be front-line enactors of programmatic rules and expectations, could subvert those logics and rationalize those subversions by drawing on a value system based in their own experience. As Fisher and Owen (2008) describe, practitioners in health care can avoid conforming to the “economies of performance” demanded by audit regimes by enacting “ecologies of practice” that draw on accumulated personal and collective experiences and commitments to providing more flexible and holistic care (c.f., Stronach et al. 2002).

This was especially clear when nurses argued that logics within the HHC benefit negatively impacted patient healing. For example, I observed a nurse, Christina, encourage a patient to eat at a restaurant, which was a violation of the benefit requirement that the patient be homebound. After the visit with the patient, I asked her to clarify the homebound requirement. She said through her experience working in HHC, she’s learned that there are psychological factors involved in healing. She reasoned, people needed to get out of their houses sometimes, not doing so could lead to or enhance depression, and depressed people do not get better. Even if

the patients were physically exhausted by these outings, she explained, they would feel mentally better.

In this example, “economies of performance” (e.g., that she police for homeboundness) came into tension with what she thought was best for the patient (and the patient’s outcomes). She justified her decision to me by drawing on her personal experience as a nurse (“ecologies of practice”) and a construction of her patient as a multi-dimensional, complex person with more than physical needs. It was also an implicit critique of the logics within the home health benefit. I noted similar critiques embedded within the small ways that nurses would ignore or actively bend rules in ways they thought would better benefit their patients, as well as in their critiques of other nurses who were too “by the book.” Many emphasized the need to have “commonsense” and flexibility when it came to applying program rules and dealing with patients. This argument placed value on local interpretations of rules that took into account context, complex situations, and imperatives (see also Dixon-Woods et al. 2012).

In another example, Sonja told me about a patient whose wound kept reopening, possibly because the patient was not fully compliant with treatment. The patient’s husband was her primary caregiver and in poor health. Because the condition had gotten to the point of being chronic (which would make the patient’s condition ineligible for home health care under benefit rules) and the non-compliance issues, the patient could justifiably be discharged. However, when I asked Sonja what she would do, she paused and thought for a moment. She said there were so many things going on affecting the situation, including her sense that the husband was overwhelmed and might have to go into the hospital for a bit, she would probably be more lenient when it came to ending service. As with Christina, Sonja took into consideration a range of situational factors in assessing her patient. The representation of the patient she provided me

was fuller than that of a chronic wound, and included the patient (and her husband's) context and needs.

While the HHC benefit was written and the program was surveyed so as to only allow certain types of patients eligibility for a particular type of intermittent acute-oriented care, nurses and agencies could, as Carol put it, "stretch" the benefit to encompass other types of people and care. As with practices of upcoding for the direct purpose of financial gain, gerry rigging the benefit explicitly for patients' benefits rested on performance of certain types of documentation. For example, a nurse noted that she had recently learned insurers would cover providing oxygen at home if the patient's blood oxygen value was below 87 percent. If she finds a patient is having trouble breathing and his or her oxygen value is 88, she will code it as 86 so that oxygen can be provided. Nurses specifically differentiated this from "fraudulent" or "abusive" documentation practices by highlighting that they were documenting "real" or "honest" patient needs. However, nurses had to be savvy and skilled in how they defined patient need and rendered it intelligible to those performing auditing both within their agencies and externally to Medicare program integrity contractors so as to have both patients and the care they provided legitimated.

Conclusion

This paper has shown how the Medicare audit systems, which are mediated by OASIS, help to coordinate how HHC is enacted and the forms in which patients are documented. As Power (1999) notes, the effects of auditing are never neutral and are always generative, often bringing unintended results. As the HHC industry becomes subject to these auditing pressures and market competition, their orientations, construction of values, and definition of quality have also shifted. This has direct implications for patient eligibility for care and the work of HHC nurses.

OASIS is a technology that is fundamentally involved in rationing limited healthcare resources in a way that seems scientific and reasonable, and using the language of quality. However, it deploys a rationality about which types of subjects are worthy of care and what types of care they can receive. The system of eligibility to HHC, during the time of fieldwork, reproduced the logic that makes acute, biological phenomena legitimate use of HHC resources, while chronic care needs were left, if not invisible, unactionable. That logic places chronic, maintenance, and custodial care within the context of private, unskilled domain and outside the realm of reimbursable services.

Audit practices contain logics that ration health care (ala the biomedical model and managed care) and marginalize nurses' professional judgment and skill. Documentation was a hub through which much of the practical tensions played out. Different actors in the system had various stakes in the knowledge generated through OASIS. For patients documentation provides a representation of their condition and their progress that can be important to accessing care. Nurses found paperwork to be both burden and distraction from care, but also the most essential means for opening up opportunities for care. For agencies, OASIS provides opportunities for both revenue and costs, as well as an orienting point for structuring internal processes and the management of trust. For insurers and their contracted auditors, OASIS was a seemingly material and rational ground for the application of metrics through which they assessed and authorized care, while also apparently surveying and neutralizing risks, and rationing scarce resources.

For nurses, OASIS was the ground in which the boundaries of the possible were laid and in which claims of legitimacy were enacted. The construction of knowledge in documentation was the result of a myriad of immediate micropractices that ranged from the taking patient blood pressure, to chit chat, to scribbled notes, to data entry. These processes constituted patients (and

the care they received) and were fed into networks, creating legitimacy not just of patients, but of providers, care, and the Medicare HHC benefit.

Nurses were able to practically manage opening up patient eligibility for care through what they chose to document, in some cases able to work the system in ways that made patients intelligible and deemed legitimately deserving of care. As in the case of James' (2012) trauma portfolios, OASIS assessments symbolically and materially represented patients as legitimate users of the HHC benefit and differentiated them from other types of Medicare patients. However, working the system via documentation in order to create opportunities for care required skill, savvy, energy, and will. These were things that not all nurses enjoyed and I noted that most did not use these across patients equally. For example, I observed that nurses seemed more willing to bend the rules for patients with whom they had closer personal relationships. While such efforts opened up eligibility at an individual level, they do not address the biases in the benefit and reimbursement system. Nor does it critique how these practices have the effect of commodifying patients and shaping the nature of access to health care (cf. Scott, 1985).

The audit processes and networks described herein are not unique to HHC but can be found throughout health care. Further research into the intersection of providers, agencies, and auditing bodies, and the ways in which these relationships constitute care, would be fruitful. Upstream studies of CMS contractors and the ways that data is rendered and acted upon would also add to the discussions and arguments here.

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APPENDIX C – UNCERTAIN CARING: CASE STUDIES IN CONDUCTING A MORAL
LIFE WHILE CARGIVING

Paper is pending publication in *Qualitative Health Research*.

ABSTRACT: In the United States, informal, non-paid caregivers provide the bulk of long term care to chronically ill older adults. While the burdens of and inequalities in this work have garnered much attention, the complex of feelings and meanings that make up these relationships have received less focus. Based on 12 months of ethnographic research in the Southwest United States, this article uses case studies of people providing care for a chronically ill, older adult family member to explore the moral dimensions of care. Through these examples, I demonstrate the often fraught and uncertain nature of these experiences, and the ways that people negotiate competing pressures and demands as they try to maintain what is important to them.

Literature Review

At this historical juncture, with anticipation of an aging Baby Boomer population, neoliberal reforms, and fiscal crises, the job of caregiving for the elderly has received renewed focus in the United States. Informal (or non-paid, often family) caregivers continue to provide the bulk of care (Houser, Gibson, & Redfoot, 2010). It is estimated that in 2009, the economic value of unpaid caregiving by adults for adults in the United States was about \$450 billion (Feinberg, Reinhard, Houser, & Choula, 2011). However, although the literature on informal caregivers highlights burdens and costs borne by those who care and there have been efforts to relieve those burdens through interventions, the complexity of feeling and meaning constitutive of caring relationships has not been fully understood. It is important to explore the moral

dimensions of care to better understand the stakes and threats in caregiving for chronically ill older adults.

Increasing health care costs and the growing prevalence of complex chronic conditions and disabilities in old age, as well as lengthening lifespans have highlighted concerns about future health care costs. Under pressure to make care less costly and more efficient, in recent years there is more emphasis on transferring caregiving tasks from highly skilled medical professionals to less highly paid paraprofessional caregivers and unpaid informal caregivers. For example, during the period of 1996 to 2002, Medicare home health patients who had caregivers listed on their medical forms experienced a greater decrease in the average number of visits from skilled (e.g., nursing) and non-skilled (e.g., home health aide/paraprofessional) personnel per care episode than users with no reported caregiver (Davitt, 2009). Home health directors in this study explained that they were now providing more caregiver education and training to both intensify their involvement with the care and ultimately discharge the patients more quickly from service. Informal caregivers have also been integrated into the standard plans of care that home health agencies provide so that informal caregivers can help to supplement, in many cases scaled back professional home health services (Dieckman, 2008).

At the same time as there is a pull back of (para)professional care and transfer in the medical sector, there is awareness that informal caregivers face multiple stresses and burdens as a result of the conditions under which they provide care. Much of the literature on informal caregivers of older adults centers on caregiving burden (e.g., Starrels et al. 1997; Feinberg et al. 2011; see Walker, Pratt, and Eddy [1995] for a critique). Consequently, informal caregivers have been targeted as an at-risk group. Moreover, concern has been expressed that caregiver burden and burnout might result in poor outcomes and expensive institutionalization of older adults, as

well as additional costs to the state (Administration on Aging, 2011). However, these discussions and efforts often do not take into account the fraught, uncertain, and meaningful moral experience of caregiving.

Caregiving as Work

Since at least the late 1970s, caregivers have been conceptually positioned as “hidden patients” (Fengler & Goodrich, 1979; Roche, 2009). As there is increased concern over who will bear the costs of an aging population and the health care costs they might bring, the state of the informal caregiving force has gained interest. A wide swath of literature has examined, to various degrees, the emotional, psychological, physical, and financial costs of caregiving to this informal workforce (Pinquart & Sörensen, 2007; Schulz & Sherwood, 2008; Vitaliano, Zhang, & Scanlan, 2003).

Caregiving to chronically ill and functionally limited older adults involves a range of activities. Levine and colleagues (2003) have described two broad domains: direct care provision and care management. Direct care provision involves assistance with activities of daily living (e.g., bathing, transferring), skilled nursing care (e.g., wound care, medication management), and cognitive support (e.g., behavior supervision, monitoring). By contrast, care management might entail tasks in the home (e.g., home modification, supervising paid caregivers, upkeep of assistive devices) and outside of it (e.g., transportation, arranging medical care, financial management) (Levine et al., 2003).

Normative expectations for caregiving in the U.S. vary by gender. In 2004, women accounted for 57 percent of spouses and 65 percent of adult children providing care to older adults with disabilities (Houser et al., 2010). Women are expected to provide the bulk of caregiving (Hooyman & Gonyea, 1999) and caregiving duties are frequently distributed along

gender lines (Hequembourg & Brallier, 2005). For example, women are more likely than men to provide hands-on care, complete a wider array of caregiving tasks, and to spend more time in care provision (Horowitz, 1985; Pinquart & Sörensen, 2006). However, there is some evidence that men might downplay their role caregiving (Matthews, 1995) and that the association between caregiving and gender is not as clear cut (Dwyer & Seccombe, 1991). While women increasingly work outside the home and their families depend on the wages they earn, expectations that they will provide the bulk of caregiving labor persist. This can create particular sources of role conflict and strain, or sandwiching, as women try to negotiate work life responsibilities, parenting, and caring for an elderly relative (Lechner, 1994).

Feminist oriented literatures point to how caregiving is labor, work that involves often unrecognized skill and experience, and places women at an unfair disadvantage (Rutman, 1996; Stoller, 1993). In addition to the tasks outlined above, caregiving also involves emotional labor. Caregivers often have to manage emotions that they feel they or their care recipient should not have, such as frustration and anger. This can add to stress and burden (Rae, 1998). Caregivers also act as advocates for and assist in the identity work of the people for whom they care (Devault, 1999). Discussions of the relational and emotional dimensions of caregiving usefully point to the negative impacts of caregiving to individuals, particularly the disproportionate impact on women who make up the majority of caregivers. Feminist perspectives also usefully point to how structural factors (e.g., gender, race, socioeconomic status) and forces (e.g., government restructuring, globalization) affect the caregiving experience of different groups and the responsibilities of the state in alleviating burden (Ehrenreich & Hochschild, 2002; Hooyman & Gonyea, 1999; Neysmith, 2000).

By focusing on caregiving stresses, caregiving is set up within the domain of public health as a site for intervention (Abel, 1990). Efforts to assist family caregivers and to lessen this burden frequently include education and training programs, respite programs, support groups, and (limited) community- and home-based services. More recently, as part of efforts to provide more person-directed and -centered care, some programs instead of hiring paraprofessional caregivers to provide care to the family member will reimburse family caregivers for some of the care they provide (Ungerson, 2005; Wool & Messinger, 2012).

However, in many cases, such caregiver interventions and supports regard stress as a problem of the quantity of care demanded and scarce resources rather than as a complex emotional response to a specific situation and relationship. In addition, they further the agenda of reprivatizing caregiving (Abel, 1990). This generally well-meaning lens is individualizing and feeds into discourses that place ever more responsibility on informal caregivers to not only care for their loved one but also to take care of themselves for the sake of their loved one. Calls for caregivers to engage in emotional and material self work for their own well-being (e.g., Olsen, 2007), often fail to recognize the fraught nature and complexity of the caregiving experience. This perspective reinforces the construction of the caregiver body as at risk and creates a greater moral imperative to care, while neglecting the often conflicting and meaningful experience of caring.

Caregiving as Meaningful

Socially, the practice and processes of caregiving are important to how we reproduce and maintain ourselves, as well as define and relate to one another (Graham, 1983). Caring can refer to explicit acts and tasks, as well as express a “moral orientation” or sets of guiding values

(Sevenhuijsen, 2000). Caregiving is also socially and personally meaningful, and it takes place within complex interpersonal and situational dynamics.

For some, identification with being a “caregiver” is a socially constructed process (O’Connor, 2007). Caregiving is not a static role that one assumes, but a dynamic position that one takes or is placed within through social interactions. As O’Connor (2007) found, there often is a lag between when one assumes caregiving tasks and when one self-identifies as a caregiver. This could be because performance of caregiving tasks is gradual and part of existing modes of care work, but also because the tasks might be so overwhelming that the person does not have time to self-reflect on their changed role. In some cases, people resisted the label of caregiver, however, because it changed the connotation of their relationship with the person and implied the loss of mutuality.

Assuming the role of caregiver for a family member can involve life restructuring and role adaptation (Wells, Cagle, Bradley, & Barnes, 2008). Caregivers’ ideas about themselves and their relationships with others involved in caregiving can affect the normative expectations they have for themselves and others in provisioning care (Goldsteen et al., 2007; Gubrium, 1988). As noted above, because caregiving expectations can vary by gender, men and women might differently construct their moral identity in relation to the care they do and do not provide. Engagement in caregiving can be challenging and subjectivity can shift as one negotiates tensions (Carlander, Sahlberg-Blom, Hellström, & Ternestedt, 2011) and the various illness trajectories (Goldsteen et al., 2007). However, the stresses and strains involved in caregiving need not necessarily be viewed in solely negative terms. The attachments and interconnections from which they stem can yield meaning and purpose (Abel, 1990).

As a central experience in the lives of many people, caring can be a route to self-meaning (Rae, 1995) and is an embodied and moral practice (Chattoo & Ahmad, 2008; Kleinman, 1999, 2010). Throughout the experience of caring, people make moral choices that are informed by cultural scripts (Chattoo & Ahmad, 2008). These choices are based in particular values, histories, uncertainties, and relationships, and limited by the interconnections of the local and broader world (Kleinman, 1999). Because moral problems are locally situated and negotiated, they are often filled with multiple claims and thus decisions are not necessarily final, but part of ongoing tensions, conversations, and adjustments (Walker 1989).

This work that follows builds on the work of O'Connor (2007) and Abel (1990) by stressing the interactional and socially embedded nature of the caregiving position. I also extend and follow Kleinman's (2006) attention to how people deal with uncertainties and lead a moral life by acting in ways that seem right. I follow Kleinman's urging to examine what is at stake for people in these local worlds and how those inform decisions (Kleinman, 1999). In this article, I address two main questions: What tensions do people describe in their caregiving experiences? How do they construct their moral identity through the ways they act to negotiate these tensions?

Through case studies of family caregivers, I highlight the shifts in relationships and identities as people confront the tensions wrought by the uncertainties and ambiguities of aging in place with chronic illnesses and disabilities. I illustrate how informal caregivers construct their moral identity and how establish and maintain a sense of what is important to them. I highlight how they draw on cultural scripts to make sense of their moral choices. Examining family caregivers' narratives of their relationships with family members, enables us to see how moral issues, related to values and identity, are represented (Goldsteen et al., 2007; Kleinman, 2006; Walker, 1998) and provide moral significance to their experiences.

Methods

This article draws on data derived from 12 months of ethnographic fieldwork in the Southwest United States that was conducted from November 2009 to November 2010. The larger project focused on Medicare-funded home health care and the cultural desirability of aging in place among chronically ill older adults (Penney, 2013a, 2013b). In this article I focus on the experiences of the family caregivers. The study was approved and conducted in accordance with the University of Arizona IRB.

For the purposes of this project, a “family caregiver” is defined as someone identified as an unpaid caregiver by someone else (e.g., nurse, home health care user) or who self-identified as a family caregiver. The caregivers I met occupied a range of roles and functions at different points in time and space. They helped the older adults they cared for transfer, supported their ambulation, kept track of medications and set up med boxes, provided transportation, did housekeeping, cooked meals, provided companionship and emotional support, coordinated and managed medical and other care, contributed financially, and generally took part in the work of chronic illness of their family member or friend.

Caregivers were identified and recruited for this study principally when I met them during job shadowing with nine home health nurses. Older adult care recipients who were identified as users of home health services and participated in the project (n=22) also referred me to their caregivers and I met others through community organizations and events. I spoke to a variety of caregivers throughout the course of fieldwork and had multiple encounters with caregivers whose care recipients also participated in the project.

I conducted semi-structured interviews with 16 informal caregivers (13 women, 3 men). All were White and ranged in age from 43 to 92. While most had occupied or were occupying

multiple caregiving roles, and in some cases were care receivers, for the purposes of the interviews I asked them about specific caregiving relationships in which they were an identified caregiver. Eight were caring for a spouse (6 were wives, 2 were husbands), six were caring for a parent (5 were daughters, 1 was a son), one for an aunt, and one for a friend. At the time of our first meeting, 10 were residing with, four lived within an hour's drive of, and two lived in a different state from their care recipient.

On average, interviews were about an hour and a half (45 minutes to three hours). Caregivers chose the sites for the interviews. Most of the interviews took place in their or their care recipients' homes. Interviews were audio recorded. The interview guide contained items related to their caregiving experience, home health care, and aging in general. Specific questions and prompts included, "Tell me a bit about how you came to care for your family member," "What is the best part about being a caregiver?," "What is the hardest part about being a caregiver?," and "How has caregiving affected your life in general?" Questions and prompts such as those provided touchstones for conversation and emergent follow-up questions based on caregivers' unique experiences.

Many of the family caregivers I met over the course of fieldwork were overwhelmed with and harried by the sometimes rapidly changing circumstances of their family members. This made scheduling and completing interviews difficult. At the same time, I frequently met and interacted with persons with past and current family caregiving experience. Thus, less structured and formal interactions with these and other caregivers, as well as interviews with community providers (n=18) and nurses (n=13) contributed to my understanding of the experience of caregiving and my analysis of the material here.

Following the interviews, detailed notes were typed up in word processing files and portions of the audio were transcribed. Typed fieldnotes were also kept and detailed less formal interactions with family caregivers. All typed notes and transcripts were compiled into a project database kept in the qualitative analysis software program Atlas.ti. These were coded using a code book constructed according to research questions, themes from the literature, and themes that emerged during the iterative process of conducting fieldwork, reading notes, and writing. For this article, four case studies were selected that illustrated specific themes around caregiver identity and associated tensions. The cases illustrate how constellations of circumstances affect the caregiving experience and the choices people make. All names and some identifying details have been changed to protect the anonymity of those participating in this research.

Results

The following four case studies are illustrative of the issues and themes that emerged from my conversations with informal caregivers. Caregivers situated themselves in their unique life histories and described the challenges they encountered as they tried to do what was best for their loved one. Each case describes how children and spouses negotiated new identity positions and constructed their moral identities based on the choices they made in their caregiving.

Themes of ambivalence, uncertainty, control, conflicting commitments, differing expectations, guilt, love, enrichment, and affirmation are variously highlighted as these tensions are explored.

"It's a Labor of Love"

I interviewed Victoria after getting to know her 84 year old mother, Hannah, and her mother's paid caregiver and Victoria's good friend, Darcy. We met at her home on a quiet, though summer sticky Saturday morning. She wore short denim shorts and a tank top, and her feet were bare. We chatted in her dark, cool living room while her husband and children slept in

the back rooms. Victoria is the youngest of a handful of children. Though they were raised in the community, she is only one of two siblings still living there. In her early 40s, Victoria exemplifies what is frequently referred to as the "sandwich generation." During our chat, while she went from laughter to tears, she described her difficulties and the "labor" involved in balancing full-time employment, motherhood, being a wife, and caring for her mother. Her story illustrates the challenges of maintaining a moral sense of self amid tensions of conflicting commitments, as well as the affirmation she received from doing her best to live a moral life with respect to her mother.

Victoria described herself as having a long-standing history of mutual care and support with her mother, who had been widowed when Victoria was very young. Her mom no longer drove, had mobility issues and a history of falling, had hearing loss, was diagnosed with diabetes and neuropathy, and had recently gone through treatment for cancer. A turning point in their caregiving had come a few years earlier when her mother broke a leg. Hannah had subsequently been hospitalized for a brief period of time, stayed in a rehabilitation facility, and then received limited home health physical therapy. Victoria described the time since this episode as one filled with uncertainty about a shared unknown future and worry about what she would have to do to help her mother stay at home.

As with many other adult child caregivers I met, Victoria described her caregiving within the moral imperative of reciprocity: "your parents bring you into this world, they take care of you, I think you owe that to them." She said it was an obligation, but not a negative one: "it's just what you do." It was something she watched her mother do for her grandparents, and something that was "natural" for her to do for her own mother. At the same time, after the recorder was turned off, she said that her adoption of the role of caregiver for her mom was thrust on her.

There was no working out in her family who would assume that role, it was hers by default as the other siblings either explicitly stated or passively showed they were not going to provide help.

Of the family caregivers I spoke with, Victoria was the most direct about her concerns about how unspecified others might evaluate her caregiving. She expressed worry that although she worked hard to support Hannah in making her own decisions, remaining independent, and maintaining her sense of dignity, Victoria did not always think her mother's decisions were wise and the negative consequences they wrought might lead others to think Victoria was neglectful. She said a particular point of frustration was Hannah's laxness toward her responsibilities for her health and condition (e.g., being overweight, moving without caution), which had negative impacts for both herself and Hannah. For example, she said, "when [my mom] doesn't move around in a safe manner, that ticks me off. It's unfair to me. Because who's gonna come to pick ya up because you're not moving the way you should be moving." She noted that Hannah was aware of this and sometimes worked to try to lessen the perceived burden on Victoria, which sometimes had the effect of only enhancing it, which made them both feel horrible.

Victoria found it difficult to strike a balance between doing too much and too little for her mom, while also taking care of herself and her other responsibilities. In articulating the latter, she drew on her mother's experience as a caregiver for her grandparents. Victoria said her mother's health problems had started when she had "put herself aside" when she was a caregiver to her grandparents. Victoria drew on this as a way of justifying attending to her own well-being and hiring their paid caregiver Darcy, a long-time friend who was out of work. She said Darcy stepped up to help where her sister, who had a difficult relationship with her mom, had not:

I know that it's not gonna get any better. How [my mom] is today is the best she's gonna get. It just goes downhill from here. (Sighs) So every now and then I'll go down that

road. And it scares the heck outta me. And thank god Darcy's like, 'Well we can do it together,' you know. So basically like she's stepping in as my sister. Or what my sister should be doing.

Besides moral support and general relief, Darcy helped ease Victoria's mind, relieved her of some tasks (e.g., cooking, cleaning, driving), allowed her to not take as much time off work, and helped her support Hannah in constructing a sense of independence and easing her worry about burdening Victoria. However, Victoria sometimes felt guilty. Laughing, she said: "How horrible is that? I mean, what are you gonna do? Damned if you do, damned if you don't." She continued:

I keep thinkin', I was like, 'Well you know, I could be going over there before work, and I need to go over there after work every day, and,' you know, somethin' to that effect. But then I start getting overwhelmed. (Slight pause) And I start breaking down, so it's not, kinda sounds selfish, though.

Near the end of the interview, when I asked her about some of the harder aspects of caregiving, she again drew on their interdependence and fears of losing Hannah: "The frustration. The fear. The overwhelming uh, sense of, responsibility. Um (Extended pause) and just the difficulty of watching your parents age. Seeing their own mortality." Despite her uncertainties in and fears of establishing her moral life as a caregiver, the recent years had been meaningful and allowed her to create a closer bond and understanding with her mother:

at the end of the day or whatever, if you have gone through and not lost your temper (Laughs) um, it's just the actual time you get to spend with 'em. That connection. And the memories that you're building. Um, it's, it's a sense of fulfillment. So at least I know that I will have felt I did what I could. (Starts to cry, chuckles) Dang! (Laughs)" The

caregiving experience deepened and continued the sense of mutuality that she described through our interview. She reflected, “My mom always tells me, she calls me her rock and I’m like, ‘Are you kidding? You’re my rock.’”

Victoria’s story speaks to the enmeshed experiences of family caregiving. She spoke of shared ambivalence over shifting roles and frustrations over the identity work that both her mother and her engaged in to try to support the construction of Hannah as independent (Devault, 1999). Her narrative points to the role of the caregiver in allowing the elderly family member to remain at home, ostensibly independent, and the cost of the independence to the love one(s) who facilitate this. Victoria described having to find a balance between supporting her mother and sometimes representing her (e.g., doing her bills, setting up her meds), and allowing her mother to make her own decisions. Sometimes this identity work came at the expense of her own moral identity as a caregiver, as she worried that others might perceive her as not doing enough to ensure her mother’s well-being (e.g., by moving in with her or putting her mother in a nursing home). Victoria desired to give her mother everything she wanted, particularly to respect her wish to die at home, but Victoria expressed anxiety about whether it were possible and what it might mean for herself. However, despite the uncertainties and fears, there remained deep and abiding love.

“I Feel Like I’m on a Rollercoaster”

I met Eleanor, a tall thin woman in her mid-60s with short dark gray hair, and her 81 year old husband (Paul), a slim man with a sharp buzz cut, when I was job shadowing their home health nurse. They lived in a new, large fabricated home in an older adult community outside of town. From their bright, clean living room they had an unobstructed view of a mountain range. Eleanor and Paul had been married more than 40 years and moved to the state 15 years previous.

They spent many years RVing across the country, enjoying the thrill of seeing what was over the next hill. His few children from a first marriage lived out of state, but he had a sister who lived in town. Although he had a long history of disability and depression, in recent years there had been a flurry of emergent health problems (e.g., fractures, bowel blockages, bladder infections, incontinence, pain, cardiac issues, spinal stenosis, falls). When I met him, he had been through three episodes of home health care and a spate of hospitalizations and nursing home stays. Over the months I visited with them, Eleanor grappled with maintaining her moral identity as wife and caregiver, while also relinquishing control, accepting help, and doing what she felt was best for her husband.

I was initially struck by Eleanor's seeming thorough grasp on Paul's condition and care. She detailed to me his care trajectory, how she transferred information between providers (e.g., detailing to the primary doctor his physical therapy outcomes), asked questions and made requests of providers, and had some understanding of insurance benefits (e.g., that he had to show functional progress to continue receiving home health). At one point, Paul even stated that as far as he was concerned, Eleanor was his doctor. More than that, Eleanor also seemed to speak for Paul, who had difficulty speaking. When interacting with me, she often would suggest an answer for Paul by looking at him and speaking in the form of a question. Or she would elaborate or expand on things he had said. She acted as his care manager and advocate, as well as facilitated his self expression.

During our interactions, I observed that she frequently affirmed Paul's feelings while also trying to shift them to be more positive. For example, after she told me that "He wants to get better." He replied, "But the longer time goes on, the more I realize (Pause) I'm never gonna get to the point of where I think I used to be." She responded firmly, but with compassion, "No,

you're not. That's a fact. But you can-, you are better than you were two weeks ago and you can continue to be better." She went on to encourage him to "keep working" and make progress.

Despite the aura of control and confidence that I discerned at our first meeting, a theme of uncertainty emerged throughout our interviews. As his capacities declined, it became increasingly difficult for her to provide support. Practical management for many caregivers, particularly if they were smaller in stature or had physical limitations, could also enhance senses of riskiness and uncertainty. Eleanor noted she had difficulty getting him into the car once when they were out to eat: "it's kind of frightening to think that I could be stuck someplace, I can't get him back in the car."

Accepting and asking for help from others was difficult. Eleanor worried about what she could ask of friends and whether the quality of care provided by health professionals would provide the kind of care that she could. Chuckling, she acknowledged,

I never used to think I was a control freak, but maybe I am, you know. I don't know. But, you know, when you love somebody and you care about them, you want the best for them and you want what you can give them. And maybe somebody else can do it better but you still lose the (Pause) the control and you lose the reassurance that somebody else is gonna make sure they don't fall or make sure they get to the bathroom or make sure they get their medications and eat and all the rest.

While she had reluctantly accepted home health care, she admitted that the nurses and therapists had been helpful practically, materially, and emotionally. They helped fill a lack in her caregiving abilities and were a benefit to Paul: "I don't have the (Long pause) I don't know what the word is, momentum? (Chuckles; pause) Inspiration, I don't know what the words are, to get him motivated every day. And, you know, that's a, uh, lotta stress too. And so it really helps to

have other people coming in and take that initiative.” They also helped to make it okay for Eleanor to let go of some of the direct care and care management tasks she had taken on by identifying places where Eleanor could use help and urging her to take care of herself for both Paul and her sake.

As time went on and his strength inexplicably failed, Paul was admitted into hospice. During the first couple weeks, Eleanor said, “I feel like I’m on a rollercoaster.” A host of tests had been unable to diagnose what was happening with Paul and it was unclear where they were in “this progression.” While she worried about where this was going and the decisions that would have to be made, she said, “I’m trying not to cross too many bridges before I get to them either, you know you can become overwhelmed with the what-ifs and the possibilities, so, just take one day at a time and try to deal with whatever that day brings.” However, the state she was in was surprising and liminal, and she expressed not knowing what she was supposed to do, particularly in relation to hospice. This was a time of transition, of shifting and undesignated roles and responsibilities, as well as diminishing hope.

My third visit with them took place at an assisted living facility in which Paul had recently been moved. Eleanor explained that the decision to move him had been made one afternoon when he had fallen to the floor as she tried to get him out of bed and into his wheelchair:

in the process of trying to lift him and get him upright, I hurt my back and um...that was obvious to both of us then that I just couldn’t do it anymore. So...as long as he was helping me [transfer him], you know with some leg movement and motion, and lifting himself some, we managed but when he stopped being able to do that or when I stopped being able to depend on him to do that, I mean there are times when he could and times

when he wouldn't, and um, that's when I knew that one of us was gonna get hurt, if not both of us, and I figured that wasn't responsible of me to keep him at home anymore.

She said that day she realized how stressed she was and "the world came crashing in."

In talking about how hard it had been to let go of the control of his care, she stated, "it's not my place anymore." In addition, relinquishing day-to-day practical caregiving had given her more freedom to return to exercising and socializing, and to generally "get on with my life."

However despite people telling her that this is what she needed to do, she felt guilty:

I still have a husband and I'm not takin' care of him (Chuckles) . . . in a sense that's hard for me to admit, that I wasn't sufficient for him (Chuckling) you know. Either physically or emotionally. But (Pause) um, you know, you get married and you think that it's for better or for worse, forever. You know, and, it's hard to accept, I guess, that there may come a time that that may not be true. You know, that that living arrangement of living together may not be the best for both people. Um, when he first left home, I said I felt like I was still married but he'd left me.

Eleanor's experience highlights a sense of shared embodied risk that was particularly strengthened as Paul's capacities failed, her energy waned, and she was unable to make up for his losses. She described this as occurring with a gradual break down of give and take in their relationship. As with several other wives I met, she talked about the toll that primary caretaking had had on her emotional and physical health, and the difficulty of adjusting to feeling more like a caregiver than a wife. All seemed emotionally and physically exhausted, with some specifically stating they were depressed. However, at the same time, putting emotional and physical distance, accepting the assistance of other caregivers, and addressing their own needs could be described as empowering (see also Rutman 1996), even as it came in tension with feelings of guilt. Amid

these shifts, she was negotiating what was the morally appropriate course of action and what were the associated obligations (see also Goldsteen et al. 2007). Throughout, she expressed that she is trying to do what was best for her husband. As she redefined her relationship, she drew on the discourses of health care professionals who said she needed to take care of herself and seek professional assistance. This helped her to maintain her moral sense of self even as she relinquished some responsibilities.

“We’re in this Position of not Freefall but could well be a Freefall”

Elijah and his wife were in their early 90s when I met them while job shadowing with their home health nurse. As with some of the people I met, in their retirement they had transitioned from spending part of the year in the community, to living there full time when traveling became too difficult, and the climate and structural conditions in their previous home were problematic. Unlike some of the others in this situation, though, their adult daughter lived in the area and was available to assist in some daily caregiving and transportation, as he did not drive much anymore.

A sparse and business-like man, Elijah anticipated some of the broader issues underlying my questions of his experience. As we sat in their very clean, newly furnished living room of their apartment overlooking a golf course, he spoke thoughtfully if reservedly/dispassionately, seeming to choose his words carefully. While many of the family caregivers I met described a sense of sharing a fate with the person they cared for, as he told me their story which he said was at a turning point, he expressed conflict with their interdependence, accelerating dependence, and his own old age experience.

Throughout our hour and a half long conversation, Elijah expressed ambivalence about his emergent role as caregiver. While his wife had mobility problems for the past 20 years, he

said things had only recently become “totally different” with her generalized weakness, recurrent falls, and recently diagnosed deep vein thrombosis. In looking back, his role as a caregiver snowballed as a continuation of his past life, and the trajectory accelerated before he was aware of it. It was not a position he sought: “[The caregiving role] was not created from my side, I just filled the vacuum . . . I have a role to play and I accept that role.”

During our conversation, he frequently referenced how his wife’s progressive dependence impacted his own sense of identity and how he resisted that to maintain independence. For example, he described his reluctance to acquire a disabled person license plate for their car so they could use accessible parking and opted, instead, for a removable placard: “I need disability [designation] but I don’t want it on the license plate. I got one that just hung when it was applicable. . . . I don’t wanna drive a car with it on. . . . I still don’t wanna make that move personally. But I did for [my wife].”

While their lives and in some way fates were intertwined, he resisted some of the territories in which his wife’s condition took them. Their home health nurse suggested they put a commode in his wife’s bedroom, a move he rejected. He explained to me:

I’m viewing it, one, where you start at the caregiver, I’m the manager on site. But I’m also looking at the big picture of how does this fit into the whole life cycle. It’s gonna, once you move the bathroom into the bedroom, you’ve changed the whole culture of the living environment. . . . I said, ‘No. When it’s necessary, yes. But I’m not, that’s something I don’t want to accelerate. Because you won’t back out of it. That’s a straight line going forward.’

He described them as being at a transition point, a precipice of possible “freefall,” entering a new phase together, one in which he doubted his abilities to perform to support both of them:

We’ve reached a point where I’ve sort of maxed out, you know, I’m going to be a non-performer if we get into big trouble. Only thing I can do is deal with the telephone, 911, ‘Somebody come help me.’ . . . we’ve had other falls. Fortunately we’ve got bruises and aches, but not breaks. And I think [my wife] understands that a break now could be pretty threatening to us. . . . we’re getting housebound in a sense and uh, clearly, it’s clearly changed the dimension of my own life. I wanna do everything I have to do here, but there’s an outside world that I totally wanna participate in. And uh (Slight pause) the dominant need is here [in the home] and not there [in the outside world].

Like some of the other family caregivers I met, Elijah expressed ambivalence about his role, how his life was impacted, and what the future held for them. He talked about filling a needed role, not choosing it. He also frequently cited instances in which changes were outpacing his readiness or abilities, and his having to take a “time out” to think through a decision. Making decisions was difficult, in part, because there were many unknowns. While he expressed gratitude for and praised the know-how and care of the professionals he had dealt with in the course of getting his wife health care, he talked about how difficult it was to make informed decisions. It leant the experience a fumbling sort of nature, even though his manner of speech and efforts at control suggested something else: “Look it’s not dealing with perfection, it’s making with human imperfection work, that’s what it is.” And through this I had the sense that he was struggling to care for and support his wife, while also feeling aspects of his identity come into question. Thus, Elijah occupied a space of moral dilemma where he grappled with his wife

and his changing needs, what he described as a “closing a life,” and the demands and expectations being placed on him.

“We’re Gonna Make Somethin’ Else Up”

While interviewing 91 year old Georgia who was being treated for cancer and receiving home health care for periodic catheter changes, I separately met and interacted with three of her daughters, Lily, Chloe, and Janet. When visiting Georgia’s bustling home, I frequently encountered her children and grandchildren, neighbors, and paid caregivers. It was difficult to schedule and complete interviews around her medical treatment and social life. My conversations with her daughters were made around their cooking food to stock in Georgia’s freezer, planning and coordinating her paid caregivers, and preparing to take her to social engagements.

A military family, Georgia and her husband moved to their community in their retirement. She had continued to live in their home during the 20 years she had been a widow. Her children, who were now in their 40s and 50s (Georgia had her children late in life), had settled with their own families across North America. About a year before I met them, Georgia decided to move into a nearby resort-style, continuing care community. Georgia picked out an apartment and was looking forward to social interactions with other residents. However, as she described it, her health “went down so fast” that she no longer qualified for the independent living residences and would have been placed in “ultimate care” (i.e., nursing home care).

Janet visited the facility and Georgia reported that afterward, Janet refused to allow her to move there: “I will not have you there. Just- they wheel you in front of a fish tank and you sit there and you watch those fish. And it’s just not- it’s not a good place.” During a 20 minute phone conversation with me, Janet recounted a similar tale, and implied the nursing home was

not a good fit for her mother and would have bored her. She also expressed resentment toward the nursing home staff and industry for making family caregivers feel guilty about deciding to keep and care for people at home. She disagreed that she was unqualified to care for her parent, stating that family care at home is the best sort of care.

Unhappy with the care options for their mother, the sisters told me they decided to create a new model or “solution.” For about half a year, the siblings had alternated taking time off work and staying with their mother. They provided broad care management for their mom (e.g., doing her taxes, keeping up with treatment and doctor’s visits, hiring and supervising caregivers) and shared direct care with paid paraprofessional and professional caregivers (e.g., bathing, cooking, health monitoring). When I met Chloe during one of my visits, she described it as highly enriching, highly stressful, and highly demanding, but also highly worth it endeavor, as long as one could afford to do it. The family had both the economic and social capital to facilitate their arrangements. The children occupied professional, flexible positions that allowed them to work remotely and/or take time off work. In addition, Georgia paid to fly her family out to see her and covered at least some of their other expenses while they were with her. Lily described this as the cheaper and “really cool” alternative to using her mother’s money for nursing home care. She said this money helped the family “be a part of her healing” and facilitated their bonding. She expressed personal satisfaction from the opportunity to see her mother regain her strength as a result of the care they were providing. Committing to caring for her mother in this way also allowed Georgia to remain in her social networks and home, a site that Lily said had become Georgia’s “soulful, wonderful place.” Lily thus constructed their model as enriching and nourishing for herself and the family system, not just her mother. Care in this instance was portrayed as reciprocal rather than unidirectional.

The siblings, who lived remotely from their mother and each other, coordinated their system of care through weekly conference calls and by divvying up responsibilities for different aspects of their mom's care and treatment. They checked in with their mom through daily phone calls and emails. It did not always function smoothly, as different people involved in the care held differing commitments to and visions for the right course of action. For example, one sister was said to have initially insisted their mother enter the nursing home so Georgia would be sure to have around the clock, continuous professional care. Lily said this caused a lot of friction and subsequently that sister had been less involved than the others. Tensions also arose when none of the siblings were able to be with their mom, so-called "gaps," where the family relied on paid caregivers to act in part as surrogates to provide proximal care for their mother. The sisters told me it was very difficult to find reliable and affordable options, and to have someone present to screen the paid caregivers and oversee their work. Despite the siblings' commitment to make this work and keep her mother at home, geographic complexities and reliance on people who might not hold the same standard of care or experience the same obligations to their mother made their situation "precarious." In turn, these tensions also posed a threat to their being able to accomplish the new model and type of care they wanted to perform for their mother and their moral identities as caregivers.

This family was one of the most explicit in their critiques of the ways in which care for the elderly was generally handled in the United States. Chloe said current models for caring for the elderly were all wrong,

we should not send someone to an institution. We should have, you know, the institution come and provide them love and care one-on-one. I think it would be cheaper for the government. I think. Offering, you know, tax incentives for families that wanna do it.

Stuff like that. I just don't think that we have thought through this, this model well enough yet. . . . It is a HUGE problem, it's a silent...silent and invisible problem. . . . So that's why we just kinda figure we're gonna make somethin' else up. You know, because WE have to be the role models for our children taking care of us, right? So (Pause) and I don't wanna go live in a nursing home, I don't want [my mom] to go live in a nursing home, so we gotta figure it out.

Thus another reason for them to engage in this form of caregiving was to serve as a model for the next generation, to help reproduce similar morals to secure their ability to maintain what was important to them in their old age.

Caregiving was a shared familial experience that was made possible by the family's commitment to keeping Georgia at home and the resources at their disposal, including finances, flexible employment, and organizational skills. At risk was their mother being placed in a nursing home. Their decisions about caregiving were frequently morally grounded in a shared, familial experience and value system, one that was committed to keeping their mom at home. While they noted some tensions and hardship, this phase was also described as a uniquely growing experience for everyone involved. When I asked Georgia the family's biggest strength, she said, "They are my strength." While she expressed worry about impinging on them, she also said she derived joy from having them there and helping to bring them together.

The underlying moral current was that the family was committed to forging what they described as an alternate path to caring for Georgia. The vision of good care they described providing placed central value on their mothers' personal needs, wants, and sources of pleasure, and maintaining her emplacement. It was also a path that they embarked on within the bounds of familial love that nourished and enriched both Georgia's healing, their bonds as a family, and the

personal growth of the members. This was implicitly, sometimes explicitly, contrasted with more institutional, professionally controlled medical models of caring for the elderly. It also contrasts sharply with predominant depictions of caregivers as working alone and care as unidirectional.

Discussion

As these case studies show, caregiving is a meaningful experience, fraught with uncertainty, change, and hard work. Each of the family caregivers morally situated themselves within their unique histories, present circumstances, and imagined futures. In these cases, there were numerous things at stake beyond keeping the family member alive and safe. These included maintaining the agency and identity of the family member, and their places in meaningful physical and social environments. Caregivers also worked to live up to what they perceived as their familial obligations, while also ensuring their own future economic and physical well-being.

All experienced tensions in trying to protect the things they valued. One tension was their shifting relationships and expectations, and how those emerged within existing family dynamics. For many of the family caregivers I met, caregiving for an elderly relative arose gradually and often as an extension of existing behavior within a relationship. Their identity as “caregiver” was cemented through their caregiving experiences and being identified as a responsible party (see O’Connor 2007). However, not all embraced the identity of caregiver. As Elijah and some others I met described, they had not chosen to take up responsibility for direct caregiving and care management, and seemed at times resigned to and ambivalent about their new positions.

Family caregivers talked about how taking on new care responsibilities for their parents or spouses had shifted their relationships. Victoria described the frustrations for both her mother and herself when she took on the “parent” role, while Eleanor spoke with indecisiveness and

sadness about the distance that had grown in her marriage. As the cases of Victoria and Georgia's daughters illustrated, siblings had differing relationships to their parents and commitments and availability to caring for them. This could engender bad feelings and a perceived burden being unequally born.

Although my sample was small, it is worth noting that in line with existing literature, there was indication that some of the distribution of care was made along gendered lines. I noted that the men I met were less involved in intimate, custodial care. For example, Elijah said his adult daughter was charged with preparing (e.g., bathing, dressing) his wife for bed each night. I also noticed that son-in-laws often were described as helping with home maintenance. By contrast, when people discussed family members not performing to expectations, it was often sisters and daughters who were blamed even when there were also brothers and husbands involved, indicating the women were allowed fewer exceptions for not engaging in caregiving.

Asking for and receiving help also required negotiation. It was difficult for many caregivers to know how to ask for help, particularly when they were concerned about overstepping, being a burden, or asking people to do something that was uncomfortable for them. In addition, many did not know where to go for help (see also Wiles, 2003). Georgia's daughters talked at length about the difficulties they encountered in trying to find and maintain paid home caregivers, and expressed confusion over their mom's eligibility for home health care through her Medicare insurance. I faced similar questions from many of the families I met. Even when additional care was offered by friends and neighbors, or paid care was suggested by health care professionals, many families were ambivalent about accepting it. Elijah expressed worry over how accepting paid help would impact their household and Eleanor was concerned about the quality of care such helpers would provide. Bringing in additional people required organizational

effort and trust, and some unknowns. It also often required resources (e.g., long term care insurance, savings, supervision), things that the families here had available, many of the other families I met did not enjoy. Even when help was accepted and it provided relief, evoked gratitude, and helped maintain the construction of the person as independent (see also Wiles, 2003), as Victoria described, it placed family caregivers in somewhat of a double bind because it could also elicit guilt over possibly not doing it themselves.

Family caregivers described a variety of things that helped them in their care work. While the people I talked to did not describe doing self care in great detail, a strategy sometimes mentioned was setting aside certain times of the day where they did something that was not caregiving to their family member (e.g., walk the dogs, play on the computer). Across the families I met, joint caregiving often helped to lessen stress and provided an extra dimension of union, strength, and meaning. People expressed finding comfort in having others join them in their efforts and experiences, and practical utility in allotting tasks and sharing information. Partners, children, and even pets, although maybe not providing much hands on care assistance, could be understanding and emotionally supportive. Friends and church groups were also provided emotional support and were frequently sources of information. Health care professionals were sometimes described as helpful in making sense of what was happening, giving practical tips, and helping to access resources. Employers who were flexible and understanding were also sources of strength. At the same time, people in any of these categories who were demanding, inconsistent, unreliable, and uncaring were also described as adding stress to the experience of caregiving.

As Lily, Chloe, and Janet's case showed, geographical distance added a level of complexity to caregiving relationships. Technologies like cell phones and email have helped to

make communication and checking in from afar more readily possible. Such communications offered caregivers opportunities to express care, keep up to date with information to aid in their care management, and in some cases alleviate worry. Siblings varied in terms of their employment and life flexibility in scheduling trips to visit, as well as available skills (e.g., medical, law, home maintenance, fact finding) and financial resources for caregiving. For some children who lived far away from their parents, it could be emotionally difficult to be so far away and not able to provide direct care on a day-to-day basis. This could elicit senses of guilt and tension for dueling responsibilities.

There were tensions involved in deciding the right course of action given many unknowns and conflicts in commitments. For the most part, people were unaware of their options, confused about the benefits available to them, and unsure about how to access them. Given both gradual and rapidly changing circumstances and their immersion in it, it could also be difficult to know what was needed and to find time and space from the emergent needs to look at the situation more holistically. Caregivers also highlighted instances in which they had to decide between doing what they thought was best for their family member (e.g., visiting more often, keeping their loved one at home, getting their family member more professional help), with maintaining their own well-being (e.g., time alone, sense of independence) and dealing with other responsibilities (e.g., parent, employee).

For all of the families, their stories were replete with the tensions concerning the value of independence. Elijah described ambivalence about accepting help for fear that it would foster dependence. Victoria talked about how in supporting her mother's efforts to maintain her independence, she worried this was neglectful and placed her mom at risk. While many described wanting to help keep family members independent and I witnessed them encourage

those family members to work at maintaining capacities, efforts to do for them either because it was easier, was a show of care, or was perceived as lessening the risk to the person, could be met by resistance. These instances were often described as morally ambiguous territories and called into question the meaning of independence.

Despite these difficulties, for the most part, the family caregivers I met also expressed that caregiving could be an affirming and nourishing experience. It was a time when they got to know the person they cared for better and provided an opportunity to express their love by taking care of the other person. However, this care was not unidirectional, but mutual and sometimes described as reciprocity. Care was also not exchanged in bounded dyadic relationships, but, as Georgia's family exemplifies, care was expressed in networks of people, which, when described that way, could add richness to the experience and the construction of moral identity.

Conclusion

Through these case studies of informal caregivers caring for an older family member, I have highlighted the shifts in relationships and identities as people confront the tensions wrought by the uncertainties and ambiguities of aging in place with chronic illnesses. I illustrated how informal caregivers construct moral identity through the ways they position themselves in their narratives and how they described doing work to maintain the things important to them. I have also indicated the mutuality between erstwhile caregivers and their care receivers, the ways in which they share risk, and the intertwinement of their fates.

In the United States, with rise of noncommunicable disease, gains in longevity, changes in residence patterns, cost cutting in medicine, ideals for "aging in place," and increased concerns about cost to State for caring for older adults, there is enhanced focus on facilitating

informal caregiving. This focus, with its bases in feminist and caregiving burden literature, has both economic and humanitarian concerns.

I observed multiple community caregiving events that provided a venue for affirming the caregiver experience, imparting education, and promoting a discourse of caregiver self-help. When job shadowing with nurses, I also observed them, to varying degrees, check in with family caregivers and urge them to take care of themselves. I often was struck at how these narratives, although well meaning, seemed dissonant from the highly charged and often fraught caregiving stories I heard. The caregiver's narratives told of much more complex, deeply historically and personally embedded experiences in which they were in various ways entwined with the person for whom they cared. The self-help narratives I heard likewise frame caregiving as sharing in embodied risk of the person cared for, but fashions that interdependence within a depersonalizing public health concern (cf. Talley & Crews, 2007). While this perspective usefully starts to focus on how the health and wellbeing of the caregiver might impact that of the care receiver and the broader public health, the suggestion of the caregiver at-risk has the tendency to individualize caregivers, make them responsible for the fates of everyone involved, and also devalue and perhaps sterilize the meaning and purpose that is concomitant with that burden.

An omnipresent idea in caregiver self-help discourse is that caregivers need to take care of themselves. In many ways this narrative is affirming that caregivers have needs and deserve to enjoy well-being. However, frequently it takes an obligatory tone, remonstrating caregivers to take care of themselves so that they are better able to care. As Victoria's story illustrates, though, this can place informal caregivers in a double bind (O'Connor, 2007) by setting at odds a focus on the self and a focus on the person they are caring for.

As these case studies show, the experience of caregiving is much more complex than is depicted in many of the discourses surrounding caregiver burden. Caregiver educational efforts that try to impart knowledge about how to become advocates for the people they care for and that urge caregivers to take care of themselves, do not address the complexity of these moral processes in which caregivers are involved. As a family caregiver named Nancy, who was caring for her husband and an elderly aunt, noted, “everybody tells the caretaker, ‘Take care of yourself,’ (Pause) but nobody tells you how to do that. (...) you just have to figure out a way for yourself and hope that it’s right.” This speaks to the fumbling nature of and very local experiences of many of the caregiver journey stories I heard.

Highlighting the ways that family caregiving is a difficult yet extremely meaningful experience does not mean not looking for ways to support families in this process or addressing the structural conditions that unequally disburse difficulties (which although centrally important, is not the topic of this article). As noted, people lack sources of good information about the complex, fragmented, and very limited social and health systems. Perhaps a better road to providing caregiver support would be to stop placing people into discrete roles and categories, and instead think about the networks of people who together are working to make the best of aging with chronic illness.

Molyneaux and colleagues (2011) argue against individualizing interventions and instead creating models and programs that would address the needs of both those who care and those who are cared for. This would place the focus on relationships and the unique, local circumstances of their evolution, and also involve, to varying degrees, caregivers and care receivers. Such programs could help those involved in care networks identify other sources of support (e.g., materials, programs, people) and engage in a dialogue about individual and shared

goals and expectations, and adapt those plans as conditions change and new information is garnered. Efforts could be made to ensure local conceptions of quality of life and preserving the things most important to the parties involved.

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