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FAMILIES AND FACILITIES: HOW THE PARENT-CHILD RELATIONSHIP CHANGES UPON INSTITUTIONALIZATION

A THESIS APPROVED FOR THE
DEPARTMENT OF ANTHROPOLOGY

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TABLE OF CONTENTS

ABSTRACT

This thesis endeavors to trace how the relationships and of the mainstream American family unit, specifically between adult children and their parents, are altered by the process of age-related institutionalization in a nursing home. The family unit is both a basic building block of society and a vehicle of cultural transmission. Families act out wider cultural trends in small-scale interactions, allowing observers a close-up, highly detailed view of societal norms. If enough families successfully deviate from those trends, they can even change a culture's norms, mores, and traditions. Thus studies of the family remain well within the purview of the anthropologist.

Introduction

As more and more Americans reach old age, more and more families find themselves responsible for their oldest members' care and upkeep, a task for which many citizens are completely unprepared. While literature addressing this problem exists, it is primarily sociological in nature. A truly complete picture of the situation requires not just a sociological but an anthropological approach.

This thesis endeavors to trace how the relationships and of the mainstream American family unit, specifically between adult children and their parents, are altered by the process of age-related institutionalization in a nursing home. The family unit is both a basic building block of society and a vehicle of cultural transmission. Families act out wider cultural trends in small-scale interactions, allowing observers a close-up, highly detailed view of societal norms. If enough families successfully deviate from those trends, they can even change a culture's norms, mores, and traditions. Thus studies of the family remain well within the purview of the anthropologist.

The first chapter, "A Brief History of Old Age," temporally and historically contextualizes the problem. It explains the demographic shifts which created America's proportionally large population of senior citizens, which is only expected to grow over the next several years, and briefly touches on how this transition is a reflection of global changes. It then explores the cultural and legal alterations which so greatly affect the experiences of older adults: retirement, the increase of chronic relative to acute afflictions, expectations for venues of care, and certain government-funded healthcare schemes. Each of these factors has changed greatly in the last century or so, and they will undoubtedly continue to be refined in the near future. The chapter concludes with a brief introduction to long-term care facilities (LTFs). This chapter lays the groundwork for a historically and culturally based understanding of modern gerontological issues, including the research question.

The second chapter, "Dependency and Demography," attempts to establish a starting point for comparative purposes. Essentially, this thesis attempts to contrast relationships *before* institutionalization with relationships *after* institutionalization, and the second chapter pinpoints the former as the onset of dependency. Dependency is very hard to pinpoint, but here it is tentatively defined as the point at which an ageing adult can no longer complete all the tasks which they could undertake at their prime, the point at which they require someone else's assistance for a task they could once complete on their own. Dependency can trigger related to ageism, that ugly prejudice with which most if not all elderly Americans are eventually forced to contend. Then the chapter explores demographic differences in ageing, with an especial focus on gender. Old age is widely considered a female domain, dominated as it is by elderly women and female caregivers, and elderly white women are much more likely than other groups to end their lives in an assisted living facility or especially in a nursing home. Racial and class differences are also briefly discussed.

The third chapter, "The Transition from Home to Institution," examines both the decision to place an ageing parent in a long-term care facility and the move itself. It emphasizes the difficulty of this choice, which is often among the most emotionally strenuous decisions of a person's life. However, hard though it may be, the choice is often necessary for the wellbeing of parent and adult child alike due to the psychological, physical, and financial strains of caregiving. This chapter lists and explicates several common health crises or long-term situations which can inspire institutionalization, then moves on to explore the actual process of moving as a task and as a rite of relocation.

The fourth and final chapter, “In the Institution,” investigates familial relationships and dynamics after the move. It compares data with the baselines established in Chapter 2, demonstrating relationships between premorbid and postmorbid bond quality. While some parent-child relationships can break apart or become estranged via the moving process, it is much more common for relationships after the move to be proportional in emotional quality to relationships afterward. Indeed, many caregivers report that their relationship quality increased after institutionalization freed them from many of the everyday stresses of assisting their parents. However, caregiving often takes new forms after the move, with aides completing physical tasks and adult children focusing on organization and finance. The chapter finishes with a brief outline of postmortem caregiving.

The conclusion briefly summarizes information from all four chapters, notes gaps in existing research, and crafts suggestions for policymakers. It reminds researchers that family care has both benefits and cons, as do the various forms of professional elder care. Families with ageing members need to explore all their options to find the best possible course of action for their particular circumstances, and they need to be open to reconsidering their choices as circumstances change.

Together, the four chapters and conclusion are a brief introduction to a critical new stage in the family unit’s life cycle, a stage that is under-researched when compared to other such phases. While more research, especially of the ethnographic kind, is still needed, this thesis will hopefully provide a starting point for gerontologists, sociologists, and especially anthropologists interested in the cultural aspects of ageing.

Chapter 1: A Brief History of Old Age

The Graying Population

One of the hallmarks of the Boasian tradition so prevalent in American anthropology is its emphasis on understanding the historical context of cultural phenomena. The theory, as taught to undergraduates in introductory courses, is that knowing where a thought came from enables researchers to better understand how and why it is expressed in its current forms. This historical understanding can also help predict future ideological iterations, making it particularly useful for applied anthropology. In the case of old age, a historical understanding explains why the institutionalization of many elders has become so relatively prevalent in recent decades and why, as a consequence, institutionalization is such an important area of study. This comprehension also delineates many of the forces that act upon elders' lives and relationships. Historical circumstances have conspired to create a large population of senior citizens with very few social roles and multiple new care options available to them.

The global and national populations of elders are both increasing dramatically. Approximately 11% of the world's population is 60 or older, a percentage expected to double by 2050 (Kanasi et al 2016:13). However, the percentage varies wildly at the national and regional levels: "From 2000 to 2030, the percentage of the population who are 65 years of age and older will increase from 12.4% to 19.6% in the USA, from 12.6 to 20.3% in Europe… and from 2.9% to 3.7% in Africa" (Kanasi et al 2016:13). The global South has lower lifespans and consequently a lower population of senior citizens, while developed nations have larger populations of elders. In 2010, the year of the most recent United States Census, thirteen percent of the US population (approximately 40.3 million people) were aged sixty-five or above, with one point one percent of the total citizenry belonging to the oldest old, defined as those eighty-five or more years of age (Bookman and Kimbrel 2011:118). These numbers are only expected to increase over the next couple of decades. Experts estimate that in 2030, "approximately 80 million Americans, or 20 percent of the population, [will be] sixty-five or older, and 2.3 percent of the population will be eighty-five and older" (Bookman and Kimbrel 2011:118). In other words, the net population of elders and the population of elders relative to younger cohorts will both increase dramatically within the next thirteen years.

Additionally, the demographic makeup of the elderly is expected to change. Currently, it is something of a cliché in gerontology that most older people, particularly in long-term care facilities, are female (NHDC 2015; Steckenrider 2000). Whites are also dramatically overrepresented as residents in caretaking institutions (Bookman and Kimbrel 2011; NHDC 2015). Experts anticipate that in the next few decades, proportionally more men will survive to older ages, and the age group's racial and ethnic diversity is also expected to increase as medicine continues to improve and become more available (Bookman and Kimbrel 2011:118). In the same way, as sex change surgeries and acceptance of non-binary individuals become more mainstream, more transgender and nonbinary individuals will age into elders. Demographic changes throughout the United States will be reflected in the changing demographics of the elderly population.

This demographic age shift is the result of several historical processes that caused national (and, for that matter, worldwide) life expectancy to greatly increase during the last century. While a great part of this shift can be attributed to lower infant mortality and fewer deaths in childbirth, much of the change is a result of better adult nutrition and improved healthcare for all age groups. Essentially, the deaths from acute and infectious diseases dropped dramatically as antibiotics and vaccinations became more accessible, opening the door for more prolonged deaths from cancers, dementia, and other chronic ailments (Buhler-Wilkerson 2007). Vaccinations and improved hygiene protected people from catching many infectious diseases in the first place. One deadly ailment, polio, was eliminated entirely. Improved communication allowed people to contact emergency services when they were experiencing a medical emergency like a heart attack or stroke, and improved infrastructure allowed these same people to quickly receive professional medical attention. Better hygiene, new technologies, and more widespread access to medications greatly decreased the mortality and morbidity of acute ailments like heart attacks, falls, and pneumonia (Buhler-Wilkerson 2007).

Since acute and infectious diseases have become so much less common and less likely to kill their victims, chronic ailments are affecting greater percentages of the population for longer periods of time. These diseases are devastating both physically and financially. Cancer, one of the great terrors of the ageing American and one of the most common causes of death in the nation, serves as a stark illustration of this double tendency. The treatment and control of cancer has swollen into a multibillion dollar industry; the National Cancer Institute estimates that annual costs of cancer are around $125 billion, while the National Institute of Health suggests that Americans spent $263.8 billion on cancer in a single year (Jain 2013:8). Simply put, cancer treatments like radiation, chemotherapy, and designer drugs are expensive, and millions of people currently require them for long periods of time. When people were more likely to die quickly from heart attacks and infectious diseases, they did not need to spend as much to keep themselves alive. Some people manage to cut their cancer costs by entering studies for experimental drugs and/or by turning to their insurance companies, and Medicare Part D helps cover the prices of certain prescription drugs, but these measures only mitigate expenditures. "Collection agencies call 46 percent of cancer patients in the United States…. Experts often attribute over 60 percent of personal bankruptcies in the United States to the catastrophic financial burden of illness" (Jain 2013:11). Clearly, a diagnosis of cancer can easily warp into monetary devastation, especially for elderly adults relying on their savings, pensions, and insurance to get by.

Afflictions like cancer, the various forms of dementia, and the generalized weakness associated with ageing tend to occur later in life than many acute afflictions (though of course diseases of both types are strongly associated with senescence). A person who would have perished from a myocardial infarction in 1905 would be more likely to survive their heart attack in 2005, only to be slowly felled by Alzheimer's disease a decade and a half later. While heart attacks kill quickly, dementia progresses slowly, hence their respective classifications as acute and chronic diseases. By definition, chronic diseases require more care and more intensive care than acute dysfunctions. Consequently, as mortality from acute diseases fell and the mortality and morbidity from chronic ailments rose, older adults began to require more long-term care. This necessity spurred the creation and refinement of the massive American long-term care (LTC) industry, which currently provides custodial and recovery care for millions of debilitated Americans and will only become more important as the national elderly population continues to grow (Dodson and Zincavage 2007).

Historical Modes of Elder Care

In most times and places, care for the elderly was considered a strictly familial obligation that was not prompted by chronological age but by frailty (Savishinksy 2000). That is, elders could generally rely on their near kin—spouses, adult children, siblings, or even grandchildren—to personally attend to them according to their physical needs. These family members were expected to aid their ailing relatives, provide a place to live, and administer medical care according to their culture's etiology and their own capabilities. Often, the sick individual was expected to reciprocate to the best of his or her ability, for example by watching over children, mending garments, or performing another form of low-intensity but necessary labor. Historically and cross-culturally, frailty was generally a family concern (Savishinsky 2000).

However, not all frail or ailing older adults had families that were willing or able to take care of them. Logically speaking, there are several reasons that a person might not have kin to care for them. Infertility obviously exists in all cultural groups, and illnesses, war, disasters, and accidents could claim all a person's offspring before they fell ill and required their children's aid. Alternately, a person's kin could survive but be cut off from her through migration, exile, kidnapping (for example into slavery), excommunication, or other reasons. At still other times, relatives could prove financially, physically, or emotionally incapable of tending to a sick senior's needs. For example, a disabled person would not be fully capable of assisting with certain more physically intensive necessary activities. While the family usually could and did shield many if not most elders from the worst assaults of old age, especially since death in those days usually came relatively quickly after the onset of ill health, some people inevitably slipped through the cracks. These individuals required another source of care if they wanted to survive (Ogden and Adams 2009).

The public poorhouse is perhaps the most important predecessor of the modern American long-term care facility. Poorhouses were projects of the local government rather than church organizations, which also sometimes cared for the elderly, and they evolved as the government of the United States changed (Ogden and Adams 2009). American poorhouses date back to colonial times. In the seventeenth century, the American colonies formed a haphazard, rather disorganized system of relief based on the English Poor Law of 1601 (Ogden and Adams 2009:141). The American Poor Law System, like the legal corpus of Elizabethan England from which it was derived, "was predicated on the assumption that older people (as well as other needy groups) were responsible for their own condition" (Olson 1982:39). This responsibility (or irresponsibility) rendered the poor unworthy of the aid that kept them fed, clothed, and sheltered. As a result, the colonial almshouse system had a strong disciplinary, almost penal, quality. "Conditions… tended to be miserable; the elderly were not infrequently housed with the insane, alcoholics, and petty criminals. Dread and fear of the consequences of dependency" were extremely widespread and "served to discipline the working class" (Olson 1982:39). The idea was that people would not let themselves become needy if they were punished for doing so, but this sort of philosophy could hardly prevent people from ageing.

Despite its massive flaws, this system helped transform the upkeep of the poor and elderly (especially those whose families could not tend to them) from a solely familial responsibility into a community prerogative. This transformation is still not complete, but people today are still much more likely than their ancestors to accept that elder care can and even should be a public initiative. The gradually transformative poorhouse system was funded by a village-level poor tax, and like elders who were tended by their families, beneficiaries were expected to partially repay their cost of living with basic labor (Olson 1982). However, this system (or, more accurately, given the relation of colonial governments to each other, *these systems*) seem to have been perceived as a communal burden more than anything else, and community members often sought ways to escape their responsibilities. The haphazardness of the systems made avoidance easy. The schemes were "outdoor" or "locally idiosyncratic," while "indoor, or institutional, relief was unknown"; therefore, several bureaucratic holes which communities could use to escape their unwanted duties continued to exist (Ogden and Adams 2009:141). Additionally, many local poorhouses had the right to refuse care to those they deemed unworthy. Strangers and outsiders could be "'warned out,' left to wander from town to town or 'passed on,' in which the constable of one town escorted them to another" (Ogden and Adams 2009:141-142). If the next town felt so inclined, it could do the same thing. Citizens who were considered unworthy, such as drunks, "were deemed not to have a right to care, and, in some communities [were] auctioned off to the lowest bidder" (Ogden and Adams 2009:142). Since these unfortunates were seen as the source of their own problems, officials could justify neglecting them.

Colonial care schemes did not become much more comprehensive or integrated after the American Revolution. Although Thomas Paine suggested a pension system that would have potentially allowed adults over age fifty to afford their own upkeep, including medical costs, or at least to avoid poorhouses, in 1796, the nascent national government did not take his advice (Ogden and Adams 2009:142). Instead, the state governments were given responsibility for the care of the elderly. Unfortunately, due in part to the low population of elderly individuals and in part to the low socioeconomic status of senior citizens who most desperately needed non-familial help, this responsibility was often granted a low level of priority. In such a young nation, one recovering from a war and attempting to hammer out its government, the needs of a small population of elders simply were not priority. Although systems did develop, most of which were based off their colonial predecessors, they were full of loopholes, the most significant of which was "that they made county adoption optional and, as a result, the system was nonexistent in many states" (Ogden and Adams 2009:143). Elder care programs administered at the state level were simply inadequate.

As care for the elderly began to be perceived as a social rather than a strictly familial problem, another profound cultural change was also affecting cultural perceptions of the elderly. Retirement in the modern sense began in the late 1800s when Western governments began to introduce social security (not to be confused with Social Security, which is a later construction dating from the Great Depression) and other forms of pension intended specifically for retirees, enabling older adults to earn income without remaining in the workforce (Savishinsky 2000). The idea was that older workers were less productive and should be phased out to make way for younger, more productive adults, and that elders deserved financial security. One of the earliest pension programs was implemented in Germany in 1889, where people were eligible to receive retirement compensation after reaching the age of seventy (Savishinsky 2000:11). Then, of course, lower life expectancies meant that relatively few people survived to retirement age, meaning that pensions were much more economically viable than they are today. When America implemented its Social Security Program in 1935, life expectancy had increased relative to 1889 Germany, but there was still less expectation that a worker would reach the retirement age of 65 than there is today (Savishinsky 2000:11).

Mass retirement and old-age pensions are a relatively recent phenomenon, but in the last century, it has become “a norm, an expectation, and a right” (Savishinsky 2000:12). Americans seem to view retirement as a natural, logical conclusion of their working lives. This decontextualizes the phenomenon and reinforces a naturalized association between ageing, non-productivity, and frailty. That is not to say that the concept of retirement is new or strictly Western; most if not all societies acknowledge that sometimes, people are simply physically incapable of hard labor (Savishinsky 2000:6-9). However, in most cases, retirement was based on physical condition rather than age. Generally speaking, disabled and debilitated people were the ones who retired from subsistence activities; a healthy octogenarian was expected to contribute more than a disabled thirty-year-old. Even in these cases, it was common for the retired individual to find another, less strenuous method of contributing to the family and/or to society, for example by raising grandchildren. The modern West simply normalized what had previously been a more exceptional status. Modern Western retirement is more institutionalized, commonplace, and expected than retirement in most other areas and times. Retirement is taken for granted (Savishinsky 2000).

In America, police and fire stations began implementing public retirement systems during the 1850s in an attempt to promote efficiency and attract more competent employees (Olson 1982:41). Policemen, firemen, veterans, and teachers were the only laborers eligible for employer-provided (which was essentially the same as government-provided) pensions at the turn of the twentieth century (Olson 1982:41). These were some of the only public protections available for elderly individuals; at the time, the family was expected to care for members who became too debilitated to work. However, by 1914, only "two-thirds of the states had enacted measures that made children legally responsible for incapacitated and indigent relatives; between World War 1 (*sic*) and 1929, legislation in [only] eleven states stipulated that failure to provide for destitute parents was a criminal offense" (Olson 1982:39). Oddly, these laws appear to have lost force over the last few decades as state and employer pensions, long-term care facilities, and generational mobility became more common.

At the onset of the Great Depression, then, America had developed a mismatched family-and-society approach to elder care which, in some ways, persists in a modified form to the present day. While the family was still expected to tend to its older, frailer members, the government and society in general acknowledged that kin groups were, for a variety of reasons, not always able to carry out these duties. People understood that the illnesses and frailties caused by old age required some form of support, but while families often could and would provide sufficient aid in the form of lodging, board, and care, federal and state support appear to have been primarily financial. “At the end of 1934, just prior to passage of the Social Security Act, an estimated 236,205 pensioners were covered by state programs; the average monthly pension ranged from 69¢ in North Dakota to $26.08 in Massachusetts” (Ogden and Adams 2009:143). However, these pensions and the equally uneven poorhouse lodging regulations appear to have been virtually the only elder care programs in the nation. There was no true, integrated system of federal-level elder care.

Federal Care Programs

The federal government finally began implementing national-level aid programs for elderly Americans in 1935, when the Social Security Act was passed. This was not the first time that a national old-age pension had been suggested. By 1929, no fewer than forty-eight separate bills had been proposed to Congress, but not one of these acts had been reported out of committee (Ogden and Adams 2009:143). The Social Security Act was simply the first *successful* national pension plan, though fortunately not the last, providing income to workers over age 65 who had participated in the workforce for at least ten years (Zelizer 2015). While the new program was mostly spurred by economic necessity and workers’ desire for a financial safety net during the frightening years of the Great Depression, it represented the steadily growing acknowledgement that old age was indeed a social as well as a familial problem. Other governmental programs would eventually build on that same premise.

While Medicare and Medicaid can trace their indirect lineage back to poorhouses, their direct line of descent begins with the Social Security Act of 1935 (Zelizer 2015). Social Security was designed to provide a pension to elderly adults, a subset of the so-called worthy poor, in an era of great financial hardship, not to provide health insurance as Medicare and Medicaid do. At the time, government-provided health insurance was simply too radical. "President Franklin Roosevelt, who proved to be extremely bold in pursuing a number of social and economic policies, chose to leave health insurance for another time when he pushed for the creation of Social Security, fearing that dealing with the issue of medical care would stifle support for his other programs, given the positions of the American Medical Association" (Zelizer 2015:6). Due to the relatively low population of senior citizens, the Social Security Act was nowhere near as important at the time of its origin as it is today. Roosevelt likely had little reason to suspect that his program, aimed at alleviating the poverty of a small percentage of the country's population, would eventually expand into one of the largest and most important programs carried out by the U.S. government, nor did he realize that it would eventually spawn two other enormous government programs, Medicare and Medicaid.

The road from the Social Security Act of 1935 to the Social Security Amendments of 1965 was not a smooth one (Zelizer 2015). While some people were coming to believe that the government should assist with elder care, even to the point of providing a degree of health insurance, most of the population seemed to think that it should remain within the family or, barring that, part of private charitable organizations. These attitudes still persist among many portions of the country, not least among senior citizens themselves (Levine et al 2006; Sanders and Seelbach 1981). Other entities had additional reasons to distrust, dislike, and fight against government-provided healthcare. When President Truman attempted to create a government healthcare system in 1949, the "AMA's counteroffensive dwarfed the typical response of a professional organization: its Washington-based lobbying campaign cost more than any similar effort by other organizations until that point in history" (Zelizer 2015:6). Fearing that Truman's program would cost them money and prestige, the American Medical Association (whose influence had helped preemptively block Roosevelt from adding health insurance to the original Social Security program) began a smear campaign against so-called socialized medicine that still resonates today. Truman's program and its supporters found themselves facing a campaign of widespread propaganda spread by trusted family doctors. Physicians warned their patients that Truman's plan would destroy the existent American healthcare system and warned that it would open the door to Communism. Democratic Senator Claude Pepper of Florida, who supported the plan, lamented that "'[t]he doctors in Florida agreed that the first three minutes of every consultation with every patient… would be devoted to attacking socialized medicine and [me]. They were so bitter that their wives took the streets and highways'" (Zelizer 2015:7). No wonder, then, that the bill was soon defeated, as was another similar attempt in 1957 (Zelizer 2015).

By the time Kennedy took over the White House in 1961, it was clear that any attempt to create a comprehensive national health plan would have to overcome massive opposition. As a result, his "administration mounted an uncharacteristically intense public relations campaign to promote the legislation" (Zelizer 2015:9). Proponents carefully tied the potential program, dubbed "Medicare" by the media, to the Social Security Act, which unlike other welfare programs enjoyed quite a bit of prestige and support (Zelizer 2015:9). They also made concessions to placate opponents, for instance assuring their old rival the AMA that "hospitals and doctors, rather than the federal government, [would] determine what fees they would charge for various services" (Zelizer 2015:17). (One needs only to look at today’s exorbitant healthcare costs to see how this concession affected ordinary medical consumers.) This intense public relations campaign, combined with the relatively liberal (though not as liberal as the national myth portrays it as) political climate and the defeat of certain powerful, vocal opponents, allowed Kennedy and his post-assassination successor to create and implement the Social Security Amendments which created Medicare and Medicaid.

Although Medicare and Medicaid were created as offshoots of the Social Security program, they are very different from their source. Social Security is a pension that can be used for anything, while the other two programs are health insurance schemes that shape “the nature of services and clinical relationships that profoundly affect its beneficiaries' well-being and life course" (Schlesinger 2015:120). Medicare Part A provides hospitalization insurance to people 65 or older who have made “prior contributions to the program via the payroll tax system that also covers Social Security" (Gray et al 2006:211). It also covers some home care “largely as an extension of… hospital coverage and as a means to facilitate shorter inpatient stays” (Schlesinger 2015:136). Part B, a more general medical insurance, must be purchased by any citizen. Part C is Medicaid, which provides insurance to low-income people and is jointly run by the federal government and state governments. Part D helps cover the overinflated costs of prescription drugs. This outline is, of course, a great simplification of a massive government program—in 2013, the average beneficiary could select from among no fewer than 18 Part C and 31 Part D options (Schlesinger 2015:131).

Complicated and confusing as they are, the Social Security Amendments have proven valuable to elders for several reasons. First and most obviously, they provide the portion of the population most in need of medical insurance with a source of financial aid for their health problems. The programs are far from complete or perfect, of course, and they far too frequently only delay financial problems, but they still provide desperately needed assistance to a group that sorely needed it. Today, the programs are so deeply entrenched that they “generally [are] taken for granted as the source of basic health coverage for America's elderly" (Gray et al 2006:211). Once controversial, Medicare and Medicaid have become as much a part of the law of the land as their parent program, Social Security.

Second and more subtly, Medicare and Medicaid helped organize senior citizens as a political force, granting them a greater amount of control over their own destinies. Older Americans had very little political power before the 1960s, when the Amendments (and the Older Americans Act, which provided a degree of protection in the workplace) gave them a greater degree of basic security (Schlesinger 2015). While few people would categorize older Americans as a true political powerhouse, or even as a completely united political force, modern politicians are much more conscious of the importance of winning their vote than their predecessors were prior to 1965. Having a better guarantee of the basic necessities allowed senior citizens to gain more political and personal agency. This political power also helped inspire new ways to view the old, as "[p]articipating in a program can also alter beneficiaries' social roles and identities" (Schlesinger 2015:119). The new identities inspired—the rising political power of the 60s and 70s, the ‘greedy geezers’ of the 80s, and the medical consumers from the 1990s to the present—are more accurately viewed “as a progressive layering-on of identities, rather than a process of sequential identity displacement" and continue to affect modern cultural views of the elderly (Schlesinger 2015:133). People today are more likely to see elders as active consumers rather than passive recipients of care—but only as long as they remain competent, knowledgeable, and savvy, difficult goals in the complicated world of medicine and healthcare, and even then they run the risk of being thought otherwise due to deeply entrenched ageist beliefs (Palmore 2005).

One negative side effect of the success of Medicare and Medicaid is that many people tend to overestimate their power. While the programs are certainly helpful to senior citizens in need, they do not by any means provide complete coverage for the costs of old age. Medicare defrays the costs of hospitalization and of certain prescription drugs but leaves things such as preventative care, non-hospital consultations, and almost all home care to consumers. As mentioned above, Medicare will help subsidize certain home care acts that were preceded by hospitalization in order to open up hospital beds—wound care, bandage changing, and other strictly medical services. It will not, however, subsidize other forms of care, like helping the gravely wounded and presumably exhausted elder feed herself or bathe (Schlesinger 2015). In a similar vein, Medicare only subsidizes post-hospitalization stays in nursing homes that are intended to help people recover from hospitalizations; it does not support full-time custodial residents of long-term care facilities, nor does it pay for care in all such facilities. Medicare only subsidizes stays in institutions officially registered as skilled nursing facilities (Giacalone 2001:57). These conditions are symptomatic of wider American healthcare policies, which focus on defeating the illness rather than supporting the person and are “centered around the primacy of the physician and the hospital as the dominant provider of health services” (Giacalone 2001:21).

Medicaid is not much better in providing coverage for institutionalization. Unlike Medicare, it is available only to elders (and certain disabled persons below age 65) who lack a certain quantity of monetary assets. In other words, it is only available to the old and poor, people who either never acquired much wealth or already spent it. This means that many older people approach bankruptcy (something all too easy to do) before they are eligible for Medicaid assistance. While Medicaid will pay for residence in certain facilities, it will not do so until the resident’s resources are all but exhausted, and it sometimes requires the resident to move to a cheaper and/or registered institution in order to receive enough money to survive. While Medicaid and Medicare are both important and useful programs, there is a great deal of room for improvement in both.

The most recent well-known federal healthcare bill, the Patient Protection and Affordable Care Act (ACA), was not directed specifically towards elders. This law focused more on lowering medical costs across the board rather than for any specific age cohort. Its most relevant contributions to elder care are probably its expansion of Medicaid, which it made available to more people, and greater availability of health insurance in general (Shin and Regenstein 2016). However, the ACA has not attained the status of Social Security, Medicare, and Medicaid, and it is likely that the program will change dramatically during Trump’s presidency if it is not destroyed outright (Shin and Regenstein 2016).

Types of Care Provider

In the latter half of the twentieth century, several demographic trends reached a tipping point that caused the emergence of the modern elder care industry. Many of these trends are clichés of studies about globalization and modernization, the forces so frequently invoked to explain everything about the modern world. As already discussed, American lifespans were continuing to grow, with more people attaining old age and a greater percentage of the population entering the ranks of the oldest old. Urbanization increased dramatically as improved farming techniques and new trade patterns placed less burdens on the American farmer. Other forms of migration also became more common as urbanites moved from city to city with greater frequency. Women entered the workforce in greater numbers than ever before. In short, America transitioned into a new, more modern nation.

The cumulative effect of these changes was a greatly increased demand for elder care. "When life expectancy was lower than it is today, the burden of caring for the aged was smaller," so longer lifespans created a market for housing and aid (Stewart 2006:74). Increased migration shook up the structure of the family as offspring moved far away from their ageing parents and were subsequently unable to tend their day-to-day needs. As women, who had traditionally been expected to tend their elderly kin (see chapter 2), entered the workforce, they had less time and energy to devote to caring for their elderly or immature family members. Essentially, there were more senior citizens in need of care than ever before, but there were fewer informal sources of care than there had been in previous centuries. In this case, necessity proved to be the mother of invention, and residences designed specifically to house older, frailer adults became increasingly common, especially in urban and semi-urban areas with a high enough population to more easily support them.

Several types of elder care emerged from this transition. In addition to traditional, family- and poorhouse-based methods, Americans have access to nursing homes, assisted living facilities, adult day cares, adult foster homes, and more. Adult foster homes are a form of long-term care in which elders move into the home of a non-related caretaker. Adult day cares look after participants during the daylight hours, after which time the seniors return to their own homes or the homes of their families or caretakers. They are often marketed as social opportunities rather than as medical or residential institutions. Alternately, elders can contract professionals to come into their homes and provide certain services such as housekeeping and meal provision (see chapter 3 for more detail).

Nursing homes and assisted living facilities (ALFs), two varieties of long-term care facility (LTC), are much more widely known than most varieties of home-based elder care. The two types of facility have an odd sort of relationship in the public mind. On the one hand, they are superficially quite similar to each other, as both varieties are long-term care institutions that staff medical professionals. On the other hand, they are often defined in contrast to each other, with nursing homes being perceived as less homelike, more medicalized, and generally less pleasant than ALFs (Imamoglu and Imamoglu 2005). Formal definitions of nursing homes tend to vary across state lines but generally refer to long-term care facilities staffed by several types of skilled nurse that do not identify as ALFs. Assisted living facilities are even more unclearly bounded (Imamoglu and Imamoglu 2005:236). The term itself encompasses at least twenty-six types of program “such as personal care and residential care” partially due to marketing and partially due to the fact that several types of program are grouped together under that name (Castle and Sonon 2007:729). The wide variety of institutions that can be defined as ALFs is one reason that they are best described in contrast to nursing home. Therefore, the assisted living facility should be defined as “a residential setting not licensed as a nursing home (NH) where personal care and routine nursing services are delivered and arranged on a scheduled or unscheduled basis" (Gaulger and Kane 2001:335).

In recent years, the line between nursing homes and ALFs has blurred further due to an influx of patients who need higher levels of care entering ALFs (Han et al 2017). This makes understanding the differences between the two organizational types more important than ever. ALFs had traditionally offered care to people less needy than nursing home patients, but in recent years, they have begun to house a wider variety of patients, with some populations being comparable to nursing home residents (Han et al 2017:27). They are the fastest-growing source of long-term care in the nation (Han et al 2017). (By contrast, the number of available nursing home beds has actually slightly decreased in the last decade or so [NHDC 2015].) It would seem that the greatest differences between the types of facility are twofold. At the regulatory level, nursing homes must be in compliance with the federal stipulations outlined in 42 CFR Part 483, Subpart B, and pass state-provided surveys, while ALFs face less stringent regulation (CMS.gov 2017 n.p.). The second great difference is one of reputation.

Generally speaking, nursing homes are viewed and portrayed much more negatively than assisted living facilities. A study that analyzed the cultural depiction of nursing homes by reading nine years’ worth of articles in four widely read newspapers found that nursing homes were only portrayed positively in 9.6% of cases (Miller et al

2012:737). They discovered that “the tone of media coverage has been primarily negative, rarely positive, and otherwise neutral” (Miller et al 2012:745). Stories about negligence, unpreparedness for natural disasters (Hurricanes Katrina and Rita took place during the period of coverage), and high costs abounded, and these negative articles were more likely to headline than the few positive articles (Miller et al 2012:742). They estimated that at least 60% of Americans were exposed to at least one negative story per year and that the tone of the articles had only worsened over time (Miller et al 2012:726-7). It is no wonder, then, that nursing homes receive lower ratings than all other healthcare providers in the nation (Miller et al 2012:726). Consequently, senior citizens and their families both prefer ALFs (Castle and Sonon 2007).

Assisted living facilities came about as a response to the negative portrayal of nursing homes. The ALF industry grew rapidly after its inception. A decade ago, there were approximately 20,000 ALFs housing more than one million elders (Castle and Sonon 2007:729). As the general population and the population of senior citizens increased over the last ten years, that number has increased. ALFs market themselves as having the good traits of nursing homes without the bad, emphasizing their hominess as opposed to nursing homes’ more highly medicalized, controlling, and institutional atmospheres. Generally speaking, they have historically catered to people in better physical and financial condition than nursing homes—that is, to residents who don’t need as much intensive medical care and can afford their prices. This allowed them to escape some of the stigma attached to nursing homes. In some ways, ALFs can be treated as high-quality, low-maintenance nursing homes. In fact, there has been a great deal of concern in recent years that ALFs will deteriorate in quality until they are no better than nursing homes, showcasing the association between high care quality and ALFs (Imamoglu and Imamoglu 2006:236). This is not to say that all ALFs are superior in cleanliness, comfort, and care (some of the most commonly used ranking criteria) to all nursing homes. Quality is a spectrum, and different people have different priorities when it comes to evaluating quality. However, generally speaking, residents and family members alike “were found to be more favorable toward assisted living facilities than nursing homes" (Imamoglu and Imamoglu 2006:235).

In America, all these non-familial forms of elder care are treated as commodities, services which consumers (either the elder or a close relative) can purchase through the free market. This is likely why so many nursing homes—10,913 out of 15,640—are for-profit, compared to 3,756 non-profit facilities and 971 institutions that are run by the government, and why the number of for-profit homes has been slowly increasing in recent years (NHDC 2015:12). While state governments fund some public nursing homes and pension programs, or at least help defray the costs, there also exist private pay LTC facilities that depend on consumers paying for their own care out of pocket. ALFs and other forms of non-familial elder care are not directly supported by government aid. In addition, while government-sponsored pensions can defray the astronomical prices demanded by nursing homes—$248 per day for private rooms and $222 per day for semi-private rooms in 2012—these reimbursements are rarely enough to pay for everything (Mullin 2013 n.p.). Ageing is still not completely accepted as a social rather than a personal problem, and even if it were, American neoliberal ideals would make it extremely difficult to guarantee free quality care for every aged person. As a result, even couples who entered retirement with a healthy nest egg might lose everything before death, their savings worn away by exorbitant LTC facility costs and overpriced hospital bills until they (or, more likely, she, her husband having predeceased her) can no longer afford to pay for lodging in the facility and are forced to move in with relatives or into a lower-quality, lower-prestige, state-run public nursing home. The demands of free market lodging and healthcare can easily devour entire inheritances.

Summary

The history of old age and elder care in America is rich and varied, and it continues to affect today's senior citizens. This history explains why institutionalization has become so relatively commonplace, why institutionalized elders and their relationships are an important area of study, and why these will remain relevant topics of study for decades to come. As demographics, state policies, and free market opportunities changed, so too did the circumstances of elderly adults. Senior citizens, ailing or not, and their families have more care options available than ever before. In the same way, they also have a great deal more financial, legal, medical, and political protection than elders of generations past. These historically specific options and protections profoundly shape both the relationships between ageing parents and their children and the culture of elder care.

Chapter 2: Dependency and Demography

The Onset of Dependency

To understand how relationships between elders and their adult children change upon institutionalization, one must first have a baseline from which to measure those changes. All comparisons require two or more relatively stable points to contrast. However, family relationships are *never* truly static, meaning that there is no obvious starting point from which to measure changes. Families change as children are born and grow; through divorces, marriages, and moves; as members quarrel and reconcile; as secrets are formed and revealed; and even from legal or career factors altering power dynamics within the home. Affection and reciprocity lend some stability to kin relationships, as do long-term living arrangements, but relationships are not quite as unchanging as they are often portrayed. This makes any comparative starting point for relationships arbitrary by necessity. For the sake of convenience and simplicity, this thesis treats the beginning of dependency as its baseline and starting point of comparison. This chapter explores how relationships begin to alter at the onset of dependency, how demographic variables affect those changes, and how some adult children take on the caregiver role in response to their parent's new frailty.

Dependency is an ambiguous, hard-to-pin-down term. To some extent, all humans are dependent on others. This is especially true in complex societies like the modern United States where one person produces food, another clothing, and others still other goods and services. No one in this culture is entirely self-sufficient. The Nursing Home Data Compendium considered residents "dependent in a given activity only if s/he required extensive assistance or required full staff performance of the activity," but this definition refers to the amount of aid required for institutional residents rather than senior citizens who remain in the community and is therefore an inadequate starting point for this thesis (NHDC 2015:5). In the context of this thesis, however, dependency refers to that point in an older adult's life when he or she can no longer carry out all the instrumental activities of daily living (IADLs) and/or activities of daily living (ADLs) that they could once perform and requires the assistance of others to maintain his or her quality of life.

Activities of daily living are those fundamental actions which people need to carry out every day, necessities such as getting out of bed, walking, and going to the bathroom (NHDC 2015). They are the essentials of survival, things most people master as toddlers or very young children. Instrumental activities of daily living are slightly more complicated but still indispensable, actions learned in later childhood through the onset of independence in early adulthood. IADLs include enterprises like meal preparation, cleaning, and financial management. Not all adults know how to carry out every IADL—husbands might depend on their wives for meals, and people unskilled with math could happily let someone more competent handle their finances. However, since these individuals never learned to carry out these acts, they are dependent in a different way than seniors. For older adults, dependence begins when they cannot perform an IADL or ADL of which they had previously been capable.

The onset of dependency can trigger, reinforce, and justify ageist tendencies in adult children. The term ageism was coined by Robert Butler, first director of the National Institute on Aging, in 1969, and refers to prejudice against people due to their age (Wilkinson and Ferraro 2002:339). Ageism is deeply entrenched in American culture, which “is so pervaded with negative stereotypes and images that most people are unaware of the many ways in which it supports ageism" (Palmore 2005:94). Since the family unit is a product of this ageist society, families and individuals are forced to confront their ageist tendencies when they are faced with incontrovertible proof—for instance, the onset of dependency, a state heavily associated with senescence—that someone within the kinship network is becoming old.

> "Aggregate results of studies conducted in Western societies indicate that younger generations, and often older people themselves, view the older generation as unattractive, dependent, sexless, and of reduced ability and worth…. Within the family, some of the most damaging stereotypes are beliefs that older adults are physical and financial burdens and that they are incapable of making autonomous decisions and handling their own affairs." (Gaulger et al 2005:147)

While these ageist beliefs are firmly entrenched in American cultural narratives, many people fail to associate them with their parents until dependency begins. Even then, the association often develops gradually as the parents become less and less capable of the tasks associated with independent adulthood, which makes them seem increasingly less capable and competent in general. Exceptions to this rule occur, of course. A relative diagnosed with a rapidly progressing form of dementia will trigger more ageist associations, and trigger them more quickly, than someone who just needs occasional help with her yardwork. Additionally, even people who remain mentally competent and physically independent may be thought less capable than they actually are simply due to their advanced age; this is one reason that companies try not to hire older adults and pressure their older employees to retire (Palmore 2005). Even the brightest and healthiest of senior citizens can be tainted by the powerful negatives associated with old age. However, it is frequently the onset of dependency rather than simple chronological age frequently that serves as a sort of wake-up call to adult children. It serves as tangible proof that the parent is becoming older and therefore less competent, a burden in the making who will likely soon become incapable of making informed decisions about what's best for her. Adult children might consequently attempt to limit their parents' autonomy (Pyke 1999). From this point onwards, unarticulated ageist ideas will subtly contaminate parent-child interactions.

Age and Gender

Different groups respond to the onset of dependency in different ways. People in different parts of the country experience dependency and old age in general in distinct ways, as do different genders and the various racial/ethnic groups and socioeconomic classes. The ways in which people experience old age are dependent on various demographic factors as well as individual preferences, particular family dynamics, and wider cultural patterns. The literature indicates that the most significant demographic influence on how a person experiences the latter part of life is his or her gender (Steckenrider 2000).

Elderly persons are much more likely to be dependent on their daughters, daughters-in-law, and granddaughters than on their male relatives (Abel 1986; Bookman and Kimbrel 2011; Dellman-Jenkins et al 2000; Steckenrider 2000). This tendency has deep historical roots and thus remains firmly entrenched in the American imagination. Simply put, women are expected to be caregivers, giving greatly of themselves in order to serve their dependent kin. This pervasive belief, already prevalent, only grew in strength after the Industrial Revolution reinforced the public/private dichotomy and the gendered division of labor. Like childrearing, tending to elderly relatives became an invisible, taken-for-granted task that fell far outside the masculine purview of ‘real’ labor (Steckenrider 2000).

Due in large part to this powerful association between women and caregiving, modern American women continue to feel much more obligated to tend to their ageing parents than their brothers and husbands. “Study after study documents that women surpass men in both quantity and quality of care provided” to their elderly relatives (Steckenrider 2000:459). Not only do daughters spend more net hours caring for their parents (in the 1980s, an “English study found that women spent nineteen minutes in the most arduous care of elderly relatives for every minute their husbands spent"), they tend to perform more intimate and intensive tasks (Abel 1986:480). Men are more likely to assist with masculine-coded IADLs such as balancing the checkbook and performing yard work (though not meal preparation or cleaning, which are coded as female) while women carry out female-coded IADLs and help with ADLs, which tend to be more physically and emotionally intensive (Steckenrider 2000). For example, helping a parent out of the bathtub involves maneuvering well over one hundred pounds (at least) of wet, naked body in an embarrassing and stressful situation in which dropping the parent could result in broken bones and hospitalization. While this task might not be as mentally strenuous as balancing the checkbook, one of the tasks men are more likely to help with, it is more physically intensive and a great deal more embarrassing.

Men and women who care for their elderly relatives perceive their actions differently as well as being perceived differently, and society tends to treat them differently (Steckenrider 2000). Since women are expected to offer aid when their kin require it, their labor is frequently taken for granted. They and those around them tend to underestimate the physical and emotional difficulty of attending to an ageing relative's needs. Therefore, women often feel overwhelmed and inadequate when they are unable to live up to their unrealistic expectations (Steckenrider 2000). Men, however, are much less likely to take their own caregiving abilities for granted, so they are often less inclined to underestimate the challenges of caretaking. They are more likely to seek and receive support, and since they are not expected to be caregivers, they are also more likely to receive encouragement and praise when they take up caregiving tasks (Steckenrider 2000). Women's unpaid work with the elderly is taken for granted, but men's labor in the exact same situation is not. Since male work is not taken for granted, it is met with more gratitude and support (Steckenrider 2000).

Due to the gendered double standard of quality and quantity of tasks performed, women are more likely to suffer from their labor. They experience more emotional stress and less reprieve than their male counterparts. They have less time for other activities, including childrearing, if they have children at home (made even worse by the fact that women are also expected to dedicate proportionally more time to this task); relaxation; household chores; and even paid work. Women's careers often suffer immensely when they become informal primary caregivers; they "are more likely than men to cut back on work hours or quit their jobs because of their caregiving duties and are thus left with less income, small savings, and reduced pensions" (Bookman and

Kimbrel 2011:124). This is especially concerning because many informal caregivers are nearing their own retirements and/or have college-aged children. More subtly, they may also lose the opportunity for promotions because they cannot travel and miss too many hours (Steckenrider 2000). Caregivers in this situation lose money that they could have been funneling into their own retirement accounts or other vital expenditures: college mortgages, emergency funds, and so on. For married women with employed husbands, it is often economically logical to let their careers fall by the wayside instead of helping fund formal care (Steckenrider 2000). Women are still paid less than men, so it makes more sense to let the wife's career suffer than to let the husband lose his job, though of course neither situation is ideal. While these happily married women can rely on their husbands' savings and benefits, many others—divorcees, the unwed, widows, or women with unemployed spouses—cannot. By tending to their parents, they risk poverty in the present and especially in the future when they themselves are old.

The labor given by daughters and daughters-in-law is not the only reason that informal caregiving is so female-dominated. Wives are much more likely to tend to their husbands than husbands are to tend to their wives. This tendency is partly a result of the association between femaleness and caregiving which makes daughters more likely than sons to care for their elderly relatives. However, there is another reason that wives are so much more likely than husbands to care for their spouses. Women are often younger than the men they marry and have higher expected lifespans, which means that husbands grow frail and die before their wives (Steckenrider 2000). Generally speaking, this allows men to have a higher quality of life than women in their seventies and subsequent years. Since men are more likely to have a live-in caregiver, they are more likely to die at home, without being institutionalized or moving in with their adult children. (Indeed, women made up 65.6% of the nursing home population in 2014) [NHDC 2015:2].) Men have more financial resources because their savings have not been depleted for their spouse's sake. They even tend to spend less time sick and debilitated, five years rather than eight (Hardwig 2009:38). Due to these factors, men are more likely to have a relatively pleasant old age.

Since men tend to have different experiences in old age, elderly fathers entering dependence have different relationships with their adult offspring than do elderly mothers. Simply put, men are less likely to need as much care from their children; they have wives who can tend to their needs, rendering assistance with ADLs and IADLs. This is not to say that older men need no assistance from their offspring; many do, However, the genders experience ageing very differently, and these diverse experiences affect how fathers (as opposed to mothers) relate to their children following the onset of dependency. In the same way, it causes adult children to interact with their mothers and fathers in very different ways, creating very different relationships in the last years of each parent's life. Paternal relationships are less likely to change and tend to change less dramatically than maternal relationships.

Although other demographic factors affect old age and caregiving, none are as influential as gender. Women and men have profoundly different experiences as caregivers and as recipients of care, two portions of the life cycle which can potentially last for decades. Women's longer lifespans and ideas about their natural position as caregivers for the old have created a powerful association between femaleness and senescence. While other demographic factors affect the experiences of ageing and caretaking, there is no equally powerful link between old age and any other demographic factor, be it age, wealth, or region of the country.

Other Demographic Factors

Members of different races also have different experiences with the beginnings of dependency. The phrase 'minorities' covers a wide variety of groups, but most of the available literature contrasts the experiences of whites and non-whites, treating non-Caucasians as a relatively homogeneous Other. Even Bookman and Kimbrel (2011) spend mere sentences explaining how non-whites differ in their strategies of elder care (though in their defense, the goal of their paper was to provide a brief, broad overview of the world of elder care, not to go into depth in any one area). Therefore, here I compare and contrast Caucasian Americans with 'Americans of color' as a monolithic other instead of with specific minority groups, and the families referred to in other portions of this thesis are generally white.

Generally speaking, non-white Americans are more likely to act as caregivers than are their white counterparts. It is widely known that the population of nursing homes and ALFs is disproportionately white; elders of color are more likely to move in with their children following the onset of dependency and less likely to move out of their children's homes before hospitalization and/or death (Bookman and Kimbrel 2011; NHDC 2015). There are several economic and cultural reasons for this trend. Institutionalization is highly expensive and it is very possible that prices will continue to rise as the ageing population increases demand. Minorities tend to inherit and earn less money than whites, two legacies of deeply embedded structural racism. Despite this lack of funds, non-whites are also less likely to enroll in government aid programs such as Medicaid (Liu et al 2007:94). Without the ability to pay for a relative's upkeep in a LTC, minorities are forced to care for their elders by themselves. Lower economic status also prevents Americans of color from hiring in-home help. For them, unpaid labor from within the family, up to and including allowing elders to move into their children's homes, is the only economically viable avenue of elder care. Other options are simply out of reach.

While financial realities provide a major impetus for minority Americans to care for and even house their aged family members, cultural factors also decrease their likelihood of institutionalization. Independence and self-sufficiency are among the quintessential values taught to all Americans, but white children internalize these virtues more deeply and profoundly. These values stem from the dominant American subculture, that is, the culture of the white Protestants who dominated (and arguably continue to dominate) other racial groups. White children are raised as part of this dominant subculture, but minority children are brought up in subcultures that place less value on independence at all costs and more value on aiding the family. Hence minorities are generally more likely to sacrifice more time and energy on behalf of their ageing relatives (Bookman and Kimbrel 2011).

Again, these demographic tendencies do not mean that whites do not value their families or that people of color are better equipped to serve their aged relatives. White Americans are simply socialized in such a way that white caregivers experience "greater depression and view caregiving as more stressful than do caregivers of color" (Bookman and Kimbrel 2011:125). Since whites, especially white men, are socialized to find caregiving more stressful, they are less able to cope with the onset of dependency and are therefore more inclined to seek outside help (Steckenrider 2000). As a result, Caucasians and minorities have different relationships with their ageing parents, with minority families more inclined to cohabitation and direct care while whites are more likely to provide financial and other indirect forms of aid.

Socioeconomic status is the third great demographic predictor of children's responses when their parents become dependent. As discussed above, families with more financial assets have more resources with which to care for their elderly members and therefore have more options than poorer clans. Lower-class senior citizens must rely on informal care from kin, neighbors, or friends; without these sources of aid, they must pay out of pocket for their care until they are completely broke, at which point they are eligible for a government-sponsored stay in a nursing home (Medicare does not fund at-home care or sojourns in ALFs, which are usually not registered as skilled nursing facilities [Schlesinger 2015]). They are therefore much more likely to move in with their kin, even if they have more severe medical conditions like immobility, dementia, or incontinence. They also consequently have less capital to leave behind as an inheritance for their informal caretakers and less capital with which to reimburse them for missing work. Hence ageing members of the lower classes require more care, especially since poverty is linked to ill health, but can grant less financial reward or reimbursement to professional or nonprofessional caretigvers.

Although the academic literature tends to focus on gender, race and socioeconomic status powerfully affect how people experience old age and caretaking. Like women, lower-income families and racial minorities are more likely to directly care for their elders for longer periods of time. In this way, old age and direct care are associated with weaker, lower-status portions of society instead of with rich white men. This subtle affiliation reinforces the relative low status of each group. Ageism is strengthened by the association of old age with femaleness, and racial minorities and low-income families often have more trouble getting ahead due to their higher rates of direct elder care. The relative lack of power of each group strengthens the association between old age and weakness, and each group's association with old age and elder care directly and indirectly impedes its ability to accumulate financial, social, and therefore political resources.

Caregiving Tasks

For obvious reasons, how adult children care for their aged parents varies greatly according to both necessity and capability. Some ageing parents only require help with higher-level IADLs like mowing the lawn, deep cleaning, or lifting heavy objects. These individuals are only minimally dependent, demanding help on a very infrequent basis (Gaulger and Kane 2001). Others lose their driver's licenses as their senses weaken and need transportation to appointments or stores. In places without adequate public transportation systems or where the public transportation does not agree with the traveler's schedule, the senior citizen needs some mode of conveyance, and calling up relatives is much cheaper than hiring a taxi. While providing transportation can be slightly more time-consuming than mowing the lawn and suchlike, depending on how much the elder travels around town, it still necessitates careful scheduling to make certain that both parties are available at the same time. It is likely that this is the point at which caregivers begin to feel a little bit of stress—nothing crippling, not yet, but enough extra work for them to notice (Faison et al 1999).

However, the stress that adult children experience is not necessarily proportionate to the amount of work done. Due to the ageist association of senescence and uselessness, some beginning caretakers overreact, feeling that their parents' requests are disproportionately demanding (Faison et al 1999). Other adult children are canny enough to realize that these early tasks are likely only the beginning. They understand that soon, their formerly independent parents will require assistance with more and more tasks. The dread of future stress can increase the amount of stress experienced in the present. Still other offspring, particularly those in late middle age, see their own futures in their parents' decline. All these reactions can cause people to resent their parents' requests more than they would otherwise (Faison et al 1999). Not everyone has this sort of response, and it is not always triggered by the beginning stages of dependency, but it is common enough to be noted. If beginning caretakers are disproportionately overstressed from the start of their tenures, they are much more likely to eventually come to resent their parents.

As parents become more debilitated, their children frequently need to take over more IADLs and may even need to assist with ADLs. For instance, about 20% of all elderly Americans require help simply to get out of bed in the morning or to bathe, and not all of them are institutionalized (Faison et al 1999:244). The heavier the burden of care becomes, the more stress caregivers experience and the more easily that stress can warp into other negative emotions and side effects. Unsurprisingly, the literature on caregiving is full of depressing stories and statistics about what has been termed "caregiver burden" (Faison et al 1999:243). The average caregiver, "a married forty-six-year-old woman with some college education who provides twenty hours of care each week for her mother," is at risk for a whole host of financial, psychological, and even physical problems (Buhler-Wilkinson 2007:628).

Financial strains for caregivers can be direct or indirect. On a direct level, caregiving often costs money (for instance gas or medical fees) while minimizing or eliminating opportunities to earn income (Steckenrider 2000). Caregivers and those to whom they give care must pay for appointments with general care practitioners, nurses, and specialists; medication and supplements; transportation; modifications to living spaces like raised toilet seats or shower bars; and, if they can afford it, professional caregiving services like adult day care or in-home aid. Additionally, they need to pay the basic costs of living—food, utilities, rent, clothing—without overextending the elders' pensions or wiping out their savings accounts. This balancing act is made more difficult by the fact that nobody knows how long they are going to live. A person entering retirement might die the next day of sudden heart failure or linger for another forty years with a variety of chronic ailments; while family histories can and do provide a rough estimate of one's death date, no one can be certain of what financial challenges they could face during senescence. Lifespans have increased enough between generations to make this measure increasingly inaccurate. For the most part, families must face the fiscal difficulties of old age unaided. Pensions tend to be small, savings accounts are finite, and while old age insurance, which is meant to protect against high healthcare costs in late life, is becoming more popular, it is still rare and mostly used by the upper and upper middle classes, whose finances are already in better condition (Buhler-Wilkinson 2007). Medical insurance does not cover many forms of care, and the government only sponsors nursing home care (not ALFs, not in-home aid, but full-out institutionalization in a certified skilled nursing facility) after the recipient is virtually bankrupt (Schlesinger 2015). The financial strains of dependency can easily destroy entire inheritances within just a few months.

At an indirect level, caregiving prevents opportunities for financial growth and creates new problems that frequently require money to be spent. Intensive caregiving can interfere in the caregiver's career, causing her to miss hours or days of work (Steckenrider 2000). Exhaustion and stress from care-related activities might also make caregivers less productive when they can come in, and they are unable to take additional shifts or work overtime. They also have a much harder time traveling on extended company trips because they need to stay near their parent(s). These factors cause employers to deny them promotions, raises, and benefits (Steckenrider 2000). This tendency is especially concerning because most caregivers are women and/or minorities (see above). While, to the author's knowledge, no study has been conducted to demonstrate a link between elder care and the lower wages received by these groups at the time of this writing, it is entirely possible, even probable, that their caregiving activities comprise one of the many reasons that white men are still paid more and generally treated preferentially in the workplace.

Most of the indirect costs of caregiving can be blamed on the many negative physical and psychological results of intensive care work. One study found that "caregivers have a 9% greater risk of health problems than demographic controls," and virtually all literature on the subject agrees that caregiving is immensely stressful in and of itself as well as causing other problems (Proulx and Snyder 2009:499). Stress is well known to cause problems, and caregivers quickly discover that

> "[c]aregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance. *Caregiving fits the formula for chronic stress so well that it is used as a model for studying the health effects of chronic stress*" (Schulz and Sherwood 2008:23, emphasis added).

This makes caregiving both mentally exhausting and physically deleterious.

Because caregiving is so stressful, the strain can often take on a life of its own. Researchers have distinguished between the primary stressors—"the demands and tasks anchored in daily care"—and secondary stressors, which "do not directly involve the tasks of providing care, but emerge as problems in other social roles, network relations, and feelings about self' (Aneshensel et al 1993:54-55). Primary stressors include the activities of care themselves, the physical dirty work and emotional strain of seeing their childhood pillars of strength brought low. These strains are powerful and draining enough on their own, but when combined with secondary stressors, they become exponentially more difficult to deal with. Secondary stressors related to caregiving are perhaps even more numerous than primary stressors, ranging from the physical ill health associated with chronic stress to the "increased tensions with husbands, children, and siblings" reported by many caregivers (Abel 1986:482-483). These strains are especially dangerous because they can easily linger long after primary factors desist (Schulz and Sherwood 2008).

One of the most powerful and common secondary stressors associated with caregiving is role captivity, which "refers to situations in which people are unwilling incumbents of social roles" (Aneshensel et al 1993:56). As dependency progresses and becomes more severe, previous relationships of parent and child (or husband and wife, or grandparent and grandchild) run the risk of being overshadowed by the unilateral provision of care. The caregiver role overtakes the subject's previous role of adult child, spouse, or grandchild; it can even overpower other relationships than that between caregiver and recipient as the giver's care work takes up more and more of her time, leaving fewer hours for the cultivation of other relationships. As the demands of dependency increase, people can easily begin to feel trapped by their filial obligations, leading to the strains of role captivity.

The stresses and challenges associated with caregiving can easily sour relationships, especially if the patient is suffering from dementia and cannot express appreciation or affection. Although caregivers doubtless realize intellectually that their parents are not at fault for their increasing debility, it is still very difficult to not feel any resentment for the person who has essentially taken over their life, increased their workload, interfered with their career, cut down on their time and energy for other relationships, and potentially drained their finances. Moreover, this quiet resentment can easily work both ways, especially if the parent is unwilling to surrender his or her autonomy. Studies have discovered "a trade-off in [patient] power and care" (Pyke 1999:661). Essentially, older adults want and to some degree expect their children to be willing to provide what they need when they need it, much as they provided care to their offspring when they were infants and young children. Older adults want to remain in control of their lives as much and as long as possible. Their children, however, already have busy lives and want their parents to fit themselves in.

Pyke indicates that the best way for parents to keep the peace with their children is to comply with them and their desires (1999). Compliance makes children more willing to provide extra care in the form of social visits and greater flexibility even as it diminishes parental autonomy. Lack of compliance, however, is perceived as manipulative, stubborn, selfish, or even unloving, traits which “were used to justify reductions in the amount of help given or their refusal to provide more" (Pyke 1999:670). However, compliance prevent grudges so much as bury them; the compliant party is not necessarily glad to have to give up power in order to receive care, help, and affection. Parents know that they *need* these things, just as their adult children know that they need some degree of freedom and compliance in order to fit caretaking into their already-busy schedules. Deference isn’t just a sign of appreciation, it serves practical purposes by minimizing disagreements and discussion. Essentially, at least one side has to give, and while this alleviates the victor’s strain, it can easily make the loser resentful, though losers appear to keep their negative emotions under wraps. "Often a family member… was unaware of the tension and resentment that another family member revealed in the interview and described her or his relationship as more harmonious than was actually the case" (Pyke 1999:664). Occasionally, this undercover anger erupts, creating the potential for massive disruptions within the family unit.

As a result of the stresses, fractures, and other consequences it creates, caregiving is often conceptualized negatively in the literature. It is “not something people are typically socialized to desire, seek, or expect," and both caregivers and those who study them consequently tend to view it as an unpleasant necessity (Aneshensel et al 1993:67). However, caregiving is not a complete morass of misery. One literature review observes that several authors “suggest that future work should increase the emphasis on the positive aspects of caregiving" (Proulx and Snyder 2009:498-999). Many caregivers view their actions not just as duties but as acts of love, affection, and appreciation for the parents who brought them into this world, cared for them in their helpless infancy years, and raised them to adulthood. Some people, especially those whose charges are not demented or overly demanded, even come to feel closer to their parents due to all the time they spend together. Dependency can lead to positive, negative, or—most commonly—positive *and* negative results.

Summary

Familial relationships enter a period of transformation at the onset of one parent’s or both parents’ dependency. The former dynamic of parents aiding children is reversed, and both groups are forced to confront internalized ageist tendencies. This state is experienced differently by various demographic groups, with gender being a particularly important predictor of an individual’s time as a caretaker and senior citizen. While some adult children report increased closeness to their parents after they become dependent, caregiving is usually conceptualized as stressful and unpleasant. Very few people look forward to caring for their ageing parents. This chapter addressed demographic variations in the experience of ageing and the relationship alterations which take place at the onset of dependency, the starting point of comparison for familial relationships before and after institutionalization.

Chapter 3: The Transition from Home to Institution

Alternative Care Options

The actual transition from home to institution is a dynamic period in the parent-child relationship. This is a time of intense negotiation, stress, and, all too often, intergenerational power struggles. This chapter explores the dynamics of the transition, changes which can greatly affect the post-institutionalization relationship. It demonstrates the lengths to which people will go to keep their parents out of nursing homes and lists several reasons that families choose institutionalization. It then explores the actual process of moving and briefly examines how caregivers aid with the move. This chapter sets the stage to explore post-institutionalization intergenerational relationships.

Sometimes, despite the best efforts of adult children, informal care simply is not enough. Parents are just too sick, their needs too great or complicated or consuming for anyone less than a dedicated professional. They have a sudden health crisis, or something happens to their caregivers, or another relative suddenly needs assistance. Sometimes the burden is too much for caregivers, whether due to the accumulation of stress or an inability to miss any more work. Whatever the reason, something has to give. The parent requires care on a level that their child is simply unable to administer. When this happens, the family must turn to another source of care, one that comes from the marketplace rather than the home.

At this point, there are still many options other than institutionalization, which most people view as a last resort and a sign of filial failure (Keefe and Fancey 2000). From the financial perspective, the best option would be to call upon other relatives for aid, granting another the position of primary caregiver. Ideally, this would shift the burden long enough for the original primary caretaker to recover, or it would allow a fresh relative to take over as primary caregiver until her services were no longer needed. However, this ideal option is not always possible. Often caretakers become caretakers simply because no one else is available; their other relatives are either dead, nonexistent, estranged, geographically distant, physically incapable, or otherwise unable to help (Dellman-Jenkins et al 2000). Geographically distant kin might be able to render direct aid, but only if the parent moved—another considerable source of stress (see below)—or if the far-off caretaker left her home for however long the primary caretaker needed to recover. Physically impaired kin might be able to help with IADLs, but by this point, the parent is likely to require assistance with ADLs. They could potentially take over some of the primary caretaker's tasks, such as keeping watch on dementia patients, but the primary caretaker would still need to assist with toileting, bathing, and so on if the secondary caregiver's disability rendered her physically incapable of helping with these activities.

Other relatives (particularly males) either do not know how to give care or do not feel obligated to give non-financial assistance. Caring for one's aged parents is not easy, nor is it "something people are typically socialized to desire, seek, or expect" to do, so not all relatives are willing to do it (Aneshensel et al 1993:67). Perhaps they feel incapable of carrying out all the necessary tasks, or perhaps they fear the emotional strain of watching a loved one decline. Non-caretakers can escape this knowledge and do not have to view the decay close-up, but caretakers cannot. Many people, as the author knows from personal experience, understandably desire to avoid seeing their beloved family member so sick and helpless on a daily basis, and parents might not want their children to see them in such a condition. Alternately, these potential caretakers do not understand how much work goes into tending to an ailing senior and feel that the primary caretaker is being lazy, trying to shirk her duties. If they don't realize how badly their kin need assistance, they might not feel obligated to grant it. At still other times, parental affliction has exhausted the mental, physical, and/or financial resources of all available relatives, and everyone acknowledges that there is nothing more to be done. In cases such as these, the family has no more members left to call upon and must turn to professional paid assistance up to and including full-fledged institutionalization in a long-term care facility.

However, family care and institutionalization (whether in a nursing home or assisted living facility, which can look very similar to inexperienced consumers even if they are actually very different) are not the only elder care options in America, merely the most common and well-known choices. Many alternatives exist, including but not limited to adult day care, adult foster homes, and various forms of in-home aid such as maid services, meal preparation, and at-home medical assistance (Gaulger and Kane 2001). These services are designed to supplement but not entirely replace family care, which does not remove the stress of caretaking entirely but is generally considered preferable to placement in a nursing home or ALF. Unfortunately, few of these supplemental options are adequately subsidized by Medicare or Medicaid, so they must be paid for out of pocket by the elderly adult or a caretaker (Schlesinger 2015). In addition, these options vary in quality, as does every type of business. Some do not always provide as much or as high-quality assistance as family care. At other times, the fact that these services are provided by experienced professionals makes them more thorough than informal, untrained aid. Service varies drastically depending on factors such as type of care provided, quality of the provider, how they compare to prior assistance offered by kin and other agencies, and how aid rendered measure up to the family's expectations, desires, and needs. In many cases, determined by her specific needs and her family's resources, the senior citizen is best served by family care supplemented by professional care used as a respite service.

One non-institutional option is to find an adult foster home (Reinardy and Kane 1999). Elders move in with a professional or semi-professional caretaker who lets them live in their home and provides assistance with ADLs and IADLs. There are often a few other seniors who live in these foster homes, though not enough to overwhelm the live-in caretaker. These residences are a sort of compromise between home care and an assisted living facility, giving supervision and assistance without the stigma of an institution. They are not the best care option for severely impaired adults because they usually just offer basic nursing services and supervision, and there is always a risk of personality clashes between homeowner and boarder or of abuse and fraud, but if the homeowner is trustworthy and competent, this option can be practically and emotionally satisfying for all parties involved (Reinardy and Kane 1999). The author's maternal grandmother spent her last years in two adult foster homes, moving to the second after repeated disagreements with the proprietors of the first. The author's entire family was very satisfied with the second foster home and felt that it suited their needs and preferences much better than an institution.

Other families, including the author's own, turn to in-home aid, the most varied subset of non-institutional respite care. They hire one or more professional to provide certain services ranging from meal preparation to cleaning to assistance with certain ADLs to basic outpatient medical assistance like administration of medications. Some providers come in a few times a week, while others move in with their charge. The sheer variety available, especially in urban areas, allows consumers to customize their services according to their needs, but it could also confuse and overwhelm people new to the world of elder care. Many people prefer in-home aid because it allows seniors to remain in their own homes for longer than would otherwise be possible.

A third option is adult day service, in which children drop their parents off in a safe environment for most of the day and retrieve them in the late afternoon or evening. This gives caregivers a much-needed break in which they can work on non-caregiving tasks (for instance, their jobs) without worrying about their parent's safety and wellbeing. This choice is particularly useful for families with lower incomes who cannot afford to quit work in favor of caregiving, a situation which is all too common among certain subsets of the population. The primary caretaker is still responsible for many IADLs, but the day care facility helps with ADLs during business hours and keeps an eye on at-risk individuals like early-stage dementia sufferers and individuals with osteoporosis.

However, not all caretakers use respite care even when they are aware of its existence. One study discovered that 29% of caregivers stopped using adult day services after a mere three months or less (Zarit et al 1999:355). The reasons for this trend are varied. Sometimes people simply dislike the service provider or find that it does not accommodate their needs. At other times, they find that the programs are too expensive for long-term use and can only utilize them only occasionally. Occasionally the parent is cognitively impaired and becomes distressed at her perceived abandonment in a strange place. Often, however, caregivers find that they have waited too long before turning to respite services and that, as a result, the programs they are attempting to use are simply inadequate for their needs. Since so many “caregivers use respite services as a last step in keeping a severely impaired relative out of a nursing home," this last situation is far too common (Zarit et al 1999:355). These caregivers started too late, so not even the combined forces of respite care and family caretaking are enough to keep an impaired parent out of a LTC facility.

The Last Resort

When their own resources are exhausted, the family reaches its limits, and respite services are not enough, caregivers turn to the last, dreaded option: institutionalization. Very few individuals want their loved ones to enter the nursing home. In fact, "for many, even the *consideration* of nursing home placement is seen as failure and leads to feelings of guilt and helplessness" (Faison et al 1999:244, emphasis added). Consequently, in the words of one widely cited text, "[t]he decision about institutionalization is probably one of the most painful and stressful made by the children of the aging, in part because of both the myths on and the realities of the nursing home in this country" (Miller 1981:421). The transition, from the moment it is conceived of until everyone has adjusted to the new reality, is one of the most stressful facets of ageing for those who move and the movers’ loved ones alike.

The fear of institutionalization, particularly in a nursing home, is a pervasive part of American culture. As discussed in chapter 1, media portrayal of nursing homes is largely negative. Although the myth of the abandoned elderly is not as accurate, many people nonetheless believe that nursing homes are “places where self-serving families 'throw away' or otherwise illegitimately abdicate their responsibility to older people" (Jervis 2006:55). Others hold that nursing homes are “a necessary evil, providing care for disabled people when families have exceeded their limits. This position maintains that NH placement doesn’t necessarily mean that families have abandoned residents but that the elder requires care beyond that which the family can provide” (Jervis 2006:55-56). While one of these opinions is more positive than the other, neither portrayal is particularly flattering. Unfortunately, these two negative portrayals are what set the stage for discussions of whether or not to move.

Triggers for Moving

Families have many different reasons for institutionalizing their elderly members, and elders have many reasons for institutionalizing themselves, but trends of motivation nonetheless occur. These trends differ according to the type of institution. Residents in nursing homes are more likely to have fallen victim to some acute medical crisis (Castle and Sonon 2007). They have strokes or other unexpected illnesses that leave them and their families with very little time to prepare for their recovery care (Levine et al 2006; Dostie and Leger 2005). After being discharged from the hospital, they are released into nursing homes in the hope that they will recover enough to move back into their homes or, barring that, into their children’s homes. Sometimes this happens, and people heal enough to leave the nursing home and die in private settings.

Other times, they never improve enough for release and remain in nursing homes for the rest of their days. By contrast, people moving into assisted living facilities are more likely to make their choices without being forced or pressured by a medical emergency (Castle and Sonon 2007:737). They choose to be institutionalized rather than being forced into it by a sudden crisis and thus have much more leeway to find an ALF which suits their needs.

Stroke is one of the more common acute precursors of institutionalization, as it frequently results in greatly increased impairment in a short period of time (Dostie and Leger 2005:1010). This situation is sadly all too common.

> "Each year, about 500,000 to 600,000 people in the United States suffer a stroke, and another 347,000 people suffer a brain injury severe enough for hospitalization. Although the onset is acute and dramatic, the recovery is slow and may last for months and even years…. Stroke and brain injuries affect cognition, speech, mobility, and relationships with others, creating particular difficulties for family caregivers, who themselves are at risk for negative health outcomes such as depression, isolation, and deterioration of chronic health conditions" (Levine et al 2006:307).

These individuals are rendered incapable of self-care, and if they cannot find a caregiver on relatively short notice, they have little choice but to look elsewhere for help.

While stroke is one of the most acute common reasons for institutionalization, in large part because of how drastically it increases dependency, it is by no means the only difficulty which can prompt sudden institutionalization (Keefe and Fancey 2000). In theory, any disease or injury which causes a sudden increase in dependency—especially increased difficulty with ADLs—could prompt patients and their relatives to turn to LTC facilities for continued care. Since these injuries and acute diseases, for example myocardial infarctions or broken hips, appear suddenly and take quite some time to recover from, they are more likely to inspire residence in nursing homes for a shorter duration of time. Certain broken bones have the potential to be particularly dangerous, as they can drastically reduce mobility (around the home, in and out of the tub, and on and off the toilet), heal slowly among older people (especially women, who are at increased risk of osteoporosis), and greatly increase the risk of another, potentially deadly fall. A severe, bone-breaking fall and the risk of further falls were major factors in the decision to move the author's maternal grandmother out of her longtime home. Elders with broken hips or legs require both assistance with many ADLs and a degree of supervision to ensure that they aren't in any danger. They also likely need assistance with certain IADLs such as cooking and cleaning, which are partially dependent on mobility. If they are unable to requisition this assistance from their kin, they must find it elsewhere, often in nursing homes.

Although acute ailments can and frequently do prompt institutionalization, chronic conditions can also create this need. One study found that dementia, an inherently chronic set of illnesses, "was the commonest (two out of three) cause of dependence" (Wright 2000:651). A more recent study determined that 36.6% of nursing home residents were severely cognitively impaired, while another 24.8% was moderately cognitively impaired (NHDC 2015:159). The various forms of dementia have the potential to be especially draining, both physically and emotionally, for family members, so it is no surprise that they are among the more common causes of admission to nursing homes. While dementia victims might be able to care for themselves during the earliest portions of their illness, as they progress, their increasingly scattered wits and slowly increasing confusion become hazardous, and they frequently require constant or near-constant supervision in order to not injure themselves or worse (Lord et al 2016). This requirement can create immense strain in the patient's primary caregiver, who would quickly learn that even people waking in the middle of the night could cause themselves great harm. A dementia patient in the later stages of the disease simply cannot live alone, at least not safely; these safety concerns are the most commonly cited reason for families to institutionalize their relatives (Lord et al 2016:4). Unmarried or widowed individuals, or individuals whose spouses are incapable of giving care (perhaps even demented themselves) must move in with someone else, whether a relative or a professional. Once the disease has progressed far enough, its victims are too much a danger to themselves to do otherwise.

These people are particularly difficult for adult children to care for in two senses of the phrase. First, the stress of constant supervision is even more exhausting than other forms of caregiving, and it often occurs in addition to assistance with ADLs and IADLs. The workload is simply immense, and the constant vigilance required denies caretakers a chance to truly relax. Secondly, it is nothing short of emotionally agonizing to watch a beloved parent deteriorate to the point that they cannot recognize their own children. Consequently, the children of demented parents are much more likely than children of parents with other disorders to entrust their kin to professional caregivers working in institutions where they do not have to constantly watch their loved one's deterioration.

Unfortunately, these children face an extra difficulty in institutionalizing their relatives. A recent British study found that families often wait until the dementia has progressed significantly before they begin to discuss placement in a care home, meaning that the patient's mental faculties have declined (Lord et al 2016). While many (though not all) elders resist or entirely refuse institutionalization, individuals with dementia are especially likely to feel that their wishes are overlooked, that they had no choice in their move (Lord et al 2016). Consequently, they are more likely to resent the new residence into which they have been forced. This study interviewed families while they were making their decisions and therefore did not follow the dementia patients into the nursing home (if they did, that study was not mentioned in their article and is probably still ongoing [Lord et al 2016]). Although this study took place overseas, British and American cultures are similar enough that American dementia patients likely have analogous experiences, a conclusion supported by the case of Elizabeth, who was institutionalized in the Upper Midwest of the United States (Jervis 2001a). Elizabeth suffered paranoid delusions associated with early-stage dementia and did not believe she belonged in a nursing home; she had to be court-ordered into the institution and was profoundly dissatisfied with it (Jervis 2001a). Although Elizabeth's unnamed daughter was not the one who forced her into a LTC facility, it is likely that Elizabeth, who in her wrath planned to sue those who had forced her into an institution, would have been utterly outraged if she had (Jervis 2001a). The semi-forced institutionalization of dementia patients can easily burgeon into the sort of resentment that poisons relationships.

Incontinence is another common reason to institutionalize one's relatives. One article goes so far as to call institutionalization "perhaps its most profound consequence…. [T]he relative risk of admission to a nursing home was 2.5 times greater for incontinent women and 3.7 times greater for incontinent men" (Anger et al 2006:281). This study found that

> "[a]lthough less than 1.4% of female nursing home residents carried an admitting or current diagnosis of urinary incontinence, as defined using administrative data, the National Nursing Home Survey identified a much greater prevalence (58.6%) of bladder dysfunction among women living in nursing homes, according to the reports from the nursing home staff. More than one half of all female nursing home residents had difficulty controlling urination, and more than one half needed assistance in using the toilet." (Anger et al 2006:285).

A more recent study discovered that about 34.3% of nursing home residents had severe incontinence of the bladder and/or bowel (NHDC 2015:2). Incontinence is a particularly difficult affliction for caretakers to handle. Helping an incontinent relative is not just physically demanding and deeply embarrassing, it is so polluting that "incontinence care poses one of the most serious threats to caregivers' sense of self and status on the job" (Jervis 2001:84). Even nursing home aides with decades of experience dislike dealing with excrement, and unprepared, non-professional carers are even less equipped to handle incontinent relatives. Caregivers who find themselves unable to handle incontinent parents frequently turn them over to LTC facilities.

It is important to note that these problems, severe and all-encompassing as they can be, do not always prompt institutionalization. As detailed in chapter 2, racial minorities are especially likely to keep their parents within the community even when they are extremely severely impaired. Married parents with healthy, retired spouses frequently find themselves benefiting from the "in sickness and in health" portion of their wedding vows, with their spouses dedicating massive quantities of time and energy to keeping them at home. Still other times, people cannot afford exorbitant facility fees but are not yet completely bankrupt, rendering them ineligible for government aid in affording institutional care. (Often, the high costs of American healthcare will wipe out these individuals' financial assets, rendering them more than poor enough to qualify for Medicaid.) At still other times, one or more person involved in the decision-making process, whether caretaker or care recipient (usually the recipient) flat-out refuses the possibility of institutionalization, and the other side lacks the power to convince or force them to accept the professional aid of a long-term care facility.

The decision to institutionalize an ageing parent is not just stressful for caregiving children and the parent herself; it is difficult for everyone involved (Giacalone 2001). Even individuals only tangentially involved with the decision-making process or bystanders—young children, siblings and half-siblings and stepsiblings of the primary caretaker, perhaps even neighbors or friends of patients and caregivers—are usually at least aware of the increased strain caused by the incipient choice. Even if the family is lucky and every potential decision-maker agrees on the necessity of institutionalization, they still need to slog through the process of finding a nursing home or assisted living facility that fits their needs, a process which can take six months or more (Castle and Sonon 2007:733). They must create lists of potential residences, research and/or tour them, budget their resources, agree among themselves that *this* particular location best suits their needs, ascertain that their choice has a bed available, and fill out the necessary application paperwork. If they are lucky, the application is accepted and the family does not have to delay the move until a bed is available or, in more urgent circumstances, repeat the search process with another institution.

However, the process of institutionalization rarely runs so smoothly. Often, not everyone agrees that it is necessary or best to move the family elders into a LTC facility (Pyke 1999). For example, people other the primary caregiver might underestimate how difficult it is to attend a full-grown adult every waking hour of the day and believe that the caregiver is trying to shirk her duties out of laziness or lack of love. The caregivers could easily come to resent these accusations, particularly if the accuser has done little or nothing to help with the situation and especially if the accuser has flat-out refused to give aid. Sibling rivalries can flare, parents might feel like they are being shunted aside, and caregivers can easily find themselves at the end of their rope only for their families to accuse them of not doing, giving, or caring enough (Hayes and Truglio-Londrigan 1985:96). If a family is not united from the start about the decision to place one or more of its members in a LTC facility, it must either swiftly convince reluctant members to go along with the plan or risk even more severe emotional turmoil as old grudges resurface, ongoing feuds accelerate, and new resentments emerge from the emotional minefield of prospective institutionalization. The situation can quickly turn very ugly.

The power struggle that results when family members cannot agree whether or not to institutionalize a parent is always complex and varies greatly according to the family's makeup. Every fight is unique and depends on everything one could imagine, including but not limited to the number of people involved, their individual personalities and resources, who wants what, quality and quantity of nearby institutions, financial resources, demographic makeup, quality of relationships, recent family history, location of members, and what exactly is wrong with the potential patient-to-be. Often the family splits into subsections, "alliances within the group consisting of 2-3 individuals" who have particularly strong opinions about what should be done (Franklin 2013:133). Sometimes one side manages to sway the other. Alternately, the two groups might reach a stalemate, perhaps imposing sanctions on each other (for instance fewer visits or uneasy silence) if certain family members are particularly stubborn (Pyke 1999). At still other times, one group might be strong enough to force its will upon the others. A parent still sound in mind if not in body could very well refuse institutionalization, and her children often cannot legally force her into a nursing home, nor can they completely abandon her to her own devices—at least not in good conscience. In any case, the losers are likely to resent being forced into what they perceive as an untenable and unnecessary position for the convenience of the victors (Pyke 1999). For their part, victors could easily come to begrudge how difficult it was to persuade their kin to see the obvious, commonsensical solution, especially if they had to make concessions to win the battle (Pyke 1999). Either situation can produce bitterness. Whatever the case, families that cannot truly agree that putting an aged parent into a nursing home is necessary run the risk of extreme internal turbulence.

The Process of Moving

Once families have decided to institutionalize an elder, they must begin the actual process of moving. The first step in this journey involves researching which facility to use. Even people whose relatives are hospitalized and must be discharged into a LTC facility on short notice have a little time to make their decision, though their choices are more affected by which institutions have immediate openings and they are more likely to be influenced by hospital workers' opinions (Castle and Sonon 2007). In other circumstances, however, aged parents could simply find a place they liked and wait for a bed to become available, so long as they did not have to wait too long and their health did not deteriorate too rapidly. As always, their exact course of action depends on a wide variety of factors: availability, affliction, recommendations, cost, and the length of their hospital stay, among other things (Castle and Sonon 2007:733).

If given all the resources, financial and availability, that they needed, most if not all ageing parents would choose to spend their last days in an assisted living facility rather than in a nursing home (Imamolgu and Imamolgu 2006:235). As Miller et al (2012) confirmed, nursing homes are only rarely portrayed in a positive light in American media, reflecting wider cultural trends. In some ways, the nursing home is the antithesis of American values: a home for the aged and frail, not the young and strong and beautiful, that greatly restricts the independence of its residents in order to better serve institutional needs. Residents cannot truly work or sustain themselves, and many of them have difficulty leaving the confines of the facility's walls (Dostie and Leger 2005; Stewart 2006). The deep association between nursing homes and these particularly American social fears makes the nursing home itself a place of dread, stigma, and visceral revulsion. If the house with the white picket fence is the latest iteration of the American dream, then nursing homes are the face of the American nightmare.

ALFs are also associated with degeneration and loss of independence, but these associations are not nearly as strong as the link between nursing homes and culturally embedded fears, so elders tend to be less opposed moving into them in comparison to nursing homes (Imamolgu and Imamolgu 2006). There are several reasons for this weaker association. First, as mentioned in previous chapters, "assisted living facility" is an umbrella term which refers to a whole hodgepodge of subtly different institutional types; an ALF is essentially any type of LTC facility catering mostly to the elderly which is not a nursing home (Gaulger and Kane 2001). This wide variety makes it difficult for ALFs to attract any single reputation. Second, many ALFs are less restrictive than nursing homes (Gaulger and Kane 2001). They offer a greater degree of freedom to residents; some units, depending on the exact type of residence, even have tiny kitchenettes in which residents can prepare their favorite foods and dine when they want to, not when the facility's schedule says they should. Third, they are considered more home-like than nursing homes, which are very firmly established in the public imagination as medical institutions for those approaching death (Gaulger and Kane 2001). They frequently offer a greater degree of privacy and are conceived of as places where one can live rather than just wait to die. Last, they tend to attract less negative press than nursing homes, with popular culture circulating fewer horror stories about conditions therein. As a result of these differences, most people regard ALFs "as preferable to a nursing home" and would prefer to place their relatives there (Imamolgu and Imamolgu 2005:245).

While type of facility is important, it is by no means the only factor considered when families are searching for an institution. People also attempt to judge the quality of particular potential residences, resulting in a "very cumbersome search and selection process … for consumers" (Castle and Sonon 2007:732). Additionally, family members in different generations tend to have different standards of judgement, with parents especially basing their initial impressions of quality on the institution's cleanliness (Castle and Sonon 2007:737). Location, cost, staff friendliness and efficiency, and services provided are also considered carefully, and of course none of those factors means anything if the facility lacks available beds or does not grant admission.

Once the decision has been made and the selected home has an available bed, the aged parent must call upon his or her kin to assist with the move. After all, it is hard enough for a young and physically fit individual to pack up all his possessions, including heavy furniture, and bring it to another place, as the author discovered firsthand in the week following her defense; ageing parents are usually moving because they are in some form or another too frail to care for themselves, let alone carry out the physically arduous task of moving. In some cases, for instance when the elder is being discharged from a hospital for (hopefully) temporary residence in a nursing home, the mover's more fit relatives only need to pack up clothing, toiletries, and a few personal effects. The 'move' is more preparation for a long stay in a hotel than a real relocation. At other times, the parent is transitioning from an adult child's home and has therefore already taken care of larger items (Dostie and Leger 2005). Her furniture is in storage or given away or sold, and many of her knickknacks can remain behind with her former host. However, in many other cases, adult children find themselves having to help their parents move permanently out of the homes in which the children grew up. This is an emotional process for parents and children alike as they are forced to surrender not just a house but a home (Perry 2014).

Moving is, in many ways, both a rite of passage and an act of reminisce, especially if the mover lived in the home for a long time (Perry 2014). Just as moving out of the parental home marks a young person's final transition to full adulthood, moving out of the adult house for an 'old folks' home' symbolizes the end of adult independence and the fullest stage of dependency. It symbolizes the complete transformation of the mover's role, with the distribution of objects symbolizing role dispossession (Perry 2014:30). As a result, this particular move is even more fraught with emotion than many others, especially if the senior citizen is leaving the home she had her entire adult life, the place she raised her children and hosted neighbors and found comfort for perhaps half a century. The culling of one's possessions, which is especially necessary if moving from a full house to a shared room in a LTC facility, is just as painful. Possessions can easily invoke memories due to "the internalization of ideas into objects," often very poignant ones: a dead spouse's favorite shirt, a collar from a long-gone pet, a crude drawing once presented by a proud child or grandchild (Perry 2014:30). Elders who move into nursing homes have acquired decades' worth of emotional detritus, and the sentimental tokens which mean so much to them simply will not fit into their new abode. They must either redistribute their goods, dispose of them, or find someplace to store everything.

Consequently, senior citizens—or, if the parents are cognitively impaired, their children—must find some way of distributing, selling, or trashing items. This redistribution is another potential source of friction among siblings because "[c]onsiderations and discussions of the redistribution of one's objects can provide the opportunity to perpetuate one's legacy among family, friends, and strangers," and various relatives might have very different ideas about how to best allot the items (Perry 2014:29). Should all siblings get an equal share, or should the primary caretaker receive more for her services? What about grandchildren, niblings and great-niblings, stepchildren, or adopted children? If two or more siblings desire the same keepsake—say a photograph featuring the entire family circa 1960—who decides who gets it and how? If the parent is still cognitively intact, he or she is the obvious arbiter of claims, but if they are cognitively impaired due to dementia or stroke, then their relatives have to find other ways to distribute possessions that are not going into the institution with their original owner. Essentially, the process of moving can widen preexisting gaps between family members and create new ones, much like caretaking itself.

Summary

The process of institutionalization is a difficult one for everyone involved. It is often prompted by situations of extreme distress, whether in the form of a sudden health crisis or as the conclusion of a long, exhausting decline that is only sometimes mitigated by respite services. The decision to institutionalize an ailing parent is frequently met with opposition from other family members, including the parent, who feel that the caretaker should do more to avoid such an undesirable outcome. While this decision does not always cause conflict, discord is a frequent enough result that people considering institutionalization should brace themselves for it. The actual process of moving can be just as difficult as making the decision, though in a different way, due to the logistics of possession redistribution and of settling a frail senior citizen into a new environment. Institutionalization symbolizes the end of part of the caregiving process, demarcates the end of the elder’s adult independence, and helps the groundwork for parent-child relationships after institutionalization.

Chapter 4: In the Institution

The Myth of the Abandoned Elderly

Many parent-child relationships change dramatically after the parent is placed in a nursing home. This chapter explores those changes, demonstrating how care frequently continues in a new form post-institutionalization and how relationship quality after the move is frequently related to pre-institutionalization relationship quality. Caretaking begins at dependency and ends not at but after the parent's death. Previous chapters covered relationships from the onset of dependency until the move; this chapter explores the final stages of the parent-child relationship within the long-term care facility.

A dependent parent's placement in a long-term care facility is complicated, emotional, and difficult. It demarcates the end of one part of a parent-child relationship and the beginning another phase, one which not everyone needs to navigate and which does not have much of a template in American (or, for that matter, much of the world's) culture due to the relative youth of LTC facilities and the U.S.'s tendency to avoid discussing issues relating to old age. While many people know in the back of their minds that they might one day have to move into and/or send their parents to a nursing home, they are often not prepared to actually do so, nor do they fully understand how different their situation will be post-relocation (Hayes and Truglio-Londrigan 1985). All that elderly parents and their adult children know when they decide to institutionalize is that their relationships will be quite different after the move.

As institutionalization of the elderly became increasingly common in America over the last few decades, a frightening cultural myth began to take shape. This myth is likely descended from, among other sources, word-of-mouth accounts of bereft, lonely seniors who had no family to take care of them and were forced to rely on poorhouses for their survival (see chapter 1). As other forms of LTC began to replace poorhouses and as LTC use became more common, an idea began to spread that these facilities were for people whose families did not care for them. Clearly, the unfortunate senior citizens who now dwelt in nursing homes and, later, assisted living facilities had been completely cut off from their kin, abandoned in an impersonal medical environment by ungrateful heirs who intended to completely ignore their filial responsibilities (but would, of course, be there when the time came to divide up the inheritance). It is no surprise that this story formed, as American moralists tend to react to most social changes by bemoaning the death of Family and Values and especially Family Values, often in somewhat hysterical language. This woeful tale is known as the myth of the abandoned elderly, and it is mostly untrue (Keefe and Fancey 2000:235).

Simply put, institutionalization does not usually equal abandonment. There are exceptions to this rule, of course, as there are exceptions to every rule, but in most cases, children remain in contact with their institutionalized parents and even manage to aid them after the move (Keefe and Fancey 2000). In the few cases where this does not occur, there is almost always an explanation that does not involve lazy offspring callously abandoning their parents for the heinous crime of growing old and frail. "Families that were emotionally close prior to institutionalization are more likely to have continued contact following placement, unlike those whose relationships were strained or distant" (Jervis 2006:56). These families are more likely to have been distant for years, even decades, before the parents became dependent. If the estrangement is more recent, it probably has more to do with conflicting ideas about the length, duration, and type of care owed to parents rather than simply not caring about the family. For instance, a working single mother of five might not see the point in moving two hundred miles to help her own mother (or moving her mother two hundred miles into her daughter's house) when the older woman could simply go across the street to the nice new nursing home or rely on her son who lives just ten minutes away. Members of the elder generation, however, are "more likely than younger ones to expect the family to care [directly] for its elderly members" (Sanders and Seelbach 1981:447-8). Such small-scale conflicts could very well balloon into full-blown estrangements, leading to a national trend of soured post-institutional relationships.

However, such estrangement is hardly common when families are healthy. It is far more likely that adult children remain in contact with and even continue to care for their parents after institutionalization, with the quantity and quality of their care loosely related to how much they were doing before and the quality of their relationships (Jervis 2006). The children of the institutionalized do not stop loving their parents or feeling obligated to help them just because the older party has moved into a nursing home or ALF. In fact, the move (and the fact that adult children are frequently the ones to suggest and encourage said move) can create an additional motivational factor to remain in touch with and assist the newly institutionalized senior citizens. As mentioned above, most people do not want to place their loved ones in a LTC facility. Merely considering it is a mark of failure that provokes shame and guilt (Keefe and Fancey 2000). The guilt of institutionalizing a parent, shame for needing to, and fear for what might become of them in a place so negatively portrayed in cultural narratives can create a powerful emotional impetus to continue to care for one's parent or parents even after institutionalization (see below section on the Costas). Alternately, the guilt of institutionalizing a relative could cause avoidance behavior, an explanation proposed by the staff of Creekside Health Care Facility to explain low levels of family involvement (Jervis 2006).

Changing Care

Although primary caregivers usually continue to render aid to their institutionalized relatives, the quantity and type of care they provide changes dramatically (Keefe and Fancey 2000). This is especially true if the parent had lived with her child beforehand and was assisted with such intimate and embarrassing but necessary ADLs as getting in and out of bed, dressing, and toileting (Dostie and Leger 2005). The change of care is completely unsurprising since this is exactly people most commonly move into LTC facilities: their primary caretakers can, for whatever reason, no longer provide them with the care they require, so they need to find other sources of assistance to take over some of, though not all, their former duties. However, many offspring are uncertain of what their new filial duties are now that their parents have been institutionalized (Keefe and Fancey 2000). Specifically, relatives tend to initially be confused about what they are still responsible for in reference to staff duties, a perplexity exacerbated by ignorance about specific homes' exact regulations (Keefe and Fancey 2000:236).

Some nursing homes and ALFs have specific policies about what visitors are allowed to do with residents, with assisted living facilities generally permitting more forms of assistance (Gaulger and Kane 2001). For instance, quite a few places forbid untrained nonprofessionals from helping residents get out of bed or go to the bathroom, even if those nonprofessionals are the resident's primary familial caregiver and assisted with those very tasks for months or even years prior to their charge's institutionalization. From the facility's point of view, this sort of policy is completely logical because it minimizes the risk of injuries (to resident and visitor both) that might result from an untrained individual attempting to maneuver a frail senior citizen, especially if that individual is overweight or obese. From the former primary caregiver's perspective, however, this policy is ridiculous because they know what they are doing, have done it (and much more, besides) before, and are aware that the institution's frequently badly overworked staff might not be able to immediately carry out this duty.

Due to a combination of lack of proximity, institutional policies, and the relief and convenience of having someone else willing and able to help their kin with basic ADLs, most caregivers eventually let the staff take over most first-tier caregiving tasks and focus their attentions on assisting with second-tier IADLs (Keefe and Fancey 2000:236). If needed, staff help patients in and out of bed, assist with mobility, bathe, toilet, and otherwise groom them. They administer medications, make sure that patients eat, and keep their charges on schedule. Essentially, they take over the dirty essentials of everyday life. Family members, especially the primary caretaker, tend to return their focus to IADLs and 'extras,' just as they did at the onset of dependency. They assist with budgeting, take their parents on outings, provide extras like new clothes or personalization of living quarters, and supervise and coordinate direct caretakers like facility staff and medical professionals (Keefe and Fancey 2000). While many relatives will assist with certain ADLs if facility policy permits and they happen to be there (for instance, helping a relative to the toilet during a visit when the staff are otherwise occupied), for the most part, they no longer need to worry about such things.

One of the most important of the many duties primary caregivers continue to carry out after their charges are institutionalized is care coordination. Many elders have an entire retinue of healthcare professionals attending to various aspects of their upkeep, and someone needs to schedule appointments with them and ascertain that they are communicating (Keefe and Fancey 2000:239). Adult children become schedule keepers, making certain that their parent's physical therapy does not conflict with their chemotherapy or oncology appointment. While they also frequently provide transportation to these appointments, for the most part, "family members perceive their responsibility to be an *overseer* of action" rather than a direct attendant (Keefe and Fancey 2000:239, emphasis added). This fits in with the general pattern of residents' kin moving away from direct care tasks to more instrumental duties. However, the transition back to instrumental care tasks is not immediate. As mentioned above, many children are confused about the extent of the duties when their loved ones move into a LTC facility. Due to the ambiguity of staff versus their own duties, many caregivers attempt to continue giving physical aid for the first few weeks or months of institutionalization before learning to restrain themselves to secondary care tasks (Keefe and Fancey 2000). Their duties change over time.

Companionship

The freedom from the dirty work of ADL assistance allows adult children to reclaim another duty that intensive care often makes difficult to carry out:

companionship. As discussed before, many individuals who provide heavy care for their parents often fall victim to role captivity as the patient-caregiver relationship overwhelms the previous bond of parent and child. The caregiver gradually comes to perceive her parent as more of a burden or full-time (and unpaid) job than anything else, subtly poisoning their previous relationship with resentment and despair while forcing them into a power struggle of compliance and care versus independence and lack of care. However, when parents are institutionalized, they no longer require as much or as intensive practical care from their children. Institutionalization creates an escape from role captivity.

Many if not most child caregivers respond to this new freedom with aplomb, taking steps to recreate a modified version of their old relationships. In 1997, about 45% of adult children visited their parents in the nursing home at least once a week, with a significant percentage of those adult children visiting more than once and many more visiting at least once a month (Keefe and Fancey 2000:235). The study did not reveal the frequency of telephone calls, but given the quantity of visits from primary caregivers and adult children who live in the vicinity of the nursing home, it is safe to assume that children and grandchildren who live too far away to visit call at least once in a blue moon. "There is evidence… that filial obligations now mean first and foremost respect for and maintaining social contact with older family members" (Ng 2002:305). Social contact is therefore both a duty and an act of affection.

Companionship, even in the loosely related form of conversations on the phone, benefits elderly adults in many ways; support from families is “vital in helping older people settling in their new environment” (Thein et al 2011). First (and perhaps most importantly) it provides proof that they are still loved and cared for even after indefinite periods of caretaking (which might have included assistance with some very undignified tasks) and subsequent institutionalization. Although the anthropological literature does not frequently speak of love (or emotions in general, for that matter), as anthropologists prefer to use such abstract mechanisms as meaning or negotiation or tradition to explain human behaviors, very few people would try to deny that most humans seek and desire love in at least one of its forms. Institutionalized senior citizens are no exception to this rule, seeking and maintaining relationships of mutual affection (Roberts and Bowers 2015). Companion visits and phone calls in LTC facilities demonstrate to institutional residents that they are still loved, their presence (or even just conversation) still enjoyed and valued. Companionship proves to people raised on the myth of the abandoned elderly that they have not been abandoned, that the myth is untrue. By spending time visiting or talking with guests and callers, elders are assured that they remain part of a loving family unit. No wonder, then, that "[s]ocial relationships have been repeatedly identified as essential to nursing home resident quality of life" (Roberts and Bowers 2015:58).

Second, companionship provides a link with the outside world that is often otherwise lacking in assisted living facilities and especially in nursing homes. Nursing homes are considered total institutions in the classical sense of the term—that is, as "place[s] of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman 1961:xiii). Due to the wide variety of institutions that may be dubbed ALFs, some of these facilities may also fall under the definition of total institution. Residents of such places are by definition apart from society to a certain degree, though arguments could be made that no man is an island and no creation is truly divorced from the society which created it. Still, it is difficult to argue against the fact that people in Goffmanian total institutions are at least slightly insulated from the outside world, living as they do within the institutional microcosm, separated from most of their old social networks, and largely unable to directly affect the rest of society, especially without help. Upon moving, people physically leave behind their old social networks, the neighbors with whom they may have lived for years or even the children in whose homes they dwelt following the onset of dependency (Perry 2014). Companionship allows residents to participate in their old social networks.

Third, companionship provides a source of entertainment, comfort, and meaning for institutionalized senior citizens. Without jobs, isolated from the majority of their old acquaintances, and placed in an environment that is not particularly stimulating, older adults are at high risk for boredom and a sense of meaninglessness. They frequently have very little to do, especially relative to their previous lives as members of the workforce, parents, grandparents, and neighbors. While LTC facilities provide entertainment options, they are quite limited relative to what people living independently can do, especially since they frequently lack their own transportation to and from the institution. Spending time with their families or otherwise communicating with them gives older adults a meaningful way to spend their time, alleviating their boredom while helping them feel like their lives still have meaning. This benefit is especially tangible when visitors bring their institutionalized kin on outings, allowing them to temporarily escape the dreary confines of their usual environments and spicing their lives with variety. The institutionalized person's offspring are particularly likely to bond with their parents on outings (Wright 2000:655).

Fourth, companionship helps maintain a degree of power over one's personal life (Savishinksy 1991). Institutionalized individuals are expected to comply with the norms and mores of their new dwelling place, with the degree of compliance related to the type and quality of the institution and to the power possessed by the institutionalized individual. Companionship creates a line of communication with people who are not regulated by the institution's demands on their time. It creates the potential for advocacy, allowing concerned kin to notice if something is wrong and forming a venue for making and addressing complaints (Savishinsky 1991). Companionship allows people to bring their concerns to concerned kin who are not part of the institution and thus have a different type of power over it and freedom from its direct retaliation (see the following section on the Costas).

However, companionship is not just beneficial for parents. Children do not gain as many advantages from it as their progenitors do, but they too benefit emotionally from maintaining social bonds with people whom they have known and loved their entire lives. "The strong feelings involved in family care-giver visits are multidimensional. They usually include love or affection, a sense of obligation and a feeling of guilt at the cared-for person now living in a care home" (Wright 2000:654). That is, companionship allows adult children to stay physically and emotionally close to their parents. It alleviates the guilt they feel for letting their loved ones go to an institution, especially if they use the companionship to check that everything is all right and their parent does not require anything. Adult child companions feel as though they are doing something (and to be fair, they are), which can help them come to terms with the new situation. It may even help them come to terms with their parents' inevitable (and probably rapidly approaching) death, since this way, they can at least comfort themselves that their loved one was not lonely in their last days, something which the author's family has found immensely helpful in dealing with grief. Companionship helps parents and children both.

The Costas

Savishinksy (1991) provides a touching example of the benefits of companionship in his ethnography of a nursing home. One of the residents in Elmwood Grove, Stavros Costa, had a devoted daughter named Katina who visited or called every day (Savishinsky 1991:72). Stavros immigrated to America from Turkey, where Greeks like him lived under the threat of persecution, when his daughter was very young. In his sixties, he began to decline, and he moved into Katina's house after the death of his wife. Katina cared for him as well as she could, even hiring a series of paid assistants, but after Stavros had a catheter inserted, he decided that enough was enough and decided to move into a nursing home. Katina agreed with his decision even though "she felt she had crossed into a moral no-man's land. It was not that she had done something bad in placing her father there; she had done something unimaginable" (Savishinsky 1991:76). While her grief, guilt, and horror were certainly exacerbated the fact that nursing homes were alien to her father's native culture, many native-born Americans are intimately familiar with her experiences. After Stavros's institutionalization, Katina visited or phoned him once a day. Although this did not completely alleviate her guilt, visiting helped lighten her conscience. Eventually she came “to feel redeemed rather than depressed” (Savishinsky 1991:77). Stavros, for his part, benefited immensely from his daughter’s continued attentions. Her constant presence gave him both pleasure and power.

Katina was not just a visitor; she was her father’s advocate as well. Besides companionship, advocacy is one of the most important tasks which caregivers can undertake. Overworked nursing home staff do not always render as much aid as they would in an ideal world. For example, Stavros was once cared for by an aide who “tended to ignore his requests to be taken to the toilet” (Savishinsky 1991:73). Katina was able to have her father given over to another, more attentive aide. Stavros may have been too shy and polite to voice his complaints to the staff, but his daughter had no such compunctions. She continually made suggestions to improve his care, and she was insistent enough that the staff listened to her. Her position also allowed her to keep a lookout for any abuse, though Savishinsky does not report her finding any (1991). Not surprisingly, the staff treated Stavros very well even when she was not there to suggest improvements or monitor his care. Katina’s continued service in the forms of companionship and advocacy diminished her guilt and greatly improved her father’s quality of life.

Differences in Care

Not every adult child gives care equal to Katina’s to their institutionalized parent (e.g. Jervis 2006). Quality and quantity of care provided post-institutionalization is dependent on several factors, one of the (if not the) most important of which is the quality of the premorbid relationship (Winter et al 2011). Someone who spent more time with her parents before the onset of dependency, who was closer emotionally to them, has extra emotional impetus to give back when her parents grow old. Affection as well as duty can lead a person to become a parent's primary caregiver when dependency emerges, and that same affection can lead her to provide more care when her relative is placed in the LTC facility. Qualitatively better relationships make any two people more likely to voluntarily spend time with each other or communicating with each other, so it is no surprise that emotionally sound parent-child dyads are more likely to stay in touch and provide assistance after the parent moves.

Gender is a second defining factor of how much care a former primary caregiver provides after the institutionalization of their charge. As discussed in chapter 2, the world of old age is a predominantly female domain, with women making up the majority of caretakers (formal and informal) and patients both. Daughters and sons have different relationships with their ageing parents from the moment of their birth, through dependency and institutionalization, and even after death (Steckenrider 2000). Since daughters are much more likely to be primary caregivers before institutionalization, they are also much more likely to be involved in their parents' post-institutionalization lives as visitors, callers, advocates, caregivers, and coordinators. While sons fulfill these roles before and after institutionalization, they are less likely to do so and therefore less frequently seen in LTC facilities.

The gender of the parent also affects familial relationships post-institutionalization. Women are more likely to end their days in nursing homes, and they spend more time in these institutions (Liu et al 2007). One study records that institutionalized mothers spend an average of 1265 days (about three and a half years) in nursing homes, while fathers averaged 897 days (approximately two and a half years) in the same environment (Dostie and Leger 2005:997). These differing averages are a result of women's longer lifespans and the demographic trends that make wives younger than their husbands, and they have implications for parent-child relationships (see chapter 2). Since institutionalized fathers spend less time in LTC facilities, they and their families have less time to adjust to this situation before death takes him. While two and a half years is more than enough time to mostly delineate staff versus familial duties, especially if the father never transfers from one facility to another, mothers and their children have 368 more days to become accustomed to their new situation, fall into a routine, and can come to take the parent's institutionalized status for granted.

To the best of the author's knowledge, few if any studies have been conducted to see if visits to nursing homes become less common the longer patients remain in the institution, but it is very possible that residents receive fewer visits as time goes by. This is because when a person is first institutionalized, her kin has reason to call and visit frequently to make certain that she is comfortable and adjusting well. They are also uncertain about their duties and might feel the need to come by every day to help with ADLs and IADLs. Lastly, since moving relatives to a nursing home is almost universally conceived of as a negative, people tend to experience a great deal of guilt once they make the decision to move a loved one into an institution. To assuage their guilt, they may be more likely to spend extra time with their kinswoman immediately after the move. However, as time goes by, their guilt can more easily be alleviated. Perhaps they are impressed by the quality of care provided, or perhaps they come to accept that there was nothing more they could have done, that institutionalization was the best decision they could have made. For whatever reason, the guilt lessens enough and they become confident enough that their parent does not need them as frequently as before. As a result, if this theory is correct, they begin to visit less frequently and/or for shorter periods of time as the months go on.

If family members do visit their institutionalized relatives less frequently as time goes on, then mothers and fathers, who are institutionalized for different lengths of time, would logically experience different patterns of visitation. Men would experience fewer total visits and phone calls but would receive them more frequently (averaged for the entire length of stay), while women would experience more total visits and phone calls but would receive them slightly less frequently (again, averaged for their total length of stay in the LTC facility). This is, of course, a broad generalization that doubtless has many exceptions. For example, a woman whose health is repeatedly in crisis throughout the length of her stay will likely receive more visits than whose health remains poor but stable for however long his is institutionalized and who passes gently and unexpectedly in his sleep one night. Fear of a loved one's immanent death prompts extra visits like nothing else, for when a person could die any day, each visit might be the visitor's last. However, parents of both genders whose health does not take any sudden downturns are likely to receive fewer visits over time, which may lead to them feeling lonelier towards the ends of their lives. Since women live longer in general and spend more time in institutions, they are therefore at increased risk of this type of loneliness if this hypothesis is true.

Unfortunately, some degree of loneliness is probably inevitable for older adults in general and institutionalized seniors in particular. As people grow older, their friends and peers also age, decline, and eventually die. The average octogenarian has likely lost many if not most of her friends, not to mention the strong possibility of having seen at least one sibling and/or spouse perish (Qualls 2014:10). People in nursing homes are especially likely to have lost their life partner or to have never had one in the first place (Dostie and Leger 2005). Institutionalized adults are further separated from their social networks by physical evacuation from their old neighborhoods. Many nursing homes don't even allow residents to bring their pets to live with them. Senior citizens go from surrounded by people they know and presumably like to surrounded by complete strangers, relying on new relationships and sometimes sporadic contact with the outside world for companionship. In these circumstances, loneliness is only to be expected.

Although institutionalization might increase loneliness by removing elders from their old social networks, including to some degree their families, it can also help alleviate loneliness and help the senior create new social bonds (Qualls 2014). The most obvious source of new friendships in many institutions is the roommate, but roommate compatibility is unpredictable and lonely elders should not get their hopes up. Additionally, residents of LTC facilities are there because they are in some way too unhealthy to care for themselves, so there is a certain element of risk in befriending literally any other resident because their health might soon collapse entirely. Many elders are befriended by staff, some of whom go so far as to form fictive kin relations with them (Dodson and Zincavage 2007). However, these new relationships, beneficial as they can be, are not guaranteed to develop, and they inevitably lack the decades of depth and development that preexisting familial relationships already have (Qualls 2014). In order to minimize loneliness, elders need to continue cultivating their old relationships, without which they feel adrift and abandoned, even as they form new relationships within the institution (Qualls 2014).

Essentially, the ability to age well, even in institutions, is determined “the older person's access to a variety of resources: physical, economic, social, psychological and spiritual" (Goleman et al 2015:2). Many of these resources can be supplied most effectively and efficiently through the family: physical caretaking, economic support, social companionship, psychological monitoring and upkeep, and even a little bit of spiritual guidance (though this is more likely to come from other sources). Strong family ties give senior citizens the means to continue enjoying their lives (even from within the confinement of nursing home) while giving them a reason to keep living (Goleman et al 2015).

Many people believe that institutionalization damages these essential family ties and thus the family-provided resources, and in some cases, they are correct. Institutionalization physically separates aged parents from their children, especially if parent and child were cohabiting prior to that move. If the caregiver and care recipient have different opinions about how much care should be provided by the child—that is, if the institutionalization is forced upon the elder by his or her offspring’s refusal to continue on—then the forced move can easily provoke feelings of resentment and abandonment. Nursing homes are certainly devastating to family finances, possessing the potential to wipe out the elder’s savings in just a few years or months, especially if combined with high health costs (Mullin 2013). However, evidence exists that institutionalization is not inherently harmful to the family unit (Dellasega 1991).

In fact, many parent-child relationships actually benefit immensely from institutionalization (Dellasega 1991). Although offspring feel guilty for considering a nursing home and even guiltier after the move, they cannot deny how much of a relief it is to no longer be responsible for their parent's trips to the toilet. Institutionalization frees them from role captivity and allows them to become companions once again rather than caretakers. This gives adult children a chance to escape their slowly increasing resentment and restore familial relationships based primarily on affection rather than primarily on duty. No wonder, then, that so many people report improvements in the quality of their relationships with their parents following institutionalization (Wright 2000). Used properly, institutionalization can help parents and children repair their relationships, allowing their bond to heal from the strains of heavy physical caretaking before the parent's death.

Postmortem Caring

Eventually, inevitably, the frail, unhealthy parent dies, leaving her children, including the primary caretaker, to live on. Yet, ironically, caretaking does not entirely end after the parent's demise (at least, not all forms of caretaking do). While the deceased individual obviously no longer needs assistance with ADLs, certain postmortem acts can be considered types of caretaking. Someone needs to plan the funeral, write the obituary, and oversee the distribution of property. Although it is the elderly person's responsibility to create a will while still mentally competent, family members must still distribute individual items to the appropriate persons, and someone needs to enforce the deceased parent's wishes. Additionally, not all testaments specify an owner for every piece of property, and not all heirs want every part of their inheritance. Someone needs to arbitrate these disputes, dividing up property and disposing of items (through sale, donation, etc.) that nobody wants. They must also attend to various bureaucratic details such as cancelling bills and informing the post office that their parent is now dead. Instead of tending to the person, these posthumous caretakers care for the estate.

Only when these details are taken care of can the caretaker truly renounce her status as such. Life after each bout of caretaking generally has three phases: “the 'post-caring void', 'closing down "the caring time"' and 'constructing life post-caring'" (Larkin 2009:1031). When their responsibilities pass, caretakers find themselves at a loss. A major purpose of their lives has just suddenly disappeared, leaving them with a great deal of extra time and energy but without as much structure and meaning. They need to learn to separate themselves from the caretaker role, coming to terms with what happened and what it meant to them. Only then can they create new meaning for themselves in their post-caring lives (Larkin 2009). However, it is interesting to note that these primary caregivers often do not entirely surrender the caregiver role, with many going on to care for other family members when they reach dependency (Larkin 2009). While part of this tendency is doubtless explained by their experience, the family handing off the caretaking task to someone who knows what she is doing, it could also result from being genuinely fulfilled by caregiving and wishing to recreate that fulfillment (Larkin 2009).

Summary

This chapter examined the parent-child relationship after the parent’s institutionalization. Although American cultural myths maintain that institutionalization is a form of abandonment, adult children continue to care for their aged parents even after placing them in a nursing home or assisted living facility. In fact, care continues throughout the remainder of the parent's life and even after the elder's death. However, the type of care they provide changes dramatically, shifting from ADLs to IADLs and companionship. Without the stress of high-intensity caretaking coming between them, many adult children and their parents find that their relationship actually improves after institutionalization, a turn of events that very few people would have expected. Distance allows them to become parent and offspring once again as opposed to patient and full-time attendant. If the dyad's relationship survives the move, it has the potential to blossom until the parent's death.

Conclusion

This thesis is intended to provide a brief introduction to the ways in which American family dynamics and relationships, specifically the relationships between adult children and their parents, change upon the age-related institutionalization of elderly adults. The first chapter contextualized the problem, providing an overview of the historical events and processes (demographic alterations, retirement, pensions, and certain acts of the federal government) which led to the current situation. The second chapter established a starting point for comparative purposes, delineating familial relationships at the onset of dependency and accounting for sources of demographic variation. It also touched on the ageist attitudes with which families must contend as their members grow older. The third chapter examined the decision to move and the move itself, processes which are difficult in distinct ways. The fourth chapter covered relationships post-institutionalization, exploring ways that family caretaking continues and emotional relationships are affected. Together, the four chapters create a broad outline of relationship changes at a pivotal but understudied part of the American family life cycle.

The thesis's results reveal the necessity of LTC facilities and affordable healthcare for older adults. While family care is preferred by policymakers, caretakers, and care recipients alike, it is not in and of itself sufficient to meet the needs of America's rapidly growing population of senior citizens. Families do not place their relatives in institutions because they are lazy or irresponsible; they view institutionalization as a desperate last resort and, often, as a failure of their filial duties. Parents are placed in nursing homes and assisted living facilities because their children are overwhelmed, undertrained, and exhausted. The mere existence and especially the prevalence of these institutions demonstrates that while family care might be the cultural ideal, it does not always work out in practical reality.

Nursing homes benefit families on many levels, practical and emotional. Practically, they provide safe living spaces where dependent residents are monitored and assisted by a team of professionally trained nurses and aides. This staff attends to residents' daily needs, providing everything from medication administration to nutritious meals to help in and out of bed. Such diligence can prevent some medical crises, especially falls and bed sores, entirely, and can nip other problems, such as malnutrition or improper use of medications, in the bud. Additionally, the staff provides a measure of security. They prevent dementia patients from wandering off and are usually within earshot if a resident falls or has, say, a stroke or heart attack. LTC facilities therefore free up huge tracts of family caregivers' time, allowing them to focus on other necessities.

On an emotional level, nursing homes and ALFs provide peace of mind, stress reduction, distance, and a chance for renewed closeness between parents and their adult children. With their relatives entrusted to and surrounded by professional aides, family members no longer need to worry about them quite so much. They still worry, of course, especially at first—even the most diligent of attendants cannot prevent every accident or crisis—but they do not need to fear for their loved ones quite so passionately if they know they are being watched and aided. This assurance alone removes an enormous source of stress. As with worry, LTC facilities cannot remove the emotion entirely, but even a small reduction can be enormously beneficial to the adult child’s mental health. This diminishment may also help improve relationships between adult children and their parents. Less negative emotion in a relationship creates more space for positive emotions to flourish. Stress and worry can easily beget resentment, but that resentment can be drastically reduced if its sources are lessened. Additionally, the physical distance created by institutionalization can also help improve relationships, especially if the parent was cohabiting with the caregiver before the move. As the saying goes, absence makes the heart grow fonder.

This is not to say that professional institutions are *the* solution to America’s burgeoning elder care crisis. Institutionalization can worsen relationships just as easily as it can improve them. Caregivers often feel immensely guilty and inadequate for even considering a long-term care facility, and elders do not always react well to the idea that they should be institutionalized. Senior citizens might feel that their offspring are lazy and ungrateful, that they are being undeservedly abandoned to a heartless medical facility because their children do not love them enough to continue caring for them. In the same way, children could see their parents’ recalcitrance as pigheaded, manipulative, unrealistic (even to the point of delusion), and/or selfish. Institutionalization is a highly emotional process for parents, caregivers, and even their extended kin and social networks. In such a highly charged situation, any friction risks sparking a conflagration.

Emotional problems leading to diminished relationship quality or even estrangement are not the only problems posed by widespread institutionalization. Practical concerns abound. Due to overwork and understaffing, care quality in many facilities is less than optimal. Many nurses only have time to attend to their charges’ physical needs, not their mental wellbeing. Other nurses go so far as to abuse their patients through physical violence, deliberate neglect, verbal cruelty, sexual harassment, or outright theft. Institutionalization is an act of trust in the facility's staff, and sometimes that trust is badly misplaced. Other common problems faced by nursing home residents include isolation, inability to form new social networks, and the financial difficulties brought on by the high price tags associated with almost all aspects of American healthcare. While nursing homes and ALFs have more benefits than their reputations would suggest, they are by no means perfect and should not be encouraged to completely replace family-based care.

Instead of championing one option or the other, policymakers ought to acknowledge the benefits and cons of nonprofessional family care, institutionalization, and alternate respite care options such as adult day care and home-based aid. What works best for one family is not at all practical for another group, so it is important to offer caregivers as many options as possible. It is also important to ensure that these options are affordable to a wide variety of people, something which government policies in their current form and in the current political climate do not favor. Lastly, these multiple options refined and optimized in order to create the best possible senescence for the greatest amount of people.

Anthropological, gerontological, and sociological research are essential tools in this quest. These disciplines are designed to examine the structures of certain aspects of society, and examination is the first step to improvement. Well-trained social scientists of every variety must conduct more literature reviews and original ethnographic research in order to find, isolate, and suggest improvements to the various flaws inherent in the current system of elder care. Researchers can create new ways to help family caregivers, to protect against elder abuse, and to iron out the imperfections of Medicare and Medicaid. Even better, they can conduct follow-up studies after changes have been implemented to determine whether or not interventions were successful, creating new ideas for further improvement. While academics cannot create public policies directly, they are more than capable of influencing and critiquing them.

There are several specific research questions that could stand to be further explored. For example, while a great deal of statistical data exists demonstrating that race, class, and gender dramatically affect how people experience old age, few if any studies have been conducted that show the qualitative ways seniors are affected by these differences. Additionally, there is no ethnography comparing a nursing home with an assisted living facility; indeed, almost all of the ethnographically studied institutions I encountered in the literature were nursing homes rather than any sort of alternative care provider. Since these programs will likely become more common in the future as the elderly population increases, they need to be critically examined sometime in the next few years.

Anthropology, with its holistic approach and emphasis on the ethnographic method, is a particularly useful discipline for this endeavor of improvement. Anthropologists are uniquely suited to learn the perspectives of everyone involved in elder care: the senior citizens themselves, their families and friends, and their assorted professional caretakers. This deep understanding allows anthropologists to act as negotiators, making one group’s ideas acceptable to the others and addressing complaints so that the solutions benefit all parties involved. Additionally, anthropologists have at their disposal a wide variety of data from other cultures that can serve to provide suggestions for future improvisation and denaturalize deeply embedded but ultimately harmful ideas and institutions. Ageism, for example, is one deeply naturalized but culturally specific potential target whose elimination or reduction would greatly improve the lot of older adults. While it is doubtful that anthropologists could eliminate ageism entirely, they are more than capable of watching out for ageist structures and assumptions.

Just as anthropology can contribute to gerontology, so too can studying age-related questions contribute to anthropology. This ambitious discipline ultimately seeks to understand all aspects of the human condition, including every part of the life cycle. Since the elderly population is increasing worldwide, the importance of studying them is increasing proportionately. The elderly residents of LTC facilities, whether there for recovery or for prolonged care, and the relationships these people maintain are therefore more relevant to anthropology in general. Additionally, understanding this particular group could potentially enable anthropologists to better comprehend other subcultures, for instance nursing home workers and future generations of senior citizens.

Thus anthropologists have both academic and practical reasons to study ageing. As the world's population of elders continues to increase, anthropological research into this portion of the population will also hopefully become more common. Ageing in the Western world might not be one of the discipline's traditional domains of study, but as a culturally bounded portion of the human life cycle, it nonetheless falls well within the purview of anthropology.

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