



Why Do Elders Leave Home Care and Enter Nursing Facilities?

Citation

Goslinga, Jill Ann. 2017. Why Do Elders Leave Home Care and Enter Nursing Facilities?.
Doctoral dissertation, Harvard Medical School.

Permanent link

<http://nrs.harvard.edu/urn-3:HUL.InstRepos:40621350>

Terms of Use

This article was downloaded from Harvard University's DASH repository, and is made available under the terms and conditions applicable to Other Posted Material, as set forth at <http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA>

Share Your Story

The Harvard community has made this article openly available.
Please share how this access benefits you. [Submit a story](#).

[Accessibility](#)

Health Policy Scholarly Report

Submitted in partial fulfillment of the MD Degree at Harvard Medical School

Date: 10 February 2017

Student Name: Jill Ann Goslinga, B.S., M.P.H.

Scholarly Report Title: Why Do Elders Leave Home Care and Enter Nursing Facilities?

Mentor Name(s) and Affiliations:

- Robin Lipson, *Chief of Staff and Chief Strategy Officer, Executive Office of Elder Affairs, Commonwealth of Massachusetts;*
- Hope Turner, *Special Assistant, Executive Office of Elder Affairs, Commonwealth of Massachusetts*

Author's Note:

The views expressed in this report are my own and do not necessarily represent the views of the Commonwealth of Massachusetts. This report was prepared for academic purposes only. The views expressed in this report are my own and do not necessarily represent the views of the Commonwealth of Massachusetts.

Executive Summary:

History of Home Care: Home care enables elders and disabled adults to thrive at home and avoid nursing facility placement. Home care services are diverse and include visiting nurses, homemakers, and personal care assistants. Early health insurance systems provided for a limited suite of home care services, and later home care use accelerated. Home care is often “pitched” as a less costly alternative to nursing facility care, although early demonstration projects failed to document cost savings. Nonetheless, home care utilization continues to grow nationwide, and federal and state home care systems allow millions of Americans to remain in their communities. Massachusetts in particular has been a state leader in progressive home care policies.

Student Role: While earning an MPH, I interned with the Massachusetts Executive Office of Elder Affairs. With a goal to strengthen home care services in Massachusetts, I conducted a chart review of elders and disabled adults living in Massachusetts who discontinued home care services after entering nursing facilities. I continued scholarly work on home care policy after returning to the Medical School with a historical analysis of American home care policies.

Methods: I extracted key quantitative and qualitative data for a geographically representative sample of 108 former home care consumers (who were not nursing home eligible at the time they received home care services), including: program details, caregiver characteristics, medical co-morbidities, recent falls, recent hospitalizations, request for nursing facility placement, home care agency involvement in discharge planning, steps taken to prevent or delay placement, and key themes surrounding home care discontinuation.

Results: Former home care consumers often (70%) had multiple informal supports, and caregivers were infrequently (16%) stressed. Most consumers had medical conditions in three or more bodily systems and took nine or more medications. About half (48%) had recently fallen and most (76%) were recently hospitalized. Consumers and family members requested placement about half (49%) of the time, and home care agencies participated in post-rehabilitation discharge planning only 37% of the time. Clear steps were taken to prevent or delay nursing facility placement in 28% of cases.

Discussion: Hospitalizations led to rehabilitation followed by nursing facility placement for most consumers. Home care agencies struggle to communicate with rehabilitation case managers and are frequently excluded from discharge planning. I suggest potential strategies to improve inter-organizational communication, as well as tackle caregiver stress and senior housing insecurity.

Table of Contents

Executive Summary	p. 2
Glossary of abbreviations	p. 4
<u>Introduction:</u> <i>What is home care, and how can it best serve elders' needs?</i>	p. 5
Definition of Home Care	p. 5
Home Care in Massachusetts: The Executive Office of Elder Affairs	p. 5
Demographics of Home Care Recipients in the United States	p. 7
Early pressures for (a return to) home-based care	p. 7
Insurance coverage for home care: from Blue Cross-Blue Shield to Medicare	p. 8
Rapid home care expansion post-Medicare/Medicaid	p. 9
Early home care policy: a look at the evidence	p. 9
Policy Changes in a New Era: Arizona's Example	p. 11
1990's to Today: Changes to Home Care Service Delivery	p. 12
<u>Student role:</u> <i>My practicum project and subsequent literature review</i>	p. 13
<u>Methods:</u> <i>Chart review data extraction and analysis</i>	p. 14
<u>Results:</u> <i>Trends in home care termination</i>	p. 17
Program and Service Details	p. 17
Caregivers and Support	p. 18
Functional Status	p. 19
Co-morbid Conditions	p. 19
Fall Risk	p. 19
Hospitalizations	p. 19
Discharge Planning	p. 20
Qualitative Themes: Patterns of Leaving Home Care	p. 21
<u>Discussion:</u> <i>Conclusions, policy implications, study limitations</i>	p. 22
Conclusions: Review of Key Findings	p. 22
Policy Implications and Next Steps	p. 23
Communication Breakdown	p. 23
Caregiver Stress	p. 24
Scarcity of Senior Housing	p. 25
Study Limitations	p. 25
Acknowledgements	p. 26
References	p. 28

Glossary of abbreviations:

ADL's - Activities of daily living

ASAP - Aging Services Access Point – Typically referred to as “home care agency”

CMMI - Center for Medicare and Medicaid Innovation

CMS - Center for Medicare and Medicaid Services

HCBS - Home- and community-based care (HCBS)

IADL's - Instrumental activities of daily living

LTC - Long-term care – Also known as long-term services and supports (LTSS)

Author's Note:

The views expressed in this report are my own and do not necessarily represent the views of the Commonwealth of Massachusetts. This report was prepared for academic purposes only. The views expressed in this report are my own and do not necessarily represent the views of the Commonwealth of Massachusetts.

Introduction: What is home care, and how can it best serve elders' needs?**Definition of Home Care**

Home care refers to a diverse set of medical and social supportive services which empower individuals with functional impairments (including the elderly, the disabled, and others living with chronic illness) to live healthfully and age comfortably at home (Benjamin 1993). In this report, I will frequently refer to home care consumers as “elders.” Although most of the consumers whose charts I reviewed are over age 65, non-elderly individuals with disabilities also receive home care services. Using the shorthand phrase “elders,” I mean to refer more broadly to elders as well as non-elderly disabled adults receiving home care services.

Examples of home-based services are plentiful, and include home visits by nurses and therapists; homemaker services like house chores, cooking or meal delivery; and personal care (to assist with activities of daily living, or ADL's). In recent decades, preferred terminology has changed; through the late 1980's and early 1990's, “home care” took precedence, but today, “home- and community-based services” (HCBS) is often preferred. In addition, many debates around the effectiveness and future prospects of home-based care use the broader term “long-term care” to include home care as well as institutional care.

Home Care in Massachusetts: The Executive Office of Elder Affairs

Massachusetts has long been a progressive leader in state-based home care policies. The Massachusetts Executive Office of Elder Affairs (EOEA) coordinates housing, health care, home care, nutrition, and caregiver support services for elders, individuals with disabilities, and their

caregivers across Massachusetts. The Executive Office of Elder Affairs history dates to the 1965 Older Americans Act, an amendment to the Social Security Act which created “a comprehensive and coordinated system of care for elderly Americans” (Butler 2013). In Massachusetts, under leadership of Governor Frank Sargent, the nation’s first state-funded home care program to offer a community alternative to nursing facility care was created. Called the State Home Care Program, this consumer-controlled agency provided independent case management and assisted elders with functional needs like eating, dressing, bathing, and other activities of daily living (Butler 2013).

Massachusetts is aging; from 2010 to 2020, there will be 30% growth in elders aged 65 and older. Most community-dwelling elders (90%) would prefer to live at home, but many need some assistance to meet this goal. Massachusetts home care services help elders thrive in their communities and postpone nursing facility placement. Each month, EOEA provides home care services for 45,000 Massachusetts elders, strengthening communities while helping individuals delay or avoid nursing facility (NF) placement for long-term care (LTC) (Home Care 2011).

Reflecting a deep understanding of the social needs of community dwelling elders, EOEA employs case managers with strong social service backgrounds to orchestrate the complex delivery of home care services. In addition to the home care professionals working directly within the EOEA, independent home care case managers across the state serve local home care agencies known as Aging Services Access Points or ASAP’s. ASAP’s in Massachusetts coordinate all elements of homecare for local elders, including: information and referrals, needs assessments, care plans, purchase of services, and monitoring of plan effectiveness. Consolidating all of these important roles into a single agency enables elders and their families to efficiently access relevant support services (Butler 2013).

I will now provide a brief overview of the history of home care policy in the United States, starting with the demographics of home care recipients and progressing through major policy advances in the twentieth century. I will survey the first major home care demonstration projects and summarize key policy recommendations put forth by leading home care experts. I will end with a brief synopsis of recent changes to both federal and state home care policies.

Demographics of Home Care Recipients in the United States

To encompass the broadest relevant population, many policy and demography studies combine the sub-populations of home care and institutional care into a unified “long-term care population” as those who require help with one or more activities of daily living (ADL’s) or instrumental activities of daily living (IADL’s). As of 2010, 10.9 million or 4% of community residents in the United States had long-term care needs (Kaye 2010). Of these, half are elderly, and 92% receive informal unpaid help, typically from family members or friends; 13% receive paid help of some sort, including Medicaid-funded state-based home care services. Median expenses for the community-dwelling long-term care population were \$928 per month (inflation-adjusted in 2009 dollars). For those with one or more ADL needs (rather than IADL needs alone, indicating a heightened level of disability), median monthly expenses were \$1069, or about one fifth the cost of institutional (nursing home) expenses. In addition to the 10.9 million community-dwelling residents with long-term care needs, in 2010 there were an additional 1.8 million nursing home residents. The nursing facility population is predominantly elderly, and their long-term care needs are typically funded by a combination of Medicaid and out-of-pocket sources. Nursing facility residents’ per-person expenses are 5 times that of community-based long-term care residents, or \$5243 per month in 2009 dollars (Kaye 2010). Long-term care needs are expected to grow as the American population ages and advances in medical technology allow younger adults to survive with formerly fatal conditions, albeit with long-term disabilities.

Early pressures for (a return to) home-based care

The home has historically served as the locus of nearly all medical care; birth, death, and convalescence after illness or injury all took place at home, with family members providing the bulk of caregiving (Benjamin 1993). In the mid-1800’s, physician house calls supplemented home-based custodial care of the ill (including ADL and IADL supports). Over time, increasing numbers of the acutely and chronically ill sought hospital-based care. By the first decades of the twentieth century, health care providers and policymakers began to prioritize hospitalization for acute illness over slow convalescence from chronic conditions. In the first decades of the

twentieth century, most chronic illnesses (e.g., congestive heart failure) were incurable, frequently terminal conditions with limited treatment options. Hospital administrators faced *tensions between caring for acutely versus chronically ill patients* during the First World War. Whereas hospitalization and treatment for an injured WWI service member might yield substantial functional improvement, a lengthy hospital stay for a patient with congestive heart failure offered less obvious benefit. Growing concern over the chronically ill “using up” valuable hospital beds led policymakers to propose home-based medical and nursing care as a viable *alternative to hospitalization*. Through the 1930’s and 1940’s, home care was seen as a less expensive alternative to acute hospitalization for the chronically ill. As discussed later, this contrasts with modern home care’s political appeal as a less expensive *alternative to institutionalization* in nursing facilities, rather than hospitals (Benjamin 1993).

Insurance coverage for home care: from Blue Cross-Blue Shield to Medicare

Montefiore, based in New York City, was an early leader among home care providers. Montefiore offered a flexible and comprehensive spectrum of home care services ranging from medical and nursing care to custodial care like homemaking and personal care services. A 1956 report by the Commission on Chronic Illness analyzed Montefiore in its review of care of the chronically ill, and recommended organized home care programs that provide a full spectrum of services with physician supervision and centralized management. At the same time, Blue Cross-Blue Shield (BCBS) provided home-based services that were explicitly linked to recent hospitalizations. Within the decade, Medicare was created with post-hospitalization home care services that mirrored BCBS’s own framework. Even so, Medicare’s home care policies were rather limited, and Medicaid’s home care services were largely an “afterthought,” according to some home care scholars – quite the irony given its role as a predominant federal payer for diverse long-term care services (Benjamin 1993).

In the early years after the advent of Medicare and Medicaid, home care utilization slowly increased. As mentioned, Medicare’s home care benefits were limited to post-hospitalization care. Although initially Medicaid coverage for home care services were optional, changes to the law in 1967 mandated home care coverage as well. Most of the growth in home care utilization derived from increases in private home care providers and hospital-based home care agencies (Benjamin 1993).

Rapid home care expansion post-Medicare/Medicaid

During the 1970's and 1980's, rapid growth in home care use paralleled accelerated growth in national health care expenditures. A major source of growth was the Medicaid 1915 (c) waiver program, passed in 1981. This waiver program offers matching federal funds for states' expansion of home and community based services as an alternative to institutional care (LeBlanc 2000, Grabowski 2006). The popularity of these waivers among home care policymakers is a direct consequence of home care being "pitched" as a cheap alternative to institutionalization. Cost and value rhetoric has largely driven policies defining home care reimbursement and regulation, often framing home-based care as a fiscally conservative alternative to nursing homes. Yet rapidly home care's expanding bill worried policymakers and politicians. With the arrival of the Reagan presidency, budgetary concerns and fiscal conservatism prompted several rigorous studies of home care's costs and effects.

Early home care policy: a look at the evidence

Home care's first major test was the Channeling Demonstration (1979–1987), a multi-state comprehensive home care demonstration project spanning the Carter and Reagan presidencies (Benjamin 1993). The Channeling Demonstration crucially identified subpopulations with differential home care expenditures. Key findings are as follows.

Male home care consumers incurred lower personal care and housekeeping costs per community day than female consumers. In contrast, consumers with cognitive impairment like dementia incurred higher personal care and housekeeping costs but lower nursing, therapy, and home health aide costs per community day than other consumers. The very elderly (aged 85 or higher) had higher personal care and housekeeping costs per community day compared to younger consumers, although these same consumers incurred slightly lower nursing, therapy, and home health aide costs. Other risk factors for higher nursing, therapy, and home health aide costs include a personal history of cancer or stroke (Liu 1990).

Those living alone, as well as those with dependency multiple ADL's, incurred higher costs in both categories. Reimbursement for case management services increased personal care costs but not skilled nursing, therapy, or home health aide costs. In summary, personal care and housekeeping costs were higher for women, older adults (aged 85 and above), and those living

alone. In addition, higher degrees of ADL limitations or cognitive impairment likewise increase personal care expenditures (Liu 1990).

Health policy analyst William Weissert reviewed dozens of home care studies, including the landmark National Channeling Demonstration, to determine whether home care services were cost-effective, improved consumer health status, or decreased caregiver burden, among other outcomes (Weissert 1991).

To assess home care value, Weissert defines home care “net costs” as the savings from avoiding hospital and nursing admissions (thus present in the control group), minus the added costs of home care and other community services. According to this formula, the Channeling Demonstration produced a 6% increase in net costs for its basic care management model, and an 18% increase in net costs for its case management plus expanded home care services model. These costs are comparable to an estimated 15% increase in net costs for home care and other community services, as summarized from Weissert’s own 1989 analysis of 27 controlled trials on home- and community-based services (Weissert 1988). Often, home care cost and value assessments were limited by poor targeting of participants as those at high risk of institutionalization, as control groups had remarkably low rates of nursing facility placement (less than 25% for 70% of the studies).

Other performance measures assessed across 27 relevant studies include effects on survival, ADL independence, and mental functioning. Unfortunately, a common theme among all three outcomes is lack of statistical significance. For example, only 8 studies demonstrated a significant change in survival, and most of these suggested that home- and community-based services improve survival. Only 7 studies reported significant effects on ADL’s, with 4 negative and 3 positive effects, leading the author to conclude overall effects were “negligible.” Only 2 studies reported significant changes to mental functioning, and both demonstrated improvement. In summary, the author notes:

“Patients who were young-old, minimally disabled, and socially supported may have benefited. But others got worse: the old-old, the severely dependent, and socially deprived patients may have become more dependent and functioned less well when given community care. These subgroup findings are tentative, however, due to small sample sizes and some conflicting results.” (Weissert 1988).

In contrast to paltry evidence for favorable survival, daily activities and mental functioning, psychosocial outcomes were more promising. In particular, the home and community services offered to treatment groups improved life satisfaction, activity participation/performance, and social interactions. In addition, informal caregivers reported significant benefits with fewer overall unmet needs (Weissert 1988).

Policy Changes in a New Era: Arizona's Example

Health policy analyst William Weissert summarized the data available on home care interventions and concluded, "These studies found home care was used mostly by those not at risk of entering a nursing home, costs increased with the provision of home care, and benefits of home care are few and fleeting" (Weissert 1991). In the early 1990's, home care utilization surged and expenditures grew 20% per year. Early in the Clinton Presidency, Weissert declared three key proposals for home care policymakers entering this new era:

- Focus on more effective targeting of those at risk of long-term institutionalization. Specifically, apply multivariate preadmission screening to offer home care services only to the most at-risk.
- Consider looking beyond cost savings or health benefits, and instead emphasize expected benefits of psychosocial outcomes for patients and caregivers.
- Adopt prospective budgeting models to set reimbursement rates that incentivize providers to minimize home- and community-based costs.

Arizona, a late adopter of Medicaid, used policy ideals set forth by Weissert to expand their home- and community-based services to while capturing significant cost savings. The Arizona Long-Term Care System was the nation's first state wide capitated program for home and community based services (Weissert 1997).

Its screening criteria are very strict, using risk models to predict a prospective client's need for long-term care in a nursing facility; expected need for nursing facility state must exceed three months for an Arizona consumer to be eligible. Home-based care services in the Arizona model are explicitly designed to substitute for (and minimize use of) nursing facility care. Capitated payment models blended home care as well as nursing facility services, incentivizing agencies to utilize the home-based care whenever feasible. Similar to the independent case management

teams in Massachusetts, eligibility for home care services under the Arizona Long-Term Care System was determined by independent assessment teams. For the first time in history of home care in the United States, Arizona showed that a statewide model of home care services can actually substantially reduce long-term care costs (Weissert 1997).

1990's to Today: Changes to Home Care Service Delivery

Federal legislation and judicial rulings since the early 1990's have led to a number of changes in home care service delivery. After loosening of Medicare rules in the late 1980's, home care spending under Medicare grew from \$3.9 billion in 1990 to \$18.3 billion in 1996 (Komisar 1997).

A major change during the Clinton administration was the Balanced Budget Act of 1997, which placed per capita volume limits on home care services. As might be predicted, home care consumers with the greatest needs were most affected (with services restricted) by this change, a major criticism of this Act. Nonetheless, spending growth slowed substantially (Feder 2000).

In 1999, in what is now known as the Olmstead Decision, the United States Supreme Court ruled that mentally disabled adults are entitled to received care in the "least restrictive setting." This ruling paved the way for broader Medicaid coverage of home- and community-based services as an alternative to institutional care. Finally, in 2000, Congress developed the National Family Caregiver Program, setting precedent for family caregivers to receive federal funding and federal support (Butler 2013).

Massachusetts has enacted multiple forward-thinking policy changes since 2000. The "Money Follows the Person" demonstration increased funding flexibility to empower individuals in nursing facilities to return to the community, and the model continues to this day. In 2004, Massachusetts unveiled the Comprehensive Screening and Service Model (CSSM), directly placing home care agency workers in nursing facilities to screen new admissions for community care options. In effect, CSSM seeks to maximize rates of consumers' return home with services, and prevent or delay institutional long-term care. In 2006, Governor Romney signed the "Equal Choices in Long Term Care Settings" bill, and in 2009 Massachusetts' Options preadmission screening program expanded community options counseling to adults of all income levels. Massachusetts home care policymakers have consistently demonstrated a passion for maximizing choices and services for elders and persons with disabilities (Butler 2013).

Student role: *My practicum project and subsequent literature review*

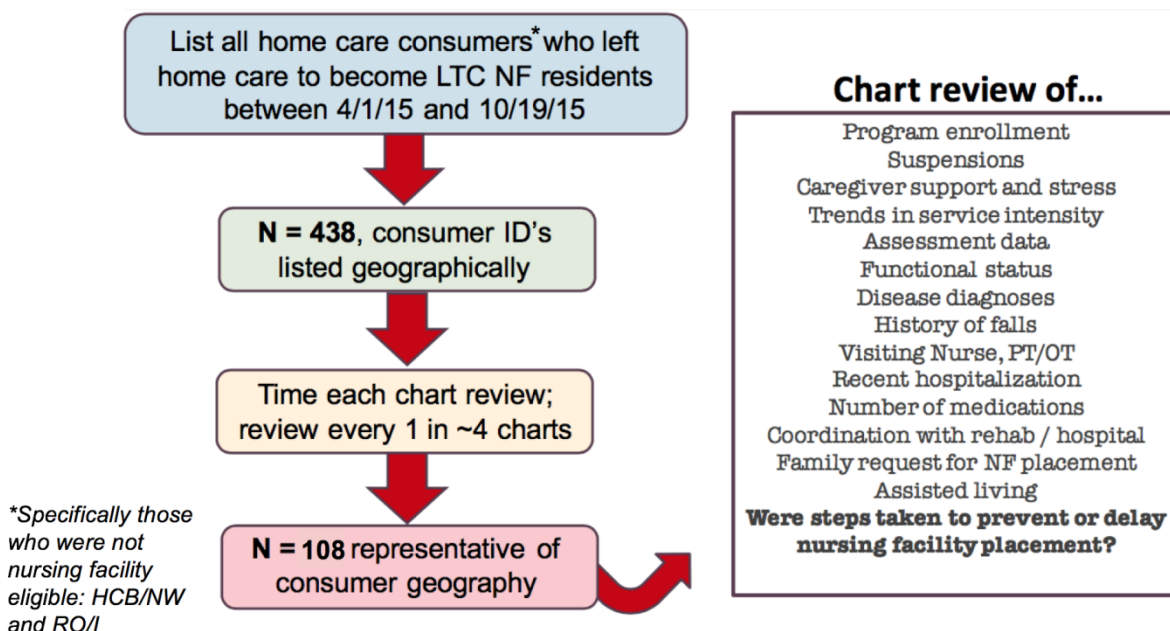
As may be evident from the previous section, I have a personal policy interest in home care and its history. In 2015-2016, I earned a Master's in Public Health with a concentration in Health Policy from the Harvard T.H. Chan School of Public Health. One component of the health policy curriculum was a student policy project, or "practicum," with an outside organization. I selected the Massachusetts Executive Office of Elder Affairs (EOEA) for my practicum experience, and as an EOEA intern I conducted a chart review of elders to better understand strengths and weaknesses of Massachusetts's home care services. As described more fully below, I extracted de-identified quantitative and qualitative data for home care consumers who terminated home care services and entered nursing facilities for long-term care. I was interested in understanding potential strengths and weaknesses faced by home care consumers. I sought to derive key themes regarding the lived experience of home care consumers, their families and other caregivers, and their case workers. I wondered whether caregiver characteristics like number of informal supports, relationship between caregiver and consumer (e.g., spouse, child, friend), or evidence of caregiver burden might correspond to consumers' or families' requests for nursing facility long-term care. I wondered how multi-system medical conditions or other measures of disability and poor health status might limit consumers' ability to thrive in the community.

I conducted my clinical chart review between October 2015 and April 2016. In May 2016, I presented my findings (below) to the home care team at EOEA, as well as policy recommendations to improve home care effectiveness for Massachusetts elders. In the summer of 2016, after completion of my Master's in Public Health and my return to the medical school, I reached out to my mentors at EOEA about the possibility of extending my home care project with a historical literature review of American home care policies. I conducted this analysis (as summarized in the Introduction, above) during my fourth year of medical school.

Methods: Chart review data extraction and analysis

Senior staff members at the Massachusetts Executive Office of Elder Affairs compiled an Excel spreadsheet template with key clinical information to extract from each consumer's home care electronic chart. Topics for each type of clinical "question" were broken down into: Details, Care Plan, Assessments, and Journal Notes.

I conducted my chart review on a geographically representative sample of nursing facility ineligible home care consumers in Massachusetts whose home care services were terminated between April 1st and October 19th, 2016. I received a list of approximately 435 consumer ID's, organized first by geographic catchment area (i.e., alphabetic list of consumers' local Aging Services Access Point (ASAP), then by consumer last name. I conducted full chart reviews on approximately 15 consecutive consumers. After these early reviews, I calculated the average time required for each chart review and decided to extract data from one fourth of participants. I maintained an even geographic distribution and ultimately extracted de-identified chart data (described below) for 108 home care consumers.



Key information in the first section, “Details,” included the participants’ de-identified home care user ID’s, the type of program enrollment (‘Home Care Basic – Non-waiver’ for the lowest income adults, and ‘Respite Over-income’ for middle-income adults), whether and when home care services were suspended (canceled) in the six months prior to home care termination, and whether consumers had listed caregiver contact information. For consumers with registered caregivers, I also recorded the caregiver relationship to home care consumer (e.g., spouse, child, friend) and details regarding caregiver referrals and support services. Under “Care Plan,” I recorded whether consumers had an active care plan, whether they received home care services, and whether intensity of services ordered and delivered changed in the last six months.

The largest question category was “Assessment.” Information gleaned in this section was directly pulled from the consumer’s most recent formal home care assessment prior to service termination. The data available in home care assessments are rich and diverse, and likewise the information collected in this section was extensive, ranging from number of informal supports, evidence of caregiver stress, functional status, medical conditions and medication use, and recent falls or hospitalizations.

The final section, “Journal Notes,” relied upon my subjective assessment of free-text journal entries to ask interesting and important questions. In the journal, home care professionals document phone calls, emails, and other forms of communication with consumers, family and other caregivers, health care professionals and home care staff during day-to-day care coordination. I read and summarized conversations between three major stakeholders: 1) family and other caregivers, 2) home care agency (ASAP) professionals, and 3) health care representatives including nurses and case managers at rehabilitation facilities. I determined, to the best of my ability, whether eventual nursing facility placement was actively selected by the consumer or the consumer’s family members. Regarding consumer or family request for nursing facility long-term care, I did not distinguish between consumers’ or families’ early or late decisions to pursue facility placement. For example, a frequent theme from my journal analysis was that family members who initially favored a home discharge later changed their minds and requested placement, often after documented conversations with health care facility case managers and other clinicians. In these instances, despite an initial preference for a home discharge, I recorded a positive consumer or family request (“yes”) for nursing facility placement.

In a similarly subjective review, I analyzed whether local home care agencies participated in hospital or rehabilitation facility discharge planning (including in-person meetings, phone calls, messages, and other remote communication). I also determined whether, in my opinion, “clear steps” were taken to prevent or delay nursing facility placement. I used a broad definition of “clear steps,” including physical therapy home evaluations (to assess safety and accessibility of home discharge), transition to an assisted living facility (miscoded as “nursing facility placement”), and evidence of clear plans to return home with increased services after additional rehabilitation. Of note, home care services automatically terminated after 90 days of suspension (a term referring to temporary cancellation of service delivery, typically while patients are hospitalized or receiving inpatient rehabilitation). In some cases, although paperwork was filed to transition from a short-term to long-term nursing facility stay, journal entries made it clear that the eventual plan was a return home with increased services. In these instances, I would record a positive “clear step” (“yes”) to prevent or delay placement.

Finally, I performed an informal qualitative analysis of key themes in each consumer’s home care journey. Frequent patterns or “stories” shared among many consumers are reported in the Results section below.

Results: Trends in home care termination

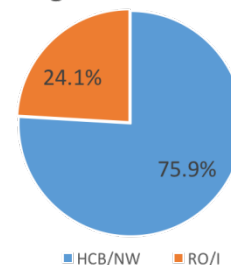
Program and Service Details

Of all consumers analyzed, 75.9% were in the Home Care Basic – Non-Waiver (HCB/NW) program, and 24.1% were in the Respite Over – Income (RO/I) program. The former serves lower income adults, and the latter expands home care access to middle-income adults. As mentioned elsewhere in this report, the HCB/NW and RO/I consumers had home care needs but were not so functionally impaired that they qualified for nursing facility placement. These consumers' transition to nursing facility long-term care was unanticipated given their baseline functional impairment – a curiosity that sparked this chart review project.

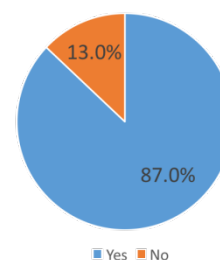
The vast majority – 87.0% – of consumers had one or more service suspensions in the six months prior to home care termination. During a service suspension, services are ordered (e.g., homemaker, meal delivery, personal care) but not delivered to the consumer. A typical reason for a service suspension is hospitalization and post-hospital rehabilitation.

Fewer than one-third (31.8%) of consumers received “Certified Home Care Services” such as a visiting nurse or home physical therapy. The remaining consumers (68.2%) received only custodial home care services, such as meal delivery, personal care, or housekeeping – supporting elders' functional independence.

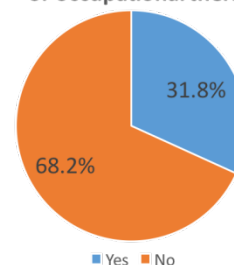
Program Enrollment



Suspension within 6 months of termination?

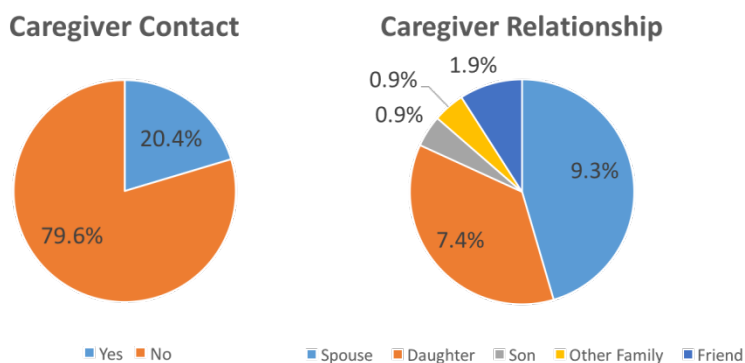


Receiving Certified Home Care Services
(E.g., visiting nurse, physical or occupational therapy)

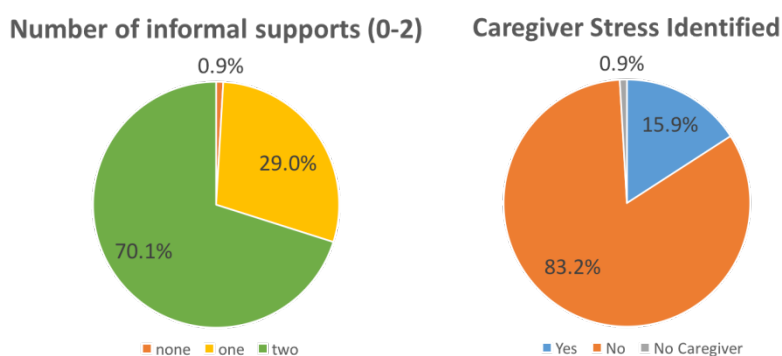


Caregivers and Support

A minority of consumers – 20.4% – had contact information for a caregiver listed in the consumer’s chart. The most common caregiver relationships reported were spouse (9.3% of total) and daughter (7.4% of total). Fewer identified caregivers were sons, other family members, or friends.



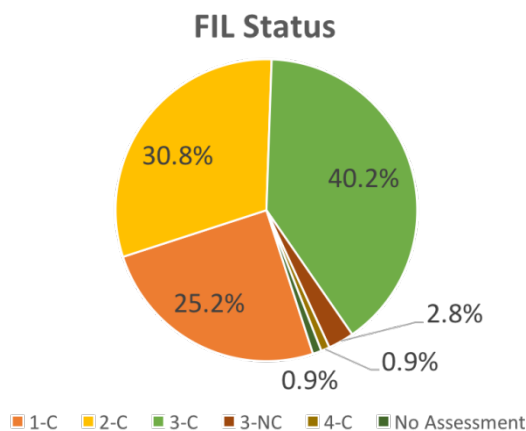
Although only about one in five consumers had registered caregiver contact information provided, virtually all consumers reported having sources of informal support. Most (70.1%) reported two sources of informal support (the maximum



reportable value), and 29.0% reported only one source of support. Overall, 83.2% of consumers’ home care assessments identified caregiver stress. Notably, caregiver stress was slightly more common among consumers with two listed sources of informal support, compared to those with only one informal support.

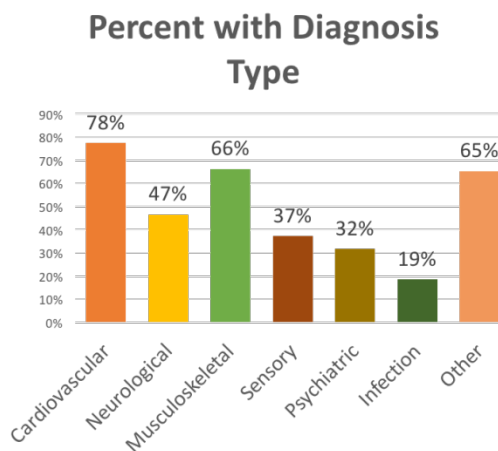
Functional Status

Although not eligible for institutionalization, many consumers had moderate degrees of functional impairment (FIL) based on ADL’s. A plurality (40.2%) of consumers were identified as having the highest level of need short of nursing facility eligibility (3-C), and only 25.2% of consumers had the lowest measure of impairment (1-C).



Co-morbid Conditions

Multiple co-morbid medical conditions are also common in this population, with the median participant living with *one or more diagnoses in three distinct body systems*. The most common diagnosis category was cardiovascular (78%), followed by musculoskeletal (66%) and "Other" (65%, includes cancer, thyroid disease,



- Common Diseases**
- Hypertension
 - Stroke
 - Congestive Heart Failure
 - Dementia
 - Arthritis
 - Glaucoma
 - Cataracts
 - Mood Disorder
 - Urinary Tract Infection
 - Cancer
 - Thyroid Disorder
 - Diabetes

and diabetes). The vast majority of consumers were prescribed nine (or more) medications. Prevalent medical conditions, including hypertension, dementia, and arthritis, are listed to the right.

Number of Medications	(0-9)
Median	9
Mean	7.27
Mode	9
Minimum	0 (N=2)
Maximum	9 (N=60)

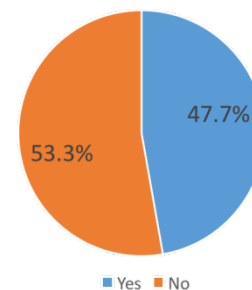
Number of Diagnoses (0-7)

Mean	3.45
Median	3
Minimum	1 (N=3)
Maximum	6 (N=5)

Fall Risk

Nearly half of consumers had reported at least one recent fall, such as a fall recorded in the consumer's most recent home care assessment or a fall documented in the consumer's journal. Despite this high fall burden, only 39.2% of identified falls resulted in hospitalization (i.e., the fall was the primary reason for hospitalization).

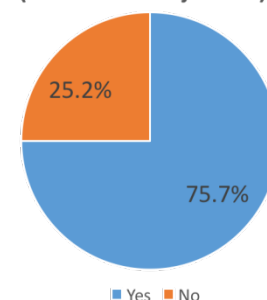
Identified Recent Falls (assessment or journal)



Hospitalizations

About three-quarters (75.7%) of consumers had recent hospitalization in the months leading up to their home care termination and nursing facility placement. Both hospitalizations recorded in the most recent home care assessment hospitalization

Identified Hospitalizations (assessment or journal)



documented in the consumer's journal were counted in this assessment.

Discharge Planning

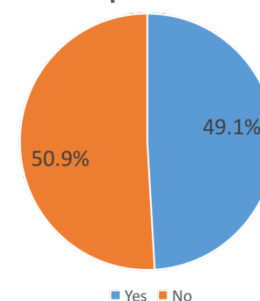
In approximately half of nursing facility placements for long-term care, the placement was ultimately requested by the consumer or family. As described in the Methods section, a "yes" in this assessment includes those who initially pursued a trial of home discharge but were persuaded to proceed with nursing facility placement.

Although this chart review aimed to study home care consumers who entered nursing facilities, approximately 9.4% of consumers in this sample were miscoded as nursing facility placement and actually entered assisted living facilities. (Note: individuals who entered assisted living facilities *were* included in this report's main analyses).

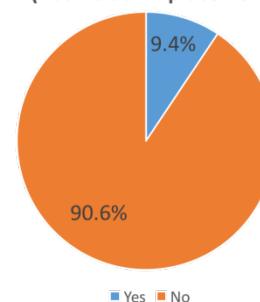
Home care agencies, or ASAP's, actively participated in discharge planning only 36.5% of the time. More often than not, discharge plans for a consumer (undergoing rehabilitation at a nursing facility) were finalized by nurses and case managers at the facility without documented conversations with the consumer's own ASAP case manager.

In 27.8% of cases, I identified clear steps taken to prevent or delay nursing facility placement (based on my subjective analysis of a consumer's home care journal). Evidence of clear steps taken almost always included documented ASAP communication with rehabilitation case managers during discharge planning. Other examples of clear steps taken include a consumer's transition to an assisted living facility (by definition delaying nursing facility placement) and physical therapy home safety assessments (part of planning a home discharge).

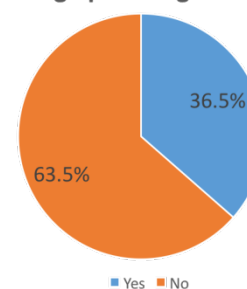
Consumer or family requested NF placement



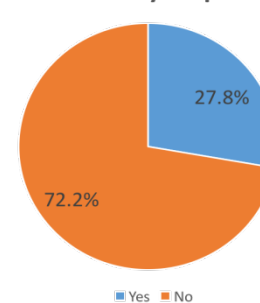
Discharged to Assisted Living (not a true NF placement)



Did ASAP participate in discharge planning meeting?



Clearly supported steps taken to prevent or delay NF placement?



Qualitative Themes: Patterns of Leaving Home Care

I identified the following key themes from free-text journal entries:

- The most common pattern of events leading to a home care consumer's nursing facility placement was a medical setback (such as infection, fall, or a stroke) which led to hospitalization followed by short-term rehabilitation. The short-term rehabilitation often took place at a facility that also provides long-term care nursing services, and often these facilities are in cities or towns other than those where the consumer's home care agency is based. If the consumer has been in the hospital and or a rehabilitation center for more than 90 days, home care services will automatically terminate for the consumer. Rarely, home care termination was merely a technicality; in these exceptional cases, journal entries documented a clear intention for eventual home discharge with additional services. Usually, however, paperwork was filed to transition to long-term-care at the nursing facility without plans for a future home trial.
- One relatively common exception to the pattern described above is that family members of consumers with dementia more often sought direct placement in nursing facilities, in absence of an acute health setback or hospitalization. Often, family members or other caregivers of consumers with dementia reported stress and progressive disease as limitations to continued home caregiving.
- Almost without exception, home care agencies were immediately aware of a consumer's hospitalization. This is evidenced by documented phone calls within a day or two of a consumer's hospitalization to homecare vendors, calling to suspend services. However, despite knowledge that the consumer was hospitalized, documented evidence of communication with hospital or revocation case managers is very limited.
- Early on after a consumer suffers a health setback leading to hospitalization or rehabilitation, family members and consumers often hoped for discharge home with additional services. However, many families ultimately requested long-term care nursing facility placement - often after documented conversations between the rehabilitation case manager and family members regarding mobility concerns safety concerns.

Discussion: Conclusions, policy implications, study limitations**Conclusions: Review of Key Findings**

In this representative sample of low- to middle-income Massachusetts home care consumers, an acute health setback (like stroke, fall, or infection) often initiated a predictable progression through hospitalization and rehabilitation at a short-term nursing facility. After ninety days in a hospital or nursing facility, home care services automatically terminated and consumers' case managers often successfully filed for long-term care conversion at the same facility.

Caregiver burden was not identified as a major factor leading to nursing facility placement in this population. Only 15% of consumers' caregivers reported stress, anger, or inability to continue caregiving during routine home visits by case managers and other home care professionals. However, it is possible that this value reflects an understatement of true caregiver burden in the home care population. Often assessments are performed with the consumer and caregiver in the same room; caregivers who struggle with burnout or various "taboo" emotions towards caregiving such as resentment or anger may feel reluctant to share this information openly. Nearly half (48%) of nursing facility placements were requested by either the consumer or a family member, often after documented conversations with rehabilitation center case managers who recommended long-term placement. Although understandably long-term care placement rises as a priority after a major health setback, family members' requests for placement may indicate caregiver burdens or unmet needs not otherwise captured by clinical home care assessments.

In addition to multi-system medical diagnoses, the median consumer took nine or more medications daily. Of note, the maximum number of medications that could be recorded in home care assessments was nine, although many participants' individual lists contained twenty or more distinct medications. Polypharmacy has many opposing definitions, ranging from "the use of multiple drugs or more than are medically necessary" to more than five medications in an outpatient (ambulatory) setting (Maher 2014). Under the latter definition, most home care consumers in this study were affected by "polypharmacy," although this does not automatically imply that consumers' medications were not medically necessary. Nonetheless, home care

professionals should be aware that use of multiple medications increases risk of medication non-compliance, inappropriate dosing, drug-drug interactions, drug-disease interactions, and adverse effects (Bushardt 2008).

Of consumers studied, only about one-third (34%) of the time were consumers' home care agencies directly involved in discharge planning. Direct involvement was broadly coded as any documented two-way communication (in-person visits, telephone calls, or messages) between short-term nursing facility case managers, nurses, or other clinical staff, and the consumers' local home care agency (ASAP). Infrequently (11%), consumers entered assisted living facilities rather than nursing facilities. Projecting from this geographically representative sample of Massachusetts home care consumers, the true rate of nursing facility placement for long-term care may be approximated at 90% of the reported total.

Policy Implications and Next Steps

Qualitative review of consumers' home care journals identified key themes associated with nursing facility placement. When poring over consumers' individual stories, patterns emerged. These patterns of home care "failure" illuminate policy challenges as well as opportunities to strengthen home-based care and community-based aging. I will discuss three major policy topics, as well as potential "next steps": 1. Communication breakdown, 2. Caregiver needs, and 3. Senior housing availability.

Communication Breakdown

A subset of home care agencies (ASAP's) documented robust and open channels of communication among hospitals, rehabilitation centers, consumers, and consumer families. Unfortunately, most of the time, communication was limited after consumers were admitted to hospitals or rehabilitation facilities. Frequently, the health care institution was geographically isolated from the consumer's local home care agency, and case managers and other home care professionals were caught in a game of "phone tag." In-person visits and interdisciplinary care meetings were very effective, yet rare. Email correspondence between home care agencies and consumers' family members was relatively uncommon but high-yield. In contrast, email or other secure message correspondence between home care agencies and case managers at rehabilitation facilities was almost nonexistent. In my analyses, case manager, nurse, social

worker, and other home care and health care professionals relied nearly exclusively upon telephones for communication outside their facility. It is unclear why this is the case, but limited access to secure messaging or distrust of encrypted emails across institutions may contribute.

Potential policy improvements, opportunities, or next steps, could include identification of “Best Practices” for discharge planning and communication among home care agencies, rehabilitation centers, and consumers and their families. For example, organizations or individual staff members with high levels of home discharge might participate in a focus group or other qualitative analyses to understand their approach to coordination across institutions, and these data could be compared to standard practices in other agencies. Alternatively, quantitative measures of agency organization, such as consumer to staff ratios, might illuminate additional elements of “high achieving” ASAP’s. Greater promotion the Comprehensive Screening and Services Model (CSSM) is also likely to improve communication and home discharge planning.

Caregiver Stress

Another identify risk factor for nursing facility placement is caregiver stress. The formal assessments I reviewed asked about key indicators of caregiver stress, including stress, anger, and inability to continue caregiving. However, as discussed earlier, these assessments might significantly underestimate caregivers’ emotional and practical challenges. One can imagine that assessments performed with both the consumer and caregiver present might lead caregivers to downplay burden or burnouts. Further, few consumers have registered caregiver contact information; caregiver contacts are part of a Massachusetts Executive Office of Elder Affairs caregiver support program. No doubt the caregiver support program is an essential tool to promote to caregiver well-being. Initiatives to increase enrollment and participation in the caregiver support program could substantially impact caregiver wellbeing and resilience.

An opportunity to improve caregiver resilience and reduce nursing facilities placement could be the addition of a targeted, forward-looking question in the home care assessment. Asking, “Are you, [primary caregiver or family member] of [Consumer’s Name], actively seeking long-term care placement options for [Consumer’s Name] in the next six months?” Such a prompt, asked every six months in home care assessments, might identify caregivers or family members who do not explicitly endorse feelings of burnout but nonetheless are considering institutional alternatives to caregiving.

Scarcity of Senior Housing

A final policy challenge associated with home care consumers' nursing facility placement regard the scarcity of affordable senior housing. A less common but relevant pattern emerged in my positive journal analyses: some homecare consumers lose their senior housing after prolonged hospitalization and rehabilitation. Of course, "home care" is much more successful when a consumer has a place to call home! Unfortunately, scarcity of affordable housing in many regions of this country have led to waiting list for limited units. It may be impossible to "hold" a senior's subsidized unit while care managers are crafting discharge plans, especially if a home discharge with increased services is deemed unlikely. Asking all hospitalized consumers, "What would happen to your home if you were away for three or more months?" could be a simple approach to identify consumers at risk of housing-based obstacles to home discharge. This early screening is likely already implemented in a subset of home care agencies, but if universally applied could allow agencies to identify consumers at risk and to target interventions.

Study Limitations

This chart review combined quantitative and qualitative analyses. Limitation of this study can likewise be categorized into: 1.) limitations in statistical analyses from the categorical and quantitative data extracted, and 2.) broader limitations in qualitative study design due to the informal and subjective nature of the thematic analysis and the absence of additional qualitative coders to validate identified themes.

Statistical analysis was limited to descriptive statistics only. I was able to identify key characteristics of the home care population that entered nursing facilities in 2015, but because I did not extract the same data from home care consumers who remained in the community, I am unable to perform formal statistical tests to determine independent risk and protective factors for nursing facility placement. (Analysis of a matched control group in a future project could be very valuable.) In addition, my data set was found to contain miscoding of nursing facility placement when consumers actually went to assisted living centers. Finally, multiple potential risk factors for nursing facility were not captured in this study, including consumers' income level, geographic location, insurance status, and other demographic factors.

Acknowledgements

Many thanks to the Massachusetts Executive Office of Elder Affairs staff and volunteers for all their support, especially Hope Turner, Special Assistant, and Robin Lipson, Chief of Staff and Chief Strategy Officer. Thanks also to Amy Rosenthal, Harvard T.H. Chan School of Public Health.

References

Kaye HS, Harrington C, LaPlante MP. Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much? *Health Aff* [Internet]. 2010 1 [cited 2015 Dec 2];29(1):11–21. Available from: <http://content.healthaffairs.org/content/29/1/11>

Home Care [Internet]. Executive Office of Elder Affairs. 2011 [cited 2016 Apr 17]. Available from: <http://www.mass.gov/elders/homecare/index.html>

Butler J. Home Care in Massachusetts - A History. Minuteman Senior Services; 2013 Jun.

Benjamin AE. An historical perspective on home care policy. *Milbank Q*. 1993;71(1):129–66.

Grabowski DC. The cost-effectiveness of noninstitutional long-term care services: review and synthesis of the most recent evidence. *Med Care Res Rev*. 2006 Feb;63(1):3–28.

LeBlanc AJ, Tonner MC, Harrington C. Medicaid 1915(c) home and community-based services waivers across the states. *Health Care Financ Rev*. 2000;22(2):159–74.

Liu K, McBride TD, Coughlin TA. Costs of community care for disabled elderly persons: the policy implications. *Inquiry*. 1990;27(1):61–72.

Weissert WG. A new policy agenda for home care. *Health Aff (Millwood)*. 1991;10(2):67–77.

Weissert WG, Cready CM, Pawelak JE. The Past and Future of Home- and Community-Based Long-Term Care. *The Milbank Quarterly* [Internet]. 1988 [cited 2017 Feb 2];66(2):309–88. Available from: <http://www.jstor.org.ezp-prod1.hul.harvard.edu/stable/3350034>

Weissert WG, Lesnick T, Musliner M, Foley KA. Cost savings from home and community-based services: Arizona's capitated Medicaid long-term care program. *J Health Polit Policy Law*. 1997 Dec;22(6):1329–57.

Komisar H. The Balanced Budget Act of 1997: Effects on Medicare's Home Health Benefit and Beneficiaries Who Need Long-Term Care [Internet]. 1997 [cited 2017 Feb 2]. Available from: <http://www.commonwealthfund.org/publications/fund-reports/1997/dec/the-balanced-budget-act-of-1997--effects-on-medicares-home-health-benefit-and-beneficiaries-who-need>

Feder J, Komisar HL, Niefeld M. Long-term care in the United States: an overview. *Health Aff (Millwood)*. 2000 May–Jun;19(3):40–56.

Maher RL, Hanlon J, Hajjar ER. Clinical consequences of polypharmacy in elderly. *Expert Opin Drug Saf*. 2014 Jan;13(1):57–65.

Bushardt RL, Massey EB, Simpson TW, Ariail JC, Simpson KN. Polypharmacy: misleading, but manageable. *Clin Interv Aging*. 2008;3(2):383–9.