Effects of Informal Care for Persons with Alzheimer's Disease and Related Dementias

Presenter: Grace Jiaxuan Nie

Mentor: Norma Coe, PhD

SUMR @ Penn University of Pennsylvania

Penn LDI Leonard Davis Institute of Health Economics

Perelman School of Medicine University of Pennsylvania

Road Map

- Project Overview
- Significance
- Aims
- Methods
- Personal Role
- Lessons learned

The Concept of Long Term Care

According to LongTermCare.gov:

"Long-term care is a range of services and supports you may need to meet your personal care need."

More specifically, LTC assists individuals with:

Activities of Daily Living (ADLs)	Instrumental Activities of Daily Living (IADLs)
Tasks essential for basic functioning: • Bathing • Dressing • Using the toilet • Transferring (to or from bed or chair) • Caring for incontinence • Eating	Tasks non-essential tasks for basic functioning, but central to independent living: • Housework • Managing money • Preparing and cleaning up after meals • Shopping for groceries or clothes • Using the telephone

Types of Long Term Care

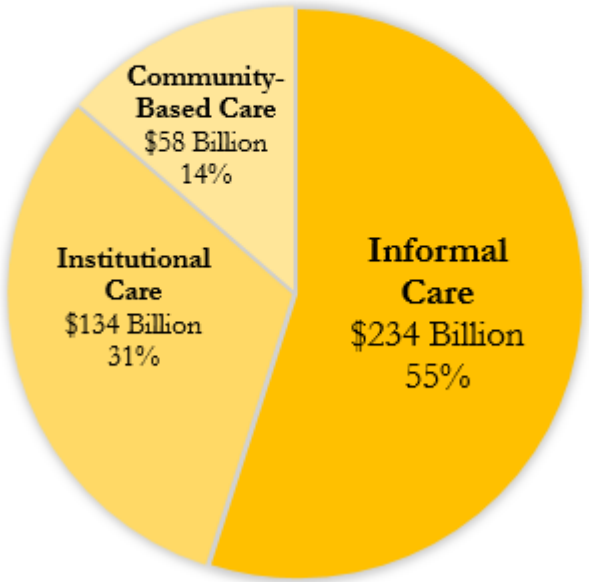
Based on location and caregivers, long term care can be classified into:

- Nursing homes
- Assisted living / residential arrangements
- Adult day care
- Home health care
- **Informal care**

Informal care: unpaid care from family and friends.

The Importance of Informal Care

Estimated Economic Value of Formal and Informal Long-Term Services and Supports for Elderly People in the United States, 2011



CBO "Rising Demand for Long-Term Services and Supports for Elderly People"
KFF "Long-Term Care: Understanding Medicaid's Role for the Elderly and Disabled"

"Among the elderly living in the community with long-term care needs, more than two-thirds rely exclusively on informal, unpaid care provided by family members – usually a spouse or a daughter. A small proportion (less than 10 percent) relies exclusively on assistance from formal (paid) caregivers ."

Why Informal Care?

- Increasing demand, stagnant supply
  - By 2050, 1/5 Americans will be over 65 years old.
  - Demand for LTC workers, measured as a percentage of non-elderly adult population, will increase from 4.8% in 2010 to 7-11% in 2050.
  - The conundrum: as society ages, the non-elderly adult population will be shrinking over the years.
- Cost effectiveness
  - "Free" care provided by the family.

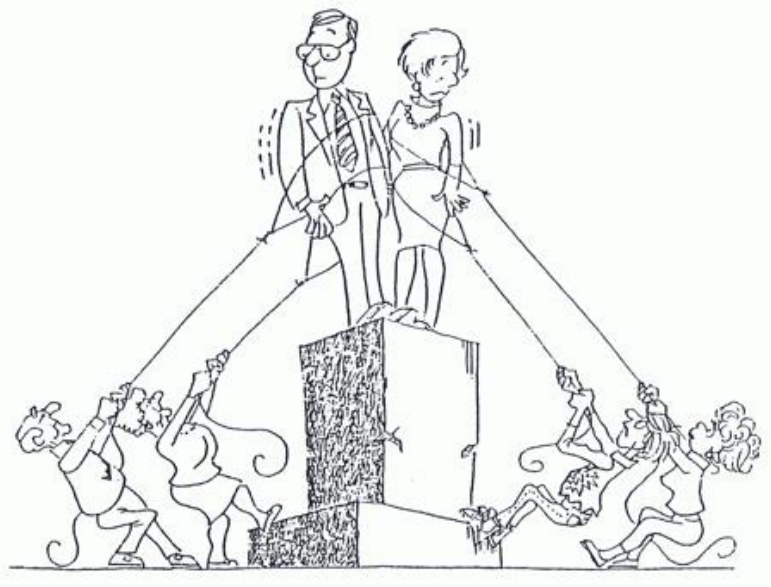
"Oh Marjorie, you should try it. The training's all government funded."

CBO "Rising Demand for Long-Term Services and Supports for Elderly People"

But, Is Informal Care Really "Free"?

Past literatures show that informal care induces caregiver burden and reduced labor market participation.

A new study suggests that the median welfare cost of informal care is about $179,478, similar to the median welfare cost of nursing home care.



Coe et al, 2018

Policies that Support Informal Caregivers

- Training: for the past 15 years, all states have participated in the National Family Caregiver Support program.
- Tax credits
  - About half of the states give out tax credits of $500 - $1,000
  - E.g. In 2001, CA gives $500 tax credits to taxpayers who need or provide informal care.
- Direct payments
  - Medicaid home and community-based service (HCBS) waiver recipients
    Option to select and pay their own caregivers. Generosity vary by states.
  - Veteran Affairs
    Stipend that supports informal caregivers.

Still, 95% of the informal caregivers receive NO support at all.

AARP Public Policy Institute "Fact Sheet: Long-Term Support and Services"
Nixon, D. Tax Incentive for Family Caregivers: A Cost-Benefit Analysis

Desired Impact

Previous studies tend to focus exclusively on caregiver burdens.

With a focus on the outcome of informal care compared to formal care, we hope to identify potential benefits of policies that support informal caregiving.

Aims

- **Aim 1:** Provide an expanded profile of the supply of publicly and privately financed formal care markets in order to look at all the potential avenues of care substitution between informal care and formal care.
- **Aim 2:** Estimate the effect of informal versus formal care on health outcomes for persons with ADRD.
- **Aim 3:** Estimate the effect of informal versus formal care on health care use and costs for persons with ADRD.

Aim 1

Provide an expanded profile of the supply of publicly and privately financed formal care in local markets, and the market-level correlation between formal care supply, informal care and ADRD prevalence.

Data (2005 – 2015)

- Area Health Resource File (AHRF): county-level, longitudinal health care supply information. E.g. Penetration of assisted living facilities or home health service.
- NIC-MAP: market rate of LTC. Facility-level information on independent living, assisted living, continuing care retirement communities, memory care and nursing care properties.

Combine AHRF and NIC-MAP to establish relationship between local market characteristics (minimum wage/nurse wage) and the supply and costs of long term care.

Aim 2 & 3

Estimate the effect of informal versus formal care on health outcomes, health care use and costs for persons with ADRD.

Data

- AHRS + NIC-MAP dataset from Aim 1.
- Health and Retirement Study (HRS): bi-annual household survey of Americans aged 50 or older. Information on health measures, family structures, and provision and utilization of informal and formal care.
- Medicare and Medicaid claims data: information on population health status and LTC utilization.

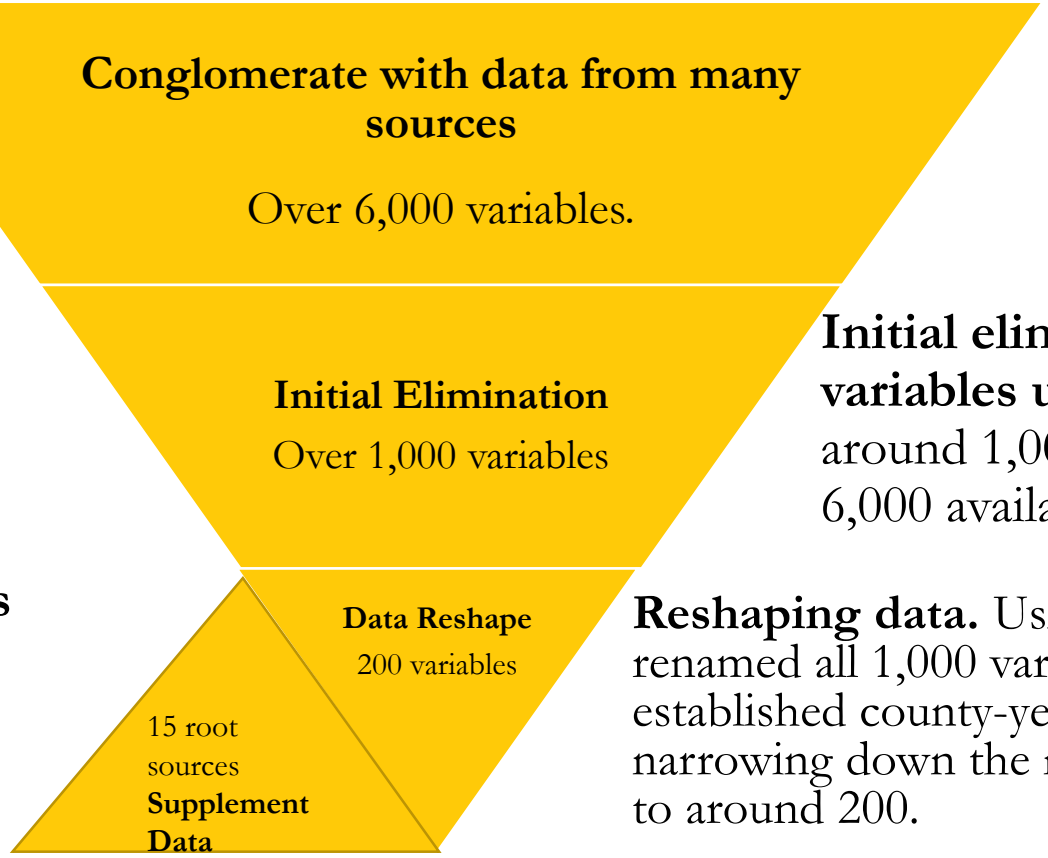
Aim 2 & 3

Estimate the effect of informal versus formal care on health outcomes, health care use and costs for persons with ADRD.

Key Variables for Regression and Analysis

Control Variables	Independent Variables	Dependent Variables	Instrumental Variables
• Alzheimer's Disease and Related Dementia • Baseline health status, measured by two-year lagged health status indicators.	• Informal care receipt • Formal care receipt	Patient Outcomes: • Physical • Mental • Emotional • Social • Deaths	• Family Structure • Formal Care Supply

Summer Progress – Aim 1, AHRF

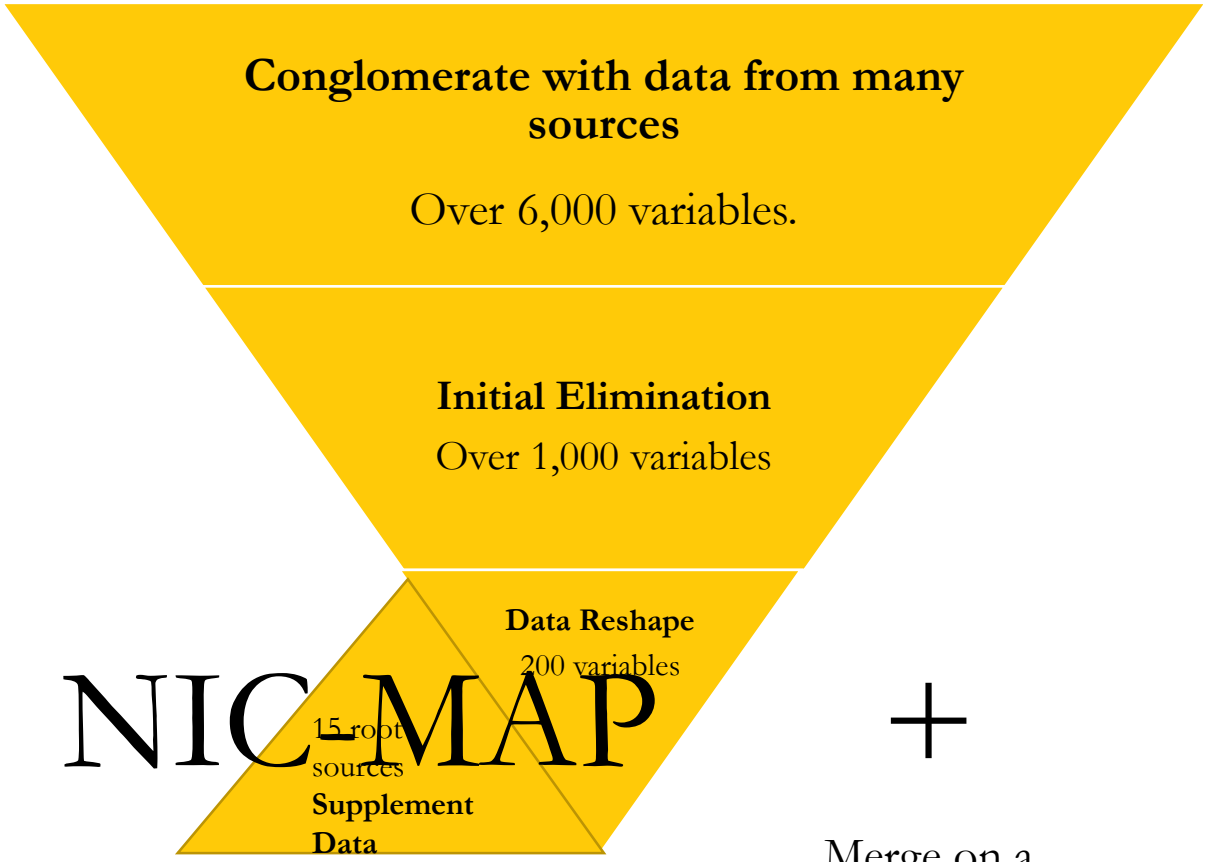


Initial elimination of irrelevant variables using SAS. Selected around 1,000 variables from over 6,000 available variables.

Reshaping data. Using STATA, renamed all 1,000 variables and established county-year observations, narrowing down the number of variables to around 200.

Going to 15 root data sources for missing years of data. Supplement the AHRF since some county-year observations were missing.

Moving Forward



NIC-MAP

+

Merge on a country-year basis.

AHRF

Lesson Learned

- Experience in data cleaning.
- Good researchers should be detail-oriented perfectionists with good patience.
- Importance of a good mentor/adviser.
- You will never know what a random conversation in the kitchen area leads to.
- Work-life balance is the key to avoiding burnout.

Acknowledgement

- Norma
- Emily
- Joanne
- Safa
- Hoag
- Renee
- Emily (LDI)
- All SUMR Scholars
- All of the mentors and friends I met throughout SUMR.

Questions?