



AAPI Caregiving Research: Chinese & Filipino Caregivers



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EXECUTIVE SUMMARY

Executive Summary

- Strong similarities are seen between both ethnic groups and the three markets, as well as in previous research conducted on caregiving in the General Market and other multicultural groups, in caregiving characteristics, habits and practices and in their information needs.
- Caregiving issues and problems are generally kept private within the family.
- Support from unpaid caregivers within the extended family is fairly common, but generally insufficient; paid caregiver support is uncommon, but frequently desired.
- Caregiver selection is not often discussed in-depth and is typically an organic process involving the consideration of a variety of factors, such as birth order, finances, and other logistics.
- Among those with traditional values, assuming the role of caregiver is a given; For others, it is a long and arduous decision-making process, involving doubts.
 - Often, assuming the caregiver role is not given sufficient planning and thought regarding implications.

Executive Summary

- Due to assuming the caregiving role, changes to relationships are mixed, but changes to caregivers' daily activities, work, social life, and health tend to be negative.
 - Caregivers do recognize the benefits of the role in their lives and some highlighted were stronger family bonds and a richer family life for the younger generation.
- Caregivers are plagued by stress, but aware of some techniques for reduction, although pressed for time to conduct them.
- The label of “caregiver” is inappropriate to their role and doesn't capture true sentiment, but no comprehensive, alternative term was found in any language.
 - “Caregivers” are seen as professionals, while respondents view their role as one from the heart.
 - The terms “helper” and “companion” were commonly used to describe the role.

Executive Summary

- End of life conversations are avoided or held in a cursory manner; there is little comprehension around end of life planning and it is rarely conducted.
- Institutional care is viewed negatively and generally distrusted, but may be considered in extreme situations.
- Awareness and usage of available caregiving resources are low.
- Respondents have a variety of information and support needs, such as training in caregiving tasks and information about available programs and resources.
 - Several mentioned interest in nutritional information and in-language information.
- Preferences for mainstream versus AAPI organizations are split, but mainstream organizations are generally more respected.
 - AAPI organizations' ability to provide communications in-language is highly regarded.
- Multiple media channels are used by the population, but print informational materials are strongly preferred.

WHO PROVIDES AND WHO RECEIVES CARE?

Typical Primary Caregiver Profile



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Age: 48 years

Marital Status: Married with kids

Annual HH Income: \$65,000

Length of Care: 5 or more years (Longer for Filipino; shorter for Chinese)

Time Spent Caregiving: From 9 hours/week to over 35 hours/week
(Some exceeded 60 hours/week)

Employment Status: Part-time or Full-time

Citizenship: US citizen

Tenure in US: About 10 - 20 years
(Longer for Filipino; shorter for Chinese)

Language: Usually bilingual

Care Recipient: Typically care for mother, who lives with caregiver

Family: Relatives live nearby

Typical Care Recipient Profile



Photo Credit: © Stephanie Rausser, 2015

Age: 75 years and older

Marital Status: Married or widowed

Length of Care: About 5 years

Language: Limited English language skills, speaks first language at home (Filipino/Mandarin/dialects)

Citizenship: US citizen

Tenure in US: Over 10 years

Caregiver(s): Receive care from multiple caregivers

Medical Condition: Consults multiple doctors, takes many medications, ambulatory (usually with help or cane), has more than one serious health issue, some have stayed in Skilled Nursing Facility

Multiple Caregivers: Unpaid Care

Support from unpaid caregivers is fairly common, but generally insufficient

- Customary that extended family members provide support (time and/or money)
- Primary caregiver's siblings typically provide second tier support
- Other family (caregiver's cousins, aunts, uncles; caregiving recipient's siblings, grandchildren) may take turns in providing caregiving support
- Family size and the number of relatives engaged in providing care have strong impact on how the primary caregiver handles challenges
- Lack of participation among family results in negative dynamics, poor relationships/ shunning

"We are five sisters. We all came here. I'm the only one who really takes care of my mother. I spend the most time with her. Maybe we all have different ways of showing our care."

Female, 57 yrs., NY

Benefits of Unpaid Support:

- ✓ Less difficult to arrange care coverage
- ✓ Reduced stress
- ✓ Increased family solidarity, closeness
- ✓ Shared financial burden
- ✓ Improved emotional and physical health

Multiple Caregivers: Paid Care

Support from paid caregivers is uncommon, but desired

- Home assistance is not very common
 - Even less common within Filipino community
- Of those with paid caregivers, many receive government support
- Of those without paid caregivers, many desire it, but financial barriers do not allow for it
 - Lack of insurance support or government subsidies, disqualified for income level



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Benefits of Paid Support:

- ✓ Less difficult to arrange care coverage
- ✓ Reduced stress
- ✓ Improved emotional and physical health

Typical Caregiving Activities

Most caregivers conduct many IADLs, some exclusively conduct these activities; Most caregivers conduct few, if any, ADLs

ADLs*	IADLs**
Helping in & out of bed	Cooking
Toileting	Cleaning house
Bathing	Doing laundry
Getting dressed	Food shopping
	Other shopping
	Attending religious services
	Taking public transportation
	Driving
	Doctor's visits
	General errands
	Recreation
	Language interpreting



Photo Credit: © Stephanie Rausser, 2015

* ADLs = Activities of daily living: Basic self-care; feeding, bathing, toileting, brushing teeth, getting in/out of bed

** IADLs = Instrumental activities of daily living: cooking, cleaning, food shopping, doing laundry, driving, errands, etc.

CAREGIVER SELECTION

Factors Influencing Caregiver Selection

Caregiver selection is often not discussed in-depth, typically organic, but involves a variety of factors

- Birth Order
 - Special privileges and responsibilities for:
 - Oldest son (Among Chinese – *Dar khe*) asks wife to take care of parents
 - Oldest daughter (Among Filipinos - *Ate*)
- Relationship to Care Recipient
 - Children take care of their parents
 - Daughters often preferred to sons
- Financial Capability
 - Usually the most financially stable takes on caregiving role
- Living Arrangements
 - Accessible to seniors, senior resources and family members
 - Sleeping space availability
- Other Obligations: Work, Childcare
 - Parenting obligations to young children
 - Demanding work hours and exceptionally heavy work load



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Accepting the Role of Caregiver

Among those with traditional values, assuming role of caregiver is a given; For others, it is a long and arduous process, involving doubts

- Role perception for those with traditional values:
 - Unquestioning loyalty to parents and elders
 - Alternative course of action unimaginable
 - Borne out of love
- For others:
 - Fear of the unknown impact to current life
 - Anxiety and isolation due to difficulty in articulating fears to others

*"I want to talk to someone but not anyone from my family. I don't want conflict in the family and anything I say will go around and bite me back."
Male, 50 yrs., South SF*



*"I want my own life ... I want my lifestyle now ... BUT my mother took care of me so well; the least I can do is take care of her now. What should I do? My life will be forever changed. I'll be living in a senior community!"
Male, 50 yrs., South SF*

IMPACT OF ROLE ON CAREGIVER

Life Changes Due to Role

Changes to relationships are mixed, but changes to daily activities and work tend to be negative

Changes in Daily Activities

- Greater frequency of IADLs* focused on care recipient
- Recreation, travel and daily exercise often decreased
- Stress reducing activities conducted less often

Relationship with Care Recipient

- Caregiver and recipient are closer
- Frequent / daily interaction creates strong bond
- Often an increase in arguments and tension

Impact on Work

- Shift from full to part-time to accommodate caregiving work
- Lower earning capacity
- Turn down small side jobs
- Reluctance to accept promotions due to time demands



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*IADLs = Instrumental activities of daily living: cooking, cleaning, food shopping, doing laundry, driving, errands, etc.

Life Changes Due to Role

Changes to social life and health tend to be negative

Relationships with Friends

- Less recreation
- Less shopping
- Lower community involvement
- Little to no travel opportunities
- Few or no nights out with friends, decreased socializing

"I brought my mother here 10 years ago. She needed eye surgery, I paid for her moving expenses and she was well after that. But now she's sick and wants me to be with her all the time. I have no time for my boyfriend."

Female, 60 yrs., NY

Health and Personal Well-Being

- Limited time for exercise
- Less focus on eating healthy
- Increase in feelings of guilt (wanting to do more for and with care recipient), anxiety, worry for their future and the care recipient's, and stress
- Some respondents spend less time on personal hygiene and appearance, which suggests possibly having impact on self-perception

One caregiver suffered a heart attack after 10 years caring for his mother

Caregiver Stress Relief

Caregivers are plagued by stress, but aware of some techniques for reduction, although pressed for time to do them

- Talk to close friends and vent
- Go to church or temple
- Do yoga and exercises regularly
- Meditate / pray
- Have “me time” away from source of pressure
- Find others who have similar experiences
- Remind themselves about the reasons they are a caregiver



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Positive Effects

Caregivers recognize the benefits of the role in their lives

- Grow closer to care recipient, despite some increase in arguments
- Maximize time with relative while still living
- Opportunity to resolve issues and emotional baggage
- Build lasting memories
- Grandchildren's lives enriched by inter-generational relationship

"My kids are growing up with my parents. Listening to them talk and discuss, it sounds so good. It's so special. They are lucky to grow up knowing their grandparents. I feel blessed."

Male, 54 yrs., Pasadena



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The Term “Caregiver” & Self-Perceptions

Label of “caregiver” is inappropriate and doesn’t capture true sentiment, but no alternative term found in any language

Associations with Term “Caregiver”	Perceptions of Themselves as a “Good” Son or Daughter
Paid profession	Unpaid
Has a start & stop duration each day	Could be a 24/7 on-call situation
Trained with specific skills	No training; often learn by doing
Has limits	Sometimes knows no limits
It’s business	Strong emotional component
One among other work options	Duty, responsibility, expected

“Caregiver? I know what the word means. It’s OK but it doesn’t mean the same thing as what I do...But I don’t know better terms...Chinese or English.”

Female, 50 yrs., Pasadena

The words “helper” and “companion” were frequently used to describe the “caregiver” role

LOOKING AHEAD

End of Life Conversation

End of life conversations are avoided or held in a cursory manner

- Very difficult to maintain cultural sensitivity in this situation
- Topic suggests caregiver is interested in recipient's wealth and assets
- Care recipients are generally not open to discuss the topic
 - Caregivers often feel the same way, despite the negative effects of not planning
- If discussed, only briefly and superficially
- Some Filipino respondents have used humor to try to introduce the subject
- Complex issues ignored
- End of life concerns often left undecided and unresolved

End of life conversations go against Asian taboos:

Superstitious belief is that talking about something negative or terrible, including death, will cause the event to happen.

End of Life Plan

There is little comprehension around end of life planning and it is rarely conducted

Lack of understanding of the term “end of life plan”

- Some believe this refers only to funeral and burial plans
- A couple mentioned a do-not-resuscitate (DNR)

For those who had created plans, discussions were fragmented and insufficient

- Conversations had a broad focus, limited goals and were piecemeal
- Focused mainly on financial aspects, such as how expenses would be covered and by whom; how assets and belongings would be divided up
- Legal aspects were usually not mentioned
- Timing and division of labor of tasks were not discussed

Institutional Care Perceptions

Caregivers (& possibly recipients) have negative views about institutional care

- Many respondents held the “traditional” view:
 - A harsh alternative to in-home care
 - A sign that the family has abandoned them
 - Patients /residents feel they are waiting for death
 - Bad press about some care institutions
 - Some had direct negative experiences involving relatives in institutions prior to passing away



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Consideration of Institutional Care

Institutional care may be an option for extreme situations

- Institutional care is viewed as acceptable when:
 - Type of care needed is beyond caregivers' skills
 - Patient's health has deteriorated to the point that care at home would be insufficient; patient is in need of continuous, 24 hour care
 - It is in the best interest for the patient's safety
- Skilled Nursing Facilities (SNFs) and rehab centers are considered potentially trustworthy providers of specialized care
- Caregivers open to institutional care believe that families still need to be actively present to mitigate feelings of abandonment and to monitor quality of care



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INFORMATION & RESOURCES

Awareness and Use of Resources

Awareness and usage of caregiving resources are low

- Low awareness overall of available caregiver support
- Some mentioned local Chinatown and community clubs, as well as other organizations, such as The Salvation Army, American Cancer Society, On Lok
 - Some evidence that the LA market may be more fragmented, with fewer connections to local/AAPI community groups
- Low usage of support services, largely due to lack of awareness and tendency to keep care within the close family

Desired Resources

Respondents have a variety of information and support needs

- Services and trainings for caregivers and families
 - How to make the decision about becoming a caregiver/caregiver selection
 - How to handle emergencies
 - Support groups for caregivers in similar situations, with similar cultures, similar challenges associated with lower acculturation levels in care recipients
 - Care for the caregivers, who are also developing their own health issues
- Government subsidized and non-profit agency services, including home care aides
- Assistance in determining qualifications for services and how to apply
- Nutrition information requirements for those ill, recovering from cancer, other serious illnesses or for post-operative care patients
- In-language information for some caregivers and care recipients



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Mainstream vs. AAPI Services

Preferences for mainstream vs. AAPI organizations are split

- Mainstream services and information are generally perceived as:
 - More reliable and professional, with better infrastructure
 - Having a better understanding and ability to communicate changes in government and non-profit policies and procedure
 - More efficient and adhering more often to best practices
- Preferences for AAPI community sources are due to in-language information and services offered
- Some had no clear preferences
- Top consideration is the organization's reputation (stability, professionalism, reliability)
 - Often made caveat that the organization would need to have in-language communication options to communicate effectively with un-aculturated caregivers and recipients

Preferred Media Channels

Multiple media channels are used by the population

- Community publications: Sing Tao Daily, World Journal, Asian Journal, Philippine News
- Mainstream newspapers perceived as highly reliable

Newspapers

Community Outreach

- In-language local meetings and orientations are popular, especially among the less acculturated Chinese community

- Hard copy, print materials were most preferred (direct mail, pamphlets at doctor's offices, local flyers, etc.)

Various Print

Media

E-Marketing

- A few mentioned social media (Facebook and WeChat are popular) and e-mail marketing

- Radio was mentioned by several
- In LA, 1300 was cited by Chinese community

Radio

Television

- Many care recipients spend a lot of recreational time watching TV
- TFC is very popular among Filipino care recipients and caregivers

APPENDIX

Methodology

- Pre-Interview Homework Assignment
 - Activities conducted for care recipient
 - Change in frequency of common everyday activities due to caregiving role
 - Select demographics & background information
- 75 minute individual in-depth interviews conducted in September
 - Process of caregiver selection
 - Family dynamics of providing care within the family
 - Relationship of caregiver & recipient
 - Impact of caregiving on caregivers' lives
 - Attitudes and beliefs about institutional care, caregiving & planning for future
 - Awareness and use of caregiving resources

您的日常活動	比以前 更多	和以前 一樣	比以前 更少
清潔房子	X		
購買食品	X		
為您或全家做飯	X		
洗衣服	X		
除購買食物之外, 為家裡購買 其它必需品	X		
為自己購物			
在院子裡干活			X
保持自己個人衛生 和外表			X
縫紉	X		

Which of the following activities do you do for the relative(s) you are caring for?	Put a check mark in the right column beside each type of care activity that you are providing.
Helping them in and out of bed and chairs	X
Bathing / Washing up	X
Using the toilet / Assisting with incontinence	X
Getting dressed	X
Cooking	X
Food shopping	X
Cleaning house	X
Feeding	X
Walking	X
Doing laundry	X
Exercising	X
Driving for your relative(s)	X
Taking public transportation	X
Doctor's visits / Communications with doctors	X
Attending church/temple services	X



Respondents

	Language	City		
		NY	LA	SF
Chinese (11)	Mandarin/ Cantonese	3	5	3
Chinese (10)	English	4	3	3
Filipino (10)	Taglish/English	3	3	4

Gender :22 Females 9 Males

Caregiver Age :40 - 65 years

Duration of Caregiving :Minimum of 6 months

Care Recipient Age :40 years & older