

# Research on Family Caregivers of Older Singaporeans: Past, Present and Future

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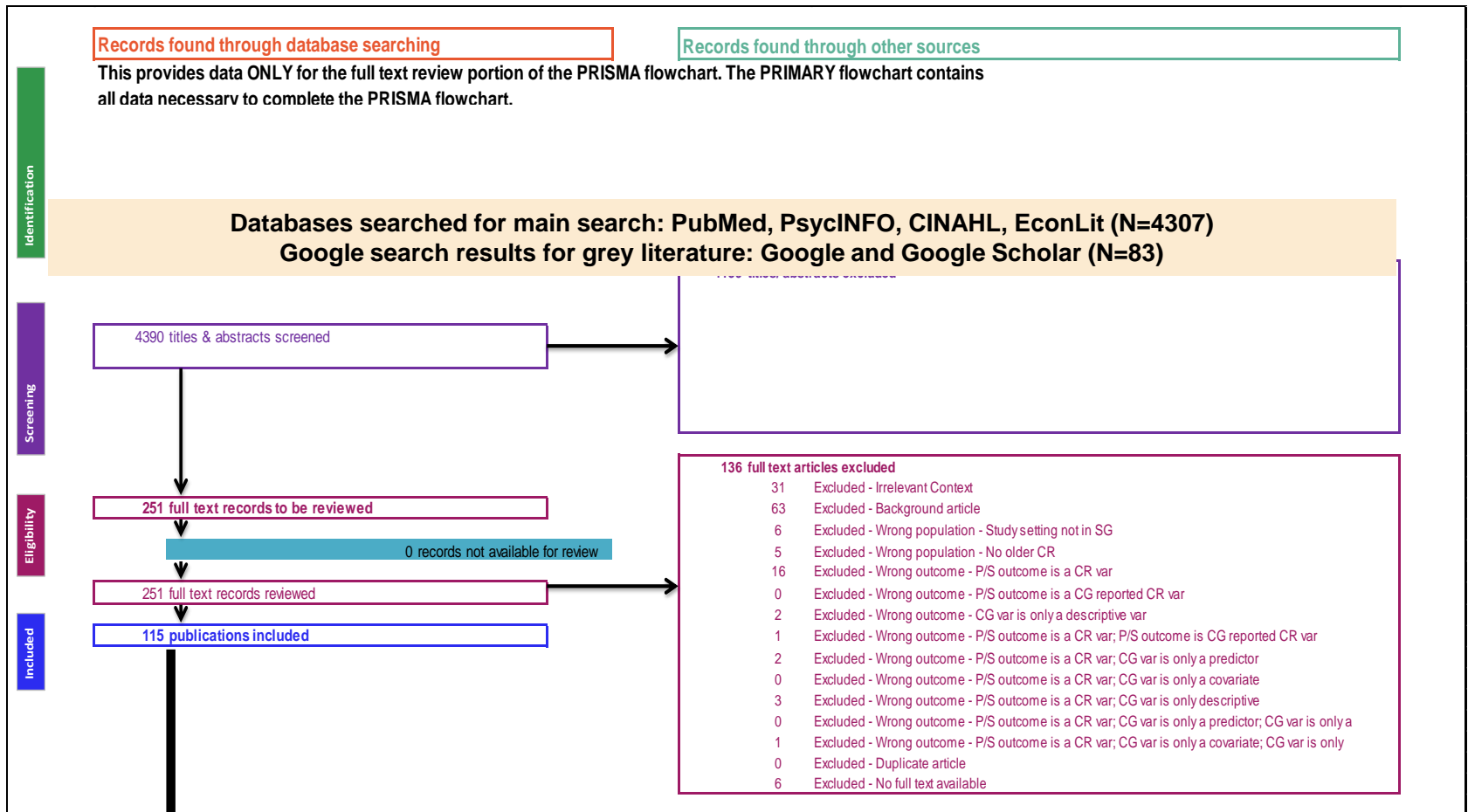
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# Past

Systematic review of studies on caregivers of older Singaporeans

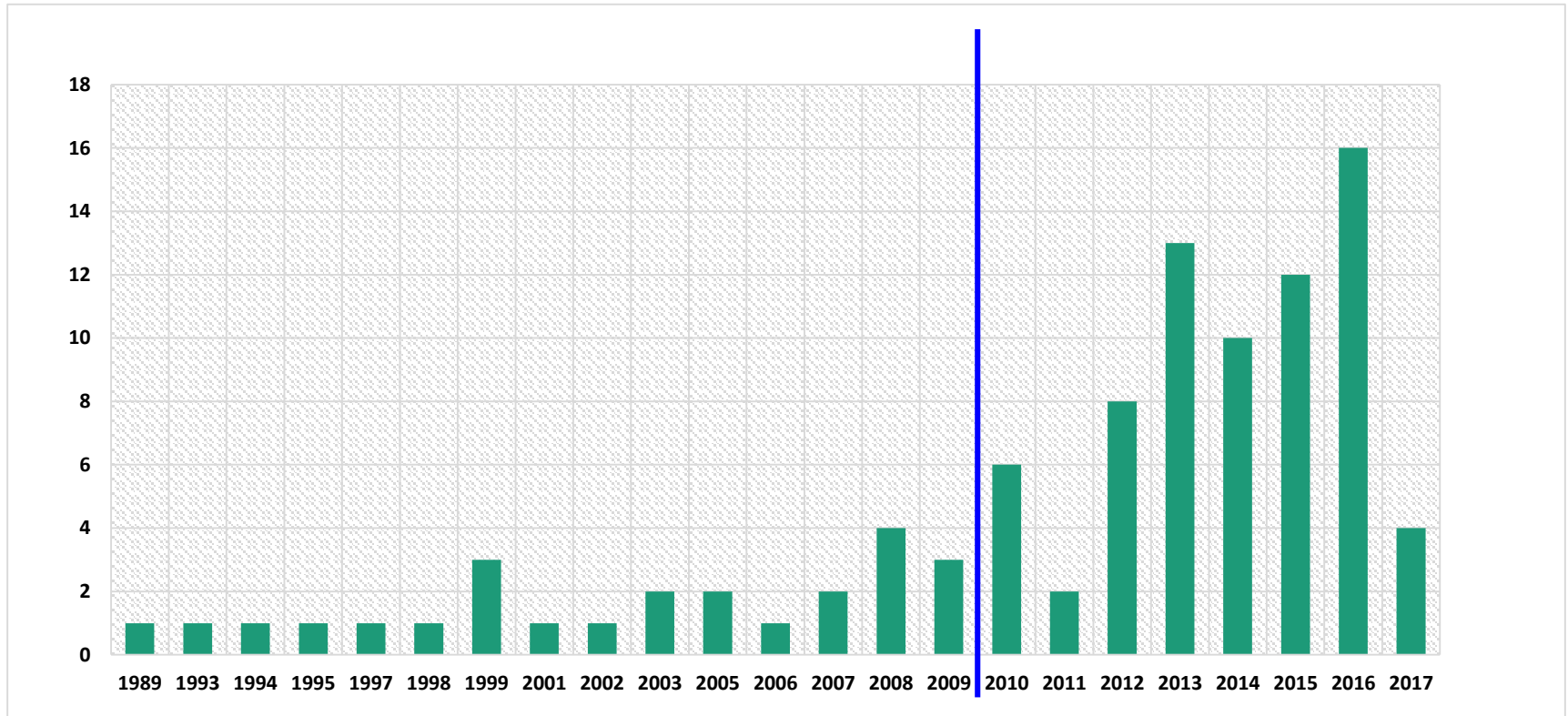
# Screening and eligibility evaluation results



**Total number of publications on family caregivers = 96**

**Detailed results will focus on publications from 2010-2017 = 71**

# Year of publication, N=96



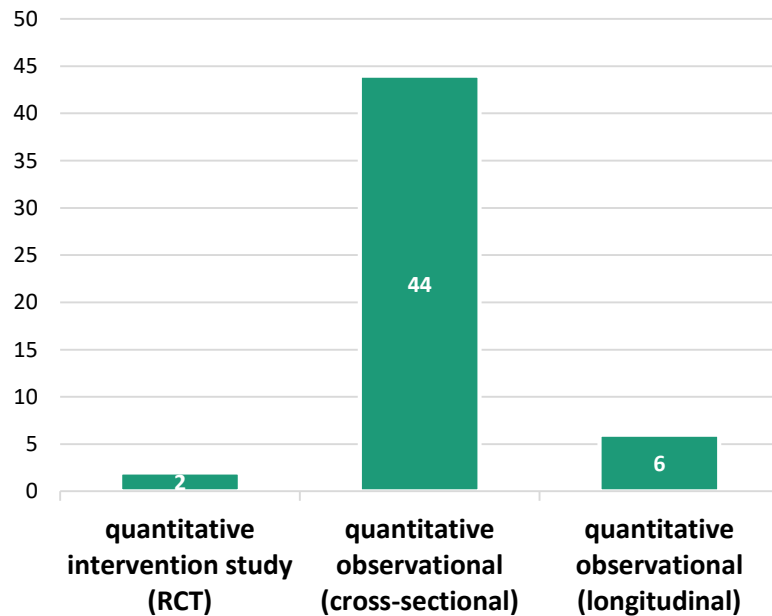
# Study type, N=71

- quantitative study
- qualitative study
- mixed-methods study

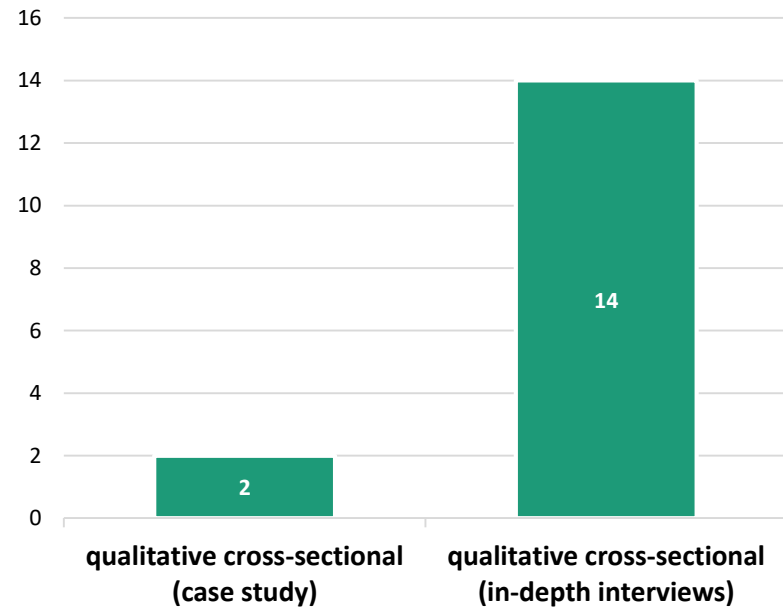


# Study design, n=71

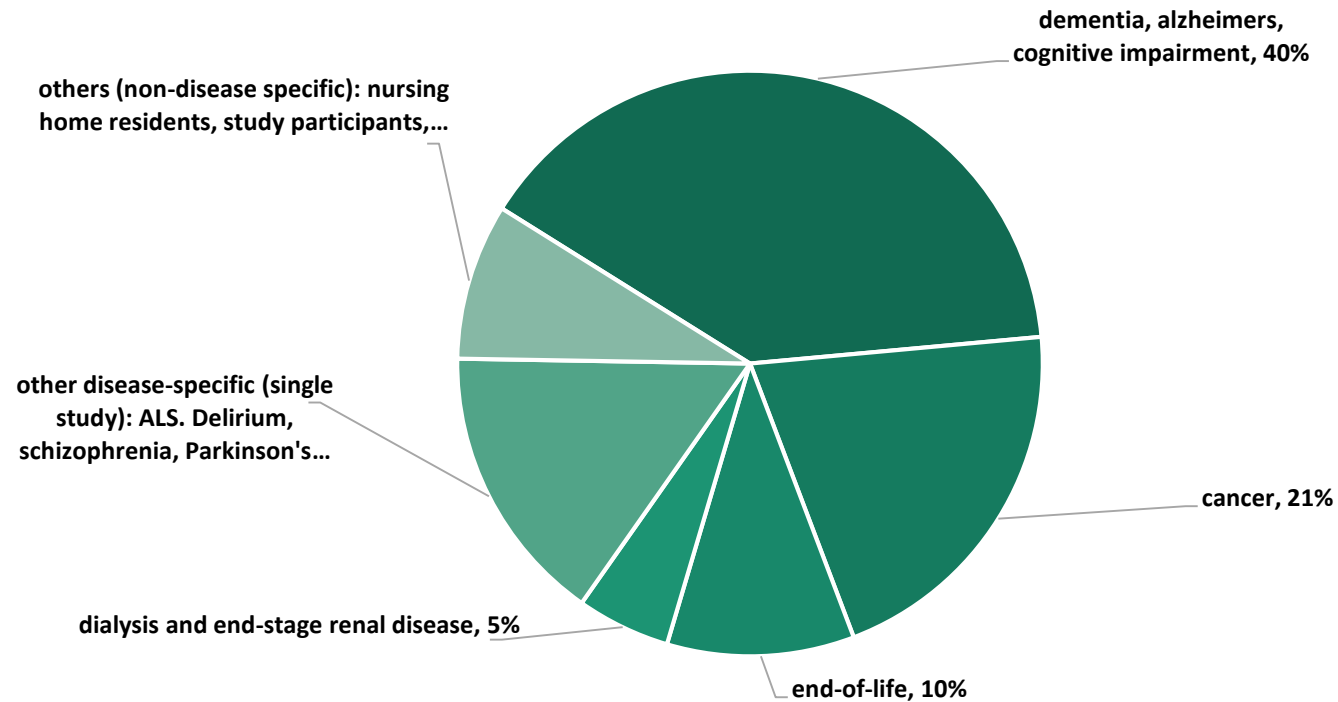
## Quantitative



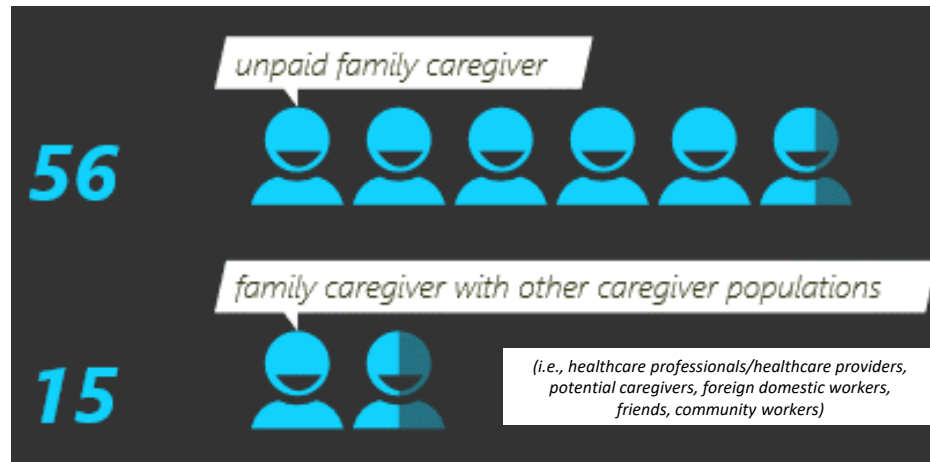
## Qualitative



# The elderly care recipient, n=71

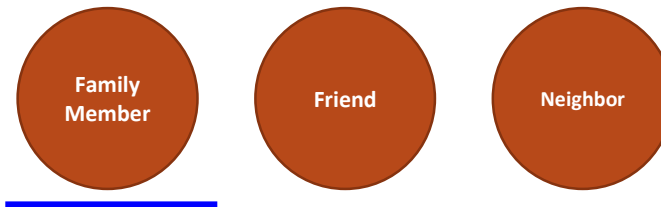


# Caregiver populations studied, n=71



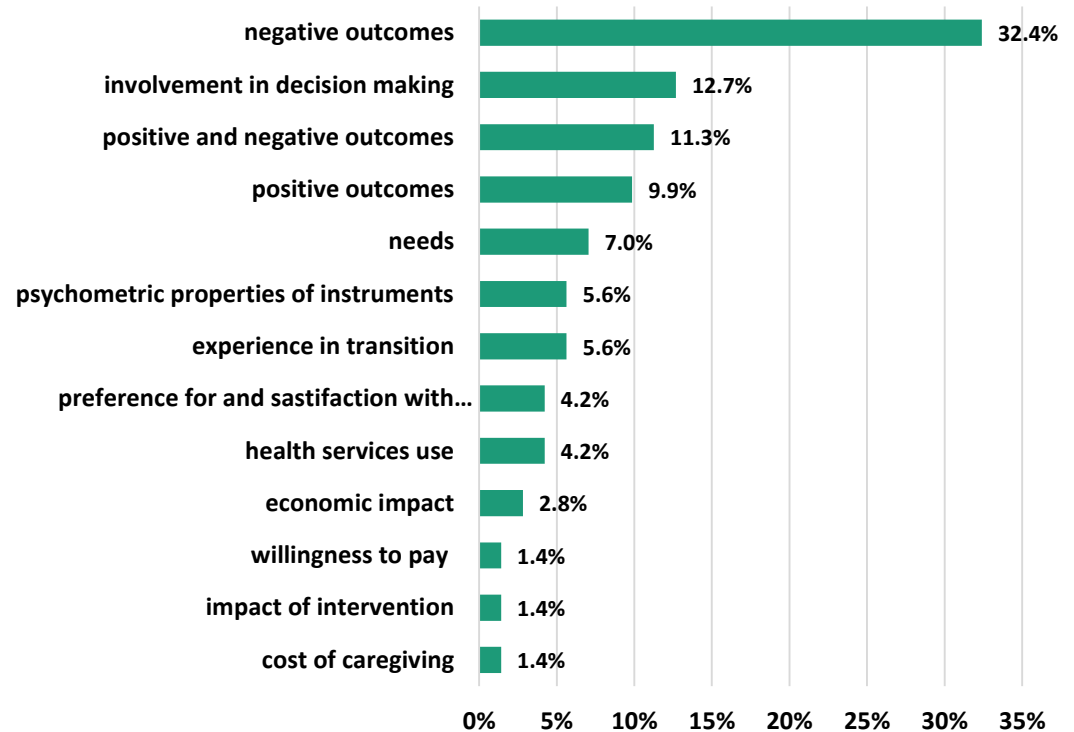


# Defining family caregivers of older Singaporeans



- most involved in providing care / ensuring provision of care
- living with and providing care and support for the patient
- has a minimum contact time of 4 hours per day with the patient (including time spent on caregiving activities alone or with the foreign domestic helper)
- providing unpaid care for the older person for a minimum of 3 months
- most familiar with the care recipient's condition
- has the primary responsibility of decision-making and care for the well-being of the patient
- ...

# Categories of caregiver outcomes, n=71



# Examples of common data collection tools (scales) used in the caregiver studies

(+)	(-)	Other
<ul style="list-style-type: none"> <li>• Positive Aspects of Caregiving (PAC)</li> <li>• Gains in Alzheimer’s Care Instrument (GAIN)</li> <li>• General Perceived Self-Efficacy Scale (GPSE)</li> </ul>	<ul style="list-style-type: none"> <li>• Revised Memory and Behavior Problem Checklist, (RMBPC)</li> <li>• Hospital Anxiety and Depression Scale (HADS)</li> <li>• Centre for Epidemiologic Studies Depression (CES-D)</li> <li>• Zarit Burden Inventory (ZBI)</li> <li>• Family Burden Interview Schedule (FBIS)</li> <li>• Family Crisis Oriented Personal Evaluation Scales (F-COPES)</li> </ul>	<ul style="list-style-type: none"> <li>• World Health Organization Quality of Life Scale – Brief Version (WHOQoL-BREF)</li> <li>• Caregiver Quality of Life Index—Cancer (CQOLC)</li> <li>• Caregiver Quality of Life Scale</li> </ul>

# Present

Summary of recently completed/ongoing research projects in Singapore

# Recent / Ongoing studies in Singapore

Study Type, Design	Study Participants	Caregiver Outcomes
<b>PISCES: Panel study Investigating Status of Cognitively impaired Elderly in Singapore (Malhotra C, Duke-NUS)</b>		
Quantitative, <b>Longitudinal</b>	Primary informal caregivers of persons with <b>severe dementia</b> ; N = 300	<ul style="list-style-type: none"> <li>• Reaction to caregiving</li> <li>• Health care utilization</li> <li>• Gain from caregiving</li> <li>• Resilience</li> <li>• Coping</li> <li>• Depression and Anxiety</li> <li>• Spiritual well-being</li> <li>• Quality of Life</li> <li>• Grief</li> <li>• Perceived prognosis (of the patient)</li> <li>• Perceived quality of care (of the patient)</li> </ul>
<b>COMPASS: Costs and Medical Care of Patients with Advanced Serious Illness in Singapore Study (Finkelstein EA, Duke-NUS)</b>		
Quantitative, <b>Longitudinal</b>	Patients with <b>advanced cancer</b> and their primary informal caregivers; N = 600	<ul style="list-style-type: none"> <li>• Reaction to caregiving</li> <li>• Quality of Life</li> <li>• Depression and Anxiety</li> <li>• Perceived prognosis (of the patient)</li> <li>• Perceived quality of care (of the patient)</li> </ul>

# Recent / Ongoing studies in Singapore

Study Type, Design	Study Participants	Caregiver Outcomes
<b>Quality of Life Study on Caregivers (Abdullah F and Tan D, NCSS)</b>		
Quantitative, <b>Cross-Sectional</b>	Family caregivers of (i) persons with <b>chronic illnesses</b> , (ii) persons with <b>mental health issues</b> , and (iii) persons with <b>disabilities</b> ; N = 3000	<ul style="list-style-type: none"> <li>• Quality of life</li> <li>• Reaction to caregiving</li> <li>• Self-efficacy</li> </ul>
<b>Predictors and consequences of work-family experiences: Study of working caregivers of older adults (Cho E, NTU)</b>		
Quantitative, <b>Longitudinal</b>	<b>Working</b> (full-time administrative staff from various educational institutions) family caregivers of older adults; N = 220	<ul style="list-style-type: none"> <li>• Work-, family- and health-related outcomes</li> </ul>
<b>A study of positive mental health in caregivers of older adults (Vaingankar JA, Subramaniam M, IMH)</b>		
Quantitative, <b>Cross-Sectional</b>	Informal caregivers of older adults in the community <i>or</i> older patients with psychiatric / neurological conditions; N = 300	<ul style="list-style-type: none"> <li>• Positive mental health</li> <li>• Life satisfaction</li> <li>• Resilience</li> <li>• Quality of life</li> <li>• Burden</li> <li>• Positive aspects of caregiving</li> </ul>

# Recent / Ongoing studies in Singapore

Study Type, Design	Study Participants	Caregiver Outcomes
<b>Caring for seniors in the community: A solutions-based approach (Thang LL, NUS)</b>		
Qualitative <b>Cross-Sectional</b> , <b>In-depth interviews</b>	Informal caregivers of frail seniors; N = 30	<ul style="list-style-type: none"> <li>• Caregiving arrangements</li> <li>• Caregiving needs</li> <li>• Interest in a trial of a caregiver app</li> </ul>
<b>A Qualitative Study of Caregivers of Dependent Elderly from Lower-Income Households in Singapore (Thang LL, Suen J, NUS)</b>		
Qualitative <b>Longitudinal</b> , <b>In-depth interviews</b>	Primary caregivers of dependent elderly who reside in low income households; N = 17	<ul style="list-style-type: none"> <li>• Support and contextual challenges</li> <li>• Coping strategies</li> </ul>

# Future

Recommendations for future research on family caregiving for older persons in Singapore



# Study Design

## Longitudinal studies

- With medium to long-term follow-up (Duration contingent on health condition or disease defining the need for care in the care recipient)
- Close follow-up intervals (4 to 6 months apart)
- Quantitative or Qualitative or ....

## Mixed-methods studies

- Collecting both qualitative and quantitative data in the same study and integrating data at some stage of the research process

## Dyadic studies

- Collect data on both the caregiver and their care recipient
- Explicitly utilize the dyadic nature of such data in the analyses

## Intervention studies

- Randomized controlled trials
- Quasi-experimental studies
- Rigorous evaluation of pilots

# Defining older care recipients

- Moving beyond specific diseases to define care recipients
  - Functional limitations (limitations in ADLs and IADLs) requiring human assistance, irrespective of underlying health condition or disease

# Caregiver Outcomes

- Largely focused on negative aspects of caregiving (e.g., burden, stress)
- Expand focus to positive aspects of caregiving (e.g., esteem; self-affirmation)
- Under-studied areas:
  - Work and caregiving
  - Bereavement among caregivers
  - Cost of caregiving
  - Technology in caregiving
- Contextualization of tools/measures to Singapore

# Foreign Domestic Workers

- Triad, comprising the caregiver, the care recipient, and the foreign domestic worker
- Impact of caregiving on the foreign domestic worker: Measurement?

# Datasets used, n=71

Data source	Count
Singapore Survey on Informal Caregiving (SSIC) 2010–2011	8
Well-being of the Singapore Elderly (WiSE) Study	3
Social Isolation, Health and Lifestyles Survey (SIHLS)	2
Healthy Older People Everyday (HOPE) Study	1
The Singapore Dementia Caregiver Profile	1
National Health Survey	1
Real-world Evaluation of Compliance and Preference in the treatment of Alzheimer's disease (RECAP)	1
Singapore Dementia Caregiver Profile Study	1
Singapore Mental Health Study	1
Others: New data specific to the study	52

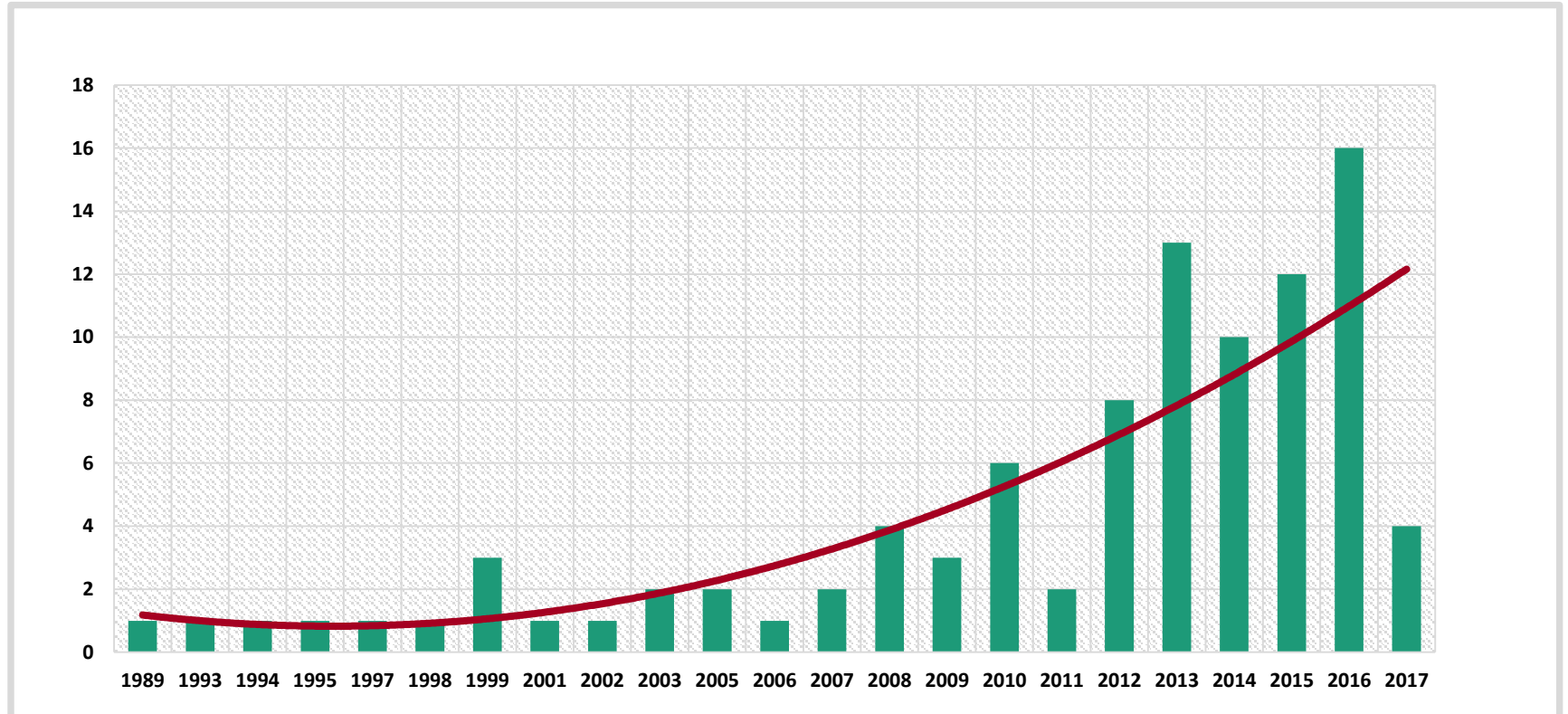
# Data sharing and linkage

- Sharing of data from studies
- Linkage with health and social service utilization

# Challenges

- Long-term involvement of study participants
- Analytical approach for complex and/or longitudinal studies
- Funding
  - Duration
  - Amount
  - Source
  - Nature

# Year of publication, N=96





# THANK YOU

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