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

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Past

Systematic review of studies on caregivers of older Singaporeans
Screening and eligibility evaluation results

Records found through database searching
- 4139 titles/abstracts excluded
- 4390 titles & abstracts screened
- 136 full text articles excluded
- 31 records not available for review
- 251 full text records to be reviewed
- 136 full text articles excluded

Records found through other sources
- 63 records not available for review
- 251 full text records reviewed
- 115 publications included

Databases searched for main search: PubMed, PsycINFO, CINAHL, EconLit (N=4307)
Google search results for grey literature: Google and Google Scholar (N=83)

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

quantitative study, 52
Study design, n=71

Quantitative
- Quantitative intervention study (RCT): 0
- Quantitative observational (cross-sectional): 44
- Quantitative observational (longitudinal): 6

Qualitative
- Qualitative cross-sectional (case study): 2
- Qualitative cross-sectional (in-depth interviews): 14
The elderly care recipient, n=71

dementia, alzheimers, cognitive impairment, 40%
cancer, 21%
end-of-life, 10%
dialysis and end-stage renal disease, 5%
other disease-specific (single study): ALS. Delirium, schizophrenia, Parkinson’s...
others (non-disease specific): nursing home residents, study participants,...
Caregiver populations studied, n=71

- 56 unpaid family caregivers
- 15 family caregivers with other caregiver populations

(i.e., healthcare professionals/healthcare providers, potential caregivers, foreign domestic workers, friends, community workers)
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
- ...

- Family Member
- Friend
- Neighbor
Categories of caregiver outcomes, n=71

- negative outcomes: 32.4%
- involvement in decision making: 12.7%
- positive and negative outcomes: 11.3%
- positive outcomes: 9.9%
- needs: 7.0%
- psychometric properties of instruments: 5.6%
- experience in transition: 5.6%
- preference for and satisfaction with...: 4.2%
- health services use: 4.2%
- economic impact: 2.8%
- willingness to pay: 1.4%
- impact of intervention: 1.4%
- cost of caregiving: 1.4%
Examples of common data collection tools (scales) used in the caregiver studies

<table>
<thead>
<tr>
<th>(+)</th>
<th>(-)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Positive Aspects of Caregiving (PAC)</td>
<td>• Revised Memory and Behavior Problem Checklist, (RMBPC)</td>
<td>• World Health Organization Quality of Life Scale – Brief Version (WHOQoL-BREF)</td>
</tr>
<tr>
<td>• Gains in Alzheimer’s Care Instrument (GAIN)</td>
<td>• Hospital Anxiety and Depression Scale (HADS)</td>
<td>• Caregiver Quality of Life Index—Cancer (CQOLC)</td>
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<tr>
<td>• General Perceived Self-Efficacy Scale (GPSE)</td>
<td>• Centre for Epidemiologic Studies Depression (CES-D)</td>
<td>• Caregiver Quality of Life Scale</td>
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<td>• Zarit Burden Inventory (ZBI)</td>
<td></td>
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<td></td>
<td>• Family Burden Interview Schedule (FBIS)</td>
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<td></td>
<td>• Family Crisis Oriented Personal Evaluation Scales (F-COPES)</td>
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Present

Summary of recently completed/ongoing research projects in Singapore
Recent / Ongoing studies in Singapore

<table>
<thead>
<tr>
<th>Study Type, Design</th>
<th>Study Participants</th>
<th>Caregiver Outcomes</th>
</tr>
</thead>
</table>
| **PISCES: Panel study Investigating Status of Cognitively impaired Elderly in Singapore (Malhotra C, Duke-NUS)** | Primary informal caregivers of persons with severe dementia; N = 300 | • Reaction to caregiving  
• Health care utilization  
• Gain from caregiving  
• Resilience  
• Coping  
• Depression and Anxiety  
• Spiritual well-being  
• Quality of Life  
• Grief  
• Perceived prognosis (of the patient)  
• Perceived quality of care (of the patient) |
| Quantitative, Longitudinal | | |

| **COMPASS: Costs and Medical Care of Patients with Advanced Serious Illness in Singapore Study (Finkelstein EA, Duke-NUS)** | Patients with advanced cancer and their primary informal caregivers; N = 600 | |
| Quantitative, Longitudinal | | • Reaction to caregiving  
• Quality of Life  
• Depression and Anxiety  
• Perceived prognosis (of the patient)  
• Perceived quality of care (of the patient) |
Recent / Ongoing studies in Singapore

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<th>Study Type, Design</th>
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</thead>
</table>
| **Quality of Life Study on Caregivers (Abdullah F and Tan D, NCSS)** | Family caregivers of (i) persons with **chronic illnesses**, (ii) persons with **mental health issues**, and (iii) persons with **disabilities**; N = 3000 | • Quality of life  
• Reaction to caregiving  
• Self-efficacy |
| **Predictors and consequences of work-family experiences: Study of working caregivers of older adults (Cho E, NTU)** | Working (full-time administrative staff from various educational institutions) family caregivers of older adults; N = 220 | • Work-, family- and health-related outcomes |
| **A study of positive mental health in caregivers of older adults (Vaingankar JA, Subramaniam M, IMH)** | Informal caregivers of older adults in the community or older patients with psychiatric / neurological conditions; N = 300 | • Positive mental health  
• Life satisfaction  
• Resilience  
• Quality of life  
• Burden  
• Positive aspects of caregiving |
## Recent / Ongoing studies in Singapore

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<th>Study Participants</th>
<th>Caregiver Outcomes</th>
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</thead>
<tbody>
<tr>
<td><strong>Caring for seniors in the community: A solutions-based approach (Thang LL, NUS)</strong></td>
<td>Qualitative <strong>Cross-Sectional</strong>, <strong>In-depth interviews</strong>  Informal caregivers of frail seniors; N = 30</td>
<td>• Caregiving arrangements  • Caregiving needs  • Interest in a trial of a caregiver app</td>
</tr>
<tr>
<td><strong>A Qualitative Study of Caregivers of Dependent Elderly from Lower-Income Households in Singapore (Thang LL, Suen J, NUS)</strong></td>
<td>Qualitative <strong>Longitudinal, In-depth interviews</strong>  Primary caregivers of dependent elderly who reside in low income households; N = 17</td>
<td>• Support and contextual challenges  • Coping strategies</td>
</tr>
</tbody>
</table>
Future

Recommendations for future research on family caregiving for older persons in Singapore
<table>
<thead>
<tr>
<th>Study Design</th>
<th>Longitudinal studies</th>
<th>Mixed-methods studies</th>
<th>Dyadic studies</th>
<th>Intervention studies</th>
</tr>
</thead>
<tbody>
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<td></td>
<td>• With medium to long-term follow-up (Duration contingent on health condition or disease defining the need for care in the care recipient)</td>
<td>• Collecting both qualitative and quantitative data in the same study and integrating data at some stage of the research process</td>
<td>• Collect data on both the caregiver and their care recipient</td>
<td>• Randomized controlled trials</td>
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<td></td>
<td>• Close follow-up intervals (4 to 6 months apart)</td>
<td>• Explicitly utilize the dyadic nature of such data in the analyses</td>
<td></td>
<td>• Quasi-experimental studies</td>
</tr>
<tr>
<td></td>
<td>• Quantitative or Qualitative or ....</td>
<td></td>
<td>• Rigorous evaluation of pilots</td>
<td></td>
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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

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