

# Thirteenth Family Research Network (FRN) Forum

*“Familial Caregivers and their Impact  
on the  
Resilience of Family Function”*

Monday, 27 April 2015  
Auditorium, Level 1, Civil Service College

THIRTEENTH FAMILY RESEARCH NETWORK (FRN) FORUM:  
“FAMILIAL CAREGIVERS AND THEIR IMPACT ON THE RESILIENCE OF FAMILY FUNCTION”  
27 APRIL 2015

# PRESENTATION II

## Families Living with Persons with Dementia

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# Families living with Dementia

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# Dementia caregivers

- In 2014, friends and family of people with Alzheimer's and other dementias provided an estimated **17.9 billion hours of unpaid care**
- Approximately two-thirds of caregivers are **women** and 34% are age **65 years or older**
- Forty-one percent of caregivers have an **annual household income of \$50,000 or less**
- About a third had to **give up or cut down on work** to take care of their relative with dementia

[www.alz.org](http://www.alz.org)

# Dementia caregivers

- Nearly 60 percent of dementia caregivers rated the **emotional stress** of caregiving as high or very high
- About 40 percent suffered from **depression**
- Due to the physical and emotional toll of caregiving, dementia caregivers incurred **\$9.7 billion in additional health care costs of their own**
- Caregivers involvement in care and **demands on them increase** as dementia progresses

[www.alz.org](http://www.alz.org)

# Dementia caregivers in Singapore



- **Well-being of the Singapore Elderly (WiSE) study**
- Aims
  - Estimate prevalence of dementia among older adults aged 60 years and above
  - Investigate impact on caregivers
- Led by the Institute of Mental Health
- Collaboration with Ministry of Health, Changi General Hospital, National University Health System, Raffles Medical and King's College London
- Conducted in 2013
- 2565 older adults and 2421 informants/caregivers were interviewed

# Dementia caregivers in Singapore\*



- 20% have given up or cut-back on work
- 46% have BPSD-related distress
- 26% experience burden of care
- 11% have psychological morbidity

BPSD: Behavioural and psychological symptoms of dementia

\*Unadjusted/unweighted estimates

# Impact of caregivers' condition

- Poor quality of life for care receivers
- Excessive service use
- Institutionalization
- Increased healthcare and societal costs

Luppa et al, 2008; Knapp et al, 2013



# Deinstitutionalization and Caregivers' needs

- If caregivers are expected to maintain their relative at home, every care must be taken to understand if their needs are met.
- Much of the work in dementia caregiving has focused on care burden and psychological impact on their caregivers.
- Little emphasis on their unmet needs that can potentially lead to burden and adverse psychological outcomes.

# Caregivers' needs

- Learning directly from caregivers about their needs is the necessary first step for planning community support services for people with dementia and their caregivers.
- No local data on caregivers' needs specific to dementia.
- Lack of simple and comprehensive measures to assess such needs.

# Caregivers' needs

- Development of a measure for caregivers' needs can offer several advantages
  - Enable assessment of multiple needs
  - Allow direct indication of needed resources and potential interventions for specific needs
  - Identify sub-groups of caregivers with a higher magnitude of need

# Study on caregivers' needs



## ■ Aims

- Understand informal caregivers' needs for dementia using a qualitative study design
- Develop a self-report measure to assess these needs

# Study on caregivers' needs



## ■ Inclusion criteria

- Singapore Citizen or Permanent Resident
- Age 21 years and above
- Family member or friend of a person with dementia
- Closely involved in providing or organising care for the person with dementia
- Willing to provide written informed consent

## ■ Exclusion criterion

- Unable to converse in English, Mandarin, Malay or Tamil

# Study on caregivers' needs



## Data collection



10 Focus group discussions  
(Number of participants: 51)



12 Semi-structured interviews

# Study on caregivers' needs

## Participant profile

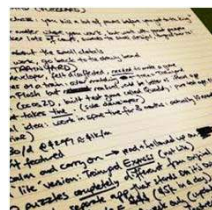


|            |                      |           |
|------------|----------------------|-----------|
| Age (Mean) | 52.9 years           |           |
| Gender     | Men                  | 25 (40 %) |
|            | Women                | 38 (60 %) |
| Ethnicity  | Chinese              | 32 (51 %) |
|            | Malay                | 15 (24 %) |
|            | Indian               | 14 (22 %) |
|            | Other                | 2 ( 3 %)  |
| Education  | No/ Some primary     | 5 ( 8 %)  |
|            | Sec. /Junior College | 10 (16 %) |
|            | Vocational           | 23 (37 %) |
|            | University           | 24 (38 %) |

# Study on caregivers' needs



## Data analysis



Audio-recording

Written notes



Verbatim transcription



Constant comparison  
Independent review

The screenshot displays the ATLAS.ti software interface. On the left, there is a 'Primary Doc Manager' window showing a list of documents with columns for ID, Name, Marks, Quota, and Author. Below it is a 'Code Manager' window showing a list of codes with columns for Name, Grounded, De., and Author. The main window shows a list of text excerpts with various codes applied to them. The codes include terms like 'QBETT2', 'Things through the letter box', 'Regular hourly contact to be kept up to date, and issue sandbags before and not after', 'Siren in the event night or day', 'The use of a siren, and to be informed of what it means', 'Someone knock on the door, or phone, police come earlier', 'An environmental person should call and give specific information', 'Siren to alert, more official', 'An official coming around and telling us', 'Something should accompany the recorded messages such as someone going along the street with a microphone giving practical advice', 'Leaflets', 'They did not contact me in anyway to alert me only after the flood I was given some information', 'Having more personal contact with residents with an elected flood warden in the area', and 'Ring people up or send people round the houses'. Each excerpt is accompanied by a list of codes and their corresponding authors.

Thematic analysis using Atlas.ti software



# Study on caregivers' needs



- **Immediate observations**
  - **Age** - Older caregivers need respite from the physical strain
  - **Gender** - Children of opposite gender than their parent experienced awkward situations while assisting in ADLs
  - **Ethnicity**
    - Indian caregivers wished that more activities could be conducted in Tamil or using Tamil movie songs at day care centres to make their relative feel comfortable
    - Malay caregivers reported lack of 'Halal' food at day care centres
  - **Services**
    - Catchment areas of ambulance services
    - Foreign domestic workers/ maids

ADLs: Activities of daily living (bathing, eating, etc.)

# Study on caregivers' needs



- **Thematic analysis yielded four distinct categories of need faced by caregivers**
  - Need for emotional and social support
  - Need for information
  - Need for financial support
  - Need for accessible and appropriate facilities

Vaingankar et al, 2013



# Need for emotional and social support

- Family acceptance, engagement and availability
- Friends' understanding
- Societal support and understanding
- Counseling for psychological problems
- Respite from emotional and physical strain
- Stigma and awareness



# Need for information

- Recognizing early signs of dementia
- Available treatments
- Administrative and legal requirements
- What to expect and do as illness progresses
- Managing behavioral problems and emergency situations
- Available hospice and homecare services
- Services for caregivers of people with dementia



# Need for financial support

- Independence in decision making and choice
- Family contribution on regular basis
- Continuity of employment
- Balance between employment and care-giving
- Engaging paid caregiver
- Administrative requirements



# Need for accessible and appropriate services and facilities

- Accessibility
- Ethnically appropriate activities, food and facilities
- Professional skills
- Transportation
- Legal assistance



# Expert panel

## Panel 1

- 6 members

With extensive experience in elder care service and/or research

1 Geriatric Psychiatrist

2 Medical Social Workers

1 Psychiatric Nurse

2 Researchers

- Modified Delphi technique
- Independent review and rating  
Single group session

- List of 25 needs
  - summary of caregivers reasons for need
  - rationale for inclusion

- Rated on relevance by panelists:
  - 1-not relevant
  - 2-somewhat relevant
  - 3-quite relevant
  - 4-very relevant

- Criteria for inclusion:  
Minimum average rating of 3

**‘Stigma/destigmatization’ was considered as part of ‘societal support’**

**‘Geographic accessibility’ of services was explicitly stated as a separate item**

# Expert panel



## Panel 2

- 10 members

Engaged in elder care service  
and/or research

3 Geriatric Psychiatrists  
2 Medical Social Workers  
1 Psychiatric Nurse  
1 Occupational Therapist  
1 Policy Maker  
2 Researchers

- Independent review and rating
- Items based on 25 needs listed  
after Panel 1

Additional item on 'alternate care arrangements' was included



# Caregivers' Needs Checklist for Dementia (CNCD)



- 26 self-report items
- 5-point response scale (Strongly agree, Agree, Disagree, Strongly disagree, I did not want (need specified)/ these services)
- Report of current needs
- Takes 15 mins to complete
- Examples of items

‘The **information** that I have received **on recognizing early signs of dementia** is adequate’

‘**Counseling** services available **for my anxiety/ worry/ depression** related to caring for my relative/friend are adequate’

# Caregivers' Needs Checklist for Dementia (CNCD)



- Translated in Mandarin, Malay and Tamil
- Administered to 109 caregivers of older adults with known dementia diagnosis during the WiSE survey
- Validation
  - Face and content validity (established in expert panels)
  - Construct validity (exploratory factor analysis)
  - Reliability (Cronbach's alpha)
  - Concurrent validity (a priori hypothesis testing)

# Caregivers' Needs Checklist for Dementia (CNCD)



| Age (Mean, SD)         |                     | 56 years (10) | n  | %    |
|------------------------|---------------------|---------------|----|------|
| <b>Gender</b>          | Women               |               | 67 | 61.5 |
|                        | Men                 |               | 41 | 37.6 |
| <b>Ethnicity</b>       | Chinese             |               | 56 | 51.4 |
|                        | Malay               |               | 22 | 20.2 |
|                        | Indian              |               | 31 | 28.4 |
| <b>Education level</b> | None                |               | 2  | 1.8  |
|                        | Minimal             |               | 6  | 5.5  |
|                        | Completed primary   |               | 21 | 19.3 |
|                        | Completed secondary |               | 47 | 43.1 |
|                        | Completed tertiary  |               | 32 | 29.4 |

# Caregivers' Needs Checklist for Dementia (CNCD)



- Exploratory Factor Analysis : 5 factor structure
- Cronbach's alpha : 0.920
- Concurrent validity : Partially fulfilled
- Unmet need associated with lower education and BPSD-related distress

BPSD: Behavioural and psychological symptoms of dementia

Vaingankar et al, under review

# Limitations



- Broad definition of 'caregiver', participants were not always the primary caregivers
- Care role and dementia stage, duration and type were not factored in
- Expert panel discussions did not include inputs from informal caregivers
- Validation was conducted in a small sample

# Conclusions



- Caregivers are willing to support their relative with dementia at home but there is a **clear demand to address their needs.**
- Caregivers need **information** to first identify the problem and then to make informed decisions and treatment choices. **Support** from family, society, employers and healthcare providers is crucial.
- A **novel, valid and reliable self-report measure** to assess dementia caregivers' need **is available.**
- **Studies in larger samples** are need for further development and validation of the Caregivers' Needs Checklist for Dementia.

# WiSE Study Team



- Knapp M, Lemmi V, Romeo R. Dementia care costs and outcomes: a systematic review. *Int J Geriatr Psychiatry*. 2013;28(6):551-61.
- Lupp M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord*. 2008;26(1):65-78.
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