WILL OUR YOUNG TAKE CARE OF US WHEN WE GROW OLD?
A QUALITATIVE STUDY OF YOUNG ADULTS WHOSE RELATIVES LOOK AFTER A PARENT WITH DEMENTIA

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Prevalence of Dementia: Global

Updated figures re: no. of people with dementia (PWD) from the ADI

- 2010: 44 million
- 2030: 76 million
- 2050: 135 million

The growth in the number of people with dementia in high income countries and low and middle income countries

(Alzheimer’s Disease International, 2010)
Prevalence of Dementia in Hong Kong

<table>
<thead>
<tr>
<th></th>
<th>Aged 65+</th>
<th>Aged 70+</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011:</td>
<td>13.3%</td>
<td>10.1%</td>
</tr>
<tr>
<td>2041:</td>
<td>30.3%</td>
<td>24.2%</td>
</tr>
</tbody>
</table>

2011 Hong Kong population pyramid

Growth of population aged 65 & over (Both sexes)

Prevalence of mild dementia among people aged 70+: 8.5%

(Census and Statistics Department 2011; Lam et al., 2008)
The Importance of Informal Caregiving

- 70% of people with dementia in the USA live at home, cared for mainly by family.
- Average number of years of survival: 4-8 years, and up to 20 years after diagnosis.

(The Alzheimer's Association, 2012)

For our society

- Costs less to society
- Delays time until institutionalization

For the patients

- Meets the patient’s desire to live at home
- Acts as an agent between patient and health professionals
- Maintains the quality of life of patients

(Mittelman, 2005; Tierney, Herrmann, Gelani, Szalai, 2003; Neundorfer, et al., 2001)
Adult Children of Caregivers of PWD

- Closely correlated with the psychosocial status and feelings of the primary caregivers
- Influenced by dementia care with different degrees of involvement

Adult children’s voices are valuable

Patients
Primary caregiver
Adult children of primary caregiver

Holistic dementia care
Findings from the literature related to family members caring for older relatives with dementia

**Family caregivers**

**Reasons**
1. Filial obligation
2. Love & compassion
3. Respect

**Impacts**

**Positive**
1. Rewarding when the relative with dementia shows improvement

**Negative**
1. Deterioration of one’s health
2. Conflicts with work
3. Reduction in the social contact
4. Worsening chronic illness
5. Distraction of family relationship

**Needs**
1. Home care services
2. Knowledge about the disease
3. Information about preparing for death
4. Financial assistance
5. Counseling

**Challenges**
1. Cognitive dysfunction
2. Problematic behavior
3. Loss of affection
4. Anticipatory grief
5. Work with health care staff who know little

(Teel & Carson, 2003; Sanders, Kelber & Noonan, 2008)

Very few studies can be found about the experiences and perceptions of the next generation of primary caregivers towards caregiving.

The Gap in Knowledge

- Care recipient
- Primary caregiver
- Adult children
- ?
Aim
To explore the experiences and perceptions of young adults regarding the care given by a member of their family to a relative with dementia

Objectives
• To explore what young adults ‘have experienced’ or ‘are experiencing’ by observing their parents giving care to a relative with dementia
• To explore young adults’ perception of the caregiving role
• To explore the impact of observing family members caring for an older relative with dementia on the attitude of young adults towards giving care in the future
<table>
<thead>
<tr>
<th>Design</th>
<th>Qualitative descriptive approach</th>
</tr>
</thead>
</table>
| Participants | Sample size: 24  
• Offspring of the primary caregiver of a relative with dementia  
• Aged 18 – 40 |
| Sampling Method | Purposive sampling  
• 13 (54%) were recruited from the Hong Kong Alzheimer’s Disease Association (HKADA)  
• 11 (46%) were recruited from personal networks |

(Aronson, 1992; Clifford, 1997; Mayan, 2009)
## Data Collection

| Collection Method | • Questionnaire on demographic data  
|                  | • Open-ended interview  
|                  |    (Semi-structured, Cantonese)  
|                  | • Audio-taped  
| Duration         | • As needed  
|                  | • Mean: 15 min  
|                  | • Range: 12-75 min  
| Place            | • Area where participants and interviewer felt comfortable and had privacy  
|                  | • Meeting rooms in 3 centers of the HKADA  
|                  | • Restaurants/ coffee shops |
Data Analysis

Transcriptions
• Transcribed verbatim

Approach
• Simple content analysis

(Aronson, 1992; Clifford, 1997; Mayan, 2009)
An example of the data analysis processes

<table>
<thead>
<tr>
<th>Line no.</th>
<th>Meaning unit</th>
<th>Code</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>J4079</td>
<td></td>
<td>照顧太好</td>
<td>年青成人對照顧者的看法</td>
</tr>
<tr>
<td>J4080</td>
<td>媽媽既照顧好好，但我覺得太好，當然佢係一個模範，一個SAMPLE，比我知</td>
<td>模範</td>
<td>對年青成人的影響</td>
</tr>
<tr>
<td>J4081</td>
<td>你要了樣樣，比我知道。媽媽將來，媽媽都會成日同我講，我老左，我都希望你好似我今天照顧婆婆咁照顧我。</td>
<td>SAMPLE</td>
<td>對年青成人的影響</td>
</tr>
<tr>
<td>J4082</td>
<td></td>
<td>知道將來</td>
<td>對年青成人的影響</td>
</tr>
<tr>
<td>J4083</td>
<td></td>
<td>成日講</td>
<td>照顧者對年青成人的期望</td>
</tr>
<tr>
<td>J4084</td>
<td></td>
<td>好似照顧婆婆咁照顧媽媽</td>
<td>照顧者對年青成人的期望</td>
</tr>
</tbody>
</table>
Trustworthiness

Credibility
- Clarification was carried out with the participants during interviews
- The data were analyzed and discussed by all members of the research team in order to achieve consensus on the results

Dependability & Confirmability
- Audio taping was done to ease audit checks
- Inter-coder consistency was ensured by frequent comparisons and reflections
- Data analysis was performed immediately after transcription

Transferability
- Thick detailed description of settings and participants

(Lincoln and Guba, 1985; Kretting, 1991; Holloway & Wheeler, 2010; Richards & Morse, 2013)
<table>
<thead>
<tr>
<th>Participants’ Characteristics (N=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td><strong>Martial status</strong></td>
</tr>
<tr>
<td>Single</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
</tr>
<tr>
<td>Bachelor degree or above</td>
</tr>
<tr>
<td>Secondary school</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
</tr>
<tr>
<td>Employed or self-employed</td>
</tr>
<tr>
<td>Student</td>
</tr>
<tr>
<td><strong>Monthly family income (HK$)</strong></td>
</tr>
<tr>
<td>≥ $30,000 (US$3,850)</td>
</tr>
<tr>
<td>$10,001 – 29,999</td>
</tr>
<tr>
<td>≤ $10,000 (US$1,280)</td>
</tr>
<tr>
<td><strong>Primary Caregiver</strong></td>
</tr>
<tr>
<td>Mother</td>
</tr>
<tr>
<td>Aunt</td>
</tr>
<tr>
<td>Grandmother</td>
</tr>
<tr>
<td><strong>FAST staging of Care Recipient</strong></td>
</tr>
<tr>
<td>Mode: FAST stage 6</td>
</tr>
<tr>
<td>Range: FAST stage 4-7</td>
</tr>
</tbody>
</table>
Results – Theme I

Caring for a relative with dementia is a time-consuming, exhausting, and long-term task.

• **G02:** “...really need to spare time for it. Not just spare some time but also **put your time and effort on it with a clear mind.** ... you must realize that it’s a **long-term task** and that you will need to bear with it until the end of his life...”

• **Z03:** “Indeed, it really is a **tiring job.** If you decided to be a caregiver to a person with dementia, you really can’t take up a **job** other than that, even a part-time job. ... It’s **concentrated work,** involving the need to look after him for 24 hours ... “

**Example:**

| G02 | the initial of the interviewer number assigned to the participant |
The participants experienced stress and strain even though they were not the primary caregivers.

- **JO4**: “It’s very annoying. Being a young adult, dining out with friends and working overtime in a job are common ... taking care of him really affects my social life.”

- **A05**: “You can never sleep well. ... [You] live with the alarm clock and need to be alert all the time.”

- **Z02**: “Taking care of a person with dementia not only consumes most of your physical energy but also creates a heavy emotional burden.”

- **Z07**: “Taking care of my grandma, I feel anxious and indecisive.... I never know where to go for help.”
Results – Theme III

All young adults expressed willingness to look after their parents if their parents were diagnosed with dementia, and they would seek professional and other help in order to provide better quality care.

- **J01**: “... it may not be safe to hire an assistant--senior home may offer more professional care...”

- **G03**: “...I have my own job and I will need someone to help. ... Hiring caregiving assistance is necessary ...”

- **A06**: “... up to my grandma’s stage, hiring assistance maybe a choice ... A senior home has more professional staff ... and they know how to take care of [people with dementia]...”
Results – Theme IV

Their caregiving experiences and their perception of their parents’ caregiving experience led to personal reflection and growth in their lives.

- **J03**: “I can imagine that I will become physically *weak* with various diseases, maybe due to genetic causes…”

- **J05**: “Life changes from time to time. You really *can’t control* it except by treasuring the moment.”

- **A06**: “... I have become *pessimistic*. It will cause you to *plan and think* about the future.”
Results – Theme V

To be cared for by their next generation is not a must, as they did not want to become a burden on their children.

• **G05:** “... they (children) will have their own jobs, their lives, their family, so I won’t **force** my children to take care of me in the future. It will be a **burden for them**. I hope that they can ... but I cannot expect it. ... I really don’t want to be a burden on them.

• **J04:** “... I would rather stay in the elderly home and not give my children **too much pressure** in taking care of me.”

• **A02:** “I won’t expect my next generation to take care me as my mother did, because I don’t want to be a burden on them.”
Discussion

Willingness to take up the role of primary caregiver?

Ho et al. (2003): Primary caregivers (Chinese Canadian female caregivers, N=12) wondered if their next generation would take care of them in the way that they took care of the relative with dementia

Our findings:

– All of the young adults in our study said that they were willing to become the primary caregiver if necessary in the future

– They also said that they would seek appropriate assistance to help them to carry out the caregiving role
Discussion

Expectations related to whether they (the young adults) will be taken care of by their offspring in the future:

Ho et al. (2003): The primary caregivers had no expectations that they would be taken care of when they became incapable of taking care of themselves

Our sample of young adults:
– did not expect to be taken care of in the future
– did not want their children to experience what their parents/relatives had gone through
Discussion

The lack of communication among the primary caregivers (parents) with their adult children (the participants) is a concern:

• The young adults believed that their parents/relatives had some expectations (that the adult children will care for them when they become really old and weak), even though the parents did not verbally express them

• However, the young adults did not initiate discussions with their parents to clarify their expectations with regard to future needs and arrangements
Discussion

• **Reflections of the adult children:**
  – Witnessing parents/relatives providing care and occasionally helping out had prompted the young adults to wonder about their own lives
  – For example:
    • they wondered if they would get the disease
    • they felt that they did not do enough for their parents
    • they wondered whether it was better for them to have a housemaid or enter an institution
Discussion

• Implications for practice
  • Education should also cater to the needs of those who are not the primary caregivers
  • Family education: communication
  • Work pattern (e.g., flexible working time)

• Implications for further research
  • Religion
  • Culture
  • Communication

• Limitations
  • Sampling biases (sources, education level, and income)
References


References


The Functional Assessment Staging Test (FAST)

- Designed for evaluating changes in functional performance and activities of daily living skills in AD patients
- A scale composed of 7 major functional levels (1-7)
- 11 sub-stages corresponding to Stages 6 & 7 (6a-6e & 7a-7f)
- It can serve as a strong diagnostic and differential diagnostic aid for clinicians

(Sclan & Reisberg, 1992)
<table>
<thead>
<tr>
<th>Fast Stage</th>
<th>Characteristics</th>
<th>Clinical Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No difficulties, either subjectively or objectively.</td>
<td>Normal Adult</td>
</tr>
<tr>
<td>2</td>
<td>Complains of forgetting the location of objects. Subjectively, has difficulty finding words.</td>
<td>Adult: Normal Age</td>
</tr>
<tr>
<td>3</td>
<td>Decreased job function evident to co-workers; difficulty in traveling to new locations. Decreased organizational capacity.</td>
<td>Compatible with incipient AD</td>
</tr>
<tr>
<td>4</td>
<td>Decreased ability to perform complex tasks (e.g., planning a dinner for guests), handling personal finances (e.g., forgetting to pay bills), difficulty marketing, etc.</td>
<td>Mild AD</td>
</tr>
<tr>
<td>5</td>
<td>Requires assistance in choosing the proper clothing to wear for the day, season, or occasion.</td>
<td>Moderate AD</td>
</tr>
<tr>
<td>6a</td>
<td>Difficulty putting clothing on properly without assistance.</td>
<td>Moderately Severe AD</td>
</tr>
<tr>
<td>6b</td>
<td>Unable to bathe properly; (e.g., difficulty adjusting the temperature of the bath water) occasionally or more frequently over the past weeks.</td>
<td></td>
</tr>
<tr>
<td>6c</td>
<td>Inability to handle the mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.</td>
<td></td>
</tr>
<tr>
<td>6d</td>
<td>Urinary incontinence (occasional or more frequent).</td>
<td></td>
</tr>
<tr>
<td>6e</td>
<td>Fecal Incontinence (occasionally or more frequently over the past week).</td>
<td></td>
</tr>
<tr>
<td>7a</td>
<td>Ability to speak limited to approximately a half dozen different words or fewer, in the course of an average day or in the course of an intensive interview.</td>
<td>Severe AD</td>
</tr>
<tr>
<td>7b</td>
<td>Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over).</td>
<td></td>
</tr>
<tr>
<td>7c</td>
<td>Ambulatory ability lost (cannot walk without personal assistance).</td>
<td></td>
</tr>
<tr>
<td>7d</td>
<td>Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).</td>
<td></td>
</tr>
<tr>
<td>7e</td>
<td>Loss of the ability to smile.</td>
<td></td>
</tr>
</tbody>
</table>

(Reisberg, 1988)