Death and Dying in Dementia Care

*The life experience of family caregivers across the journey of dementia care*

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Introduction

• With increasing rates of dementia among elderly, many people will be affected by this disease; either by having the disease or by caring for a relative with dementia

• Since almost all of person with dementia (PWD) are taken care at home, family caregivers will play a crucial role in caring of PWD in Indonesia

• The dementia care journey may start years before getting diagnosis of dementia, then going through devastating period of home care, end of life issues & grief in bereavement and ...

• the physical and emotional impact of caring may last for several years after the death of care recipient.
Purpose of study

• To examine the dementia caregiving experience from the perspective of bereaved family caregiver

• To examine post-caring effect on physical & psychological health of family caregiver
Methods:

• This is a qualitative descriptive study

• Six former family caregiver who visited our memory clinic were recruited using convenience sampling.

• Each caregiver participated in one semi-structured interview in Indonesian ranging from 90 minutes to 150 minutes in length.

• Interviewed was performed by neurologist (Ong) and conclusion on each theme was made in a panel with two clinical psychologists (Febi Rosa and Novianti) in our memory clinic.

• Informed consent of each participant was obtained and this study has been approved by IRB of Adventist Hospital Bandung-Indonesia
Themes of interview consisted of:

1. Getting a diagnosis
2. Managing at home
3. End of life issues
4. Grief in bereavement
5. Post-caregiving physical health and psychological effects:
   A. Sleep disturbance
   B. Changes in health & psychological status
   C. Learning to life again (letting go of care, filling the gap, guilt, personal growth & triggers)

Guiding questions (Corey 2018)
1. Can you share with me your caregiving experience?
2. Tell me your life since .......passed away.
3. Describe how your life changed when...died.
4. What were the positive aspects of being a caregiver?
5. What were the negative aspects of being a caregiver?
6. What are the positive aspects of no longer being a caregiver?
7. What are the negative aspects of no longer being a caregiver?
8. How are your physical and psychological health before, during, and after your caregiving?

• Peacock et al. The journey with dementia from the perspective of bereaved family caregivers: a qualitative descriptive study. BMC Nursing 2014, 13:42
• Corey et al. When Caregiving Ends: The Experiences of Former Family Caregivers of People With Dementia. Gerontologist, 2018, Vol. 58, No. 2
Mrs Siti (pseudoname), a 63 YO MD, caregiver of husband with bvFTD-MND, described her 4 years journey of caregiving.

Interview was done 15 months after death of care recipient.
A. Getting a diagnosis

“At first, I thought he was his post-power syndrome... How come a devoted husband and wise father changed to a childlike, selfish, stubborn man with no sense of empathy... Can you imagine, how hard was the three years time before we got the diagnosis...”

- “In a gathering, he lost his table manner, he pointed to a lady and say “Are you the wife of Mr X who just died yesterday?” (which was not true)
- “Instead of facilitating his daughter’s art performance, he drove my car to Jakarta doing for nothing”
- “he wasted money on investment that is not clear, swapping credit card everywhere, causing a lot of debt”
- “I watch him playing a doorbell, and breaking into the neighbour's bedroom
Mrs Siti’s description: A journey of caregiving of PWD FTD-MMD

A. Getting a diagnosis

”He was good in driving, therefore I asked him to fetch me at my office. But one day, he drove my car out of town until running out of fuel then calmly he called me up as if nothing happened and I had to pick him up.”

“And finally, came the day he climbed down from second floor balcony just to get out of the house........I was so shocked, I cried and asking help from my son, my helper, my neighbors, and it took two hours to bring him into the living room”
B. Managing at home

“After thorough diagnostic work-up and explanation from doctor, we realized it was not his fault all these years, it was the deteriorated brain causing loss of his mind & personality”

• “Along with my son, daughter, my mom & domestic helper we discussed the trajectory of the disease,… we decided to take care of him at home until the end of his life ”

• “My helper and my son or daughter were in charge for day time, and I took care of him for evening and night”

• It was the support & prayers from our family, friends has enabled us to go through the years full of struggling…… but sometimes it was also funny if I recalled his childlike behaviors “It is not a big deal”, “So I have to be nice and wait for you here?”
B. Managing at home

• “I prayed for hours and cried before God in the midnight......My prayers changed from arguing, questioning to accepting the will of God.... I realized it was my destiny. I had to keep peace with myself and let go everything....Surrendering to God has enable me to accomplished my the responsibility of taking good care of him”

• It was the end of his third year illness, I noticed that he was not be able to rise his hands, therefore I had to bath and get him dressed. He got also breathlessness...... he was diagnosed as having Motor Neuron Disease.... Oh, My God, he was fully alert and he had to breath through the respirator for 15 months ....I just could not imagine it.
“I noticed him losing weight months by months”, but he looked happy when we had his birthday cake cut with my family & the staffs of ICU.

At the end of 15 months of admission, after several episodes febrile caused by pneumonia, the platelets counts declining...,I knew septicemia was going to take his life.”
D. Grief in bereavement

• Lots of sympathy statements mentioning his kindness from his former colleagues, staffs and friends which were really comfort to me.

• ”I was so sad losing a devoted husband and lovely father of my children, who was so kind and patient, who used to teach us forgiving the mistakes of others. Even though he had totally changed to be an selfish and childlike man. we still loved him, … we had to let him rest beside God.”
E. Post-caregiving physical & psychological status

“Problem with sleep?. No, I did hypnotherapy by myself if encountered one. I always pray before sleep and also sometimes in the midnight”

”......but six months after his death, I ventured to open his cupboard......I cried out loud seeing all his personal items was so neatly put inside the drawer as he always did. This is the first time I cried out-loud after his death, .....from that on....I felt just came out of my dream, it was really a release to me”
"My hypertension and diabetes got worse during caregiving, and now I am still in rigorous management of them"

"Now I focus on my son and daughter’s need, I share caregiving with my friends and others, ...I share with patients in my clinic twice a week”.

"Guilty? I have some, I should had understood his illness earlier and cared him better, but I try to not to rehearse it”

” I feel closer to my God, ...I am more patient now, I’d like to encourage caregiver and their family strengthening their faith to God to go through all life trials”

Mrs Siti’s journey of caregiving of PWD FTD-MMD

e. Post-caregiving physical & emotional status
<table>
<thead>
<tr>
<th>Pseudo-name Participant caregiver</th>
<th>Age</th>
<th>Relationship</th>
<th>Length of caregiving</th>
<th>Length of post-caregiving</th>
<th>Caregiver Occupation</th>
<th>Recipient Dementia Type</th>
<th>Family support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Rita</td>
<td>49</td>
<td>Daughter</td>
<td>13 years</td>
<td>3 months</td>
<td>Employee</td>
<td>AD</td>
<td>Helper</td>
</tr>
<tr>
<td>2. Veronica</td>
<td>45</td>
<td>Daughter</td>
<td>8 years</td>
<td>36 months</td>
<td>Dressmaker</td>
<td>AD</td>
<td>Helper, 2 teen children, husband</td>
</tr>
<tr>
<td>3. Bernadette</td>
<td>60</td>
<td>Spouse</td>
<td>14 years</td>
<td>12 months</td>
<td>Employer</td>
<td>AD</td>
<td>Helper, 3 adult children,</td>
</tr>
<tr>
<td>4. Nur</td>
<td>66</td>
<td>Spouse</td>
<td>9 years</td>
<td>12 months</td>
<td>Housewife</td>
<td>PDD</td>
<td>Helper, 3 adult children,</td>
</tr>
<tr>
<td>5. Paul</td>
<td>54</td>
<td>Son in law</td>
<td>9 years</td>
<td>9 months</td>
<td>Employee</td>
<td>AD</td>
<td>Wife (on hemodialysis), 2 adult children, 1 helper</td>
</tr>
<tr>
<td>6. Siti</td>
<td>63</td>
<td>Spouse</td>
<td>4 years</td>
<td>15 months</td>
<td>MD</td>
<td>bv-FTLD + MMD</td>
<td>2 adult son &amp; daughter, grandma and 2 helper</td>
</tr>
</tbody>
</table>
Result and discussion
A journey to diagnostic

*In this study, it took a lengthy time before care-receipient received a diagnostic.*

- “For a moment she did not recognize me “who are you, I thought it was due to aging as we get old until her behavior were so bad 4 years later, I brought her to specialist (Rita)

- “He forgot and misplacing stuffs, his response was so slow when we engaged in conversation.....he was diagnosed as AD about 2 years later” (Bernadette)

- “At first he could not do speed dial of his cellphone... then he drove his motorbike and visited his relatives early morning 03.00 AM (we could still tolerated it) until he aggressively bit his helper 8 years later (Vero)

- “He left the venue of our son’s wedding (fifth year of his PD treatment)” (Nur)

Caregiver tried to normalize changes in the care receiver’s behavior before accepting that something is “going on” (Davies, 2011)

Managing at home

All participants decided and prepared to take care of their love ones at home.

• After discuss with my brother and sister, I decided to care of my father with the support of my husband and my two kids. (Vero)

• Knowing it will be a long-term care of my husband at home, we decided to share caregiving with my son, daughter and helper. (Bernadette)

• I installed hand grips and make a safety environment for my mum (Rita)

• I have to work, my wife was on routine hemodialysis, my father in law (sequelae of stroke) could not handle his wife, so we decided to have domestic helper (Paul)

In Asian countries, many family caregivers have to stop or work fewer hours, take unpaid leave to take care of their relatives at home ....sending an elderly/spouse to nursing home implies a failure of responsibility. (Kua 2010)

Kua KE. in Dementia A Global Approach. 2010
Finding strength to carry on caregiving

In this study, religion played an central role in caregiving along with family, relatives and institutional supports.

• I believed God would enable me to go through this long journey. “Heaven lies under the feet of your mother” (Quran) Rita

• “God has His purpose on me, I have to have my thyroid chemo while taking care of my husband,... I love him so much (Bernadette)

• We brought our tiredness, sadness all into morning and night prayer to HIM with my husband and two kids everyday (Vero)

• Surrender to God was the only thing I could do. We are ordered to respect our parents (Psalm). Priest and friends gave great support. (Paul)

• I think I was the combination between faith to my God and love to my husband (Siti)
Religion & culture in caregiving

• In this study, all family caregivers used spiritual coping to ease their problems, including being more religious while in their current situation. This is in line with reports by Kristanti (2018) and Alfonso (2010)

• The value of being chosen by God for the role of a caregiver strengthened their caregiving motivation. The attitude toward their soul mates or reward of caring to their parents in heaven were the “drive” in caregiving. (Kristanti 2018)

• In traditional cultures like most of China and India, the setting of caregiving is one of “duty”, “obligation” or “karma” Alfonso (2010)

Alfonso et al. in Dementia A Global Approach. 2010
End of life issue

Even though it has proven to be not significant, the practice of putting on feeding tube, hospital admission and medical intervention in severely ill dementia patients still exist in Indonesia.

• I felt pity on him because he was not taking food few days and he was so weak, I asked nurse to install a tube for my father (Vero)

• I bought him to hospital when he was severely illness, and doctor said he got pneumonia and we admitted him(Bernadette)

• I agreed to have tracheostomy for him for bronchial toilet and respiratory support on ventilator” (Siti)
Grief in bereavement

In this study participant described losses pertaining changes in relationship, roles, independence and memory.

- I was so sad because the disease seized all of his nobleness a few years before he died (Siti)
- I felt as if I lost my power to continue this life the moment my mom passed away, but as the time goes by, I realize that she got no choice and that may be the best for her. Everybody has their own destiny...(Rita)
- I still remember when we went for a tour, I was so dependent on him. Now I grieve loss of the person I had been relying on had left. (Bernadette)

Similar multiple loss and grief in dementia care has been reported by Doka (2010)

Post-caregiving changes in physical & psychological status

<table>
<thead>
<tr>
<th>No</th>
<th>Themes &amp; Sub-themes</th>
<th>n (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sleep disturbance</td>
<td>5 of 6</td>
</tr>
<tr>
<td>2</td>
<td>Changes in medical &amp; psychological status</td>
<td>4 of 6</td>
</tr>
<tr>
<td>3</td>
<td>Learning to live again</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>Letting go of the role of caregiving and or filling the gap</td>
<td>4 of 6</td>
</tr>
<tr>
<td>B</td>
<td>Guilt &amp; regret</td>
<td>4 of 6</td>
</tr>
<tr>
<td>C</td>
<td>Acknowledging personal growth</td>
<td>5 of 6</td>
</tr>
<tr>
<td>D</td>
<td>Trigger</td>
<td>3 of 6</td>
</tr>
</tbody>
</table>
Sleep disturbances

• **Two of six participants recounted for having post-caregiving nightmare**
  
  • Rita who lost her mother 3 months ago reported “Shortly after mom’s death, I had nightmares and I had to do self hypnotherapy before it disappeared within 1 month”
  
  • Paul who lost his mother in law (9 months ago) and his wife (8 months ago) described: ”The memories of telephone ringing still awakes me till now, reminding me of the call of father in law”

• **Five of six participants described having difficulties initiating and maintaining sleep for the first week**
  
  • Three participant described totally improved, in 1 to 3 months, while 3 others improved but never returned to baseline sleep.
Changes in medical health

• Two of six participants had acute changes in health
  
  “I was admitted for few days after the 2 weeks terrible flue and lost weight” (Rita)

• One of six participants had a cascade of non-acute health problems
  
  “I am still having vertigo and diarrhea which goes and goes” (Paul)

• 3 of 6 participants developed or got worsen vascular disease during and post-caregiving
  
  • 1 participant had palpitation and coronary artery disease during caregiving, improved post-caregiving and now still on treatment (Nur)
  
  • 1 had dramatic weight gain (Veronica)
  
  • My hypertension and diabetes got worse during caregiving and still in intensive treatment
Changes in psychological status

- Three of six participants described having psychological problems

  “I felt stressed and anxious immediate after death of Mom” (Rita)

  “My concentration is still bad, I am easy distracted. My colleagues have to remind me when I am “blank” (Paul)

  ” I had been living in a dreamlike life until I had my fist cry after his death” (Siti)
Learning to live again

Participant described the unique transitioning phase in five commonalities (sub-themes):

1. **Letting go of caregiver role**
2. **Filling the gap**
3. **Guilty & regret**
4. **Acknowledging personal growth**
5. **Trigger**

“For the first one week, I did not know what to do, I avoided social meeting....”
Rita

“I have to rearrange my life again, I know that...... ......Nur

“I am still trying to “move on, you know that doctor..”... Paul

“I kept on moving on” by focusing on my son & daughter and religious activities”
Siti
Filling the gap

Most of participant used constructive copying by involving themselves in both non-caregiving and caregiving activities

“I have a daily call with my son and daughter... I am seeking for His purpose on my life, I have once a week jogging now.... ’ Paul

“I started my father’s business & sharing with other caregiver” Rita

“I continued dressmaking & caring of my family” Vero

“I join religious & caregiver meeting, spend more time with my son (ill) & starting small business on handmade beads” Nur

“ I share my caregiving experience with my friends and religious meeting”. Siti
Guilty & regret

Most of participant describe some guilty feeling that they should had served their love ones better

• “I should had delivered better care and not causing decubitus” (Rita)

• “I should had been more patience with him” (Vero)

• “I should had bring my wife and parents in law for a tour, now I have no more change to do it ... (Paul)

• “I should not mad at him if I knew the disease earlier” (Siti)
Acknowledging personal growth

Almost of our participants described positive effects of caregiving in personality and their religious practice

• I grew in faith, It was His plan for me to look after my husband even I was on my thyroid cancer treatment (Bernadette)

• I shared with my friend about toileting, bathing and feeding my Dad. (Vero)

• If not accompanied by Him, I would not be able to go through the journey to the end. (Paulus)

• I am more patient now, I encourage caregiver to strengthen their faith to God to endure all life trials” (Siti)
Trigger prompted sadness or anger

• I removed the bed we shared and all medical appliances he used to use to prevent sad memories (Nur)

• I cried out loud when I saw his personal items neatly put in the drawer, as he always did” (Siti)

• Seeing a family gathering event always reminds me my wish to bring them on a tour. (Paulus)
Limitation of this study

- The small sample size, predominantly female participants, convenience sampling, disproportionate number of spouse and adult-child caregiver, and large variability in the length of post-caregiving (3-36 months) may limit the generalization of the findings of this study.
Summary

• This descriptive study yielded rich insight in the experiences of bereaved family caregiver across all stages of dementia caregiving journey, and also provided changes in their physical and emotional status years after death of their love ones.

• This understanding can benefit health care professional to provide appropriate support to family caregiver in their clinical practice.

• Further study on the long-term effects of caregiving on health and well being is needed.
Acknowledgment:

“To all former caregivers participated in this study, who had made possible for this study to be conducted, I express my deep gratitude to all of them. Your contribution had made this teaching material beneficial for all participant in this congress. May God bless you and your family”
Thank You