Family caregivers’ life orientation based on diaries

Tarja Välimäki, PhD
I will talk about

• A diary study based on family caregivers’ unstructured diaries

• Salutogenic orientation in family caregiving

• Changes in family caregivers’ lives in the first year after AD diagnosis of a loved one
ALSOVA study
A prospective, controlled study of the effects of psychosocial rehabilitation in Finland in 2002 – 2011.
Multidisciplinary approach with medical, nursing science, health economics, psychology, and pharmaceutical researchers.

240 dyads, person with AD, and the primary caregiver.

Inclusion criteria:
Person with AD aged 65 +
Very mild or mild dementia (CDR 0.5 - 1)
Daily contact with a family caregiver
Life orientation

• A global view of life as comprehensible, manageable, and meaningful

• Reflects person’s ability to comprehend the entirety of a stressful situation and leads to capacity to use available resources

• The idea that the way people see their lives has an impact on their health

   (Antonovsky 1993, Eriksson 2007)
Aim

*To describe family caregivers’ life orientations during the first year after the diagnosis of AD*
Diaries

• Unstructured diaries that family caregivers wrote in their homes after first study visit in the ALSOVA study

• What is your life like now that a member of your family has Alzheimer’s disease?

• Caregivers were highly motivated to participate in the study

• Writing was voluntary
Method

Data

83 diaries by family caregivers

Length varied from one to 19 pages, the mean was 5 pages

In total, 446 pages of text

Analysis

Qualitative inductive content analysis, both manifest and latent content

ATLAS.ti and Word software

I had personally met all caregivers, also took field notes.
## Participants

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>n</th>
<th>Person with AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Age range</td>
<td>41 - 85</td>
<td>54 - 90</td>
</tr>
<tr>
<td>Mean</td>
<td>67.4</td>
<td>75.6</td>
</tr>
<tr>
<td>Time from dg to 1. study visit (months)</td>
<td>6.7 ± 1.0</td>
<td>6.7 ± 1.0</td>
</tr>
</tbody>
</table>
Findings

Restructuring life in its entirety

- Changes in family caregivers’ personal environment
- Familial cohesion
- Creating a new future for the family
Changes in the family caregivers’ personal environment

• Transition from a family member to a family caregiver
  • Continuous need to adapt in daily life, caregivers’ emotional lives and their physical settings

• Living in a tunnel
  “It feels like I’m practically imprisoned, since I can’t go out like I used to”

• Finding harmonizing elements in their life
  – Finding mental space by working outside the home, through hobbies
    “At times, it’s absolutely necessary to be able to take a breather…to take a walk alone”
Familial cohesion

• Challenges emerged in the family level

• Family caregivers tried to maintain warmth in family relations

• The onset of AD pulled parents away from their children
  • Neuropsychiatric symptoms; verbal insults, aggression were hard to bear

• Children as caregivers slipped from the child’s role
  “I can no longer be his daughter, now that I’ve become his caregiver against my will”
Two possible new future prospects for family caregivers

Hopelessness

• Concern about whether they would have sufficient strength to carry on
• The worst scenario was having AD themselves

"It is possible to recover from cancer, but not from this disease"

Confidence

• AD got a place in family caregivers’ life
• Ability to concentrate on satisfactory aspects in their lives
• An idea of a “good year” gave hope

“One can get used to everything, even get numb to Alzheimer’s… it has become a family member"
Conclusions

• Family caregivers live in a transitional stage with changing role as a spouse, a parent, and a child

• Changes in relationships and family roles take place gradually, starting before the AD diagnosis is set

• Family caregivers are told to carry on life as usual but at the same time they are supposed to take major responsibility for care and family life
Suggestions for further operations

• The onset of AD poses a threat to family caregivers’ health and emotional stability

• At the time of AD diagnosis, family caregivers’ health and well-being should be recognized in memory clinics

• The person with AD and their family members should be referred for continuous counseling given by a nurse specialized in dementia
Publications


Välimäki, T. et al. 2009. Caregiver depression is associated with a low Sense of coherence and Health related Quality of life. Aging & Mental Health 13(6), 850-858.
ALSOVA study group

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Thank you for your attention!

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