Professionally active family carers of persons with dementia

– how can caregiving affect work performance?

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Kirsti Hotvedt, RN, MPH. Ageing and Health - Norwegian National Advisory Unit

Ingun Ulstein, MD, PhD. Old-Age Psychiatric Department, Oslo University Hospital

Lene Povlsen, RN, DrPH. Unit for Health Promotion Research, University of Southern Denmark
Background

The situation in Norway

- The population in Norway is 5 million people
- 71 000 persons with dementia
- 250 000 family carers of persons with dementia
- Increased risk of health problems associated with burden of care

- Part time jobs or retire from work
- Financial problems
- Continue to work can give respite and joy

Benefits when working and caring for an elderly family member

- The majority of persons caring for a older family member are in the age group 50-66 years

- 50 percent in the age group 45-65 years have caregiving options for their parents, 70 percent of these are working

- In Norway there are different kind of support both in the Health Care Services and at the working places

- Varying what is legally required and works in practice

(Gautun and Hagen 2010, HOD 2011)
Objectives

The objective of this study was to examine and describe whether caring for persons with dementia affects work performance.

The study also looked at the relationship between various characteristics of the family carers’ situation and functioning at work; and how they coped with obligations both as carers and professionally active.
Methods

• The study is based on data from two former Norwegian cross-sectional studies in 2002-2004 and 2008-2009

• Data for the present study was collected from questionnaires completed by 594 family carers who answered the question:

*If you are still professionally active, does caring for a family member with dementia affect your work performance?*
Results

Answers to the question:

*If you are still professionally active, does caring for a family member with dementia affect your work performance?*

- 224 (37.5%) Yes
- 316 (53.2%) No
- 54 (9.1%) Don’t know
Affected work performance and caregiving - I

**Affected work performance** (n=540)
- Significantly more women and daughters described affected work performance
- No significant difference was found regarding the residence of the person with dementia
- Significantly more family caregivers who were living together with the person with dementia, described affected work performance
Affected work performance and caregiving – II

Burden of care

• More family carers reported «Medium» to «Lot of strain» than «Not at all» to «Little strain» (n=433)

• Significantly more burden of care if the persons with dementia lived in their own homes (n=433)

• Significantly more caregivers reported affected work performance and simultaneously a high level of burden of care, but no significant differences on affected work performance whether the persons with dementia lived in their own homes or nursing homes (n=391)
Affected work performance and caregiving – III

The association between affected work performance and formal help (n=368)

- Significantly more family carers reported affected work performance where the person with dementia lived in their own home with formal help
- The majority reported a high degree of being “satisfied” with the formal help
- Significantly more family carers reported affected work performance in the group that was «Not satisfied»

Experience of support from other family members and friends (n=324)

- Significantly more family carers responded «Yes» to the question concerning respite/help among those who simultaneously responded that they did not experience being affected at work
# Associations between characteristics of the family caregivers and affected work performance (n=72)

## Caregiver characteristics

<table>
<thead>
<tr>
<th></th>
<th>Yes (N=49)</th>
<th>No (n = 23)</th>
<th>p-verdi</th>
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</thead>
<tbody>
<tr>
<td>Gender, women, n (%)</td>
<td>39 (52.7)</td>
<td>13 (18.9)</td>
<td>0.06</td>
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<tr>
<td>Age, mean (s.d.)</td>
<td>50.8 (8.1)</td>
<td>51.7 (9.0)</td>
<td>0.68</td>
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<tr>
<td>RSS, mean (s.d.)</td>
<td>22.5 (10.88)</td>
<td>14.3 (8.87)</td>
<td>0.002</td>
</tr>
<tr>
<td>GHQ case score, mean (s.d.)</td>
<td>8.9 (8.58)</td>
<td>3.7 (4.68)</td>
<td>0.01</td>
</tr>
<tr>
<td>GHQ anxiety, mean (s.d.)</td>
<td>10.3 (5.27)</td>
<td>7.4 (3.48)</td>
<td>0.03</td>
</tr>
<tr>
<td>GHQ depression, mean (s.d.)</td>
<td>3.1 (3.13)</td>
<td>2.4 (2.15)</td>
<td>0.33</td>
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<tr>
<td>GHQ lack of well-being, mean (s.d.)</td>
<td>5.2 (1.63)</td>
<td>3.8 (0.95)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>GHQ coping failure, mean (s.d.)</td>
<td>5.9 (2.84)</td>
<td>4.4 (1.56)</td>
<td>0.04</td>
</tr>
<tr>
<td>GHQ social dysfunction, mean (s.d.)</td>
<td>4.2 (1.30)</td>
<td>3.5 (0.99)</td>
<td>0.03</td>
</tr>
<tr>
<td>NPI-distress, mean (s.d.)</td>
<td>14.2 (10.34)</td>
<td>10.1 (9.09)</td>
<td>0.08</td>
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</table>

## Patient characteristics

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<th>No (n = 23)</th>
<th>p-verdi</th>
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</thead>
<tbody>
<tr>
<td>Gender, women, n (%)</td>
<td>36 (49.3)</td>
<td>19 (26.0)</td>
<td>0.33</td>
</tr>
<tr>
<td>Age, mean (s.d.)</td>
<td>77.2 (9.6)</td>
<td>76.8 (8.0)</td>
<td>0.59</td>
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<tr>
<td>DAD-%, mean (s.d.)</td>
<td>50.4 (21.68)</td>
<td>65.3 (20.18)</td>
<td>0.01</td>
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<tr>
<td>NPI FxG, mean (s.d.)</td>
<td>25.4 (21.26)</td>
<td>19.4 (18.01)</td>
<td>0.17</td>
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<td>MMSE sumscore, mean (s.d.)</td>
<td>20.4 (5.81)</td>
<td>22.4 (3.00)</td>
<td>0.31</td>
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</tbody>
</table>

GHQ= General Health Questionnaire; NPI=Neuropsychiatric Inventory; DAD= Disability Assessment for Dementia; s.d.= standard deviation
Family caregivers’ descriptions – qualitative data

210 relatives answered the question *How does caring for a family member with dementia affect your work performance?*

81% were women, 26 spouses, 173 children, and 11 had another relation to the person with dementia.

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<th>Categories</th>
<th>Sub-categories</th>
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<tr>
<td>Caregiving during working hours</td>
<td>Practical tasks</td>
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<td>Burdens of care</td>
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<tr>
<td>Caregiving’s influence on working hours and routines</td>
<td>Absence from work</td>
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<td>Coping strategies</td>
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Caregiving during working hours

**Practical Tasks**
- Interruptions and disturbances due to telephone calls from and to the person with dementia
- Coordinating assistance and practical help during work hours like phones to the health care services and driving the family member to various appointments

**Burden of Care**
- Physical, mentally and emotional
  - Tired
  - Exhausted
  - Lack of sleep
  - Stress
  - Time pressure
Caregiving’s influence on working hours and routines

Absence from work
• Paid and unpaid Leave of absence
• Use of sick notes
• Reduced working hours
• Spontaneously leave during working hours

Coping strategies
• Rearrange appointments both at work and private
• Flexible working hours
• Catch up lost working time
• Less time on their own or with other family members
Conclusions

- Simultaneously being professional active and a family carer for a person with dementia may have a negative impact on work performance
- The functional impairment of the person with dementia may affect the family carer negatively during working hours
- Family carers experience a dilemma between maintaining an optimal work performance and the caregiving tasks
- Practical care tasks, interruptions and concerns during working hours as well as absence from work, is perceived as stressful and exhausting
Implications

• Increased accessibility of health services based on the persons with dementia and the family carers’ individual needs should be prioritized in the national policies and guidelines.

• The family carers’ professional work situation should be included as a topic in follow-up of family carers in the health care system.

• Formal health services should be organized to ensure that the persons with dementia are well cared for so that the family carers to a lesser degree need to be the organizers for the services.

• Increased flexibility at the working places should match the family carers’ needs.