Family Caregivers Waiting Placement of Cognitively Impaired Persons

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Background

- Rising incidence of dementia
- Caregiving of dementia persons is particularly stressful
- Caregivers of dementia persons more likely to consider placement
- Waiting period continues to be lengthy
Purpose

➢ to explore
  ● the experience of family caregivers while waiting placement of their family member with dementia
  ● how family caregivers cope during this waiting period
Research Questions

- What are the experiences of family caregivers while waiting placement of their dementia family member
- How do family caregivers cope while waiting placement - what is the relationship between services used and caregiver perception of coping
Research Methods

- Both qualitative and quantitative methods were used
- Participants recruited at time of admission to CAPS wait list
- Data collection at baseline and every four months thereafter until placement
- Ethical clearance from the joint Health Research Ethics Board of the University of Alberta and Capital Health Authority
Findings

Study Participants

- 41 participants admitted to the study and interviewed once
- 27 interviewed twice (65.9%)
- 10 interviewed three times (18.5%)
- 15 interviewed after placement (39%)
  (2 weeks – 3 months)
Study Participants – the caregivers

- Age – mean 60.4 years
- Gender – females 31 (73.2%); males 10 (24.4)
- Relationship to dementia person
  - Adult child – 21 (51.2%)
  - Spouse – 14 (34.1%)
  - Other – 5 (12.2%)
## Findings: Health Sleep Deprivation and Burden

### Baseline, Four Months Later, & Post-Placement

<table>
<thead>
<tr>
<th>Caregiver variables</th>
<th>Time 1</th>
<th>Time 2</th>
<th>After Placement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health rating (range 0-10)</td>
<td>6.97 (n=35)</td>
<td>7.30 (n=20)</td>
<td>6.82 (n=11)</td>
</tr>
<tr>
<td>Sleep needed (daily)</td>
<td>5-11 hours (mean 7.3)</td>
<td>5.5 – 10 hours (mean 7.5)</td>
<td>4.8 – 9 hours (mean 7.04)</td>
</tr>
<tr>
<td>Sleep received (daily)</td>
<td>3.5-10 hours (mean 6.2)</td>
<td>2.5 – 9.5 hours (mean 6.1)</td>
<td>4.5 – 7 hours (mean 5.76)</td>
</tr>
<tr>
<td>Sleep deprivation (daily)</td>
<td>1.1 hours</td>
<td>1.4 hours</td>
<td>1.1 hours</td>
</tr>
<tr>
<td>Caregiver Burden (range 10-84)</td>
<td>40.46 (n=24)</td>
<td>35.82 (n=17)</td>
<td>42.91 (n=11)</td>
</tr>
</tbody>
</table>
Findings – Service Utilization

- Just over half of caregivers used homemaker services (n=21; 52.5%).
- Fifteen caregivers (37.5%) used bath assistance.
- Nine caregivers (22.5%) used sitter/in home respite services.
- Eleven (27.5%) caregivers used other home-care support services.
Relationship among Key Variables

Perceived Health
- time spent caregiving ($r = -.303; .05$)
- caregiving interferes with health ($r = -.656; .001$)
- burden ($r = -.619; .001$)
- fatigue ($r = -.517; .001$)
Relationship among key variables (cont)

Burden
- Fatigue ($r = .739; .001$)

Sleep deficit
- Caregiving interferes with health
  ($r = .528; .001$)
- Fatigue ($r = .605; .001$)
- Burden ($r = .375; .05$)
Crisis as Initiator

- featured strongly in the data
- crisis alerted caregivers of deterioration
- many past crisis, each precipitating action
- looming crisis, “what if anything would happen to me”
The Waiting Begins

- Synchronicity
  relationship between caregiver readiness for placement and bed availability

“she wasn’t that bad, if you know what I mean… I broke down and said ‘no, we won’t do it’”
Control
- great exertion to remain in control
- spiraling out of control

“…it is awful. Now, I’m kind of floating, I don’t know whether I am doing the right [thing] or not”
The Waiting Begins

- Reciprocity
  - the influence of past and present relationship between caregiver and dementia person on current situation.

“I don’t want to [use services] because Mom’s memory is still good enough, she would be upset if I wasn’t doing it [caregiving], … so I can’t”
After Placement

- Bonded Relationships
  - reciprocal relationships continue
  - deeply embedded in past history
  - fuels a genuine caring, of having deep concern for their family member

“It’s just part of my life. My mom cared for me – now I care for her”

“I always feel the need to stop if I am driving by [the nursing home].”
After Placement

- **Attempting Continuity** - struggling with transition from primary caregiver to now watching strangers doing the care
- Trying to retain some control
  - frequent visits - not very satisfying
  - doing numerous tasks associated with caring
  - being vigilant of staff
  - wanting the same quality of care as had been given at home
After Placement

- Attempting Continuity

“I make her special meals, take them to the home, and leave them in the fridge”

“I go there and check his sock drawers...to make sure that he’s got his own clothes...cause things do get mixed up over there”
After Placement

- Sorting out the Change
  - ambivalence
  - strategies to manage the change
  - dealing with the system
Ambivalence
- questioned the decision; felt relief; guilt

“…it’s harder putting her into a place than it is having her at home…”

“…did I do the right thing, is he in the right place…”

“It helps that much of the physical care is done by others, but I feel guilty ‘cause I could make her care better if I was with her more…”
Sorting out the change (cont)

- keeping busy
- support from friends and family if available
- being able/not able to ‘let go’

“Sometimes, I haven’t kind of come to grips with that yet of how much time I should have to myself…”
Dealing with the system

- some were satisfied and others discontented with the quality of care "staff always seems to be happy when I come… that made me feel good"

- frustrated with system rules and regulations "very frustrated with the system"

- lack of communication between caregivers and staff: “you can’t rock the boat”
Discussion

- Caregiving experience while waiting placement
  - struggled with their responsibilities
  - uncertainty/pending crises
  - moderate caregiver burden and caregiver reaction
  - chronic sleep deprivation
Discussion (cont)

- Caregiver coping while waiting placement
  - embedded within the dyad relationship
  - intensity and quality of this relationship does not change after placement
  - sleep deprivation influences caregiver coping
  - relatively low levels of services used
Chronic accumulative effect of inadequate sleep contributes to break down of the synchrony and reciprocity within the dyad.

Because of sleep deprivation their ability to function physically and emotionally becomes compromised.

We suggest that it may be their chronic sleep deprivation that is a major contributing factor to the caregivers’ inability to continue in their role.
Discussion (cont)

- Why the low service utilization?
  - if services generate more hassles than help for caregivers, they will not be used
  - services facilitate caregiver coping only if those services facilitate the relationships within the dyad
Clinicians must recognize:

- The impact of services on caregivers - if too much of a hassle services will not be used; caregivers already ‘on the edge’
- The relationship between caregivers’ readiness and actual placement of dementia persons.
Practice Implications (cont)

- That caregiving is embedded within the dyad relationship
  - be committed to maintaining the synchrony and the reciprocity within these relationships
  - focus on services that refresh and restore caregivers
  - be sensitive to caregivers’ reluctance to receive services
  - caregivers must be supported to overcome their hesitancy
Policy Implications

- If institutionalization is to remain a last resort, then the following issues need to be addressed:
  - how community-based services are provided
  - the working conditions of non-professional workers
  - the matching of services/workers with dementia persons and their caregivers
Research Implications

- explore the relationship between sleep deprivation, service utilization and caregiver coping.
- health care system approach to the ‘waiting for placement’ issue needs to be explored in some detail
Conclusion