Carers' experiences of the role of Extended Aged Care at Home-Dementia packages

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Behavioural and psychological symptoms of dementia (BPSD)

- Behavioural symptoms
  - Agitation
  - Aggression, verbal and physical
  - Disinhibition, eg sexual
  - Wandering away from home

- Psychological
  - Depression
  - Delusions
  - Hallucinations
  - Fearfulness
  - Dysphoria
  - Irritability

(O’Connor, Ames, Gardner, King, 2009 X2)

BPSD > Increased carer burden and institutionalisation
BPSD in the community

- 56% of people with dementia in the community have at least 1 BPSD:
  - 27% apathy
  - 24% agitation/aggression and depression\(^1\)
- Strategies developed and tested in residential settings
- Effective strategies: carer education, music therapy, recreation, relaxation, validation, person centred care and aromatherapy
- Family carers’ approach > Limited strategies\(^2\)

\(^1\)Lyketsos et al 2000; \(^2\)Ward et al 2003
### Care programs available for older Australians inc. those with dementia

<table>
<thead>
<tr>
<th>Care level</th>
<th>Community based</th>
<th>Residential care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>Home &amp; Community Care (HACC)</td>
<td>NA</td>
</tr>
<tr>
<td>Low (as assessed by an Aged Care Assessment Team)</td>
<td>Community Aged Care Package (CACP)</td>
<td>Low level care (prev. hostel)</td>
</tr>
<tr>
<td>High (as assessed by an Aged Care Assessment Team)</td>
<td>Extended Aged Care at Home (EACH) and Extended Aged Care At Home Dementia (EACHD)</td>
<td>High level care (prev. nursing home)</td>
</tr>
</tbody>
</table>
Extended Aged Care at Home-Dementia

• Introduced as part of the 2004-05 Australian Government Budget Initiative, Helping Australians with Dementia, and their Carers - Making Dementia a National Health Priority;

• As at 30 June 2010 there were 2,583 EACHD packages allocated across Australia.

• Eligibility (as assessed by an Aged Care Assessment Team):
  – High level complex care needs because BPSD,
  – eligible for high level residential care,
  – prefer to receive an EACHD package
  – be able to live at home with the EACHD package

• Daily subsidy: CACP - $36.05; EACH - $120.50; EACHD – $132.89

• Average LOS: <6 months
Schedule 2: Specified care and services for EACH Dementia (DoHA, 2005)

- EACHD packages-flexible in content but generally include:
  - qualified nursing input, particularly in the design and ongoing management of the package.
  - clinical care,
  - personal assistance,
  - meal preparation,
  - continence management,
  - assistance to leisure activities,
  - emotional support,
  - therapy services,
  - home safety and modification, as well as
  - additional levels of service to meet the specific needs of care recipients who experience behaviours of concern and psychological symptoms associated with dementia.
Suggested EACHD methodologies include:

- Service Strategies and
- Behavioural strategies
  - CM > knowledge, skill, experience in delivery of dementia care & behaviour management
  - Detailed care plan > range of service partners (GP, behavioural management specialists, psychogeriatricians, other health and community service providers)
  - links to specialist mental health & dementia specific services
  - Use psycho-social approaches in care and support to address underlying causes of behaviours of concern
Aim of study

To explore carers’ perceptions of the role of EACH-D packages in the context of providing care for someone with high level dementia care needs

TODAY – focusing on the program aims of targeting and managing BPSD
Method

- In depth interviews with family members caring for someone with dementia
- Neuropsychiatric Inventory (12 symptoms – severity, frequency, distress to carer)
- Respite and interpreters offered
- Audio recorded and transcribed
- Summary reports to participant
- 3 month phone follow up
- Thematic analysis
Participants

- Recruited through ACAS and EACHD service providers
- 23 family members caring for someone eligible for EACHD:
  - Group 1: On a waiting list for EACHD (n=8)
  - Group 2: Currently receiving EACHD (n=9)
  - Group 3: Previously accessing EACHD (before residential care placement) (n=6)
Participant profile

- Carer; 91.3% female; age=58.3 (SD=13.6, range: 36-83)
- Care recipient; 56.5% female, age=82.9 (SD=5.6, range: 71-94)
- 21 metro; 2 rural
- Recruited from 2 ACAS and 3 EACHD providers
Relationship to person with dementia

- Daughter: 60.9%
- Wife: 26.1%
- Husband: 4.3%
- Son: 4.3%
- Friend: 4.3%
Country of birth
### Neuropsychiatric Inventory (NPI)

<table>
<thead>
<tr>
<th></th>
<th>Group 1</th>
<th>Group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of symptoms /12</td>
<td>Median 8</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>6-12</td>
</tr>
<tr>
<td>Severity by frequency /144</td>
<td>Median 57</td>
<td>53</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>16-111</td>
</tr>
</tbody>
</table>
NPI symptoms (%)

- Delusions
- Hallucinations
- Agitation
- Depression
- Anxiety
- Elation
- Apathy
- Disinhibition
- Irritability
- Motor behav
- Sleep disturb
- Eating disturb

- Current study
- Lyketsos-moderate
- Mega-severe

*Not included in Lyketsos et al, 2000 or Mega et al, 1996 studies
Carer distress (NPI-D)

- 6pt Likert scale; score range 0-60
- Previous research: 8.7 (SD=6.9) (Kaufer, 1998)
- Group 1: median=20, range 2-42
- Group 2: median=19, range 2-35
- Severely/Very severely distressed:
  - Agitation (35.3%),
  - Motor disturbances (29.4%),
  - Irritability, depression, disinhibition, sleep disturbances (23.5%)
Most difficult aspect of dementia

• Most common responses:
  – BPSD: particularly aggression, sleep disturbances and repetitive questioning
  – Impact on relationships due to communication difficulties
“He was, yeah, very, um very angry and verbally aggressive and that’s what I found really difficult to deal with, and just the lack of sleep in that at that time he was probably getting up six, seven, eight, ten times a night”. (Wife, Group 3)
“With dad its the not remembering what he says to mum, his anger, I feel like he is getting angrier all the time, mostly, I think a lot towards me, but little niggly things all the time to mum and I feel like I’m growing up again with dad, ‘cause it’s like he’s gone back and he thinks that I’m still ten years old and he can still tell mum what to do, you know. And he calls you all horrible names.” (Daughter, Group 2)
“He’s not there anymore, he’s here and yet he’s gone. It’s very difficult because I used to, we used to sit at the table together, or in the bedroom, or walking, discuss things, you have somebody. It is the most difficult thing.” (Wife, Group 1)
# Strategies employed

<table>
<thead>
<tr>
<th></th>
<th>Waiting list (n=8)</th>
<th>Current clients (n=9)</th>
<th>Previous clients (n=5)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average number</td>
<td>2</td>
<td>3.6</td>
<td>3.8</td>
</tr>
<tr>
<td>psychosocial strategies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participants reporting</td>
<td>5</td>
<td>5</td>
<td>3</td>
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<tr>
<td>pharmacological</td>
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<td></td>
<td></td>
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<tr>
<td>strategies</td>
<td></td>
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</tr>
<tr>
<td>Participants reporting</td>
<td>4</td>
<td>1</td>
<td>1</td>
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<tr>
<td>passive strategies</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Participants reporting</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>negative strategies</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

*Friend participant did not identify strategies and was excluded from analysis
Psychosocial strategies

• Address unmet needs
• ABC model
• Stress threshold
• Person centred care
• Positive social environment
• Validation
• Reality Orientation
• Be flexible/innovative
• Exercise/ activities/ outings
• Sensory
• Environmental modification
• Diversion
Other strategies

• Passive:
  – Ignore symptoms
  – Get used to symptoms
  – Don’t take things personally

• Negative:
  – Treat in childlike way
  – Convincing/ yelling/ instructing someone to do what they want
Dementia education

• Formal courses (eg Alz Aus; 9)
• Talking to health professionals/ service providers (6)
• Accessing the Internet (6)
• Books (5), brochures (4) and booklets (2)
• Alz Aus counsellors (5)
• TV documentaries (4)
• Talking to friends and other carers (3)
Previous life/employment experience

- Having another relative with dementia
- Occupation:
  - Nurse
  - Aged care/information services
  - Disability care
  - Speech pathologist
“I had no idea before I started. I mean, I suppose I did have more than most in that my background is, I’m a speech pathologist...I’ve worked in rehab and I’ve worked with special needs kids. So, I’m used to the mindset of, you know, we’ve looked at the ABC stuff and what did provoke it and then, you know, looking at what the client’s needs are.” (Wife, Group 3)
Barriers to education

- 70% of participants reported obstacles:
  - Overwhelmed by information
  - Not enough time/respite
  - Information too broad/ not specific to individual needs
  - Poor timing in accessing information (early or late)
“I used to just sit there and cry... this is so awful and I’m listening to their stories... things that they were saying were just, I think, they were scaring me, because, not meaning to, but I was just thinking, oh my god, all these things that happen... but yeah, that course was um, like it told you a lot, it was very interesting and there was a lot of information but because he’d just been diagnosed... I just thought that was a bit too early for that course in my case.”

(Wife, current client)
BPSD support through EACHD

• 4/12: EACHD provided dementia expertise and support for BPSD

• Case managers:
  – Nursing or welfare background/ extensive dementia training
  – Anticipated needs
  – Suggested useful strategies
  – 1 participant was a nurse working for the EACHD agency
“She was very good, very supportive, very professional… the case manager suggested the little key holder outside, you know, with the pin numbers so that, ‘cause sometimes mum’d still be in bed when the carers came in the morning and they’d be knock, knock, knocking and worried about her and she might just still be asleep or whatever… So little things like that, that they, that she initiated that I might not have thought of, that were all in mum’s interests and meeting mum’s needs… she anticipates mum’s needs in the way I do, you know?” (Daughter, Group 3)
“She [case manager] knows as much as I do I think about dementia... I don’t know what she knows actually, I know that she’s been very helpful in this situation, in referring to other people.” (Husband, Group 2)
“I probably worked through all that stuff myself before, before [EACHD agency] came on the scene. We’d been to a couple of Alzheimer’s Association things, um and I found there, they separated the carers and the patients and I found there that I’d worked through everything.” And “the EACH-‘D’, the D is for dementia but I don’t know why they need to add it on. I don’t know, maybe you get more respite care or something, I don’t know.” (Partner, Group 2)
Conclusions

• Targeting EACHD: high levels of BPSD
• Broad range of strategies across participants
• Waiting list clients > fewer effective strategies?
• Barriers to information, but still access to large amount
• Limited to carers’ experiences (CMs views not captured)
• 1/3 carers reported dementia expertise and BPSD strategies through EACHD > fulfilling program guidelines?
Future directions

• **Scope for a more systematic approach to BPSD management for EACHD clients:**
  – Targeted to individual needs
  – Drawing on effective intervention studies
  – More systematic approach to identifying causes and possible strategies
  – Monitoring effectiveness of strategies

• **Seek Case Managers’ perspectives on current practice**
SAVE THE DATE

National Dementia Research Forum
Sydney, Australia
22 & 23 September 2011

International Key Note Speaker
Ronald C Petersen
Director Mayo Alzheimer’s Disease Research Research Centre, USA

Closing date for abstracts: 30 June 2011
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