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A cross-sectional study during COVID-19 of the social care-related quality of life of people with dementia and their carers in England

Measuring the outcomes of people with dementia who are unable to self-report and their carers (MOPED)

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Disclaimer

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The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.
Background

• Over 767,000 people living with dementia in England and Wales
  • The majority (~two thirds) live in their own home.

• Community-based social care is designed to maintain independence and QoL of people living with dementia and their unpaid carers.

• However, they are often overlooked in social care research.
  • E.g., Adult Social Care Survey in England (ASCS) – exclusion of people unlikely to be able to self-report from sample.
Aims

1. To establish the feasibility, construct validity and reliability of **ASCOT-Proxy**
   • Designed for use when someone is unable to self-report, even with adapted methods (e.g. adapted interview, easy read)

2. To establish the feasibility, construct validity and reliability of **ASCOT-Carer**
   • Previously validated in a heterogeneous sample of adult carers in England (Rand et al, 2015) and identified as a suitable instrument *by carers of people with dementia* (Gridley et al, 2019)

3. To determine the factors associated with the social care-related quality of life of people with dementia (**ASCOT-Proxy**, proxy-reported) and their carers (**ASCOT-Carer**, self-reported)
Methods

• A survey of carers of people living with dementia in England
• Online or postal questionnaire
  • Individual characteristics
    • **Carer:** age, gender, ethnicity, overall health
    • **Care-recipient:** age, overall health, I/ADLs, cognitive status
  • Caregiving situation: hours of care per week, co-residence, and self-reported financial impact of caring
  • Type, intensity and satisfaction with community-based care services
• Outcome measures
  • **Self-report:** ASCOT-Carer, EQ-5D, C-DEMQOL, CES
  • **Proxy-report:** ASCOT-Proxy, EQ-5D-Proxy, DEMQOL-Proxy
ASCOT-Proxy

- Personal cleanliness and comfort
- Food and drink
- Personal safety
- Clean and comfortable home
- Social participation and involvement
- Control over daily life
- Occupation
  
  Doing things that I value and enjoy
- Dignity
23. Thinking about the food and drink the person you represent gets, which of the following statements best describes his/her situation?

*Please say* what you think *in the first column. Then say* how you think the person you are representing would answer *in the second column. Please write in the comments box if you wish to add anything to your answer.*

The person I am representing...

*Please tick (✓) one box for each column*

<table>
<thead>
<tr>
<th>My opinion (What I think)</th>
<th>What I think the person I represent thinks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gets all the food and drink s/he likes when s/he wants</td>
<td>☐</td>
</tr>
<tr>
<td>Gets adequate food and drink at OK times</td>
<td>☐</td>
</tr>
<tr>
<td>Doesn’t always get adequate or timely food and drink</td>
<td>☐</td>
</tr>
<tr>
<td>Doesn’t always get adequate or timely food and drink, and there is a risk to his/her health</td>
<td>☐</td>
</tr>
</tbody>
</table>

Ideal state
No needs
Some needs
High-level needs
ASCOT-Carer

Social participation and involvement

Control over daily life

Occupation

Personal safety

Feeling supported and encouraged

Self-care

Time and space to be myself

Doing things that I value and enjoy

Eating well, exercise, sleep, medical appointments
COVID-related Policy Phases in England

1. Pre-first national lockdown
   January to 25 March 2020

2. First national lockdown
   26 March to 03 July 2020

3. Minimal restrictions
   04 July to 13 September 2020

4. Regional tier system
   14 September to 04 November 2020

5. Second national lockdown
   05 November to 01 December 2020

6. Reintroducing tier system
   02 to 29 December 2020

7. Third national lockdown
   30 December 2020 to 07 March 2021

8. Easing restrictions
   08 March 2021 to study end (April)
Participants

**Inclusion criteria:**
A friend or family member of someone living with dementia, who:
- Lives at home (not in a nursing or residential care home)
- Uses at least one type of social care service
- Would not be able to answer a postal or online questionnaire, even with help.

**Carers:**
- Average age of 62.4 years
- 75.7% female
- 94.6 % white/white British
- 47% provided ≥50 hrs of care per week

**People with dementia:**
- Average age of 81.5 years
- 48.9% were parents of carer
- 41.5% were partners/spouses of carer
- 57.8% lived in same household as carer
### Unmet Social Care Need (% of sample, n=313)

<table>
<thead>
<tr>
<th>Category</th>
<th>ASCOT-Carer</th>
<th>ASCOT-Proxy proxy</th>
<th>ASCOT-Proxy proxy person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home cleanliness and comfort</td>
<td></td>
<td>10.9%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Personal cleanliness and comfort</td>
<td></td>
<td>14.4%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Food and drink</td>
<td></td>
<td>15.7%</td>
<td>10.2%</td>
</tr>
<tr>
<td>Dignity</td>
<td></td>
<td>21.1%</td>
<td>35.1%</td>
</tr>
<tr>
<td>Control over daily life</td>
<td></td>
<td>51.8%</td>
<td>55.3%</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td>71.6%</td>
<td>74.8%</td>
</tr>
<tr>
<td>Social participation</td>
<td></td>
<td>58.8%</td>
<td>62.9%</td>
</tr>
<tr>
<td>Personal safety</td>
<td>3.2%</td>
<td>11.8%</td>
<td>16.0%</td>
</tr>
<tr>
<td>Self-care</td>
<td>32.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time and space</td>
<td></td>
<td>62.6%</td>
<td></td>
</tr>
<tr>
<td>Feeling supported and encouraged</td>
<td></td>
<td>50.2%</td>
<td></td>
</tr>
</tbody>
</table>
## Results: ASCOT-Carer

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>.039</td>
<td>-.005 to .083</td>
<td>.082</td>
</tr>
<tr>
<td>Aged ≥ 65 years</td>
<td>.019</td>
<td>-.025 to .063</td>
<td>.403</td>
</tr>
<tr>
<td>Ethnicity: Black, Asian, multiple/mixed</td>
<td>-.072</td>
<td>-.155 to .011</td>
<td>.088</td>
</tr>
<tr>
<td>Self-rated health: good or very good</td>
<td>.124***</td>
<td>.082 to .166</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>MDS CPS: severe impairment</td>
<td>-.057**</td>
<td>-.094 to -.019</td>
<td>.003</td>
</tr>
<tr>
<td>Co-resident with care-recipient</td>
<td>-.059*</td>
<td>-.117 to -.001</td>
<td>.044</td>
</tr>
<tr>
<td>≥ 50 hrs care per week</td>
<td>-.069*</td>
<td>-.124 to -.013</td>
<td>.015</td>
</tr>
<tr>
<td>Financial difficulty due to caring</td>
<td>-.094***</td>
<td>-.132 to -.056</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Satisfied with services</td>
<td>.142***</td>
<td>.105 to .178</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Survey completion by C-19 phase</td>
<td>-</td>
<td>-</td>
<td>Not Sig.</td>
</tr>
<tr>
<td>Survey online</td>
<td>-.021</td>
<td>-.073 to .032</td>
<td>.443</td>
</tr>
<tr>
<td>Constant</td>
<td>.651***</td>
<td>.562 to .739</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

* <.05, ** <.01 *** <.001
Results: ASCOT-Proxy

• **Proxy-Proxy rating**
  - Suitability of home design; co-resident with carer; >50 hrs unpaid care/week; hours of home care per week; use of day services or activities (+ve)
  - Severe cognitive impairment; regional tier system (Sept/Nov 2020) (-ve)

• **Proxy-person rating**
  - Aged 65+; I/ADLs with difficulty; severe cognitive impairment; reintroducing tier system (Dec 2020); third national lockdown (Dec 2020 to March 2021); easing restrictions (March 2021 to study end) (-ve)
  - Paid and unpaid care intensity or type (Not Sig.)
Conclusions

• High % of unmet social care-related need, especially among carers
• Those carers at risk of poor social care-related QoL are those with poor health, caring for ≥50 hrs/week, and experiencing financial difficulties due to caring
• Satisfaction with care associated with better outcomes for carers
  • ‘Whole family approach’
  • ‘Think carer’
• Impact of C-19 restrictions
  • No significant association with carers’ QoL
  • Significant negative association with PLWDs’ QoL
    • At introduction of restrictions with a tier system (proxy proxy)
    • At latter stages from reintroduction of tier system through to study end (proxy person)
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