Enhancing our understanding of measuring quality of life of people with dementia who are unable to self-report

Dr Barbora Šílarová (she/her)¹
Dr Stacey Rand¹, Ann-Marie Towers² & Professor Karen Jones¹
¹Personal Social Services Research Unit (PSSRU), University of Kent
²Centre for Health Services Research (CHSS), University of Kent
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

• People with dementia living at home represent a growing group of social care services users.

• It is important to understand the impact of social care on their quality of life and how community based social care services may best support them.

• It may be difficult to collect such information from people who have memory or communication difficulties.
Background – ASCOT Proxy

• To work around this, an adapted version of the Adult Social Care Outcomes Toolkit (ASCOT)* questionnaire, ASCOT-Proxy, has been developed.

• *The ASCOT questionnaires are used to collect information on the quality of life of people who use social care services and their carers.
Background – ASCOT Proxy

- Personal cleanliness and comfort
- Food and drink
- Safety
- Clean and comfortable accommodation

- Social participation and involvement
- Control over daily living
- Occupation
- 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...

<table>
<thead>
<tr>
<th>Gets all the food and drink s/he likes when s/he wants</th>
<th>My opinion (What I think)</th>
<th>What I think the person I represent thinks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gets adequate food and drink at OK times</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Doesn't always get adequate or timely food and drink</td>
<td>□</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>
<td>□</td>
</tr>
</tbody>
</table>

Ideal state

No needs

Some needs

High needs
The Aim

• To understand whether ASCOT-Proxy is easy to complete and measure what it is intended to measure – that is, social care-related quality of life (SCRQoL)
Participants – MOPED study

**Carers:** 62.4 years (SD:12.0); 75.7% (n=237) females; 94.6% (n=296) White/White British; 47% (n=147) provided 50+ hours per week of care; 14% (n=268) provided ≥ 10 years of care

**People with dementia:** 81.5 years (SD: 9.4); 90.4% (n=283) were partners/spouses/parents; 57.8% (n=181) lived in the same household

**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.

<table>
<thead>
<tr>
<th>Survey mode</th>
<th>Recruitment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>JDR</td>
<td></td>
</tr>
<tr>
<td>Postal</td>
<td>8</td>
<td>55</td>
</tr>
<tr>
<td>Online (Qualtrics)</td>
<td>165</td>
<td>85</td>
</tr>
<tr>
<td>Total</td>
<td>173</td>
<td>140</td>
</tr>
</tbody>
</table>
Results
Distribution of responses - ASCOT-Proxy
Distribution of responses - ASCOT-Proxy

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>P-Proxy</td>
<td>275</td>
<td>.597</td>
<td>.219</td>
</tr>
<tr>
<td>P-Patient</td>
<td>275</td>
<td>.642</td>
<td>.218</td>
</tr>
<tr>
<td>Difference</td>
<td>275</td>
<td>-.046</td>
<td>.220</td>
</tr>
</tbody>
</table>

Pr(|T| > |t|) = 0.0006

Correlation between Proxy-Proxy and Proxy-Patient
Spearman's rho = 0.54 (moderate correlation)
Feasibility (acceptability) - ASCOT-Proxy

Missing values: n out of 313

- Proxy-Patient: Dignity
  - Proxy-Proxy: Dignity
  - Proxy-Patient: Control over daily life
  - Proxy-Proxy: Control over daily life
  - Proxy-Patient: Occupation
  - Proxy-Proxy: Occupation
  - Proxy-Patient: Social participation
  - Proxy-Proxy: Social participation
  - Proxy-Patient: Personal safety
  - Proxy-Proxy: Personal safety
  - Proxy-Patient: Personal comfort and cleanliness
  - Proxy-Proxy: Personal comfort and cleanliness
  - Proxy-Patient: Accommodation
  - Proxy-Proxy: Accommodation
  - Proxy-Patient: Food and drink
  - Proxy-Proxy: Food and drink

- 22 Missing values
- 21 Missing values
- 5 Missing values
- 3 Missing values
- 2 Missing values
- 4 Missing values
- 6 Missing values
Internal consistency (reliability) - ASCOT-Proxy

**Proxy-Proxy**
- Number of items in the scale: 8
- Scale reliability coefficient: 0.68

**Proxy-Patient**
- Number of items in the scale: 8
- Scale reliability coefficient: 0.69

Cronbach's alpha (a coefficient of reliability) > 0.6 is considered acceptable
## Construct validity - ASCOT-Proxy

<table>
<thead>
<tr>
<th>Measures of related constructs</th>
<th>Proxy-Proxy</th>
<th>Proxy-Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spearman's rho</td>
<td>Spearman's rho</td>
</tr>
<tr>
<td><strong>Health-related quality of life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EQ-5D-Proxy-Proxy</td>
<td>0.3 weak</td>
<td>0.4 moderate</td>
</tr>
<tr>
<td>EQ-5D-Proxy-Patient</td>
<td>0.2 weak</td>
<td>0.4 moderate</td>
</tr>
<tr>
<td><strong>Proxy-rated condition-specific quality of life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DEMQOL</td>
<td>0.2 weak</td>
<td>0.4 moderate</td>
</tr>
<tr>
<td><strong>Overall quality of life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proxy-Proxy</td>
<td>0.5 moderate</td>
<td>0.4 moderate</td>
</tr>
<tr>
<td>Proxy-Patient</td>
<td>0.3 weak</td>
<td>0.6 moderate</td>
</tr>
</tbody>
</table>
Structural validity - ASCOT Proxy

Factor 1
Basic needs
- Personal cleanliness and comfort
- Food and drink
- Safety
- Clean and comfortable accommodation

Factor 2
Higher order needs
- Social participation and involvement
- Control over daily living
- Occupation
- Dignity
Summary - ASCOT-Proxy

• ASCOT-Proxy is a feasible, valid and reliable measure of social care-related quality of life.
• There is a difference between proxy report perspectives.
• Further analysis of ASCOT-Proxy are needed (construct and structural validity).
• Role of mode of administration (online vs postal).
Our Team

Professor Karen Jones
Co-Investigator

Ann-Marie Towers
Co-Investigator

Dr Stacey Rand
Chief Investigator

Della Ogunleye
Research Advisor

Aakta Patel
Research Advisor
Thanks for your attention!

Contact: b.silarova@kent.ac.uk

@BarboraSilarova