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Recruitment, consent and data collection in research involving care home residents with dementia – lessons from the EPIC trial

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Leeds Beckett University

Research Team of the Year
Background

• Over 16,000 care homes (nursing and residential) in England (CQC 2016)
• Resident population of over 460,000 (CQC 2016)
• One-third of people with dementia live in a care home (Knapp et al 2007)
• Estimated that c.70% of care home residents have dementia (Alzheimer’s Society 2016)
• Issues with care quality and meeting of resident needs
Conducting trials in care homes

- Significant need for research in this setting
- Comparatively few RCTs conducted in care homes
- Care homes therefore not ‘research ready’
- Poor understanding of research and its processes and procedures
- Many see value in being research active
EPIC trial (Surr et al 2016) recruitment of care home residents with dementia to research

- Follows standard process for assessment of capacity
  - Individual informed consent OR appointment of personal or nominated consultee
- 145/726 (20.0%) personal consent
- 263/726 (36.2%) personal consultee
- 318/726 (43.8%) nominated consultee
EPIC trial challenges - approaching personal consultees

- Access to personal details – data protection
- May not visit frequently/live at a distance
- May not respond to correspondence
- Can be left with ‘unknown’ status of invited participants
- Personal views rather than participant’s wishes
EPIC trial solutions – personal consultees

- Clear information about role
- In person to consultee
- Posted to consultee
- Returned direct to researcher
- No response
- Follow-up letter
- Returned
- No response
- Appoint nominated consultee

2 weeks → 2 weeks
EPIC trial challenges - approaching nominated consultees

- Finding suitable individual
- Concerns about role and providing advice on residents wishes
- Concerns about family views if personal consultee did not respond
- Staff turnover and finding replacement consultee
EPIC trial solutions – nominated consultees

- Where possible one consultee for multiple residents
- Spend time explaining role and discussing concerns
- Emphasise right of residents to take part in research if they would wish to – not be excluded due to non-response of family
- Emphasise ability to withdraw later if relatives make contact and advise differently
Resident outcomes QoL - challenges

• Consistent person to report/complete measure (self vs proxy)
• Discrepancy between self vs proxy reports (Arons et al 2013; Buckley et al 2012)
• Sensitivity in moderate/severe dementia
• Residents
  – Suitable measure for moderate to severe dementia
  – Items relevant to care home residents
  – Burden/time
  – Enjoyable and not cause distress
• Staff
  – Turnover and availability
• Relatives
  – Engagement
  – Frequency of visiting
Resident outcomes - solutions

• DEMQOL
  – MMSE 10+
  – 28 items

• QOL-AD
  – MMSE 3+
  – 13 items
But .... QOL-AD

The QOL-AD (Participant Version) from Logsdon et al (2002)

QOL-AD-res (Edelman et al 2005)

Removes two items and adds four new ones:
- people who work here,
- ability to take care of oneself,
- ability to live with others, and
- ability to make choices in one’s life

<table>
<thead>
<tr>
<th>Instructions: Interviewer administers according to standard instructions. Circle participant responses.</th>
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</thead>
<tbody>
<tr>
<td>1. Physical health</td>
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<tr>
<td>2. Energy</td>
</tr>
<tr>
<td>3. Mood</td>
</tr>
<tr>
<td>4. Living situation</td>
</tr>
<tr>
<td>5. Memory</td>
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<tr>
<td>6. Family</td>
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<tr>
<td>7. Marriage</td>
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<tr>
<td>8. Friends</td>
</tr>
<tr>
<td>9. Self as a whole</td>
</tr>
<tr>
<td>10. Ability to do chores around the house</td>
</tr>
<tr>
<td>11. Ability to do things for fun</td>
</tr>
<tr>
<td>12. Money</td>
</tr>
<tr>
<td>13. Life as a whole</td>
</tr>
</tbody>
</table>
Summary

- Conducting trials in care homes with people with dementia can be challenging
- Lack of/no consistent, direct access to relatives
- CH staff not used to research roles and processes
- Lack of suitable measures for use in this population
- Be pragmatic and do things differently/push boundaries
EPIC trial team

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References


