Improving Care for People with Dementia Living in Nursing Homes: WHELD AND COVID-WHELD

Clive Ballard and Joanne McDermid on behalf of the COVID WHELD team
Alzheimer’s centre of Excellence

Cutting edge research from dementia care
(Professor Linda Clare), Professor Louise Allan to genomics/epigenetics
(Jon Mill, Katie Lunnon)

Ranked 28 in the World in Leiden rankings for research quality
Living with Dementia in Residential and Nursing Care

• 40 million people living with dementia globally
• In Europe & North America 1/3 people with dementia live in residential care homes or nursing homes
• Majority of people have moderately severe or severe dementia
• Quality of care provided is variable, inconsistent and often poor
• Widespread use of harmful antipsychotic medications
Major Adverse Outcomes with antipsychotics over 6-12 weeks
(FDA, Schneider et al 2005, Ballard et al 2009)

• Parkinsomism
• Sedation
• Gait disturbance
• Increased respiratory infections
• Oedema
• Accelerated cognitive decline (2-4 fold)
• Stroke (>3 fold)
• Other thrombo-embolic events (up to 80%)
• Mortality (1.5-1.7 fold)
DART AD: Differential Survival
Ballard et al Lancet Neurology 2009

Differences in the survival rates in the DART-AD trial

<table>
<thead>
<tr>
<th>Number of months</th>
<th>Survival rate on placebo</th>
<th>Survival rate on antipsychotic</th>
</tr>
</thead>
<tbody>
<tr>
<td>24</td>
<td>71%</td>
<td>46%</td>
</tr>
<tr>
<td>36</td>
<td>59%</td>
<td>30%</td>
</tr>
<tr>
<td>42</td>
<td>53%</td>
<td>26%</td>
</tr>
</tbody>
</table>
Figure 1: Fossey et al 2006 BMJ 12 NH n=347
WHELD Factorial Study: 16 care homes, 300 people with dementia

Main aim:
To find out the most effective combination of psychosocial treatments for residents to improve quality of life, reduce prescribing and reduce falls

Pilot Interventions: Developed with support of international advisory board

- Person Centred Care
- Social Intervention and Pleasant activities
- Antipsychotic Review
- Exercise

www.exeter.ac.uk/medicine
WHELD: Key Results
Ballard et al Am J psychiatry 2016
(16 care homes, 277 participants with dementia)

• AR significantly reduced antipsychotic use by 50% (OR 0.17, 95% CI 0.05 to 0.60, p=0.006).
• AR and SI significantly reduced mortality (OR=0.36, 95% CI 0.23 to 0.57, p<0.001)
• Benefits in mortality were achieved without a worsening of neuropsychiatric symptoms in people receiving AR and SI (-0.44, CI -4.39 to 3.52, p=0.82)
• EX significantly improved depression (-4.74, CI 0.76 to 8.72) and neuropsychiatric symptoms (-4.01, 95% CI -7.91 to -0.10, p=0.045).
• SI significantly improved quality of life (6.04, 95% CI 0.24 to 11.84, p=0.042)
• Combination of both SI and AR (p<0.04) and EX and AR (P<0.02) also significantly improved apathy
WHELD Dementia Champion RCT
Ballard et al PLOS Medicine 2018

- 2 arm randomized single blind clinical trial (WHELD intervention vs treatment as usual)
- 69 care homes/nursing homes
- 9 month duration
- Key outcomes
  - Primary outcome
    - Quality of life (DEMQOL)
  - Key Secondary outcomes
    - Agitation (CMAI)
    - Service utilization/Cost (CSRI)
- Completed prior to randomization and after 9 months
**Effect estimates of WHELD intervention in comparison to TAU on key outcome measures**

(Multiple Imputation Analysis) (n=847, 69 care homes)

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Adjusted effect (SE)*</th>
<th>p-Value</th>
<th>Mean difference (SEM)</th>
<th>95% CI of mean difference</th>
<th>Effect size (Cohen’s D)</th>
<th>Number needed to treat$^\Delta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEMQOL-Proxy (n = 553)</td>
<td>R = 0.12 Z = 2.82</td>
<td>0.0042</td>
<td>2.54+ (0.88)</td>
<td>0.81, 4.28</td>
<td>0.24</td>
<td>9</td>
</tr>
<tr>
<td>CMAI (n = 553)</td>
<td>R = 0.11; Z = 2.68</td>
<td>0.0076</td>
<td>4.27+ (1.59)</td>
<td>−7.39, −1.15</td>
<td>0.23</td>
<td>6</td>
</tr>
<tr>
<td>NPI-NH (n = 547)</td>
<td>R = −1.5; Z = 3.52</td>
<td>&lt;0.001</td>
<td>4.55+ (1.28)</td>
<td>−7.07, −2.02</td>
<td>0.30</td>
<td>9</td>
</tr>
</tbody>
</table>

*Adjusted effect takes into account baseline value, age, sex, Clinical Dementia Rating, site, and clustering within care homes.

Overall treatment costs less for the Intervention group than the group receiving treatment as usual.
tEACH: eLearning study

- National Dementia Strategy for England: improve training of staff working in care homes & QoL for people living with dementia
- Partnered with Social Care Institute for Excellence (SCIE) to develop and evaluate an e-learning training intervention based on the principles of the WHELD programme
- Pilot RCT of 187 care staff and 130 residents in 16 care homes over 8 months demonstrated significant benefits in staff attitudes to PCC with a combination of the e-learning intervention and facilitation support
eLearning delivery

- 16 CHs received online programme: 8 with Research Therapist support, 8 online only

- **Bespoke interactive multimedia content** created specifically for care staff – five 25-minute modules to be completed over 6-week period in CH
Approaches to Dementia Questionnaire

![Graph showing changes in ADQ scores between treatment (Treat) and control groups. The graph indicates a significant difference in ADQ PC and ADQ total scores, with asterisks representing statistical significance: ** for p < 0.01 and *** for p < 0.001.]
## Dementia Care Mapping (n=130)

<table>
<thead>
<tr>
<th>Treatment 2 v treatment 1</th>
<th>22-23% benefit in WIB</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Timepoint 2</strong></td>
<td></td>
</tr>
<tr>
<td>WIB</td>
<td>T=2.8 p=0.006</td>
</tr>
<tr>
<td>Timepoint3</td>
<td></td>
</tr>
<tr>
<td>WIB</td>
<td>T=1.3 p=0.18</td>
</tr>
<tr>
<td>Treatment 3 v 1</td>
<td></td>
</tr>
<tr>
<td><strong>Timepoint 2</strong></td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>Timepoint3</td>
<td></td>
</tr>
<tr>
<td>WIB</td>
<td>T=2.89 P=0.004</td>
</tr>
</tbody>
</table>
Sustainability of eLearning: Qualitative study

• ~30 care staff from a number of CHs participated in semi-structured interviews, including managers, senior carers, team leaders and care assistants six months post-intervention completion

• Staff interviewed were positive about the eLearning programme and found the material easily accessible, thought-provoking, realistic and ‘stuck’ with them – referencing the use of video and reflective thinking exercises as particularly useful
COVID Challenges for Care Homes

- Threat of COVID to residents and staff
- 159% increase in all cause mortality for residents
- Staff absence/illness, increased agency staff
- Stress and burnout for staff
- Challenges with visiting and maintaining contact with families
- More limited support from specialist services and primary care
- Isolation
- Increased antipsychotic use

Howard et al 2020 Antipsychotic prescribing in COVID
DOI: https://doi.org/10.1016/S1474-4422(20)30370-7

COVID WHELD

• Ongoing MRC programme in UK
• COVID adaptations of WHELD
  – Champion model with virtual coaching
  – Improved digital resources
  – Platforms for peer support, sharing best practice
• Optimization and 4 month RCT in 1280 care homes
The iWHELD interactive hub

- Live online support sessions with an iWHELD coach
- Peer-peer networking and collaboration
- A digital hub of ideas, activities and takeaway resources
MVP: COVID WHELD Pilot Phase

- Managers and care staff from 160 care homes field tested different components of the COVID WHELD programme
- Overall very Positive feedback
- Digital access sufficient (65% desktop, 30% mobile, 5% tablet)
- **THE IT WORKED!** Enjoyed the “missions” and bite size resources
- peer-to-peer support via coach sessions and community platform enabled multiple connections across staff and homes and addressed staff needs in the moment
- Feedback suggested better sign-posting on the site would be helpful
- Suggestions re highest priority materials and clearer requirements for champions
- Recommendations to reduce the complexity of registration and repeat sign-in
Testimonials from qualitative pilot feedback

Positive participant feedback so far highlights the potential of iWHELD:

“I found this session to be very positive especially discussing issues around those individuals living with dementia who cannot express their needs and wishes very well and who also do not have family to fill in any blanks in knowledge about that individual”.

“I am excited to learn more and use this portal as both a guide and a place to deliver my personal experience/knowledge, to help myself and others in similar positions deliver the best care”.

“Very helpful and good to share ideas for improvement. Felt everyone contributed and gained from call. Lots of ideas to enhance experience in [our] unit”.
Next Steps

• 4 month RCT OF 1280 care homes (approx. 5000 residents, 6000 staff)
• 2-4 champions per care home
• Digital resources with virtual coaching
• Resident outcomes: Quality of life, GAS, Neuropsychiatric Inventory, Health Economics
• Staff Outcomes: Attitudes to Dementia
• 1st participants consented and 1st block to be randomized in March