Discrete Choice Experiments to Understand Crises in Dementia

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ALZHEIMER’S DISEASE INTERNATIONAL 2014
**ACKNOWLEDGEMENTS: SHIELD**

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<thead>
<tr>
<th>Name</th>
<th>Role and Title</th>
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<tbody>
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</table>

*Support at Home - Interventions to Enhance Life in Dementia Research Programme funded by the National Institute of Health Research, Grant number: RP-PG-0606-1083. The Sponsor of this research programme is North East London NHS Foundation Trust.*
Two discrete choice experiments (DCE) were conducted with family carers of people with dementia and healthcare professionals.

- To determine the relative importance of the identified attributes of home treatment interventions, by examining the preferences of staff and family caregivers.

- To identify the relative importance of factors which contribute towards a crisis risking admission.
Microeconomic Consumer Theory

Individuals will make decisions in order to maximise their utility/benefit
Applications of DCEs in Healthcare Research

• In healthcare, resources are scarce (demand exceeds supply)

• In healthcare, choices need to be made services and interventions for patients. Costs and benefits must be compared.

• Choices reveal information about patient preferences (DCE)

• *Opportunity cost and CHOICES*: something is only of value if we are willing to give something up for it. Consumers/patients make trade-offs which we can observe in DCEs to ascertain what is important and how important

• MRC recognises the need for more than just QALYs to value patient experiences: Importance of factors beyond health outcomes
Experimental Design DCE 1: Causes of Crisis

- Five attributes
  - Wandering behaviour
  - Aggressive behaviour
  - Family carer workload
  - Risks/hazards in the home
  - Physical health

- 5 attributes have 4 levels within them (Level 0, Level 1, Level 2, Level 3).

- 4 of the attributes are qualitative and non-linear variables (dummy variables in our utility function) and 1 is quantitative (family carer workload).

- Orthogonal main effects only design with no interaction effects.

- Binary choice model (Yes/No)

- Fractional factorial

- Probabilistic choice model, random effects logit model (probit).
Home Treatment Package Questionnaire

Section Two - Crisis Scenarios

You will now be presented with a series of 8 scenarios involving a person with dementia and a family carer. We would like for you to read each scenario and state whether you think the presented situation would lead to a crisis. There are no correct answers, we are seeking for your opinions only.

1/8: Do you think it is possible that a person with dementia experiencing a combination of the following circumstances would lead to a crisis situation which results in a possible hospital admission?

- Daytime wandering behaviour is present, with some disruption to the carer and/or neighbours. The person with dementia may leave the home even when asked not to. They sometimes gets lost but usually manages to find their way. The wandering behaviour is manageable with minimal associated risks.

- No aggressive/violent behaviour is displayed.

- The carer is providing around 28 hours of direct care per week for the person with dementia (e.g. assisting with personal care such as bathing and dressing, preparing meals, telephone support, administering medication, household chores, shopping, running errands or accompaniment to appointments).

- The person with dementia may often leave the front door and windows open and neighbours have reported strangers going into the house. The person with dementia cannot manage the heating and hot water systems in the house. There is a damp smell in the house to suggest that there have been floods in the bathroom or kitchen. There is a serious safety risk in the home associated with electrical equipment and cooking (i.e. leaving the gas on).

- The person with dementia may have experienced dehydration and some weight loss due to poor diet or lack of food. The person with dementia’s mobility is restricted, resulting in difficulty in walking and the risk that they have falls at home and outside the home. There is a history of recurrent chest infections or urine infections. There are signs that chronic conditions such as diabetes mellitus and arthritis are inadequately managed.

Yes

No
The following attributes had a statistically significant effect on family carers choices (1% significant level):

- FAMILY CARER WORKLOAD
- RISKS/ HAZARDS IN THE HOME (Level 0 and Level 1)
- PHYSICAL HEALTH PROBLEMS (Level 0 and Level 1)

Relative to the base case (W/B Level 3, A/B Level 3, R/H Level 3, P/H Level 3), the fewer the risks/hazards in the home the lower the likelihood of a crisis.

Relative to the base case (W/B Level 3, A/B Level 3, R/H Level 3, P/H Level 3), the fewer the physical health problems the lower the likelihood of a crisis.

Family carer workload (time): The more time the carers spent with their relatives, the lower the likelihood of a crisis.
## Results: Experimental Design
### DCE 1- Causes of Crisis

<table>
<thead>
<tr>
<th>Attribute and Level</th>
<th>Symptoms/ Descriptors</th>
<th>Crisis Risk</th>
<th>Minutes of care provision lost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Least severe scenario – level 0 for all attributes</td>
<td>No identified risk within the identified attributes</td>
<td>35.11%</td>
<td>N/A</td>
</tr>
<tr>
<td>1 level increase for risks/ hazards in the home with all other attributes set at Level 0</td>
<td>Cooking hazards, forgetting to close windows and turn off taps etc.</td>
<td>59.25% (+24.14%)</td>
<td>180 minutes per week</td>
</tr>
<tr>
<td>1 level increase for physical health problems with all other attributes set at Level 0</td>
<td>Difficulties with walking or having signs of an inadequate diet</td>
<td>58.3% (+23.19%)</td>
<td>173 minutes per week</td>
</tr>
<tr>
<td>1 level increase in both physical health problems and risks/ hazards in the home with all other attributes set at Level 0</td>
<td>Cooking hazards, forgetting to close windows and turn off taps, difficulties with walking or having signs of an inadequate diet</td>
<td>78.95% (43.84%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Highest risk scenario</td>
<td>Night &amp; daytime wandering, severe physical &amp; verbal aggression, strangers entering the home, unable to manage heating, hot water/ cooking systems, malnutrition &amp; dehydration, recurrent falls in/ out of home, chronic health conditions, not taking prescribed medication.</td>
<td>99.67%</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Results: Experimental Design
DCE 1- Causes of Crisis

• The following attributes had a statistically significant effect on HCPs choices (1% significant level):

  ❑ FAMILY CARER WORKLOAD
  ❑ WANDERING BEHAVIOUR (Level 0, 1 and 2)
  ❑ AGGRESSIVE BEHAVIOUR (Level 0, 1 and 2)
  ❑ RISKS/ HAZARDS IN THE HOME (Level 0 and Level 1)
  ❑ PHYSICAL HEALTH PROBLEMS (Level 0, 1 and 2)

• Relative to the base case (W/B Level 3, A/B Level 3, R/H Level 3, P/H Level 3), the fewer the risks/ hazards in the home the lower the likelihood of a crisis.

• Relative to the base case, the less frequent or severe the aggressive behaviour the lower the likelihood of a crisis.

• Relative to the base case, the fewer the physical health problems the lower the likelihood of a crisis.

• Relative to the base case, the less frequent or severe the wandering behaviour the lower the likelihood of a crisis.

• Family carer workload (time): The more time the carers spent with their relatives, the lower the likelihood of a crisis.
## Results: Experimental Design
### DCE 1- Causes of Crisis

<table>
<thead>
<tr>
<th>Attribute and Level</th>
<th>Symptoms/ Descriptors</th>
<th>Crisis Risk</th>
<th>Minutes of care provision lost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Least severe scenario (Level 0 for all attributes)</td>
<td>No identified risk within the attributes</td>
<td>33.16%</td>
<td>N/A</td>
</tr>
<tr>
<td>1 level increase for wandering behaviour with all other attributes set at Level 0</td>
<td>Daytime wandering, sometimes getting lost, some disruption to neighbours</td>
<td>37.34% (+4.18%)</td>
<td>46 minutes per week</td>
</tr>
<tr>
<td>2 level increase for wandering behaviour with all other attributes set at Level 0</td>
<td>Daytime wandering, often getting lost, serious disruption caused to carer and neighbours</td>
<td>42.99% (+9.83%)</td>
<td>104 minutes per week</td>
</tr>
<tr>
<td>1 level increase in aggressive behaviour with all other attributes set at Level 0</td>
<td>Some verbal aggression, irritability</td>
<td>35.48% (+2.32%)</td>
<td>25 minutes per week</td>
</tr>
<tr>
<td>2 level increase in aggressive behaviour (with all other attributes set at Level 0)</td>
<td>Moderate physical aggression, and highly unpleasant/threatening verbal aggression</td>
<td>58.33% (+25.17%)</td>
<td>257 minutes per week</td>
</tr>
<tr>
<td>1 level increase for risks/ hazards in the home with all other attributes set at Level 0</td>
<td>Cooking hazards, forgetting to close windows and turn off taps etc.</td>
<td>38.42% (+5.26%)</td>
<td>28 minutes per week</td>
</tr>
<tr>
<td>1 level increase for physical health problems with all other attributes set at Level 0</td>
<td>Difficulties with walking or having signs of an inadequate diet</td>
<td>44.75% (+11.59%)</td>
<td>122 minutes per week</td>
</tr>
<tr>
<td>2 level increase in physical health problems (with all other attributes set at Level 0)</td>
<td>Dehydration and weight loss, restricted mobility resulting in falls in/out of the home, recurrent infections, chronic conditions are not adequately managed</td>
<td>82.92% (+49.76%)</td>
<td>564 minutes per week</td>
</tr>
<tr>
<td>Base case (Level 3 for all attributes) – Most severe scenario</td>
<td>Night &amp; daytime wandering, severe physical &amp; verbal aggression, strangers entering the home, unable to manage heating, hot water/cooking systems, malnutrition &amp; dehydration, recurrent falls in/out of home, chronic health conditions, not taking prescribed medication.</td>
<td>99.99%</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Experimental Design DCE 2: Home Treatment Crisis Interventions

- Four attributes
  - Technology and home adaptations
  - Direct payments for home care (+ respite)
  - Healthcare professional support
  - Carer support/ education/ training

- 4 attributes have 4 levels within them (Level 0, Level 1, Level 2, Level 3).

- 3 of the attributes are qualitative and non linear variables (dummy variables) and 1 attribute is quantitative (Direct payments).

- Multiple forced choice model (A/ B/ Neither) based upon high crisis case example.

- Fractional factorial design.

- Willingness to accept (WTA) compensation to forgo components of the home treatment package intervention.

- The model will be a **main effects design with two way interactions**.

- Mixed Effects Logit Model applied for regression analysis.
Please now consider the following three home treatment intervention packages (1/10)
To remind yourself of the crisis scenario please [click here](http://www.surveymonkey.com/s/DO_NOT_USE_THIS_LINK_FOR_COLLECTION?sam=7ao8uG2XFIr4Ao%72b2GMoewUEF2%72RujQ9MNJfD7rem6E3d) (OPENS A NEW WINDOW)

**Intervention A**
- Medication reviewed following a clinical assessment. Referrals made to dementia support services. Health and social care professional involvement in development and implementation of care package following an assessment of care needs. A health/social care professional routinely visits the person with dementia on a weekly basis. In an emergency, a specialist healthcare professional can be contacted during extended hours (e.g. 7am – 10pm) and a home visit can be arranged if required.
- Family carer receives no direct payments**.
- The family carer is provided with some education/training in coping skills and regularly attends care support groups. Family carer is signposted to services providing advice and information on welfare/pensions/legal matters and counselling. Family carer is given some relevant information leaflets. Family carer is receiving some outreach support from voluntary organisations. Family carer is advised to use the internet and local directories to search for additional information.
- An OT safety and risk assessment has been carried out and extensive safety measures put in place. The person with dementia is equipped with a telephone, emergency pull cords and a community alarm. Adaptations have been made in the home including rails around the bath and toilet in the home and rails on the stairs. Specialist assistive technology has been implemented, which could include a gas sensor, a falls detector and an entrance/exit sensor.

**Intervention B**
- Medication reviewed and monitored following a clinical assessment at home. Referrals made to dementia support services. In an emergency, a duty worker can be contacted on a telephone helpline.
- Family carer receives £180 per week in direct payments**.
- No carer support/education/training is provided.
- Occupational Therapist (OT) safety check carried out and some safety measures put in place. These include ensuring that handrails on stairs are safe and that the person with dementia has access to a telephone and a walking aid.

**Intervention C**
- Medication reviewed following a clinical assessment.
- Family carer receives no direct payments**.
- No carer support/education/training is provided.
- No safety checks put in place, no safety expertise advice/risk assessments given.

**Direct payments can be used to purchase the following services:**
- Day care @ £50 per day
- Specialist home care services @ £15 per hour (one hour is two visits in a day)
- Sitting services @ £15 per hour
- Emergency respite in the home @ £15 per hour

*Which Home Treatment Intervention would you choose for a carer and person with dementia in this crisis where there is a risk of hospital admission? (Select one answer only)*

- [ ] A
- [ ] B
- [ ] C
Results: Experimental Design
DCE 2- Crisis Interventions

• Using the results from the MIXLOGIT regression analysis with main effects only, the following attributes had a statistically significant effect on family carers choices (5% significant level):
  - DIRECT PAYMENTS
  - TECHNOLOGY & HOME ADAPTATIONS (Level 1, 2 & 3)
  - HEALTHCARE PROFESSIONAL SUPPORT (Level 1, 2 & 3)
  - CARER SUPPORT/ EDUCATION & TRAINING (Level 1, 2 & 3)

• Relative to the base case (TECH Level 0, HCP Level 0, CST Level 0), more technological and home adaptation interventions were preferred to less technological and home adaptation interventions.

• This was similarly the case for healthcare professional support and carer support/ education/ training.

• The higher the direct payments, the higher the chance that the intervention package would be chosen.
### Results: Experimental Design
### DCE 2- Crisis Interventions

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Level Descriptor</th>
<th>Willingness to accept compensation</th>
</tr>
</thead>
</table>
| **Health & Social Care Support**  
**LEVEL 1** | Medication review, referrals made to dementia support services, duty worker helpline support | £361.01 |
| **LEVEL 2** | Level 1 plus implementation and development of care package, weekly routine home visits, specialist HCP contacted during extended hours | £368.44 |
| **LEVEL 3** | Level 2 plus, daily home visits and access to specialist HCP 24 hours a day. | £348.34 |
| **Carer Support, Education & Training**  
**LEVEL 1** | Signposted to family carer support groups and services, for advice and information, relevant information leaflets, advised to use the internet and local directories to search for additional information. | £275.23 |
| **LEVEL 2** | Level 1 plus education/training on coping skills, outreach support from voluntary organisations. | £486.81 |
| **LEVEL 3** | Level 2 plus access to support from Admiral Nurse, regular counselling, extensive training on coping and relaxation. | £727.64 |
| **Technology & Home Adaptations**  
**LEVEL 1** | Occupational Therapist (OT) safety check carried out and some safety measures put in place e.g. safe bannisters, access to a phone and a walking aid. | £394.49 |
| **LEVEL 2** | Level 1 plus telephone and a lifeline, rails around the bath and toilet in the home and rails on the stairs, medication dispensers. | £535.43 |
| **LEVEL 3** | Level 2 plus emergency pull cords and community alarm. Specialist assistive technology has been implemented, which could include a gas sensor, a falls detector and an entrance/exit sensor. | £677.94 |
Results: Experimental Design
DCE 2- Crisis Interventions

• Using the results from the MIXLOGIT regression analysis with main effects only, the following attributes had a statistically significant effect on healthcare professionals’ choices (1% significant level):

  - DIRECT PAYMENTS
  - TECHNOLOGY & HOME ADAPTATIONS (Level 1, 2 & 3)
  - HEALTHCARE PROFESSIONAL SUPPORT (Level 2 & 3)
  - CARER SUPPORT/ EDUCATION & TRAINING (Level 1, 2 & 3)

• Relative to the base case (TECH Level 0, HCP Level 0, CST Level 0), more technological and home adaptation interventions were preferred to less technological and home adaptation interventions.

• This was similarly the case for healthcare professional support and carer support/ education/ training.

• The higher the direct payments, the higher the chance that the intervention package would be chosen.
## Results: Experimental Design

### DCE 2- Crisis Interventions

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Level Descriptor</th>
<th>Willingness to accept compensation</th>
</tr>
</thead>
</table>
| **Health & Social Care Support**   | **LEVEL 2**  
Level 1 plus implementation and development of care package, weekly routine home visits, specialist HCP contacted during extended hours                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | £685.47                           |
| **LEVEL 3**                        | Level 2 plus, daily home visits and access to specialist HCP 24 hours a day.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | £806.44                           |
| **Carer Support, Education & Training** | **LEVEL 1**  
Signposted to family carer support groups and services, for advice and information, relevant information leaflets, advised to use the internet and local directories to search for additional information.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | £504.83                           |
| **LEVEL 2**                        | Level 1 plus education/ training on coping skills, outreach support from voluntary organisations.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | £761.66                           |
| **LEVEL 3**                        | Level 2 plus access to support from Admiral Nurse, regular counselling, extensive training on coping and relaxation.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | £1173.79                          |
| **Technology & Home Adaptations**  | **LEVEL 1**  
Occupational Therapist (OT) safety check carried out and some safety measures put in place e.g. safe bannisters, access to a phone and a walking aid.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | £707.86                           |
| **LEVEL 2**                        | Level 1 plus telephone and a lifeline, rails around the bath and toilet in the home and rails on the stairs, medication dispensers.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | £1070.34                          |
| **LEVEL 3**                        | Level 2 plus emergency pull cords and community alarm. Specialist assistive technology has been implemented, which could include a gas sensor, a falls detector and an entrance/exit sensor.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | £1393.84                          |
Concluding Remarks

• This is the first time a DCE has been conducted in the area of dementia research. Although the complexity was noted and experienced by the respondents, we had 502 respondents to our study.

• Physical health problems was the leading risk factor which could lead to crisis according to both HCPs and family carers.

• Family carers did not consider the psychiatric factors (wandering, aggressive behaviour) to be significant risk factors which could result in crisis leading hospital admission and had more concerns about their relatives’ physical health and vulnerability and safety issues.

• Carers identify and classify situations as potential risks earlier than HCPs.

• For both groups, carer education/ training and support and technology and home adaptations were the most preferred interventions.

• We cannot assume that carers and HCPs have homogenous preferences. Heterogeneity was present amongst the respondents, MIXLOGIT with main and interaction effects was the most suitable model to represent the data.

• Findings from this study should be used to inform the development of home treatment services in the UK.
Thank you for listening!

Any Questions?

Email: sandeep.toot@ucl.ac.uk