Crises in dementia: Causes and remedies

Sandeep Toot

North East London NHS Foundation Trust & University College London

UK DEMENTIA CONGRESS 2013
# ACKNOWLEDGEMENTS: SHIELD

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*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.*
Research Aim

To understand crises in the homes of people with dementia living with their family carers and crises interventions which help support families in crisis.
HTP: Crises and remedies

Process of evaluating the causes of crisis and appropriate interventions for people with dementia and development of HTP
Cochrane Review: Case Management approaches to home support for people with dementia

Siobhan Reilly, Claudia Miranda-Castillo, Reem Malouf, Juanita Hoe, Sandeep Toot, David Challis & Martin Orrell

Key Findings:
- 8229 records screened – 13 trials involving 9615 participants with dementia
- Reduces institutionalisation at 6 months (n= 5561, OR: 0.83) (p = 0.04)
- Reduces behavioural disturbance at 18 months (n= 206, MD: -6.14) (p = 0.009)
The most consistent findings in the literature on case management for people with dementia was that it reduces admission to long term care in the short term (< 6 months).

Case management reduced behavioural problems in people with dementia both in the short term and long term follow up.

Case management also improved carer burden in the short term but not in the medium or long term.

Interestingly, there did not appear to be any improvements in patient outcomes such as patient quality of life, cognition, and depression.

Variability of the case management intervention across the studies meant that it was difficult to ensure the transparency, replicability and integrity of this complex intervention.

Process evaluations are particularly important for interpreting outcomes, and for understanding how an intervention is implemented across multiple sites. Future studies should consider including quality measures to help ascertain the active ingredients of case management by relating these to outcomes.
The Effectiveness of Crisis Resolution/ Home Treatment Teams for Older People with Mental Health Problems: A Systematic Review and Scoping Exercise

Sandeep Toot, Mike Devine & Martin Orrell


**Objective**

To assess the effectiveness of crisis resolution/ home treatment services for older people with mental health problems.
Systematic Review 1

Results – Scoping Exercise

- Specialist Home Treatment Team Model
- Generic Home Treatment Team Model
- Intermediate Care Model

Home treatment services
Results & Conclusion

- The strongest evidence (CEBM Level C) found was that crisis resolution/home treatment services for older people with mental health problems reduce the number of admissions to hospital.

- For all other outcomes, including maintenance of community residence and length of hospital stay, the evidence is very weak.

- In practice, interventions delivered should be based on clinical evidence & theoretical models as well as driven by government policy.

- The intermediate care model may be most appropriate for people with dementia presenting in crisis.

- There is clearly a need for a randomised controlled trial to establish the efficacy of crisis resolution/home treatment services for older people with mental health problems in the UK.
Aims of the review:
To systematically review the evidence of risk factors associated to crisis in dementia leading to hospital admissions using a conceptual framework based upon; behavioural/ psychological; caregiver; environmental; vulnerability; and physical health related factors.

Study update:
2938 references were identified in the searches and 10 studies were included in the final review.

People with dementia were more likely to have either orthopaedic (e.g. falls/ fractures) or respiratory/ urological (e.g. infections) precipitants of admission than those without dementia.

Psychiatric and behavioural disturbance was found to increase the risk of admission for people with dementia in relation to those without.

Disruption to the social and environmental milieu often precipitated admission for people with dementia provided one of several possible explanations for subsequent behavioural and psychological disturbances.

This review highlighted the importance of a more holistic approach to providing community dementia care, encompassing the cognitive, behavioural, psychological and physical needs of people with dementia and providing responsive care packages and health education to both people with dementia and their carers.
Risk factors associated to crisis for people with dementia & their carers leading to nursing home placement: A Systematic Review

Aims of the review:
To systematically review the evidence of risk factors associated to crisis in dementia leading to nursing home placement using a conceptual framework based upon; behavioural/ psychological; caregiver; environmental; vulnerability; and physical health related factors.

Study update:
• 2938 references screened.
• ST, TS, MD are currently conducting quality assessment and data extraction for 39 references.
• Results and analysis to be completed and review written up for publication by Spring 2014.
Focus Groups Study

Causes of crisis and appropriate interventions: The views of people with dementia, carers and healthcare professionals.

Sandeep Toot, Juanita Hoe, Ritchard Ledgerd, Karen Burnell, Mike Devine & Martin Orrell

Aging & Mental Health, Nov 2012, DOI: 10.1080/13607863.2012.732037

Objective:

To conduct focus groups with people with dementia, family carers and healthcare professionals to identify factors which could precipitate crises and identify interventions to help manage crises for people with dementia living at home and their carers.
Conclusion

- People with dementia focused on risks and hazards in their home, whereas family carers emphasized carer stress and their own mental health problems.
- Staff, in contrast were concerned about problems with service organization and coordination leading to crises.
- Physical problems were less commonly identified as causes of crises but when they did occur they had a major impact.
- People with dementia were favourable towards support from family and friends, access to mobile phones and home adaptations to reduce risks.
- Carers were keen on assistive technology and home adaptation.
- Both carers and staff valued carer training and education, care plans and well-coordinated care.
- Staff were the only group emphasizing more intensive interventions such as emergency home respite and extended hours services. Very often, carers and people with dementia prefer the less resource intensive approaches.
- Specialist home care was highly valued by all groups.
Objective:
The aim of the questionnaire was to identify what are the primary causes of crises, what interventions can
i) prevent a crisis
ii) be most useful in a crisis.
Key Findings:

831 people started the questionnaire of which 719 (87%) people completed the questionnaire.

### CAUSES OF CRISIS

<table>
<thead>
<tr>
<th>Behavioural/ Psychological</th>
<th>Physical Health</th>
<th>Family carer</th>
<th>Vulnerability</th>
<th>Environmental</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wandering</td>
<td>Falls</td>
<td>Family carer burden</td>
<td>Inability to identify risks</td>
<td>Physical hazards in the home</td>
</tr>
<tr>
<td>Physical aggression</td>
<td>Infections</td>
<td>Sudden absence of family carer</td>
<td>Poor eating/drinking</td>
<td>Hazards related to daily living</td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>Delirium</td>
<td>Physical health</td>
<td>PWD is abused</td>
<td>Living alone</td>
</tr>
</tbody>
</table>
Key Findings:
INTERVENTIONS IN A CRISIS

**Professional Healthcare Support**
- Earlier referrals to support services
- Implementation of a co-ordinated care plan
- Support/ training for HCPs working with PWD

**Home/ Living Environment**
- Maintaining a routine of daily living tasks
- Administering/ monitoring medication
- Presence of family carer

**Social Care Support**
- Specialist training for home care staff working with PWD
- Provision of home care services
- Provision of day care/ centre services

**Family Carer**
- Family carer education/ training
- Planning care/ support services with carer
- Family carer support groups

**Preventative**
- Access to HCPs 24/7
- Easy access to A&E services
- HCPs available during extended working hours

**Useful in crisis**
- Communication equipment
- Presence of family carer
- Supportive friends/ neighbours

**Social Care Support**
- Immediate/ emergency provision of care
- Access to emergency services
- Centralised database of PWD and their needs

**Family Carer**
- Emergency access to respite in the home
- Emergency access to respite in care home
- Emergency access to respite in a day hospital/ day centre
Objective:

To conduct narrative inquiry interviews with family carers of people with dementia to understand the nature and diversity of experiences of family carers around the time of crisis for their relative with dementia.
Key Findings & Conclusions

Carers with resolved narratives and crises
- Very proactive approach in getting diagnosis for relative with dementia.
- Wanted support and information which increased their self efficacy.

Carers with adapted narratives and crises
- Delayed seeking help.
- Dealt with crises on a reactive basis.
- Feelings of guilt.

Carers with unresolved narratives and crises
- Resistance to changing their behaviour or approach in order to cope better in crises.
- Lack of understanding of their relative’s dementia, coupled with lack of supportive personal/ professional relationships ➔ resentment/ blame.

Carers can be empowered/enabled in a crisis if they have information and support in early stages of relative’s dementia.
DISCRETE CHOICE EXPERIMENT

Sandeep Toot, Verity Watson, Mandy Ryan & Martin Orrell
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.
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).
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.
The following attributes had a statistically significant effect on family carers choices (10% 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>Crisis Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base case (Level 3 for all attributes) – Most severe scenario</td>
<td>99.52%</td>
</tr>
<tr>
<td>Moving from Level 0 for R/H and P/H to Level 1 for R/H and P/H, with all other attributes set at Level 0</td>
<td>84.63% (+37.99%)</td>
</tr>
<tr>
<td>Moving from Level 0 to Level 1 for P/H, with all other attributes set at Level 0</td>
<td>69.32% (+22.68%)</td>
</tr>
<tr>
<td>Moving from Level 0 to Level 1 for R/H, with all other attributes set at Level 0</td>
<td>68.05% (+21.41%)</td>
</tr>
<tr>
<td>Level 0 for W/B, A/B, R/H and P/H – Least severe scenario</td>
<td>46.64%</td>
</tr>
</tbody>
</table>
Results: Experimental Design
DCE 1- Causes of Crisis

• The following attributes had a statistically significant effect on HCPs choices (10% significant level):
  
  - FAMILY CARER WORKLOAD
  - WANDERING 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 (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.

• Relative to the base case (W/B Level 3, A/B Level 3, R/H Level 3, P/H Level 3), 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.
<table>
<thead>
<tr>
<th>Attribute and Level</th>
<th>Crisis Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base case (Level 3 for all attributes) – Most severe scenario</td>
<td>99.94%</td>
</tr>
<tr>
<td>Moving from Level 0 Level 1 for W/B, with all other attributes set at Level 0</td>
<td>53.26% (+3%)</td>
</tr>
<tr>
<td>Moving from Level 0 to Level 2 for W/B, with all other attributes set at Level 0</td>
<td>63.9% (+13.64%)</td>
</tr>
<tr>
<td>Moving from Level 0 to Level 1 for R/H, with all other attributes set at Level 0</td>
<td>55.3% (+5.04%)</td>
</tr>
<tr>
<td>Moving from Level 0 to Level 1 for P/H, with all other attributes set at Level 0</td>
<td>75.51% (+25.25%)</td>
</tr>
<tr>
<td>Moving from Level 0 to Level 1 for P/H, with all other attributes set at Level 0</td>
<td>92.13% (+41.87%)</td>
</tr>
<tr>
<td>Level 0 for W/B, A/B, R/H and P/H – Least severe scenario</td>
<td>50.26%</td>
</tr>
</tbody>
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Results: Experimental Design
DCE 2- Crisis Interventions

- Data cleansing currently underway and final analysis expected to be completed by December 2013.
Thank you for listening!

Any Questions?

Email: sandeep.toot@ucl.ac.uk