Effectiveness of peer support and joint reminiscence for people with dementia and their family caregivers: findings from the SHIELD Carer Supporter factorial randomised controlled trial

Georgina Charlesworth on behalf of the SHIELD CSP team
Overview

• Background:
  – SHIELD
  – Befriending and Peer support
  – Reminiscence

• Trial design & methods

• Findings: participants, effectiveness, cost-effectiveness

• Discussion: uptake & attendance, satisfaction
SHIELD

• Support at Home - Interventions to Enhance Life in Dementia
• Funded by the NIHR Programme Grants for Applied Research (PGfAR; Applic No RP-PG-0606-1083)
• Grantholders: Martin Orrell (UCL), Bob Woods (Bangor), David Challis (Manchester), Esme Moniz-Cook (Hull), Ian Russell (Swansea), Martin Knapp (LSE), Georgina Charlesworth (UCL)
• SHIELD programme workstreams:
  • Maintenance Cognitive Stimulation therapy
  • Peer Support (Carer Supporter Programme)
  • Crisis Intervention
Befriending

• Befriending and peer support
  – reduces depressive symptoms in both the short and long-term (systematic review; Mead et al., 2010)
  – reduces feelings of carer isolation, learning how others coped successfully gives carers hope for the future (Greenwood et al., 2013)

• Befriending and Costs of Caring (BECCA) trial (Charlesworth et al., 2008, BMJ)
  – ‘Intention to treat’ analysis did not show any benefit of befriending compared to usual care
  – Low uptake. Reduction in depression approached significance when analysis limited to those who engaged with treatment
  – Longer & higher quality support from peer befrienders
Peer support

• Definition of peer support - ‘provision of knowledge, experience, emotional, social or practical help to a peer’
• A ‘peer’ can be defined as being similar in terms age, gender, marital status, or similar in terms of experience
• SHIELD ‘Carer Supporter’ Intervention
  – Name chosen by carers and consumer advocates at consensus conference
  – Provided by current or former carers of people with dementia
  – As for BECCA, volunteers provided listening ear
  – In addition, support volunteers were encouraged to provide encouragement and morale support
Joint group reminiscence

• Group reminiscence sessions for persons with dementia and their family carers

• Contrary to pilot projects and Cochrane review, there was no evidence of benefit for people with dementia or their family caregivers (Woods et al, 2012)

• Some evidence that higher attendance was associated with an increase in anxiety for carers

• Balancing needs of carer and person with dementia?
Design and Methods
CSP-RYCT Trial Design

- Factorial randomized controlled trial
- Participants: family carers & people with primary progressive dementia in community settings in England
- Interventions all 10 month duration: 3 month weekly phase followed by 7 months of 2 hours per month
- CSP combined with joint group reminiscence: carer supporter volunteers invited to attend reminiscence groups with carer and person with dementia
Peer support volunteers

- Organisations hosting Carer Supporter Schemes employed part-time co-ordinator for recruitment and support of volunteers
- Carer Supporter volunteers screened (interview, police checks, character references and observation at orientation and awareness sessions)
- Orientation & awareness: 6 x 2hr modules supported by manual and DVD
  - Role of carer supporter
  - Dementia awareness, experience and resources
  - Key listening and helping skills
  - Boundary issues and health & safety scenarios
Remembering Yesterday, Caring Today (RYCT)

- ~12 dyads: person with dementia and a family carer
- 2 facilitators, ~12 project workers (including peer support volunteers), + musician (if possible)
- All ‘team’ attended 1 day training with originator
- Community venue, transport provided
RYCT 12 week programme

1. Introductions - names & places
2. Childhood & family life
3. School days *
4. Starting work & working lives
5. Going out & having fun *
6. Weddings
7. Homes, gardens & animals *

8. The next generation - babies & children
9. Food & cooking *
10. Holidays & travel*
11. Celebration
12. Rounding up & evaluation

* Carers’ sessions (communication & reminiscence at home)
Multisite: 13 rounds over 7 sites

**Northamptonshire**
Family Carers = 36  
People with dementia = 34

**Berkshire**
Family Carers = 29  
People with dementia = 29

**Norfolk**
Family Carers = 49  
People with dementia = 49

**North London**
(4 centres)  
Family Carers = 177  
People with dementia = 169
## Data collection
**(baseline, 5 months, 12 months)**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Carer (self)</th>
<th>Person with dementia</th>
<th>Carer rating of PwD</th>
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</thead>
<tbody>
<tr>
<td>Primary Outcome: SF-12 (UK version)</td>
<td>✔</td>
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<tr>
<td>Hospital Anxiety &amp; Depression (HADS)</td>
<td>✔</td>
<td>✔</td>
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<td>Positive and negative Affect (PANAS)</td>
<td>✔</td>
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<td>COPE-Index</td>
<td>✔</td>
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<td>Personal Growth (PGI)</td>
<td>✔</td>
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<tr>
<td>Social Exchange (PANSE)</td>
<td>✔</td>
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<tr>
<td>Quality of Caregiver / Patient Relationship (QCPR)</td>
<td>✔</td>
<td>✔</td>
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<td>Coping (Brief-COPE) and self-efficacy (RSSE)</td>
<td>✔</td>
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<tr>
<td>Neuropsychiatric Inventory (NPI)</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>EQ-5D</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>QoL-AD</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>DEM-QoL</td>
<td>✔</td>
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</tbody>
</table>
Results
CONSORT flow diagram of participant allocation

640 Referred
639 Screened

Excluded N=347
Primary eligibility reason (N=177)
Primary consent reason (N=170)

292 Informed consent

Lost prior to randomisation
N = 1

291 Randomised

CSP
Baseline
n = 48

Follow-up 1
n = 42

Follow-up 2
n = 42 (88%)

CSP/RYCT
Baseline
n = 97

Follow-up 1
n = 84

Follow-up 2
n = 80 (82%)

TAU
Baseline
n = 47

Follow-up 1
n = 39

Follow-up 2
n = 36 (77%)

RYCT
Baseline
n = 97

Follow-up 1
n = 90

Follow-up 2
n = 83 (86%)

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## Participant Characteristics

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<th>Carers</th>
<th>People with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (% Female)</td>
<td>68</td>
<td>54</td>
</tr>
<tr>
<td>Age (Mean yrs)</td>
<td>67</td>
<td>80</td>
</tr>
<tr>
<td>Ethnicity (% White British)</td>
<td>89</td>
<td>89</td>
</tr>
<tr>
<td>Education (% School only)</td>
<td>70</td>
<td>83</td>
</tr>
<tr>
<td>Kinship (% Spouse)</td>
<td>63</td>
<td>-</td>
</tr>
<tr>
<td>Cohabitation (% living alone)</td>
<td>-</td>
<td>20</td>
</tr>
<tr>
<td>Dementia Severity (CRD)</td>
<td>-</td>
<td>Mild 63% Moderate 27% Severe 10%</td>
</tr>
</tbody>
</table>
Effectiveness analysis

• Includes all participants, whether or not they took up the offer of an intervention

• Model used:
  - Dependent: outcome at 2\(^{nd}\) follow-up (baseline as covariate)
  - Fixed: factorial effects of RYCT/TSU & CSP/TAU (treatment allocations)
  - Random: round
  - Other covariates: kinship (stratification data), gender

• Findings:
  • No evidence of effectiveness for family carers for either one-to-one peer support or joint group reminiscence (RYCT)
  • Some evidence (effectiveness & cost-effectiveness) of benefit to the quality of life of the person with dementia from carer being offered both carer supporter and joint reminiscence
Discussion
Could poor outcome be due to low satisfaction with intervention?

- 71 questionnaires available on satisfaction with carer supporter scheme
- 86 relationship-focused questionnaires

Findings
- High levels of satisfaction with Carer Supporter scheme and relationship with the Carer Supporter
- Most participants said that they would ‘definitely recommend’ the scheme to a friend
- High levels of positive interactions
- Low levels of negative interactions

Lack of effectiveness not due to poor intervention
Poor outcome linked to low intervention uptake?

Number of dyads randomised \( n = 291 \)

<table>
<thead>
<tr>
<th>Dyads Allocated (n)</th>
<th>Uptake n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 to 1 peer support (CSP)</td>
<td>49</td>
</tr>
<tr>
<td>Reminiscence</td>
<td>97</td>
</tr>
<tr>
<td>Combined intervention: RYCT or CSP RYCT &amp; CSP</td>
<td>97</td>
</tr>
</tbody>
</table>
‘Dose’ analyses

• Variables added into the model:
  • RYCT: number of sessions attended by carer
  • CSP: the number of meetings between carer and Carer Supporter
  • Combined intervention: number of times both carer and Carer Supporter attended RYCT sessions

• Findings
  • Higher attendance at RYCT was associated with an increase in problem-focussed coping and a reduction in conflict
Conclusions

• There is no evidence in favour of 1 to 1 peer support for carers or joint group reminiscence therapy as a ‘standard’ treatment for all carers
• Joint group reminiscence may be cost-effective for maintaining quality of life for people with dementia
• Carers who took up the offer of peer support were positive about the experience
• The REMCARE finding of increased carer anxiety was not replicated in SHIELD - possibly due to the greater emphasis on carers in the SHIELD interventions
• Higher attendance at RYCT was associated with an increase in problem-focused coping
SHIELD CSP Outputs


Disclaimer

The views and opinions expressed in this presentation are those of the authors and do not necessarily reflect those of the Department of Health/NIHR.