Effects of ‘Dementia First Aid’ training on knowledge and attitude of family carers of people with Dementia: findings of a feasibility study

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Conflict of Interest

• None
Acknowledgement

• I would like to thank following colleagues for their contribution to the development, delivery and evaluation of ‘Dementia First Aid’ Course:
  – Dr. Sajjad Siddiqui (Senior Trainee Psychiatrist)
  – Dr. Virendra Marwah (Senior Trainee Psychiatrist)
  – Dr. Suzanna Rongpi (Senior Trainee Psychiatrist)
  – Dr. Charles Heinson (Psychologist)
  – Dr. Rahul Tomar (Consultant Psychiatrist)
  – Dr. Lauren Huzzey (Consultant Psychiatrist)
  – Richard Pogson (Dementia care nurse)
  – Dr. Tim gale (Professor of Psychology, University of Hertfordshire)
THE CONTEXT
Dementia in the UK: Facts & Figures

- National Dementia strategy launched in 2009
- **800,000** people living with dementia (2012)
- By 2050 - **1.7 million**
- Dementia costs **£19bn a year** (more than the costs of cancer, heart disease or stroke)
- Two thirds are looked after in the community by **670,000** family carers
People across England can see local information about dementia services including:

• Diagnosis rates
• Memory services
• Hospital Care
• Antipsychotic prescribing
• Dementia-friendly communities
• Research
By 2015 ....

- Diagnosis rate of 48.7%
- 47,000 Dementia Friends
- 34 Dementia friendly communities
- Research funding: £20 million available to 6 pioneering research projects
- G8 dementia summit

But, very Little for Family Caregivers’ Training!
FAMILY CAREGIVING
Dementia & Family Caregiving

• Provided by one individual, especially by spouse or daughters

• Compared to caring people with physical impairment, dementia caregiving is most stressful
Difficulties of Caring

Time Constraints
- As dementia progresses, needs increase, less personal time – ↑ feeling of burden

Psychological symptoms
- Depression & anxiety are common
Stress/Health Model of Caregiving & Associated Interventions
(Schulz & Martire, 2004)

**Stress/Health Process**

**Primary Stressors**
- Care-Recipient: Disability, Problem Behaviors, Loss

**Secondary Stressors**
- Family Conflict, Work Difficulties

**Appraisal of demands and adaptive capacities**

**Perceived Stress**

**Emotional/ Behavioral Response**

**Morbidity/Mortality**

**Interventions**
- Pharmacologic Treatment, Family Counseling
- Social Support
- Education
- Skills Training
- Self Care, Preventive Health Practices
- Communication
Effective Interventions

• Multi-component
  – Combined interventions targeting multiple levels of the stress/health model and multiple individuals simultaneously

• Single-component
  – Interventions with high intensity (frequency and duration)
Aspects of Effective Interventions

• Clinically meaningful
  – Treatment of anxiety and depression in caregivers

• Socially meaningful
  – Saving cost
  – Delaying institutionalisation
    *(hospital admissions, care home placements)*
Beyond Knowledge & Skill

• **Currently**, intervention effects are larger for increasing caregiver **knowledge** and **skills** than for decreasing **burden** and **depression**

• **Ability** to care also needs attention
Dementia First Aid Course

- Provides knowledge
- Influences change in attitude
- Teaches first aid skills, and
- Enhances ability to care by promoting personal growth through stress management techniques (e.g. mindfulness)
DEMENTIA FIRST AID
What is Dementia First Aid?

- **Dementia First Aid** is the help offered to people with dementia who have problems remembering things and making decisions, or who are no longer able to live independently without support.
Dementia First Aid Course

- Dementia First Aid course is a *manual-based, problem solving, stress reducing, and crises preventive* training programme that teaches carers how to *recognise* the common symptoms of dementia, how to offer and provide initial *help*, and how to *cope* and *deal* with common challenging behaviours.

- Dementia First Aid course does *not* teach people to provide a *diagnosis* or *therapy*.
Evolution of Dementia First aid Course

FROM 12 TO 8-HOUR COURSE
Inspired by Mental Health First Aid

• MHFA Programme developed in Australia by Betty Kitchener in 2001
• Introduced in England in 2007
• I was trained as a MHFA Instructor in Kathmandu, Nepal in December 2010
Dementia First Aid Advanced Course for Trainers
November, 2013

12-h DFA Course + 12-h course presentation in pair
12-h Dementia First Aid Course for Carers
December, 2013
From 12 to 8h Course, March 2014

Reasons: Too long for carers and Too much for trainers
DFA 8h Course Programme

MODULE ONE (Knowledge Module)

- **Session I**
  - Overview of dementia
  - Impact of dementia on the person
- **Session II**
  - Information and support for carers
- **Session III**
  - Coping with emotions of caring: Carer’s stress and burden
- **Session IV**
  - Mindfulness based stress reduction technique
  - Q & A + Feedback

MODULE TWO (First Aid Module)

- **Session I**
  - Behavioural and Psychological symptoms of dementia (BPSD)
- **Session II**
  - Dementia First Aid Action plan: FACE
- **Session III**
  - First Aid for common psychological symptoms of dementia
- **Session IV**
  - First Aid for common behavioural symptoms of dementia
  - Q & A + Feedback
FACE: DFA Action Plan

1. Face
   - Face the situation with compassion

2. Assess
   - Assess the risk & assist in crisis

3. Counsel
   - Counsel the person

4. Engage
First Aid Course In Alzheimer’s (FACIAL) Research Project

• **Randomised Controlled Trial** – proposed in October 2013 to investigate:
  – Does DFA increase knowledge and attitude of family caregivers of people with dementia?
  – Does it prevent referral to psychiatric services?
  – Does it prevent institutionalisation?

• **Feasibility study**
  – Set up in December 2013
  – Completed in March 2014
Feasibility Study

• To explore accessibility, compliance, content and delivery of 8-h DFA Course
• Sample required: 10% of 150 (n = 15) participants in the intervention group
• 25 family caregivers living in Northwest Hertfordshire (St Albans & Hemel Hempstead)
• Each module delivered by a pair of Trainers using power point presentation based on a pre-prepared Manual
Dementia First Aid Course

Manuel for Family Carers

For a 8-hour First Aid Course in Alzheimer’s (FACIAL) Research Project in Hertfordshire

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Pre- & Post-test Questionnaire

• Phase One (December, 2013)
  – Questionnaire consisted of knowledge, attitude, competence, and strain
  – Caregivers found it time consuming

• Phase Two (March, 2014)
  – Alzheimer’s Disease Knowledge Scale (ADKS)
    – 30 true/false items
    – We added “don’t know’ option to investigate subjective gap in carer’s knowledge
    – Resulting score being the number answered correctly
ADKS: 7 Content Domains

1. **Life impact** (items 1, 11 and 28)
   Example (item 11): Most people with Alzheimer's disease live in nursing homes - **False**

2. **Risk factors** (items 2, 13, 18, 25, 26 and 27)
   Item 27: Genes can only partially account for the development of Alzheimer's disease - **True**

3. **Symptoms** (items 19, 22, 23 and 30)
   Item 22: Trouble handling money or paying bills is a common early symptom of Alzheimer's disease - **True**

4. **Treatment and management** (items 9, 12, 24, and 29)
   Item 29: Alzheimer's disease cannot be cured - **True**

5. **Assessment and diagnosis** (items 4, 10, 20 and 21)
   Item 20: Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease - **True**

6. **Care giving** (items 5, 6, 7, 15 and 16) and
   Item 6: When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away - **False**

7. **Course of the disease** (items 3, 8, 14 and 17)
   Item 8: In rare cases, people have recovered from Alzheimer's disease - **False**
Demographic Questions

• Age group
• Gender
• Relationship
• Primary or secondary carer
• Receive any help from children or others
Delivery of DFA Training

• Trainers were mental health professionals employed by HPFT for dementia care
• Trainers had received 24 hours (4 half days) training
• Presented in pair
• A copy of manual handed over to each participant in the beginning
• Pre-test & Post-test done with ADKS
Results: Demography

Pre-test Data
- 26 participants
- 24 completed the ADKS
- 58% female
- Most were older (61% > 60 years)

Post-test Data
- Only 15 participants
- 13 completed ADKS
- 77% female
- Most were older (62% > 60 years)

• Majority Primary caregivers
• Most had received additional support from family or paid carers
• 46% patients were diagnosed between 3-6 months
### Percentage of caregivers answering Correctly

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<th>Domains</th>
<th>Items</th>
<th>Pre-Test Score (n=24)</th>
<th>Post-test Score (n=13)</th>
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<td></td>
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<td>Mean</td>
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<td>Mean</td>
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<td>Life impact</td>
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<td>Course of the disease</td>
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## Percentage of caregivers answering “Don’t know”

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<td>35</td>
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*Reduction in proportion of carers who answered ‘don’t know’ shows improvement in their knowledge*
Discussion

• 12-h Dementia First Aid course is effective
• It enhances the caregiver’s knowledge of dementia
• Only 13 participated on day two
  – Too long?; Other reasons?
• Will it prevent psychiatric referral and institutionalisation?
  – Only follow-up study can find that out
Conclusions & Comments

- 8-h Dementia First Aid manual-based course delivered by a trained and qualified professionals enhances carer’s knowledge of dementia in Hertfordshire, UK
- Should it be delivered in one day or reduced to 4 hours?
- Will the 4-h course as effective as 8-h course?
- How long does the effect last?
  - 6-month and longer follow-up study can find that out
What the trainers and caregivers say about DFA course

VIDEO FEEDBACK
12-H COURSE
A Psychologist
A Nurse Manager
A Family Caregiver
After the Course
After 12-H
After 8H...
Final feedback
What do you think?

THANK YOU