

Benefits of attending a 'Dementia First Aid' course for family caregivers of people with early dementia: findings of a pilot evaluation

Rahul Tomar, Arun Jha, Tim Gale & Lauren Huzzey

Abstract

Objective: Pilot evaluation of the impact of a 'Dementia First Aid' (DFA) training course on the knowledge and attitude of family caregivers of people with early dementia.

Methods: The participants in the study were primary family caregivers of people with dementia residing in northwest Hertfordshire. The 4-hour 'Dementia First Aid' course was delivered by NHS professionals. The training was organised once every second month from November 2015 till March 2017. The course provided overview of dementia and its impact on the person and their families, mindfulness based stress reduction, and the dementia first aid action plan for crises. The participants were asked to complete the Alzheimer's disease Knowledge Scale (ADKS) before and after the completion of the course & complete carer burden scale (Zarit Burden Scale). Participants were asked to complete the scales after six months.

Results: The study sample comprised 65 people who had completed the DFA course. All completed pre- and post-training measures (ADK and Zarit burden scale), and a further 34 provided follow-up data approximately 6 months later. The scores were compared using a correlated group t-test. ADK scores improved significantly immediately after attending the course ($p < 0.0001$). For the subgroup that completed data at 6 months, the improvement in scores was sustained.

Conclusions: This 'Dementia First Aid' course appears to be effective in improving family caregiver's knowledge of dementia and this knowledge was sustained at 6 months follow up.

Keywords: Alzheimer's disease; caregivers; early dementia; first aid; knowledge; pilot evaluation

Abbreviations: DFA- Dementia First Aid; ADKS- Alzheimer's Disease Knowledge Scale

Introduction

A family carer or caregiver is someone who gives a substantial amount of unpaid care and support regularly to a relative, partner or friend. Currently, there are over 850,000 people living with dementia in the UK, of which two thirds are looked after in the community by primary carers, and the demands on individuals and families are set to increase¹. Without the work of unpaid family carers, the formal care system would be likely to collapse.

Many people in the UK still do not feel comfortable talking about dementia, especially with their own families. A recent survey of more than 2,100 carers, of which 17% of respondents cared for a person with dementia, found that 75% of carers were not prepared for all aspects of caring. Nor were they prepared for the emotional impact, lifestyle or relationship changes of their caring role². Failure to prepare and support carers in their role not only affects their own personal health and wellbeing, but can also lead to the early and potentially avoidable admission of people with dementia into formal care.

As dementia progresses, family members often provide care under high level of stress for longer periods of time. The effects of being a family caregiver, though sometimes positive, are generally negative on their psychological and physical health,

life expectancy and quality of life³. It is therefore important to educate carers of family members with dementia to improve their knowledge of, and attitude towards people with dementia. Poor knowledge about dementia has been found to result in the underutilisation of support and treatment services, and in poorer outcomes of people with dementia and their caregivers such as inadequate care of the disease, misinterpretation of behaviours and increased caregiver stress due to failure to seek appropriate support⁴.

Currently there is too much reliance on people with dementia and carers seeking out information for themselves. The result is that people do not receive the information they need because they do not know what to ask for. Despite the existence of information for carers, people report that their information needs are not met. Information is provided too late or not at all. A key problem is that people have to ask for information, rather than it being provided proactively.

It has been found that education and training programme covering the information⁵, or an individual training programme⁶, improve attitudes towards caring for people with dementia as well as general knowledge of dementia⁷. Psychosocial interventions have also been demonstrated to reduce caregiver burden and depression, and delay care home admission⁸. A systematic review⁹ of 44 randomised controlled

trials has found statistically significant evidence that group-based supportive interventions impact positively on caregivers of people with dementia.

Coon et al (2003)¹⁰ found that psychoeducational skill training, in small groups, improved both the affective states and the type of coping strategies used by caregivers. On the other hand, an information-orientated programme failed to improve caregiver's mood¹¹, and a befriending scheme was not effective in improving carer's wellbeing¹². Similarly, a randomised controlled trial did not show preventive effects of family meetings on the mental health of family caregivers¹³. Livingstone et al (2013)⁶, on the other hand, have found encouraging results of a manual based coping strategy programme in their London study.

A suitable training programme is therefore required for building caregivers' knowledge and skills. We have developed a *Dementia First Aid* (DFA) course for the family carers of people with early dementia. This is a problem solving, stress reducing, and crisis preventive training programme. The DFA course was inspired by the principles of Mental Health First Aid programme¹⁴, developed in Australia in 2001 and introduced to England in 2007 by the National Institute for Mental Health in England.

Dementia First Aid Course

Description of the course

Dementia First Aid course is delivered over 4 hour in a group setting. Each participant received a course manual prepared by the author AJ. The content covered an overview of dementia, impact of dementia on the individual, impact of caring on families, mindfulness-based stress reduction training, and a detailed discussion of Dementia First Aid Action Plan for crises associated with behavioural and psychological symptoms of dementia (BPSD).

In November-December 2013, a group of 8 health care professionals, working within the specialist mental health services for older people in Hertfordshire, were offered the 12-hour advanced Dementia First Aid course, followed by an additional 12-hour practice training of presenting the course to a group of family carers of people with recently diagnosed dementia.

Evolution of DFA course

The original 12-hour Dementia First Aid course was delivered over three half days. Although the course was well received by both carers and trainers, the dropout rate was high. This was mainly due to the carers struggling to make alternative arrangement to look after the person with dementia while they were away. The course was therefore changed to 8 hours and then reduced to 4 hours based on feedback received by the carers.

The main aim of this pilot evaluation was *to investigate the potential benefits of a Dementia First Aid course in terms of the*

knowledge and attitude of family carers of people with newly diagnosed dementia.

Methods

The participants were the primary family caregivers of people with dementia residing in northwest Hertfordshire. The DFA course was organised once every two month from November 2015 till March 2017.

An invitation letter, along with details of the pilot assessment, was sent to all those carers of people whose dementia was diagnosed recently in memory clinic and all participants were given at least 4 weeks' notice prior to the course.

Selection criteria included: being aged 18 or above, the primary carer of a person with newly diagnosed dementia (i.e. currently providing at least 20 hours of direct care per week) & residing in Hertfordshire.

The training was delivered by a pair of qualified DFA instructors, who were mental health professionals experienced in dementia care in the NHS. The training was conducted using a power point presentation, group work, and audio-visual clips based on a specially designed DFA manual.

Evaluation questionnaire

The participants were asked to complete a questionnaire on their own at the beginning of the programme. Oral consent from participants were obtained prior to filling out the questionnaire, the participants were made aware that participation in the pilot assessment was voluntary and would not pose any barrier for them to join the programme.

Participants were given Alzheimer's disease Knowledge Scale¹⁵, a questionnaire comprising of 30 questions before and after the training. They were also asked to complete the Zarit Burden Scale a 12 item self-reported scale¹⁶ to measure carer burden.

After 6 months the participants were contacted to complete ADKS and Zarit Burden Scale. ADKS is therefore completed thrice and Zarit Burden Scale is completed twice during the study.

Statistical analysis

The data collected were analysed in two ways. First, ADKS data collected at pre-test were compared to post-test scores to examine change in participants' knowledge. The participants' knowledge at the end of 6 months was also compared to pre and post-test scores. Similarly Zarit Burden Scores at the time of initial assessment were compared to scores 6 month post training. To evaluate the effect of the training, answers to the structured questions given at pre- and post-test and scores at 6 months were compared using a correlated group *t*-test.

Results

The study sample comprised 65 people who had completed the DFA course. All completed ADKS pre- and post-training and

completed Zarit Burden Scale, and a further 34 provided follow-up data approximately 6 months later.

Sample characteristics:

Mean (\pm SD) age = 66.9 (\pm 13.8) years (range 31-90). 23 attendees were male, 42 were female

ADK scores

Looking first at all 65 attendees:

ADK scores for whole sample		
	Pre-course	Post-course
Mean	16.7	21.2
SD	5.7	4.5
Min	0	10
Max	26	29

ADK scores improved significantly immediately after attending the course ($p < 0.0001$).

Score improvement was not predicted by gender ($p > 0.3$), and the correlation between score improvement and age was not significant ($R = 0.023$). We did not examine age and gender further.

Analysis of sample of 34 who provided long-term follow up data:

ADK scores for sub-sample			
	Pre-course	Post-course	6+ Month
Mean	17.2	22.0	21.0
SD	4.9	4.5	4.8
Min	1	11	7
Max	24	29	29

For the smaller sample, ADK scores improved significantly immediately after attending the course ($p < 0.0001$), and this was sustained at the longer-term follow up ($p < 0.0001$). Although the mean ADK score dropped by a point at 6+ months, this was still a significant improvement over the pre-course (baseline) score.

Comparing post-course ADK score with 6+ month follow-up ADK score, no significant difference was observed ($t[33] = 1.48$, $p = 0.15$), suggesting that knowledge was not lost to a significant degree.

Zarit Burden Scale Scores

The response rate Zarit Burden scores was not good as only 19 of the sample completed this at 6 month follow up. The score for this cohort increased by 3.58 points, which was borderline significant and is expected as dementia is a progressively declining condition.

Discussion

This is the first report on the level of dementia knowledge among family caregivers in the UK before and immediately after the implementation of a novel post-diagnostic dementia training programme, the Dementia First Aid Course and whether the knowledge sustains after 6 month.

The mean pre-course score on the ADKS in the sub-sample that completed test at 6 months was significantly lower at 17.2 than 22.7 reported by Smyth et al. (2013)⁷. It was expected that the level of dementia knowledge would improve after attending the course and the findings largely fulfilled this expectation. There was a significant difference between the pre and post training score with p value < 0.0001 . Further there is evidence that the knowledge sustained after 6 months of the training.

The intervention studied in a recent British trial⁶ is an individual therapy programme, consisting of psychoeducation about dementia, carer's stress, behaviour management, and relaxation techniques. The effectiveness of the programme on carer's depression and abusive behaviour was significant. To provide individual training for a huge number of families may not be possible in the NHS. Therefore, a group based training approach employed in our study may well be more sustainable.

The carer's burden of care as measured by Zarit burden scale at the time of training and 6 months later showed only a modest increase of 3.58 points. However, it was apparent that training could not affect the relentless progression of dementia, most of which were of the Alzheimer's type.

Limitations

Being a pilot evaluation, the sample size of this study was small. This pilot assessment may be limited by the fact that participants were not randomly selected. Since the current evaluation was conducted in only one part of the County, the sample may not reflect a wider community. The knowledge gained during the course was sustained at the end of 6 months. However training did not reduce carer burden nor it was clear whether the new knowledge and skills will be effective in preventing crises. Brodaty et al (1989)¹⁷ reported reduced psychological morbidity of the carer following dementia carers' programme but cautioned against delay in institutionalisation of patient at the expense of the morbidity of the carer.

Finally, the present pilot evaluation was uncontrolled and non-randomised, so we do not know to what extent any impact is due to the dementia first aid training, passage of time or experience of caring. A randomised controlled study with follow-up measurements on caregivers' knowledge, sense of burden, psychological health and wellbeing, would be the ideal next step.

Key points

- Most people with dementia live at home and are cared for by their spouses, children or other family members, but these carers are not usually offered adequate information and training about dementia and the impact of caring at the time of diagnosis.
- This paper describes the effectiveness of a short (4-hour) version of a novel training programme, the 'Dementia First Aid' course, for family caregivers of people with early dementia. The Dementia First Aid course includes overview of dementia including Alzheimer's disease,

impact of dementia on the person and their family caregivers, principles and practice of 'mindfulness' to enhance coping ability, and first action plan for common behavioural and psychological symptoms of dementia.

- 'Dementia First Aid' course, appears to enhance caregivers' knowledge of dementia.

Conclusions

The significance of these results can be placed in the wider context of proactive dementia training for family caregivers at the time of diagnosis. The results are important in demonstrating that having dementia training is associated with improved knowledge.

This study adds to the existing literature and has implications for both care and policy regarding community care of people with dementia, and emphasises the importance of dementia training as a routine component of post-diagnostic support.

Although knowledge alone does not necessarily translate into change in care, nor does high quality of care solely depend on broad education about dementia⁷, our results suggest that the dementia first aid course is effective in changing the knowledge and attitude of dementia caregivers. Hopefully, this will also enhance their ability and skills of caring, which may in turn reduce caregivers' sense of burden and wellbeing. A randomised controlled study with follow-up measurements is required to support these claims.

Competing Interests

None declared

Author Details

RAHUL TOMAR, FRCPsych, Logandene Elderly Care Unit, Hemel Hempstead, Herts UK. ARUN JHA, FRCPsych, Logandene Elderly Care Unit, Hemel Hempstead, Herts UK. TIM GALE, PhD, Research & Development Department HPFT Learning & Development Centre, The Colonnades, Hatfield, UK. LAUREN HUZZEY, MRCPsych, Seward Lodge Elderly Care Unit Lilbourn Drive Hertford, UK. CORRESPONDENCE: ARUN JHA, FRCPsych, Logandene Elderly Care Unit, Hemel Hempstead, Herts UK. Email: arun.jha@hpft.nhs.uk

References

1. Alzheimer's Society. 2012. Dementia 2012: A national challenge. London: Alzheimer's Society.
2. Alzheimer's Society. 2013. Building dementia-friendly communities: a priority for everyone. London: Alzheimer's Society.
3. Jones C, Edwards RT, Hounsoms B. 2012. A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. *International Psychogeriatrics* 24:1, 6–18, doi:10.1017/S1041610211001207.
4. Spector A, Orrell M, Schepers A, Shanahan N. 2012. A systematic review of 'knowledge of dementia' outcome measures. *Aging Res Rev* 11(1):67-77.
5. O'Sullivan G, Hocking C & Deb S 2014 Dementia: The need for attitudinal change. *Dementia*, Jul;13(4):483-97.
6. Livingston G, Barber J, Rapaport P et al. 2013. Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial. *BMJ* 347:f6276.
7. Smyth W, Fielding E, Beattie E, Et al. 2013. A survey-based study of knowledge of Alzheimer's disease among health care staff. *BMC Geriatrics* 13:2.
8. Gallagher-Thompson D, Lovett S, Rose J, McKibbin C, Coon D, Futterman A, Thompson LW: Impact of psychoeducational interventions on distressed family caregivers. *Journal of Clinical Geropsychology* 2000, 6(2): 91–110.
9. Thompson CA, Spilsbury K, Hall J et al. 2007. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics* 7:18.
10. Coon DW, Thompson L, Steffen A et al. 2003. Anger and depression management: psychoeducational skill training interventions for women caregivers of a relative with dementia. *Gerontologist* 43(5):678-89.
11. Sutcliffe C, Lerner S. 1988. Counseling carers of the elderly at home: a preliminary study. *Br J Clin Psychol* 27:177–178.
12. Charlesworth G, Shepstone L, Wilson E. et al. 2008. Befriending carers of people with dementia: randomized controlled trial *BMJ* 336:1295.
13. Joling KJ, van Marwijk HWJ, Smit F, van der Horst HE, Scheltens P, et al. 2012. Does a Family Meetings Intervention Prevent Depression and Anxiety in Family Caregivers of Dementia Patients? A Randomized Trial. *PLoS ONE* 7(1): e30936. doi:10.1371/journal.pone.0030936.
14. Kitchener BA, Jorm AF. 2002. Mental health first aid training for the public: evaluation of effects on knowledge, attitudes and helping behavior. *BMC Psychiatry* 2: 10.
15. Carpenter B, Balsis S, Ottingam P, Hanson PK, Gatz M (2009) The Alzheimer's Disease Knowledge Scale: development and psychometric properties. *Gerontologist* 2009 Apr; 49(2):236-47.
16. Bedard, M, Molloy, B, Squire, L, Dubois, S, Lever, J and O'Donnell, M. 2001. The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, 41(5): 652–657.
17. Broadly H & Gresham, M 1989. Effect of a training programme to reduce stress in carers of patients with dementia. *BMJ* 1989; 299, 1375-9.



This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.