

Living Well with Dementia groups in Primary care: a feasibility study

A feasibility study of translating "Living Well with Dementia" groups into a Primary care IAPT service¹

Richard Cheston and Liz Howells OBE²

Corresponding author name and address:

Richard Cheston, University of the West of England, Glenside Campus, Stapleton Road, Bristol, UK, BS16 1DD

tel: 0117-3288927; fax: e-mail: Richard.Cheston@uwe.ac.uk

Keywords: dementia, Alzheimer's disease, group psychotherapy, recovery, psychosocial interventions

NB: This is NOT the final document. This is the document submitted for publication

¹ This project was partially funded through a Research and Capability Fund grant from AWP R&D department (ref: 13-14-006)

² Clinical Director, LIFT Psychology, Avon and Wiltshire Mental Health, Partnership (NHS) Trust

feasibility study of translating "Living Well with Dementia" groups into a Primary care IAPT service

Abstract

Background and Aims: this study reports on a feasibility trial in which the LivDem model of group support for people affected by dementia was trialled within a Primary Care, IAPT setting

Methodology: five people affected by dementia and their carers were recruited into the study, although one man withdrew before the start due to illness. Joint sessions were held on the first and the final meetings, with parallel group sessions for people affected by dementia and their carers for the remaining eight sessions. One person affected by dementia and their carer withdrew due to illness before the end of the sessions

Results: a self-report measure of Quality of Life suggested improvements for two of the three people affected by dementia who completed all of the sessions. The proxy ratings of carers indicated improvements for all three participants. Qualitative interviews were carried out with participants and carers to assess acceptability.

Discussion: the improvement in QoL-AD scores of participants are consistent with that found for the LivDem intervention within secondary care. At the same time, concerns remain about the fit between the LivDem intervention and the way in which Primary care psychology is structured particularly if therapists are not actively supported by a dementia specialist and if a parallel carers' group is not run.

A feasibility study of translating "Living Well with Dementia" groups into a Primary care IAPT service

Background

"Living well with Dementia" or LivDem groups are designed to encourage people affected by dementia to discuss their feelings about the illness within the setting of a Memory clinic. A pilot trial of the LivDem groups provided some preliminary evidence for their use in people who have recently received a diagnosis of dementia (Marshall et al, 2014). However, for the LivDem intervention to be accessible, then it needs to be delivered within a range of settings, including Primary Care. Consequently, we report here on a LivDem group that was established within a Primary Care IAPT service in the South-West of England. The protocol was registered on-line (ISRCTN05413972) and the project was granted ethical approval from NRES³ and the University of the West of England⁴.

Method

Recruitment. Following Marshall et al (2014) the principal inclusion criteria were that participants must have received a diagnosis of dementia (excluding Frontal-Temporal dementia) within the previous 18 months. Potential participants also acknowledged, at least occasionally, that they have a memory problem, had adequate communication skills to enable group participation and a mild or moderate level of cognitive impairment. Potential participants were recruited from primary care teams, and the local Memory clinic. Eight referrals to the project were made, and five people affected by dementia were recruited to the study, although one man was forced to withdraw due to illness before the first session. Demographic Information about participants is provided in Table One. All participants had capacity to provide consent.

Insert Table One about here

³ Permission granted by NRES Committee South Central - Oxford C, 10th October 2013, IRAS ref: 133510

⁴ Permission granted by HAS Faculty of Health and Applied Science, University of the West of England, 14th November, 2013. Ref: HAS/13/11/145

The LivDem intervention. Group participants and their carers attended the first and the final sessions together, with separate groups then being provided for participants and carers for the remaining eight sessions. Sessions for people affected by dementia involved a mixture of psycho-educational material (for instance about the causes and treatment of dementia), skills training (e.g. in relaxation), and a psychotherapeutic focus on helping participants to discuss their experiences of dementia – and in particular the emotional impact of the illness. The parallel support group for carers shadowed the content of the participant sessions. At the end of every session, participants were provided with a handout describing the main issues that had been covered, and carers and participants with dementia were encouraged to discuss topics between sessions. A DVD of people affected by dementia talking about different aspects of their illness, and which paralleled the content of the sessions could also be played during sessions at the discretion of the group facilitators. Attendance rate in the two groups was identical at 85 per cent, although one participant (Isobel) and her carer (Leslie) did not attend the last two meetings due to illness.⁵

Data collection. Participants completed the Quality of Life in Alzheimer’s disease scale (QoL-AD; Logsdon et al. 1999) during the first and the final sessions. Carers also completed a proxy rating of their perception of the quality of life of their partner.

Acceptability and translation: the lead author conducted telephone interviews with three participants and their carers in the week after the intervention finished, and also convened a focus group with the IAPT therapy staff who facilitated both the participant and the carer groups.

Results

Insert Table Two about here

Quality of Life. As can be seen in Table One, QoL-AD ratings by two of the three participants, as well as all three of the proxy scores provided by carers improved over the course of the intervention.

⁵ Data related to this project is available on request from the lead author

The qualitative interviews largely confirmed this picture of change: all three carers described the groups as being helpful, while of the three people affected by dementia only Elsie (whose QoI-AD score increased) felt that they had not been helpful. Therapists described important changes for participants, especially in the way in which participants spoke about their illness. K (Psychologist working in the LivDem group) said *“I found it really powerful in terms of change, how they think about dementia, and how that changes. To go from being unable to talk about dementia ... there was stigma in how they viewed it, and we were taking away the fear”*.

For one couple (Ruby and Ron) in particular, the group seems to have been important in helping them to understand and empathise more with each other and to adjust to the difficulties they were facing. K described how *“at the start they were very polarised, and at the end session they held hands”*. Ruby and Ron also described changes:

Ruby: *What has been said and done has been very helpful, he did begin to understand what I've been trying to tell him, but he doesn't take it all in*

Ron: *I think it helped her (Ruby) to come to terms with her own illness ... She is more willing to talk about her illness and the problems it causes. The memory loss*

Discussion: translating the LivDem study into a Primary Care setting.

IAPT's initial mandate was to provide support for adults with depression and anxiety using a stepped care module (Department of Health, 2008; Turpin, Richards, Hope, & Duffy, 2008). Within the LIFT stepped care system all therapists work at different levels up to their expertise: in the LIFT approach (Least Intervention First Time) everyone is offered a low level intervention initially and can opt back in to receive more. In this study, LivDem groups were located within Step Two, in which the aim of therapy is to provide guided self-help, for instance by therapists suggesting strategies that may be helpful, but not intervening more actively to ensure that these ideas are acted upon. Although the LivDem model fits within this ethos, this model of work presents a number of challenges when applied to people affected by dementia:

Recruitment. Of the eight people referred to the project, only three referrals were from a Primary Care setting, with the other five being referred from a local Memory clinic. IAPT services typically rely on self-referral, often using on-line processes, and may need to take a more active approach to initiating referrals when working with people affected by dementia, for instance by drawing on local memory services and third sector agencies.

Minimum Data Set. All IAPT services are required to administer the Minimum Data Set (MDS) to clients at the end of every session as a way of monitoring change. This involves standardised self-report questionnaires designed largely for use by adults of working age. However, very quickly it became apparent that all of the participants struggled to complete these questionnaires, and this form of data collection was abandoned.

Engaging with therapeutic material. In this study, the lead author provided not only training, but also visited the IAPT service regularly, providing informal support and supervision for therapists. Anecdotal feedback from a second LivDem group which has subsequently been run but which did not have the on-going support from a dementia specialist, was that clients had quite complex needs, which therapists lacking a background in dementia struggled to meet. Thus, although the lack of familiarity of therapists with the needs of people with dementia did not seem to be an issue in this study, there is a danger that the expectations of step two therapist for clients with dementia will be unrealistic – for instance in their ability to remember sessions material and to initiate the use of new self-help strategies. Similarly, group participants may work with therapists who are unused to working with older people, especially those who have a cognitive impairment, and as a consequence struggle with even the basics of therapy such as hearing, understanding or retaining information that they are given.

Support for carers. In this study a parallel group for carers was run in which topics and ideas from the participant group were explained to carers, as a way of encouraging them to support the take up of these strategies. The group for carers also provided peer support and stress management. Although

labour intensive, this form of joint working is invaluable, particularly given therapists' lack of experience with people affected by dementia, and the otherwise passive nature of IAPT services compared to more traditional secondary care and memory services.

In conclusion, access to Primary Care psychological therapies by Older People has been disappointing in recent years, with many IAPT services now recognising a need to improve the training of therapists, and to meet the shortfall in service delivery by providing new services. The preliminary data gathered here is broadly supportive of providing LivDem groups within a primary care context. Thus, the improvement in QoL-AD scores of Daphne and Ruby are consistent with that found by Marshall et al (2014). At the same time, concerns remain about the fit between the LivDem intervention and the way in which Primary care psychology is structured particularly if the intervention is seen as a Step Two intervention, if therapists are not more actively supported by a dementia specialist and if a parallel carers' group is not run.

Acknowledgements.

We would like to thank all the participants for their involvement in the study, and additionally psychologists based at the LIFT psychology service in Swindon: Marianne Evans, Rosa Hoshi, Kim Jackson-Blott, Brian O'Cealligh and Karen Wiltshire

Table One: participant and carer demographic information.

	Participant age	Diagnosis	MMSE score	Carer age	Relationship
Daphne and Dennis	80	Mixed dementia	20	85	Husband and wife
Elsie and Nigel	84	Alzheimer's disease	22	62	Mother and son
Ruby and Rod	79	Alzheimer's disease	23	50	Mother and son
Isobel and Leslie	83	Vascular dementia	19	54	Mother and daughter

Table Two: changes in Quality of Life ratings before and after the group.

	Participant rating before intervention	Participant rating after intervention	Difference between participant ratings	Carer rating before intervention	Carer rating after intervention	Difference between carer ratings
Daphne	36.83*	37.92*	+1.09	30.33*	32.5*	+2.17
Elsie	42.25*	36.83*	-5.42	29.25*	40	+10.75
Ruby	27	29	+2	18.5*	21	+2.5
Isobel	29.45*			47		
* = pro-rated score						

References

Department of Health (2008). *Improving Access to Psychological Therapies (IAPT) Commissioning Toolkit*. London: Department of Health: The Stationery Office.

Logsdon, R. G., et al. (1999). Quality of Life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging*, 5, 21-32.

Marshall A, Spreadbury J, Cheston R, Coleman P, Ballinger C, Mullee M, Pritchard J, Russell C and Bartlett E (2014) A Pilot Randomised Control trial to compare changes in quality of life for participants with early diagnosis dementia who attend a "Living Well with Dementia" group compared to waiting list control, *Aging and Mental Health*, DOI: 10.1080/13607863.2014.954527

Turpin, G., Richards, D., Hope, R., & Duffy, R. (2008). Delivering the IAPT programme. *Healthcare Counselling & Psychotherapy Journal*, 8 (2), 2-7.