

A feasibility study of translating “Living Well with Dementia” groups into a Primary Care Improving Access to Psychological Therapy service (innovative practice)

Dementia

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Abstract

This paper describes the use of the “Living Well with Dementia” or LivDem model of group support for people affected by dementia within a Primary Care setting. Five people affected by dementia and their carers joined a 10-week group, although one man withdrew before the start due to illness. Joint sessions were held on the first and the final meetings, with separate 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. 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 their experience of the group. Although both people affected by dementia and their carers found the LivDem intervention helpful, concerns remain about the continued need for support by a Dementia specialist.

Keywords

dementia, Alzheimer’s disease, group psychotherapy, recovery, psychosocial interventions

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Background

“Living well with Dementia” or LivDem groups are designed to encourage people affected by dementia to discuss their feelings about the illness, and has previously been used within the setting of a Memory clinic. A pilot trial of the LivDem groups provided some preliminary evidence for their use with 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 Improving Access to Psychological Therapy (or IAPT) service in the South-West of England. IAPT services have been developed in the UK over the last 10 years as a way of ensuring wider access to Psychological therapy. IAPT services are based within primary care and deliver short-term, evidence based psychological therapies often with an emphasis on Cognitive-Behaviour Therapies. Although initially developed to help people affected by depression and anxiety return to work, most IAPT services now provide a range of psychological treatments for many different illnesses. The protocol was registered on-line (ISRCTN05413972) and the project was granted ethical approval from NRES¹ and the University of the West of England.²

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 1. All participants had capacity to provide consent.

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

Table 1. 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 |

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%, although one participant (Isobel) and her carer (Leslie) did not attend the last two meetings due to illness.³

Data collection

The participants completed the Quality of Life in Alzheimer's disease scale (QoL-AD; Logsdon, Gibbons, McCurry, & Teri, 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

Quality of Life

As can be seen in Table 2, 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.

Table 2. 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.

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 QoL-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 Least Intervention First Time (LIFT) stepped care system all therapists work at different levels up to their expertise: in the LIFT approach 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 participants may 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 are 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.

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2. Permission granted by HAS Faculty of Health and Applied Science, University of the West of England, 14 November 2013. Ref: HAS/13/11/145.
3. Data related to this project are available on request from the lead author.

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Author Biographies

Richard Cheston spent 25 years working as a Clinical Psychologist in the NHS, and is now Professor of Dementia Research at the University of the West of England. In both roles he has been involved in developing psychological interventions for people affected by Dementia including the adaptation of group psychotherapy.

Liz Howells, OBE, is Clinical Director of LIFT Psychology, currently part of Avon and Wiltshire Partnership Trust. She is a Clinical Psychologist by training and has worked in the primary care facing psychology service since setting it up in 1993.