
The Living well with dementia groups project

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Overview

- Living well with dementia groups – NIHR/RfPB funded pilot study
 - Why be interested in this?
 - What is the LivDem intervention?
 - What did we find?
 - Outcome changes
 - Process changes
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Why did we do this?

- An early diagnosis - may help people to
 - adjust to the illness
 - prepare for the future
 - reduce stress
 - But is there a post diagnostic gap?
 - Need for evidence based, accessible and sustainable intervention
 - That aims to promote adjustment to dementia
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Preliminary work

- Previous work suggested that
 - 10 week long groups led by a Clinical Psychologist seemed to lead to improvements in depression
 - Similar groups in the USA associated with improvements in quality of life, depression and family communication
 - But also some dangers in providing too much information at too soon a point
 - However, some questions remain
 - Can we teach non-psychologists with little experience of therapy to lead groups?
 - How would this work within the NHS?
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Living Well with Dementia Groups

- Two year pilot RCT funded by NIHR – led by Dr Ann Marshall
 - 60 people randomised to receive
 - Eight week plus two intervention (8+2); or
 - Treatment as Usual (Waiting list control)
 - Trained memory clinic nurses to use manual
 - Seven groups set up in Hampshire and Wiltshire
 - Measured Quality of Life, self-esteem and depression
 - Data collection at baseline, end of group and 10 week follow-up by researcher blind to group allocation
 - Main aim is to test for future larger trial
 - Follow-up interviews with 17 participants – acceptability
 - Sessions were recorded – fidelity measure and process research
 - Also small study in Primary Care
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Participants

- Participants are
 - ❑ referred from memory clinics
 - ❑ have a recent diagnosis of either Alzheimer's disease, Vascular Dementia or Lewy Body dementia with an MMSE of at least 18
 - ❑ acknowledge, at least occasionally, that they have a memory problem;
 - ❑ do **NOT** have significant mental health problems
 - Six to eight participants in each group
 - ❑ Joint sessions with family at start and at end
 - ❑ Primary care project has a parallel group for carers
 - Session length is 75 minutes
 - ❑ Can include playing a DVD - <http://www.southernhealth.nhs.uk/services/mental-health/older/memory-matters/memory-matters-films/>
 - ❑ Handouts at end of every session
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Structure of Living Well with Dementia group sessions

Pre-group: setting the scene (with families)

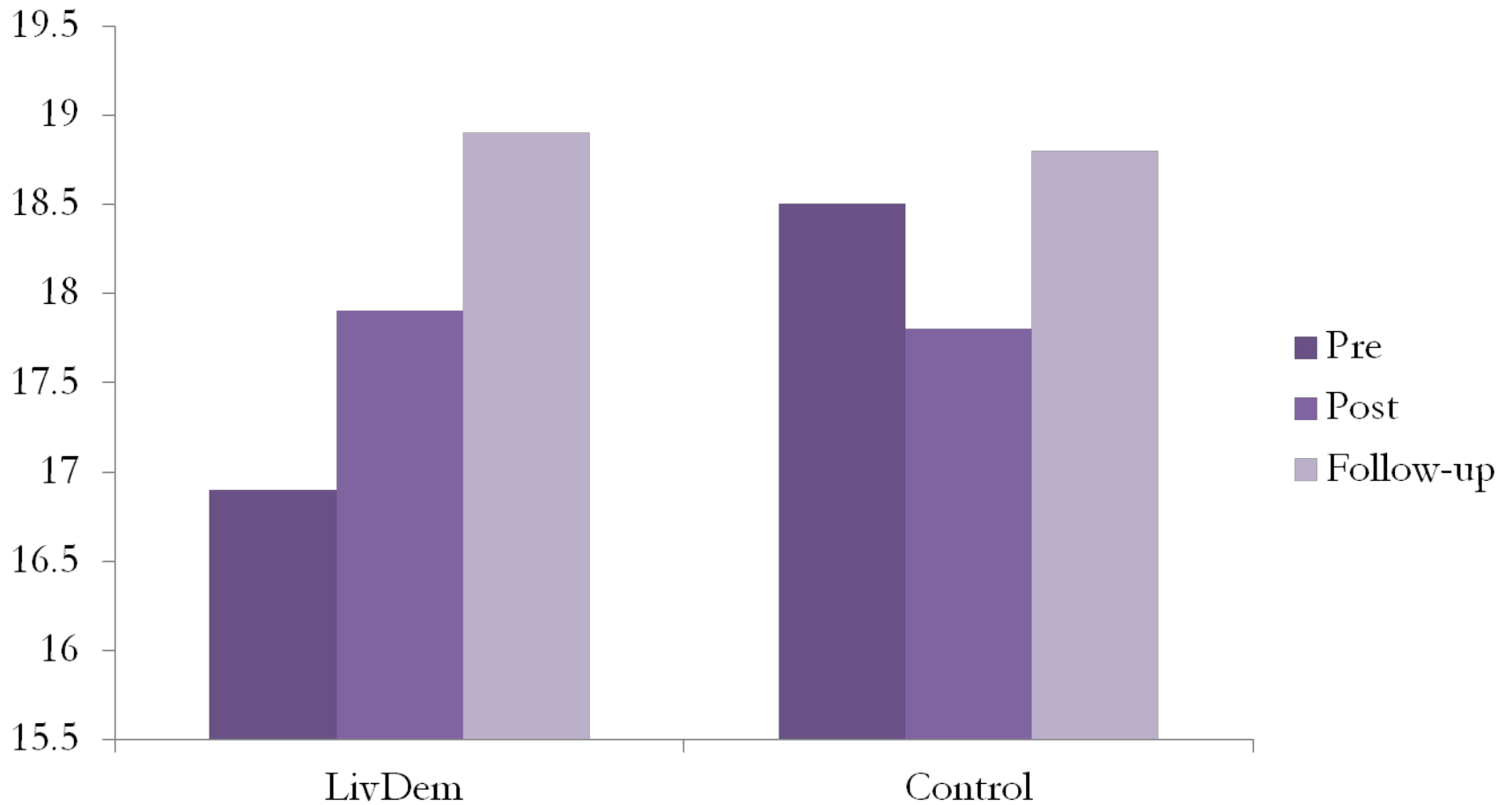
Session one and two: identifying memory problems
and strategies

Session three, four and five: finding a way through
feelings, coping with stress, relationships and
social situations

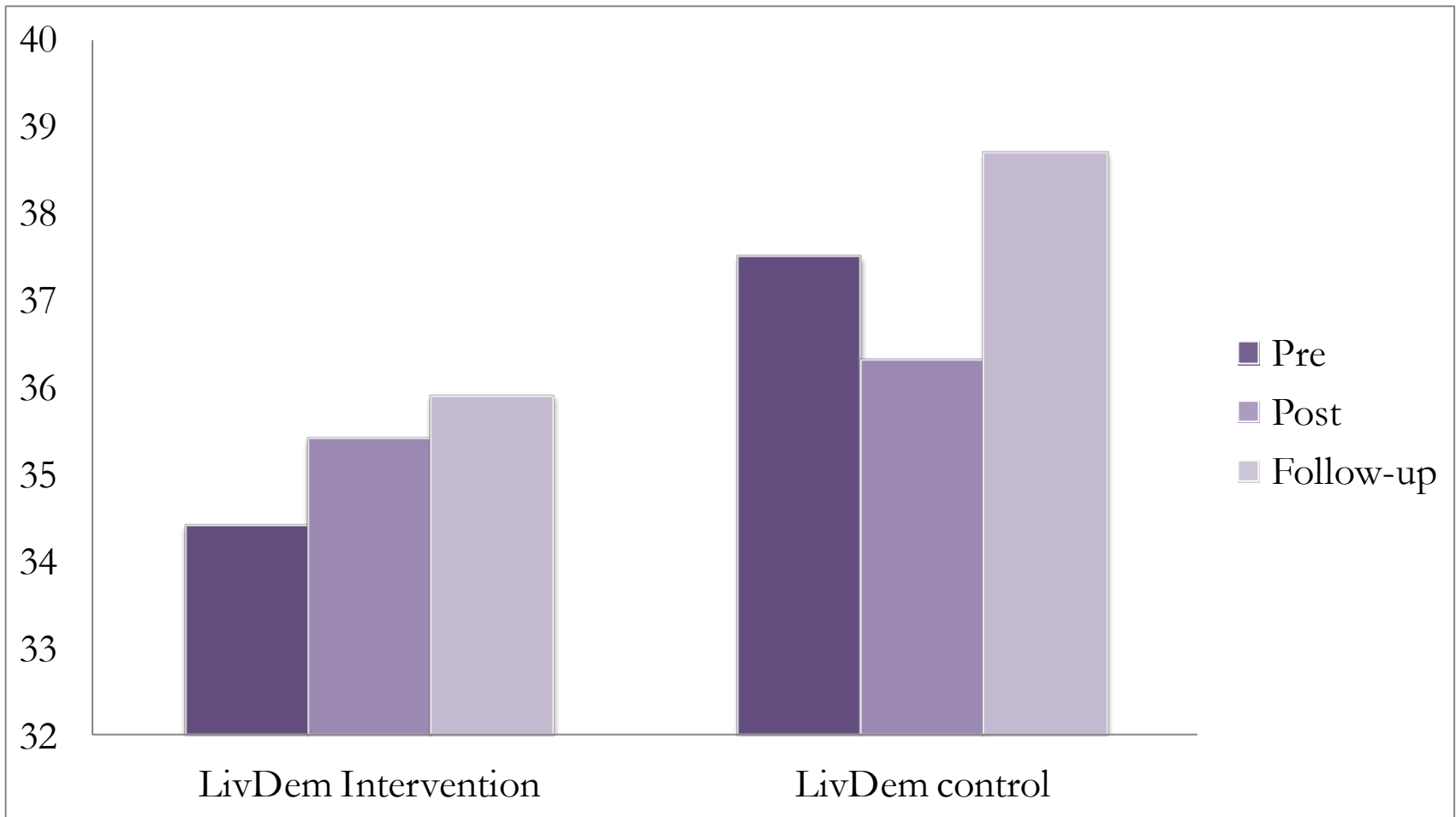
Session six, seven and eight: information about
dementia, living as well as you can, staying active

Post-group: Bringing it all back together (with families)

Self-esteem



Participant rated Quality of Life



People with dementia

- Generally felt positive about the groups
 - Some felt that they had benefitted
 - *Well I suppose the biggest thing is you realise that there's a lot of people with dementia, you know, that you're, you know, it's not just a very small thing, it's a big thing. And I suppose that makes you feel a wee bit better doesn't it? [laughing] You know, that you're not the only one."*
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Carers – learning about dementia

- Carers felt
 - Positively about the groups
 - Generally felt that they were beneficial for people with dementia
- *There's two important things about that group as far as you're concerned. One you've already mentioned it makes you realise that you're not alone but the other, probably the most important thing, is it encouraged you in front of other people to stand up and say "I have dementia". . . I think up until that hospital session S was in denial that she had it but after that she wasn't in denial and that helped a hell of a lot I think."*

Therapists

- Therapists
 - All felt the groups were worthwhile
 - Generally patients benefit
 - Also felt they benefited - learnt new skills and enjoyed doing the groups
 - *You know, you're often looking for little things, you're not, you know with dementia you're not looking for huge great leaps and changes and you often have to put a lot of work in to get something back from people but when you see that I think that really makes you feel like you've done something."*
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Concerns

- Participants had different cognitive levels
 - some benefits, but also drawbacks
 - Did people retain anything?
 - Not everyone wanted to continue
 - People with sensory loss sometimes struggled
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Process of change

- Dementia involves both emotional as well as cognitive challenges
 - *“Oh God”, I as good as lost myself”, “I have lost myself”, “I am lost”*
Frau Auguste D, (1901)
- Important to build a model of change
 - to understand what it is about therapy that helps people to change
- We recorded sessions and looked to see whether the way in which people talked about their illness changed

Changes in how people talk: Level 1

Facilitator: When you had your diagnosis did it affect you in any way?

Mary: No, no, no, I said well if I was dying or something like that you've got to carry on ... there's no good moan, no use sitting there thinking about it is there? So I just carry on what I can do

Level 3

Facilitator: ..You were watching the television just now people were talking about how they felt when they first had their diagnosis.

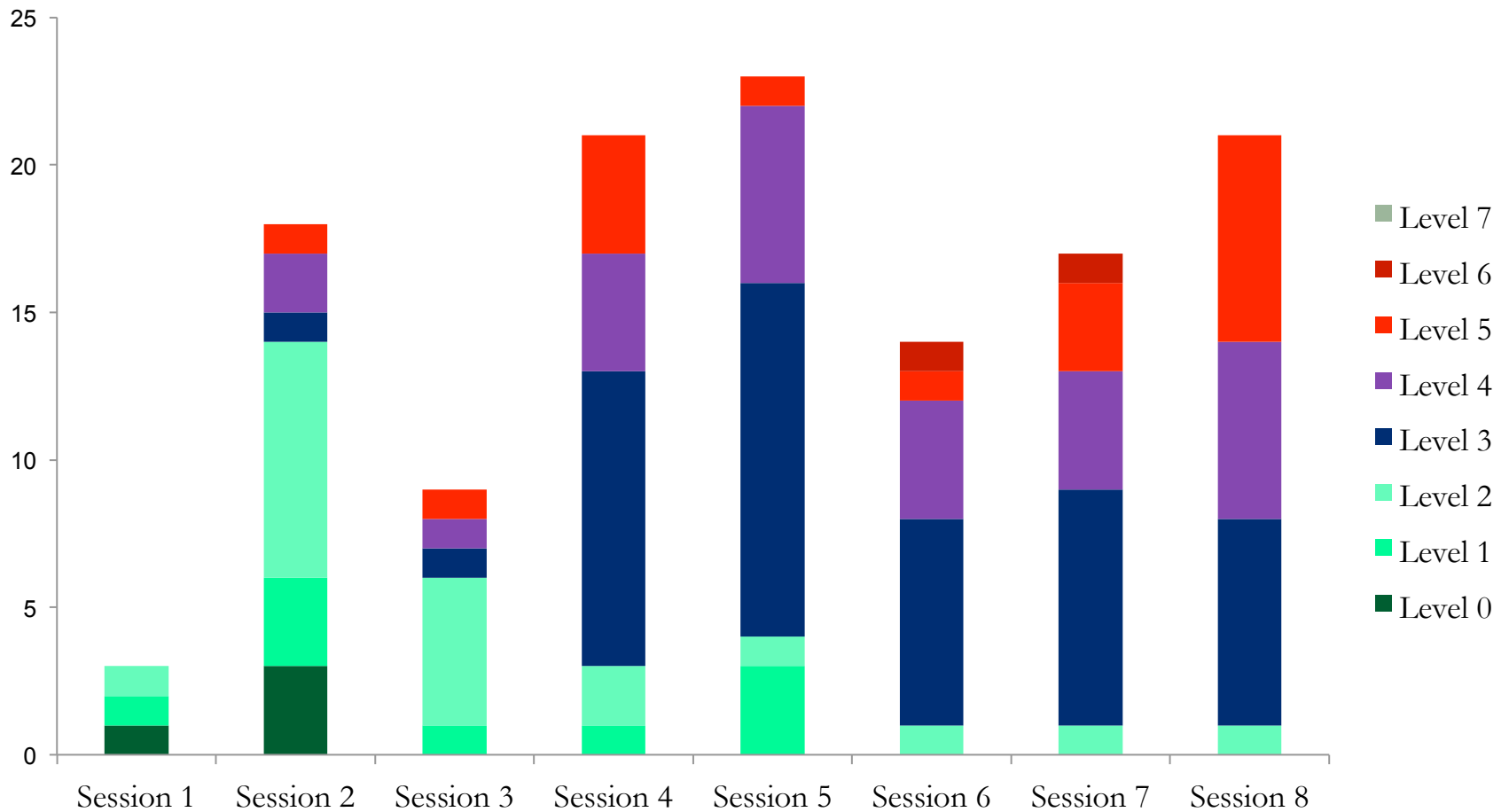
Gina: It does it makes you feel you know that you're going downhill very fast.

Graham: That's right, it makes you feel that it's far more serious than you imagined it to be.

Level 5

Graham: I was told I had dementia and the best thing I could do was tell everybody. I've done exactly that, I've told everybody that. If I could tell you the truth I don't think they've taken one blind bit of notice

Markers across sessions



Main issues about process

- “Awareness”
 - is crucial to “living as well as possible” with dementia
 - involves psychological and social as well as neurological elements and particularly powerful emotional dynamics
 - oscillating ambivalence rather than an all or nothing phenomenon
 - all participants showed evidence of change, but none could be characterised as only falling into one phase
 - critically important to address fears – including those around loss of control

Conclusions

- A group intervention can be taught and delivered by:
 - Memory nurses with little experience of therapy groups; and
 - IAPT therapists with little experience of dementia
 - Some preliminary evidence that groups can
 - Reduce depression and increase self-esteem
 - Help (some) people to be more able to talk more openly about their illness, and to adjust to it
 - Intervention seems acceptable to participants, families and therapists
 - Some elements of research process (e.g. blinding) work better than others (e.g. randomisation)
 - To work towards application for larger, national, trial
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 - Disclaimer
 - The views expressed here are not necessarily those of the MHF, the NHS, the NIHR or the Department of Health.
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