

Living Well with Dementia Groups: changes in participant and therapist verbal
behaviour

Richard Cheston^{1*}, Ann Marshall², Angharad Jones³, John Spreadbury⁴ and Peter
Coleman⁵

30th August, 2016 (in press *Aging and Mental Health*)

Main body of text word count: 4,342

Funding: this work was supported by a grant from the National Institute of Health Research, Research for Patient Benefit funding stream, under grant number PB-PG-0610-22005.

Acknowledgements. We would like to thank all of the participants and their families for participating in this research. The project team would also like to thank the group facilitators (Kathy Chapman-Hill, Jackie Shearing, Lorraine Conduit, Rachel Crane, Angela Lynch, Kate Wilson, Rebecca Burke, Heather Baldwin, Rachel Woodward, Alison Moren, Sue Ward, Helen Williams, Debbie Bolton, Emma Reed, Susan Ryan and Nicki Short) as well as the project steering group members including Professor Clive Holmes, Elizabeth Bartlett and David Higgenbottom. In addition Lauren Gating, Andrea Hiron and Saskia Boisevin assisted in the analysis of material.

Key words: Alzheimer's Disease; psychotherapy; awareness; insight; dementia

* denotes corresponding author

¹ Professor of Dementia Research, Health and Social Sciences, University of the West of England, Coldharbour Lane, Bristol, BS16 1QY

² Consultant Clinical Psychologist, Southern Health Foundation Trust, Newtown House, Eastleigh, SO50 9DB

³ The Memory Team, Cardiff and Vale University Health Board, Llandough Hospital, Penarth, CF64 2XX

⁴ Faculty of Medicine, NIHR CLAHRC Wessex, University of Southampton, Southampton, SO17 1BJ

⁵ Emeritus Professor of Psychogerontology, Faculty of Social & Human Sciences, University of Southampton, Southampton SO17 1BJ

Living Well with Dementia Groups: changes in participant and therapist verbal behaviour

Abstract (247/250 words).

Objectives. This paper reports two, related, analyses of verbal material from seven *Living Well with Dementia* groups: the first examines changes in the verbal behaviours of participants across the course of the sessions in all seven groups; while the second contrasts therapist behaviour in two groups.

Methods. In the first analysis, recordings of three sessions from each group were transcribed and participant descriptions of dementia were analysed using the Markers of Assimilation of Problematic Experiences of Dementia (MAPED) rating procedure. In the second analysis, therapist behaviour in weeks two and eight from two groups (named F and G) was analysed using the Hill Counsellor Verbal response rating scale. Inter-rater reliabilities for the two sets of ratings were “good” and “very good” respectively.

Results. For the MAPED ratings, a five by four contingency table was analysed using chi-squared, which indicated a highly significant change in assimilation. Post-hoc analysis suggested that there were significant higher levels of level 1 and 2 markers in the first two sessions and level 4 for sessions 5 and 6. Facilitators used significantly more direct guidance and information giving behaviour in the second session at Location F compared to Location G.

Conclusions. The results suggest important changes occurred in the way that dementia was described across the seven LivDem groups: this includes both reductions in the avoidance of direct references to dementia after the first two

sessions, as well as an increase in “insight” statements. Directive facilitator behaviour may be associated with poorer outcomes.

Living Well with Dementia Groups: changes in participant and therapist verbal behaviour

Introduction

In the UK, government strategies in all four devolved countries have been to prioritise the development of robust methods of identifying people affected by dementia at an early stage in their illness (Department for Health, Social Services and Public Safety, 2011; Department of Health, 2009; Scottish Government, 2010; Welsh Government, 2011). A significant factor directing this policy is the belief that early diagnosis facilitates people with dementia being able to plan ahead and to take control of their illness. This, in turn, is thought to improve long-term quality of life and to reduce carer-giver strain. However, despite this emphasis on early detection, there are widespread concerns that not enough support is provided to people affected by dementia and their families once they have received a diagnosis (Watts *et al*, 2014). This is especially problematic for the significant number of people diagnosed with dementias such as vascular dementia, for whom prescribing of cholinesterase inhibitors is not an option and where non-pharmacological approaches are the only available treatments.

Living Well with Dementia groups. The Living Well with Dementia (or LivDem) Group therapy intervention focuses on enabling the person affected by dementia to adapt to their illness. The intervention incorporates elements of psychotherapy (e.g. a focus on encouraging participants to share feelings associated with dementia such as embarrassment, worry and sadness) and psycho-education, including information about memory loss, dementia and

medical treatments. The content of the ten sessions has been standardised into a treatment manual⁶.

In a pilot study comparing the impact of LivDem to a waiting list control condition, seven groups were established. All seven groups were led by staff working within NHS memory clinics from a range of professional backgrounds (five were Occupational Therapists, four were Psychiatric Nurses, three were Nursing support workers with the remaining two facilitators being a psychology assistant and a trainee Clinical Psychologist). Prior to working on the project, facilitators' experiences of group work was also varied, with over half having no previous experience of working in a group context. All the facilitators attended a two day training course, and received supervision from Clinical Psychologists at least three times during the course of the intervention.

The group consisted of eight weekly sessions of 75 minutes. Groups had between five and seven participants, all of whom had dementia. Family members or friends were invited to a preliminary and concluding session, but otherwise did not attend any of the eight LivDem sessions. The content of sessions was delivered in pairs: sessions 1 and 2 set out a simple model of how memory works and were designed to facilitate participants discussing their experiences of memory loss; sessions 3 and 4 focussed on the relationship between stress and memory; weeks 5 and 6 described the different forms of dementia and issues around telling others about the diagnosis; while the final two sessions looked at practical ways to "*live well*" with dementia. The pairing of sessions allowed facilitators to have some flexibility in how they delivered the content across

⁶ Available on request from the first author

these two sessions (see Table 1), while the pace of the sessions was intended to avoid potential problems that can arise from giving participants too much threatening information at too early a point. 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.

TABLE 1 ABOUT HERE

All of the participants had received a diagnosis of either probable Alzheimer's disease, vascular dementia or dementia with Lewy Bodies within the previous 18 months. Participants were excluded from the study if they had a significant pre-morbid history of mental health problems. Sixty participants were randomly allocated to one of two conditions: the LivDem group intervention; or to a usual care control arm. The protocol was registered on line (ISRCTN 25079950)⁷, and received approval from NRES Ethics Committee South Central - Oxford B.⁸ The overall attendance rate at sessions was 83 percent. Changes in levels of outcome measures in the two arms of the pilot study have been reported elsewhere (Marshall et al, 2014). Briefly, the study met its recruitment targets, with a relatively low attrition rate for the intervention arm. As a pilot study, the trial was not powered to find statistically significant results and although there was improvement in the intervention group compared to the control group for quality of life and self-esteem, after controlling for baseline variance, these

⁷ <http://www.controlled-trials.com/ISRCTN25079950/>

⁸ REC Number 11/SC/0363, approval dated 18th November 2011, protocol amendments accepted on 28th June 2012 and 23rd August 2012

findings were not significant. However, the effect size of 0.46 is consistent with that found for other facilitator led support groups (e.g. Logsdon et al, 2010).

Alongside testing for differences in outcome measures, we have also begun to look at the process of change that occurs within the intervention. The use of process measures within psychotherapy complements more conventional outcome measures and plays an especially important role in developing new forms of psychotherapy. For instance, psychotherapy process research can help to identify therapist behaviours that either block or enhance the change process.

Assimilation of Problematic Voices: a Process model of psychotherapy change.

The Assimilation Model of Problematic Voices (e.g. Stiles, 1999, 2001; Stiles et al, 1992; Honos-Webb and Stiles, 1998; Honos-Webb, Lani and Stiles, 1999) suggests that most experiences an individual encounters during their life can be routinely absorbed into their identity. However, some experiences are too threatening to allow an easy assimilation. When an individual is faced by such a psychologically problematic experience then, instead, elements of the experience may be initially pushed away from conscious awareness. Awareness of these problematic experiences is voiced gradually and indirectly, as the dominant voice is that of the continuity of identity. The assimilation of the problematic experience occurs through a dialogue between these two voices.

A series of qualitative studies have used an adapted form of the Assimilation model (the Markers of Assimilation of Problematic Experiences of Dementia or MAPED) to examine the nature of the psychological change that is required for people to “*come to terms with*” dementia. Amongst other findings, these studies have described the importance of disclosures of shame within a group (Watkins

et al, 2006), the reciprocal turn-taking discourse of couples (Snow, Cheston and Smart, 2014) and the use of metaphors or stories as indirect explorations of threat (Cheston, Jones and Gilliard, 2004). More recently, Cheston (2016) has described how a fear of loss of internal control may act to prevent people with dementia from being able to articulate especially problematic or threatening aspects of their dementia.

Process analysis of LivDem sessions. A preliminary process analysis of one of the seven LivDem groups has suggested that the 4 participants in this group talked more openly about their dementia at the end of the eight, participant-only sessions compared to the beginning (Cheston et al, 2015). However, this preliminary study looked at only one group and did not address differences in therapist behaviour.

Aims of the current study. In this paper, we will describe two studies: in the first study we will sample all seven locations where LivDem was implemented during the pilot trial, taking three sessions at random from each location, and use the MAPED process of analysis to identify whether there were changes in participant discourse about dementia over the course of the groups. In the second study, we will use MAPED to identify potentially important clinical differences between two locations. We will then examine whether there are differences in therapist verbal behaviour in these two locations.

Study One: changes in participant verbal behaviour (assimilation of dementia) across sessions

Methodology

MAPED analysis. The MAPED scale and procedure used in this study to identify markers of assimilation was adapted by Lishman, Cheston and Smithson (2014) from the Markers of Assimilation of Problematic Voices Scale (Honos-Webb and Stiles, 1998; Honos-Webb, Surko and Stiles, 1998; Honos-Webb *et al*, 1999)⁹. Ratings of these markers take into account both the use of language to frame dementia and the emotional intensity that surrounds this discourse (see Table 2).

INSERT TABLE 2 ABOUT HERE

Use of the MAPED scale involves reading a transcript of therapy or an interview and identifying passages in which there are specific speech markers or characteristic descriptions of dementia. Each stage or level of the Assimilation process can be identified through a number of different speech markers. For instance, a passage would be coded as falling into level 1 (*unwanted thoughts*) if the account included an indirect description of one aspect of dementia such as memory loss but without explicitly recognising this as being related to dementia. At the same time the person's level of affect also indicates the presence of distress (e.g. feelings of anxiety, anger or sadness). A marker of a Level 1 ratings carries with it the implication that elements of dementia are being avoided because this is experienced as being frightening or destabilising to the person's emotional equilibrium. Level 1 markers include: changing the conversation; locating the existence of dementia elsewhere by talking about other people and not themselves as having dementia; limiting the problems they are experiencing; references to fears of being mad or abnormal; asserting that other areas of

⁹ The MAPED coding frame is attached to this paper as a supplementary material

functioning are unimpaired or that they can be easily overcome; or other speech acts that minimize the significance of the dementia experience. In contrast, a level 2 marker involves a greater recognition of acknowledgement of the problematic material in which the person appears to be in distress that appears to arise from some internal conflict relating to dementia. In subsequent levels, the person is more able to name the problematic material (level 3), making links with the past or otherwise finding some distance from the emotional intensity of the problem (level 4), working through the psychological problems caused by the problematic material (level 5) and identifying partial solutions (level 6).

The process for identifying markers consists of five steps:

- *Selection of sessions and transcribing.* All participants in the LivDem study gave their consent for each session to be audio-recorded. Fifty-one of the fifty-six sessions which were solely for people with dementia across the seven different sites were recorded. For each site, three sessions were transcribed (see Table 3), which meant that for each of the eight sessions, either two or three transcriptions were available for analysis.

INSERT TABLE 3 ABOUT HERE

- *Familiarisation.* The initial step of the analysis involves intensive exposure to the transcripts, making systematic notes to locate passages that relate to change, cognitive loss or expressions of heightened affect.
- *Extracting passages.* Speech markers are identifiable events in discourse that recur throughout the transcripts and that indicate important clinical phenomena (Honos-Webb, Lani and Stiles, 1998). In this analysis RC identified 410 extracts in which one or more of the group participants either

referred directly to an aspect of dementia or were provided with a clear opportunity to do so (e.g. through a question by a facilitator) but avoided doing so.

- *Training.* The third author was trained in using MAPED by the first author, which included rating 16 extracts that had originally been analysed by Lishman, Cheston and Smithson (2014). Overall agreement level after training was 81% with a Kappa score of 0.691 (SE = 0.126) which is considered to be 'good'.
- *Rating passages and clarifying disagreements.* The third author then independently coded the extracts, with the first author independently coding those 148 extracts where confidence levels were rated as being low (a score of 3 out of 5 or less). Thirteen extracts were discarded as being unclassifiable. Of the remaining 135 extracts, there was agreement on 114, with the remaining 21 extracts being resolved through discussion. The weighted Kappa score was 0.736, which indicates that the strength of agreement between the two raters can be considered to be "good"¹⁰.

Results

In all, ratings of 397 extracts were made (see Figure 1). Although, there are potentially eight MAPED levels, the final level (mastery) was not used as a code, while level zero (warding off) was coded just three times, from one session only and a level six marker (problem solution) was identified just twice. Accordingly, markers from levels zero and six were treated as outliers, and trimmed or

¹⁰ <http://graphpad.com/quickcalcs/kappa2/>

excluded from the analysis. Sessions were grouped into pairs, reflecting the way in which they were structured during the intervention.

INSERT FIGURE 1 ABOUT HERE

Differences in assimilation across sessions. A chi-squared analysis using a 5x4 contingency table showed that the interaction between MAPED stages and sessions was highly significant ($\chi^2(12) = 48.109, p < 0.001$). In order to determine which elements of the contingency table were significant, we took adjusted Z-score values for each of the twenty cells and calculated their p values (Beasley and Schumacker, 1995; Garcia-Perez and Nunez-Anton, 2003). Z-scores above 1.96 are taken to be significant, but where multiple comparisons are made, as was the case with this analysis, then it is necessary to adjust the level of significance according to the number of cells, which in this case reduced the significance level to $p = 0.0025$. The z-value for three cells were significant at this level. Two cells were from sessions one and two, for level 1, unwanted thoughts ($z = 3.3579, p = 0.0008$) and level 2, vague awareness ($z = 3.2768, p = 0.001$) suggesting that the proportion of markers from the early levels of assimilation were significantly higher in the first two sessions, than in later sessions. The third cell where the z score was significant was for level 4, insight during sessions five and six ($z = 3.7622, p = 0.0002$).

Study two: changes in therapist verbal behaviour across sessions

In order to explore the potential for differences between groups, we used the MAPED ratings to identify groups where was a clear contrast between locations. One pair of groups (F and G) both provided sessions from weeks two and eight (demographic details of participants in both locations are provided in Table 4).

INSERT TABLE 4 ABOUT HERE

There were, however, important differences between participant behaviour in the two sites. In Location F there was a decline in numbers of extracts that were MAPED from 23 in week two to 7 in week eight. Moreover, the modal average rating in both week two and week eight was level 3 (*problem clarification*), and while there were two *working through* markers in week two, there were none in week eight. Both factors suggest that there was minimal therapeutic change occurring within this location. By contrast, in Location G, the number of overall number of markers increased from 16 in week two, to 21 in week eight, while the modal marker shifted from level 2 (*vague awareness*) in week two to being jointly level 3 (*problem clarification*) and level 5 (*working through*) in week eight.

Methodology

In order to examine the role that therapist behaviour in the two locations might play in these differences in participant behaviour, we analysed the therapist verbal behaviour in the extracts using the Hill Therapist Verbal Response Category system (Hill, 1978). This measure has been widely used within Psychotherapy process research and classifies therapist or counsellor behaviours into 14 categories.

Ratings of all Location F verbal behaviours were made by the first and third authors, with the first author and AH (an experienced psychotherapist and clinical psychologist) rating therapist behaviours for Location G. Agreement levels were 83% for Location F (Kappa= 0.811; SE = 0.043; 95% confidence interval from 0.727 to 0.895) and 89% for G (Kappa = 0.867; SE = 0.036; 95%

confidence interval from 0.797 to 0.937) both of which can be considered as 'very good'.

Results

In order to analyse therapist verbal behaviour we combined the Hill ratings in terms of four categories: minimal response (minimal encourager and approval/reassurance); guidance (information and direct guidance); questions (open and closed questions); and empathic listening (restatement, reflection, non-verbal referent and interpretation) and established a 4x2 contingency table. It was only possible to analyse therapist behaviour at the two locations for week two, as there were insufficient behaviours from Location F for week 8 to permit an analysis.

INSERT FIGURE 2 ABOUT HERE

Analysis of behaviours from week two indicated that there was a significant difference between the two locations ($\chi^2(3) = 8.46, p = 0.037$). As Figure 2 indicates, in both groups there was roughly similar use of minimal encouragement and approval reassurance across sessions – both of which are typically short, supportive phrases that either aim to encourage participants to continue talking). Although facilitators asked fewer questions in Location F in both week two (28% of behaviours) and eight (26.7%) compared to Location G (40% and 43.66% respectively), post-hoc analysis indicated this was non-significant. However, the main difference between the two locations in week two was that the facilitators in Location F used far more information giving and direct guidance behaviours (30%) than did the facilitators in Location G (7.5%).

Post hoc analysis using an adjusted significance level of 0.0063 indicated that this difference in guidance behaviour was significant ($z = 2.754$, $p = 0.0059$).

Discussion

Living Well with Dementia groups are intended to help people who are affected by dementia to talk more openly about their illness and thus to adjust to their diagnosis. Although the Marshall et al (2015) pilot study was not powered to find statistically significant results, there was a trend towards an increase in levels of self-esteem and quality of life in the intervention group compared to the control condition. As part of the process of developing the intervention, it is important to identify whether there are indeed changes in the way in which participants talked about their dementia, and to examine the influence of therapist verbal behaviour on assimilation.

The Assimilation model describes awareness as developing through a continuum of eight stages, each of which can be identified by characteristic changes in speech. When a threatening event occurs, for instance a diagnosis of dementia, then according to the model, awareness of that threat is experienced in terms of a dialogue between at least two, contrasting, voices. Typically, a Dominant voice will initially express the importance of maintaining the status quo, whilst a Problematic voice articulates uncertainty and the need for change. At first, only the Dominant voice is heard, and the expression of the Problematic experience may be completely warded off, or pushed away. Gradually, however, the problematic and dominant voices combine, so that the problematic experience is fully assimilated into that person's awareness. Movement along this continuum, from warding off to mastery, is characterised by changes in emotional intensity,

so that as the person begins to voice the problematic elements of their experience, so they are likely to become more distressed (see Figure 3).

INSERT FIGURE 3 ABOUT HERE

Changes in participant verbal behaviour.

This study indicates that the discourse of participants in LivDem groups changed significantly over the course of the eight sessions. More specifically, there was a shift after the initial two group sessions away from Level 1 and 2 markers, towards markers suggestive of more assimilated levels. In addition, there were significantly more ratings of Level 4 (insight) markers in weeks five and six.

The significantly higher number of level 1 and 2 markers in the first two sessions, suggests that during this period there is a tendency towards avoiding engaging with dementia directly. Level 1 and 2 markers are indicative of the person with dementia pushing away knowledge of their dementia. In level 1, the person acknowledges that they experience an aspect of dementia such as memory loss, but avoids discussing or naming their illness directly. Dementia is not specifically identified by name, and is, instead, referred to through euphemisms such as “it”, “the thing that is wrong”, or confined to specific, less threatening symptoms. Cheston (2016) has referred to this as the Voldemort phenomena similar to the way in which most characters within the Harry Potter stories are too afraid to directly name the villain, preferring to use terms such as “he-who-must-not-be-named”. In a level 2 marker, the dementia is still not explicitly acknowledged, but the hallmark of this level is the distress that arises from an internal conflict relating to dementia. The person may describe feeling sadness, angry or worrying, sometimes seeming to be puzzled or confused about

what is happening to them, or feeling overwhelmed and that things are getting worse.

Elsewhere, the process of emotionally engaging with the dementia diagnosis has been described as being one of “*oscillating ambivalence*” (Robinson, Clare and Evans, 2005). This is consistent with the findings of our study: as the group progresses, so the growth of insight, or awareness, is marked not just by an increase in higher levels of assimilation (as indicated by the significantly higher number of level 4 markers in weeks 5 and 6), but also by a lessening of the tendency to push dementia away. The capacity of people with dementia to acknowledge and name their illness is not just an issue of academic interest, as the association between insight, challenging behaviour and care-giver burden has been widely recognised (e.g. Rocca et al, 2010). As one care-giver in the study reported (unpublished thematic analysis):

“Well although [insight] seems small is very, very big. I mean once you’ve accepted you’ve got a problem then you will accept people trying to help you more. But if you’re in denial that you have this problem then of course you’re not prepared to accept help from anybody.” [Carer.13, Lines 1227-1231]

Changes in facilitator verbal behaviour.

There were marked differences between MAPED ratings of two locations in week eight: in site F, not only were there far fewer extracts that could be MAPED, but a far higher proportion of the extracts (six of the eight) were initiated either by participants rather than by a facilitator. In contrast in site G, in week eight only 4 of the 23 extracts were initiated by participants. In therapeutic terms, location G seems to be a healthier site – there are not only more markers in week eight than

in location F, but those that were identified suggest a clear, therapeutic, progression with facilitators being actively involved in helping the group to move on. In location F, by contrast there are fewer Level 1 and 2 markers in week two, and instead a preponderance of level 3 and 4 markers. We therefore examined whether there were differences in therapist behavior in the two sites.

The analysis indicates that one difference in therapist behaviour in the two locations is that in Location F, therapists used significantly more information giving and direct guidance behavior. There was also a non-significant trend towards asking fewer questions. In effect, the analysis suggests that location F facilitators tended to say more, and to listen rather less to participants. This may inadvertently have contributed both to the higher frequency of level 3 and 4 markers, and also had the effect of closing down discussions within the group and interfering with the ability of participants to explore the emotional significance of their dementia.

In clinical terms, groups are sometimes said to progress through a series of stages which have been characterised as forming, storming, norming and performing (Tuckman, 1965). In location F in week two, the dominant therapist behaviour of information giving and direct guidance may have been more appropriate behaviours for the later stages of the group where the group has become established and participants feel more confident in each other's company. However, at an early stage, therapist behaviours of listening, encouraging and questioning may all have been more appropriate. It is possible, therefore, that the differences in participant assimilation of dementia in week

eight between locations F and G is associated with the different forms of therapist verbal behaviour in earlier weeks.

The differences between the two locations may be similar to the differences between the impact of psychotherapeutic and psycho-educational groups found by Cheston and Jones (2008). In a small trial the authors attributed differences in outcome that included increases in depression and anxiety in the psycho-educational arm to the tendency within this condition to talk about too threatening material at too early a stage in group development.

The role of qualitative research approaches within the development of psychotherapeutic approaches to dementia care. The use of mixed methods designs in counselling psychology research has grown in the last two decades (Hanson et al, 2004), as the use of both qualitative and quantitative methodologies in a single body of research may enrich the study findings in ways that using a single methodology could not do. Over the last thirty years, the assimilation model put forward by Stiles and colleagues (e.g. Stiles, 1999, 2001; Stiles et al, 1992) has been used to make sense of those changes that occur during psychotherapy regardless of the therapeutic orientation of therapists. This detailed, qualitative approach complements trials in which psychotherapy is positioned as a quasi-medical intervention that can be assessed through pre and post intervention assessment.

The application of Stiles' assimilation model to the discourse of people with dementia has both clinical and theoretical implications for dementia care: markers are clinically important as they identify different opportunities for engaging with people affected by dementia in talking about their illness; they are

of theoretical significance because they enable a more nuanced understanding of the psychosocial barriers and facilitators affecting awareness. Thus, the assimilation model suggests that ambivalence plays a central role in the processing of psychologically problematic material: that people can be in two minds about the challenging experiences that affect them. Within a clinical context, then, the initial task within therapy is for people to be able to name their problems as being dementia – something that is only possible if people are supported so that they are able to work through their ambivalence at their own pace and without being emotionally overwhelmed (e.g. Cheston, 2013, 2015). Once people are able to talk about the dementia, then they are able to find some emotional distance from the illness. Where therapists behave in a way that does not support this exploration and naming, then this may interfere with the therapeutic process.

In this study, Study 1 provided evidence that there was a process of discursive change in the way in which LivDem participants framed their dementia: in the first two weeks there was significantly higher use of Level 1 and 2 markers indicating that the dementia was being pushed away, or engaged with indirectly. This is consistent with the assimilation model. However, study 2 suggested that in location F, an over-reliance by facilitators on information giving and direct guidance in week two might be associated with poorer, long-term outcomes in week eight. One interpretation of the results from Study 2 is that the facilitators in location F did not achieve a therapeutic balance between telling and asking and that consequently, the participants in their group were not able to achieve quite the same changes in discourse between sessions 2 and 8 as shown by in location G. At the same time, we recognize that this is only one of a number of

possible explanations, and the potential association between therapist over-reliance on telling behaviours in the initial stages of a group and poorer participant outcomes needs to be more rigorously tested in future research.

Conclusion and future directions for research. The role of both individual and group psychotherapy with people with dementia is steadily growing. While much of this research frames evidence as concerning change in pre and post intervention outcome measures, it is also important to examine the process of change. Thus a recent review has concluded that it is important to address other challenges:

“... for instance whether the goal of psychotherapy is to improve insight, to reduce anxiety and depression or to reduce challenging behavior and carer stress? Importantly, there is a need to develop a more nuanced understanding of those elements of therapy that helps people affected by dementia to change or, equally relevantly, not to change. (Cheston and Ivanecka, 2016, p 27).

Helping to understand both the process through which participants become more able to name their illness and at the same time to step back from the emotional pain of the diagnosis, and also the way in which facilitator behaviour augments or detracts from this process is important. As such, this study helps us to understand more about the nature of psychological support, and to adapt the LivDem group intervention to meet the needs of participants.

Disclosure statement - none of the authors has any financial interest or benefit arising from the direct applications of their research

References

- Beasley, T. M., & Schumacker, R. E. (1995). Multiple regression approach to analyzing contingency tables: Post hoc and planned comparison procedures. *The Journal of Experimental Education*, 64(1), 79-93.
- Cheston R, Gatting L, Marshall A, Spreadbury J and Coleman P (2015) Markers of Assimilation of Problematic Experiences in Dementia within the LIVDEM project, *Dementia: the International Journal of Social Research and Policy*, published on-line 2nd September, 2015, doi: 10.1177/1471301215602473
- Cheston R and Howells L (2015) A feasibility study of translating "Living Well with Dementia" groups into a Primary care IAPT service (innovative practice), *Dementia: the International Journal of Social Research and Policy*, published on-line 17th April 2015, doi: 10.1177/1471301215582104.
- Cheston R and Ivanecka A (2016) Individual and Group Psychotherapy with people affected by dementia: a systematic review of the literature, *International Journal of Geriatric Psychiatry*, first published on-line 7th July, doi 10.1002/gps.4529
- Cheston, R (2013) Dementia as a problematic experience: using the Assimilation Model as a framework for psychotherapeutic work with people with dementia, *Neurodisability and Psychotherapy*, 1 (1), 70-95
- Cheston R (2015) The role of the fear-of-loss-of-control marker within the accounts of people affected by dementia about their illness: implications

for psychotherapy, *Quaderni di Psicoterapia Cognitiva*, 37, pp 45-66 doi:

<http://dx.doi.org/10.3280/qpc2015-037003>.

Clare L, Quinn C, Jones IR, Woods RT (2016) "I Don't Think Of It As An Illness":

Illness Representations in Mild to Moderate Dementia, *Journal of Alzheimer's Disease*, Preprint, pp 1-12, DOI: 10.3233/JAD-150794.

Department for Health, *Social Services and Public Safety (DHSSPS) (2011).*

Improving dementia services in Northern Ireland: A regional strategy.

Belfast: DHSSPS.

Department of Health (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health.

Garcia-Perez, M. A., & Nunez-Anton, V. (2003). Cellwise residual analysis in two-way contingency tables. *Educational and psychological measurement*, 63(5), 825-839.

Hanson, W. E., Creswell, J. W., Clark, V. L. P., Petska, K. S., & Creswell, J. D. (2005).

Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology*, 52(2), 224.

Hill CE (1978) Development of a Counselor Verbal Response Category System,

Journal of Counseling Psychology, 25 (5), 461-468

Honos-Webb L and Stiles, W (1998) Reformulation of Assimilation analysis in terms of voices, *Psychotherapy*, 35 (1), 23-33.

Honos-Webb, L., Surko, M., & Stiles, W. B. (1998). *Manual for rating assimilation in psychotherapy: February 1998 version*. Unpublished manuscript.

Department of Psychology, Miami University, Oxford, Ohio

Honos-Webb, L., Lani, J. A., & Stiles, W. B. (1999). Discovering markers of assimilation stages: The fear of losing control marker. *Journal of Clinical Psychology, 55*, 1441-1452.

Honos-Webb, L., Surko M., Stiles W. and Greenberg, L. (1999). Assimilation of voices in psychotherapy: the case of Jan. *Journal of Counselling Psychology, 46*, 448-460.

Lishman E, Cheston R and Smithson J (2016) The Paradox of Dementia: meaning making before and after receiving a diagnosis of dementia, *Dementia: the International Journal of Social Research and Policy, 15* (2), 181-203 - first published on line 27/2/14 (DOI: 10.1177/1471301214520781)

Logsdon, R., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. *Journal of Gerontology, Series B: Psychological Science and Social Sciences, 65B*(6), 691-697.

Robinson L, Clare L and Evans K (2005) Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples, *Aging and Mental Health, 9* (4), 337-347

Rocca P, Leotta D, Liffredo C, Mingrone C, Sigaudò M, Capellero, B. Rocca G, Simoncini M, Pirfo E and Bogetto, F. (2010). Neuropsychiatric symptoms underlying caregiver stress and insight in Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders, 30* (1), 57-63.

Rosow K, Holzapfel A, Karlawish JH, Baumgart, M, Bain LJ and Khachaturian AS (2011) Countrywide strategic plans on Alzheimer's disease: Developing the framework for the international battle against Alzheimer's disease,

Alzheimer's and Dementia, 7 (6), 615–621

Scottish Government (2010). *Scotland's National Dementia Strategy*. Edinburgh:

Scottish Government.

Stiles W (2001) Assimilation of Problematic Experiences, *Psychotherapy*, 38, 4,
462-465

Stiles W, Meshot C., Anderson T and Sloan W (1992). Assimilation of problematic
experiences: The case of John Jones. *Psychotherapy Research*, 2, 81-101.

Stiles, W (1999) Signs and Voices in Psychotherapy, *Psychotherapy Research*, 9
(1) 1-21.

Tuckman, B (1965) Developmental sequence in small groups. *Psychological
Bulletin*, 63(6), 384-399.

Watkins B, Cheston R, Jones K and Gilliard J (2006) "Coming out with Alzheimer's
disease": changes in insight during a psychotherapy group for people with
dementia, *Aging and Mental Health* 10 (2); 1-11

Watts S, Cheston R, Moniz-Cook E, Burley C, and Guss R (2014), Post-diagnostic
support for people living with dementia, in R Guss et al (on behalf of the
Faculty of the Psychology of Older People, and in collaboration of people
living with dementia and the Dementia Workstream Expert Reference
Group) *Clinical Psychology in the Early Stage Dementia Care Pathway*.
British Psychological Society: London

Welsh Government (2011). *National Dementia Vision for Wales*. Cardiff: Welsh
Government.

Table 1: Structure of Living Well with dementia intervention.

Week	Attended by	Title of session	Content
Preliminary	Participants and carers	Welcome and Introductions	Introduction to the group and to other participants, familiarisation with structure, discussion of recovery model
One and two	Participants	Problems and frustrations with memory	Participants identify problems associated with memory loss. Description of nature of short-term memory loss – compared to filing letters in a filing cabinet.
Three and four	Participants	Finding a way through feelings and coping with stress	Discussion of emotional impact of memory problems and other cognitive symptoms. Discussion of the impact of anxiety on memory loss - practicing relaxation
Five and six	Participants	What is dementia? Impact of the diagnosis on friends and family.	Focuses on the process and assessment and diagnosis. Information about different types of dementia, treatment and choices (e.g. driving). Discussion about whether to tell others about the diagnosis
Seven and eight	Participants	Living as well as you can. Staying active	Importance of healthy lifestyle – activity, diet and preparing for the future
Consolidation	Participants and carers	Bringing it all back together	

Table 2: Markers of Assimilation of Problematic Experiences of Dementia Scale (MAPED) (from Cheston et al, 2015)

Assimilation level	Content and affect	Markers
0. Warded off	Content is un-formed and features avoidance. Minimal affect, reflecting successful avoidance	
1. Unwanted thoughts	Emergence of thoughts associated with dementia or memory loss. Further discussion may be avoided and dementia is likely to be talked around rather than named directly. Unfocused strong emotions (e.g. anxiety, fear, anger sadness) are more salient than the content	<ul style="list-style-type: none"> a) Changing the conversation b) Telling a contradictory story c) Fear-of- loss-of- control (e.g. being mad or abnormal) d) dementia is located elsewhere or referred to indirectly (e.g. as "it") e) the significance of dementia is otherwise minimised
2. Vague awareness	The problematic experience of dementia is acknowledged and uncomfortable associated thoughts are described. The person is in distress, and this seems to come from some internal conflict relating to dementia, so that in talking they seem to be caught up in the moment of the emotion. Affect focused on acute psychological pain or panic	<p>Expressions of</p> <ul style="list-style-type: none"> a) Feelings of sadness, depression, worry or anxiety. b) Anger or irritation about some aspect of dementia c) Puzzlement or confusion about what is happening to them. d) Feeling overwhelmed or that things are getting worse. e) Stories that point to the problem but are not clearly described. f) Use of metaphors to talk about the problem
3. Problem statement or clarification	The person acknowledges the existence of dementia as a problem and attributes this to an illness such as dementia. Affect is negative but manageable	<ul style="list-style-type: none"> a) Describing their reaction to dementia, which may include mixed feelings (e.g. "yes But") b) The person appears 'stuck' and sees no way out. c) Developing a clearer understanding of dementia (e.g. asking questions or being curious) d) Describing contradictions in the illness e) Describing that previous difficulties in recognising the

Participant and Facilitator verbal behaviour in LivDem groups

		problem
4. Understanding/ insight	The person acknowledges the existence of dementia and is able to describe how this makes them feel, or how they react to this. They are able to stand back from their feelings. Curiosity of affect, with mixed pleasant and unpleasant recognitions	<ul style="list-style-type: none"> a) Describing situations where their feelings differ in intensity b) Emotional distance from the dementia (e.g. through use of humour) c) Making links between dementia and others areas of their life d) Making links between the past and the present e) Comparing themselves with others in a worse position
5. Application/ working through	The person both acknowledges the existence of a dementia and can also point out what needs to get worked on. Business-like positive affect that is optimistic or hopeful and linked to strategies	<ul style="list-style-type: none"> a) Weighing up attempts at a partial solution to the problem (e.g. taking medication). b) Acknowledging deterioration and explicitly describing some acceptance.
6. Problem solution	The person acknowledges that they have a dementia, and have achieved a successful solution for a specific problem. They recognise change in their lives. Affect includes positive satisfaction or pride linked to accomplishments	<ul style="list-style-type: none"> a) Achieving a change in their life in living with the dementia that they feel positive about. b) Change in their understanding of what is happening to them or their relationships with others c) Comments on how others have noticed that they have changed
7. Mastery	The person is able to integrate dementia into the whole of their life. Dementia is acknowledged and recognised but no longer defines them as a person. Affect is neutral (i.e. this is no longer something to get excited about)	<ul style="list-style-type: none"> a) The person successfully uses their new solutions in new situations

Table 3: analysis of sessions from different group locations

	Session Number							
Location	1	2	3	4	5	6	7	8
A					X		X	X
B	X		X			X		
C			X	X		X		
D	X				X	X		
E	X		X		X			
F		X					X	X
G		X		X				X
Total number of sessions analysed	3	2	3	2	3	3	2	3

Table 4: Participant baseline demographic and clinical characteristics.

	Location F (n=5)	Location G (n=5)
Age	72.2 (range: 73-82)	72 (range: 51-87)
Gender		
Male	0	2
Female	5	3
Living status		
Living with spouse	4	2
Living with children	0	1
Living with parent	0	1
Living alone	1	1
MMSE score	23.6 (range: 18-27)	22.2 (range: 18-30)
Education		
Secondary School	3	3
Further education	2	2
Diagnosis		
Alzheimer's Disease	3	2
Vascular Dementia	2	2
Mixed dementia	0	1
Taking dementia medication		
Yes	3	3
No	2	2
Taking anti-depressant		
Yes	1	2
No	4	3

Figure 1: Coding of levels of assimilation across sessions

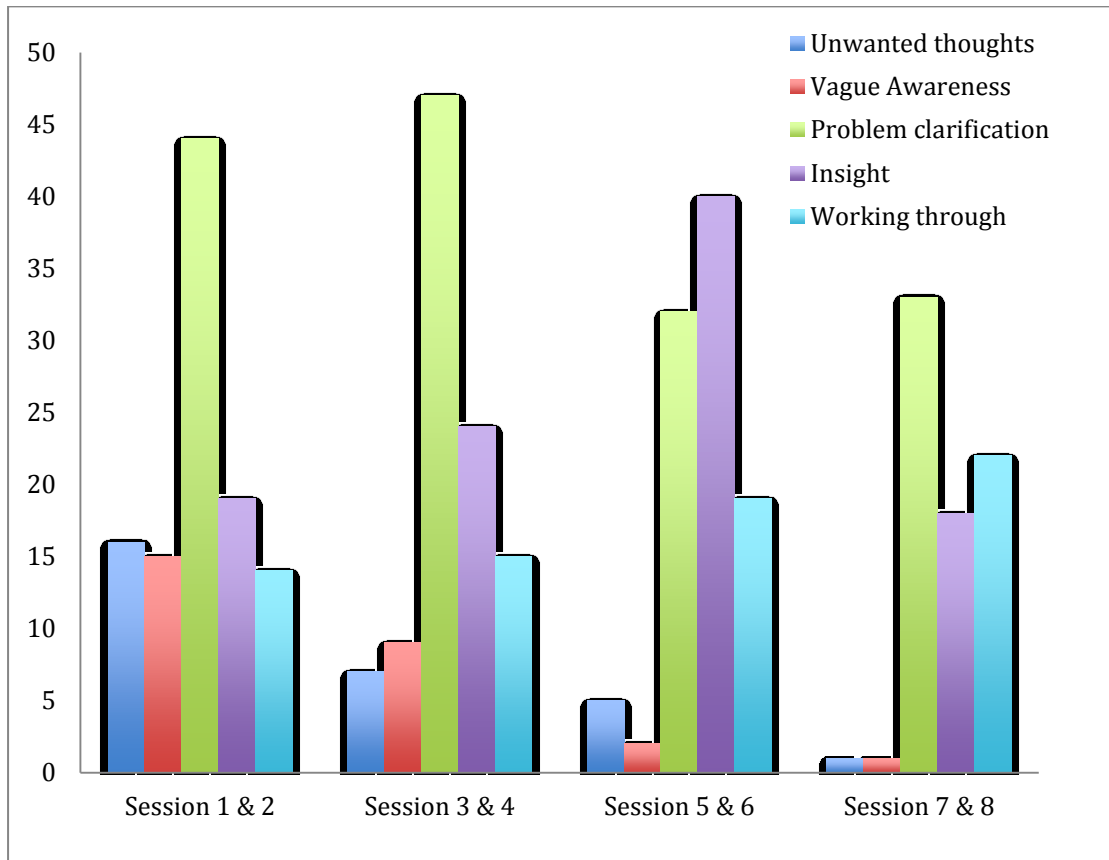


Figure 2: graph illustrating Session Two percentage of therapist verbal behaviour in Locations F and G

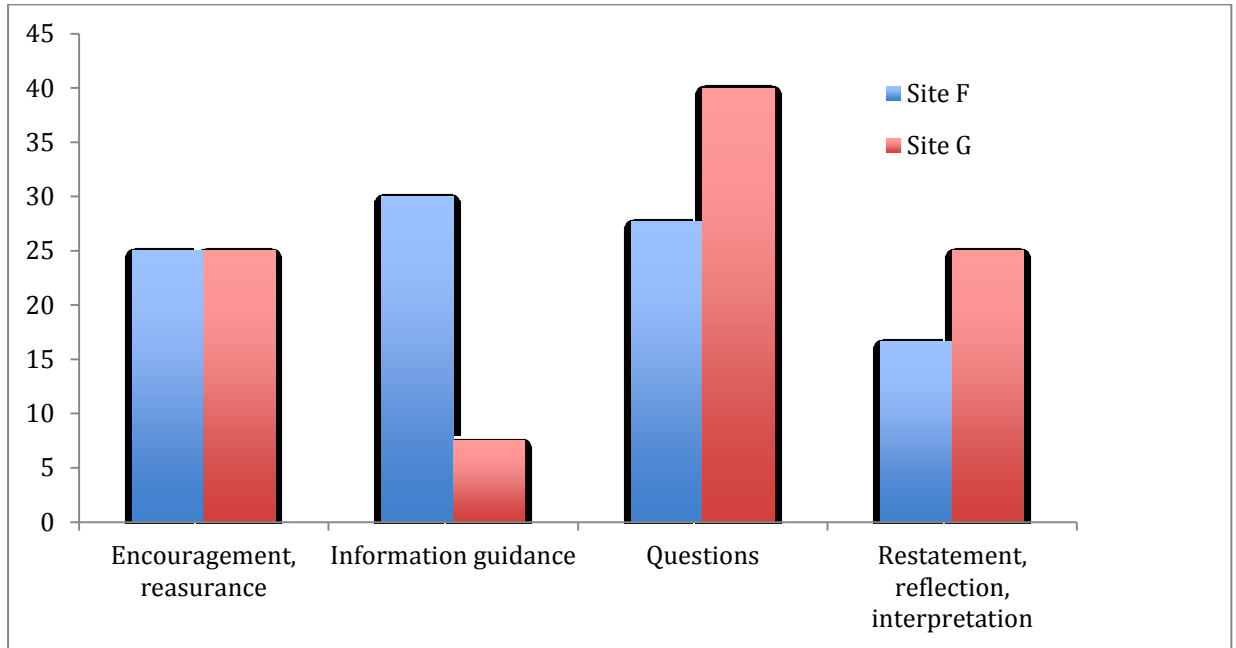


Figure 3: the relationship between levels of assimilation and affect

