

**Supporting carers of older people with dementia: a case study of
intervention programmes**

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Abstract

Caregiver burnout in dementia is concerned with physical and emotional exhaustion, involving the development of a negative self-concept and an unhealthy or resentful attitude toward the caregiving role. This paper explores two interventions aimed at alleviating the psychological strain on carers, and resulting in a supportive environment for carers to perform their role. The paper explores key concepts involved in the facilitation of behavioural change, and the promotion of emotional growth through self-expression culminating in a better quality of care for the person living with dementia.

Introduction

Caregiver burnout in dementia is concerned with physical and emotional exhaustion, involving the development of a negative self-concept and an unhealthy or resentful attitude toward the caregiving role (Haley, Brown & Levine, 1987). Carers generally spend the majority of their time in very close contact with the dependent and have limited associations with the outside world making the situation a crisis and encouraging residential care. Chenoweth and Kilstoff (1998) first explored the prevention of caregiver burnout through the role of mediation over a decade ago, having noticed an increase in overburdened relationships. Grounding research in its day, their idea was to rebuild relations through communication and support, improving motivation and encouraging re-conceptualisation of the dementia care role. On reflection, it seemed unfeasible that little had been uncovered on the role of repressed emotion, or in developing interventions so important to their release. Both studies had documented these predictors as amenable to interventions that helped diffuse challenging situations, but few researchers followed their lead in reconstructing suitable models, despite claims that Schofield's claims that findings were conclusive. Even fewer studies have attempted to address mediation despite psychological demands placed on empowerment and identity. In order to establish supportive interventions, it was important that tools were utilised that accurately reflected the needs of the carer situation, while encouraging a more optimistic and productive approach to the care role (Haley et al., 1987, Brodaty & Green, 1996). In order to support the carer appropriately, it was imperative that interventions reflected the seriousness of the issue, while reducing the burden of care. Ideas drawn upon in the following paper represent key concepts involved in the facilitation of behavioural change, promoting emotional growth through self-expression cumulating in a better quality of care for the dependent.

The Importance of Praise and Thanks (Reciprocal Behaviour)

In 2006, Walter Nord wrote extensively on the theory of social exchange and the value of reciprocal behaviour, insisting that humans have a basic desire for approval.

Many contemporary theorists use the terms 'approval' and 'disapproval' as a definition of appraisal or reprisal, whereas Homans (1958a) promotes a distributive justice, arguing that reward will be proportional to investment. It is here that the dementia care role can become problematic, sacrifice is difficult, and few people are able to achieve it, having done something that is praiseworthy they may feel it merits some praise. Unfortunately, a person with dementia may have awareness of the sacrifices made in the provision of their care; it may not be that they are ungrateful, but that they are unaware of the current situation. Even when moral reasoning justifies a compliance with social exchange, if the cost of caring overrides the benefit the scales are likely to tip.

Group Hugs (Group work only)

In her book on Hug Therapy, Kathleen Keating (1995) suggests that there is something godlike in *everyone*, that all individuals have the power to make another feel cherished. Keating (1995) believed that each person has the inner ability and the power to give (and receive) kindness, warmth, support, healing, security, and perhaps most important of all 'belonging'. The basic qualities that humans possess are simple, cost nothing, but may convey more than words (Vanderbilt, 2000). In a complex world that has grown increasingly impersonal and materialistic, the one thing that remains unconditional is 'touch' (Evardson, Sandman, Ramussen, 2003). Touch is the most powerful healing one can offer to another and that one can bestow on the 'self'. As with praise, hugs appear to play important role in intervention (Vanderbilt, 2000, Evardson, Sandman, Ramussen, 2003). The giving and receiving of praise and hugs was made easy through adopting the person-centred approach to mediation, epitomising Carl Roger's (1951) theory of empathy, congruence, and unconditional positive regard (non-judgemental attitude).

Person-Centeredness

The 'Person-Centred Approach' is devoted to Rogers' unique understanding of personality and human relationships, with extensive applications in psychotherapy, counselling, educational and other group settings (Rogers, 1951).

In his work 'A Way of Being' Rogers spoke in depth about the humanistic approach to psychology and its relationship with person-centred care. Rogers believed, the more natural the attitude of the professional, the greater the perception of the client (Rogers, 1980). Client-centred theory considers the client who is incongruent, that is 'untrue to the self'. While vulnerable and anxious, they have the psychological experience of an attentive therapist (Rogers, 1957). During treatment, the therapist experiences and manifests three basic attitudes in the relationship congruence, empathy, and unconditional positive regard. Over time, the process of self-actualisation motivates change, enabling the person to feel better about who they are they become 'congruent' (Rogers, 1957).

Self-actualisation is developed by creating an interpersonal environment, which communicates a particular attitude, congruency, empathy, and unconditional positive regard being essential to the constructive change that allows the carer to move on (Rogers, 1951). The person centred approach places value on the fact that authority rests in the person's view, not the professional's (Rogers, 1951). In dementia care, this suggests that for positive change to occur the carer must move in their own direction at their own pace, pursuing growth in their own distinctive way. The function of the facilitator is to mediate the actualising process with focus on 'self-authority' (Bozarth, 1985). Self-authority is reinforced through the facilitators own trust in the process, the belief that the carer can become fully functional (Rogers, 1961).

Reminiscence

Reminiscence and the life review was indispensable in the planning of interventions, with widespread research demonstrating the therapeutic benefits that accompany the reflection of positive experience, from Lewis (1974) and Hall and Buckwalter (1987) to Coleman and O'Hanlon (2004). As well as releasing negative emotion from the past, reminiscence may help the carer come to terms with current identity issues (Coleman, 1996, Hooker and McAdams, 2003, Cappeliez and O'Rourke, 2006). Positive reminiscence channels memories in a focused direction by re-addressing the negative, then reflecting on a positive alternative, also known as, 'restructuring the life narrative' (Connelly, 1990).

Narrative inquiry has a long intellectual history increasingly used in studies of educational experience. One theory in educational research holds that humans are storytelling organisms who, individually and socially, lead storied lives. The study of narrative is the study of the ways humans experience the world, each are storytellers and characters in their own and other's stories, beginning the story, living the story, and selecting stories to construct and reconstruct narrative plots (Connelly, (1990). Defined as the six foci of ageing, Hooker and McAdams (2003) believed that certain concepts could be nurtured, solidified and organised to contribute to a more integrative and comprehensive understanding of personality, as well as its importance over the life span. These included traits, states, personal action constructs, self-regulation, self-narration and life stories, all process constructs of personality and ageing (Hooker et al., 2003). In a continuation of this research, McAdams, Anyidoho, Brown, Huang, Kaplan and Machado (2004) tested five hypotheses connecting the 'Big-Five' personality traits to life-narrative indices of emotional tone, theme, and structure. McAdams et al. (2004) recruited independent groups of students and adults to complete a self-report measure of the 'Big-Five' personality traits.

Participants provided written accounts of key life-narrative scenes including reminiscence of life's high, low, and turning points. Content analysis revealed that neuroticism was positively associated with an emotionally negative life-narrative, with agreeableness correlated with narrative themes of communion, such as friendship and caring for others, while openness was strongly associated with the structural complexity of life narrative accounts, in both samples. McAdams results raised an interesting debate on the context of contemporary research, theorising on the narrative study of lives, and emphasising the importance of reminiscence in narrative research (McAdams et al., 2005). Although Bazzini, Stack, Martincin, and Davis (2007) later argued these ideas, finding preliminary support that laughter may have a more potent influence on well-being, than reminiscing about positive events.

Discursive Psychology and Communication

Discursive psychology is concerned with group processes, involving attitudes and construction of the social world through concepts, ideas, and images using narrative discourse. Social discourse is the way people manage their interests through conversational dialogue as a means to assess the best situational outcome, introducing humour to lighten the burden of the carer role through mediated expression. The introduction of resentment-reducing catharsis using facilitated activities was an amalgamation of approaches designed by the researcher, based on the evidence from the previous studies, and piloted in two interventions.

The Interventions

Pilots were developed over a two-month period based on a combination of psychological theories, aimed at supporting carers in the release of emotion through mediated interaction and facilitated timeout. Both pilots were constructed using information collated from earlier phases of this research, focused on reducing the burden believed to promote distress. The following sections describe and evaluate these interventions in the prevention of caregiver burnout in dementia.

Design Considerations

In designing a support programme, careful planning was involved in structuring the programme around the needs of the carer and in designing a more carer-orientated form of support. Primarily, there was evidence disclosed in the case studies from the exploratory phase, followed by the endorsement of that evidence confirmed by the survey study used in phase two. In addition, there were issues to consider in ensuring that interventions were dissimilar to those pursued elsewhere, projecting the research forward, and fulfilling financial criteria with respect to future funding. Financial considerations were integral to promoting the research outside academia and implementing preventative strategies within policy guidelines. Importance was on current initiatives and the prevention of emotional burnout. The success of the project and coexisting issues of dementia care was always the foremost priority as opposed to rehashing current ideas and

managing the aftermath as and when it occurred. The implications of delivering continued support and, sustaining that support across the caregiving population was crucial in determining interventions that were adaptable.

Ideas and Limitations

When considering limitations, it was essential to pilot more than one intervention in order to gain a comparison, the first being an on-call telephone intervention focused on facilitated interaction. Designed for the home carer, call support was a way of exploring the care situation and facilitating change on a more personal level, the difference being the researcher called the carer. The second pilot was a facilitated emotional expression group, designed to release repressed emotion through group mediation using humour and catharsis to develop autonomy through social exchange (Homans, 1958b). Both interventions were compatible with the models of emotional coping and facilitated mediation, as well as with services already in place; these acted as a point of reference based on Pusey and Richards (2001) review of effective psychosocial interventions. Similar considerations were applicable in developing group interventions suitable for carers (Haley, Brown & Levine, 1987) with emphasis on emotional significance, physical ability, time constraints, and location. A confidential environment was critical in establishing favourable conditions for releasing personal emotions and strengthening relationships weakened by dementia (Pusey & Richards, 2001, Haley, et al., 1987).

Main considerations included:

1. To enable communication with people, other than the person with dementia
2. To recognise the importance of adopting the person-centred approach in facilitating disclosure and expression of emotional distress (resentment)
3. To offer a safe non-judgemental environment for carers to release emotion

4. To replace the formal support meeting with a more relaxed informal approach, promoting understanding and acceptance of the care role
5. To provide a friendly, empathic environment where issues can be addressed
6. To facilitate communication, using person-centred skills to motivate an emotional release.
7. To enable the release of emotions through interactive communication, addressing reactive attitudes and promoting alternative thinking
8. To provide the opportunity for timeout without guilt, or need for self-incrimination

Financial Considerations

Focused on the needs of the dementia carer, interventions were cost effective and adaptable to other care situations, and were not dementia specific. Programme elements met with criteria that were adaptable across care networks with a view to developing a support manual accessible to all areas of care. The following list comprises the financial considerations highlighted during the design phase.

1. Interventions to be adaptable and manageable across care domains to include town, and rural populations
2. Financial expenditure to be concurrent with current measures of support, with local budgets a primary concern
3. Manageable interventions using minimal volunteer support

4. To provide a cost-effective alternative to current support in the prevention of caregiver burnout and reducing the financial implications of long-term care

Intervention One: The On-call Sessions

The Introduction

The aim of the pilot studies was to evaluate the effectiveness of facilitated interventions in motivating the release of repressed emotion in carers of people with dementia and the reduction of caregiver burnout. Earlier evidence had suggested that carers suffered from fear derived after enduring multiple losses without emotional support. With no outlet for communication and little timeout, feelings had turned to resentment, exacerbated exaggerated by guilt, emotions had been masked, repressed or denied. Completed in December 2007, two pilots were conducted consecutively beginning in early November and ending mid-December. The rest of this paper evaluates these interventions followed by a summary of achievement.

The first intervention was a facilitated on-call, support service, similar to the prime-line National Health Service (NHS) but differing in the method of delivery. Funded by the NHS, current prime-line call services provide specific help for people who live on their own, those who care for a dependent, and those described as vulnerable. The original idea was to provide an emergency call-line that enable people to continue independent living and/or provide continued care for another within his or her own home. Run by a team of experienced people, care lines provide emergency support but, as a rule, do not include person-centred or on-going care. The usual aim of a care-line is to provide answers to a variety of consumer questions, usually health related, however, it is important to consider that most help-lines do not have access to the caller's medical records, but still offer practical support, advising on hospital admission or sending for ambulatory services. Help lines are a way of signposting people in difficulty to a particular resource or service, related to a specific situation, set up for those at high risk with no alternative solution. These lines are at risk if the advice given is inappropriate

and lead to further complications, particularly if an advisor fails to get the right information and makes an unqualified judgement. In comparison, the present intervention required the carer to be 'on-call' at a time suitable for them where interactive a trained facilitator offering communication outside the care role instigated telephone support.

Unlike existing services responding to emergencies, the on-call support line was a way to facilitate emotional release prior to the point of crisis. The on-call pilot was operational over a 14-day period with call length and closure at the discretion of the carer.

Aim:

The aim of the on-call pilot was to assess the feasibility of providing a service that gave ongoing support without the fear of humiliation, promoting the identity of the carer with a sensitivity gained from person-centred communication. In short, to explore the impact of telephone support, initiated by a facilitator, in the familiar setting of the carer's own home.

Key aspects:

The release of emotional distress facilitated by the researcher using tools including humour, praise and reminiscence and counselling skills in the development of one-to-one interaction and person centred communication.

Rationale:

The rationale for this intervention was to provide the carer with an impartial source of communication, delivered empathically and removing the fear of confrontation. The provision of a support line specifically focused on the carer heightened the importance of the caregiving role. It was hypothesised that increasing the carer's sense of identity would encourage them to feel valued, maximising their chances of reintegrating with society.

Ethics

Carers were informed of the research aims and objectives including aspects that may influence their willingness to participate. Carers were also informed that the researcher would be taking a participatory role in the study as their facilitator. All information was strictly confidential and anonymity protected, with no form of deception involved. Carers were made aware of their rights of withdraw from the research, and that personal information would be destroyed. No carer was put at risk during any part of this study and all were offered ongoing support should it be required. On completion, the researcher informed participants that help and advice was available if required. All the carers were thanked, and debriefed, following a discussion of their research experience, to monitor any unforeseen effects. All gave consent for participation in the weekly interviews and recording of their voice for transcription. All the carers involved in this research gave consent to their anonymous inclusion in the event of publication. Ethical consent was received from the University of Southampton, School of Psychology Committee prior to the commencement of research, with ethical guidelines adhered to at all times.

Method

During the month of October 2007, seven carers volunteered from two local care groups in the Southampton area, to participate in a two-week telephone support trial, having expressed an interest in participation during the survey phase of the research. Prior to commencement of the study, each carer was briefed on the aims and content of the research, and of their right to withdraw at any time without question. All information was strictly confidential, with each carer asked to sign a consent form. Following the briefing, each carer received verification of the research content and two copies of the new 10-item survey, accompanied by written instruction on its completion at the beginning and end of the study. Pre-paid, post-dated envelopes ensured the return of each survey at baseline and completion.

Scores were useful in evaluating the carer's emotional progress in relation to each emotional theme. All communication was participant-led and facilitated by the researcher whose role was to maximise conversation using humour, empathy, and encouragement. Building trust was tantamount to achieving the interactive rapport that had been so successful in the home-visit phase where providing support within the carer's own environment, proved fundamental in the process of emotional release. Carers chose when and where they received calls enabling them to take control over the time of each call and its duration. This was dependent on how convenient it was to speak due to the emotional situation in the home. When desired, calls took place without the dependent, allowing the carer to experience timeout. While some carers were undoubtedly organised with prepared conversation at the ready, others learned to structure the calls into their daily routine. As it was not always possible to adhere to absolute times, each carer was given an appropriate time for each days call, for example between 7 pm and 8 pm. all that was required of the carer was a home telephone and the provision of their time, all costs were financed through the research. In case of emergency, an answer machine was desirable but not essential. Principal features included,

- a) Call duration determined by the carer
- b) Conversation topic was optional, predetermined by the carer
- c) The number of calls completed

Procedure

Carers in the on-call intervention began at two-week intervals, where intermittent start dates ensured that participants would not all be receiving calls at the same time, with only one facilitator this was impractical. The researcher called the carer once each day at a pre-designated time. If there was no reply and where there was an answer machine, the facilitator would leave a message acknowledging the call and stating that a repeat call would follow in 30 minutes. If there was no response on the second call, it was assumed that the carer was either committed elsewhere and the call service was resumed the following day.

Optional responses enabled the carers to have choice and control over each call. In circumstances where a carer was unable to commit to a call, they were actively encouraged not to curtail their usual activities, but to schedule the calls around them. The idea was to provide the carer with the opportunity to communicate, not to encroach on their lifestyle. The researcher's role was to instigate each call and to facilitate communication during conversation in any direction the responder wished to go. Similar to exploratory study, prompt questions were used, such as 'How has your day been?' or 'how did that make you feel?' mostly, carers were encouraged to lead the conversation. As calls were not recorded focus was on re-occurring patterns taken from documented field notes.

The aim was to build a biographical image of the care situation by recognising thematic repression, before carers found themselves unable to cope (Schur & Whitlatch, 2003). Recruited from care groups in Southampton, each carer received and completed the appropriate documentation prior to the start of the study, including pre and post-test surveys and consent forms. The evaluation survey was an abridged version of the national survey developed in stage two using ten items in place of the original 20. More concise and practical to complete while still representative of the five identified themes.

Quantitative Analysis of Pre and Post-Test Surveys

The 10-item revised survey was completed by each carer pre and post-intervention, monitored scores identified a significant decrease in each of the five themes of emotional burden for each carer depicted using the related sample t-test ($M = 63.86$, $SD = 13.397$) versus ($M = 52.14$, $SD = 11.992$), significant at ($t = 3.432$, $df = 6$, two-tailed $p = .014$). The greatest decrease was fear suggesting that facilitated communication with a neutral mediator can help a carer to voice their anxiety, releasing the burden of unexpressed fear. Communication, loss, and resentment shared similar reductions where the least effective was timeout, perhaps a result of the carer still being 'in' the care situation. The overall

decrease in each of the five themes over the two-week period of the study is shown below (see figure 1 and table 1).

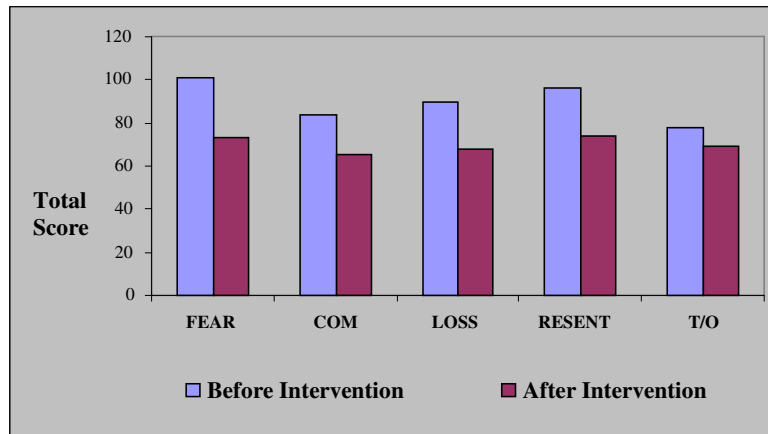


Figure 1 Theme Distributions Pre and Post Intervention

Table 1 On-call: Individual Mean Scores Pre and Post Intervention

Case		Fear	Com.	Loss	Resent	T/O	Total
1	Before Intervention	13	8	11	13	8	53
	After	10	9	10	9	12	51
2	Before Intervention	11	7	10	11	9	48
	After	5	4	8	5	5	27
3	Before Intervention	13	12	13	12	10	60
	After	10	10	10	10	10	50
4	Before Intervention	19	17	17	18	17	87
	After	12	12	14	14	9	61
5	Before Intervention	14	12	11	12	10	59
	After	14	7	5	16	14	56
6	Before Intervention	16	13	14	16	14	73
	After	11	12	12	12	11	58
7	Before Intervention	15	15	14	14	10	68
	After	12	12	14	14	9	61

A Biographical Narrative of Case Studies

It is important to note, that while carers were on the telephone, they were not completely isolated from the care environment, in order to achieve maximum affect the on-call intervention was tailored each individual situation. While the on-call pilot achieved a reduction in emotional burden in all the carers involved, there were financial issues to address. While costly in the short term, savings over time may have a distinct advantage for society long-term. In order to provide a more compact overview of the care situation case biographies are condensed. All names and identities are fictitious.

Mrs Q

'Recently bereaved' is how Mrs Q feels over her reluctant decision to admit her husband to residential care, finally unable to cope with her husband's persistent shadowing that was 'suffocating' her. This decision had followed a decline in health; she was emotionally and physically exhausted. Overwhelmed and with little support, Mrs Q remembers feeling torn between continuing her husband's care and putting him into residency, and had delayed the decision for almost a year. Following his wife's hospitalisation, situations took a turn for the worse and Mr Q went into residential care. On her return from hospital, she fainted confessing she could no longer continue with homecare. Mrs Q's decision shocked the family but was long overdue, she loved her husband dearly but his constant shadowing had eventually become too much. Mrs Q said she felt driven to insanity, realising that hospitalisation was her only chance of escaping her husband's incessant persecution she had allowed him to be admitted into residential care. While Mrs Q had understood her husband's attachment behaviour, it had not made it any easier to manage, she remembers feeling an array of emotions, relief for reprieve, but guilt and regret over her decision to let go. Mrs Q had a loving respect for her husband, and saw the call-line as her opportunity for release, detailing visits to the care home as her way of releasing guilt. Mr Q constantly told her how 'pleased he was to see her' and 'how much he adored and loved her', which made this increasingly difficult, *'Every time I visit he sits there, arms out stretched saying 'oh there you are darling, I do love you'*. Mrs Q realised he had been unaware that she had been away. Facilitation helped Mrs Q accept that she was the only thing that remained constant in his life and effort was concentrated on her needs, developing her strengths and maximising the quality of her time in between visits. Eventually, Mrs Q accepted that visiting less frequently did not affect how pleased her husband was to see her and felt confident that visiting every three days would suffice, long hours spent at the care home had become detrimental to her health. Following a fall, Mr Q refused to get out of bed, which found Mrs Q questioning her decision, new objectives were set around what was achievable. During facilitation, rewards were discussed and Mrs Q began taking time out for herself,

having lunch with her daughter and shopping with a friend, all signs of self-recognition and identity (Kitwood, 1997). While it was important to guide Mrs Q in decisions that would enable her rest, it was equally important these decisions came from her. Forgiveness played a big role in helping Mrs Q accept her situation, releasing guilt and acknowledging the support she needed for herself, '*Oh I shall miss these calls, our little chats, I don't know what I shall do without your friendly voice at the other end of the line...*' Mrs Q's case reflects the views of Boaz and Muller (1991) who argued that the emotional burdens and limitations on daily life influence the decision to stop care, where the lack of timeout had been a key contributor. This is be further complicated by anxiety and guilt derived from a deep-seated commitment to the dependent and fear of being judged by the family (Lundstrom, Saveman, Eisemann, & Astrom, 2007). Chenoweth and Kilstoff's (1998) ideas on rebuilding relations through communication had come too late for this carer.

Mr F

Mr F describes himself as '*a square peg in a round hole*' unwilling to change his ideas, this attitude spilled over into his role as carer for his wife. Mr F was chair of the local dementia support group and from the first call, conversation revolved around the next project on dementia. The truth was that, unable to resolve his wife's problem, Mr F felt devalued as a provider, instead of expressing how he felt; he misplaced these emotions on those around him, trying to solve the challenges of dementia for everyone else. Mr F gained assurance of his identity through role definition; every thought was devoted to how he could improve care. At 84 years old, Mr F had ensured his wife stayed interested in life with day-care attended twice weekly; during which, he would attend multiple dementia meetings. Diagnosed with Alzheimer's, Mrs F had been declining for eight years and was now in the final stage with double-incontinence. Mr F was doing too much and his health had started to deteriorate alongside that of his wife's. Each call was a rendition of the last, with Mr F discussing everything but his own needs, he eventually confessed that dementia was a mask for his emotions and something needed to change, the call intervention it seemed, had arrived at a time of crisis. Mr F had grown

increasingly frustrated with his wife's refusal to eat anything but puddings and negative regard to toileting. Early calls focused on Mr F's refusal to take time off from dementia. In allowing him to make decisions, he began to accept that he could adapt his lifestyle to accommodate support giving him space for himself. Mr F decided to employ a domestic so he could spend time in the garden, when he collapsed with a stroke and the pilot was suspended. Mr F was hospitalised and later transferred to a convalescent home, residential care was the only option for his wife from which she never returned. One warning too many, Mr F took sought advice and Mrs F remained in care. During this period, the call-line was invaluable, Mr F was insistent on finishing the trial, needing the emotional support. At first, full of guilt and denial, Mr F would talk of taking a few days off then collecting his wife from care, in reality; he knew this would not happen. Sensitive not to distress him, but mindful of the issues to be addressed, facilitation combined reflection with sensible goals for the future. The facilitator encouraged a realistic understanding of what had led to recent events, as it was important he regained his confidence and integrity. Mr F had good intentions, but admitted he had repressed feelings about his wife by focusing on others. A period of recovery Mr F accepted his wife was now in care and began to view things from a new prospective. More accommodating to change, Mr F spoke of how he had been feeling in the weeks leading up to his stroke, then promptly retired from his role as Chairman of the dementia support group. Mr F had denied his long-term resentment by throwing himself into others problems and avoiding timeout. In doing so, he had mimicked the investigative research of Schofield, Murphy, Herrman, and Bloch (1998) that had identified long-term resentment and diminished life-satisfaction as a liability to institutional care, which was exactly what had happened.

Mr H

By his own admission, Mr H was largely misunderstood; he agreed this was partly because of his abrasive, self-protective manner, which he admitted, had regularly caused offence. An only child of a submissive mother and abusive father, Mr H vowed '*never to follow my father's footsteps*'. Instead, he had engaged in the long-term care of his friend

who had fallen into deep depression following his wife's death, later diagnosed as dementia. Single with no family, Mr H moved in with his friend to become his full-time carer. At the start this arrangement had worked well, both had similar interests and enjoyed times together, but over time the dementia worsened, other symptoms developed and his friend became incontinent with an inoperable hernia. On the first call Mr H admitted to feeling at his lowest, on the verge of placing his friend in care, what stopped him was a promise made to his friend's deceased wife that he would care for her husband until he died. Calls focused on helping Mr H recognise his current situation and adjust to a lifestyle change. Nonetheless, finding a level of communication that suited Mr H was difficult as he would swing from remorse to resentment, desperate to rekindle the relationship with his friend and equally distracted on finding someone to blame. Mr H felt he had lost everything that mattered, and directed his grief toward his friend, he in turn, became increasingly difficult to handle messing beds and chairs which always ended in rows. Mr H described his friend as defiant, refusing food unless it was soup or ice cream, worsened by his inability to swallow. In addition, Mr H was encountering problems of his own, in remission from cancer he developed diabetes and blamed God for giving him too much to deal with. Facilitation took the role of recognition, praising achievements and exploring ways Mr H could adapt his care style now situations had changed. Mr H enjoyed praise, which became a valuable tool in developing a new approach to managing challenging behaviour. Time was devoted to helping Mr H understand the progression of dementia, that now in the final stage, his friend may not be around forever making time spent together more important. Motivated, Mr H entered a more constructive phase, concentrated on making his friend's life more comfortable and saving time and unnecessary arguments. Planned menus' took into account swallowing difficulties avoiding the annoyance of discarded meals. Facilitation gave Mr H the support he needed while allowing him to express his resentment during a destructive time, by the last call Mr H had day-care support and had started experiencing 'timeout'. This situation reflects the view of Bryden who identified multiple losses on a continued were the hardest to accept, but that corrective interventions could reduce susceptibility to burnout. This is exactly what happened with Mr H, without support, loss might have

emerged as resentment or denial (Martin-Cook, Remakel, Svetlik, Hymn & Weiner (2003).

Mr D

Mr D was a gentle, placid man with a wicked sense of humour, very receptive and open to suggestion, who described his wife as, *'the centre of my life'*. Diagnosed with mild dementia in 1999, Mrs D had been gradually declining over a period of eight years. Early calls involved a lot of reminiscence, Mr D spoke regularly of days together filled with memories and humorous tales, he loved to talk about the allotment they tended where Mrs D would potter with her shrubs, and he would nurture his miniature trees. At his happiest when rekindling the past, he spoke only about his wife.

'Since my wife's diagnosis, I have never had a moments thought other than that I would take care of her for the rest of her life'.

As time went by, Mr D began to sharing his feelings blurred by the onset of dementia, he often admitted that caring for his wife was her reward for caring for him, joking that the roles had simply reversed. As Mr D became comfortable with the facilitator, conversations grew deeper and he began to reveal the reality of the situation. On the surface, everything was fine but reality always seemed to bubble just below the surface. Mr D never revealed his own feelings on the situation that had befallen him, masking his emotions with humour. Nonetheless, a good rapport developed and Mr D became more receptive never once ending a call, he would talk until the facilitator bought closure. Mr D was encouraged to design a care plan that would allow timeout from the care role, something he had thought he did not need. In an on-call setting this was ideal, the facilitator offered resources and Mr D put them into practise. By the second week Mrs D had care support Mr D had peace of mind should the need arise, and it did, three days later. Quite unexpectedly, Mrs D took a tumble while Mr D was out, with care in place; Mrs D was cared for until her husband's return. Understanding the seriousness of a situation often clarifies its importance, during the follow-up call Mr D admitted how

much it had upset him, he now understood the importance of accepting outside support, recalling the time had rebutted the idea he expressed appreciation for the facilitated guidance. Mr D's gratitude was immediately reflected back, it was important he feel in control, accepting things would get harder helped him understand there may be a time when he must continue alone. Taking timeout now would place him in a stronger position in the future. Mr D had a fear of letting go, where according to Lundstrom, Saveman, Eisemann & Astrom (2007) cognitive impairment, memory loss, and physical degeneration can affect the carer in many different ways. In Mr D's case, grief, loss and anxiety are all signs that he may not have been coping, burdened by constant pressure he felt overwhelmed by his situation and unable to detach current affairs, from ongoing issues. According to Gillespie (2005), this can lead to unproductive problem solving. O'Connell, Bailey & Walker (2003) suggest that emotional release may encourage the carer to view the care role from more positive perspective and that is exactly what Mr H did, while previously unthinkable, taking timeout by accepting support and had potentially saved a life.

Mrs K

Mrs K had been a carer all her life, in her occupation as counsellor and Samaritan and as full-time carer for her husband with dementia. Mrs K had a large family who constantly lent on her for support. Mrs K was 'everybody's carer' with little time for herself. In 2007, this situation reached crisis, Mr K had declined to stay at day-care and was increasingly violent around the home. Following a further diagnosis of cancer, Mrs K had no option but to transfer his care to a hospice where after a few weeks he died. Vivacious and fun loving, with no time for self-pity, Mrs K threw herself into family life entering a deep phase of denial. Filling her life was Mrs K's way of coping with bereavement, with no time for self-indulgence she repressed her emotions and suffered a stroke just days before the on-call intervention. To her credit, the moment she returned home, Mrs K called the facilitator determined to partake in the research, needing to talk with someone outside her immediate family.

Calls began low key, focused on breaking down the barriers she had built to contain her grief. Mrs K admitted feeling inconsolable about her husband's passing in a hospice. Despite thinking this was what she wanted, she now felt differently. Racked with guilt, she admitted going to her family to keep busy and feel she was 'needed'. This situation had backfired, and Mrs K felt her family had taken her help for granted. Taking all the help on offer, they had wrongly assumed she was fine and heaped their own problems on her. Unable to say no Mrs K had tried to accommodate everyone eventually suffering a stroke. Facilitated calls allowed Mrs K to relive these moments, and she realised she had been doing too much. During calls, she described her family as, *'Putting on me' and giving me their troubles'*. However, she also spoke about guilt, *'I feel so guilty if I do not help them'*. It seemed to help Mrs K to put her emotions into words, and she admitted she had been partly to blame, *'Looking back, I think I may have asked for it'*. Calls were devoted to exploring different ways that Mrs K could learn to say 'no' without appearing uncaring, listening to others' difficulties, but remaining emotionally detached. While Mrs K found this difficult, she began to recognise her children were adults and needed to find their own way in the world. Calls explored ways that Mrs K could care for her family from a comfortable distance, signposting her family to available resources instead of providing it for them.

Mrs K began to understand the role stress was playing in her life, that she had been denying her grief and running from herself, scared that if she let her emotions out, she might never be able to stop. Laughter seemed to help Mrs K accept her husband's death and start to focus on herself; by the end of the pilot, she had resumed her pre-stroke interests, taking pleasure in reporting her achievements. A asked how she felt she replied, *'oh... do you know, its so nice to talk to someone outside of the immediate family who is genuinely interested in me, your make me feel important, I really feel they are doing me some good'*. Mrs K had been in denial, exaggerated by the loss of her husband and a sense of helplessness, which according to Wright, Hickey, Buckwalter, Hendrix, and Kelechi (1999) consumes emotion quicker than it, can be replenished. A good example of failure in understanding the carer's loss.

Mrs R

Recently bereaved, Mrs R lost her husband three months before the start of the pilot, following a fall and brake to his leg, although he was hospitalised, he had slowly declined until the end. Prior to his death Mr R was diagnosed with dementia. Unprepared for his sudden passing Mrs R was finding it hard to come to terms with. Mrs R was habitually cathartic; her obsession for activity had increased following her husband's diagnosis where she felt unable to spend long periods in the home. It is hard to say whether this was a reaction to the illness, or avoidance in accepting it. However, following Mr R's death, the situation reversed, disorientated, her husband death had been harder to accept than Mrs R had thought and all activity became silent.

During calls, Mrs R described returning to the empty house after the funeral unable to cope with the silence. Facilitation took on a yoyo effect; Mrs R would slip in and out of grief, using cathartic speech patterns in a flurry of nonsensical narrative. The facilitator's role was to mediate the conversation while knowing when to move things forward and when to back off, empathising with loss and encouraging expression. Mrs R would often resort to avoidance tactics when emotions ran too deep; listing the tasks, she still had to do. Of course, the reality was that Mrs R was not *doing* anything, having 'to do lists' gave her focus for not doing it, and a mask for her denial, she refrained from activities that once were important, with the excuse she had '*too much to do*', avoiding her friends meant avoiding her feelings.

Mrs R had also started to reminisce about her earlier life in Africa, deciding to use this as a base, the facilitator started with the early years and moved forward toward the present and slowly Mrs R began sharing. At times Mrs R would retreat, consciously changing the subject, but progress was steady and encouraging. Each expression about her husband was praised which seemed to further her progress by keeping her focused. The loss of her husband had left a void in Mrs R's life, the on-call intervention had filled it, voicing her achievements was her way of seeking approval. Mrs R often called the facilitator before her allocated time, '*Oh I thought I'd just check in case I missed you...*'

While not necessarily a bad thing, it was important Mrs R did not become reliant. Mills (1997) suggests that exploring new ways of coping helps the carer move away from old patterns of behaviour, where an appreciation of how they *feel* they are coping is a measure of their willingness to accept repressed emotion. This was the case for Mrs R as gradually her approach changed, speech grew calmer, family took on new significance, and she began making plans for the future. Ironically, facing her past had helped Mrs R cope with the present; the loss of her husband had affected Mrs R more than she had imagined, exaggerating a need for social interaction. Brodaty & Green (1996) had claimed that extroverts crave social activity without which, resentment builds up and communication breaks down. Penson, Dignan, Canellos, Picard, & Lynch, suggest that support and communication are effective coping skills, both received during on-call facilitation, which had a profound effect on Mrs R's recovery (Sorrell, 2005).

Mrs P

On first impressions, Mrs P appeared confident and well-adjusted, losing her husband to dementia she came across as self-sufficient, but impressions can be deceiving. From the beginning, Mrs P talked only of plans, specifically a visit to India with her grand daughter; she never once spoke about her past. Despite her disposition there was an insidious side to her story, she had never come to terms with how her husband died, let alone contemplate showing any emotion, the facilitator's role was to encourage disclosure. When asked about her husband, Mrs P would give quite a performance, as if his presence meant nothing in her life, after many hours of 'humourous' tête-à-têtes, she began to present a rather different account. She admitted she had always bottled her emotions, feeling her opinion counted for nothing.

What followed was a fascinating documentary of her fight and determination to hold her head high. As Mrs P began to appreciate that calls were for her, she began to open up. Mrs P admitted she had never shared a close relationship even with family, a hospital Matron she had learned to fend for herself. Protectively cynical of emotion, Mrs P revealed snippets of her past before guardedly changing the subject, especially a trip to

India that she had planned for years with her husband. Following his death, she had decided impulsively to go with her granddaughter, although she did confess to feeling apprehensive about travelling. She had purchased her suitcase, but it remained unpacked, almost symbolic she could still change her mind. Calls would start with detailed narrative about her day, but as trust developed, she began to speak frankly about her insecurities, suddenly changing direction when deeper issues surfaced, deflecting the conversation to more generalised subjects. What surfaced was her need to stay 'strong' to remain controlled in a crisis. Sharing emotion was alien to Mrs P when a nerve was exposed she would recoil, using avoidance tactics to regain composure. Reactive behaviour was the norm, immediately camouflaged with, oh, did I tell you about the time...'. Unperturbed, the facilitator persevered, encouraging Mrs P to share these emotions in way that was symbolic to her. The suitcase appeared to be a big issue, one raised repeatedly during calls, with reference to the fact that she still had not packed. It seemed that 'packing' reminded her she was travelling without her husband, forcing her to admit he was gone. While the case sat empty she could avoid confrontation, the one thing that may bring closure on the past.

Mrs P became an expert at deflection, frequently off on a tangent; the facilitator was proficient at reflecting things back. Thus, she began to progress, speak openly about her husband, their life together and his gradual decline with dementia. Mrs P explained how her husband was booked into respite while she was to visit a friend, barely starting her journey, she was called to find that her husband was hospitalised, Angry and resentful, she recollected advice; her husband was doing fine. Mrs P had arrived to find his family-saying goodbye, *'I expected to find him sitting up in bed... I even stopped on the way to the hospital to collect his false teeth'*. Unable to share the memories of that day she had buried her emotions inside, until now having no one she wanted to share with, she had put a lid on her emotions. Releasing these feelings was the turning point for Mrs P, she was able to move forward and finally packed her case, on the final call she vowed to become *'an independent traveller'*!

Results

While an overview tells a story, there was a great deal of repressed emotion in each, documenting speech and highlighting features enabled the facilitator to depict reoccurring patterns. Carers seemed to find it easier to express emotion on the telephone without face-to-face confrontation. Carers had particular patterns of speech they would use during calls, *'Oh I am at my wits end', or 'I got so cross now I feel guilty'*. Many carers wanted advice on what they should do, particularly around issues of care, however the role of the facilitator was to reflect questions back so they could express their emotions and explore the solutions themselves, the first stage toward implementing change (Please see table 2)

Table 2 Key Themes from the On-Call Intervention

Carer	Emotional Theme	Example of Narrative Text
Mrs Q	Timeout	<i>'I just need some space some time on my own'</i>
	Communication	<i>'Do you know what I want...some 'normal' conversation...'</i>
Mr F	Resentment	<i>'I admit I am resentful, I watch as she just pushes food around the plate for an hour...'</i> <i>'I get anxious at times about what others may think...'</i>
	Timeout	<i>'I admit, I don't do anything for me, I don't know how to, my life revolves around dementia, I know I need to take time for me'</i>

Mr H	Resentment	<i>'Yes...yes I am very resentful, sometimes I think he does it on purpose,... you know just to annoy me...'</i>
	Loss	<i>' I miss him, I feel like I have lost by best friend and my whole life which I have devoted to his care ... and sometimes I think ... was it all worth it..?'</i>
Mr D	Timeout	<i>'I do need to do something else ... I know that, but she is my life, she is all I live for...'</i>
	Fear	<i>' Yes I am scared of life without her, at least she is still here, I just want to take care of her while I can, I don't know how I will go on without her, she is my life...'</i>
Mrs K	Fear	<i>'I get anxious, I feel so alone ... I feel that no one needs me anymore'</i>
	Loss	<i>" I admit that I don't know how to cope without X being ... well just 'there'"</i>
Mrs R	Loss	<i>'Oh Gosh, he was always so intelligent... now... well he is a shadow of the man I knew and loved, well now I feel that, well... he is just there....'</i>
	Communication	<i>'All communication is gone now and well... I have never told my children how I feel... you</i>

		<i>know... well they have their own lives... they don't want to listen to me going on... that's why I try to keep busy...'</i>
Mrs P	Resentment	<i>'Yes I do feel angry and resentful, too right! and I can never forgive the hospital for letting me believe he was doing 'fine'</i>
	Communications	<i>'I feel I have to fend for myself, put on a show, I have never been good at showing emotion, there was no one I could talk to...'</i>

Discussion: On-call Pilot Study

Based on Patterson and Grant's view (2003) that emotional changes that accompany the care role need to be addressed if the carer is to adjust to dementia, the call pilot was centred on understanding the mixed emotions that accompany the challenges of dementia care. The aim of this intervention was to facilitate the release of repressed emotion resulting from the caregiving role while guiding the carer through a process of self-directed change. Fortinsky, Kercher & Burant, (2002) had already identified that carers were interested in learning how to manage dementia effectively with good communication skills and intervention strategies as an alternative to drugs, where the anonymity of calls had encouraged some profound revelations. Calls had provided some much-needed timeout as well as creating space for open disclosure, reducing levels of burden in all carers, and supporting Depp, Sorocco, Kasl-Godley, Thompson, Yaron, Rabinowitz and Gallagher-Thompson (2005) beliefs, that managing situations rather than reacting to them, helps impart a course of action that assists in the management of a given situation. These carers had had spoken openly about their lives, using the call time for reflection.

In this research, the confidential nature of calls certainly encouraged the building of trust without the anxiety of face-to-face confrontation, while the absence of body language

could be was a weakness, audio perception, verbal silences, and grammatical punctuation became key skills in the recognition of emotional repression. Important emphasis was on the role of the facilitator, whose responsibility was to reduce apprehension and maximise the release of emotional through sharing. With no visual contact, it was essential to demonstrate empathic understanding of the complexities involved in dementia care as well as allowing each carer the wisdom to develop their own ideas. An integral aspect of the call intervention was empowerment allowing carers a choice in what they released. Facilitated discussion helped identify solutions by reflecting over past challenges and developing strategies for change. This reflected on the works of Chenoweth & Kilstoff (1998) who examined the rebuilding of damaged relationships through communication and support using the model of facilitated mediation following an increase in burdened relationships. Calls were optimistic with carers keen to learn and develop a new understanding of their role, either as carer or as the recently bereaved.

Many carers spoke of loss, either of the person or of their own identity. Evidence suggests that practitioners overlook loss fixating on the dependent and their diminished quality of life (Mills, 1997) and by family who fail to understand how loss affects the carer (Groot & Vernooij-Dassen, 2005). According to Foleya, Tung & Mutran (2002) feelings of loss can be anticipatory, including loss of 'self', understanding these emotions being essential to their release. Kitwood (1997) insisted, the preservation of self-identity was dependent on understanding, internally as well as externally and involved perseverance. While all the carers expressed a need for change, it was finding the means that was more complex.

The Facilitated Emotional Expression Group Pilot

Introduction

The second pilot intervention incorporated in six facilitated emotional expression groups, conducted on a weekly basis with 14 volunteer carers. Activity-based, sessions diversified from the usual meeting-type format, which often lack the emotional support that prepares the carer for dementia (Haley, Brown & Levine, 1987). Despite the best of

intention, support groups vary enormously due to the diversity of volunteers, time available to commit and availability of funds. As a rule, support groups provide a meeting place for carers to gain information offering advice on a range of different topics, but few include deep emotional support. In comparison, the facilitated emotional expression group intervention would provide six-week support focused on the release of repressed emotion through humour fun and activity.

Aim:

To manage unresolved emotional issues by pioneering psychological theories focused on developing the acceptance of dementia as an *illness* while reducing resentment experienced through lack of reciprocal behaviour, thus facilitating adaptation to the care role.

Key Aspects:

Focus on shared 'fun' activities and communication. Exploring a more functional lifestyle focused on reminiscence and reflection.

Rationale:

The rationale for the facilitated emotional expression group was to provide 'real' timeout for the carers, away from the dementia situation, while facilitating emotional expression through reminiscence, humour, and catharsis.

To challenge the support of existing services with a more creative alternative (Pusey & Richards, 2001) targeted toward the reduction of burden that precipitates caregiver burnout in dementia.

Ethics

Carers were informed of the aims and objective of the study, with full disclosure of all aspects that might affect their willingness to participate. No form of deception was involved. Carers were informed the researcher would assume a participatory role as their group facilitator. Interventional activities were trialled by the research team prior to their

inclusion and evaluated for safety. No carer was at risk. All carers were conversant on their rights of withdraw with no carer coerced to partake against their will. Carers were informed, all information was strictly confidential; should they wish to withdraw participation, any data by which they may be personally identified would be destroyed. Prior to the study, all the carers were in good health and had signed consent forms, including anonymous inclusion in the event of publication. Consent was given by the University of Southampton Ethics Committee, with guidelines adhered to at all times. All of the carers were thanked and debriefed following an informal discussion in relation to their research experience. Further support was available on request

Materials

To facilitate each group session, various materials were essential to the efficient running of the session and included items such as, projector screen, flip chart, name badges, mini-bus hire, hall hire, tools for activities, refreshments, Dictaphone, etc. Most materials were either negotiated at minimum cost, or donated freely to minimise cost to budget, ensuring the study was replicable in other locations.

Location, Design and Equipment

The venue for the six facilitated emotional expression group sessions formed part of a Sheltered Accommodation, complex located on the outskirts of Southampton. The location of the hall was ideal in relation to transport needs and was large enough to accommodate a group. All of the carers lived close to the venue ensuring good accessibility and maximum attendance. The Lions Club Charity loaned a Minibus to transport the carers during a 'timeout' session, while the University of Southampton provided tools used for emotional intervention. The layout consisted of a large table on the far side of the room in preparation for the initial icebreaker, a shared lunch. Tables were located around the room ready for the paired activities, including a large semi-circle at the far end, used for group work (see figure 2).

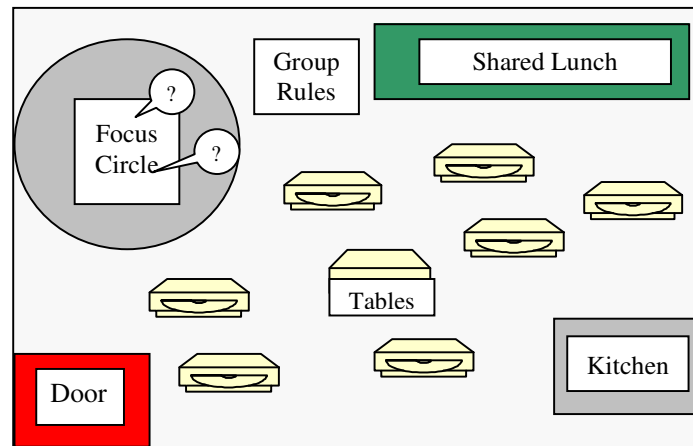


Figure 2 Layout of Green Fields Hall during Group Sessions

The Participants

On the 14th September 2007 and following ethical approval from the University of Southampton, 16 dementia carers, volunteers from a local dementia support centre in Southampton, were invited to attend an informal meeting with the researcher, six weeks prior to the commencement of the study. All attended and were each thanked for their time and commitment. The aim of the meeting was to generate enthusiasm for the research and to explain what it hoped to achieve. The researcher explained the aims of the intervention, outlining what constituted each session and the role of facilitated mediation. It was important carers understood what was expected, as well as the benefits they may gain. The, followed by a more informal discussion of the venue, location, attendance availability, and session times. All felt that Friday, 11.30-2 pm would be the most appropriate allowing lunch to become a shared experience, with carers being responsible for their own contribution. Despite the well-being of the carer being synonymous with the care delivered, carers were genuinely surprised that focus was on their needs, with 14 signing up for the pilot. Carers were aged between 70 and 82 years, and included 3 males and 11 females. Two of the carers had been recently bereaved, while the remaining 12 were providing full-time care for a person with dementia in their home.



Session One: The Participants¹

The Structure of the Emotional Expression Sessions

Facilitated sessions were activity-based designed to be productive in the release of emotional burden thought to precipitate burnout the following tables provide an overview of how each session was structured (table 2 and 3)

Table 2 The Emotional Expression Group: Session Format

11.30	Tea and welcome
11.40	Group Interaction/ 'shared lunch'
11.50	Briefing on sessions group focus
12.00	Commencement of first session
12.45	Tea break
13.00	Introduction of session circle
13.45	Break for prizes and raffle
13.55	Group thank and hug session

¹ The use of all photographic material was consensual

Table 3 The Emotional Expression Group: Weekly Format

Week 1 Key:	Group presentation, aims, goals, group rules, introduction to circle work Group interaction and communication cheese and wine competition
Week 2 Key:	Personal interaction: introduction to fear circle and Bishops Waltham quiz Confronting denial and the emotional release of fear
Week 3 Key:	Personal and group interaction: introduction to the loss hat /disorientation Confronting loss: promoting a deeper understanding of dementia
Week 4 Key:	Day trip: ten pin bowling introducing cathartic activity through exercise Introducing timeout
Week 5 Key:	Social interaction: the reminiscence circle and team sports Exploring resentment, solving unresolved issues through reminiscence
Week 6 Key:	Focus on release: fancy dress, farewell circle and party games Emotional release through humour and cathartic activity

Group Rules

Group rules included an element of humour so as not to make the occasion seem too formal, while highlighting the importance of health and safety. It was important that the group built a good rapport with each other, but equally important that they respect each other's views and opinions in order to establish and maintain their identity (See table 4).

Table 4 Group Rules

-
1. Confidentiality and Anonymity at all time
 2. Don't interrupt each other, let others finish what they are saying
 3. No intimidation, sayings things calmly gets you heard
 4. Be kind. Do not attack others or use defamatory language.
 5. Use caution when discussing distressing topics

6. Do not argue with each other, you are all important with valid opinions
 7. Do not speak over each other
 8. Anything you wish to discuss privately can be done at the end of each session
 9. Health, fire and safety
 10. Learning, activity, and Fun
-

Method

Carers were posted information packs explaining the aims of the research, prior to the start of the study, including two copies of the revised 10-item survey. Carers were to complete one survey at the start of the study, and one on completion. Both surveys were to be returned, in the pre-dated and addressed, post-paid, envelopes provided, as an indication of their progress, and to monitor the effects of facilitated mediation. Due to session limitations, the first was introductory, focused on building communication and enabling maximum progress in minimum time. The pilot began positively with fourteen carers in attendance. On arrival at the first session, each carer was presented with a name badge and personal notebook in which they could record information that was more personal.

Group One: The Introductory Session

During the first session, the carers were understandably hesitant tending to stay with those they recognised or those they had previously spoken with. This apprehension seemed natural, as most of the carers had been restricted to their home environment with little means of companionship. The facilitator took measures to ensure the first session was one of friendly interaction, encouraging the carers to interact and get to know each other over a shared buffet-style lunch.



Buffet Style Shared Lunch

Following lunch, the session began with an explanation of the group rules followed by a preparatory session, with carers asked to move around the room introducing themselves to one another. The researcher and two assistants partook in this exercise, introducing themselves to the carers before gathering them for a presentation on intervention, and the role of facilitated mediation. While explaining the structure of the six group sessions, the researcher remained vigilant in not revealing the actual agenda. All of the carers showed genuine interest in the project and seemed enthusiastic about being involved. The presentation concluded with a question and answers session followed by a tea break in preparation for the activity session. Designed to build on interactive communication and encourage working as a team, the facilitator had designed a cheese and wine competition.

Activity Session

The facilitator divided the main group into two teams and selected team leaders, who chose members to represent their team. Selecting team leaders was an important part of each session, and although initially the role of the facilitator, it was allocated to the carers by week three to encourage a sense of control. Teams were directed toward two tables at either end of the room containing a selection of unlabelled cheese and wine. The idea was to guide each team in a tasting session, competing against each other for points. Intended to be a bonding task, things unexpectedly gathered momentum, the carers began

laughing and reminiscing about their past, sharing stories about their dependents when they had tasted this wine or that, and giggling as they tried to recall which country they had been visiting.

Without prompting, the carers were already experiencing the use of laughter in releasing shared emotion; they were enjoying companionship and some long-awaited timeout. As the facilitator withdrew into the background, it had quickly become clear that having fun in a facilitated environment, outside of the care role was something that was going to work. With each carer insisting they were 'right' because, they had tasted this wine while holidaying in the South of France... or 'shopping in Peru'. However unintentionally, this exercise had triggered a session of nostalgic emotional release.

Cheese and Wine Competition



Ending the Session

With team scores announced, the losing team shared a large pack of kitchen scourers, and the winners, a box of chocolates, where shrieks of laughter accompanied the more 'humourous' gifts. For the closing task, the facilitator gathered the carers at the end of the room, asking them to form a circle while joining hands. Interestingly, this request seemed to surprise the carers, who showed disbelief at what they were being asked to do, '*Oh, I am not doing that; I will sit this one out*'.



'Oh, I'm not doing that...I think I'll sit this one out'

During these moments, facilitated mediation proved invaluable, as the facilitator drew the carers into the circle, encouraging them to hold hands. Carers were invited to thank the person on their left for their contribution to the session and asking their permission for a hug, then to repeat this with the person on their right. Leading by example, the facilitator demonstrated this task with the assistants. Quite surprisingly, the carers followed suit, thanking the carer next to them for their contribution to the group. As carers became aware of the purpose of the exercise, a group hug followed, any anxieties masked by laughter. It seemed as if the carers had been waiting a long time for such shared compassion. The session ended with a dance-out of the venue to the sixties melody 'March of the Mods'. With no hesitation, the carers formed a line and quick-stepped out of the room. For a first encounter, the facilitated approach had worked well in encouraging the release of emotion.

Group Two: Exploring the Release of Fear

At the next group session the carers arrived impeccably on time and dressed immaculately, This is motioned, not only because of the marked difference in how carers greeted each other, embracing as if they had known each other for years, but for the noticeable change in dress code. The first session had seen carers arrive 'smart' but casual, in modern slacks and sweaters. The second group arrived in their 'Sunday best'

suited and booted as if going to church, as one carer described, '*this is our ONE day out...*' Another surprise was that carers had already begun sharing contacts, arriving at the venue in pre-booked taxis. As if on cue, a power failure just as carers arrived, cut power to the venue, resulting in changes to the schedule, with no music for the first activity, improvisation was required. With all inhibition abandoned, carers were asked to form couples, either with someone born in the same year or with someone who had the same shoe size. Collecting their lunches from the buffet, they sat down in couples to share stories with their new companion. The aim of this exercise was to facilitate communication between more diverse couples, encouraging shared emotion with someone unknown. Following lunch, carers were allocated five minutes to share their greatest fear, with a further five minutes to explore the solution. The process was repeated, but with different partners and a different theme, this time carers were to share their happiest memory of their dependent.

Carers seemed to enjoy sharing their stories, showing empathy for each other's dilemma, and releasing some deep-seated anxiety with someone who understood. Having the confidence to release personal fear can be very empowering and can often boost self-esteem. Nonetheless, attention is drawn to the order of events, where carers were asked to release painful emotion first, counteracted by positive memories, returning the carers to a comfortable place. This was the structure throughout the emotional expression intervention, deeper sessions followed by fun always closing on a 'high'.

Listening To Each Other



'Really, do you think so...I might try that'

The Fear Circle

Relaxed from a tea break, carers joined the fear circle at the end of the room, where they were provided stationary, asked to document their greatest fear and to place it into a hat labelled 'FEAR'. An exercise in emotional release, the facilitator took each fear from the hat and it was discussed as a group, when a carer recognised a fear as their own, they had a choice, to take ownership themselves or to remain anonymous allowing the facilitator to take the lead. As the carers began to explore solutions on how to manage each fear, the facilitator withdrew into the background, it was important that mediation was only used when necessary.

Increasing autonomy was an integral element of the group sessions, building confidence during the release of emotion by encouraging the carers to resolve fearful issues by sharing the experience with others. The fear circle was intense for a second session, but with facilitated support, it had produced the required affect. It was noted, that carers interacted better in a circle than in the more formal meeting-based format.



The Fear Hat

The Bishops Waltham Quiz

With power restored the session continued with a quiz, the researcher had composed twenty-questions based on the historical past of the carers' hometown. Divided into teams, carers had ten minutes to read and retain as much information as possible from fact sheets prepared by the facilitator. In dementia, it is often easier for the dependent to recall things from the past than to recall events short-term. The aim of this task was to impart a better understanding of what it must feel like to forget. The team leaders were each given a 'squeaky mascot' and told they must, 'squeak before you speak'. The first team to 'squeak' could answer the question. Laughter resonated, as each carer tried desperately to remember what they had read, and how easy it is to forget, even without dementia. Structured around the person-centred approach (Rogers, 1999), the facilitator had placed emphasis on camaraderie where meeting others with similar responsibilities seemed to enhance a more positive attitude.

Becoming Part of a Team

Session two ended in the same manor as the first, a fun raffle, group hug and a dance off to March of the Mods. This time the mood was different, knowing what was expected, the carers seem to feel more comfortable, affirming themselves as a team they no longer required facilitator guidance. Those whom were hesitant in the previous session were beginning to find their way, positively empowered, they had discovered they could still be carers as well as having laughter-filled fun.

Becoming Part of a Team



Group Three: Understanding Loss

The third session was low in numbers, with four carers unwell, and one carer suffering a stroke, very unfortunate for the well-being of the carer, but particularly sad as this carer had been so enthusiastic about realising a personal ambition, which was to talk about his resentful emotions. Excelling at the previous session, this carer vowed to return to the group when able, and they did! Despite low attendance and concern for those who were missing, the smaller team seemed to take on more responsibility, hugging each other on arrival and sharing their feelings over lunch. This group definitely had a more intimate feel, almost as if there was strength in small numbers, a deeper connection. It had been noticeable that while choosing lunch, many carers were linked arm-in-arm and what began as a moment of despair became one of the most enlightening.

Following lunch, the tables set for a game of 'speed-mating', with carers asked to sit in couples while the facilitator explained the rules. On the sound of a claxon, the carers were to exchange information, to include,

- a) Who you care for and why (background)
- b) Levels of current support
- c) Describe your current lifestyle
- d) Describe your wedding day

One of each pair would be the 'mover' the other would remain seated, at the sound of the claxon, the 'movers' must immediately go to the next available table, and begin the process again with their new partner. Carers were reminded that the facilitator would be recording conversation², identifying key issues was central to the research, and necessary for the final expression of emotion structured into session six. It was important the facilitator understand why the carers had felt unable to disclose their feelings prior to the study, why these feelings had been repressed, and how a facilitated environment had encouraged them to release and accept change.

The Loss Circle: Letting Go

Following the tea break, the carers were invited to join the 'Circle of Loss' and to document their greatest experience, placing them as before, in the newly labelled hat 'LOSS'. Next, the facilitator read each statement aloud, engaging the carers in a group discussion. Surprisingly, each carer decided to own their loss and spoke openly to the group about how it had been affecting their life. Special appreciation goes to Z who cried, but remained in control,

'I have never spoken of this before, not to anyone not even my wife I just could not, but today in this group, I need to say it. My son, my only son was 'blown to

² Dictaphone recordings were consensual.

bits' aged 22, on one of the largest war ships as it docked in Southampton. After he was buried we never had another child or spoke of him again, never, not to anyone, and not to each other, we just could not talk about it.

Today is the first time in my life that I have felt able to talk about it, that is what this group has done for me'

Always smiling, Z had always joined in all the activities but rarely spoke, noticing this early on, the facilitator had made an extra effort to include him, there was clearly a reason for this silence, but only Z could decide when to disclose it. All of the carers praised Z for his shared emotion, taken back by his sudden contribution; they knew that Z loved praise, particularly on his arrival at each session. The door would open and Z would present a large bag of goodies ready to give to the group at the shared lunch. When thanked he would glow with pride, demonstrating the value of empowerment in raising self-esteem and autonomy (Homans, 1958a). This carer's disclosure was verification of his progress, breaking a silence repressed for over 55 years. Suppressed fear can be torturous and may cause irreparable health problems over time, this had been a turning point, *and 'I feel like a great weight has been lifted from my shoulders'*. Another success was J, always bubbly she had bought a ray of sunshine to the group where, following Z's disclosure she felt ready to tell her story. Through tears J spoke of her loss, with an aggressive type of dementia, she had been unable to cope with her husband's violent outbursts, fearing for her health, she had agreed on residential care. Now the initial relief had passed she felt 'wretched' longing to bring him home. The group helped her to confront her guilt and accept the situation by encouraging her to move on. During the session the facilitator had withdrawn from the circle, the carers were facilitating themselves, taking turns to mediate conversation. With permission, they all received a gentle shoulder rub which seemed appropriate and affirmed, Evardson, Sandman and Ramussen (2003) and Kim and Buschmann's (2004) beliefs, on the healing properties of unconditional touch.

Activity Session: The Minefield'

Designed to present loss in its deepest form, the activity session focused on the loss of perception. Carers were to tackle the 'Minefield Assault Course'. During the tea break, the assistants arranged an obstacle course consisting of paper plates loaded with potato crisps. In two teams, carers were to line up at the start point then make their way up the minefield, weaving in and out of the plates without landing on a 'mine'.

On the sound of 'crunching' a panic alarm would sound and the team responsible would lose a point, the anomaly was that the participating carers would be blindfolded, inducing the loss of perception. Group members were to instruct the pace and direction, with both teams participating simultaneously. To add to the confusion, the blindfolded 'carer' had to rely on voice recognition, as well as remembering which carer's voice belonged to their team, to avoid going in the wrong direction. This task was well-received, with each carer experiencing what it must feel like to be disorientated, hearing commands they could neither understand nor co-ordinate,

'I never realised until now how awful it feels to lose something, I feel so disorientated, I think I am beginning to understand'.

'Blindfolded and Disorientated'



This intervention was an achievement for the carers who admitted, losing their sight had left them feeling vulnerable and more than a little exposed, each resolved to be more

understanding and forgiving of their dependent, and to try to and view things from the cared-for's point of view. Group three concluded with all the carers receiving a raffle prize, they had worked hard and deserved recognition for their success. As they skipped out to 'March of the Mods', one carer said, *'you have had me doing things I would never have thought I would do, not in a million years...'*

Group Four: Introducing Timeout

Session four was focused on the release of emotion through catharsis and timeout. It had become increasingly apparent that those in greatest need were the carers who appeared most reserved. What these carers did not reveal was almost more important than what they did. With this in mind, the facilitator dedicated a session to cathartic release conducted outside the 'safe' environment of the usual location, providing *real* 'timeout'. Carers were off for a fun session of Ten-Pin Bowling, where the idea was to release their emotions on the ball. As they arrived for the group and began to share the events of their week, the carers seemed to sense that something was different, and there was a general buzz of excitement as carers were heard laughing and trying to guess their fate. Meanwhile, the facilitator had organised the arrival of a mini-bus to transport them to the venue. There were squeals of laughter as the researcher announced a change of agenda and lunch rescheduled for 1.45 pm. Observing the carers grow increasingly excited over a simple change in the usual routine was interesting. Doing something out of the ordinary seemed to induce a childlike quality far-removed from the inflexible role of the 'caregiver'.

On arrival, there was a flurry of activity as the carers laughed at their bowling-booties, at that moment, the only burden being the weight of the balls! Separated into teams, the atmosphere stepped up as the carers rediscovered their youth, bowling against each other with rapturous applause, when someone scored a 'strike'. For the researcher, importance was on the emotions released regardless of the score with carers hugged and praised after every turn. Carers finally left the venue red-faced but happy, not wanting the fun to end it continued on the bus, where the melodious sound of 'Ten Green Bottles' could be heard

above the chatter. Carers arrived back just in time for their shared lunch and raffle. As homework, carers were to find a childhood photograph and bring it with them to the following session, but not to share it with other members prior to the session. A little concerning were the overheard exchanges between carers regarding the build-up to the final session '*what will we do when this ends, I look forward to this all week, where will we go?*'. The facilitator decided not to comment until the last session, where considerations included the time needed to plan and facilitate each group and the availability of facilities. Re-evaluate the situation at the end of the pilot was the more professional option.

Group Five: Reducing Resentment through Reminiscence

Focused on changing perspective, session five focused on releasing resentment through positive reminiscence and forgiveness, taking the carers back to a time when they were involved in a different kind of caring relationship; one that was reciprocated. Involving a central theory, it was essential that issues were explored sensitively, while helping carers to understand that life-changes are generally unavoidable. Based on the view that accepting transitions may make them easier to accommodate, it was the facilitators belief that remembering a time when reward outweighed the cost (Homans, 1958a), would be happier and healthier, encouraging the carers to be more forgiving now that situations had reversed. The aim was to provide the carers with the emotional strength to manage the challenges of dementia, without suppressing resentment. On arrival, the carers were to share their lunch with someone they had not shared with before. Each carer was to discuss a major challenge associated with their care role that made them feel frustrated, and/or resentful. After ten minutes, one person from each table was to move to the next, and repeat the process again with a different carer. This exercise focused on helping the carers feel comfortable communicating with others while removing them from their comfort zone. On the completion of four rotations, carers were asked to return to their original pairing and to focus on their life-story including, where they grew up, where they met their dependent, and recollections of their fondest memory. Carers were asked to avoid discussion on dementia.

Sharing Resentment



9.7.1 The Reminiscence Circle

After ten minutes of interactive conversation, the carers were invited to a viewing of the photographs they had bought to the group, which they seemed to find immensely humorous. Forming a circle for the group activity, carers were to identify the photograph presented by the facilitator. The reminiscence exercise focused on reducing inhibition, using humour to lighten the mood before confronting resentment. Carers rewarded each other with applause when they guessed correct, laughing with each other when they got it wrong, they were learning benefits of sharing.

Who Are You?



As they would be sharing their memories with the group, they were to include,

1. Where they had met their dependent
2. Their courtship/ friendship days
3. Their wedding day or special day including date, year, time of day and weather
4. How many years they had been together prior to the onset of dementia
5. How hard they had found accepting the care role

With acceptance and forgiveness a key role in the release of resentful emotion, it was the facilitator's belief that reminiscing over positive experiences shared before dementia may be a guide for releasing the resentful emotions that came after.

The familiarity of the circle would provide a safe environment for the carers to share the frustrations they had found difficult to confront on their own.

Releasing Resentment Using Reminiscence



Sharing their memories bought an air of contentment to the group, helping to breathe new energy into their relationships. More importantly, reminiscence work helped the carers to accept that dementia was an *illness*, out of acceptance came forgiveness.

A time of reflection, many spoke through tears, while others relied on humour, whatever the means the result was the release of deep-seated emotion. Facilitation was important in ensuring that each carer had the opportunity to speak, and that emotional release was rewarded with praise.

Tea Break



The Activity Session: Team Sports Day

The second part of group five was an activity designed to recapture the freedom of childhood (Butler, 1989), where carers were divided into teams and informed they were to partake in a Carer Sports Day. The course consisted of an egg and spoon race, hula-hula dancing, netball, walking along with a book on their head; a taste and smell test, ending with one minute dancing to the 'twist'. Teams competed against a stopwatch with the fastest team receiving a shared prize. To avoid risk and ensure facilitation, carers competed at intervals. Aside from cathartic exercise and building on team spirit, this session released a great deal of tension through the shrieking and laughter that accompanied each task, humour helped the carers to work together, praising each other for what they achieved. It was an happy group of carers that finally left the session, amazed at what they had achieved, with enough in reserve for a group hug and dance to March of the Mods.

Team Sports



Group Six: Reminiscence and Release

The final session focused on interactive emotional release through group catharsis and humour, discussing key issues exposed during conversations recorded in previous sessions. The facilitator had documented each carer's most reoccurring statement and linked it to one of the relevant themes, loss, fear, resentment, communication, or timeout. On arrival, carers were presented with a personalised envelope, characterised by their name and emotional theme deemed by the facilitator as being most appropriate to their care situation. Carers were to find someone with the corresponding theme and sit together at the tables provided. Inside was a note scribed with a corresponding statement that represented that best represented the carer at the start of the pilot. Carers were to open their envelopes and read the statement inside and to share it with their fellow carer,

discuss how they felt the statement applied, and how it had become dysfunctional to their life. Carers were to suggest a way to resolve and forgive the situation as a way of moving forward, the only requirement was that they accepted feedback positively. Couples had twenty-minutes of discussion time before joining the facilitator at the circle to present their statement, explaining how they felt and how it relation to their theme.

The Emotional Expression Circle

Carers must decide for themselves their reasons for repression and explain this to the group along with how they could resolve it. A test of integrity, the aim was to explore how comfortable the carers felt with each another, after six sessions of intense mediation, and how prepared they were to express their private sentiments. What followed was remarkable, each carer took responsibility for their statement, sharing its meaning, and how they intended to change it. Without exception, all the carers gave accreditation to the circle and the activity sessions, one carer admitted to attending a group meeting for years, and never sharing more than 'hello', after only six sessions, these carers were communicating freely. Becoming a small community, they had learned to forgive themselves by releasing inhibited emotion in a safe and confidential setting. Many admitted feeling surprised at their ability to consider change, admitting that addressing issues in a group environment was easier than struggling on alone.

When asked how supportive the interventions were in releasing repressed emotion, the carers agreed it was the best thing they had ever done, not just for their own growth but also for the development of their relationship with their dependent. Asked why they had continued, they confessed to feeling valued and appreciated, while wanting to contribute to the research, they had also wanted others to benefit from the outcome. Asked why they felt valued, they replied that it was a mixture of praise, respect, and having someone to listen to them. All the carers gave positive feedback on the facilitated support they had received, and the help they had received from each other, one carer describing group mediation as '*the highlight of my week...*' The closing of the circle signified the emotional release of personal issues discussed inside the group. Each carer had their own

personalised helium balloon, labelled with their name and the emotion they had mastered during their six weekly sessions. Amid a lot of laughter, each carer shouted goodbye to their 'named' emotion, accepting its presence, but forgiving it for burdening them for so long. Finally they let go, releasing the emotion to the universe, applauding and thanking each other for the shared opportunity and resolving to stay in touch.

The Release of Repressed Emotion



Party Timeout

As a thank you, the facilitator presented each member of the emotional expression group with photographic memorandum as a reminder to stay in touch. Activity based, the humorous element of this session was the farewell party, which marked the end of the pilot. Focused on fun and reminiscence, the carers were to attend in costume fancy dress, either 1920's Charlton-style or a pantomime character from childhood. After enjoying a shared buffet, carers participated in a consortium of games focused on coordination, fun movement and exercise, including the party games 'Simon Says' and 'Musical Chairs'. This group took longer to close as none of the carers wanted to leave³, such a change from the first session where carers had left promptly at 2pm and highlighting the achievements of facilitated support.

Party Timeout

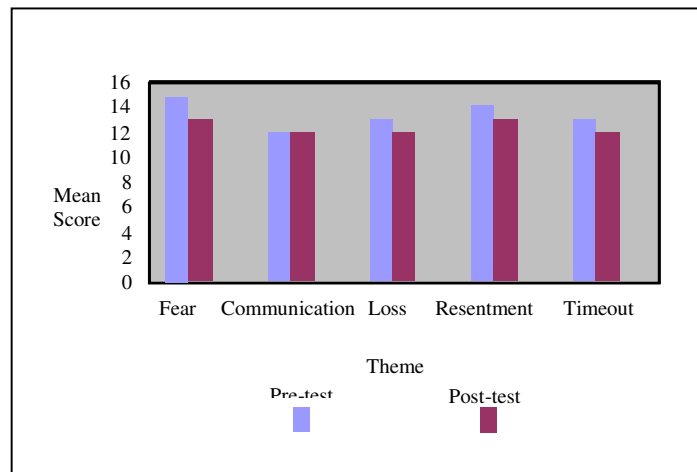


Quantitative Analysis

At the close of the session carers completed the revised 10-item survey, these carers replicated those in attendance at the first session, making pre and post-test scores a categorical comparison. Although completing the survey at the close of each session would have highlighted particular themes, this may have presented false results due to health-related irregularities in attendance. All the carers had attended four or more sessions, which given their age and commitments, was only to be commended. A related samples t-test confirmed that pre-test mean scores for fear, loss, resentment, communication and timeout ($M = 13.40$, $SD = 1.140$) were significantly different from the mean scores at post test ($M = 12.40$, $SD = 5.48$) where $t = 3.162$, $df = 4$, two-tailed $p = .034$. The only theme with no overall change was communication, suggesting that this

was not an issue for this particular group of carers during an intervention that was immensely interactive (please see Figure below).

Overall Analysis of 10-Item Survey Pre and Post Intervention



On completion of the pilot interventions, the carers were thanked and debriefed, with a change in attitude evident, this was an encouraging example of what can be achieved using mediation as a facilitated intervention.

Discussion

The emotional expression intervention was inspired and based upon the research of Chenoweth and Kilstoff (1998) almost a decade ago, exploring the values of early intervention with facilitated mediation, developed by Wolcott (1991) as a tool for marriage guidance. Chenoweth and Kilstoff (1988) had examined the building of relationships through communication and support, acting as facilitators while bringing a new perspective to the dementia caregiving role. The current intervention had the additional function of releasing repressed emotion, the acceptance and adaptation to lifestyle change and endorsing the presence of dementia (Spijker, Vernooij-Dassen, Vasse, Adang, Wollersheim, Grol, and Verhey, 2008). In combining empowerment with

the release of repressed emotion, the incorporation of humour, reminiscence and catharsis, had further enhanced the results. Linking emotional release with wellbeing had been based on Steffen, McKibbin, Zeiss, Gallagher, Thompson, and Bandura's (2002) view that, emotional expression has a positive affect on the reduction of anger, anxiety and burden, while helping to mediate change.

In the current pilot, facilitated mediation proved extremely beneficial in a group setting, particularly when it involved activity (Wolcott, 1991). Although the facilitator assumed a key role, with carers engaged, the facilitator would recede into the background, supporting Vega's (2006) belief in empowerment. Facilitated activities were well-received by all the carers, supporting the researchers belief that while informative meetings are useful, they may not provide the more personal support that carers gain from each other. Sharing knowledge definitely had an affect on the understanding of dementia care, eliminating unfounded fears and encouraging them to continue. While mediation developed the expression of emotion, humour enhanced group relations when situations became tense, muted or compromised. This pilot supports evidence that interventions can be useful in encouraging carers to consider their style of care, reshaping their environment and experimenting with care that includes timeout for themselves. The introduction of thought-provoking exercises helped these carers to explore their identity and to find different ways to preserve emotional well-being. With emphasis on the 'whole' person, developing interventions specifically designed to guide the release of emotion, enhanced self- expression in those who had been resentful of their current situation.

Summary

There was evidence that when in a balanced frame of mind, carers were more inclined to view dementia from the dependent's perspective, rather than from a place of resentment, where interactive communication played a key role. The aim was to develop the carers understanding of dementia, reaching a stage where they could release antipathy and adjust to a new style of living. Emotionally stronger, all of the carers were now in a

stronger and 'healthier' position, to manage their care situation. Confirmation that humour helped carers to release emotion was particularly evident during circle tasks, where making light of distressing situations enabled carers to confront challenges without the feeling of emotional overload. Humour dominated the notebook entries, which seemed to make challenging emotions easier to manage, while catharsis enhanced a sense of well-being through psychological fun.

Author's Reflections and Reflexive Account

It would have been inappropriate to close this paper without emphasising the impact of the pilot interventions as part of an ongoing form of support for persons who provide care. Furthermore, they were a collective achievement with each person taking an active role in their success. Without the rigidity of a quantitative study, this research was very much an experimental process with scope for improvisation, too controlled the humour may have been missing, too little and the emotional emphasis could have been lost. In hindsight, the next stage would be to test the interventions against a control group, adding strength to their validity and providing a quality standard to the research.

The interventions developed in this research were compatible with the current understanding of caregiver burnout, as well as structurally proficient at diffusing burden through emotional release. While beneficial to the carers in this research, greater availability may help to reduce the severity of repressed emotion a broader scale. That is not to say that the interventions did not have weaknesses, stricter controls would increase validity providing a more rigorous evaluation. Throughout this experience, I have developed as a researcher, learning to utilise methods while applying established theories in an unusual but perceptive way, in order to create new hypotheses necessary for psychological growth.

An experience in self-evaluation, this project has taught me to look outside of the box, working alongside practical assumptions in such a way that participants remain oblivious of the psychological concept behind them. Using a more informed approach can raise

awareness of what is expected. Whereas unorthodox methods can have a double-blind, effect allowing changes to occur more naturally. Modifying the life-course can be fearful in itself, perhaps more so in the more mature who live their lives based on experience, the gentle nature of facilitated mediation helped to guide these carers through through-uncharted territory, having a gradual but substantial affect. Comfortable with their emotions, they were free to explore new perspectives on dementia care as an alternative for resenting its existence.

Hypothetically, psychology is concerned with recognition of research and evaluating its value to society, based on theoretical truths, the interventions in this research were not conventional but had significant and far-reaching effects. With burnout a recognised contributor to residential care, facilitators are now able to gain deeper insight into what constitutes emotional burden, while implementing the appropriate intervention. There is always more to research, particularly regarding the vigour in methodology that makes this science unique.

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Appendix I

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Caregivers Burnout Study by Pilar Callaby of Southampton University – Dept of Psychology - A revue of the results of a Focus Group of Carers of Patients with Dementia.

This revue was prompted by the death of Pilar Callaby in August 2012 and follows a reunion of surviving members of the Focus Group of Meon Valley Carers Together which ran for 6 sessions at monthly intervals during 2007. Those who were able have briefly written their views, which are collated here. Summarised it can be clearly seen that all participants considered the Focus Group as organised by Pilar Callaby to have been of benefit to them personally and to have benefitted others in the group. All would wish to see such opportunity for other carers and for the concepts devised by Pilar Callaby to be developed for more general use by the Caring Community.

In preparing this revue I recognise the need to be realistic and to at least try to remain unbiased by the fact that as Chair and founder of the Meon Valley Carers Together (MVCT) charity and as sole Carer of my wife I was Pilar's Collaborator in the work and a participant Carer during 5 of the six sessions. I was not however present at the Fancy Dress Session held in late 2007, which was filmed and recorded by Southampton University, as I had collapsed with a Sub Arachnoid Haemorrhage possibly the result of stress and high blood pressure as sole carer for my wife, who died 4 months later in a Care Home necessitated by my stroke.

Several factors must be recognised in assessing the utility of the Focus Group work :-

- Probably the most important is the fact that all participants were volunteers and thus joined in the hope/expectation of a benefit in their unremittingly stressful life.
- Secondly the membership also came largely from the Middle Classes in a primarily Rural Area.
- Thirdly most of the Carer membership, of MVCT, were women, who generally display more social skills.

- The counter argument regarding the willingness of members must be that most were elderly like me (then aged 83) who are notably resistant to any new ideas, and in addition were certainly not all friends or neighbours at the outset.

At the formation of MVCT both the lack of support by the Statutory Health and Social Services, and the absence of suitable publicity made it more difficult to communicate with the lower classes in a very wide rural area, and especially those living alone, both of whom were less socially able and felt uncomfortable in groups of new people. Finance and lack of transport also had a bearing. Initially a number of “Upper Class” men (Retired Senior Naval Officers) joined us, but while they were comfortable their wives were less so, and one sent her husband alone with his live-in Carer. None lived long enough to participate in the Focus Group and no others of that class joined later. It can be reasonably assumed that the various privately run Care Homes and agencies provide Care Services for these people.

The imbalance of male and female carers as volunteers in the Focus Group simply followed the pattern of Dementia in the community. Although the trend is changing, men tended to be older than their wives and thus more likely to suffer with Dementia. This was certainly the pattern in MVCT. Although very occasionally a male carer would join us, we were aware that some men of our acquaintance wished to be totally independent, and despite their problems refused help or support.

Notwithstanding the apparent imbalance of participant groupings in the Community I believe that among the Focus Group members there was very clear evidence of the benefit of the methods used by Pilar but especially from three quite different members of the Focus Group who were present and were filmed at the Fancy Dress session.

Sadly only one of these three is still alive and by chance is the oldest member – currently aged 93.

T. survived Dunkirk and after the war had a son who joined the Merchant Navy and was serving on a foreign Tanker which was lost at sea. He felt unable to talk to anyone about his loss or grief, but did so literally out of the blue at the Focus Group Fancy Dress Session. He has clearly stated how beneficial Pilar’s work was to him personally in that regard.

S. A quiet reserved lady of lowly background. She lived in a Council House caring for her husband, whose dementia caused behavioural concerns in public that were a challenge and embarrassment to her. Following the Focus Group she lost her reserve and became happy and spoke freely at the Fancy Dress Session. Sadly she has since died.

M.A former Personnel Manager, with a Degree and high Christian values, she married rather late and her older husband then developed Dementia. She found it difficult to take part in any activity at MVCT at which the realities and implications of Dementia were discussed. She had to be persuaded to join the Focus Group by a friend, but then was recorded at the Fancy Dress Session explaining how beneficial she had found the Focus Group despite her reluctance. Sadly she has also since died.

During the planning for the Focus Group both Pilar and I recognised that if successful in our small subject group, as it has proved to be, then it would be essential to develop the Focus Group process into scheme that did not depend upon the undoubted special skill, enthusiasm and Psychological qualification of Pilar, or upon levels of funding at even the limited level available for the Focus Group work.

It is my view that, while the skill, innovation and dedication of Pilar is not simply available on demand, it is certainly not the case that similar results cannot be obtained by others who lack Pilar's unique abilities but follow her method. Pilar, very sensibly, moved her plan forward in steps at each meeting. Firstly there had to be fun, music and food (to which members contributed), and numbers were limited by considerations of space, support staff (2/3 friends as volunteers). Carers had also necessarily to arrange transport between themselves and a sitter for their Cared-for so that they could relax without worry. This was quite deliberately excluded from the funded work since it was not probable that similar funding would be provided by a Local Authority if the scheme was more generally adopted.

In the course of six group meetings, Pilar planned a number of other activities and these included a Bowling Alley, a Treasure Hunt/picnic in the New Forest, an Indian Dinner party when we all dressed in that style. These led progressively to the key events at which wittingly or otherwise she used Game Play techniques for the results she intended - effectively a tailored variant of "truth or consequences" in which both the truth and the consequences for participants lead to a positive outcome for the group as well as for individuals, and that peer pressure from the group many of whom will be strangers ensures that all group members take a full part in a light hearted and cheerful way. This both increased the bonding between members but most importantly broke down their reserves so that they were able to release their fears and concerns..

At about the time when Pilar had closed the Focus group it was found that a formal Game existed which had been designed for an entirely different training purpose and could be adapted for our purpose. However the usual factors prevented Pilar from developing the game specifically for Carers. The first was the lack of funding for the project and her need to complete her PhD work. The second was the NIH (Not invented here) view of her next employer.

There is no reason in principle why the scheme cannot be completed at a relatively low cost, tested and made available to Dementia Care Groups initially and be based upon the methodology used by Pilar. Further development would also be of great benefit for other specialist Care Groups.

The need for better support of Carers for Dementia must remain a very high priority as our population continues to age and the number of people with a form of Dementia increases.

It is therefore very strongly recommended that action be taken to initiate a development study based upon Pilar's work and led by the Psychology Dept of Southampton University.

Note- the Focus Group was one half of the PROCASS plan in which Pilar arranged to phone every member of the group at their homes at regular intervals in order that the Carers might share and discuss their particular concerns at that time. This scheme was popular and made the carers feel free to talk and valued for what they were doing. Similar schemes are operated by some Care Charities using trained volunteers.

Focus Group members views:- A number of transcribed responses by former Focus Group members follow. Initial only and age where available is given for each respondent :-

T aged 93- When I first met Pilar I was feeling isolated. My wife had Alzheimer's and we had not been in the area very long. I was always private person who did not make friends easily but Pilar broke through that shyness. Pilar was able by sheer personality to get people together and persuade them to do what she envisaged she will be sadly missed.

J aged 91. Pilar was courageous lady. She was a great organiser who had the forethought to bring a group of carers together and then learn about the difficulties they faced each day (I was one of that group) not by outright questioning, which could have seemed patronising, but by a caring and very happy way. Her memory will be with me always of how she made my life more bearable.

E aged 88 If all carers had received the wisdom and treatment that we her Focus Group received, life would have felt much less hopeless for more people. It is difficult to analyse why she had the ability to change our lives, doing things we would not have dreamt of before Pilar. She gave us a life other than the difficulties we faced day after day.

We had complete trust in her and each other through her.

If only what she had could have been patented, she would have been a wealthy lady.

I become quite upset, when via television I see people receiving awards for various good deeds, well deserved I am sure, but if anyone earned recognition it was Pilar.

Our respect and admiration for Pilar showed in the Focus Group get together held in memory of Pilar.

A. The meetings we had with Pilar made us to some extent forget our troubles for a few hours at least, to speak to other people and make friends with them and realise that they were experiencing the same emotional problems as we were. Pilar made the meetings fun as well as discussing more serious matters with us. I still think carers are undervalued and more could be done to help.. Carers themselves are put under such a strain that their health suffers. Hopefully Pilar's work will help to rectify this eventually.

B aged 75. Pilar was very courageous to tackle the subject of Caregiver Burnout. .Elderly Carers rarely consider themselves and talk about their feelings. Pilar was able to draw us out, make us feel special-even though it was just for short time, and to make us understand that all these feelings of guilt were normal. It would be nice to know that other students were able to carry on the valuable work that Pilar started.

T aged 74 I remember Pilar as a kind caring and thoughtful girl working so hard with our Focus group, the activities she planned for us and so much fun. Pilar deserves recognition for her work.

R. The Focus Group I attended run by Pilar made a huge difference to my coping with Tom's dementia. I came away feeling that ,meeting with others and having some fun, brought a sense of normality to an otherwise isolating experience.

The group was helping all of us that were caring for loved ones to really open up and be able to share that sense of loss- not only the dreadful decline of the Cared for, but the loss of not being able to have a life of our own. Thank you Pilar.

Appendix II: Focus Group Reunion

