



Hampshire Creative Arts project for people with Dementia

Alzheimer's Society
Portsmouth

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December 2014

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2. Abstract

The Alzheimer's Society currently run several creative art groups across Hampshire and whilst feedback is positive, no formal evaluation has been conducted with these groups. This project consisted of three pilot activity groups based on stimulating art, music and drama across Hampshire, and aimed to provide an evaluation of the creative art groups which would aid the Alzheimer's Society in assessing the viability of expanding this service. Observations of participation in the groups and interviews with carers were coded using content analysis and thematic analysis respectively. Eighteen participants took part– 9 carers and 9 people with dementia. Participants were aged between 65 and 90 years old. Alzheimer's disease and Vascular Dementia were the most common diagnosis of those participants with dementia. Themes to emerge included practicalities such as the room use and timing of the groups, as well as peer support and much-needed respite that carers gained through the groups. An improvement in mood, of being able to relax and just enjoying the activities were themes that emerged for the person with dementia. For future groups, the capabilities of participants should not be taken for granted but activities that everyone can achieve should be incorporated. A familiar structure to the groups may aid participation and an important theme to emerge was the importance of providing carers with the opportunity to discuss their tensions and worries, and it is suggested that bringing this element in to future groups could be considered.

Keywords:

Alzheimer's disease; dementia; creative arts; activity groups; observations; interviews, semi-structured; older people; program evaluation

3. Introduction

It is predicted that the number of people with dementia in the UK will rise to one million by 2021 (Alzheimer's Society, 2014). In line with this increase there will also be cost implications. In the UK alone, the current cost of dementia is £23 billion and set to rise (Department of Health, 2013). In order to improve the care experienced by people with dementia and those caring for people with dementia, the government have recommended that improved awareness and high quality treatment is delivered at every stage in every setting. Research is needed to ensure that this is possible, however research developments to date have mainly focussed on the pharmacological treatment of dementia with limited success, and yet more still needs to be done to explore the potential of non-pharmacological treatments to improve mood, behaviour, social or cognitive problems for older people with dementia (Vink, Birks, Bruinsma, & Scholten, 2003).

As drug treatments do have limited success, the exploration of the effectiveness of non-pharmacological treatments is becoming ever more important and is advocated as the first choice (before drug treatments) in a growing number of guidelines for the care of people with dementia (Kontos, Mitchell, Mistry, & Ballon, 2010; American Geriatrics Society and American Association for Geriatric Psychiatry, 2003; Cohen-Mansfield & Mintzer, 2005). These guidelines include the UK's National Institute of Clinical Excellence (NICE) guidelines for dementia care (2006) which recommends arts-based approaches for patients with co-morbid agitation and challenging behaviour. Additionally, measures to promote psychological wellbeing, as opposed to just physical care, are now being introduced within residential or nursing homes but it is equally important to consider how these measures can be delivered within the community too (Pulsford, 1997) as two thirds of people with dementia still live within the community and are often cared for by family members (Alzheimer's Society, 2014).

Evidence is building to support that creative arts groups appear to be effective in promoting independence, a good quality of life and higher levels of well-being for both the person with dementia and their carers. Music therapy is an example of this and although it is now widely applied as an intervention for older adults, its levels of effectiveness are not properly understood (Li, Chen, Chou & Huang, 2014). Additionally, research exploring the

effectiveness of activity groups for older people have tended to use formalised scales, such as the Quality of Life – Alzheimer’s Disease (QoL-AD), to assess the effectiveness of the groups (for example, Brooker & Duce, 2000; Camp & Skrajner, 2004; Davidson & Fedele, 2011; Ryland, 2012) but the qualitative experience of the participants is rarely explored directly and this could be due to the methodological challenges of research in this field (Zeilig, Killick & Fox, 2014).

The Alzheimer’s Society currently run several creative art groups across Hampshire and whilst feedback is positive, no formal evaluation has been conducted with these groups. If psychological treatments such as these are to be considered as a high quality intervention, an assessment of the value of these groups and exploration into the viability of expanding creative arts groups is needed. This report is the output of a collaborative evaluative project between the University of Portsmouth and the Alzheimer’s Society of an arts group, a music group and a drama group run for people with dementia.

4. Project Aims

The Alzheimer’s Society ran three pilot activity groups, based on stimulating drama, art and music, across Hampshire. These workshops ran weekly for up to five months, including end of project productions and exhibitions. It has long been known that stimulating the brain through creative art, music and drama is beneficial to people with dementia, but this project was carried out by the University of Portsmouth specifically for the Alzheimer’s Society.

The project explored whether there are benefits to the person with dementia through attending the groups, and if so, whether the benefits extend to their lives and the lives of those caring for them, outside of the group activity. The aim was for the project to provide an evaluation of these specific creative arts groups which would aid the Alzheimer's Society in assessing the viability of expanding this service.

5. Aims of the Creative Art Groups

The objectives of the groups were to:

- Provide stimulating activity for people with dementia, enhancing their wellbeing
- Encourage self-expression, use of imagination and emotional engagement
- Improve scope of services offered by the Alzheimer's Society
- Determine viability of rolling out the service to extend reach

6. Ethical considerations

This study has been reviewed and given a favourable opinion by the University Of Portsmouth Faculty Of Science Research Ethics Committee. There were no significant ethical concerns. Whilst the project did involve observing people with dementia attending a creative arts group, the group is a standard intervention already in place. All interviews were conducted with carers of the person with dementia who were not considered vulnerable. Participants were recruited through the facilitator of the creative arts group and were free to withdraw from the project, however data which had already been collected and analysed was not able to be withdrawn. As it was considered that interviewing carers about the relationship they have with the person with dementia may be a sensitive subject, support services were identified should any distress become apparent.

7. Method

1.2 Design

1.2.1 Observations

A Content Analysis approach (Hancock, 1998) was used to analyse the observations. Observations were carried out at each group using an observation guide to record acts of social engagement and interaction, and well-being. The observation guides were adapted with the help of carers whose partners were currently attending an art group in Milford-on-Sea. Observations were recorded using field notes.

1.2.2 Interviews

A qualitative Thematic Analysis approach (Braun & Clarke, 2006) was used to explore participants' opinions and experiences of the creative art groups. Semi-structured interviews were conducted using a framework which was designed to provide a structure for the interview. The interview schedules were developed with the help of carers whose partners were currently attending an art group in Milford-on-Sea. Interviews were audio-recorded for ease of verbatim transcription.

Four sets of interview were carried out in order to identify any perceived changes, both individually and relational, whilst attending the group: a baseline interview was conducted with carers of those being observed prior to attending the group and two subsequent interviews were carried out at regular intervals until the end of the groups when the follow-up interview was conducted. It was the case that for some of the interviews the PWD wished to be in the room at the same time and in these cases, their words are included in the interview.

1.3 Sample

1.3.1 Groups

The project consisted of three pilot activity groups based on stimulating art, music and drama across Hampshire. These workshops ran weekly in Portsmouth, Petersfield and Winchester for 15 weeks between January and June 2014, including the end of project productions and exhibitions.

1.3.1.1 Group characteristics

Art group

Eight people (including the 3 observed participants) attended the art group; all had a diagnosis of dementia. The group was a taught art class taken by a facilitator with a background in further education teaching, with knowledge of dementia. The art classes were held in Winchester over 15 weekly sessions. Carers were expected to drop off their partners, picking them up at the end of the session. However the partners of Participants 4b and 6b

decided to stay have refreshments and chat with each other. Participant 5b's partner did not stay.

The session was run with group members sitting at their designated work station each week and copying from a chosen picture. The facilitator and volunteers would assist group members in painting techniques, chatting about the picture being created and also offer advice or suggest different techniques to produce different effects. Each time a group member completed a piece of work, and with permission from the group member, the painting would be displayed to the entire group, the work would be discussed and congratulated with a round of applause. The final session of the art group was an exhibition in which all art work was displayed - framed pictures were awarded to each group member. Family, friends and invited guests were present.

The building consisted of three rooms; one small room, one larger room and a kitchen. Both rooms were light and airy with big windows on one side looking out over fields. Tables were set out with two seats at each end and two seats in between at each side. The tables were set up with each person having a stand to place books to work from, a paint set, brush, water and cloth. Each person sat in the same place each week. Classical music was played quietly in the background. A table was set up adjacent to participants table for carers with refreshments, biscuits and newspapers. Ample parking was available and the venue was easy to find.

Drama Group

The drama group was facilitated by The Red Sauce Theatre Company. Matt Smith, Senior Lecturer in Applied Theatre at the School of Media and Performing Arts (University of Portsmouth), supported the practitioner of the drama group in her delivery of the sessions, as her consultant and mentor. Mr Smith has written a report around this aspect of the project which is presented in Appendix 1 as a supporting document to the main project report.

The drama group was initially attended by 10 people (including the 3 observed participants). It was an innovative activity in which the facilitator wanted to explore the emotional side of dementia through drama. The sessions were held in a day centre in which all participants already attended. Carers of the participants observed did not attend the sessions. The sessions

generally started with a warm up activity in which the facilitator played background music and encouraged group members to perform hand and leg movements. Instruments and flags were then given out and these were used in time with the music. A bubble machine was then activated along with music. Following this the facilitator generally acted a scenario which focused on the relationship difficulties between a mother and daughter in which the mother had dementia and requested feedback from the group as to how to expand the scenes. The session would end with the facilitator approaching group members for feedback. The final session was a production of the play that had been developed over the 15 week period. Family were present at the final session.

The sessions ran over 15 weekly sessions in an old school building and participants were in attendance for the whole day, both prior to and after the group activity. The room was carpeted, had a television and photographs of staff and day centre attendees displayed on the walls. The seats were set in an oval shape around the outside of the room.

Music Group

The music group sessions were known as ‘Music Unlocking Memories’ and were facilitated by an established musician who studied at the Royal College of Music, as well as the Berlin Philharmonic Academy in Paris and the Bournemouth Symphony Orchestra. The music sessions were held in a church hall in Petersfield over 13 weekly sessions. The final session was a music session with a local choir in attendance. Family, friends and invited guests were also present at the final session.

At its peak 42 people (including the 6 participants) attended the music group. This comprised of people who had a diagnosis of dementia, and their carers. The sessions would always open with the facilitator playing a piece of music, usually with an Oboe. Following this, song sheets and instruments would be distributed and a selection of songs from different genres were played on an MP3 player. The facilitator would introduce the songs, giving background to the song choices, reminiscing about times when he played in the Bournemouth Symphony Orchestra and accompany the music with an instrument. He would also attempt to engage with those attending but approaching them and tapping his instruments with them, singing to them and playing to them.

The music group was held in one large room with chairs in an oval shape around the outside of the room. The room was light and airy. Parking was problematic for some members as the nearest car park only offered parking for an hour and half so did not provide enough time for the group. A car park providing longer periods of parking was at a local supermarket and whilst this was a short walk it did pose problems for those with limited mobility. However, this did not seem to prevent attendance.

1.3.2 Participants

Participants were recruited purposively if they attended one of the creative art groups as they were able to provide their experience of one of the groups. No age or gender restrictions were stipulated.

1.3.2.1 Participant characteristics

Participants were aged between 65 and 90 years old. There were 18 participants who took part in total – 9 carers and 9 people with dementia (PWD). Nine of the carers were female, while only 3 of the PWD were female. Three PWD were observed for each creative art group and their carers were interviewed. Alzheimer’s disease and vascular dementia were the most common diagnosis of those participants with dementia. Participant characteristics are presented below in Table 1.

Participant Attrition – Participants 1 and 3 withdrew from the study. Participants 11a and 11b only took part in 3 interviews due to joining the group later and replacing Participants 1a and 1b. Participant 10a was undergoing hospital treatment and so took part in the Baseline interview, Interview 1 and Follow-up interview only.

Table 1 – Participant Characteristics

Participant number	Gender	Carer/PWD	Ethnic origin	Age	Diagnosis
Music					
M2a	F	Carer	British	69	
M2b	M	PWD	White Irish	76	Parkinson's Disease and Alzheimer's Disease
M7a	F	Carer	White British	83	
M7b	M	PWD	White British	85	Alzheimer's Disease /Frontal Temporal Dementia
M11a	M	Carer	White British	73	
M11b	F	PWD	White British	68	Alzheimer's Disease
Art					
A4a	F	Carer	White Irish	65	
A4b	M	PWD	White British	65	Vascular Dementia
A5a	F	Carer	White British	77	
A5b	M	PWD	White British	79	Stroke/Vascular Dementia
A6a	F	Carer	White British	80	
A6b	M	PWD	White British	82	Alzheimer's Disease
Drama					
D8a	F	Carer	White British	66	
D8b	M	PWD	White British	67	Alzheimer's Disease /Dementia with Lewy Bodies
D9a	F	Carer	White British	53	
D9b	F	PWD	White British	77	Vascular Dementia
D10a	F	Carer	White British	67	
D10b	F	PWD	White British	90	Vascular Dementia

1.4 Approach

Participants were recruited through Alzheimer's Society Coordinators. Each member of the group and their carer was given a Participant Information Sheet to inform them of the details of the project. Those who did not wish to take part in direct observations (e.g. the researcher noted down the participant's behaviour on an iPad) but were members of staff, facilitators or volunteers at the group were also required to be given a Participant Information Sheet as they too were required to give or refuse consent of indirect observations (e.g. the researcher did not directly observe the participant but as they were in the room they may have been indirectly observed). If potential participants indicated that they would like to take part in both the observations and the interviews, their details were passed on to the researcher who then contacted them.

8. Procedure

1.5 Observations

The observations were carried out at each of the group sessions. Observations were carried out identifying three major themes; engagement, socialisation and independence. The theme of engagement observed whether participants took part in the activity and if so how (e.g. did they paint, sing along, take part in the drama activities), socialisation observed whether participants developed or used social skills with the group (e.g. did they begin to talk with other members, to their carer, group facilitator, did they settle within the group environment) and the independence theme observed whether participants had developed independence whilst attending the group (e.g. making decisions about their art work, interacting independently of their carer, respond with feedback in drama) (see Appendix 2 for the Observation schedules).

1.6 Interviews

Interviews were held in the participants own home as this was most convenient to them. The interviews provided data on the characteristics of those taking part and gave context to their day to day life, other groups they attended and dementia-related behaviours that could be classed as challenging.

Each participant was contacted the day before the interview to double check that they were still happy to take part. If so, the researcher arrived at the participants home as arranged. On arrival for the Baseline interview, the researcher checked that the participant had had more than 24 hours to read the information sheet and to understand what was involved by taking part in the study. If so, then the researcher reviewed the details of the study. The participant was asked to read, and if in agreement, sign (or mark if the participant had difficulty writing) the informed consent form. The participant was reassured that their interview would be kept confidential and reminded that they could stop the interview whenever they wished by either telling the researcher that they wished to stop or by turning off the audio recorder. The researcher checked the participant was happy to continue and asked if they had any questions. When ready, the audio recorder was turned on and the interview began.

The interview was terminated when the questions had been covered or when the conversation came to a natural end. After the interview, the participant was thanked for their time and the researcher checked if they had any questions. At the Follow-up interview the participants were given a debriefing form to read and keep which detailed how participants' could withdraw their data at a later date. This procedure was repeated for each interview (see Appendices 3 and 4 for Interview Schedules)

1.6.1 Data protection

In order to protect the participants' data, all information collected from each participant was pseudo-anonymised. Each participant was given an identification number which was entered into a password protected file next to their name. Only the research team had access to the encryption key. Participants were not identified by name in any subsequent report or publication and any names that the participant used in the interview were also removed or replaced with a fictional name. All audio recordings and transcripts were kept in a password protected file. All data collected will be kept in a locked filing cabinet within the University for a period of at least five years after the appearance of any associated publications, after which it will be destroyed. Any aggregate data (e.g. spreadsheets) will be kept in electronic form for up to one year after which time they will be deleted. Participants were informed of this in the information sheet.

1.6.2 Participants' validation of transcript

Audio recordings were transcribed verbatim. When the data preparation had been completed, the interview transcript was sent back to the interviewee for approval, if they had agreed to check the transcript. Participants were asked to check that they were happy with the transcript of their interviews.

The transcript was taken to the participants' homes by the researcher, who asked for the participant to notify them within one week if they did not agree that the transcription was a true reflection of their interview. If the participant did not agree with any aspect of the transcript then they were invited to contact the researcher who would amend the transcript accordingly. Ultimately, all participants were agreeable with the accuracy of the transcript of their interview.

1.7 Analysis

The findings from the observations of the groups were analysed in conjunction with the semi-structured interviews which were carried out on a 4-weekly basis with the carer of the person with dementia. The aims of both observations and interviews were to explore whether attending the group and the activity had an impact on the daily life of those attending the groups and those caring for them.

All data were analysed thematically. The observational data was coded using a 10 stage content analysis method (Hancock, 1998), while the interview data was analysed using a 5 stage thematic analysis (Braun & Clarke, 2006). Qualitative data analysis software was used to aid this process (Atlas.ti, version 7.1.4).

9. Results and discussion

The main aim of this study was to explore the personal aspects of attending the creative art groups and whether attending the groups provided the participants with any perceived benefits that continued away from the group and after the groups had ended. Observations of the group sessions and interviews with the carers and PWD were analysed and the results are presented as follows.

Presentation of results and discussion

As the aim of the observations was to observe the engagement of the PWDs attending the groups the results and discussion for these are presented for each creative art group. The interviews aimed to explore the personal side of the sessions overall and whether attending the groups provided any perceived benefits that were transferred outside of the groups. As such, the themes of the interviews have been presented as an overview of the creative art groups.

Each interview theme demonstrates the commonality of the participants' experiences as well as their individuality. Therefore, not only do the themes cover the common experiences of the participants but also the diversity within those experiences too, allowing the reader to understand what is important for the participants but also have an understanding of how this may vary for each person.

The master themes and minor themes for the observations and the interviews are presented in Tables 2 and 3 below, and each theme is discussed with relevant quotes from the participants in the following section.

Table 2 – Major and Minor themes for Observational data

Observations	
Major Themes	Minor Themes
Art group	
Engagement Socialisation Independence	Positive emotion: pride, increase in confidence and ability Joint interest: discussing paintings, engaging in dialogue around things in common Decision making: choosing materials, colours and techniques
Drama group	
Engagement Socialisation Independence	Emotional response: crying Interaction: engaging with facilitator, members of group and staff Decision making: refusal to engage, choosing own instruments
Music group	
Engagement Socialisation Independence	Change in mood Play

Table 3 – Major and Minor themes for Interview data

Interviews	
Major Themes	Minor Themes
Life changes	Changing roles Changing plans
Benefits of the groups for carers	Gaining peer support through the groups Groups providing respite Hoping groups would improve symptoms of dementia
Benefits of the group for the person with dementia	Improving mood through interests outside of the home Being with others who understand Positive outcomes regardless of memory
Practical aspects of the groups	Losing the groups Practicalities of the groups

1.8 Observational data

1.8.1 Art group observations

Three participants were observed during the art groups: Participant A4b, A5b, and A6b.

1.8.2 Major Theme – Engagement: actively taking part in the activity, accepting assistance, responding to assistance

All participants sat and actively engaged in the activity for most of the course. Participants A5b and A6b showed high levels of engagement. Participant A4b slept whilst in the group which may be largely due to his condition and the medication he was taking however when assisted by a volunteer he actively took part and produced finished paintings but required prompting. All participants responded well to assistance, the pictures that were chosen to paint also appeared to encourage reminiscence with Participant A6b talking of his time in Hull and painting pictures which were in common with his previous occupation.

1.8.3 Major Theme – Socialisation: interacting with member of the group, volunteers and facilitator.

Participants A5b and A6b sat together and throughout the course chatted about their paintings, complimenting each other's work and talking of their previous occupations. As time progressed they widened this to other members of the group complimenting others' work, giving encouragement and applauding when pictures were displayed.

1.8.4 Major Theme – Independence: unassisted painting, making requests.

Participants A5b and A6b would often sit in their designated seats on arrival and start painting unassisted. Participant A5b was very focussed on the activity throughout and would state when he thought he was making progress and when he was not happy with his work. He would also request assistance from the facilitator if he wanted help with techniques.

Participant A6b brought in a photo album from home to show members of the group photographs from his time working abroad and various places he had visited when living in Hull. Whilst Participant A4b's partner remained at the group for the initial sessions, on the 10th session she started to leave for part of the session as Participant A4b has settled into the sessions and she was confident he could be left alone. However towards the end of the course

Participant A4b did insist on his partner sitting with him on two occasions and it appeared he wanted reassurance. He also on two occasions threw a paint brush across the room towards his wife. On one occasion he blamed Participant A5b who became angry, however the situation was diffused quickly.

1.8.4.1 Minor theme - Positive emotion: pride, increase in confidence of ability.

It became clear that all participants were showing signs of pride in their work. When a picture was finished the facilitator would ask participants if she could share the picture with the rest of the group. This request was met with a look of embarrassment which seemed to quickly turn to pride. Participant A5b commented that 'I can't do much but I can do this'. He also punched the air when his painting was shown. The paintings of each member were produced in card-form and also as framed paintings. The cards were given to each member and pride in their work was observed as they showed their partners the cards. Participant A5b was observed telling his wife 'I did that' with a smile. He also stated that the sessions were too short and that time passed so quickly whilst he was there.

All participants showed an increased confidence as the sessions progressed, which showed itself through the participants declining help and suggestions, instead opting to choose their own methods or stating what they wanted to do with the paintings. Participant A6b requested crayons rather than paints as he preferred this method however crayons were not available and were not brought to future sessions.

1.8.4.2 Minor theme - Joint interest: discussing painting, engaging in dialogue around things members had in common.

Participants A5b and A6b would often be seen and heard discussing their paintings and also previous occupations and their time in National Service. As time progressed all participants were seen and heard engaging in dialogue with other class members. Participant A4b did not engage as readily in dialogue however he did appear to listen intently to conversation held between the facilitator and other members of the group particularly when his partner was absent from the group.

1.8.4.3 Minor theme - Decision making choosing materials, colours and techniques

As time progressed all participants began to become more confident in choosing techniques and deciding how they wanted their painting to look at times refusing assistance and/or refusing to adopt a suggestion made.

In summary, the Art group enabled participants to engage in an activity that was suited to a person with any ability - the people attending just happened to have dementia. This appeared to give members increased levels of confidence and pride in their achievements but also seemed to surprise family members and the Alzheimer's Society staff. For example one member of the Alzheimer's Society staff said:

"I would never have given this kind of activity to someone with dementia. I provided an activity in another setting in which I offered a piece of plastic and paper that when water was applied colours came out, I thought this was providing an activity that had dignity and respect. After seeing this group in action, a proper taught art class with paints and brushes and books I now know this is respect and dignity and I would use the other tools now".

This demonstrates a form of malignant social psychology (Kitwood, 1997) in which the expectations placed on people with dementia may be lower than necessary due perhaps to the concentration on what the person is no longer capable of doing. An important message for all staff working with people with dementia deriving from this may be to reduce misplaced good intentions of preventing PWD from failing as this may also prevent PWD from achieving.

1.8.5 Drama group observations

Three participants were observed during the drama groups: Participant D8b, D9b and D10b.

1.8.6 Major themes - Engagement - actively taking part in the activity

All participants engaged in the warm up session of the activity. This entailed hand and leg movements to music. This was the only consistent action of engagement taken by all participants. They all remained seated when the play was being acted out but engagement was intermittent. Certain activities were not carried out by some members. Some activities, such as writing and being asked to carry out homework where actions were involved,

participants may not have been able to achieve due to their condition and participant carers were not present to remind the PWD later. Participants did take part in other activities related to the drama but only if prompted by staff members although their understanding of what was being asked of them was impossible to ascertain. However Participant D8b and Participant D10b did show signs of understanding but Participant D9b appeared confused often. Participant D8b did appear to have a good understanding of the story line and both Participant D8b and Participant D10b contributed to the story line's development. A bubble machine was in operation after each warm up session and Participant D9b appeared mesmerised each time by the bubbles.

1.8.7 Major Theme – Socialisation: interacting with member of the group, volunteers and facilitator

At the end of most sessions there was an individual feedback session and both Participant D8b and Participant D10b both spoke candidly about their relationships with their carer when asked by the facilitator. Both Participant D8b and Participant D10b appeared to make the connection between the developing story of difficulties in relationships and their own experiences with their carers. Participant D9b did not take part in the feedback session as she did not appear to understand what was being asked of her.

1.8.8 Major Theme – Independence: making own decisions

Participant D8b and Participant D10b made clear when they wanted to engage and when they did not. Both refused certain activities. Participant D9b appeared to engage openly in the warm up session in which hand and feet movements were required.

1.8.8.1 Minor Theme - Emotional response: crying

The play acted out difficulties in relationships with a person with dementia and her daughter. Participant 8b cried in the first session whilst watching the play and also again in a later session when the two actors hugged each other.

1.8.8.2 Minor Theme – Interaction: engaging with facilitator, members of the group and staff

All participants engaged in conversation with day centre staff. Participant D9b often chatted to another group member who was sat next to her and the staff members. Participant D8b and Participant D10b engaged with staff members and the facilitator when approached. In the later sessions, Participant 10b became more vocal, calling out instructions for the development of the play and joining in with the activity when verbal engagement was required contributing to the story line.

1.8.8.3 Minor Theme - Decision making: Refusal to engage, choosing own instruments

Whilst Participant D8b and Participant D10b largely engaged with the activity both refused to cooperate with the facilitator at times. All participants decided upon their instruments for the warm up activity.

In summary whilst all participants engaged in the warm up session only Participant D8b and Participant D10b contributed to the story line. The Drama group did invoke emotion in Participant D8b and also produced conversations between facilitator, Participant D8b and Participant D10b, which may suggest they connected with the story line, their own experiences of having dementia and the relationship difficulties they have experienced. The activity may have beneficial qualities in relation to connecting emotionally to the story line however a sound knowledge of the audience and also a plan of action when emotional responses are exhibited may have been beneficial.

1.9 Music group observations

Three participants were observed during the music groups: Participant M2b, M7b and M11b.

1.9.1 Major themes – Engagement: actively taking part in the activity.

All participants engaged with the activity throughout. All sang along with music sheets and played instruments. When approached by the facilitator all engaged in tapping instruments against the facilitator's instrument. All remained seated throughout and were observed tapping feet and hands. Participant M11b often swayed in her chair to the music. Participant M7b sang enthusiastically in each session.

1.9.2 Major Theme – Socialisation: interacting with member of the group, volunteers and facilitator

As the weeks progressed chatting to other members of the group on arrival and between songs was observed. Participant M2b began to make attempts to get the researcher's attention throughout the sessions. Pulling faces to try and make the researcher laugh, he also played hide and seek with the song sheets, hiding behind the sheet and then peeking around it to interact with her. He also began bantering with the facilitator.

1.10 Major Theme – Independence: choosing own instruments and requesting songs

All participants would choose their own instruments. They were also observed refusing instruments when alternatives were offered. Participant M2b was observed requesting Irish songs when Welsh songs were a theme.

1.10.1.1 Minor Themes - Change in mood

Attending the music group appeared to have the ability to lift participant's mood. All participants appeared to be more upbeat upon leaving the music group. This also appeared to be the same for the carers, at times carers appeared to be agitated when arriving but seemed more relaxed when leaving.

1.10.1.2 Minor Theme - Play

The music group appeared to have the ability to promote play. The group appeared to facilitate Participant M2b's mischievous nature and as the sessions progressed he spent much of the time attempts to play games to interact with others and promote laughter. He would often play hide and seek with his music sheets and pull faces at both the researcher and the facilitator. He would also call out to the facilitator with a result on one occasion of making the group laugh. The group appeared to enable him to have fun.

In summary, all participants actively engaged with music group from beginning to end in all sessions. Attending the group appeared to lift the mood of all participants and also the carers who attended with them. The group also enabled some participants an environment in which he could have fun and the ability to be gregarious with others.

1.11 Interviews

1.11.1 Major Theme - Life changes

One of the main aims of the project was to evaluate the creative art groups. In order to do this, it is necessary to set some context around the lives of those who are attending the groups to gain an understanding of why they wanted to attend the groups and how they were coping with their loved one being diagnosed with dementia. Participants found that their lives had changed from the diagnosis of dementia, and even before with the arrival of the symptoms of dementia. This meant that the roles of the couples were changing along with their life plans:

1.11.1.1 Changing roles

One of the main themes to emerge was how the carer's role has changed from partner or family member to that of carer. The change in role was made more difficult by the effects of their loved ones dementia which included mood and behaviour changes, sometimes unpredictable behaviour, forgetting who family members were, forgetting they had been to the group, or not being as capable as before. These were a source of frustration for the carers and for the PWD themselves. Some PWDs had become less sociable since diagnosis and this could also be due to not being as confident around others in terms of being able to hold a conversation or doing simple tasks. Most of the participants had found this change in role difficult to cope with:

D8a: and I've had to do everything I mean I don't know how I got through last year erm because it's just too much (crying) sorry

I: it's alright take your time

D8a: and I just feel as though everything has been heaped on me erm like I keep saying I hate this I want it to end I really do ... I just don't like it anymore (D8a, BI, 16.23)

I: Okay right okay so the first question is what was life like prior to Freda being diagnosed so erm you know what was your relationship like prior and so what is it like now

D9a: erm a lot easier the children had left home and were finding and I had just got my life back actually you know what I mean so erm yes so I was sort of planning for me and then all of a sudden erm it it just grows on you all of the you know you just think oh that's not quite right and you just check it out and all of a sudden erm your life is not for your life you know because it happens so slowly that erm yes but I was I was actually thinking the children have gone erm haven't got sort of the financial erm holds on me that I did have so I could actually I don't know go to the hairdressers spa you know just really treat me but no it wasn't to be (laughs)

I: it was kind of kind of your time

D9a: my time all went yes... and it and no more worries you see you think oh you know no more worries (D9a, BI, 17.5)

Carers felt the weight of their new role in terms of having to take responsibility for all the financial aspects, as well as the practical elements, of running the home. Even if the PWD helped with the chores, they still needed to be watched over. Many of the carers struggled with being solely responsible, and having to care for the PWD, in addition to adjusting to how their lives have changed since the diagnosis of dementia. This includes feelings of despair and hopelessness, not being able to see a way out or how the future will be:

M7b: um I mean obviously when you're told you've got it you sink into depths of despair and it must come over in waves for him, as it comes over for me, and we both have to give a bit more I suppose, I should give more than I do because I expect the same standard as I've had in the past and I've got to accept that I'm not going to get it, but he cannot reasonably see that he is being difficult where if you've got a normal mind you realise 'gosh I was a bit of a mean over there' but he cannot see that, he doesn't do anything wrong any more, it's me that's doing everything wrong (M7b, II, 6.42)

1.11.1.2 Changing plans

The diagnosis had also resulted in altering routines and life plans. Most participants had had busy, full lives before dementia had been diagnosed. Some participants who had already retired had to change their plans to fit in with the illness with carers struggling to come to terms with how their loved one was changing, while also having to observe the frustration that the illness caused that person. Overall there were feelings of sadness but also fear of the future and what it held:

M7b: it changed, I think it made us realise that were not young anymore and we've got to place the future we've got to think of wills and probates and we've been trying to sell our caravan and we've got some land that were trying to sell and so we can sort that money out and sort of beat the government with it if we can (laughs) I mean we put it into trusts for the children but now we've decided to sell it we can sort things out, but we've got to sort the future out. (M7b, BI, 15.19)

1.11.2 Major theme – Benefits of the group for carers

In terms of what the groups might bring, most were not sure what they expected of the group, if anything, while other participants hoped that it would give the person with dementia some stimulation:

*I: ok, um what are you hoping to get out of the group,
P20a: nothing actually (P20a, BI, 20.26)*

*A4a: yeah, it's stimulating Graham and the more he goes the more I expect it to
stimulate him more, and that's what I want*

I: yeah, so do you think its delivering that right now?

A4a: yes I think it is (A4a, I2, 1.31)

After an initial uncertainty most participants seemed to enjoy the groups and looked forward to going. Mainly it was the carers who decided that the PWD would go to the group with the hope that the groups might improve the symptoms of dementia. For themselves, carers felt they gained peer support in the group but also some respite as some used the time to get things done that would be difficult with the PWD with them.

1.11.2.1 Gaining peer support through the groups

Some of the carers attended the groups and used them to meet other carers. Some participants said it was nice to be able to speak to others who are in a similar situation as they are the only ones who really understand what they were experiencing, and they valued the peer support. In some cases even other family members had not yet accepted that their loved one had been diagnosed with dementia so almost denied it. Alternatively, some family members were supportive of the carer and helped where they could. One carer said that the group helped make her feel like she could cope, while another carer said that after not being able to see a future by the end of the group she felt like there was light:

I: So, if it changed your day on that day, tell me how, in what way?

*M2a: I just felt I could cope with anything. I just felt, Oh it can just float over my
head. It doesn't matter what happened it will float over my head. (M2a, FUI, 1.18)*

*M7a: I couldn't see a future and thought of my friends, so many of them are in homes,
and I thought of John down in Devon, how Elaine everyday took a bus into Tiverton
to sit with him and he didn't know her and she did this for months and months even
Christmas day, she got a taxi in to the nursing home, and sat with him and I could
only see that, a blank wall. But by the end of the music, how can I describe it, a
search-light going out at an angle, there was light. I know there is darkness there but
we're coping, we're living through it and the days when I'm in a really bad way are
tucked around the corner there but on other days I have this future this light. (M7a,
FUI, 6.19)*

1.11.2.2 Groups providing respite

The groups also allowed the carers a bit of time to themselves. It was generally felt that it was not a good idea to leave the PWD at home and that it would be too distressing for both carer and PWD to do so:

M11a: no because I can't leave Madam ... well I could but I don't know I'm I'm not shall we say putting my faith into her staying in the house and doing nothing (laughs) because ... it would cause terrible distress (M11a, BI, 20.33)

This of course meant that if the carer was not with the PWD then they needed to find someone else who could be with them. The group provided this for the carers as they could either stay at the group or leave the PWD there, knowing the staff would look after them. Some of the carers who stayed at the group found that group relaxed them in terms of taking part in the activities. This was also because the carers knew the PWD was happy and occupied so the carers felt that they were 'off duty' and as such could relax:

M7a: well the Alzheimer's changed his personality there's no doubt about that you know it's been changing for the last two years I suppose and it did get so bad eventually, doctor xxx, but on a Thursday he's back to his old self again, without a doubt, um its we're retired, we enjoy going out like that, and Thursdays is a good day that way, I think it stimulates him, it wakens something inside there which err does him good so therefore it does me good um its nice, he gets up Thursday mornings bright er chivvies me a bit to come on, I don't want to be late, and um and of course it rained every time I think we've been hasn't it, so you pad around there and err but as soon as you go in, there's so much warmth from the whole atmosphere when you go in you can feel this you can relax there's contentment and I think that helps a lot, you're very relaxed, I'm relaxed then which helps me, I'm not tense anymore, I'm not having to argue with him or suggest he does anything um so we can sit there and enjoy it and when we come out if its fine we can walk around Fareham but we've usually got somewhere else or something that afternoon to go to and so therefore it's a good day of the week and er he responds to it, so therefore it reflects back on me doesn't it, and I enjoy the music too, very much indeed and it's nice to sing the old songs, songs that he wouldn't sing years ago, but he sings now quite happily so that's done you good (M7a, II, 6.41)

Other carers chose to use the time to do tasks and chores that were more difficult when with the PWD with them:

A4a: yeah, well while he's attending er I'll probably pop down and do some shopping,

I: yeah so it'll give you a little bit of time to get some stuff done
A4a: yeah cos sometimes er Bill too tired to get out of the car and then I'm, all the time I'm aware, that he's on his own in the car, and if he wanders, I won't know where to look for him (A4a, BI, 13.17)

I: so for you how are you finding Dennis's attendance at the group?
A5a: Well it gives me an extra hour and half, to do other things that I find quite difficult to do, when we are together just an extra bit of time, really but erm yes that's basically what I get out of it I think
I: Okay so it gives you that opportunity to do bits and pieces that
A5a: yes
I: need doing but you don't
A5b: yes but I don't get around to necessarily doing them when Dennis around (laughs) (A5a, II, 0.1)

1.11.2.3 Hoping the groups would improve the symptoms of dementia

Another motivation for going to the groups was that carers hoped that it would help reduce the symptoms of dementia. This was a main driver for carers in that they would try anything that they thought (or had heard) might help to reduce the effects of dementia. It also seemed that not all carers had accepted the long term prognosis of dementia but hoped that it would improve. Carers reported that they liked the activities groups as it gave them a glimpse of the PWD before dementia:

I: so what do you hope to get out of the group Bill? If anything?
M7a: well I suppose if it helps with the Alzheimer's part and makes me feel less annoyed or short tempered or something that's what I was hoping the music ... would lull me down as it were (M7a, BI, 15.28)

M2b: Because it just goes on and on and on and on and he talks about things that have no relevance, he also sees things that aren't there erm and and you know I just so therefore I'm really quite pleased when he gets into a group (...) he doesn't last long he can't keep that up for very long but I'm really quite please even if it's just for 15 minutes, even if just for half an hour and hour erm it it's a little of the old Frank comes through erm and I feel then very relaxed because I feel I can leave him I can move away and do my own you know talking and that sort of thing whereas at home he appears to be very very needy very clingy which is totally unlike the person he was and worries about everything (M2b, II, 3.90)

1.11.3 Major theme – Benefits of the group for the person with dementia

There were three main positive benefits for the PWD in attending the groups. Firstly, carers reported that attending the groups improved the PWD mood and this could last for several

hours, if not until the next day. Secondly, although there was a problem in terms of some of the PWD remembering that they had been to the group, they still seemed to enjoy their time there. Thirdly, all of the groups had an outcome at the end of the course – the music group had a session with a local choir performance in attendance, the drama group held a play and the art group had a presentation. The participants felt very proud of their products of the groups.

1.11.3.1 Improving mood through interests outside of the home

Although the groups were not thought to be “*life-changing*” (A6a. I2, 3.9), carers reported that the PWD were happier after the group and this mood very often continued for the rest of the day. This had an impact on the couple’s relationship. One carer joked that she would like the PWD to have an hour of the group each morning. Some participants looked for other groups to go to as well because they realised that activities outside of the house helped the PWD, not only in terms of improving mood, but also that it kept them occupied and gave them a new interest. Most of the participants had busy diaries with lots of events and other commitments and this was one of the reasons why:

M11a: ... I’m certain I know, I don’t know if it applies to other people that, because of she feels inadequate, I mean I’m saying things here that might get me in trouble later ... um she’s better off out of the house ... so the more time, you can spend away from the home, the better you are ... um like, I won’t go into all the details of last Thursday but take it from me, the morning was a disas, absolute hell before we left this house, and we picked up Sheila and her husband ... and we drove, saw you first thing, you arrived more or less the same time didn’t you ... and in we went ... and within as soon as the atmosphere changed there, and the music, all the rest of it, her mood changed from a disaster to quite happy, (M11a, BI, 20.9)

I: yes yes so when Dennis won’t paint at home and stuff do you how does that make you feel?

A5a: well I just I don’t I don’t worry about it now anymore I just you know he doesn’t (...) he doesn’t want to do it at home so there’s no point in worrying about it really (...) if he’s happy doing it with other people then that’s fine (...) but I don’t say oh you know you’ve got all these why don’t you do it but (...) erm I might have done before. (A5a, II, 2.29)

A4a: ... but the reason for the art class was that I said he’d done it on that cruise and he’d had five hours and he painted a little picture cos this morning he asked me on the landing who painted the picture and erm I told him he had and he said oh, and

I'm hoping that where he had the stirrings of an interest in it before, these art classes might erm restart that interest again, cos that was a new interest to him (A4a, BI, 13.26)

1.11.3.2 Being with others who understand

Going to activities served several purposes for the PWD. Some participants enjoyed the activities as they brought back memories. Some enjoyed the 'hands on' aspects of the group in being able to play the instruments, sing or being able to paint. For most, an important part of the groups was the other people who attended. Participants enjoyed being with, and indeed felt more comfortable with, people who were going through the same thing and therefore had a better understanding of the problems. The group also provided someone other than the carer to talk to:

6a: and then get in a great big circle of chairs and Sandra leads exercises, vocal and simple stretching exercises and then we just sing, like today it's been themed as Burns night so we've been singing Scottish songs and we have some beanbags which we I think its coordination from one hand to the other, and then she has us passing them on which causes a lot of confusion (laughs) on the on like my Bonnie lies over the ocean my Bonnie lies over and then you've got to get one from there and then pass it, well some people just can't do it

6b: it's all about the timing

6a: so somebody finished up with a lap full of beanbags (laughs) and half of them don't have any (laughs) its good fun (A6a/b, BI, 18.22)

A5a: amazing changes but we get on I think the more the more Dennis gets to interact with other people it does make it easier at home then because if it's just us two sitting here looking at each other you know its erm it gets a bit sort of (laughs)

A5b: you see I used to

A5a: it's like you go to the stroke club and you always you always well there again you say (sigh) do I I don't think I'll go today and then he says yes he's had a nice day I like going there

A5b: (laughs)

A5a: they're all in the same boat so they're all you know they've all got the same problems more or less and its seeing people that he knows (A4b/a, FUI, 4.18)

Carers felt that the groups gave the PWD a bit of independence and the confidence to socialise with people again, as well as to make their own decisions:

I: Umm, overall what does, umm David attending this art group mean to you?

A4a: Me, the stimulation for him

I: and how does that make you feel?

A4a: good, that he's doing something instead of just coming out with me all the time and erm, that he's thinking for himself, cos when he's with me all the time he'll just say well "whatever you think", and I keep saying "it's not whatever I think, it's whatever he thinks", but because I am with him all of the time and I make quite a lot of the decisions then it's sort of just handing me the box and saying "right you do it" and this way he's making decisions on his own I mean even if it's only to decide whether to change the colouring he's paints or change the picture slightly that he's painting, it's a decision

I: mmm and how does that make you feel?

A4a: that makes me feel good, and knowing that he can do it (A4a, I2, 1.23)

1.11.3.3 Positive outcome regardless of memory

Most carers reported that the PWD did not really speak about the group afterwards as by the time they had got home or back into the car it had been forgotten about. This was not necessarily regarded as a negative aspect as the carer felt pleased that the PWD was happy while actually doing the activity. Some participants reported that the groups gave them as a couple something to talk about and gave the PWD something to focus on:

I: mm how does how tell me about how that makes what impact that has on you

A6a: its its terrible to think that he can't even remember what he's been doing for the last 2 hours I feel I feel for him because he's I mean I have to think to myself what was I doing last week at this time and I get a bit concerned but not to know what in fact I don't know how many times I've told him about you coming today, he just can't retain it can you,

A6b: what

A6a: your memory just won't retain what I'm telling you

A6b: sometimes it does can't remember often

A6a: (laughs)

A6b: but sometimes there's still hope dear (A6a/b, FUI, 5.22)

D9a: but that's not to say it's a bad thing because anything that stimulates and involves them, that is really positive, just because they don't remember they are happy, doesn't mean to say that its negative the fact that we're happy

I: for that moment

D9a: yes that is the best thing ever

I: yes because I like to think that even if you can't remember why you're happy the fact that you were happy then promotes positive emotions

D9a: inside of the brain yes

I: produces a positive erm affect and therefore

D9a: you feel needed and sociable and part of

I: and feel better

D9a: yes

I: about

D9a: everything yes (D9a, FUI, 8.7)

I: so how do you feel about it the fact that the group isn't there anymore
D10a: well I feel a bit upset
I: mm
D10a: you know for my mum
I: yes
D10a: not for me for my mum because at least it gave her something to focus on
I: mm
D10a: other than her in her world sort of thing (D10a, FUI, 2.9)

1.11.3.4 Feeling proud of ability

Both carer and PWD were proud of the product of the group, especially with the art group as they liked that they could show off the cards to friends and family, perhaps as a way of saying that the PWD was still able. However, not many people carried on doing the activities outside of the groups but preferred to do them during the group with other people around:

I: and you've got the cards that you've produced
M2a: yeah, but that's not fair
M2b: yeah
M2a: our Keith took one off yesterday, didn't yah
M2b: it's a relief
M2a: yeah
I: so how....how does it feel to have those cards?
M2a: I think it's great, the kids are knowing that I was getting some more and they were thrilled to bits when they saw the first one
I: and how does that make you feel Keith? Having these cards that, you know, other people can look at and see what you've....see what.....see what you've achieved?
M2a: Proud
M2b: proud in myself and made up
M2a: it makes me proud of him
M2b: for achieving that
M2a: don't it?
M2b: yeah (M2a/b, I2, 1.17)

A5a: well that's why the painting is good
A5b: yes I didn't realise I was so good
A5a: (laughs)
I: but I mean well you've produced some good paintings haven't you
A5b: I've quite enjoyed it yes
A5a: yes (P5/b, I2, 2.12)

1.11.4 Major theme - Practical aspect of the groups

1.11.4.1 Losing the groups

The prospect of the group closing and what it would mean for the participants was already being brought up by the second interview, with some of the participants exploring how far they could feasibly travel if their group moved location rather than ended. Some couples thought they would look for other groups once these had finished or thought about booking Dial-a-ride to take them to the group, whereas others thought they were already busy enough and would not look for a new group. Some participants reported that they missed the groups when they finished and the people that they had made friends with, that there was “*quite a gap in the week*” (A6b, FUI, 5:13). Most participants said they would attend another group if it was organised. It was also suggested that the participants would be happy to pay towards the groups. Sadly, some carers felt that the PWDs health had declined since the end of the group:

A6a: but say he was going to somewhere in Portsmouth or in Havant it would be worth the journey wouldn't it

I: because at the moment he's kind Southampton way, so it's Romsey and Hythe and the New Forest which so I don't know

A6b: he comes from Sway doesn't he, and we know Sway and it's quite a journey...

A6a: if you had to go all that way, it's too far for you to go

A6b: I'd probably travel, I mean if it was Portsmouth, you know Southsea and even Chichester, I'd probably be happy to do it then but as you say if he's running it down Southampton that will be little out of our way (A6a/b, II, 6.9)

A5b: looking for, see we're not painting

A5a: yes that's it he's missing the painting

I: really

A5a: yes

A5b: do you know we had a good, see that was the thing about painting it was a good crowd in there I mean I don't know it was just nice

A5a: you enjoyed that didn't you?

A5b: yes very nice

I: so not so not just the painting, the crowd

A5b: the crowd

A5a: the company yes (A5a/b, FUI, 4.1)

I: whether the drama group being in her life had any impact?

D10a: not now no

I: no

D10a: no she's gone back she's reverted back to what she was before but even worse

now you know she wasn't interested in anything she's not interested in anything
I: was she when the drama group was going on
D10a: yes
I: you think she was
D10a: I think she was
I: in what way
D10a: I think she's more sort of her mind was more alert but now its deteriorated
right down its gone down quite a bit in the last couple of weeks
I: mm
D10a: this is why I now have to make sure there is nothing happening any more than
it has done or her condition has worsened (D10a, FUI, 2, 5)

1.11.4.2 Practicalities of the group

Participants also talked about the practicalities of the group. They liked that the Art group building had two rooms although participants thought that the small room got quite noisy and this could cause problems for hearing. There was praise for the facilitators of the art and music groups. Some PWD found the groups tiring, in fact one person had a nap while there, although some carers would like the sessions to be longer.

A6a: erm well the small room works if we leave it must work better for you but the big
room because we were quite a long way away from the group, and that worked as
well
I: so what did what did that provide for you then with the bigger room
A6a: erm well just the same we were able to talk more comfortably and easily,
because there was a distance between us all, whereas I say the smaller room is very
nice if we leave during I'm sure that must be nicer for people doing the group doing
the art because its its more cosy isn't it
I: mm in what as in the small group the small room is nicer for them
A6b: just for them on their own, it doesn't really suit for two groups to be in there at
once I don't think, you get cross feeding you know, no matter how careful you are the
sound gets across and its disturbing
A6a: and also some of the cared for and one particularly he's always looking towards
this area and whereas if she's not there (A6a/b, 11, 5.7)

Not all of the carers went to the groups because some of the groups were based at the day care centre where the PWD would go anyway. The effect of this was that the carer did not learn what the PWD had been doing as usually the PWD could not remember and the carer may not want to ask them in case it caused the PWD stress in trying to remember:

I: mm okay so have you noticed any problems with erm the group that the group has
had or I mean because this is slightly
D8a: nobody has said anything to me I mean I've spoken to Jill and Terri, the girls
who pick him up and that

I: yes

D8a: and I said what he like and they said he no problem at all

I: mm

D8a: and that's all I get really (D8a, II, 7.4)

I: okay have you asked her any questions about the drama

D9a: no no we just you know was it alright have you enjoyed yourself yes yes no

I: okay

D9a: because I feel that if she doesn't remember I to plug things erm it might cause her stress and she you know she still does get quite upset you know if something's happened and she remember it and she doesn't even its not as if she's ever been married and had children she thinks my dad's her brother (D9a, II, 8.3)

1.11.5 The experience of the research process

During the follow up interviews, carers talked of feeling generally unsupported in terms of taking on their new role of carer. Some said that being a part of the research was good as it gave them the chance to talk to someone outside, and they felt that it gave them a purpose. This was an unexpected finding but poses the questions around carers needing more support in terms of being able to talk through their experiences:

I: yes so what have you liked about the research project

D10a: I've liked the just he interacting and talking to you knowing that you most probably after today as well seeing mum obviously that when I talk when I actually talk to you I like to share it with you because I can't talk to anyone else, apart from my husband, and erm my brothers just yes yes no (laughs)

I: so so do you think what does talking to me give you

D10a: it helps me, it helps me through you to sort of not vent my anger or anything but just the frustration of it all, you know now you know

I: okay and you can do that with me why and not someone else

D10a: because I don't see anyone else (laughs), I mean I talk to Jackie obviously but I mean the only subject with her is and it will be what mums been up to

I: yes so you can't necessarily talk about you and how you feel

D10a: mm she knows I've got problems (D10a, FUI, 2.17)

I: What I want to know if whether being part of the research process, having conversations with me has been beneficial to you?

M11a: I believe so and I'd like it to continue as it makes me more relaxed, that we something I want to speak to you about as I said before.

I: OK, in relation to having these conversations, what is it that makes the difference from conversation with me to having conversations with your peer support people or anybody else.

M11a: Because you are completely and utterly neutral, because you're not reacting

because the peer group and people in it may have had some of the same problems and all the rest and we all react differently, as different individuals, so they will sometime react and tell you things they think you want to hear, well you're not doing that if that makes sense. (M11a, FUI, 3.17)

10. Conclusion

The interviews and observations have drawn out the aspects of attending the creative art groups that were important to the participants. The themes from the interviews highlight aspects of the groups that were important to both the carer and the PWD and the themes from the observations reflect these aspects within the activity of the groups. The practical aspects of going to the groups were also discussed and there are some points that can be taken in to consideration if future groups are to be organised. These points include the use of different rooms for the groups and the length of the sessions (Participant A4a suggested the sessions could be two hours long for example).

Overall, for the carers, they were affected by changes in their life such as learning to cope with their new role as carer and life plans that had to change to accommodate the symptoms and prognosis of their loved ones illness. Carers gained valuable peer support through the groups, which allowed them to talk to other people who were having similar experiences and so understood what they were coping with. The groups also allowed the carers a limited amount of respite, if they wanted it and this allowed them to carry out tasks and chores that were difficult to do when with the PWD. One of the main hopes that carers had of the groups is that the activities would alleviate the symptoms of dementia for their loved one.

The themes of the interviews suggest positive outcomes of the creative art groups for the PWD and these are reflected in the themes of the observations. The creative art groups appear to improve the mood, not just of the PWD but also of the carer, and there are several proposed reasons for this. The PWD also enjoyed being with other people in the same or a similar situation. They felt that they could relax in this company as there was an understanding of their capabilities, with no pressure of expectation on them if their symptoms caused them any difficulties with either interacting with the others in the group or with taking part in the activity itself. Although several of the PWD did not seem to be able to remember the activity groups later in the day or the next day, this did not seem to be a concern as they

had mostly enjoyed their time while they were at the group and so this made the carers happy too.

Based on these findings would it be worth the Alzheimer's Society's consideration around developing certain aspects of the creative art groups as this type of group has the potential to help address some of the tensions and problems experienced by PWD and their carers. For example, it could be ensured that the groups are developed with an understanding around what the objectives of the activity are, as well as what the participants are capable of achieving. For example, avoiding asking members to write down their thoughts when they have lost the ability to write well, or not setting homework for a person with a cognitive impairment when their carer is not present. As mentioned earlier, choosing an activity that was suitable for a person of any ability could be significant as not only did this aspect of the groups surprise family members and Alzheimer's Society staff but it appeared to give members increased levels of confidence and pride in their achievements. This could be a very important message as even members of staff offering activities to people with dementia can have the best intentions but may still presume that the person cannot perform certain tasks, without exploring this further.

Furthermore, a structured approach to the classes may be helpful as a changing structure could be confusing. A consistent, familiar structure may encourage fuller participation of the group members as they know what to expect. Finally, an additional unexpected finding of this project was that the process of being involved in the research seemed to be cathartic for the carers in particular. Carers generally felt that they did not receive the correct external support around becoming a carer. What the correct external support is really needs to be explored in more detail but it became apparent during the interviews that the carers utilised this opportunity to talk through their worries and stresses with a person to whom they had no emotional connection. If this type of arrangement could be integrated in to the creative art group setting then this could resolve some of the major tensions of the carers too.

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1.11.6 Appendix 1 - Innovation fund report and reflection from Matt Smith

Text in italics is from original project document.

<p>Original brief and my role</p>	<p><i>The University of Portsmouth will evaluate a Creative Arts Service for people with dementia and their carers. The service, encompassing a variety of creative and expressive activities from poetry to visual arts, will include workshops and performance. Drama workshops will involve gentle movement to music and drama games, evolving into a performance featuring storytelling in character, role-play, mime and physical theatre. Audience participation is encouraged but not essential. The sessions can be used as a discussion stimulus about real life issues that people can face.</i></p> <p>In relation to this project my role was to support the practitioner Rachel Goodhall in her delivery of the sessions. I was in the role of consultant and mentor.</p>
<p>Perceived benefits</p>	<p><i>Benefits include:</i></p> <ul style="list-style-type: none"> • <i>engagement & communication</i> • <i>improved confidence & wellbeing</i> • <i>improved general health</i> • <i>use of imagination & emotional engagement</i> • <i>opportunity to discuss difficult topics</i> <p>The engagement of the drama group was a difficult task, but was approached in an innovative way. Communication was encouraged but often involved a great deal of sensitive practical methods in the session. There is a fine line between encouraging and coercing communication in group based practice.</p> <p>The confidence of both the practitioner and the group developed through the sessions. This was profound during the performance celebration where partners and carers were present. If laughter and smiles are indicators of wellbeing there was evidence of this in the sessions.</p> <p>Through my encouragement Rachel explored some areas of drama that are challenging and imaginative. Using objects and masks in theatre practice can be powerful for participants and the audience. The use of objects and developing devised material with the group provided some very authentic and emotional material in the sessions.</p> <p>The use of Rachel as performer and character was very innovative and powerful as she explored issues of dementia through her performance. This provoked discussion around the</p>

	<p>issues. Then the difficult task was to use the reactions to develop further creative material with the group. As a forum for discussing issues of dementia the drama was provocative and direct. As a social practice drama can provide a space for discussing our states of being. In this project the drama work did affect this outcome. I saw a great deal of participants coming out of their shell and reacting to the drama in the space.</p>
<p>The way the partnership worked</p>	<p><i>This project forms a partnership between the Alzheimer’s Society, University of Portsmouth, and Red Sauce Theatre Company.</i></p> <p>I found my position in relationship to the partnership unique in my experience. In supporting the drama practitioner I often helped in making sense of the partnership. The partnership did mean that the arts practitioner was dealing with the pressures of the needs of the group, the research project and the Alzheimer’s Society. At times it meant that the aims were blurred in the process. My emphasis in meetings with Rachel was to encourage her to focus on the group and the creative process rather than the external pressures of the project. Advice from other members of staff connected to the project was very useful and welcome but did not always present a consistent view between individuals. For artists working within this context the need to have the opportunity to reflect effectively and discuss their own issues is a very important resource in this type of practice. The pressures and criticism of the drama practice did enable the delivery of the sessions to improve towards a very positive outcome, especially on the final session.</p>
<p>Reflection on project</p>	<p>Overall I was pleased with Rachel’s reaction to the way we worked together in consultation on this project. I was also very pleased to see the way that research can positively inform practice as it is happening. This is a difficult terrain to cover when individual’s agency is part of the process. This is one of the demanding aspects of applied theatre. Having the slightly unusual relationship to the project through my role as mentor was an important learning experience. Thankfully Rachel was very open in her feedback about how I was affecting her practice.</p> <p><i>Thank you so much Matt for taking the time to write up your feedback. It is fantastic for me to have your help!! Really appreciate all your comments and ideas, which I intend to use. I am really fortunate to have this experience! (email exchange)</i></p>

Future and legacy

If the outcome of this six-month project demonstrates that 'creative and performing arts' activities would be a beneficial addition to our services in accordance with the Alzheimer's Society's outcomes as defined in our Five-Year Strategy, funding can be sought from other sources.

The staff in the day centre clearly wanted the drama work to continue and this feels like a strong incentive to continue sessions. The role of creative consultancy feels as though it could continue and I would be very keen to develop this further. This could be in the form of practice as research as well as collaborating with other research disciplines. Through discussions it feels as though with the drama practice the research was only just beginning and needs much more development. I would be interested in developing this further.

My suggestions for future

- Host an event at Eldon to discuss findings of project and possible new projects.
- Develop other links in project – for example New Theatre Royal.
- Develop a yearlong project for the work to develop more fully.
- Continue to use UOP in both consultancy and research roles.

I would like to thank all those involved in this project and I was very pleased to have been a part of this challenging work.

Matt Smith October 2014

1.11.7 Appendix 2 – Observation Schedules

Study Title: Hampshire Creative Arts Project for People with Dementia and Their Carers: A Qualitative Evaluation

Observation Schedule – Music Group

Participant Number

Code **Brief description of behaviour**

The categories below are a guide to possible descriptions of observed behaviour, however a fuller description of the observation will be added to the noted section found below each list of behaviours.

MUSIC RELATED ACTIVITIES

- a. moving to music e.g. tapping on fingers, feet etc
- b. singing
- c. clapping
- d. whistling
- e. no observable response to music
- f. any other movement indicating engagement with the activity

NOTES

a.
b.
c.
d.
e.
f.

OTHER ACTIVITIES

- g. Sleeping

- h. Walking
- i. Standing
- j. Sitting
- k. Other (Described below)

Notes

g.
h.
i.
j.
k.

NEGATIVELY PERCEIVED BEHAVIOURS

- l. Individually-defined challenging behaviours
e.g. repetitive conversational themes, moving furniture
- m. Physical aggression behaviour observed
- n. Loud repetitive vocalizations/verbal aggression
- o. Inappropriate (sexual) behaviour
- p. Perseveration/talking to oneself
- q. Walking
- r. Other (described below)

Notes

l.
m.
n.

o.
p.
q.
r.

INTERACTION

FACILITATOR

- s. Patient initiated Interaction with facilitator (s)
- t. Facilitator interaction with patient
- u. Ignores input from facilitator (s)
- v. Other (described below)

Notes

s.
t.
u.
v.

OTHER GROUP MEMBERS

- w. Interaction with other group members (patient initiated, group member (initials))
- x. Ignores input from others

Notes

w.

x.

Adapted from Taylor-Powell & Steele (1996).

Study Title: Hampshire Creative Arts Project for People with Dementia and Their Carers: A Qualitative Evaluation

Observation Schedule – Drama Group

Participant Number

Code Brief description of behaviour

The categories below are a guide to possible descriptions of observed behaviour, however a fuller description of the observation will be added to the noted section found below each list of behaviours.

DRAMA RELATED ACTIVITIES

- a. participation in story telling
- b. joining in with drama movements
- c. clapping hands
- d. emotional reactions, no verbal e.g. smiling, crying, laughing
- e. no observable response to drama
- f. any other movement indicating engagement with the activity

NOTES

a.
b.
c.
d.
e.
f.

OTHER ACTIVITIES

- g. Sleeping
- h. Walking
- i. Standing
- j. Sitting
- k. Other (described below)

Notes

g.
h.
i.
j.
k.

NEGATIVELY PERCIEVED BEHAVIOURS

- l. Individually-defined challenging behaviours
 - e.g. repetitive conversational themes, moving furniture
- m. Physical aggression behaviour observed
- n. Loud repetitive vocalizations/verbal aggression
- o. Inappropriate (sexual) behaviour
- p. Perseveration/talking to oneself
- q. Walking
- r. Other (described below)

Notes

l.
m.

n.
o.
p.
q.
r.

INTERACTION

FACILITATOR

- s. Patient initiated Interaction with facilitator (s)
- t. Facilitator interaction with patient
- u. Ignores input from facilitator (s)
- v. Other (described below)

Notes

s.
t.
u.
v.

OTHER GROUP MEMBERS

- w. Interaction with other group members (patient initiated, group member (initials))
- x. Ignores input from others

Notes

w.

x.

Adapted from Taylor-Powell & Steele (1996).

Study Title: Hampshire Creative Arts Project for People with Dementia and Their Carers: A
Qualitative Evaluation

Observation Schedule – Art Group

Participant Number

Code Brief description of behaviour

The categories below are a guide to possible descriptions of observed behaviour, however a fuller description of the observation will be added to the noted section found below each list of behaviours.

ART RELATED ACTIVITIES

- a. drawing in pencil
- b. painting
- c. choosing a picture
- d. no observable response to art group
- e. any other indicator engagement with the activity

NOTES

a.
b.
c.
d.
e.

OTHER ACTIVITIES

- f. Sleeping
- g. Walking
- h. Standing
- i. Sitting
- j. Other (described below)

Notes

f.
g.
h.
i.
j.

NEGATIVELY PERCIEVED BEHAVIOURS

- k. Individually-defined challenging behaviours
 - e.g. repetitive conversational themes, moving furniture
- l. Physical aggression behaviour observed
- m. Loud repetitive vocalizations/verbal aggression
- n. Inappropriate (sexual) behaviour
- o. Perseveration/talking to oneself
- p. Walking
- q. Other (described below)

Notes

k.

l.
m.
n.
o.
p.
q.

INTERACTION

FACILITATOR

- r. Patient initiated Interaction with facilitator (s)
- s. Facilitator interaction with patient
- t. Ignores input from facilitator (s)
- u. Other (described below)

Notes

r.
s.
t.
u.

OTHER GROUP MEMBERS

- v. Interaction with other group members (patient initiated, group member (initials))
- w. Ignores input from others

Notes

v.

w.

1.11.8 Appendix 3 - Interview Schedule 1

Participant number

Verbal explanation of project & process: YES í NO í

Written information given: YES í NO í

Consent Form signed: YES í NO í

1. Briefly describe the project again before starting the interview:

“I would just like to go over the project and what we will be doing today again with you, before we start the interview. This study is looking to evaluate creative arts groups run for people with dementia. I am here today to talk to you about how you found out about the group as well as your experience of attending the group.

If there are any questions you do not want to answer, you do not have to. I would like to stress that there are no right or wrong answers and I am interested to hear about your experience and opinions. I will tape record the interview so that I can remember all that has been said. I would also like to remind you that the contents of your interview will be kept confidential and that you are free to withdraw at any time. If at any time you wish to stop the interview you may either ask me to stop the tape or you may stop it yourself. Do you have any questions before we begin?”

2. Check interviewee ready to start interview.

3. Test recording equipment.

Semi-structured interview schedule – Interview 1

The following is a brief overview of the topic areas to be considered. It is likely that the content of the interview schedule will develop and may incorporate other areas as the researcher reflects upon each interview as it takes place. It is also likely that the order in which the topics are addressed may change according to the flow of the interview.

The prompts/explore sections in italics will be raised only if not covered spontaneously by participants.

Living with a partner who has dementia

1. Can you tell me what life was like with your partner before they were diagnosed with dementia?
 - a. *Have you noticed any changes to daily life, or not?*
 - b. *Have you noticed any long-term changes, or not?*

2. Has the diagnosis made any difference to your life together now or not?
 - a. *If so, can you explain the differences?*

Attending the creative arts group

3. How did you hear about this creative arts group?

4. How was the decision made for your partner to take part in the creative arts group?
 - a. *Was it suggested to you that you both attend the creative arts group? Or did you and/or your partner make the decision?*

5. What are you hoping to get out of the group?
 - a. *Has it met your expectations so far?*
 - i. *If so, can you explain how?*
 - ii. *If not, can you explain why not, and what were you expecting?*

6. What is your partner hoping to get out of the group?
 - a. *Has it met your partner's expectations so far?*
 - i. *If so, can you explain how?*
 - ii. *If not, can you explain why not?*

Other groups attended

7. Does your partner attend, or have they attended any other groups?
 - a. *Which groups do they attend?*

- b. What happens at that group?*
- c. What do you and your partner think about that group?*
- d. How often do they attend that group?*

Thank individual for participating in the interview. Inform participant of what will happen next. Arrange next interview slot (if applicable). Assure him/her of confidentiality of responses.

SWITCH OFF TAPE RECORDER

1.11.9 Appendix 4 - Semi-structured interview schedule for Interview 2, 3 and 4.

Participant number

Verbal explanation of project & process:	YES	í	NO	í
Written information given:	YES	í	NO	í
Consent Form signed:	YES	í	NO	í

4. Briefly describe the project again before starting the interview:

“I would just like to go over the project and what we will be doing today again with you, before we start the interview. This study is looking to evaluate creative arts groups run for people with dementia. I am here today to talk to you about how you found out about the group as well as your experience of attending the group.

If there are any questions you do not want to answer, you do not have to. I would like to stress that there are no right or wrong answers and I am interested to hear about your experience and opinions. I will tape record the interview so that I can remember all that has been said. I would also like to remind you that the contents of your interview will be kept confidential and that you are free to withdraw at any time. If at any time you wish to stop the interview you may either ask me to stop the tape or you may stop it yourself. Do you have any questions before we begin?”

5. Check interviewee ready to start interview.

6. Test recording equipment.

Semi-structured interview schedule – Interview 2, 3 and 4

The following is a brief overview of the topic areas to be considered. It is likely that the content of the interview schedule will develop and may incorporate other areas as the researcher reflects upon each interview as it takes place. It is also likely that the order in which the topics are addressed may change according to the flow of the interview.

The prompts/explore sections in italics will be raised only if not covered spontaneously by participants.

- 1) Do you think attending the group has changed your life in any way?
 - a) If so how
 - b) Could you describe the difference it has made to you
 - c) Could you describe the difference it has made to your partner
- 2) If you think there has a change to your life what do you think is responsible for the change?
- 3) Do you think that attending the group has had any demonstrable effect in your partners life?
 - a) Independence – if so how?
 - b) Socialisation – if so how?
- 4) Overall what does your partner attending a creative arts group mean to you?
- 5) In your opinion, who do you think gets the most out of attending the group?
 - a) Why ?
 - b) How?
- 6) Has your relationship changed in any way since your partner started attending this group?
 - a) If so how?
 - b) Could there be any other reason for this change?
- 7) Did the group deliver what you expected?
- 8) Is there a question you would have liked me to ask which I haven't?
- 9) Is there anything you would like to add that you think we should know or think about?

Thank individual for participating in the interview. Inform participant of what will happen next. Arrange next interview slot (if applicable). Assure him/her of confidentiality of responses.

SWITCH OFF TAPE RECORDER