

# **Specialist Music Workshops for People Living with Dementia and their Relatives/Carers – an Evaluation**

**January – July 2022, at the GAP project, Broadstairs, Kent**

This study was not a formal research project, but an evaluation of a series of workshops inspired by the use of music with three main aims:

- i) for people living with dementia and their relatives/carers to have an enjoyable and meaningful time together outside of their usual roles of carer and being cared for;
- ii) for the relatives and carers to learn methods of using music to improve the quality of life of those they care for and themselves;
- iii) to create tools to facilitate this, ie a book of favourite songs and related pictures and life stories to sing and talk about with family and friends, a poster with images from reminiscences inspired by singing; and attractive posters with words to poems inspired by listening to music.

The workshops were inspired by four chapters from a book edited by the project facilitator which was published in 2020: “Living Well with Dementia through Music – a resource book for activities providers and care staff” (Richards). The chapters are written by music therapists Alison Acton and Harriet Powell, and dance/movement therapist Nicola Jacobson-Wright (see references below).

The funding from the Music Therapy Charity supported the work exploring methods of data collection and analysis, compiling a questionnaire and analysis of the data, and the work involved in writing up the project.

## **Research Questions**

The study aimed to answer the following questions:

- (i) Can music workshops which include training for caregivers make a significant impact on the wellbeing of people living with dementia?
- (ii) Can they make a significant impact on the wellbeing of caregivers?
- (iii) Can they help to improve the care given at home?

## **Research Hypotheses**

Underpinning the study were the following research hypotheses:

- (i) Music has the potential to play a significant part in improving the quality of life of many people living with dementia and their carers/relatives (Bowell and Bamford, 2018, Hsu et al, 2015, Ridder et al, 2013).

(ii) Music can provide an enjoyable and meaningful way for people living with dementia and their carers/relatives to come together outside of their usual roles and interact with others facing similar issues (Unadkat et al, 2017)

(iii) If given adequate support and guidance, carers/relatives can use music to good effect as part of the care they give in the home (Grady and Melhuish, 2020)

(iv) This can be helped by the creation with the couple of personalized tools for use in the home (Acton, 2020, Powell, 2020)

## **Dates**

The project was about to start in April 2020, but had to be postponed due to Covid 19. The workshops were able to start in January 2022, and continued until July 2022.

## **Methodology**

Questionnaires were completed before and after the workshops – the DEMQOL was used for the people living with dementia, and the C-DEMQOL for the carers. These questions are designed to ascertain whether or not the sessions have contributed to increased psychological well-being, motivation, relaxation, stimulation, enjoyment and overall quality of life. There was also a questionnaire designed to collect some demographic information about the person with dementia, including their age and the type of dementia with which they were diagnosed. A questionnaire was also designed for the carers in order to clarify their role and the amount of time spent caring for the person with dementia. In addition, each pair of participants completed together a questionnaire with specific questions about their experience of the workshops and their resulting use of music and the tools created at home.

## **Recruitment**

Participants were initially recruited from post-diagnostic support groups at the Thanet Mental Health Unit where I work, and the GAP project who funded the workshops. In April 2020, there were 13 referrals, however by the time the workshops were able to take place in January 2022, the circumstances had changed for many of these couples, with some people passing away and others experiencing more severe symptoms of dementia, so that their carers felt that they would not be able to focus sufficiently to benefit from the workshops. However, there was a sufficient number expressing an interest in attending to plan to begin the workshops, and I reduced my days working for the NHS in order to free up time to start the work. There was then a significant spike in Covid cases between the middle of December 2021 and the beginning of January 2022, and this is likely to have prevented some couples from attending.

In the end, two couples attended out of those initially referred, and new participants had to be recruited from scratch as the workshops were starting. At this time, social distancing was observed, and discussions had about whether those attending would prefer masks to be worn.

The post-diagnostic support groups in Thanet were no longer running due to Covid, however some referrals came from the community team. Most new referrals came from word of mouth from participants and carers already attending just after the start of the workshops. There was a total of 7 couples who attended during the 6 months. Three couples started at the beginning of the workshops, and stayed until the end. In addition, one of the carers brought 2 people with dementia to the groups, so those able to complete the questionnaires were 3 carers and 4 people living with dementia.

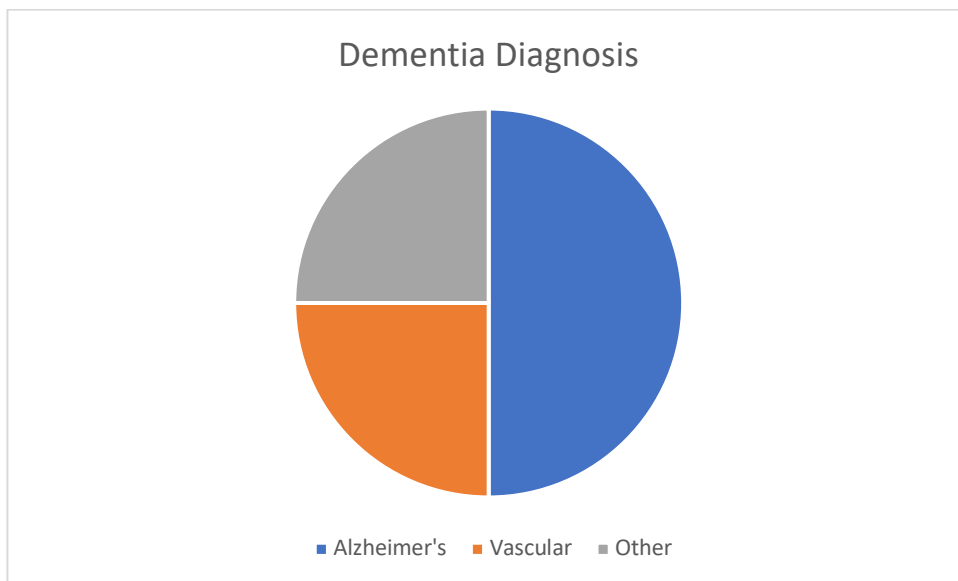
## Data Analysis

The results were analysed using statistical analysis. As part of this, the DEMQOL and C-DEMQOL results were analysed using a two-tailed T test, which showed if the means of scores from each questionnaire were significantly different.

## Summary of Results

### Demographic information

Of the participants with a diagnosis of dementia (N=4), 75% were female. Two had a diagnosis of Alzheimer's Dementia, one had a diagnosis of Vascular Dementia, and one had a diagnosis of another type of dementia (not mixed, lewy body or frontotemporal dementia). The time since diagnosis ranged from a year and a half to 5 years.



Three carers took part in this study (one was the carer for two people with dementia). They had a variety of relationships with the people they cared for; daughter, spouse and a professional carer. The hours that they spent caring for the people with dementia also ranged from 1-5 hours per week, to 25+ hours per week.

### CDEMQOL

For 2 out of 3 of the carers, the CDEMQOL total score improved following the music workshops, and the average or mean score of all participants improved across all subcategories (see figures in bold typeface). However, this is not considered a significant change, as the “p” value (see right hand side

of table) representing the probability that these results could have happened by chance, is more than 0.05.

Where there were missing responses, subcategory scores were averaged using the CDEMQL measuring tool provided by the developers of this measure.

	Time Point A				Time Point B				Two-tailed T-test		
	Mean	SD	Min	Max	Mean	SD	Min	Max	t Stat	df	p
<b>CDEMQL (Total)</b>	<b>94.30</b>	18.10	73	106	<b>98.33</b>	18.01	80	116	-1.02	2	0.42
<b>Meeting personal needs</b>	<b>14.67</b>	7.57	6	20	<b>15.33</b>	7.23	7	20	-2	2	0.18
<b>Carer wellbeing</b>	<b>17.93</b>	5.48	12	23	<b>19.67</b>	4.51	15	24	-0.74	2	0.54
<b>Carer-patient relationship</b>	<b>24.33</b>	3.06	21	27	<b>24.67</b>	5.51	19	30	-0.23	2	0.84
<b>Confidence in the future</b>	<b>18.67</b>	4.04	14	21	<b>19.67</b>	3.21	16	22	-1.73	2	0.23
<b>Feeling supported</b>	<b>18.67</b>	2.52	16	21	<b>19.00</b>	2.00	17	21	-1	2	0.42

#### Wellbeing of People with Dementia

The total QOL score (as measured by an adapted version of the QOLAD) decreased following the music workshops. Again, this change is not considered significant.

	Time Point A				Time Point B				Two-tailed T-test		
	Mean	SD	Min	Max	Mean	SD	Min	Max	t Stat	df	p
<b>Total Quality of Life Score</b>	<b>27.5</b>	3.87	22	31	<b>25.5</b>	2.08	23	28	1.26	3	0.30

#### Responses to evaluation questionnaire

Question	Percentage of responses			
	Not at all	A little	A fair amount	A lot
How much did the person you care for enjoy coming to the music workshops?				100%
How much did you enjoy coming?				100%
How much did you both enjoy the workshops as a way of spending time together?				100%
As a couple, how much did you enjoy the following activities:				
Singing?				100%
Reminiscing?				100%
Making your scrap book?				100%
Making your poster?			25%	75%
Reading poetry written by others?			33.3%	66.6%
Creating our own poems		33.3%	33.3%	33.3%

	Moving to music following directions?				100%
	Creating our own movements to music?				100%
	Have the music workshops had a positive impact on the wellbeing of the person you care for?				100%
	Have they had a positive impact on your own wellbeing				100%
	Have they had a positive impact on your relationship?				100%
	Have you been using music more often during the time you spend together outside the workshops?			50%	50%
	Are you likely to in the future?			50%	50%
	How much confidence would you say you have now about using music as part of your role as carer?				100%
	Have you been able to use the scrap book/poster/poems together and/or with others?			25%	75%
	Are you likely to do so in the future?			25%	75%

Question	Percentage of responses			
	Very unlikely	Possibly	Quite likely	Very likely
How likely are you to attend other music activities in the community as a result of the music workshops?		25%	25%	50%

Comments:

Have you been able to use the scrap book/poster/poems together and/or with others?

- "Showing family and friends (mum's proud to show it)"

Are you likely to do so in the future?

- "Mum forgets that she's already shown people"
- "Will keep music activities going in a slightly different format until music sessions restart"
- "Whenever we get the opportunity"

Do you have any other comments about the music workshop?

- "We both loved it hope it can continue"
- "Excellent - I feel for clients and carers we need more available for people to attend. Cathy was excellent"
- "Client benefited greatly. Felt valued & contributions she made were welcomed. She didn't want group to finish. Fantastic teacher"
- "Brilliant workshop, very engaging for every client. Thoroughly enjoyed coming each week. Positive results."

### **Key themes and findings:**

This study used only a very small sample, and for the results to be more reliable a larger sample would be needed. However, it is clear from the results of the last questionnaire that all the participants gained a considerable amount from the workshops, and it would appear from this that all the hypotheses above are correct, and that the answer to each of the questions is “Yes”. Participants especially enjoyed singing, reminiscing, creating their scrap book of songs and related stories and images, and movement to music. The carers all felt very confident about using music as part of the care they offered, were already using the tools created at home and were likely to do so in the future.

There is, however, a noticeable contrast between these results and those shown by the DEMQOL and C-DEMQOL. Some possible reasons for this are:

- (i) Dementia is a progressive disease, and without the music workshops the wellbeing of the people with dementia may have deteriorated further, and there might not have been the small improvement in the wellbeing of the carers. It may be useful for future research of this kind to include a control group so that comparisons can be made.
- (ii) It is possible that the sense of support, hope for the future etc asked about in the DEMQOL and C-DEMQOL questionnaires may have decreased partly as a result of the fact that the workshops were about to end.
- (iii) This project raises the question as to how best to capture the general level of wellbeing of people living with dementia and their carers. The C-DEMQOL questions in particular are quite long and in-depth, and it was difficult to be able to facilitate the time to do them justice during the workshops. They felt like a chore to be completed as quickly as possible. In any future research, I would like to devise a method which can be better integrated into the workshops as a whole, perhaps periodically recording short discussions.
- (iv) Through informal discussions with the carers, it was clear that issues and challenges unrelated to the workshops arose during the 6 months between questionnaires, for example physical health needs, transport issues, the need for respite care, and caring for children in addition to a mother living with dementia. As one carer commented as she completed the C-DEMQOL at the end: “Music is great, but it’s not everything is it?” It is therefore suggested that for the work of music therapists and workshop facilitators to have the greatest impact, we need to be working more closely together with staff from community teams and facilities to help to identify and meet as many as possible of the needs of the people with whom we are working.

### **Developments as a result of this study:**

Both the participants and the workshop funders at the GAP project were keen for the music workshops to continue, and discussions are currently taking place with new music workshop facilitators. In my work for Kent and Medway NHS and Social Care partnership Trust (KMPT) with older people on mental health wards, we are starting to work more closely with community services both within and outside the NHS, to look at ways in which service-users get the support they need after discharge. I have begun using poetry alongside music in some

of my individual and group work as a music therapist. I have demonstrated the interventions described, and discussed aims and issues involved, in training work with staff on the wards, psychology staff in our Community Mental Health teams, and psychology trainees at Salomons Institute for Applied Psychology. A psychology undergraduate student working with me is about to start implementing some of the interventions described on one of the KMPT Older Adult wards. A presentation of this evaluation has played a significant part in enabling me to secure a post as a music therapist working within the psychology team for the Community Mental Health Service for Older People at the Thanet Mental Health Unit. This is the first art, drama or music therapy post in a CMHSOP (Community Mental Health Services for Older People) team at KMPT.

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**Becky Grubb – Assistant Psychologist**

**20/02/2023**

**References:**

Acton, A. (2020) ‘Every Picture Tells a Story’, in Richards,C. (ed.) *Living Well with Dementia through Music – a resource book for activities providers and care staff* London: Jessica Kingsley, pp 127-137

Acton, A. (2020) ‘What’s in a Word?: The Creative Use of Music and Poetry’, in Richards,C. (ed.) *Living Well with Dementia through Music – a resource book for activities providers and care staff* London: Jessica Kingsley, pp 117-126

Bowell S., Bamford S.M. (2018) ‘What would life be – without a song or a dance, what are we? A report from the Commission on Dementia and Music’. Accessed on 20/02/2023 at <https://ilcuk.org.uk/wp-content/uploads/2018/10/Commission-on-Dementia-and-Music-report.pdf>

C-DEMQOL – a dementia quality of life measure – Brighton and Sussex Medical School – Prof Sube Banerjee, Dr Stephanie Daley:

<https://www.bsms.ac.uk/research/neuroscience/cds/research/cdemqol.aspx>

Accessed online 13/01/2023

DEMQOL – a dementia quality of life measure – Brighton and Sussex Medical School – Prof

Sube Banerjee: <https://www.bsms.ac.uk/research/neuroscience/cds/research/demqol.aspx>

Accessed online 13/01/2023

Grady, M. and Melhuish, R: (2020) ‘Bringing Couples Together: Using Music to Support Care and Maintain Relationships’ in Richards,C. (ed.) *Living Well with Dementia through Music – a resource book for activities providers and care staff* London: Jessica Kingsley, pp 90-97

Hsu, M.H., Flowerdew, R., Parker, M., Fachner, J. and Odell-Miller, H. (2015) 'Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study.' *BMC geriatrics* 15, 84

Jacobson-Wright, N. (2020) 'The Use of Music to Inspire Dance and Movement' in Richards, C. (ed.) *Living Well with Dementia through Music – a resource book for activities providers and care staff* London: Jessica Kingsley, pp 108-116

McDermott et al (2014) 'The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists.' *Aging and Mental Health* 18, 6, 706-16

Powell, H. (2020) 'Musical Lives' in Richards, C. (ed.) *Living Well with Dementia through Music – a resource book for activities providers and care staff* London: Jessica Kingsley, pp 60-79

Ridder, H.M., Stige, B., Qvale, L.G. and Gold, C. (2013) 'Individual music therapy for agitation in dementia: an exploratory randomized controlled trial.' *Aging and Mental Health* 17, 6, 667-78

Salomons Institute for Applied Psychology: <https://www.canterbury.ac.uk/science-engineering-and-social-sciences/salomons-institute-for-applied-psychology/salomons-institute-for-applied-psychology.aspx>

Unadkat, S., Camic P.M., Vella-Burrows, T. (2016) 'Understanding the experience of group singing for couples where one partner has a diagnosis of dementia.' *The Gerontologist* 57, 3, 469-78



