



LFT Charitable Trust Post-Project Report

Evaluating the Effectiveness of a 6-Week Shared Reading Programme to Improve Wellbeing for Those with Early-Stage Dementia and Their Caregivers

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| Executive Summary

This project was supported by the LFT Charitable Trust. Verbal developed and delivered a dyadic six-week Shared Reading pilot programme to improve mental wellbeing, foster connections, and build relationships for those with early-stage dementia and their caregivers.

A dyadic intervention design was selected to improve the wellbeing of both those with early-stage dementia and their caregivers. While a diagnosis of early-stage dementia is associated with poor wellbeing and social withdrawal (Caddell & Clare, 2012), caring for and supporting someone with dementia can also lead to poor wellbeing and social isolation (Messina et al., 2022).

We designed a Shared Reading programme to help overcome challenges such as low mood and social isolation for both those with early-stage dementia and their caregivers. This programme targeted aspects of positive wellbeing such as forging social connections, the importance of self-care and more.

This intervention was delivered at the Verbal Arts Centre in Derry~Londonderry. Sessions were facilitated and co-facilitated by Verbal volunteers and employees respectively who had completed Dementia Awareness Training.

Anxiety scores significantly reduced in 60% of participants with early-stage dementia, with depression scores improving in 40% of participants. The most notable wellbeing improvements included participants feeling less troubled by negative thoughts and feeling more happy and content during their day.

Caregivers embraced taking part in the programme and wrote their own poems for self-expression. They also provided feedback on directly observing changes in their loved ones and the joy that it brought to them as a carer, highlighting the benefits of a dyadic intervention and including caregivers when improving wellbeing for those with dementia.

All participants enjoyed taking part in the programme and would take part in a similar programme again. Participants enjoyed the storytelling nature of the programme as it encouraged others to share their stories and their experiences of living with dementia. The ability to discuss the stories and share their own stories helped participants to spend time with and make friends with others.

The findings of this programme not only demonstrate the benefits of arts-based interventions in improving wellbeing and fostering friendships for those with early-stage dementia, but highlight the benefits of a dyadic intervention design by encouraging their caregiver to take part and share their story also.

Introduction

Dementia is a clinical syndrome defined by progressive impairment to cognitive functioning (NICE, 2019). An estimated 820,000 people in the United Kingdom live with dementia (Leung et al., 2015); this figure is expected to increase to 115 million worldwide by 2050 (Alzheimer Disease International, 2020).

Individuals living with dementia can experience a range of mental health difficulties. Kuring et al. (2018) found that 1 in 4 and 1 in 7 people with dementia experience significant levels of depression and anxiety respectively. Receiving a diagnosis of dementia at the early stages of the syndrome is associated with poor mental wellbeing, low self-esteem, and social withdrawal (Caddell & Clare, 2012), indicating a need for interventions to improve the wellbeing of those with early-stage dementia. However, a diagnosis of dementia can also impact the wellbeing of loved ones as those who help care for those with dementia are more likely to experience mental health difficulties such as increased anxiety, depressive symptoms, stress and loneliness (Messina et al., 2022).

A review of interventions developed to help those with dementia identified that the least common type of intervention was psychotherapeutic interventions aimed at improving their mental wellbeing, self-esteem, and social support (Stephen et al., 2021). The scarcity of

psychotherapeutic interventions for early-stage dementia stresses the importance of addressing the care gap by using talking-based interventions to improve the wellbeing of those with dementia (Cheston & Ivanecka, 2017).

Creative interventions have been shown to help boost mental health and wellbeing for individuals with dementia and their caregivers (Emblad & Mukaetova-Ladinska, 2021). Such creative interventions can enhance mental wellbeing by embodying the Dementia Care Model's principles of enriching relationships, encouraging engagement through conversations, and validating their emotions (Clark et al., 2019). Utilising elements of the Dementia Care Model through a dyadic intervention design, which includes both the participant with early-stage dementia and their caregiver, has the potential to deliver information and support to both parties through engagement and conversation (Smrokowska-Reichmann et al., 2024).

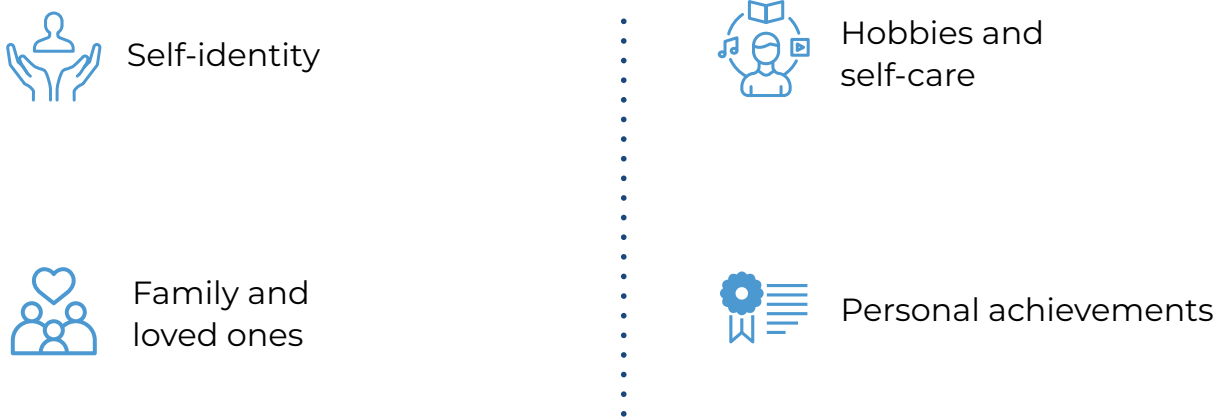
The aim of the programme is to develop and pilot an arts-based programme using Verbal's Shared Reading model to improve mental health and wellbeing, foster engagement and communication, and to build upon relationships between those with early stage-dementia and their caregivers.

Methods

The Programme

A six-session intervention designed to improve mental wellbeing for both those with early-stage dementia and their caregivers was delivered at the Verbal Arts Centre, Derry~Londonderry.

Sessions were designed using Verbal’s Shared Reading model to facilitate self-reflection and discussion related to the following topics:



Shared Reading Model

This intervention was developed using Verbal’s Shared Reading Model. This model is derived from Affective Bibliotherapy (Shechtman & Nir-Shfir, 2008, Heath et al., 2005), a process involving the guided reading of literature combined with targeted discussions. Shared Reading fosters change and understanding in others by gently breaking through defence mechanisms to help develop insight (Shechtman & Nir-Shfir, 2008). Stories act as an “intermediary object” between the person and their problems (Gray et al., 2016), offering a less direct but appropriate way of discussing their emotions and experiences in a safe and inclusive environment (Detrixhe, 2010).

Programme Development

Poetry was selected by Verbal's Literature Team to align with the mental health themes previously outlined. In the Shared Reading Model, discussions are guided by psychologically-informed annotations written by Verbal's Psychology Team to prompt personal and group growth, healing and understanding. These annotations are guided by key psychological frameworks, including Cognitive Behavioural Therapy to change unhealthy thoughts and behaviours, and Acceptance and Commitment Therapy to accept and/or change emotions and behaviours.

This programme was delivered by a volunteer and co-facilitated by a member of staff at Verbal; both had received Dementia Awareness Training prior to programme delivery.

Programme Assessment

Participants with early-stage dementia completed a questionnaire before and after taking part in the intervention; questionnaires contained the same psychological measures to allow direct comparison pre- and post-intervention. These measures are:



Geriatric Depression Scale - Short Form

The Geriatric Depression Scale is a 4-item measure to assess symptoms of depression and low mood in older populations (van Marwijk et al., 1995). The Geriatric Depression Scale has previously been used in research to identify symptoms of depression in those with early-stage dementia (Burgener et al., 2009). Lower scores are indicative of positive mood and a hopeful outlook.



Geriatric Anxiety Inventory – Short Form

This is a five-item measure designed to assess symptoms of anxiety in older adults (Byrne & Pachana, 2011). This scale has been validated for use in those with early-stage dementia (Stanley et al., 2013). High scores are indicative of high levels of anxiety.

Procedure

This programme was delivered at the Verbal Arts Centre building between February-April 2024. Before the first session, participants and their caregiver were provided with a list of session themes and were encouraged to bring along relevant photographs, magazine cut-outs or literature to each session which demonstrated their personal connection to the theme. Participants with early-stage dementia completed the pre-programme questionnaire before the beginning of the first session.

During each session, participants would be read a poem pertaining to themes of wellbeing, staying well and self-identity. Poems were selected by Verbal's Literature Team and structured breaks were implemented for discussions. The Psychology Team developed questions for these breaks that would encourage discussion and reflection on the theme. The programme was delivered in six sessions delivered once per week. Participants completed the post-intervention questionnaire at the end of the programme.

Verbal employees used the memorabilia provided by participants each week to create a physical Memory Book for participants to enjoy after the programme was completed. Each participant was presented with their Memory Book at the programme showcase event at the end of April 2024.

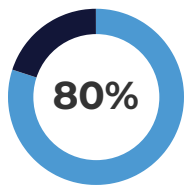
Data Analysis Strategy

Quantitative data were entered, cleaned and statistically analysed by the Verbal Psychology Team using SPSS Version 29. t-tests were used to explore whether scores on psychological measures significantly changed before and after taking part in the intervention.

Statistical significance was explored when analysing data. Statistical significance refers to the probability that a finding happened due to a specific cause, most likely the result of the programme. In alignment with established guidelines, results were considered as statistically significant if $p < .05$. This means that we can be at least 95% sure that a finding was not due to chance or coincidence.

Results: Participant Overview

This programme was delivered to eight participants in total. A matching pre- and post-programme survey was available for five participants.



Female

Participants who took part ranged between ages 66-78, with a mean age of 74 years old.

The majority of participants were female (80%) and all participants described themselves to be of white ethnicity. Three participants (60%) were of a Catholic religious background while two (40%) were of a Protestant religious background.



Results: Participant Wellbeing

Programme Results: Anxiety

↑ **60%**

Improved anxiety scores

Participating in this programme led to a **significant reduction in anxiety symptoms** ($t=2.45, p=.035$). **60% of participants** experienced improvements to their anxiety levels after taking part, including a **25% reduction** in the number of symptoms of anxiety experienced. Following the programme, **40% of participants** felt less nervous and troubled by negative thoughts.

↓ **40%**

Felt less worried by negative thoughts

↓ **25%**

Reduction in no. of anxiety symptoms

Programme Results: Depression

Overall depression scores improved in **40% of participants** after taking part in the programme. The programme particularly helped participants to feel happy and content during their days as this increased in **40% of participants**.

↑ **40%**

Improved depression scores

↑ **40%**

Felt happier

Results: Programme Feedback



Enjoyed
taking part

All participants enjoyed taking part in the programme, enjoyed the poetry selected in the programme, and would take part in a similar programme again.

Participants were asked to provide written feedback on the programme and what they particularly enjoyed. Responses were organised into the following themes:

Theme 1: Socialising

“

There was a relaxed approach to [the] process.

The most common theme identified from participant feedback was how much participants enjoyed “*meeting new people*”. Participants noted how they enjoyed “*discussions*” and “*the talking generally*”, feeling that there was a “*relaxed approach to [the] process*”.

Theme 2: Storytelling

As a result of meeting new people and the relaxed style of programme delivery, participants enjoyed the ability to “*share experiences*” such as “*chat[ting] with people who know how I feel*”. As well as sharing their own story, participants enjoyed the “*sharing [of] others’ stories*” as this bonding experience helped with the “*realis[ation] we all have differences and yet [are] similar*”.

“

We all have differences and yet [are] similar.

Caregiver Feedback

Verbal's facilitator for this programme maintained records of positive comments provided by caregivers throughout the programme. These comments read as follows:

“

[Participant] seems more like herself here, she is loving these chats.

“

This makes a big difference to her week, she really looks forward to Tuesdays.

“

We've found it is so important that she keeps her mind active, so this is perfect for her.

“

This is the first place since being diagnosed that she's been treated like a human being. Everyone gave her space to be included in the conversation and didn't just speak at her.

“

[I loved] watching how animated my sister became when given time to share her thoughts. She felt valued.

“

This programme is brilliant for them, she loves listening to stories and telling her own. She will be raging when it's over!

The facilitator also noted that during one of the sessions, a caregiver wrote a piece of poetry at home and read it to the group. According to the session facilitator:

“She said the best way to get people to listen to how she was feeling was through storytelling.”

These findings in tandem indicate that caregivers benefited from the programme in a range of ways, including joy at the person they care for visibly enjoying themselves and feeling personally empowered to tell their story in order to utilise the wellbeing benefits of storytelling.

| Discussion

We designed a dyadic six-week Shared Reading programme for those with early-stage dementia and their caregivers. The aim of this programme was to improve mental wellbeing for participants and their caregivers, along with providing opportunities for reminiscence and memory recall both within sessions and longer term through the creation of a Memory Book.

Mental wellbeing improved for those with early-stage dementia after taking part in the programme. 60% of participants experienced a significant reduction to their anxiety levels, with 40% of participants improving in their overall depression scores. These findings indicate that Shared Reading is an effective tool for improving the wellbeing and anxiety levels of those with early-stage dementia.

As a dyadic intervention, we designed our programme to be of benefit to both those with early-stage dementia and their caregivers. Caregiver feedback indicated that the programme had an uplifting effect on those they care for as they felt 'talked to' rather than 'talked at'. As the programme progressed, caregivers felt more confident sharing their story with others, suggesting that watching their loved ones foster friendships and share their story empowered caregivers to use storytelling for their own self-expression and wellbeing.

One of the largest wellbeing changes found in participants was the ability to feel happier in their everyday lives. As noted in both participant and caregiver feedback, the programme helped participants to make new friends, share their story and to learn from the stories of others. Fostering social connections between those with early-stage dementia is paramount due to the high rates of loneliness and social isolation for those with dementia (Caddell et al., 2012). The inclusion of their caregiver not only provided a sense of security to participants when meeting new people, but helped caregivers by observing the wellbeing benefits to participants directly and by engaging with storytelling and creativity themselves.

In conclusion, our Shared Reading programme was successful in improving the mental wellbeing of those with early-stage dementia, helped participants to connect with others, and empowered their caregivers to share their story. As this was a pilot project to test its effectiveness in this population, these findings suggest that Shared Reading is an effective creative tool for improving wellbeing, fostering friendships and providing an avenue for participants to share their story with others.

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Thank you

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