

A Literature-Based Intervention for Older People Living with Dementia

An evaluation report by the Centre for Research into Reading,
Information and Linguistic Systems

University of Liverpool



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CENTRE FOR RESEARCH
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INFORMATION AND
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PREFACE

“ One of the greatest challenges of our time is what I'd call the quiet crisis, one that steals lives and tears at the hearts of families, but that relative to its impact is hardly acknowledged. Dementia is simply a terrible disease. And it is a scandal that we as a country haven't kept pace with. The level of diagnosis, understanding, and awareness of dementia is shockingly low. It's as though we have been in collective denial. ”

The words are the Prime Minister's, from a speech announcing increased funding for dementia research which coincided with the writing of the final stages of this report. Sir Mark Walport, Director of the Wellcome Trust has added, 'The dementia challenge will not be resolved by the natural sciences alone. It will also require progress in social care.' What follows in this research and evaluation report, conducted by the Centre for Research into Reading, Information and Linguistic Systems at the University of Liverpool, deals with what cannot be resolved by the natural sciences alone.

It concerns an intervention based on the reading-aloud of literature in a series of older people's care settings, and carried out through the work of The Reader Organisation and its Get Into Reading project. It should be stressed that this is not simply a matter of reading to the people who attend these groups: the aim is to encourage active human involvement at both individual and social levels.

For your convenience I here summarise the main sections and findings of this report.

Sections 1 and 2: Background and The Intervention

- Many of you reading this report will be familiar with the background to this 'quiet crisis', but on pages 4–6 we provide the general context and offer an introductory account of The Reader Organisation and its work
- The aims of the evaluation are listed on page 6
- The nature of the Intervention itself – what exactly is Get Into Reading? – is described on pages 8 and 9

Section 3: Methodologies

- The research method is articulated on pages 12–13, including matters of design and logistics

What must be stressed here is the necessity of a mixed methodology:

- On the one hand, we are committed to qualitative analysis, offering through interviews and case-studies an understanding of the human reality of what has been done
- But we are equally committed to providing strong quantitative evaluation. If reading is to claim a radical role in dementia care – to attract funding and to earn its place on the public agenda rather than be dismissed as a soft or arty pastime – then there is a duty to provide and to test carefully-gathered statistical evidence as to its benefit and value

Sections 4 and 5: Results and Conclusions

- Qualitative outcomes, including those relating to quality of life and to effects on staff-carers, are set out in detail on pages 15, 17, 19, 20, 21
- Statistical analyses are illustrated on pages 23–28

The major conclusion on pages 29–31, from sources both qualitative and quantitative is:

- that reading-group activity produces a significant reduction in dementia symptoms.

Specifically, there are strong indications that the power of a literary language can both trigger relevant past experience and prompt fresh acts of thought.

Section 6: Recommendations

On page 32 we offer proposals as to the nature of future research, future use and future training, in the light of our major recommendation:

- that the Get Into Reading model should be extended to all care homes and other care-settings for older adults.

We know that not everyone will want to read every section in detail. But I would urge you not to miss out on the individual case studies, inserted throughout this report to give you a feel for what is at stake and what has been achieved.

For these six human stories, in which only the names are fictionalised and the locations anonymised, please read, with care, pages 7, 11, 16, 18, 22 and 34. The Project Workers from The Reader Organisation were Katie Clark, Dr Clare Ellis and Emma Gibbons, who wrote the case studies.

Indeed, Read With Care may be an apt summary of what is here reported.



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SECTION I

BACKGROUND

Dementia

There are currently over 800,000 people living with dementia in the UK and there are an estimated 670,000 family and friends acting as primary carers (Department of Health 2012; Lakey et al., 'Dementia 2012: A national challenge'). Dementia currently costs the UK economy £23 billion a year, a figure that will grow to £27 billion by 2018.

However, as highlighted in the most recent report published by the Alzheimer's Society, the 'spend is often not being deployed effectively and is not delivering good outcomes for people with dementia and carers.' (Lakey et al., p. iv). The Government has recognised the issue of dementia as a national challenge and has argued for the fundamental importance of improving the quality of life for people living with dementia and their carers.

In March 2012, the Department of Health published a ground-breaking report calling for major improvements in dementia care and research by 2015. Building upon the publication of its first National Dementia Strategy in 2009, which called for improved awareness, earlier diagnosis and intervention, and a higher quality of care enabling people with a diagnosis of dementia to live well, the government is more than doubling overall funding for dementia research to over £66 million by 2015 and the Prime Minister has made a personal call for research that develops a better understanding of the mechanisms of the disease, and helps create new possibilities for intervention and improvements in translating research into practice.

There is a clear need not only for the development of arts and social interventions that might improve the wellbeing of those living with dementia, but also for more research into which interventions work well and why. While there have been several studies that have explored the impact of singing projects for people living with dementia which have found

positive health and wellbeing outcomes (Korb, 1997; Cohen et al., 2006, 2007; Bungay et al., 2008), there has been relatively little work done on how a literature-based intervention might impact on the behaviours of those living with dementia. The present report addresses the impact and effect that a specific literature-based intervention called Get Into Reading, designed and practised by The Reader Organisation, might have on the health and wellbeing of people living with dementia.

The Reader Organisation

The Reader Organisation is an award-winning charitable social enterprise working to connect people with great literature, and each other. Its mission is to build a reading revolution and create environments where personal responses to books are freely shared in reading communities in every area of life. Beginning life as a small outreach unit at the University of Liverpool in 1997, the national charity (established in 2008) pioneered the weekly 'read aloud' model at the heart of their Get Into Reading project, which currently delivers over 300 groups each week in all four corners of the UK. They take place in a variety of locations, including hospitals, prisons, corporate boardrooms, schools, GP surgeries, libraries, community centres, care homes, and supermarkets. The stimulating, friendly and non-pressured environments provide stability, support and enjoyment for people who attend, establishing shared meaning and connections across social, educational and cultural boundaries.

The Reader Organisation works with forward-thinking partner organisations in a variety of sectors, including public and mental health, education, criminal justice, social care (older and younger people), local authority, corporate and voluntary, to ensure that the experience of shared reading can be enjoyed by as many people as possible, particularly those that may not have access to literature, or to other social activity. The charity has recently been recognised by *The Observer* and NESTA as one of 50 New Radicals in Britain, transforming society through its innovative approach, and awarded the Social Enterprise Mark demonstrating that its trade income is reinvested for social good.

www.thereader.org.uk

The Reader Organisation and Dementia

The Reader Organisation has been delivering Get Into Reading in a range of settings for older people and those living with dementia for the last five years. It is now delivering projects across the North West, South West, South East and is currently developing a new project in Scotland. It has worked in partnership with Wigan Memory Service, Mersey Care NHS Trust, Greater Manchester West Mental Health Trust, Bupa Care Services, Knowsley PCT, Halton Borough Council, Wirral PCT, Liverpool Mutual Housing, Liverpool City Council, and a large number of care homes across the country. It is currently running 35 weekly groups in older people's and dementia care settings, including care homes, hospitals, day centres, sheltered housing and community centres funded by The Headley Trust, Bupa Care Services and local PCTs and councils. The Reader Organisation has a growing body of anecdotal evidence which shows how Get Into Reading has acted as a positive intervention in relation to the health and wellbeing of those living with dementia but is now working towards gathering a body of quantitative data to supplement this qualitative evidence.

Centre for Research into Reading, Information and Linguistic Systems

The current report builds on and adds to the existing evidence base about reading and health by collecting data in the specialist field of dementia. It has been conducted by the Centre for Research into Reading, Information and Linguistic Systems (CRILS) at the University of Liverpool. This is a new independent research unit, created in 2011 by its director Professor Philip Davis and deputy director Dr Josie Billington. It is the first such centre to take scholars and researchers from a School of English Literature into an Institute of Psychology, Health and Society, within the Faculty of Health and Life Sciences, to work with researchers in science and practitioners in medicine and in psychology, across the disciplines, in bringing reading and the study of reading into closer relation with health and

wellbeing. Several of its collaborators were involved in the previous pilot research evaluations mentioned below.

Robust research into the patient benefits of the Get Into Reading model is in its early stages of development. Observed and reported outcomes for participants have included: being 'taken out of themselves' via the stimulation of the book or poem; feeling 'good', 'better', 'more positive about things' after taking part in the group; valuing an opportunity and space to reflect on life experience, via memories or emotions evoked by the story or poem, in a convivial and supportive environment; improved powers of concentration; a sense of common purpose and of a shared 'journey'; increased confidence and self-esteem; sense of pride and achievement; valued regular social contact and decreased sense of isolation; improved communication skills including introduction to new forms of verbal expression (Robinson, 2008). These preliminary findings resonate with other innovative research into reading and health, which suggested that reading a literary text together not only harnesses the power of reading as a cognitive process: it acts as a powerful socially coalescing presence, allowing readers a sense of subjective and shared experience at the same time (Hodge et al, 2007). Related research suggests that the inner neural processing of language when a mind reads a complex line of poetry has the potential to galvanise existing brain pathways and to influence emotion networks and memory function (Thierry et al, 2008). The possibility that shared reading can help make those micro-happenings last longer and bite deeper – both at the point of delivery and in its effects over time – is a key area requiring dedicated research.

One of the most significant pieces of research relevant to this proposal is a 12-month pilot study of the benefits of reading in relation to depression, funded by MerseyBEAT (a collaboration of University of Liverpool and Liverpool PCT) and researching shared reading groups in a GP surgery and a mental health drop-in centre in Liverpool (Billington et al, 2011). The project is a partnership between the Schools of English, Medicine and Health Sciences at The University of Liverpool and The Reader Organisation, and has developed an innovative

multidisciplinary approach to mental health research, integrating arts and science methodologies. The expertise of a clinician (specialising in depression), a social anthropologist, a linguist, and a literary specialist are combined in the analysis of quantitative and qualitative data, seeking to establish 'mechanisms of action' in the shared reading model (group dynamics, Project Worker's role, which literature works and why) and to offer qualitative evidence of how these operate and interact in practice.

This project received a special commendation 'for contributions to the field of arts and mental health research' from The Royal Society for Public Health, September 2009. In addition, in 2011 The Reader Organisation worked in partnership with the Wirral Primary Care Trust to carry out an internal pilot evaluation of the shared reading groups that were being delivered in specialist dementia care homes on the Wirral. An external evaluation was overseen by Professor Kinderman (Head of the Institute of Psychology, Health and Society and Professor of Clinical Psychology at The University of Liverpool), which focused on three shared reading groups in dementia care homes. In each study there were significant improvements in mood, agitation and concentration levels as well as social interaction rates.

Aims of the Evaluation

The current evaluation will specifically assess to what extent the shared reading intervention impacted upon behaviours symptomatic of dementia. Its aims are:

1. To understand the influence that reading has on older adults with dementia in different healthcare environments
2. To identify staff perceptions of the influence that engagement in a reading group has on older adults living with dementia
3. To investigate any changes in dementia symptoms of older adults participating in a reading group, with specific relation to statistical analysis

Case Study

Betty, Care Home 1

The group is held each Wednesday from 2.30 to 3.30pm. Sarah or Tracey, both Activities Coordinators, join the group each week. For the last couple of months it has been necessary to hold the group in the big lounge where there are about 20 residents of which probably 10 or so engage in the group. The residents don't usually choose to read aloud although they will often read out particular lines.

Betty is a regular at the Care Home 1 group. She is 93 years old. Since before Christmas, Betty's health seems to have deteriorated, but she is still keen to come to the group and share poetry. One week when she was not in the group I was told she was in the quiet lounge and didn't want to move. When I went to say hello however, she was most put out and said 'I would have come, I love the poetry.' So we read a couple of poems together, just the two of us. Betty particularly likes poems about the sea. As a child she lived in Flint in Wales, but always visited Talacra on the coast and has clear memories of it. Eventually her father built a bungalow at Talacra and she recalls many holidays, including a sad one when some young men were drowned. Betty also has a strong memory of being cut off by the tide and being 'guided' back to shore by a dog. She never knew what became of the dog. Another great favourite of Betty's is 'Pedlars' by W D Rands. She remembers it as one of the first poems she learned as a child. She and the other members of the group had a really good conversation about seeing gypsies travelling in traditional wooden caravans and remembering the tinkling sound they made as everything inside moved around.

Betty had a happy marriage, but does not seem to have had children of her own, although she fostered them. She also loved to garden and seems knowledgeable when we read poems about nature or gardens. Betty has plainly always loved to read. She says her mother loved poetry and she thinks that's where her love of it originates. She recalls a mobile library (a horse and cart) coming to her childhood home in Flint. Her mother would keep the more 'grown up' books on a high shelf, but as they got older, Betty and her siblings were allowed to reach for these.

SECTION 2

THE INTERVENTION

The Model: Get Into Reading

The Get Into Reading model is the specific literature-based intervention that was evaluated in the present study. It has been nationally lauded as a positive health and social care intervention and was highlighted in the Department of Health's New Horizons consultation document as a non-pharmacological/medical intervention that can help improve quality of life. The model is distinguished from other reading therapies (which characteristically rely on 'self-help' books) in:

- i) emphasising the importance of serious, 'classic' literature and its role in offering a model of human thinking and feeling (Davis, 2009)
- ii) reading such works aloud so that the book is a live presence and not just an object of study or chat

The principal feature of the Get Into Reading model is shared reading: all reading material is read aloud in the session itself and open-ended discussion is encouraged by the Project Worker. Group members participate voluntarily as they wish and interact in relation to what is happening in the text itself (in terms of narrative, characters, place and setting, themes, description, language) and what may be happening within themselves as individuals (in terms of reflections about personal feelings and thoughts, opinions and experiences) as an articulated and evolved response to the shared reading of the text and wider group discussion.

The basic structure of the Get Into Reading model is flexible enough to be adapted for different settings and for the needs of different client groups. The Get Into Reading model, for example, often follows a running time of an hour and a half, with short stories or whole novels being read aloud over a course of weeks or sometimes months and with each session concluding with a poem to promote further

reflection on the story read in the session. However, when reading with people living with dementia, the model is adapted in order to make the reading experience more easily accessible and meaningful, and to overcome obstacles common to people with dementia such as poor concentration, loss of short-term memory, difficulty in following conversations, difficulty in thinking and reasoning, anxiety and depression, and confusion and disorientation. The administration of antipsychotic drugs for people with dementia can also compound these issues with the problems of excessive tiredness and drowsiness. The Get Into Reading model, therefore, has to take these factors into account and makes the following changes:

a) Choice of reading material

Prose material can still be read in shared groups for adults with dementia but often in the form of short extracts from novels or very short stories rather than longer short stories or novels. It is also important that the prose material selected does not rely upon a plot or narrative but can be more discursive and episodic to allow for group members to move in and out of the story without having necessarily to keep track of what has gone before and what may follow after. However, poems work particularly well in shared reading groups for people with dementia and are used much more frequently than prose material. Reasons for this are various and have been found to do with both the form and content of poetry as an active genre of communication. The language of poetry is often more compressed and immediately striking than that found in prose; rhyme and rhythm in the formal structures of the genre help to stimulate and maintain concentration; the poems are usually on one single page, making it less likely that group members lose their place. Lastly there is the factor that people in the shared reading groups were of the generation when poetry was learned by heart in schools, and it is therefore often the case that group members with even the most severe levels of dementia are able to recite poems that they learned at school word-perfect.

b) Presentation of Reading Material

The Project Workers will generally read in a much louder voice than they might usually deploy and also take more time in describing what has happened in the story/poem before moving on to discussion, in order to make the experience as live and as palpable to the group members present as possible. The reading is thus more dramatic than might usually be the case in a standard community group.

c) Conduct of Session

The Project Worker has to think very carefully about the use of questions to generate discussion. Often the general format of a Get Into Reading group will move from asking questions about the narrative and characters to ones which encourage personal reflection and require members perhaps to draw on personal past experiences, such as 'Have you ever experienced anything like this?' or 'Does anyone here remember feeling like that?' Questions which ask group members to draw on their memories are however to be handled with the utmost care when reading with people with dementia. The Get Into Reading intervention

is not a reminiscence project. Nonetheless, the literature read aloud and discussed often stimulates memories and encourages people to share personal experiences from their past. Literature may often be selected to draw on generational experiences and chosen for the degree of triggering resonance it might be presumed to have with the group members in question. As time goes on, the Project Worker gets to know the group members and can then choose further material on the basis of developing knowledge of the individuals. However, group members are encouraged to enjoy the literature as an experience in the present moment as much as a medium for reflecting on past experiences, and the reading material selected therefore has to be able to stand alone as a moment in itself so that members are free to enjoy it however they choose – whether that be in terms of the past, present or an imagined hypothetical future.

d) Time of Session

The sessions are shorter than the standard hour and a half and last no longer than an hour.





Case Study

Matthew, Care Home 1

Matthew has early on-set dementia and is much younger than most of the other patients on the ward. He rarely interacts with the other people and appears quite isolated and depressed, talking only in monosyllables and taking a long time to respond to questions. His speech seems slow and impaired: he struggles not only to find words to be able to express himself but also to find the will or desire to make such acts of communication in the first place. I noticed during a session that centred upon an extract about summer-time from Laurie Lee's *Cider with Rosie* that Martin seemed to be looking about him more than usual and to be listening attentively to what was being discussed by the other group- members. I asked him what he'd like to eat during a hot day in summer. He replied in a single word – 'Fruit'. I asked him what kind of fruit. He said 'Apples, oranges.' This response was quite a breakthrough for Matthew. On that basis I risked asking him if he'd like to re-read a poem I'd just read to the group – 'Apples' also by Laurie Lee:

Behold the apples' rounded worlds:
juice-green of July rain,
the black polestar of flower, and the rind
mapped with its crimson stain.

The russet, crab, and cottage red
burn to the sun's hot brass,
then drop like sweat from every branch
and bubble in the grass.

The poem is five stanzas in length and is quite challenging to read in terms of its rich metaphorical language. When I invited Matthew to read it, he paused for several moments and then answered, 'Yeah, alright then.' He read the poem word-perfect. He also read it at a speed which was at much more of a pace with normal conversation: he was fluent and focused. The words on the page were providing him with a voice once again that could be shared, and moreover, with a voice that he wanted to share. Everyone in the group watched Matthew as he read as if seeing him anew.

At the end of his reading I thanked Matthew for reading and remarked that he had a wonderful reading voice. He smiled and said, 'Thank you for saying so.' The group moved on to talk a bit about the poem, but at the end of the session I came back to Matthew and asked him if he had enjoyed the session. Once again he took several moments to respond and then answer, reverting somewhat to his slower voice but this time managing to articulate himself in full. He said, 'Yeah. It was elevating.'

SECTION 3

RESEARCH METHOD

Participants

All participants in the care homes and day centre had received a diagnosis of dementia; however, the development of their illness varied. Some were in the early onset stage of dementia whereas others could present more severe symptoms. Those who attended the hospital groups were either being assessed for or had been diagnosed with dementia. Other older adult participants were experiencing comorbidity and had been diagnosed with both dementia and a mental health disorder. These were included in the mental health reading group. Again, the level of illness progression varied with some participants being able to make coherent contributions whereas others were only able to listen to the reading material. Participants were excluded from the groups if the staff felt that their illness was too advanced, if they were bed-ridden, or if the individuals did not want to attend the group.

In the current study, 61 service users and 20 staff members were involved with the project, either by attending and engaging in a group and/or by being interviewed by the researcher. 87 sessions were conducted in total.

Evaluation Design

The evaluation of the reading groups differed depending on whether the groups were being conducted in the day centre, care homes or hospital environment. Two care home groups were conducted on a Wednesday, one care home and one day centre group were conducted on a Thursday and two hospital groups were conducted on a Friday. All groups were carried out in the same week by two Project Workers from The Reader Organisation (one running the two Wednesday care home groups and one running the remaining groups).

For the day centre, the reading group was evaluated weekly for 20 weeks using the

Neuropsychiatric Inventory brief questionnaire (NPI-Q) described below. This was undertaken so that a more detailed evaluation could be conducted to identify when or if any changes in participants occurred. A baseline evaluation was collected prior to the start of the group. The group was then conducted for 14 weeks, with a break for Christmas leaving a 4-week follow-up where no reading was carried out.

For the care homes, a waiting list control design was used over a 6-month period. Baseline data was conducted at all care homes prior to the start of the reading groups. One care home had no reading group for 3 months and then offered a reading group for 3 months. The remaining two care homes continually held a reading group for 6 months. Originally, it was planned to have one care home reading for 3 months and then not reading for 3 months, however administrative issues meant that two of the three care homes offered a reading group to residents for the whole 6-month period. The NPI-Q was administered at the end of each month (approximately every 4 weeks) resulting in a monthly evaluation of the reading groups.

For the hospital groups, both reading groups began simultaneously; however the NPI-Q was only administered to the dementia reading group as this scale is not applicable to those with mental health issues. Evaluation of the reading group with mental health participants was done via qualitative interviews with staff who attended this group. These groups began early January but no baseline data was collected as authorisation for the researcher to evaluate the groups was only obtained after the groups had begun. Table 1 illustrates the different levels of data collection for the day centre, care homes and hospital groups.

Qualitative interviews were conducted with seven staff members who either participated in the groups themselves or had extensive knowledge of the service users who participated, and a consultant. These were carried out at all sites during the fifth and sixth months of the evaluation and provide more insight into staff perceptions of the reading groups. Informal discussions with some service users were also conducted after a reading session to identify their views of engaging with a reading activity.

Week Commencing	Day Centre	Care Home 1	Care Home 2	Care Home 3	Hospital Group A (Dementia)	Hospital Group B (Mental Health)
10.10.11	Baseline*	Baseline*	Baseline*	Baseline*	N/A	N/A
17.10.11	Reading*	Reading	Waiting	Reading	N/A	N/A
24.10.11	Reading*	Reading	Waiting	Reading	N/A	N/A
31.10.11	Reading*	Reading	Waiting	Reading	N/A	N/A
07.11.11	Reading*	Reading*	Waiting*	Reading*	N/A	N/A
14.11.11	Reading*	Reading	Waiting	Reading	N/A	N/A
21.11.11	Reading*	Reading	Waiting	Reading	N/A	N/A
28.11.11	Reading*	Reading	Waiting	Reading	N/A	N/A
05.12.11	Reading*	Reading*	Waiting*	Reading*	N/A	N/A
12.12.11	Reading*	Reading	Waiting	Reading	N/A	N/A
19.12.11	Reading*	Reading	Waiting	Reading	N/A	N/A
26.12.11	NO GROUP	NO GROUP	NO GROUP	NO GROUP	N/A	N/A
02.01.12	Reading*	Reading	Reading	Reading	N/A	N/A
09.01.12	Reading*	Reading *	Reading	Reading	Reading	Reading
16.01.12	Reading*	Reading	Reading*	Reading*	Reading	Reading
23.01.12	Reading*	Reading	Reading	Reading	Reading	Reading
30.01.12	Waiting*	Reading	Reading	Reading	Reading	Reading*
06.02.12	Waiting*	Reading *	Reading*	Reading*	Reading	Reading
13.02.12	Waiting*	Reading	Reading	Reading	Reading	Reading
20.02.12	Waiting*	Reading	Reading*	Reading	Reading	Reading*
27.02.12		Reading *	Reading	Reading*	Reading	Reading
05.03.12		Reading	Reading	Reading	Reading	Reading
12.03.12		Reading	Reading	Reading	Reading	Reading
19.03.12		Reading	Reading	Reading*	Reading	Reading*
26.03.12		Reading*	Reading*	Reading	Reading	Reading

Table 1: Description of the different evaluation designs planned for the day centre, care homes and hospital reading groups. ‘*’ represents the week data was collected.

Measures

Mixed methodology was used to evaluate the reading groups. The NPI-Q assessed staff views of any changes in dementia symptom severity for the participants who attended the reading groups. It measures 10 behavioural areas which are delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, and motor disturbance. Two neurovegetative areas are also assessed: night-time behaviour and appetite. For the group conducted at the day centre, the question relating to night-time behaviour was not applicable as all participants return to their own homes after attending the day centre. The NPI-Q uses a dichotomous Likert response scale of yes (symptom present) or no (symptom not present). If the staff member provides an affirmative response, they were

asked to rate whether the symptom is mild (1), moderate (2) or severe (3).

A semi-structured schedule was used for the interviews, with all interviewees being asked the following questions: how was the group being received (by staff and service users), whether the structure of the group was appropriate, and was there anything about the group that could be improved. Other questions that were asked arose as a result of the responses given by the staff member.

Data analysis

Descriptive statistics are reported for the monthly NPI-Q scores. The interviews were analysed using thematic analysis to identify key themes that arose from the data.

Reading Material

The list of poems and prose extracts used in this project can be downloaded here:

<http://thereader.org.uk/research/>

All the seasons run their race
In this quiet resting place...
Here be shadows large and long;
Here be spaces meet for song

'A Garden Song'



SECTION 4

RESULTS

4.1 Qualitative Findings

Key Question a) How has engaging with the reading group affected those who participate?

Enjoyment

The reading group appears to be a positive activity in all of the care homes, hospital wards and day centres that took part in this evaluation. The majority of staff who were interviewed reported how the service users were 'really enjoying it [the reading group]' (Staff member 1, Care Home 1) and would often 'join in' (Staff member 2, Care Home 2). One interviewee commented that with other activities, one service user 'never used to join in but then did' (Staff member 1, Day Centre) and this was attributed to the service user engaging with the reading group. Enjoyment therefore appears to be central to service users' engagement with the intervention.

The reading groups often had a staff member present as well as the service users and Project Worker, and comments were made during the interviews that staff enjoyed the activity just as much as the service users appeared to enjoy it. One staff member reported that another member of staff who attended the group had come up to her at the end and said that the poetry was 'really making sense' (Staff member 1, Hospital Ward 1) suggesting staff can also benefit from engaging with the reading group.

The positive perception of the reading group was not just limited to those who interact daily with service users but was also felt to be a good activity by consultants. Feedback was obtained from the consultant after she had visited the group. She reported that she was 'very impressed with it' (Consultant 1, Hospital Wards 1 and 2) and felt that it was a good activity to offer to the service users. She reflected that the reading activity was both stimulating and soothing as well as being educational, something that one of the service users themselves reported.

“ [the reading group] is soothing and stimulating at the same time. ”

The consultant felt that the reading group can 'engage people' (Consultant 1, Hospital Wards 1 and 2) which is something the Project Worker and GIR model aims to facilitate through the participant discussions. The consultant was positive in her view of the group and wished that she had been able to stay for the whole duration of the group she visited.

Active Listening and Listening Skills

Engaging with the group appears to facilitate participation and allow service users to express themselves by giving them the freedom to 'speak their mind' (Staff member 1, Hospital Ward 1). Yet it was acknowledged that not all of the engagement was verbal, and within the mental health context it was reported that service users sometimes engaged with the group by 'actively listening' (Staff member 2, Hospital Ward 2), assessed by the service users' non-verbal behaviour.

The reading group itself was perceived by one member of staff to be good for people who were visually impaired 'because it focuses on listening skills and not the visual, which is not a barrier' (Staff member 2, Hospital Ward 2). This was reiterated by another staff member working in a care home who suggested that supplying 'magnifying glasses' (Staff member 1, Care Home 3) would help those service users who had poor vision to follow the reading material. This staff member recommended providing magnifying glasses as one way the groups could be improved.

Case Study

Edna, Hospital Ward 2

Hospital Ward 2 is for older adults with mental health issues such as depression, anxiety, and psychosis. The ward operates on a 12 week assessment basis and in-patients can be discharged at different points, with new people taking their place. The reading group has therefore acted as a supportive intervention amidst such change and has also acted as a much needed diversion for people who often seem to be waiting to go home. As one group member said to me, 'It passes an hour whilst you're in here.' The older adults on this ward do not have a diagnosis of dementia.

Edna did not initially want to attend the reading group when it first started on the ward. I remember the day I first met her sitting out in one of the corridors. I tried to speak to her about the reading group and she very politely and also very definitely declined, 'No thank you, I am not interested.' Then in the second week she decided to come along after hearing about how the first session had gone from the other in-patients and members of staff. She was curious but still very quiet at first. I read an extract from Brian Keenan's *I'll Tell Me Ma* and Edna listened attentively throughout. After I had read the story and had already paused several times throughout for discussion, I asked if the group had enjoyed it and suddenly Edna spoke. 'I liked the story because I liked to listen to you read it aloud. It reminds me of some of my friends who were from Ireland too and how they always used to say "Ma".' She smiled then and seemed fully relaxed and contented. Edna continued to attend the group until she was discharged. She became increasingly animated as the weeks went on and grew to become one of the most talkative members of the group. One of the things that most struck me about Edna's involvement was how the reading material was able to inspire her with new thoughts and ideas and also questions, which when articulated and shared with the group seemed to re-invigorate Edna herself. I always remember reading the poem by Ted Hughes called 'Roger the Dog': Edna broke the initial contemplative silence after the poem was read, saying 'I'm just wondering what kind of a dog would be called Roger?' She smiled and then laughed a little as the other members smiled in recognition of her question. 'I mean,' she continued, 'would it be a small dog or a big dog or what? A terrier perhaps.' It is the 'just wondering' from Edna that can be so meaningful both to individuals and the group; it is the 'just wondering' which can move a person from feeling trapped in a single continuous mode of thought and feeling to being opened out into a new arena and with a new focus, however small.

Memory

The discussions focused on the poem or story that was read and enabled service users to talk about their own experiences. These discussions often 'spark memories of their [the service user's] life' [Staff member 1, Care Home 1] which were sometimes raised after the group had finished.

When the Project Worker mentioned the author of a poem or story she was reading, one staff member reported hearing a service user say 'I've heard of him' and reiterated how discussing the reading material seems to trigger 'their [service users] memories' (Staff member 2, Care Home 2). This was supported by the Project Worker herself reporting how one service user in the group offered a memory he had related to Rudyard Kipling's poem 'If'.

“ I asked him if he liked the poem 'If', and he replied 'I grew up with it. I read it at school – I used to have a set part of the day each week put aside for poetry.’ ”

(Project Worker; quotation from dementia participant attending men's reading group, Care Home 2)

One staff member commented that some service users 'remember that it [the group] is every Friday' (Staff member 1, Hospital Ward 1), with one participant commenting to the same staff member that 'the nice lady from Liverpool is coming in tomorrow'. The Project Worker also observed this effect when one participant in the men's group in Care Home 2 asked for a specific poem one week called 'The Green Eye of the Little Yellow God' by J. Milton Hayes and then remembered reading it the week later in response to another poem, 'Mandalay' by Rudyard Kipling.

“ When reading 'Mandalay' the participant turned to the Project Worker and said 'This is like that other one – 'The Green Eye'. We had that one last week, didn't we? Well this seems to follow after that one somehow.’ ”

(Project Worker, men's group, Care Home 2)

This reflection implies that the reading group has an effect on short-term memory, although it is not possible to state what influence the reading has or how this occurs in patients with dementia. Further research into this would help identify exactly how a reading intervention can influence short-term memory.

The Project Worker reflected how allowing participants to reminisce was important, but that it was also good to allow them to use their imagination and to create experiences that may be in the present or in the future.

Attention, Concentration and Presentness

A powerful literary language helps to establish present attention in group members – for example, by the act of reading aloud (evidenced in Case Study p.11); stimulating new thoughts (Case Study p.16); provoking concentration on specific lines or phrases (Case Study p.34); and through calmly shared enjoyment.

Case Study

Keith, Day Centre

The day centre is a large open space, very popular with local residents. There is a regular client group and in total there can be up to 20 to 30 people in the day centre at any one time. Service users usually arrive in the morning and are taken home at 3.00pm. The activity organisers provide a range of pursuits throughout the week, one much favoured activity being karaoke. The reading group takes place in a designated part of the main room and gathers about 8 to 10 participants each week, with both males and females participating. Members are in very different stages of dementia, with some participants appearing very lucid and focused whilst others appear to be at a more advanced stage of the condition. The large open space can also distract the members at times and make it difficult for them to concentrate. Nonetheless the stories and poems have been able to hold a range of personalities together and in particular provide an opportunity for some of the quieter members in the day centre to express and assert themselves.

Keith is one of those quieter members and has attended every week since the project began. He clearly enjoys listening to the stories and poems being read aloud and follows them with great attention and focus, often looking up in wonder or excitement with a knowing smile as we come to the end of reading a section. I remember the time when Keith volunteered to read 'No Bread', a poem about a boy who has forgotten to buy all the items on his mother's shopping list and bring the bread home from the shop. After reading the poem, an activities worker asked Keith if the poem brought back any memories to him. He laughed and said 'Too many!' At which point another group member said, 'Oh come on, you wouldn't have been without her.'

When reading Thomas Hood's poem of childhood 'I remember, I remember', Keith shared thoughts about how he wished he was a child again because he 'used to go out and meet people back then'. In response to Robert Louis Stevenson's 'From a Railway Carriage', he said he had gone on a train journey once to London and described how he saw all kinds of things - feeling that these memories just 'jumped out' at him on reading the poem. On another occasion, prompted by a short story on childhood, 'The Lumber Room' by Saki, he said that he still likes to look at pictures and paintings and old photographs and to think about and imagine what might be going on in each scene.

Keith really settled into the routine of the reading group and seemed to anticipate it each week, often coming up to me before the session as I sat down at the table to ask 'Are you here to do the reading today?'

Real Personal and Social Context

The reading group was also perceived to provide a real context in which group members could place their experiences and talk about them without it appearing artificial, giving them an actual purpose.

“ It kind of gives a focus for a discussion point whereas if you went and asked somebody a personal question about their life it might feel a bit reticent because it's not in context... it leads on to a social discussion about their memories and things and their feelings. ”

(Staff member 2, Hospital Ward 2)

This was reiterated by the Project Worker, who reflected how different people appeared to get different things from their engagement with the group. Some seemed to like sharing their thoughts and stories whereas others simply benefitted from being able to speak aloud.

“ Sometimes there are people who are really a lot more engaged and they get a lot from it from sharing their thoughts and feelings and being listened to. Other people it's just a basic case of actually having the chance to speak... The poem enabled one person's voice to come out in a way that was articulate and fluent. ”

(Project Worker)

The reading group was also felt to facilitate social relationships by encouraging social interaction which had a specific purpose, such as discussing a particular aspect of a poem or story.

“ It was great to have these sorts of group that have a social element but it's not particularly focused on them and that there is a reason and a purpose behind it. ”

(Staff member 2, Hospital Ward 2)

The Project Worker reported how social relationships were observed through interchanges that occurred between participants which made sense as opposed to random or disconnected comments. This tended to happen when participants read something that had them 'really engaged' (Project Worker) and captured their imaginations and interests. The Project Worker felt that it was important to ensure literature was chosen that could enhance these relationships and provide an opportunity for them to engage in present experiences as well as in past experiences.

The Influence of Outsiders

An interview with a staff member who worked with mental health service users raised the point that engaging with the group:

“ Gives the patients a sense of identity, of who they are, and being able to contribute to something, and there is a purpose there and that it is not connected to the hospital. ”

(Staff member 2, Hospital Ward 2)

Being viewed as independent from the hospital was perceived to be good, as the activity is seen as being separate from the hospital and conducted by a guest rather than by a member of staff.

Key Question b) How practical is the reading group as an activity?

The Literature and Literary Form

The staff interviewed felt the reading material used in the groups was good, regardless of whether or not the service user had mental health issues and/or dementia. One hospital ward staff member felt that 'short stories work well because they are short' (Staff member 1, Hospital Ward 2) while another reported the 'poems have gone down well because they are a more manageable length' (Staff member 2, Hospital Ward 2). The flexibility of the reading material was perceived as a strength, as 'doing stories then poetry worked well' (Staff member 1, Day Centre), especially when the content featured 'pirates and the sea' (Staff member 2, Day Centre), 'school' (Project Worker) and 'travel' (Project Worker). The different topics enabled the participants to share their stories or to comment on their experiences so that group members 'can create their own space in that present moment' (Project Worker). The Project Worker however did acknowledge that sometimes the same reading piece could work well in one setting but not in another and that there was no one piece that worked in all settings. In her view, it was important to have a 'variety in one session' (Project Worker) and that it was the range that was important.

One staff member working on the hospital wards reported that the Project Worker had thought about the use of visual imagery which she felt might help the service users. She suggested this could be a recommendation for improving future groups and was emphasised by the Project Worker who thought visual imagery 'would not detract from the reading but can enhance the reading experience and also provide... an extra form of stimulus for the group members that would help them re-engage' (Project Worker). The Project Worker reflected on how the groups could be improved by bringing in the other senses (e.g. physical objects relating to the reading material) and this is something that could be used in future reading groups.

The Project Worker reflected on how she 'had to think a lot more about what I read' due to the variety of individuals within the group (e.g.

those at different stages of dementia, all-male groups etc) and to provide a range of literature covering a variety of topics to ensure all participants engaged with the session. Often, material was chosen that might spark memories and 'resonate from their own lives' (Project Worker), showing a link with the memory theme discussed above. Prose as well as poems appeared to work well, and that if the right extract was chosen, 'the voice that prose can give... can be such a rich resource' (Project Worker) that can complement the use of poetry.

Duration of Group

The reading group itself was perceived to run for an appropriate length of time (one hour) which could fit in with the other daily activities that occurred at each place, and this was reiterated by the Project Worker who felt an hour was sufficient. At the day centre, staff reported having the group run in a morning relaxed the service users and contrasted well with the afternoon activity of karaoke. 'Chilled morning, lunch, then a wild time' (Staff member 1, Day Centre).

The Environment

Staff commented that the venue for the group was important, as sometimes service users would walk around if the activity was conducted at a table but appeared more settled if it was run with service users sitting in more comfy chairs. One staff member said they had recently moved their group into a more informal setting (the main lounge) and as such, more residents were 'benefitting from it' (Staff member 1, Care Home 3).

The Project Worker also reflected on how the group venue was important and felt that some of the environments were not great but acknowledged that this was something you just had to 'work around' (Project Worker). She commented on the importance of having a staff member in the group, for both practical and supportive reasons (e.g. by bringing another voice to the group, enhancing equality between staff and individuals with dementia, etc).

Key Question c) What are the overall perceptions of the reading group as an activity for mental health and dementia service users?

The Project Worker

The Project Worker was perceived to have an important effect on both staff and service users. Staff working on the hospital wards reflected how having someone come in that's 'passionate' (Staff member 1, Hospital Ward 1) really helps on an in-patient ward. The Project Worker was praised for 'learning the names of the clients' (Staff member 2, Hospital Ward 1) which was valued by staff. The same staff member also commented that the Project Worker was very good at 'engagement', had 'good eye contact' and that her voice was 'loud but not domineering, commanding' making 'clients want to listen'. It was also reported that the atmosphere on the ward in general had improved since the group had been running. This was reiterated by the consultant, who felt that the Project Worker 'had a lovely manner with them [the service users]' (Consultant 1, Hospital Wards 1 and 2).

The independent perspective of the Project Worker was felt to be beneficial and one staff member on the hospital ward suggested it would be good to have an independent view of how the service users interacted with the groups that could be held in the service users' records. This could then be used by the staff and consultants when assessing the service user. The consultant endorsed this proposal, especially valuing input into how group-members interacted.

Recommended Changes/Improvements

The following list describes some of the previously mentioned recommendations for changes or improvements that could be made to the groups by staff as well as those observed by the researcher:

1. Providing magnifying glasses for those who are visually impaired
2. Ensuring sufficient extra copies of the literature are available for unexpected new arrivals
3. Using visual imagery and song alongside the written word might help those who cannot follow the reading material

4. The Project Worker could provide a short written evaluation about how the service users interacted with the group as this could help doctors during their ward-round by providing an independent perspective.

Overall staff members held positive attitudes about the reading groups especially since the service users themselves appear to enjoy the activity. 'If the service users are happy then we're happy' (Staff member 1, Day Centre).

Informal Feedback Groups

A selection of group members were informally asked what they thought of the reading sessions. The majority commented that they enjoy the session, with one emphatically saying 'oh yes!' (Group member 3, Day Centre) when he was asked if he enjoyed the activity. When asked what it was that they had enjoyed, one member said he found it 'interesting' (Group member 6, Hospital Ward 2) while another reported he liked hearing 'different voices, different opinions' (Group member 1, Day Centre). This was reiterated by another service user in a different group who reflected that it is 'good to hear different opinions from people' (Group member 4, Care Home 2).

One service user commented that 'you have to learn to read, otherwise you don't get anywhere' (Group member 2, Day Centre), indicating how reading is an important skill in everyday life. Engaging in the activity was also perceived to be 'educational' (Group member 5, Care Home 2) suggesting reading the literature can promote learning if new information is read and discussed.

One service user liked the use of complete poems as it 'provides a structure to focus on' (Group member 4, Care Home 2), indicating how the poems provide a context for discussions. Furthermore, the same group member reported how it was good to connect with people especially since they were 'all private' (Group member 4, Care Home 2) residents.

Case Study

Dan, Care Home 2

Care Home 2 has both male and female residents, the group for the current evaluation taking place downstairs on the male unit in the lounge space. About 8 to 10 men participate each week. Often when I first arrive they appear very sleepy and rather quiet and, though sitting in a communal circle, are not engaging in conversation with each other. The task here is to stimulate the group, in contrast to some of my previous groups where membership has been predominately women and where one of the purposes of the intervention has been to soothe and relax those who have shown high levels of agitation and anxiety. Sometimes relatives or friends will also be present during the reading group and it is often the case that the reading offers a common focus. It clearly pleases visitors to hear their loved ones talk with enthusiasm but also focus and direction.

Dan, like many of the men in the reading group, is someone who has a lot to say, but due to his dementia and his social environment often struggles to find opportunities for articulating what he wants to talk about and to have his peers listen to him and understand what he is saying. Dan wants connection and struggles to get it, but he is also a man who wants to provide connection to others - yet often ends up somewhat lost in the process. I remember at the start of one reading group, for example, another group member was trying to remember when it was that he had been at home with his daughter on a particular occasion. He suddenly turned to Dan, whom he had only just met (being recently admitted to the home), and asked 'Do you know what weekend it was?' Dan looked slightly dazed in that he didn't know what the man was talking about, but replied 'Yeah, it was the weekend just gone.' Dan's response seemed to settle the man but also revealed to me how important the sharing of connections and meaning was for Dan and the rest of the men in the group, and how the reading group could provide one such valuable opportunity.

After one session, when I had read and discussed Tennyson's 'Charge of the Light Brigade' and an extract from *Black Beauty*, I asked Dan what he thought of the reading session and he replied with great clarity, 'I was enthralled by it.' Another member, who'd been listening, asked 'Enthralled by it - well what does that mean?' Dan replied promptly, and again with a clear sense of connection and direction, 'What does it mean? It means I couldn't put it down - that I was gripped by it.' He, like many of the other men, have also enjoyed the opportunity to discuss difficult life issues that they themselves have experienced. A popular subject has been war and battles, for example. After one session when I had read a range of material from Kipling, Dan said 'This stuff isn't for the faint hearted - it's about proper things, real things.' He has spoken a lot about his own experiences in the army. The familiarity of 'Charge of the Light Brigade' or 'If' by Kipling has also provided a great boost to the confidence levels of the men and touches upon cornerstones of knowledge which they have retained and are eager to share again - when we were reading 'Charge of the Light Brigade', Dan started telling me all about the history of the battle that lay behind the poem: 'It's still there,' he said at the end. It was clearly important to Dan and the rest of the group that they knew more about the subject matter than I did and had much valuable experience and insight to bring to the discussion.

4.2 Statistical Findings

Day Centre Reading Group

The results of the NPI-Q scores for the participants in the day centre reading group were fairly consistent over time. The majority were perceived not to show any changes in their symptoms and were often rated as not presenting with the symptoms: statistical evaluation on this group is therefore impractical to conduct as no significant changes would be detected due to little change being reported by staff. The only changes that were observed are shown in Table 2.

Participant	Symptom	Week
3	Agitation – moderate	7
	Disinhibition – mild	7
	Agitation – moderate	8
	Irritability – moderate	8
4	Elation – moderate	3
5	Depression – mild	16
6	Elation – moderate	3

Table 2: Symptom presentation reported by staff for some of the participants in the day centre reading group (n = 7)

N.B.

(i) Despite the lack of statistical analysis, staff reported how they felt the reading group had a positive impact on those who attended. The group was held in a communal room and although the group formed a small circle, those who were not directly involved were able to listen to the reading and may have benefitted informally from the intervention. This could not be evaluated in the current design but would be something that could be addressed in the future.

(ii) The symptoms that were reported as being present were depression, elation, agitation, disinhibition and irritability. Staff commented how one participant began joining in with other activities which they attributed to the participants' enjoyment of and engagement with the reading group. It is possible that this enjoyment could be related to elation (being

good and excessively happy), a symptom which was perceived as being present in a couple of participants although the link is tentative and no evidence proves that this is indeed the case.

(iii) One possible explanation for the results for the day centre group could lie with the measure used to assess the participants. The NPI-Q focuses on the presentation of dementia symptoms, their severity and the distress the symptom causes the individual. The current study focused on asking about the severity of the symptom which, although useful, may not be representative of this group of people. If the presentation of the symptom is not as pronounced in this type of environment, it may be that it is due to its early onset. Consequently, it may be more informative to ask about the distress the symptoms cause the individual rather than how severe they are.

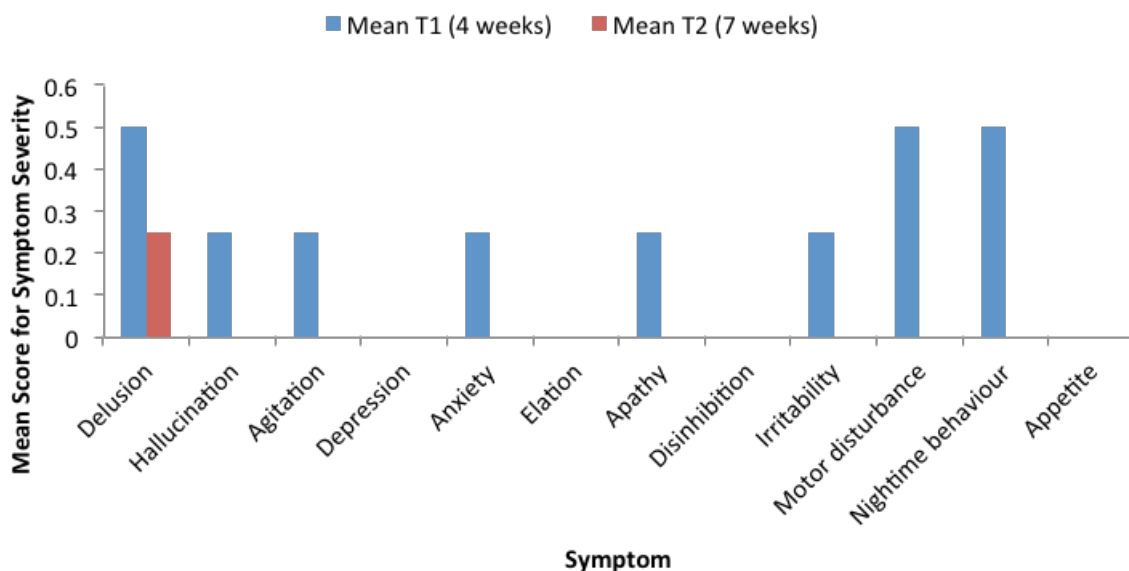
Hospital Ward 1

The results of the NPI-Q for the hospital reading group are shown in Graph 1. Due to the nature of the ward, only four participants were able to be followed throughout the assessment period (at Time 1 and Time 2) as one participant was no longer at the hospital at Time 2 and another three participants joined the group at Time 2 but were not present at Time 1. As the graph indicates, there appears to be an overall reduction in the perceived severity of most of the symptoms with a mild presentation being perceived at Time 1 changing to no symptom present at Time 2. No change was observed for depression, elation, disinhibition or appetite over the 7 weeks of the reading group. The reduction in symptom severity supports the qualitative findings which suggest participants positively engage in the group by contributing to the group discussions.

By Week 10, hallucination, apathy and motor disturbance had reappeared, although some of the more mood-related symptoms such as elation and depression remained absent. Caution must be applied to the results, however, as only four participants have been followed-up, therefore it is only possible to draw tentative rather than generalised conclusions.

The NPI-Q was not conducted for the group in Hospital Ward 2 as these group members had a mental health issue and/or dementia. The NPI-Q measures the severity of dementia symptoms only and is not applicable for people who have a mental health diagnosis making it inappropriate to use with this group. Consequently, there is no NPI-Q data for the group conducted in Hospital Ward 2.

Hospital Group Mean NPI-Q Scores



Graph 1: Mean scores for the NPI-Q evaluation conducted for the four participants who attended the hospital dementia reading group at 4 weeks (Time 1) and at 7 weeks (Time 2). Absence of a red column on the right indicates the symptom is not present.

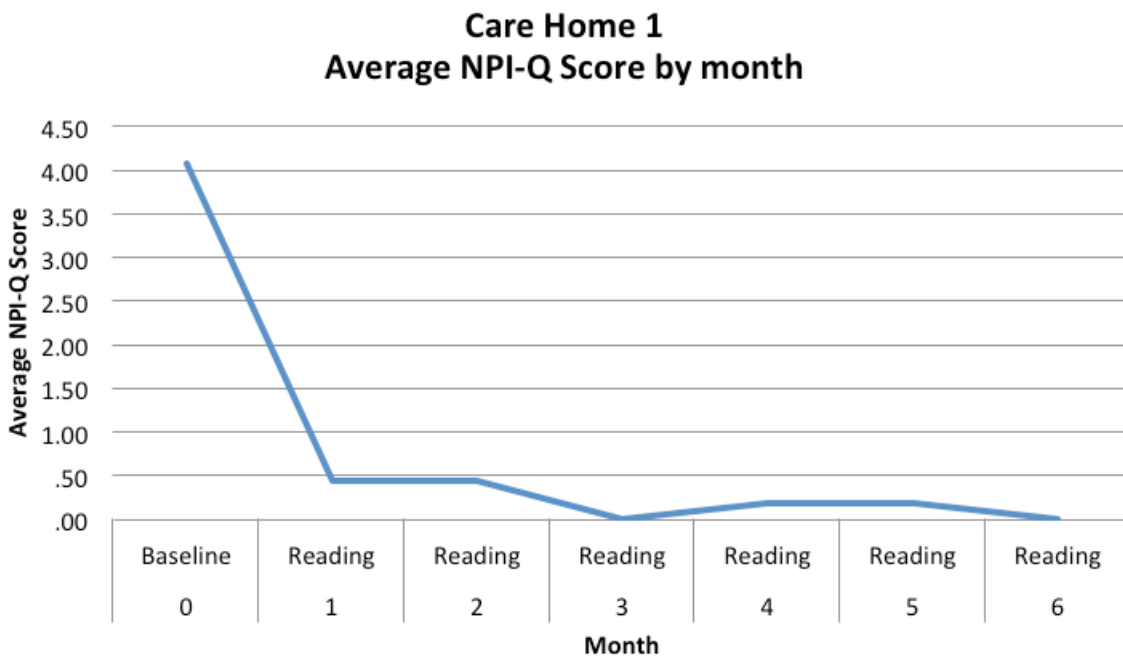
Care Home 1

Continuous reading for 6 months

Graph 2 shows the average NPI-Q scores for all of the participants who engaged with the reading group. As can be seen, symptom scores were lower throughout the reading period than at baseline.

The low mean scores for each of the symptoms at each monthly interval suggest that overall, the symptoms were not perceived to be present in the majority of group members. An improvement was found by Month 3, although some symptoms (motor disturbance, depression, irritability, apathy, anxiety, hallucinations and agitation) were reported as being present again in Months 4 and 5. Of these, only depression and motor disturbance appeared consistently in the latter months, and that with only minimal increase followed by further subsequent decrease.

Appetite and night-time behaviour were the two symptoms that did not appear after baseline. It is interesting that these neurovegetative symptoms are the ones that do not reappear during the reading intervention rather than the behavioural symptoms which may be more fluctuating in presentation. Sleep is necessary in order to restore memory function (Larner, 2012) and it is possible that the lack of sleep disturbance may facilitate the effects of the reading group on memory function that was reported by staff members.



Graph 2: Average NPI-Q score for the 6-month period (n=16)

Care Home 2

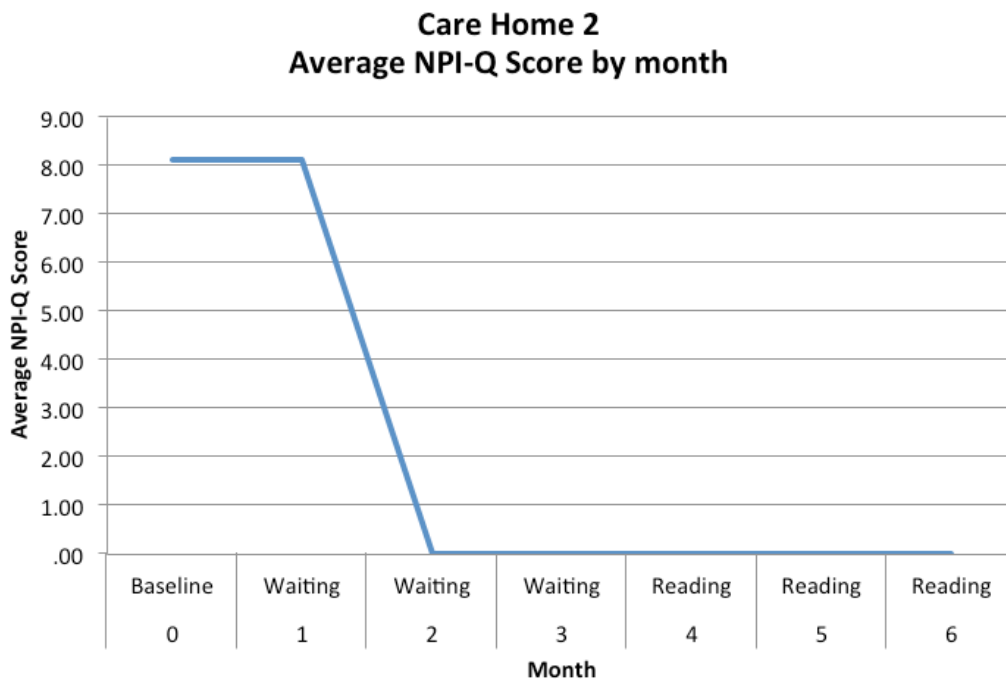
Waiting for 3 months, Reading for 3 months

Graph 3 shows the average NPI-Q scores for all of the participants who engaged with the reading group. As can be seen, symptom scores were lower throughout the reading period than at baseline.

The most prevalent symptoms during the waiting period appear to be agitation, disinhibition and irritability yet no symptoms are reported by staff during the latter months. This supports the qualitative comments by staff who perceived participants to enjoy the group by suggesting that their symptom presentation is

not as pronounced during this period as might otherwise be expected.

The scores were exactly the same for baseline and Month 1 which, when investigated, were due to the staff member perceiving there to be no change in the participants during this 8-week period. The staff member considered the participants were the same in terms of their symptom presentation and severity which is why he gave them the same scores in Month 1 as he gave at baseline.



Graph 3: Average NPI-Q scores for the 6-month period (n = 8)

N.B. The sudden fall in symptoms during the waiting period is surprising, though the sustained maintenance of that fall during reading remains most significant. In relation to the waiting period:

1. Care Home 2 was connected to the day centre and it is possible confounding variables such as staff discussing the coming reading groups or the desire to portray the home and day centre in a positive manner could potentially bias the results. The methodology did not control for these variables, a limitation that would need to be addressed in future studies.

2. The second month of the waiting period was December when extra Christmas-related activities were offered to participants, with potentially positive impact. In future it is important to identify exactly the activities offered in the previous month and include a measure to assess their overall impact on participants' general wellbeing and quality of life.

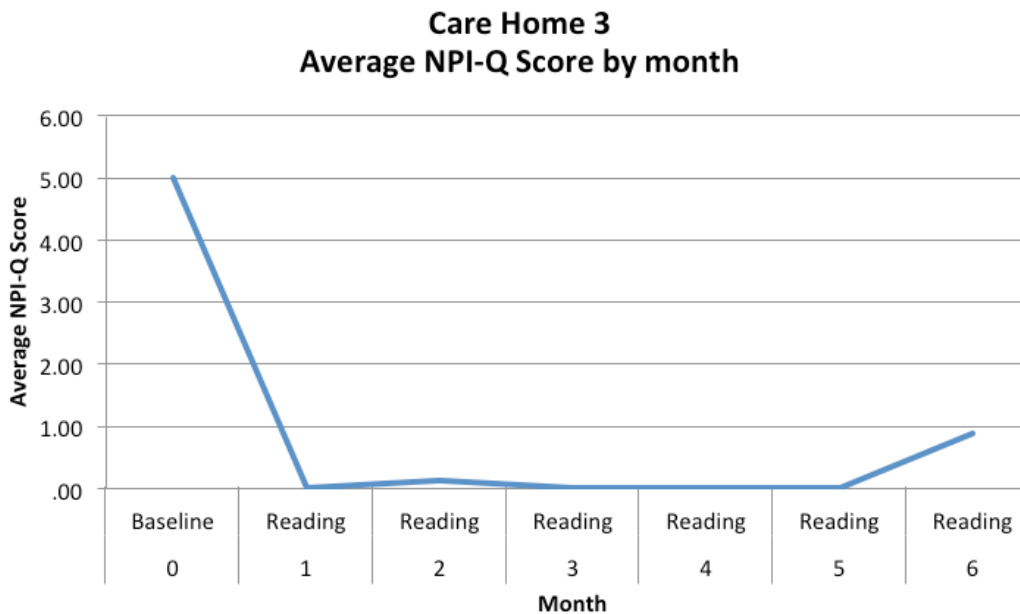
Care Home 3

Continuous reading for 6 months

Graph 4 shows the average NPI-Q scores for all of the participants who engaged with the reading group. As can be seen, symptom scores were lower throughout the reading period than at baseline.

The average scores for each symptom suggest a reduction in the presentation of symptoms during the reading period. Elation was the only symptom prevalent in Month 2 and had completely disappeared from Month 3 onwards. One reason for this could be the promotion of a weekly newspaper article which the care home produces. Residents are encouraged to submit articles for the newspaper, which is then distributed and discussed during the week. These discussions are similar to those

conducted by the Project Worker, suggesting the participants in this particular group may be more susceptible to literature-based activities such as reading and writing. The newspaper activity was established before the reading group intervention began, therefore it cannot be the only reason for the change observed, but as one staff member reflected, engaging in the newspaper discussions may have helped facilitate the reduction in symptoms observed during this evaluation.



Graph 4: Average NPI-Q scores for the 6-month period (n = 9)

Further Statistical Analysis

A repeated measures analysis was performed to identify any significant changes that occurred during the baseline, waiting and reading periods. Since only one of the care homes had a baseline – waiting – reading period (Care Home 2), the analysis was performed on this data only. The results indicate the changes seen in the graphs above are not statistically significant, using a significance level of 0.05. They are however approaching significance ($F(2,6)=0.630$, $p=0.051$), even with such a small sample size ($n = 8$) which suggests that engaging in a reading activity may have some influence on the severity of dementia symptoms. Detecting a difference that is approaching significance is indicative of potential changes in symptom severity which, given that there were only 8 participants in this sample, is a positive message. It is not possible however to disregard other potentially influential factors that may have affected the results, yet the qualitative evidence supports the changes that can be observed in the statistics.

When the baseline statistics ($\bar{x} = 5.52$, $SD = 6.13$, $n = 33$) were compared with the average monthly reading statistics ($\bar{x} = 0.39$, $SD = 1.42$, $n = 33$), a highly significant result was found which again is significant at the $p < 0.05$ level ($F(1;32)=24.74$, $p<0.005$). As discussed above however, the significant changes may be due to a drop being observed from baseline rather than any actual effect of the reading group. Despite this, the changes are indicative of how reading may help reduce the severity of symptoms experienced by individuals living with dementia.



SECTION 5

CONCLUSIONS

Major summary conclusions

- In light of quantifiable data of limited but indicative status together with strongly supportive qualitative evidence, engagement in reading-group activity produced significant reduction in dementia symptom severity
- Staff interviews indicated a contribution of reading groups to wellbeing

Specific Conclusions

Previous research (Billington et al., LivHIR) identified four key components of a reading intervention:

- | | |
|-----------------------|--------------------|
| 1. The Literature | 3. The Group |
| 2. The Project Worker | 4. The Environment |

Support for these emphases has been found by this pilot study:

1. The importance of the enlivening content of the literature read (poems and stories, length of literature)
2. The passionate and engaging Project Worker kept participants' attention through good verbal and non-verbal behaviour. Appreciation of the Project Worker was felt to be important and staff felt that as long as the service users were happy with the activity, then they too were happy
3. The discussions allow participants to share memories that relate to the literature (group discussion)
4. The comfort of the group environment, its informality and quiet, and also its possible openness, physically, to those in its vicinity: all these are significant

The current evaluation however extends these previous findings by identifying other aspects of the intervention that were perceived to be important:

- **Listening** – Active listening and listening skills were identified as some group members preferred to listen to the reading material being read aloud rather than follow it by reading the written word.
- **Social Context** – Emphasis on establishing social relationships and facilitating social interaction was identified in this evaluation. It was perceived that the reading group allows members to interact with each other in a meaningful context which is not related to other hospital tasks such as taking a patient's history or establishing symptom presentation.
- **Outsiders** – The impact of having external organisations provide activities for the service users, whilst also offering an independent perspective that can aid their carers. Staff commended this external insight into service-user interaction, potentially enhancing patient care by identifying previously unidentified issues.
- **Memory** – Past research indicates long-term memory can be positively influenced by interventions; however the current study also suggests a possible effect on short-term memory. This is unexpected and requires further research.
- **Identity of person** – Externally to be perceived as suffering with dementia rather than a dementia sufferer; internally, the sense of who one is in some continuity of relation with who one has been.
- **Attention, Concentration and Presentness** – The power of literary language stimulated fresh acts of relevant response through engagement and enjoyment.
- **Treatment** – Staff and consultants expressed consistent support for the intervention and its effect on patient care.

Limitations

Although the statistical results indicate staff perceive participants' symptoms improve during the reading group periods, it is not possible to say definitively that engaging in a reading group is the cause of this improvement.

Another limitation is despite efforts being made to ask the same staff member to rate the symptoms of the participants each month this was not always possible due to staff sickness or not being available on the day of data collection. The impact of individual differences therefore is unknown and this applies not only to staff but also to the service users themselves. For example, it is unclear whether or not participants in the current evaluation enjoyed reading and engaged in a lot of personal reading prior to the reading group and this could be a potential factor that influenced their engagement with the group.

Need for future research

The current evaluation has been beneficial in raising research issues/questions that both require and set an agenda for further investigation.

First, the effect of the reading group appears to differ depending on the situational context (e.g. day centre, hospital environment or care home). Reasons for this are unclear, as it may be due to differences in dementia symptom severity or onset, different levels of healthcare available or individual differences of the people involved. A randomised control trial (RCT) where participants in one group receive the intervention (the intervention group) and participants in the second group do not (the control group) could be conducted to address this, with a control and intervention group being conducted in all healthcare settings. These participants could be matched to allow confounding factors such as other activities both past and present, and individual differences (e.g. medication, past medical history, independent living, etc.) to be controlled so conclusions could be drawn that relate specifically to the effects of the intervention. Any RCT however should include a qualitative component as

this has been an essential part of the current evaluation. Although quantitative measures can assess changes in the clinical symptoms of dementia, qualitative interviews provide the opportunity to explore the interaction that occurs during and outside of the intervention as well as the humanistic elements that may be influenced as a consequence of engaging in the reading intervention (e.g. enhancing social relationships, providing an activity that can be done with other carers such as family members etc). Further to interviews with primary care staff, interviews with family members would also be beneficial to obtain their perceptions of any changes in the reading group participants.

Secondly, the current evaluation focuses on identifying any changes in symptom severity but considering the fluctuating nature of the condition, it may be more applicable to look at how the reading sessions can influence an individual's quality of life rather than the symptom severity. Clinically, addressing symptoms and helping to restore a balance for the individual is important, yet other quality of life factors such as social relationships and optimism are equally important and may be facilitated through the reading group. Some factors that may reflect quality of life have been found in the current study (e.g. enjoyment) but these have not been systematically investigated and could be a more accurate indication of how effective the reading group is for people with dementia. It would be important to consider this in relation to any possible relation between reduction in symptoms and any corresponding reduction in drug medication.

Thirdly, people engage with the reading sessions at different levels and to capture this, an observational or case-study design could be employed in future research. During the sessions, small changes in individuals can be observed longitudinally by monitoring the number of contributions they make to discussions or whether or not they choose to read aloud. These are important as they will all differ for each person. For example, someone who has been scored as having mild aggression or agitation may calmly read aloud a poem or keep quiet while others are talking and appear relaxed during the group. This would be in contrast to what staff experience on a daily

basis and may reflect some calming influence being derived from the reading group. Observing changes in this way allows for quantitative statistics to be obtained alongside the in-depth understanding of how people can be affected by engaging with a reading group.

Fourthly, people do not necessarily have to contribute to discussions to be actively engaging with the reading group. Non-verbal behaviour such as listening is important as it may help alleviate more emotional symptoms such as agitation or elation, but how the reading sessions influence this is unclear. This could be investigated by comparing different methods of reading, such as the use of a reader reading the literature out-loud and providing the written reading material with the use of audio-books requiring the participant to listen to the literature rather than following the written word. The current evaluation identified the impact the reading group had on active listening and listening skills, as a theme from the comments made by staff relating to how the reading group can impact on service users, and it is unclear

whether the same effect could be replicated using an audio book or whether it is the presence of the reader and the ensuing discussion that facilitates the reduction in symptom presentation. Furthermore, the impact of using different sensory cues when reading (e.g. pictures, objects etc) is unclear and for those who may be visually impaired, being able to use their other senses such as touch may heighten their reading experience.

Overall, future research must include a larger sample size to verify the results of the current pilot evaluation. Yet the flexibility of the GIR model shows how it can be used in different healthcare environments, from residential care homes to in-patient settings, and that providing this type of activity may have some role in reducing the severity of dementia symptoms.

Further research would include Randomised Controlled Trials; comparison with other interventions (newspapers, self-help books, music); analysis of class/educational background; social changes (e.g. multiculturalism).



SECTION 6

RECOMMENDATIONS IN RELATION TO CONCLUSIONS

a) Care homes

Providing it fits within existing structures and a supportive environment, and assuming that one member of staff is always willing and able to attend each group, it is recommended that the Get Into Reading model should be extended to all care homes.

b) Project Workers' Reports

Staff and consultant recommended the use of confidential Project Worker Reports from the reading groups feeding into ongoing assessment of patients and service users. This indicates that the reading intervention is not merely a pastime but could be valuable in patient assessment, particularly in relation to interaction with others.

c) Future research

Further research should not confine statistical analysis to the symptoms of dementia patients but extend its methods to consider the quality of life. This would include more extended use of service-user focus groups and interviews with family members. Such research would also concentrate upon any possible correlation between reduction in symptoms and reduction in drug usage.

d) Future training

The aspiration of The Reader Organisation to enhance the experience and perception of human individuality within dementia care homes is justifiably worthy of continuance.

The creation of accredited training is one possibility that deserves examination in terms of spreading and maintaining high-quality national provision, especially if embedded as an option within existing health and social care courses at degree or diploma level. For training in this area to be recommended by a national body such as NICE further research as outlined in c) above will also be necessary.



The Hidden Singer

The gods are lost
for their love of grace
Above and below them all
is a spirit that needs
nothing but its own
attachment.
Its hands and more.

Case Study

Edith, Jane and Emily, Care Home 3

Edith reads aloud each week and managed it again today despite having a very bruised face due to a fall at the weekend. She is very hard of hearing but reads beautifully (we usually make signs to each other to indicate it is her turn, or I point to whoever is going to read to let her know). Edith often seems very moved when she reads and today 'The Heavenly City' by Stevie Smith brought tears to her eyes. She doesn't appear to get upset, just to find reading poetry moving. Jane was then persuaded to read another poem, this time 'A Little Song of Life'. She said, 'I am improving with practice'. We both thought we remembered singing this poem as a hymn at school, so we had a go at it, but couldn't really remember the tune! Next the group read 'Friendship' by Caroline Norton and Jane said 'some people mean a lot to you and that says it'. Jane doesn't usually make comments apart from 'nice', or 'liked it'.

Jane suffers from marked tremor and has halting speech (I think due to a stroke). Since reading Wordsworth's 'I Wandered Lonely as a Cloud' fluently and clearly two weeks ago, she is much keener to read aloud. Today Jane read 'Tell Me' by Elizabeth Jennings to start us off. She read really well and when she finished said, 'I'm getting better, I like it.' Emily congratulated her on reading well and Jane seemed really pleased. Emily does not read aloud in the group as her sight is failing, but with the aid of a magnifying glass she follows each poem, particularly loving those that are spiritual or about nature. She loved the final line of this poem 'Two roots of one great tree' and kept repeating the line. Emily often keeps copies of the poems she particularly likes to read at night if she can't sleep. Today Emily presented me with a letter written in verse about the reading group, including the line 'such peace and joy she brought to us that day filled me with delight.' I have typed her letter up for you to read.

Emily's Poem

A big thank you

For the Lady who reads poems for us residents on Wednesday

A kind lady has visited us to read a poem or two,
She also encouraged us to read one or two too.
Such peace and joy she brought to us that day
Filled me with delight.
You have put such happiness in my life,
I am now able to sleep better at night.
Although I am 101 years of age and partially blind –
You have given me the inspiration
(With my magnifying glass)
To read more and write and unwind.
You certainly gave me a lift, which I appreciate.
Enjoying reading poems definitely eases my mind.

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RESEARCH TEAM BIOGRAPHIES

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Dr Janine Carroll graduated from Liverpool John Moores University with a BSc Applied Psychology and worked for the civil service and University of Liverpool, before embarking on a PhD investigating the psychological and contextual factors that contribute to personal and professional development in medical students at the University of Manchester, completed in 2011. She is now a researcher in the Department of Mental and Behavioural Health Sciences at the University of Liverpool.

Professor Philip Davis is Director of the Centre for Research into Reading, Information and Linguistic Systems. Recent publications include *Why Victorian Literature Still Matters* (2008), *Bernard Malamud: A Writer's Life* (2007), *Shakespeare Thinking* (2006), and *The Victorians 1830–1880* in the Oxford English Literary History series (2002). He has research interests in literature and brain-imaging and is currently writing a biography of George Eliot and preparing the complete works of Bernard Malamud for publication by the Library of America. He is also series editor for 'The Literary Agenda' – a series of short polemical monographs on the future of literary studies in the twenty-first century, to be published by Oxford University Press.

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Please note that for purposes of patient confidentiality, pseudonyms have been deployed in all of the case histories for the present report. The individuals in the photographs have not been part of this research project. All images © Bupa Care Services

‘Enjoying reading poems definitely
eases my mind’

(Service User)

‘If the service users are happy then
we’re happy’

(Staff member)