



Can she still read? How some people living with dementia responded to the reading experience

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This presentation reports on a feasibility study designed to explore the reading experiences and preferences of people who find reading challenging because of cognitive impairment. Participants were seven articulate volunteers claiming to enjoy reading, who had been clinically diagnosed with dementia. Each was given three versions of Charles Dickens' *A Christmas Carol*: a children's version, the original Dickens, and an adaptation in which the language was simplified to Flesch Kincaid grade level 2. It was hypothesized that the participants would prefer the adapted version. The researchers conducted, recorded and transcribed two focus group discussions with the participants. The three main themes that emerged were the participants' backgrounds in reading, ease of reading, and engagement with the texts. Tentative findings were that participants enjoyed the reading experience and discussion, appreciated some adaptations, but preferred the original language to that of the adapted version.

Mary's story

'She really can't read any more,' Mary's daughter confided to one of the researchers, a psycho-geriatrician. 'Well, she can't remember anything about it, can she? So we sometimes give her children's books to read, because she can probably cope with those. But she's getting so difficult; angry and obstructive. We don't know what to do with her.' However, when the researcher asked her if she liked reading, Mary said yes, she did, and most particularly, she liked reading romance. Mary had been diagnosed with Alzheimer's disease, and soon afterwards she was admitted to a residential care facility, where the researcher visited her again. She appeared happier than she had been at home, and the researcher observed that

on the bedside table there was a Mills and Boon romance, in large print. 'Is that a good book?' she asked. Mary smiled. 'Oh, yes, I like romance,' she said.

Overview of dementia

In 2015, a World Health Organisation report (Prince et al., 2015) stated that 47 million people were living with some kind of dementia worldwide. These were the ones who had been diagnosed. The numbers are projected to rise to 75 million by 2030. With reference to the human life span, 3 score and 10 was considered a normal innings in biblical terms, and in the twentieth century, celebrating one's 80th birthday was thought to be noteworthy. However, now the average lifespan in New Zealand is 83.2 years for women and 79 for men (Stats New Zealand, 2012). 70 is the new 50. With this life expectancy, we'd probably all like to think we will depart the planet with our mental faculties intact. Sadly,

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that's not always the case; in the Western world, where people are living longer, a larger proportion of the population is also suffering from some form of dementia. So what to do about it? As yet there is no cure for Alzheimer's, but therapeutic care exists. Initiatives that aim to help people with dementia live as well as they can with the illness, already use cognitive enhancing medications, and increasingly, psychosocial interventions. These have started to include bibliotherapy.

Mary's story illustrates an assumption that is sometimes made about people living with dementia; that because they cannot remember what a book is about, there is no longer any point in giving them books to read. However, the reading process itself may provide a response to some of the most frequent concerns expressed by people living with dementia; loneliness, lack of agency, lack of self-worth and boredom. As yet, there have been few studies on reading related to people living with dementia, and none dealing with their lived experiences of reading adapted texts. This paper describes a study, supported by Ryman Health Care, designed to investigate how people living with dementia felt about the reading process, and what kinds of reading they liked. While not conducted in a second language learning environment, this research is expected to be of interest to some extensive reading practitioners due to the use of simplified texts and attention to affective aspects of shared reading.

Literature Review

Bibliotherapy

The Reader Organisation (www.thereader.org.uk), or TRO, is the brainchild of Dr Jane Davis, and has revolutionized attitudes to reading across generational, societal, and mental health spectrums in Britain.

It advocates an approach called Get into Reading, using shared reading as a way of promoting reading, thereby building communities and improving mental health. The award-winning author Jeanette Winterson (2010) wrote: "Jane [Davis] found that reading aloud . . . makes people calmer, happier, self-reflective, saner and more open-minded." With reference to dementia, Winterson (2010) quoted Davis: "And what we have found is that for people with early Alzheimer's or dementia, the poetry sessions check the deterioration."

Get into Reading is already being used in groups designed to combat depression (Billington et al., 2010), and also with people living with dementia (Carroll & Kinderman, 2011). Comments from residents included, "You feel like you're with it. Yes it's lovely, like you're with the crowd." "You can go there and your imagination can take you anywhere." "It gives you an uplift . . . I feel happier and uplifted."

The staff confirm that it improves the mood of the residents:

"After the poetry's finished they [the carers] have gone, 'Oh my god, I can't believe how calm she is, she isn't half settled today isn't she? She's not agitated in any way. Even though she hasn't been able to read out loud, she can still read it, you know, in her mind.'"

So why reading as opposed to other stimulative therapies?

It is true that not everyone enjoys reading. However, Victor Nell, in his study of ludic reading, observed that humans have an insatiable appetite for narrative (Nell, 1988, p. 47). He quoted from Homer's *Odyssey*, written 3000 years ago: "Odysseus' tale was finished, and such was the spell he had cast

on the whole company that not a sound was heard throughout the shadowy hall." Today, although we may lack Odysseus' audience's opportunity to access extended oral narrative, we still want to be entranced by the tale encoded in the black squiggles on the white page. We recognize the magic and the power of words: eloquent people have the power to persuade; dumb is another word for stupid. So it is sad that many retirement homes are dumb, silent places; people sit around quietly nodding off, or staring vacantly at a television screen. Yet, as the studies described above show, many of these people can still decipher a text. They may sometimes be confounded by too many squiggles, too little white space, not enough guidelines. However, if they could continue to read, or hear those squiggles being brought to life through shared reading, what additional benefits might this bring?

How we read

Today, reading is an essential part of functioning in society, but this does not mean that everyone who can read is a ludic, or pleasure, reader. Different reading purposes mean different ways of reading. We do not always have to remember what we read to enjoy it. Louise Rosenblatt (1978) explained the differences in her transactional theory of reading response. She described a continuum of reading purpose, with, at one end, the goal of reading purely for information (efferent), and at the other end, of reading purely for pleasure (aesthetic). It is the difference between product and process. Rosenblatt proposed that in reading a text, we create a mental map of it, which she calls the 'evocation.' It is to this, and not directly to the text, that we respond. When we read for factual information, facts are the items that we 'foreground' to extract from the text, so person A's 'evocation' of a

washing machine manual would likely be very similar to that of person B.

But when we read for pleasure, it is not so. As Tolkien (1964) said in *Tree and Leaf*, his essay on reading, if an author describes a mountain, or a stream, or a valley, the image called up in the mind of the reader is a composite of every mountain, stream or valley that reader has ever encountered. A work of fiction will trigger different responses in each individual reader. One person may choose to foreground linguistic pictures, another, the sound and rhythm of the words, or a memory. The process, not the end product, is the purpose.

Michael Burke (2011), came to a similar conclusion when he proposed that it is possible that reading stimulates a personally created input "grounded in the indistinct, unconscious remembrance of past events, past locations and past loved ones" (p. 57). Burke suggested that memories triggered by literature emerge from the "affective maelstrom of the subconscious mind" (p. 104), and that "the brain is continually awash with processing activities" (p. 53). Thus reading is a highly creative process.

Shakespeare or airport blockbusters?

Burke (2013) suggested that the kind of reading we do has a formative effect on our own language. He argues that in the brain of a keen ludic reader, frequent, regular repetition of reading actually refines and speeds up the progress of the electrical impulses triggered by the activity, improving their transmission and efficiency. This claim supports the idea that the brain is a muscle that needs exercise, and its performance can be improved by appropriate stimulation. It is endorsed by Jane Davis, quoted by Winterson (2010, para. 6): "Richness changes the brain . . . The brain grows on what feeds it." Thus it is important to feed readers with

good, nourishing writing. This idea is also supported by a study performed by Keidel et al. (2013). They used functional MRI to show that Shakespeare's use of words activated wider brain networks than everyday language tasks did, and, in fact, created a kind of 'neurological tempest'. This sounds rather like Burke's 'affective maelstrom.'

Reading by people living with dementia

Although the Get into Reading projects initiated at the University of Liverpool and the Carroll and Kinderman pilot project have demonstrated that shared poetry reading is beneficial for people living with dementia, to date there has not been an investigation into their lived experience reading alone, or reading adapted narrative texts. Therefore, the researchers' aim in the feasibility study was to investigate the lived reading experiences of some people living with dementia, particularly reading adapted texts, in the hope that the results would illuminate some of those areas. The researchers' initial hypothesis was that adapted text with simplified language would be preferred by participants.

Methodology

Rationale for adaptation

The study required that the participants compared an original, 'normal' text, a children's version of the same story, and a version that was lexically and syntactically simplified. Each version had to be a well-produced book, so the researchers could not use photocopied sheets. But the first problem was the principles guiding the simplified adaptation. The New Zealand Ministry of Health Guidelines (Ministry of Health, 2012) for writing for people with cognitive impairment indicate that they need simplified syntax and high frequency vocabulary. They are similar to

recommendations for writing for people with aphasia by Rose et al. (2012) and Dietz et al. (2014). From these recommendations the researchers formed the hypothesis that a diminishing vocabulary and short-term memory loss would present major difficulties for people living with dementia. Using the Flesch Kincaid (n.d.) readability scale to measure the syntactic complexity of texts, and Lextutor Vocabulary Profiler (Cobb, 2017; Heatley et al., 2002), to gauge the level of vocabulary, the researchers produced a version of *A Christmas Carol* with the language adapted to FK grade level 2, and with simple vocabulary, to accommodate people with dementia ranging from mild to severe.

A Christmas Carol was selected for several reasons. The feasibility study was planned for early December, so it was seasonal. The writing of Dickens needs no apology. This story was likely to be known by most of the participants, it was relatively short, and it was out of copyright. The original illustrations were also out of copyright, so some could be used to produce an attractive and colourful book, with the support of Ryman Health Care, at relatively low cost.

Study

The researchers obtained approval from the Health and Disability Ethics Committees of the Ministry of Health to carry out the study. Eight willing participants were found through advertisement, though one subsequently dropped out. Four had been diagnosed with mild to moderate dementia and were living at home, and the others were in residential care facilities. They were initially interviewed separately, to get their consent, biographical details and reading preferences. They then they took part in one of two focus groups held in a residential care facility. Two weeks prior to the

Table 1. Analyses of Texts Used in Feasibility Study

Text Version	Flesch Kincaid			Lextutor			
	Word number	FK Ease	FK Grade	1st 1000 most frequent words	2nd 1000 most frequent words	Academic word list	Words not included in other lists
A (children’s)	750	5	5th	68.8%	11.65%	1.13%	18.42%
B (original)	32,398	6.4	6th	81.12%	6.6%	1.42%	10.86%
C (adapted)	1496	2.4	2nd	82.85%	7.25%	0.11%	9.71%

focus groups, each participant was given three versions of *A Christmas Carol*:

- A. A children’s version
- B. The original Dickens in large print
- C. The version adapted to FK level 2.

Each participant was asked to read the texts before the focus groups took place, although it was difficult to ascertain whether they had done this or not. However, at the focus groups, excerpts from each version were read aloud, and discussed. The discussions

were recorded, and subsequently transcribed, coded and analysed by the researchers using Interpretational Phenomenological Analysis (IPA).

Results

Reading preferences

Participants preferred fiction over non-fiction, especially action, crime and romance. Biography was their non-fiction preference.

Table 1 shows that the vocabulary levels are similar in the original Dickens and the

Table 2. General Reading Attitudes

Super-ordinate themes	Sub-ordinate themes	Examples from data
General Reading Attitudes	Interest in reading	FG1 1: <i>Books always took me to another adventure, another world.</i> FG1 2: <i>Books are important, comforting. Especially if you’re ill for a long period</i>
	Interest in book clubs	FG2 3: <i>Book clubs . . . that’s a great idea. We could descend on them with our ideas!</i>
	Family attitudes to reading	FG1 2: <i>There were always books around in the house.</i> FG1 3: <i>Reading wasn’t part of family life. I came to it when I was older.</i>

Table 3. Preference for the Original Language of Dickens

Super-ordinate themes	Sub-ordinate themes	Examples from data
The Voice of Dickens	Dislike of over-simplifying	FG1 1: <i>Book A was too simple. It lost the voice of Dickens</i>
	Enjoyment of text	FG2 3: <i>Yes, yes, Marley was dead. It's lovely . . . Marley was as dead as a doornail.</i>
	Response to language itself	In response to 'Everyone knew old Ebenezer Scrooge was the most tight-fisted miser you could meet, a squeezing, wrenching, grasping, scraping, clutching covetous old sinner': FG2 2: <i>Piss off, you old bastard!</i> FG2 3: <i>Oh, yes I love it!</i> FG2 2: <i>Explain covetous to me!</i> FG2 3: <i>Covetous is when you take something and you keep it!</i> FG2 2: <i>And you shouldn't do that!</i> FG2 3: <i>Never!</i> In response to: 'No one ever stopped Scrooge in the street to say, My dear Scrooge, how are you?': FG2 2: <i>Give us a kiss!</i>

Table 4. Recommendations from Participants

Super-ordinate themes	Sub-ordinate themes	Examples from data
Recommendations	Cast of characters	FG1 3: <i>I have difficulty in remembering who the characters are.</i> Researcher: <i>Should we have a cast of characters?</i> FG1 3: <i>Yes.</i>
	Pictures	FG1 2: <i>Too many pictures (Book C)</i> FG1 1: <i>The illustrations were lively (Book C)</i> FG1 1: <i>The illustrations were childish (Book A)</i>
	Quality of paper and size and type of font	FG1 2: <i>In Book B the sans serif font and yellow paper and narrow margins made it difficult.</i> FG2 2: <i>I liked the white paper in Book C</i> FG1 3: <i>I like the large print.</i> FG1 1: <i>I like the serif in Book C; it leads you on.</i>
	Quantity of text on page	FG1 4: <i>In Book B there's so much writing it's daunting.</i> FG1 1: <i>In Book C, not enough writing.</i> FG2 2: <i>In book C, not too many words on a page.</i> FG1 2: <i>Not enough writing.</i>

adaptation; the difference between them was in the number of words in the texts. The adaptation (version C) is at a much lower FK level than the other two because the sentences are shorter and less complex.

Main themes

Three main themes were identified from the analysis of the transcripts: these were general reading attitudes, preference for the original language of Dickens, and recommendations from the participants. Examples of comments are shown in the tables below. The focus groups are designated FG1 and FG2, and each participant is identified only by number.

The study was not able to establish any findings around reading alone, as it was impossible to quantify how much (if any) reading our participants had done before the focus group meetings. We had asked carers to keep journals on behalf of the participants, but only one did. Thus, the focus of this discussion is on the effects of shared reading.

Discussion

How the results diverged from the hypothesis

In contrast to the initial hypothesis, the participants were not impressed by the carefully adapted text. Instead, what they responded to was the original text of Dickens. The ram-bunctious Dickensian hyperbole sparked off a chorus of delighted comments, for instance, *"It's lovely"* to Marley being as dead as a doornail, and *"piss off you old bastard"* in response to the description of Scrooge (Table 3). The texts stimulated discussion. Particularly among the moderate to severe dementia participants, discussion was provoked by the words themselves: the meaning of covetous, for example (Table

3). They liked the illustrations in the adaptation, but some thought there were too many. They did not like the illustrations in the children's version; *"Frankly, childish"* (FG1 1).

The lived experience of People living with Dementia

In the study by Clare et al. (2016) of the experience of living with dementia in residential care, certain themes emerged: lack of agency, loss of self-esteem, sense of loneliness, and boredom. The importance of looking back over one's life and reliving past events is highlighted. Decisions are made for people with dementia, and assumptions are made about them, as in the case of Mary, so they lack agency, and hence sense of identity. Joining a shared book group and discussing meaningful topics may alleviate loneliness and boredom, and may confirm a sense of self. One participant with moderate to severe dementia, identifying herself as a reading addict, quoted her mother as saying disapprovingly: *"Where's L? She'll be sitting with her nose in a book!"* She had been a primary school teacher, and described the effect of reading on children thus: *"It gives them [children] a marvellous feeling of power."*

Reading evoked memories from earlier stages in life; one man said he had often been ill as a child, and as result, had read a great deal. Another person said: *"Reading wasn't part of family life."* These comments led to repartee and discussion among the participants, dispelling the notion that people living with dementia are totally inward-looking. All their comments confirmed that reading had a positive effect on communication and self-expression, and that it was a pleasurable social experience.

These results overturned the researchers' original hypothesis that the compromised

short-term memory typical of people living with moderate to severe dementia would affect their ability to understand original texts. Even participants with moderate to severe dementia had no problems understanding the original language of Dickens. They did have difficulty in “remembering who the characters are” (FG1 3), and some found it preferable to have “more blank on the page, which doesn’t intimidate as much [as the original]” (FG2 3). So there was a requirement for original text, but not too much of it, presented in an easily readable format, with a cast list of characters. This bears out the results of the Billington study (2010), and the Carroll and Kinderman pilot study (2011), where original poetry was enjoyed in groups sharing reading.

Conclusion

The literature review and the tentative findings of the feasibility study strongly suggest that reading and discussing appropriately selected and/or adapted, but not simplified, classic texts and poetry can be enjoyed by people with various levels of dementia, in contrast to the original hypothesis. Shared reading appears to respond to some of the needs of this group of people, by exercising neural pathways, eliciting memories of the past, and helping to support a sense of identity. Reading ‘good’ literature may have more benefits than reading pot-boilers; unusual use of language is common in literary texts and it appears to stimulate the brain more than the prosaic language which may appear in the average blockbuster. Whatever the truth of this, adapting texts by authors who have been dead for over 70 years avoids the problem of copyright. Certainly the feasibility study participants responded more enthusiastically to the rich language of Dickens than to the simplified adaptation, but more research into the benefits of bibliotherapy

for people living with dementia is needed. There is a clear message that people like Mary can certainly still read. However, it is the process, not the product, that they enjoy.

Following these findings, and with the support of Bupa Health Care, the researchers have re-adapted *A Christmas Carol*, and have also developed four new books: a selection of poetry, adaptations of two Katherine Mansfield stories, an Arthur Conan Doyle Sherlock Holmes story, and Louisa M. Alcott’s *Little Women*. These will form the basis of an extended study to be conducted in New Zealand, Australia, the UK and possibly the US to further investigate the effects of reading classic literature in book groups on the quality of life and cognitive abilities of people living with dementia. We hope this will pave the way for more such investigations.

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