Literature and Dementia,
Nurturing an Oceanic Mind

Dr B Sally Rimkeit
Dr Ben Werkmeister
Psychological Medicines Department
University of Otago; CCDHB
Presentation Outline

1) What is an Oceanic Mind?

2) Why study shared reading for people living with dementia?

3) Theory of Mind.
The Oceanic Mind

1) Michael Burke - “Literary reading, cognition and emotion: an exploration of the Oceanic Mind”

   Literary reading induced:
   
   a) mental imagery
   b) Reading moods
   c) Reading places
   d) Literary Themes
   e) Style.

2) Liverpool study. MRI - Shakespeare activates more neural connections
Cognitive reserve

1) Nun study.

2) Reading increasing cognitive reserve.

3) Protective against Alzheimer's disease.
1) The Recovery/Discovery Model for Brain Health.

2) Cognitive Stimulation Therapy – CST.

3) Arts-based interventions: music, dance, visual arts.

4) What are the benefits of shared reading?
Our Hypotheses

Participating in a dementia-friendly book group

1) Stimulates an Oceanic Mind.

2) Improves quality of life.

3) Improves mood, sense of thriving and cognition.

4) Helps to retain theory of mind.
Our Research

1) Feasibility study.

2) Pilot Randomised Control Trial (RCT).

3) Qualitative thematic analysis.

4) Linguistic analysis.

5) Fully powered international RCT, based in Care Homes.
Theory of mind
Dementia-friendly libraries

Literary Alzheimer’s, A qualitative feasibility study of dementia-friendly book groups

Peer Reviewed

R Sally Rimbert and Gillian Carridge
Medical Specialist in Psychogeriatrics, University of Otago & CCDHB, Wellington, New Zealand
Dean of Faculty of International Studies, IPU New Zealand, Tertiary Institute, Palmerston North, NZ

Despite the estimated 47 million people living with dementia and despite reading being one of our most popular cultural activities, there is lack of research around how people with dementia experience reading and what tools can be used to help them to enjoy a good read. Current RLA Guidelines for Library Services to Persons with Dementia are unhelpful, as they encourage the stigmatization and infantilisation of the adult with dementia. There have been few strategic efforts by New Zealand libraries to engage those living with dementia to continue reading. Nelson and Canterbury libraries are some exceptions, providing ‘dementia-friendly’ book groups.

This report summarises the findings of a qualitative study, which looks at how people living with dementia experience reading literary fiction and how such activity is best facilitated for creativity and enjoyment. The findings of the study refute Tobin’s ‘regression hypothesis’ of dementia. What was striking in both focus groups was the preserved command and appreciation of language, and the stimulation of sharing the “wonderful words” of the featured author Charles Dickens. To support memory deficits, while preserving the stimulation of the original language, the following modifications were found to be helpful: providing a cast of characters, reducing the amount of text, and regularly repeating references.

Introduction

“The path of a reader is not a runway but more a hike through a forest, with individual twists and turns, entanglements and moments of surprise” (Holden, 2004).

Alzheimer’s disease, with its plaques and tangles underlying neurodegeneration of the brain, must certainly alter the path of the adult reader, though the experience of reading while living with dementia is poorly understood. Referring to British cultural commentator John Holden’s quote above, is personhood in dementia so lost that his or her perception of these twists and turns are also lost? Does the narrative fail to awaken in the reader entanglements of past and recent memories? Are moments of cursum undeceaintrae lost? Does the path through the forest become so dense as to impede the journey altogether?

Despite the estimated 47 million people living with dementia worldwide (World Health Organization, 2012) and despite reading being our most popular cultural activity (Holden, 2004), there is minimal evidence-base around how people with dementia experience reading and what tools can be used to help them to enjoy a good read.

Depending on the disease type and stage of the disease, dementia such as Alzheimer’s cause progressive cognitive impairments including poor concentration, slowed executive functioning (i.e., abstracting, organizing, and planning) and poor working memory, which can lead to difficulty attending to and retaining information from books. Strategies for maintaining this important leisure pasture, which may improve quality of life and cognition for the elderly (Larcher & Greenhalgh, 2014), are needed. Parity due to inadequate social and community support to motivate and encourage reading, many people with dementia forget reading for pleasure early in their disease course, possibly losing a favourite pastime prematurely (Moos, 2011).

John Holden posits that the public library is part of the city’s ‘creative cluster’ or genius loci (2004), and one can argue that it is the most obvious place of community support to “foster the joy of reading” for its citizens (Public Libraries of New Zealand and Local Government New Zealand, 2012). As Former Chair of the NZ Association of Public Library Managers, Ian Littleworth, writes, “Public libraries sit at the heart of local communities throughout New Zealand.” Whilst there have been impressive efforts in engaging youth in reading and literacy (The National Library of New Zealand, 2017), there have been few strategic efforts to engage the elderly, especially those living with dementia. Searching through the Public Libraries of New Zealand. A Strategic Framework 2012 – 2017 (Public Libraries of New Zealand and Local Government New Zealand, 2012) there is no reference to ‘dementia’ or ‘Alzheimer’s’ whatsoever, and it appears that the reading needs of elderly citizens living with dementia are largely ignored. Known local initiatives to engage patrons living with dementia in reading groups include Nelson (Baker, Carridge, & Rinkiklæ, In press) and Canterbury Public Libraries.