

The Role of Reading Classic Fiction in Book Groups for People with Dementia is Better Understood through Use of a Qualitative Feasibility Study

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Evidence Summary

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A Review of:

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Abstract

Objective – To explore how people living with dementia experience reading classic fiction in book groups and what benefits this intervention provides.

Design – Qualitative feasibility study.

Setting – Day centre within a care home in the North Island of New Zealand.

Subjects – Eight participants with a medical diagnosis of dementia – four community dwellers who attend day centers, and four residents of a secure dementia unit in a care home.

Methods – Investigators used surveys, focus groups, and interpretative phenomenological analysis (IPA), for ideographic analysis of the data.

Main results – Following analysis of the focus book group data, three superordinate, with

related subordinate, themes were found: 1) the participant as a lively reader. The participants shared childhood memories of reading and when they became adults, how they encouraged reading within the household and with their own children. Subordinate themes included: recall, liveliness of discussion, and interest in reading and book clubs; 2) the participant as guardian of the voice of Dickens. Participants believed that, when the language is simplified, the beauty and rich imagery of Dickens is lost. Subordinate themes included: oversimplifying “loses the voice of Dickens”, familiarity, and continued play on words; and 3) the participant as a discerning book reviewer. The participants offered a number of ‘dementia-friendly’ suggestions, including the use of memory aids and simplifying text. Subordinate themes were expressed as four recommendations: use cast of characters; illustrations pick up the energy of the story, but balance quantity with risk of being childish; the physical quality of the text and paper; and chunk quantity of text while keeping the style of the original author. The choice of using classic fiction that was already well known was validated by the participants, who had some preconceptions about Ebenezer Scrooge, and described him by using epithets such as mean, an old bastard, and ugly. The participants found the investigators’ adapted version to be oversimplified, as short excerpts of the original Dickens seemed to evoke emotional and aesthetic responses of appreciation. Therefore, when creating adaptations, it is important to preserve the beauty of the original writing as much as possible.

Conclusion – This qualitative feasibility study has provided a better understanding of how people living with dementia experience classic fiction in shared book groups. For individuals with Alzheimer’s disease, language skills may be well-preserved until later in the disease course. For example, the focus group participants demonstrated an appreciation and command of language, as well as enthusiasm and excitement in the sharing of the original Dickens with others. They suggested the use of memory aids, such as including a cast of characters, and repeating the referent newly on

each page. Participants also suggested that the adapted version be shortened, to use a large font, and to include plenty of pictures. The choice of using classic fiction was validated by the participants, as they found these tales comforting and familiar, particularly when they included such colorful characters as Ebenezer Scrooge. Finally, people living with dementia should be encouraged to enjoy books for the same reason other adults love to read – primarily for the creative process. Classic fiction may be adapted to enhance readability, but the adaptation must be done in a thoughtful manner. While memory deficits occur in Alzheimer’s disease, an appreciation of complex language may be preserved until the later disease stages.

Commentary

This study highlights how people living with dementia experience classic fiction in shared book groups. The findings build upon the understanding of experiences identified by Billington (2013), who found that engagement in reading-group activity appeared to produce a significant reduction in dementia symptom severity. Her findings suggested three themes for effective reading group engagement: its components; enjoyment, and a renewed sense of personal identity; and enhanced listening and memory. Billington suggested that a randomized controlled trial (RCT), along with a qualitative component, could further research in this area, by addressing issues of individual differences amongst participants. In fact, the investigators for this study have published five adaptations, based on classic fiction, drama, and poetry, for a pilot RCT and linguistic analysis of dementia-friendly book groups, in preparation for a 2018 multicenter, international RCT. The findings of a systematic review by Latchem (2014) on the role of reading on the health and well-being of people with neurological conditions concluded that, while research in this area is limited, a number of studies reported reduced agitation, and increased engagement, in people with dementia. Latchem also suggested that RCTs, along with qualitative research, are needed to provide an in-depth and rich understanding of

the effect of reading interventions for people living with dementia.

This study had specific shortcomings – it explored the experiences of just eight participants with a medical diagnosis of dementia, in one location, the North Island of New Zealand, and at one particular point in time. O’Cathain (2015) published a guide for researchers who are assessing qualitative research within feasibility studies for RCTs. She recommended that further qualitative, and quantitative, research on how dementia is experienced by this population, in other health care settings and countries, involving a larger, more diverse, sample, and over a longer period of time, would strengthen the key findings and applicability of the study. She also stressed the importance of having an experienced qualitative researcher as a part of the feasibility study design team.

The findings of this research study have the potential to assist programs in psychology, geriatrics, linguistics, and library and information science to develop curricula on research study design. Study results may also assist associations and organizations involved in educating, preparing, and supporting health professionals at every career stage to develop the actions, mindsets, and skills needed to facilitate and advance knowledge about how people with dementia experience reading classic fiction. In addition, this study could influence writers to create new adaptations of

classic fiction, and market it to day centres and care homes. Health sciences or public librarians may be inspired to start a book group for people with dementia. The findings may also serve to inform the design preferences in printed education materials for people with dementia.

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