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The role of reading on the health and well-being of people with neurological conditions: a systematic review

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Objectives: Little research has been conducted that investigates the benefits of reading for people with neurological conditions despite its age old use to improve well-being. The aim of this study was to identify and review the evidence of the effect of ‘lone’ reading, reading aloud and shared reading groups on the health and well-being of people with neurological conditions in clinical and long-term care settings.

Methods: A literature search was conducted incorporating a systematic search of electronic databases, internet searching, ‘snowballing’ technique from references of relevant studies and consultation with clinicians and academics in the field.

Results: Twelve studies (five quantitative, three qualitative and four mixed methods) met the criteria for inclusion in the review. No randomised controlled trials were identified. Significant heterogeneity in the results of the quantitative studies precluded statistical data synthesis. Thematic analysis and synthesis was applied to the three qualitative studies and the qualitative data of the mixed-method studies. All but one of the quantitative studies reported that the reading interventions had a positive effect. The evidence from the qualitative studies demonstrated multiple positive effects of shared reading groups.

Conclusions: The effect of ‘lone’ reading, reading aloud and shared reading groups on the health and well-being of people with neurological conditions is currently an under-researched area. Although this review reports encouraging results of positive effects, the results should be viewed with caution due to the lack of randomisation, the small numbers of participants involved, and the limited and heterogeneous evidence base.

Keywords: dementia; stroke; long-term care

Introduction

Long-term neurological conditions affect nearly 1 billion people worldwide (World Health Organisation, 2006) and 8 million people in England alone (Neurological Alliance, 2012). Neurological conditions arise from damage to the brain, spinal cord or nerves, as a result of illness or injury (Neurological Alliance, 2012) and commonly cause physical, cognitive, behavioural or communication impairments (Connell & Tyson, 2012; Turner-Stokes et al., 2007). There are many different types of neurological conditions with some being most prevalent in the young; however, the risk of developing neurological conditions, such as stroke (Asplund et al., 2009) and dementia (Lobo et al., 2000) increases with age.

The role the arts have to play in our health is now more readily recognised within healthcare (Eakin, 2003) and is supported by an ever-expanding evidence base (Baumann, Peck, Collins, & Eades, 2013). Research into the health benefits of singular arts interventions or mixed arts programmes for people with neurological conditions such as stroke and dementia has identified a range of positive benefits (Baumann et al., 2013; Gotell, Brown, & Ekman, 2009).

The therapeutic benefit provided by reading literature was first recognised by the ancient Greeks and Romans who realised that text could be used as a therapeutic tool (McCulliss, 2012). Reading has been considered as a way

to maintain general mental well-being since the 1930s (Turner, 2008) and as a treatment for mental health conditions since the 1800s (McCulliss, 2012). There has been a significant uptake of the use of literature in mental health-care in recent years with multiple ‘books on prescription’ schemes being implemented across the UK since 2002, where general practitioners (GPs) ‘prescribe’ books in addition to or instead of medication (Furness & Casselden, 2012).

The role of reading in enhancing the health and well-being of older people, those with learning disabilities and those in long-term care settings has also begun to be researched. For older people (especially those in long-term care facilities), reading aloud in a group has been reported to enhance socialisation and provide a valuable link to the world outside of the immediate care setting (Bond & Miller, 1987). The use of literature as a therapeutic tool for people with learning disabilities has only recently been considered, with the outcomes for this group of people including the development and understanding of emotional responses and a gaining of confidence (Cocking & Astill, 2004). Given the acknowledged benefits of reading to general mental health, mental health conditions and more recently, for older people in long-term care and those with learning disabilities, it is possible that reading may also have positive effects on the health and well-being of people with neurological conditions.

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This systematic review was inspired by the work of The Reader Organisation (TRO), a national charity in the UK, whose 'Get into Reading' (GiR) model forms the foundation of an extensive social inclusion programme based on shared reading (Billington, Dowrick, Hamer, Robinson, & Williams, 2012b). The principal features include the reading aloud of English literature, predominantly 'classic' fictional texts such as *Silas Marner* by George Eliot or poetry such as *Crossing the Bar* by Alfred Lord Tennyson, in a group session, interspersed with any discussion that is stimulated by participants' responses to the text. The text is read aloud by the facilitator or any member of the group that wishes to, which ensures that any text, no matter how complex, can be accessible to everyone and does not exclude those who have difficulties with literacy (Davis, 2009). TRO's model of shared reading is distinct from other reading therapies in that it emphasises the importance of reading 'classic' literature, moving away from the idea of prescriptive 'self-help books'. TRO's founder Jane Davis explains that reading 'classic' poetry and prose is important as 'the more difficult, the more rich, the less immediately relevant a text the more therapeutic it might be. If the connection with a book comes as a surprise, an active emotional discovery, there may be a more dynamically creative result' (Davis, 2009, p. 174). She highlights that reading a fictional text enables the reader to have a response to and relationship with the text that is personal to them in comparison to reading an instructive text that has limited scope for engagement.

To date little research has been carried out on the effect of group reading interventions with people with neurological conditions (Robinson, 2008). The aim of this review therefore was to establish the role of this type of intervention and/or its components (reading aloud, shared reading in a group, individual or 'lone' reading) on improving the health and well-being of those with neurological conditions, and to identify the strength of the current evidence and any gaps in the literature in order to inform future research.

Methods

Search strategy

The search incorporated a number of strategies: a systematic search of electronic databases, internet searching, 'snowballing' technique from references of relevant studies and consultation with clinicians and academics in the field. Nine electronic databases (AMED – Allied and Complementary Medicine Database, BNI – British Nursing Index, Cochrane Library, CINAHL PLUS – Cumulative Index to Nursing and Allied Health Literature, EMBASE, ERIC – Education Resources Information Centre, MEDLINE, PsycINFO, Web of Knowledge) were searched from the inception of each database to May 2012 (Week 3) for relevant published literature. Databases were selected to cover an extensive range of health, education and social science disciplines. The search strategy combined indexing terms (for those databases that use

MeSH terms) and free text words (for further details see <http://www.liv.ac.uk/psychology-health-and-society/staff/janette-greenhalgh/>). The search strategies did not include any date or methodological filters that would limit results to a specific study design.

Inclusion criteria

Studies investigating the effect of lone reading, reading aloud or shared reading in a group on the health and well-being of adult or paediatric patients with any neurological condition, in any clinical, community or long-term care setting were included in the review. Studies reporting any clinical outcome measure or subjective outcomes, whether identified through qualitative or quantitative data collection methods and only those reported in English were included.

Exclusion criteria

Studies which included adult or paediatric participants with developmental or learning disabilities or those with a purely mental health diagnosis were excluded. Studies reporting reading interventions for 'normal' development of language or numeracy skills, functional magnetic resonance imaging studies using reading to identify impairments or speech and language therapy interventions tailored for individual patients were also excluded.

Studies identified by the search strategy were assessed for inclusion in two stages. First, all relevant titles and abstracts identified via electronic searching were screened by one reviewer (J. Latchem) to identify potentially relevant studies for inclusion in the review. Second, full text copies of these potentially relevant studies were obtained and assessed for inclusion using the inclusion/exclusion criteria. The inclusion of each article at this stage was considered and discussed by the two reviewers (J. Latchem and J. Greenhalgh). Disagreements were resolved through discussion.

Quality assessment

Two reviewers (J. Latchem and J. Greenhalgh) independently assessed the methodological quality of each included study. As studies with differing or multiple methodologies were included in the review, separate quality checklists were required. A bespoke quality checklist was devised for use with the quantitative studies (see Table 1 for checklist items). The items included in the checklist were based on guidance published by recognised experts in the field (Centre for Reviews and Dissemination, 2008; Crombie, 2004). For the qualitative studies, a modified quality checklist based closely upon the nine key questions defined by Popay, Rogers, and Williams (1998) was used (see Table 2 for checklist items). Four mixed-method studies were included in the review and therefore the quantitative and qualitative components were each assessed using the relevant checklist. Discrepancies between quality grading were resolved through discussion.

Table 1. Quality assessment: quantitative studies.

Study	Are the aims of the study clearly stated?	Was the design appropriate for the study question?	Was a control group used?	Was the control group appropriate?	Were the eligibility criteria for entry into the study specified?	Was the number of participants stated?	Were the baseline characteristics of the participants presented?	Were the baseline characteristics of both groups similar?	Were any co-interventions identified that may affect results?	Was the outcome measurement valid and reliable?	Were outcomes assessed blind?	Are the statistical methods described?	Were there any unexpected withdrawals?	Are reasons for withdrawals stated?	Are at least 80% of participants accounted for in the final analysis?	Are any outcomes measured but not reported?	Were any conflicts of interest detailed by the researchers?	Was the impact of any conflict of interest discussed?	Did the study report appropriate ethical approval?
Agresti et al. (1989)	Y	Y	Y	Y	Y	Y	Y	N/S	Y	Y	N/A	N/A	N	N/A	Y	N	N	N/A	N
Billington et al. (2012a)	Y	Y	Y ^b	Y	Y	Y	N	N/A	N	Y ^c	N/A	Y	N	N/A	Y	N	N	N/A	N
Billington et al. (2012b)	Y	N ^d	N	N/A	Y	Y	N	N/A	N	Y ^c	N/A	Y	N	Y	Y	N	N	N/A	N
Billington et al. (2012c)	Y	Y	N	N/A	Y	Y	N	N/A	N	Y	N/A	Y	N	N/A	Y	N	N	N/A	N
Billington et al. (2012d)	Y	Y	N	N/A	Y	Y	N	N/A	N	Y	N/A	Y	N	N/A	Y	N	N	N/A	N
Clair (1996)	Y	Y	Y ^b	Y	Y	Y	N	N/A	N	Y	N/A	Y	N	N/A	Y	N	N	N/A	N
Cohen-Mansfield et al. (2010)	Y	Y	N	N/A	Y	Y	Y	N/A	N	Y	N/A	Y	Y	Y	N	N	N	N/A	N
Gardner et al. (2000)	Y	Y	Y ^b	Y	Y	Y	Y	N/A	N	Y	Y	Y	N	N/A	Y	N	N	N/A	N
Skeajner and Camp (2007)	N	Y	N	N/A	Y	Y	Y	N/A	N	Y	N/S	Y	N	N/S	Y	N	N	N/A	N

Note: Y: Yes (item adequately addressed).

N: No (item not adequately addressed).

/: Partially (item partially addressed).

N/A: Not applicable.

N/S: Not stated (item not stated).

^aSee post-injury.

^bParticipants acted as own controls.

^cIt is noted in the study limitations that participant symptoms were not always rated by the same member of staff throughout the data collection period.

^dNo 'before' measure.

Table 2. Quality assessment: qualitative studies.

Study	Does the research, as reported, illuminate the subjective meaning, actions, and context of those being researched?	Is there evidence of the adaptation and responsiveness of the research design to the circumstances and issues of real-life social settings met during the course of the study?	Does the sample produce the type of knowledge necessary to understand the structures and processes within which the individuals or situations are located?	Is the description provided detailed enough to allow the researcher or reader to interpret the meaning and context of what is being researched?	Are different sources of knowledge about the same issue appropriately compared and contrasted?	Are subjective perceptions and experiences treated as knowledge in their own right?	Is the data collection and analysis process described well enough to demonstrate how research has moved from a description of the data, through quotation or examples, to an analysis and interpretation of the meaning and the significance of it?	Do any claims made regarding generalisability to either other bodies of knowledge, populations or groups seem appropriate and justified?	Is there acknowledgement of any limitations and areas for further research?
Billington et al. (2012a) ^a	Y	Y	Y	Y	Y	Y	Y	Y	Y
Higgins et al. (2005)	Y	Y	Y	Y	Y	Y	Y	Y	Y
Holm, Lepp, and Kingsberg (2005)	Y	/	/	Y	N/A	/	Y	Y	Y
Robinson (2008)	Y	Y	Y	/	Y	Y	/	N/A	N

Note: Y: Yes (item adequately addressed).

N: No (item not adequately addressed).

/: Partially (item partially addressed).

N/A: Not applicable.

N/S: Not stated (item not stated).

^aPlease note that the four mixed-method studies (Billington et al., 2012a) were presented in a single research report with the qualitative results analysed, synthesised and presented collectively. Therefore, these studies are referred to as one here.

Data synthesis

The methods, designs and reading interventions included in the quantitative studies were heterogeneous and therefore it was inappropriate to combine their results in a meta-analysis. The data from the qualitative studies were combined using meta-synthesis using thematic synthesis, an approach developed by Thomas and Harden (2008). Thematic synthesis involves the organisation and subsequent thematic analysis of the findings from multiple qualitative studies. Here the process detailed by Thomas and Harden (2008) was followed but in short, anything labelled 'results' in the qualitative studies (including researcher thematic analysis, direct quotations and case study reflections) was inputted into the data management software program QSR NVivo9 (QSR International Pty Ltd, Doncaster, Victoria, Australia), and analysed thematically, subject to a process of free line coding, the construction of initial descriptive themes and the final development of analytical themes ready for presentation and discussion. Results were presented in the form of 'key themes'.

Results

A total of 5622 non-duplicated records were identified by the electronic search strategy and a further 18 articles were identified through snowballing, consultation with experts and Internet searching. All were screened for inclusion and 70 were identified as potentially suitable. The full text was obtained for these articles and the inclusion/exclusion criteria applied.

Finally nine publications (seven peer-reviewed articles and two non peer-reviewed research reports) reporting 12 studies in total were included in the review. This included five quantitative studies, three qualitative studies and four mixed-method studies reported in one publication (Billington, Carroll, Davis, Healey, & Kinderman, 2012a). (Please note that five different studies were reported in the Billington et al.'s (2012a) publication but only four met the inclusion criteria for this review.)

Results for the quantitative and qualitative components of the mixed-method studies are reported separately. The review process is presented in Figure 1.

Methodological quality

The quality of the quantitative studies was variable, each with differing strengths and weaknesses. Quality assessments of all included studies are presented in Tables 1 and 2. No randomised controlled trials (RCTs) were identified. Six of the studies were quasi-experimental trials. One study used a control group (Agresti, Corrigan, & Gribble, 1989); in the remaining studies participants acted as their own controls (Billington et al., 2012a; Clair, 1996). Two studies were uncontrolled (Cohen-Mansfield, Marx, Dakheel-Ali, & Regier, 2010; Skrajner & Camp, 2007) and one was a single-subject study (Gardiner, Furois, Tansley, & Morgan, 2000).

Five of the seven included qualitative studies were considered to be of good methodological quality

(Billington et al., 2012a; Higgins, McKeivitt, & Wolfe, 2005). One study (Robinson, 2008) was a short report and much detail of the study and results were missing, which prevented detailed assessment of its overall quality (Table 2).

Due to the variability of study design and methodological quality, the quality assessment was of limited use. The process did however lead to the identification of methodological issues for discussion and has given rise to methodological recommendations for future research in this area.

Study characteristics and findings

Quantitative studies

Table 3 describes the key characteristics of the quantitative studies included in this review. The quantitative studies investigated the effect of shared reading in groups, in pairs, lone reading silently or reading aloud. The studies included a total of 266 participants (see Table 4 for participant characteristics). Eight of the nine quantitative studies investigated the effect of a reading intervention on behaviour (e.g. agitation) (Billington et al., 2012a; Clair, 1996; Cohen-Mansfield et al., 2010; Gardiner et al., 2000; Skrajner & Camp, 2007). One study (Agresti et al., 1989) presented short stories to participants in three different modes (story read to the participant, participant read the story silently, participant read the story aloud) and measured the effect the different delivery modes had on recall.

In the eight studies investigating the impact of reading on behaviour, a positive impact on the behaviour of interest was found. Three studies reported that reading had a statistically significant positive effect by increasing alert responses (Clair, 1996), reducing agitation (Cohen-Mansfield et al., 2010) and increasing levels of engagement (Skrajner & Camp, 2007). Billington et al. (2012a) (Care Home Group 2) found positive effects for the reduction in the severity of agitation, disinhibition and irritability but these were not statistically significant. The remaining Billington et al. (2012a) studies (Hospital Group A, Day Centre and Care Home 1 and 3) and Gardiner et al. (2000) reported positive effects of shared reading groups in reducing the severity of multiple symptoms caused by dementia, including agitation, anxiety and disinhibition; however, it was not possible to carry out a statistical analysis to determine whether these results were statistically significant due to missing data or small sample sizes. In the Billington et al. (2012a), Hospital Group A and Gardiner et al. (2000) studies, the positive effects measured were found to last up to a week in one case (Gardiner et al., 2000) and several weeks in another (Billington et al., 2012a). As neither of these studies were RCTs, however, the suggestion that reading interventions could have a lasting positive impact on symptoms caused by neurological conditions should be viewed with much caution.

Three studies (Clair, 1996; Cohen-Mansfield et al., 2010; Gardiner et al., 2000) investigated reading interventions along with other interventions on the behaviour of

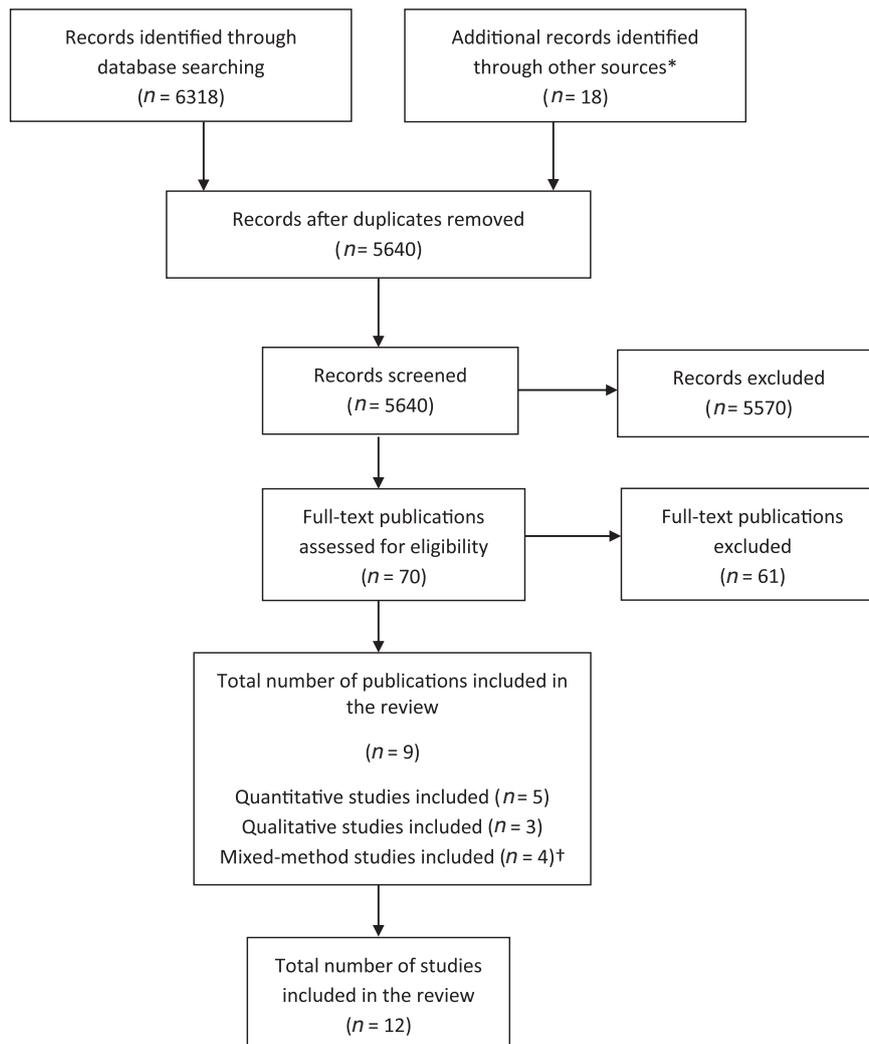


Figure 1. Flow diagram.

*Other sources included consultation with experts, internet searches, and snowballing from reference lists of relevant studies.

†Please note that four included studies were reported in a single research publication hence the higher number of studies included than publications.

people with neurological conditions. Two studies (Clair, 1996; Gardiner et al., 2000) showed that reading in pairs was as effective as music interventions at producing positive effects on behaviour and in the other study (Cohen-Mansfield et al., 2010) the reading intervention was better than practical tasks or one-to-one interaction at reducing agitation and as effective as a music intervention.

A number of methodological problems were identified. Investigating the effects of multiple interventions on the same population within a single study may create a cumulative effect and mask the actual effect of a single intervention. Of the three studies (Clair, 1996; Cohen-Mansfield et al., 2010; Gardiner et al., 2000) investigating the effects of more than one intervention or stimulus on the same population, two studies (Clair, 1996; Cohen-Mansfield et al., 2010) delivered multiple interventions in short bursts, one following another, with only brief non-intervention periods in between. Neither of these studies addressed the potential of a cumulative effect nor documented any justifications for the intervention and non-intervention timings they used. In the Gardiner et al. (2000) study, which investigated the impact of two

interventions on the disruptive behaviour of two participants, interventions were delivered to participants on different weeks with a gap of a week in between the completion of one intervention period and the beginning of the next.

Unlike all of the other studies, Agresti et al. (1989) did not find a positive result, with no statistically significant differences observed in recall between the different modes of delivery. The authors of this study noted, however, that this result could be due to a number of limitations to their study including the variation in reading levels of participants.

Qualitative studies

Table 5 describes the key characteristics of the included qualitative studies. The qualitative studies included a total of 126 people (see Table 6 for participant characteristics) and reported qualitative findings thematically. The four mixed-method studies (Billington et al., 2012a) were presented in a single research report, with the qualitative results already having been analysed, synthesised and presented thematically. Therefore, the presentation of the

Table 3. Study characteristics: quantitative studies.

Study, country and setting	Aim of study	Sample	Intervention	Study design	Data collection	Outcomes
Agresti et al. (1989) USA Acute rehabilitation unit	To investigate the possible long term benefits of story presentation mode on recall ability (of patients with head injuries).	$n = 24$ Intervention (Head injury group) = 12 Control (spinal cord injury group) = 12	Babcock Story Recall Test Portland Paragraph Memory Test Each short story presented in three different modes to each participant: overt passive (Standard administration) Covert active (silent reading) Overt active (reading aloud)	Quasi-experimental controlled study Stories counterbalanced for order and presentation mode	Recall assessed at three time points after each intervention mode delivered: Immediately After 20 minutes After 48 hours	Number of units of information recalled
Billington et al. (2012a) UK (Day Centre Group)	To assess the impact of the shared reading intervention 'Get into Reading' upon behaviours symptomatic of dementia.	$n = 61$ people with dementia across the four studies. (No site-specific participant number given) and 20 staff members	'Get into Reading' groups. Reading group facilitator and/or group members read English literature aloud. Group discussion based around the text Once weekly sessions per site 10 sessions with a 1-week break followed by a further 4 once weekly sessions As above 12 once-weekly sessions with no break	Quasi-experimental before and after study study own group control study	Neuropsychiatric Inventory Brief Questionnaire (NPI-Q) was assessed pre- and post-programme of intervention	NPI-Q scores
Billington et al. (2012a) UK (Hospital Group A)	As above	As above	As above 12 once-weekly sessions with no break	Quasi-experimental uncontrolled before and after study	As above	As above
Billington et al. (2012a) UK (Care Home 1 and 3)	As above	As above	As above 10 sessions with a 1-week break followed by a further 13 once-weekly sessions	Quasi-experimental uncontrolled before and after study	As above	As above
Billington et al. (2012a) UK (Care Home 2)	As above	As above	As above Baseline taken, then 11 weeks with no intervention followed by 13 weeks of once-weekly sessions	Quasi-experimental uncontrolled before and after study	As above	As above
Clair (1996) USA Nursing home	To determine the effects of unaccompanied live singing compared to reading and silence on alert responses in persons with dementia	$n = 26$ people with dementia	Interventions of unaccompanied singing, reading aloud newspaper articles and silence for 2 minutes were compared 4×30 -minute sessions on 4 sequential days	Quasi-experimental own group controlled trial	Participants were video-taped during interventions. The number of 'alert responses' (tailored for each participant) that occurred during each 15-second interval were counted	Frequency of alert responses and comparison between interventions
Cohen-Mansfield et al. (2010) USA 7 nursing homes	To assess the relative effect of different types of stimuli on agitated behaviours of nursing home residents with dementia	$n = 111$ people with dementia	25 different predetermined stimuli (including reading a large-print magazine) were delivered over a period of 3 weeks, with participants receiving approximately 4 different stimuli per day. Each stimulus was delivered over approximately 3 minutes	Quasi-experimental repeated measures with randomised assignment of conditions	Three-minute observations at baseline (no intervention) and during interventions – observed agitation behaviours recorded using Agitation	ABMI Number of agitation behaviours observed during 3-minute observations.

(continued)

Table 3. (Continued)

Study, country and setting	Aim of study	Sample	Intervention	Study design	Data collection	Outcomes
Gardiner et al. (2000) USA Nursing home	To investigate the effectiveness of music and reading strategies to deal with disruptive behaviour in agitated patients	$n = 2$ people with neurological conditions	Book intervention – looking at pictures in the books, portions of text read aloud and holding conversations about contents of pictures and text Music intervention - listening to music and music production (rhythm instruments, autoharp and ukulele) 4 weeks of treatments – 10×10 -minute interventions each week Question asking reading groups – reading group led by a person with mild dementia. English literature read aloud by one person. Questions pre-formulated and asked by the facilitator in order to stimulate discussion related to the text	Quasi-experimental single subject design study	Behavior Mapping Instrument (ABMI) Observations prior, during and after intervention using Disruptive Behaviour Rating Scale (DBRS)	DBRS median scores
Skrjajner and Camp (2007) USA Nursing home and adult day health centre	Not stated	$n = 22$ people with dementia and/or a Mini Mental State Examination score of 23 or below	Question asking reading groups – reading group led by a person with mild dementia. English literature read aloud by one person. Questions pre-formulated and asked by the facilitator in order to stimulate discussion related to the text	Quasi-experimental before and after uncontrolled trial	Observations using Menorah Park Engagement Scale (MPES) Baseline observations of participants engaging in other group activities were taken using the MPES. MPES observations taken during the intervention (Question asking reading group sessions)	MPES scores

Table 4. Participant characteristics: quantitative studies.

Study	Participant number	Diagnosis and diagnostic measures	Gender	Age range (years)
Agresti et al. (1989)	24	Intervention group – 12 closed head injury (clear of post-traumatic amnesia) Control group – 12 spinal cord injury	Intervention group, Male = 8, Female = 4 Control group, Male = 6, Female = 6	Intervention group 18–45 (mean 29.4) Control group 19–39 (mean 26.6)
(Billington et al. (2012a)	81	61 service users and 20 staff members participated in reading groups or were interviewed All participants in the care homes had a diagnosis of dementia, those in the hospital groups either had a diagnosis of dementia or were having investigations for dementia	Not stated	Not stated
Clair (1996)	26	All participants were diagnosed with late stage dementia – at Stage 7 of the Global Deterioration Scale. All were ‘nonverbal’ and ‘nonambulatory’	Male = 4, Female = 22	62–83
Cohen-Mansfield et al. (2010)	111	All participants had a diagnosis of dementia and displayed at least minimal levels of agitation behaviour	Male = 22, Female = 89	Not stated. Mean age 85.4
Gardiner et al. (2000)	2	1 participant had a diagnosis of Weber’s Syndrome and organic personality disorder secondary to a head injury, subsequent CVA and sub-dural haematoma 1 participant had a diagnosis of Alzheimer’s Disease Participants were selected due to high levels of disruptive behaviour	Male = 2	Head Injury participant aged 67, Alzheimer’s disease participant aged 72
Skrajner, and Camp (2009)	22	All participants had a diagnosis of dementia or a Mini Mental Score of 23 or below	Male = 1, Female = 21	Not stated. Mean age adult day centre participants 75 (SD 8.4) and Special Care Unit 89 (SD 6.0)

results from these studies will be referred to as one here, as data cannot be separated in order to determine whether each theme was apparent in each study.

Through data synthesis seven key themes emerged: engagement and attentiveness, social contact, symptomatic impact, sensitive topics, self-expression, personhood, identity and individuality, and enjoyment. Five of the seven key themes identified were evident in all of the qualitative studies, the theme of ‘Personhood, identity and individuality’ was evident in three out of the four studies and the theme ‘Enjoyment’ evident in two of the studies.

Themes from qualitative studies

Engagement and attention

Across all of the studies it was highlighted how the shared reading groups engaged and motivated participants and held their attention as well as providing welcome stimulation. For people with neurological conditions, the shortness of poetry ‘held people’s attention, as they found that they could master the “entire” work without too much mental effort and could remember words, phrases or passages if they were unable to read and relied on listening’ (Robinson, 2008, p. 7).

Social contact

The experience of reading together, particularly its social impact, was noted across all qualitative studies. Whereas

some of these experiences were consistent across the data-set, it is important to note that there were differences in study settings; for example, one study was based on an acute hospital ward and another in a long-term care home. The different effects the group situation had on individuals was also recognised within studies. However, three key areas were reported consistently – the importance of context, interaction and fellowship.

The provision of a ‘real’ situation in which to share experiences was observed and valued, and the reading groups also provided participants (especially those who had neurological conditions other than dementia such as stroke) with an opportunity to discuss topics other than their condition (Robinson, 2008). The reading groups facilitated social relationships and fellowship between participants. A noticeable increase in the level of interaction between participants was recognised by staff and discussed specifically within those studies that were ward based, where the reading groups provided an opportunity for people to get to know other patients on the ward, breaking down social and psychological barriers and making the ward a more personal and friendly environment for patients (Higgins et al., 2005).

Symptomatic impact

All of the qualitative studies provided evidence of the impact of the intervention on clinical symptoms of neurological conditions, with the impact upon memory being the

Table 5. Study characteristics: qualitative studies.

Study	Aim of study	Sample	Intervention	Study design	Data collection	Outcomes
Billington et al. (2012a) ^a UK Day centre, care homes and hospital settings	To assess the impact of the shared reading intervention 'Get into Reading' upon behaviours symptomatic of dementia	$n = 81$ 61 people with dementia across the four studies (No site-specific participant number given) and 20 staff members	'Get into reading' groups. See Table 4	Qualitative study	Semi-structured interviews, case studies	Themes relating to health and well-being
Higgins et al. (2005) UK Stroke rehabilitation ward in a teaching hospital	To investigate the delivery of an arts-based intervention to stroke patients	$n = 29$ Interviews conducted with 21 people post-stroke and 8 professionals (1 Speech and Language Therapist, 2 nurses, 1 reading director and 4 readers)	Text chosen by patients, read aloud by actors followed by group discussion stimulated by the text 12 group sessions were held lasting approx. 20 minutes involving, on average 4 participants in each group	Multi-method qualitative study	Participant observation, in-depth interviews	Themes relating to health and well-being
Holm et al. (2005) Sweden Not stated	Explore the therapeutic benefits of storytelling in patients with dementia and formulate pedagogic implications for the field of nursing with the focus on dementia care	$n = 9$ 6 people with dementia and 3 care givers	Reading group. Stories read aloud by a facilitator for approx. 20–30 minutes followed by group discussion of subjects stimulated by the text	Qualitative study	Reflective diary (narrative)	Themes relating to health and well-being
Robinson (2008) UK Neurological Rehabilitation inpatient unit	To capture (1) what happens when people get together in a group to read a text aloud, and to talk about the text and (2) to explore how participation in a reading group may relate to aspects of their physical and emotional recovery	$n = 7$ 5 people with neurological conditions 2 volunteers	'Get into Reading' groups. See Table 4 4 reading groups held once a week over 1 month	Multi-method qualitative study	Observation and 1 focus group	Themes relating to health and well-being

^aPlease note that the four mixed-method studies (Billington et al., 2012a) were presented in a single research report with the qualitative results analysed, synthesised and presented collectively. Therefore, these studies are referred to as one here.

most frequently mentioned. The reading groups were said to 'spark memories' (Billington et al., 2012a), and the act of reading poetry in particular was found to stimulate childhood memories in many participants. Alongside the importance of memory, the groups also provided an opportunity for participants to be 'present', in the moment. Several project workers not only reflected on the importance of reminiscing, but also commented on the value of participants using their imaginations to create experiences that were in other temporal domains – the present or the future. These project workers also noted the importance of selecting literature that could facilitate and enable participants to focus on present experiences as well as reminiscing about the past. This was considered as being particularly poignant

for people with dementia who are often not orientated to time or place and become distressed by this.

Sensitive topics

All studies reported how the sharing of poems and stories and the social context of the group, by offering fellowship and support, provided a space in which participants felt comfortable discussing sensitive topics and sharing their thoughts and feelings. Many personal experiences and emotions were discussed within the groups including war experiences, loneliness and the need for social contact. The reading groups were even described by participants and healthcare professionals as being 'emotionally

Table 6. Participant characteristics: qualitative studies.

Study	Participant number	Diagnosis and diagnostic measures	Gender	Age range (years)
Billington et al. (2012a) ^a	81	61 service users and 20 staff members participated in reading groups or were interviewed All service user participants had a diagnosis of dementia, those in the hospital groups either had a diagnosis of dementia or were having investigations for dementia	Not stated	Not stated
Higgins et al. (2005)	29	21 participants were post-stroke, 3 were healthcare professionals and 5 were reading service personnel	Male = 11, Female = 10 (stroke patients who were interviewed). Gender of staff not stated	32–86
Holm et al. (2005)	9	6 participants had a diagnosis of dementia, classified as either intermediate or severe. Severity determined through DSM - IV classification system and 3 were paid carers	Male = 1, Female = 5 (dementia participants). Gender of carers not stated	73–90
Robinson (2008)	7	5 participants had neurological conditions and 2 were volunteers	Not stated	Not stated

^aPlease note that the four mixed-method studies (Billington et al., 2012a) were presented in a single research report with the qualitative results analysed, synthesised and presented collectively. Therefore, these studies are referred to as one here.

therapeutic' and 'cathartic', addressing participants' spiritual and emotional/psychological needs.

Self-expression and sharing

The context of the groups provided participants with the opportunity to express themselves. Three studies reported that reading groups had resulted in positive responses from participants who were not normally known to be particularly communicative or describe how the groups aided those with speech difficulties.

One case study presented within the work of Billington et al. (2012a) described a young man who had difficulties communicating and had not spoken at all throughout several groups until he was asked to read. The project worker reported:

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. (Billington et al., 2012a, p. 11)

In the Higgins et al. (2005, p. 1394) study, a nurse who had witnessed the reading groups was impressed by the effects of the intervention and noted how well the group facilitators communicated with dysphasic patients. As a result the nurse 'began reading to patients herself as an evening activity. She explained that it was often difficult to build a rapport with non-communicative patients and that reading was an extra resource to draw on'.

Personhood, identity and individuality

The reading groups were considered by participants to create a personal and sensitive setting, which was in

contrast to the depersonalisation felt by many in the hospital setting. Through discussion of the texts, the reading groups provided not only a social context for people to share their own experiences with one another, but also as importantly 'allowed some patients to reconnect with elements of their identity and self unaffected by stroke' (Higgins et al., 2005, p. 1394). Through drawing on their own past experiences for discussion or reflection, participants could also establish their 'identity as people with lives, as well as patients with neurological conditions' (Robinson, 2008, p. 6).

Enjoyment

Two studies reported how much enjoyment participants experienced when taking part in the reading groups. This was identified by the researchers, staff and participants themselves: 'At the end of the session I came back to Matthew and asked him if he had enjoyed the session. He said, "Yeah. It was elevating"' (Billington et al., 2012a, p. 11).

Discussion

Main findings

Due to the variety of reading-based interventions and methodological approaches taken within the included studies, a single or all-encompassing conclusion here is neither possible nor satisfactory. The impact and effect of lone reading, reading aloud and shared reading in a group on the health and well-being of people with neurological conditions is currently an under-researched area. The studies assessed and reported here included people with dementia, post-stroke and brain injury but this literature is limited. Although a number of different types of reading interventions have been researched and reviewed here, research in this area has to date most predominantly focused on the impacts of shared reading rather than lone reading interventions. There is however an even larger dearth of evidence on the effect of reading interventions

for people with other neurological conditions such as Parkinson's disease and multiple sclerosis and for paediatric patients with neurological conditions.

However, research detailed in this review, although limited, is encouraging. A number of individual studies reported statistically significant results of positive effects; for example, the reduction of agitation, increase in levels of engagement and number of alert responses in people with dementia. However, these results should be considered with caution due to the methodological issues highlighted earlier.

Studies in this review not only provide evidence of the impact of reading in the moment, but also suggest the presence of a lasting effect, of up to a week in one case (Gardiner et al., 2000) and several weeks in another (Billington et al., 2012a). Clinicians working with people with neurological conditions know all too well the difficulties, the repetition and the hard work required in order to create lasting positive change in the symptoms caused by neurological conditions. Such evidence claiming the potential of 'carryover' comes from only a small number of studies and is to be considered with extreme caution. Nonetheless, the results are encouraging and further research would be useful to investigate the long-term benefits of reading therapies.

A more focused conclusion from the qualitative results can be made due to the consistency of results and subsequent synthesis. The evidence from the qualitative studies consistently demonstrated that shared reading groups engaged and motivated, provided an appropriate context for the facilitation of social interaction, connection and fellowship, evoked memories, provided a platform for self-expression and the sharing of feelings, and helped to re-establish personhood and identity; the groups, therefore, contributed meaningfully to the well-being of the participants with neurological conditions. The context provided through shared reading is important because appropriate context and meaning is necessary in order to positively influence neuroplastic changes within the nervous system following injury or disease (Cramer et al., 2011; Dimyan & Cohen, 2011).

For those with neurological conditions, their family and friends, and for the clinicians and carers working with them, symptoms such as agitation and memory loss, communication difficulties and loss of personhood and identity are all too often a lived experience that cannot simply be managed or restored by medication. The evidence presented here demonstrating not only a range of positive effects during the delivery of shared reading, but also the potential of a lasting effect should prompt further research in this area. In light of the potential benefits of reading interventions identified here we hope that this review will be of interest to nursing and therapy staff working with people with dementia or stroke in hospital, rehabilitation settings or long-term care facilities, activities co-ordinators working in long-term neurological care settings who have the daily task of providing group activities and to relatives of people with neurological conditions.

Challenges, strengths and limitations

This review presented a number of challenges primarily due to the breadth of the question set. Careful framing and setting of inclusion/exclusion criteria was required in order to capture the potential impacts of all components that make up the GiR model of shared reading. Due to the methodological variation of included studies, quality assessment and synthesis of multiple study designs and mixed-method studies were required.

The utilisation of mixed-method study designs, where both quantitative and qualitative data are collected, is an evolving area of research design and practice. Recognition of the need and ability to handle mixed methods and multiple data types is especially relevant for interventions of an arts-based nature in a context where the measurement of outcomes in health and well-being are multi-dimensional and this review offers an example of how to manage this in a systematic review.

Meta-analysis is seen as 'gold standard' evaluation methodology but it is only possible if RCTs have been conducted on the topic and that they measure the same, or very similar outcomes and that multiple studies have been conducted. In the case of arts interventions and the example given by this review, synthesis of data in a meta-analysis is simply not possible or appropriate. Whereas systematic literature reviews in the main focus on assessing the effectiveness of an intervention, in reviews with multi-method and/or mixed-method studies, a lack of RCTs, and experimental-based designs, it may be more useful to adopt a 'realistic synthesis' approach (Pawson, 2002, 2006; Wong, Greenhalgh, Westhorp, & Pawson, 2012) – synthesising evidence to build theories about how and why an intervention may or may not be working, the likely mechanisms for how the intervention works and for whom. Further methodological work and reviews such as this one are needed to provide ideas, options and examples of how best to review and synthesise mixed- and multi-methodological studies.

Recommendations for future research

Further empirical research is required to investigate and assess the evidence for the effect of reading interventions such as the GiR model of shared reading and/or its components on the health and well-being of people with neurological conditions. Further qualitative research is required to capture the important subjectively experienced effects of the intervention and to provide an in-depth and rich understanding and a theoretical basis on which to inform and aid the construction of further quantitative research design.

The research within this review points towards a potential that group reading interventions could reduce agitation in people with dementia, for example. Further quantitative research to investigate this could be used to confirm or refute this early finding. No RCTs that investigate the effect of reading in people with neurological conditions have been found. Trials with this level of rigour however are needed within this area of research.

Researchers should consider the role that cluster randomised trials or appropriately constructed controlled before–after study designs might play in providing a more robust evidence base, which will also be powerful in the context of the on-going dominance of the persuasive power of numbers in Western culture and the hierarchy of evidence-based paradigms. Although we separate our considerations here into qualitative and quantitative designs, the recognition of the place of mixed-method study design is growing and is well placed to investigate the impact of shared reading.

We have identified a number of issues related to the research design of the quantitative studies in this review such as short observational time periods of intervention effect. The observation and measurement of the implementation and effect of reading interventions over much longer periods of time is required in order to fully ascertain the depth and length of any effects. We have highlighted studies that investigated multiple interventions within the same study in rapid succession but did not demonstrate any consideration of how each intervention may impact on the effect of the other or the overall outcome. Appropriate consideration and careful study design is needed in instances where multiple interventions or stimuli are to be investigated within a single study.

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