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Reading is Caring – Evaluation Report

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Evidence Base

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Disclaimer: The views expressed in this report are solely those of the authors and the research participants. The authors are not liable for the accuracy of any information gathered to compile this document. All data collected is to be construed as contributions towards meeting the aims of the study. The authors accept no liability for errors or omissions in this document and accept no responsibility for loss or injury which may occur as a result of reliance placed on any part of its contents. The research team is only able to consider data presented during the course of the project.

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Summary of the impacts of Reading is Caring

Reading is Caring is based on the notion that shared reading is a tool that can help a person with dementia and their care partner or care staff to maintain their relationship; help the carer to find ways to join their loved one on their unique dementia journey; and also, through personal reading, find some respite from the stress caused by their caring responsibilities.

This evaluation of the pilot phase of Reading is Caring (2019-21) has demonstrated the following:

1. Reading is Caring offers **comfort** to people living with dementia. It promotes relaxation in everyday situations and relieves stress in more challenging circumstances.
2. Reading is Caring supports the **inclusion** of people with dementia in activities as they become more involved and responsive than may usually be the case.
3. Reading is Caring provides people living with dementia a means to share aspects of their **identity** and validates the things that are important to them and that have shaped who they are.
4. Reading is Caring offers an enjoyable, stimulating form of **occupation** for people with dementia. It also provides a focus for further conversation, reflection and discussion – and potentially other activities.
5. Reading is Caring supports **attachment** and feeling close to others as reading can prompt people living with dementia to share memories they have not done previously; play a more equal part in caring relationships; and make connections at a deeper level than is often possible through everyday conversation.
6. Reading is Caring workshops have helped care partners and care staff to feel more **confident in engaging in shared reading**, particularly in reading aloud and slowing down their reading where appropriate (which may feel unnatural at first), but also using different types of text and integrating shared reading with other activities.
7. Reading is Caring impacts on **caring relationships** in a variety of ways, in particular, in bringing together the wider family and support network of the person with dementia in a shared endeavour. Shared reading is seen as a highly positive aspect of caring relationships.
8. Reading is Caring also has an impact on the **mental health and wellbeing of care partners and care staff**. It can be useful, not just to the person with the dementia, but also to the care partner/care staff in stressful situations, and can help care partners/care staff to feel they are making a positive difference.

1. Introduction

Evidence Base, Research and Evaluation Services based at Birmingham City University (BCU) was commissioned by Scottish Book Trust to undertake an evaluation of the Reading is Caring Programme Pilot (2020-21).

A pilot project was developed because Scottish Book Trust believe that reading together and sharing personal stories is a powerful mechanism to connect people, support relationships and provide activities that prioritise authentic, equal participation from each partner. The concept of the pilot project was drawn from the Scottish Book Trust's involvement with delivering the Reading Agency's Reading Friends programme which focused on shared reading with volunteers in order to tackle loneliness and isolation. Parallel to the delivery of the Reading Friends programme, Scottish Book Trust identified a gap in supporting people living with dementia and their familial carers and Scottish Book Trust wished to explore the efficacy of shared reading as a tool for supporting these relationships.

Reading is Caring is based on the notion that shared reading is a tool that can help a person with dementia and their care partner or care staff¹ to maintain their relationship; help the carer to find ways to join their loved one on their unique dementia journey; and also, through personal reading, find some respite from the stress caused by their caring responsibilities.

The aim of the Reading is Caring pilot project was to test a range of ways in which shared reading may be useful to people living with dementia and their care partners and/or care staff in order to equip each participating caring relationship with the tools to tailor a shared reading approach which works best for them. The programme achieves this by offering training to care partners and care staff on how to bring a shared reading aloud approach into their relationship with the people they care for. The training covers practical techniques and person-centred approaches around components such as text selection; reading voice and pace; using illustration and objects in parallel with reading; and asking questions. The training also covers making life story book boxes that are bespoke for the person living with dementia. Care partners and care staff are then encouraged and supported to build regular shared reading into their relationship with the person living with dementia.

Aims of evaluation

In this context, the aims of the evaluation are:

- To assess progress against the project outcomes for *people living with dementia*, namely
 - People living with dementia experience better one-to-one relationships with their care partners/care staff and as result, there is evidence to suggest that their feelings of connectedness and personhood are improved
 - People living with dementia experience reflections through sharing stories, which helps them to contribute to their caring relationships in a more meaningful way

¹ Throughout this report, care partner is used to refer to familial or other non-professional carers; care staff is used to refer to those employed in a caring role (e.g. care home workers, healthcare staff).

- People living with dementia have memories (or imagination) evoked, which encourages better listening and so improves their relationships with their care partners/care staff.
- To assess progress against the project outcomes for *care partners and care staff*, namely:
 - Care partners/care staff develop the confidence to use shared reading as an approach to create and maintain their relationship with a person with dementia
 - Care partners/care staff are more positive about their caring relationship
 - Care partners/care staff are better able to manage their own mental health and wellbeing by using reading for pleasure.
- To capture unintended outcomes from the perspectives of people living with dementia, their care partners/care staff and project workers.
- To gather evidence that will inform future development of the project.

Within the evaluation, we considered the effectiveness of:

- the workshops from the perspectives of care partners and care staff
- additional support available to participants to develop their shared reading skills and confidence.

2. Context

Person-centred dementia care

Reading is Caring can be situated within a person-centred conceptualisation of dementia that focuses on living well. Person-centred care is an approach to caring for people with dementia that puts their individual interests, background and needs first. It ensures that their care is designed around them and that the person with dementia is treated as an equal partner in developing care that best suits their needs.

Person-centred care typically starts with conversations with the person with dementia, their family and other loved ones, to fully understand their needs. It places an emphasis on life story work, and the person living with dementia's hobbies, abilities, history and personality are considered first and foremost. It recognises that the need to know the person and understand their experiences requires ongoing listening, learning and action. This ethos is at the heart of Reading is Caring, which starts from understanding the person with dementia and exploring their interests, history and preferred ways of engaging and interacting with others.

The principles of person-centred care assert:

- the human value of people living with dementia , and their families and carers
- the individuality of people living with dementia, and how their personality and life experiences influence their response to dementia
- the importance of the person's perspective
- the importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

In addition, the principles emphasise the importance of taking account of the needs of carers (whether they are family and friends or paid care workers), and supporting and enhancing their input (NICE, 2018).

In this evaluation, we particularly draw on Tom Kitwood’s (1997) model of psychological needs as a framework to discuss the approach, and the impact, of Reading is Caring. This draws attention to the importance of comfort, inclusion, identity, occupation and attachment. Table 1 identifies some ways in which this is reflected in the Reading is Caring workshops.

Psychological needs & wellbeing	Examples from Reading is Caring workshops
Comfort	Ideas for where and when to carry out reading e.g. comfortable, lighting, additional sensory stimuli
Inclusion	Reading with a range of people the person with dementia has a connection to: care partner, professional care staff or wider family Reading texts that are meaningful to the person with dementia and the care partner/care staff
Identity	Based around the idea of creating and using a ‘life story book box’ where texts, objects etc. that are important to the person are brought together – things that are thought likely to spark memories and trigger responses
Occupation	Reading as an enjoyable activity (not a chore) A meaningful, hopefully stimulating, activity Linking reading to other activities e.g. cooking, visiting places
Attachment	Emphasis on reading <i>together</i> – connecting in different ways through the texts Different ways of reading (person with dementia reads, care partner/care staff reads, alternating, scripts...)

Table 1: Examples from Reading is Caring workshops mapped onto Kitwood’s (1997) model of psychological needs

Support for carers

The Reading is Caring workshops are designed to be delivered to a care partner or member of care staff. The approach is designed in line with NICE (2018) guidelines, in particular, by:

- developing personalised strategies and building carer skills
- training to help them provide care, including how to understand and respond to changes in behaviour
- training to help them adapt their communication styles to improve interactions with the person living with dementia
- advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing
- advice on planning enjoyable and meaningful activities to do with the person they care for.

The support provided to carers through Reading is Caring is:

- tailored to their needs and preferences and to what they want it to achieve
- designed to help them support people living with dementia
- available at a location they can get to easily and in a format suitable for them.

Impact of Covid-19

The arrival of Covid-19 in the UK in early 2020 had profound implications for people living with dementia and their carers, and therefore for the delivery of Reading is Caring. Some of these issues are outlined briefly below to provide context to the situation in which the pilot project was implemented.

Impacts on potential participants

People with dementia are at high risk from Covid-19 and, if infected, are more likely to experience severe outcomes (Numbers & Brodaty, 2021). Alongside this immediate risk from the disease itself, older adults with dementia, and especially those living in care homes, are at high risk of worsening psychiatric symptoms and behavioural disturbances as a result of social isolation – absence of regular visitors and restrictions on social activities – during the pandemic (Numbers & Brodaty, 2021).

In addition to an impact on people with dementia, the coronavirus pandemic has, of course, also affected those who care for them. In particular, social isolation and a decline in their own mental health amongst family carers has been widely reported (e.g. Newton Medical Practice, 2021). A report by Carers UK in spring 2020 found that 70% of carers were providing additional care as a result of the pandemic, and a similar percentage (69%) were providing more emotional support. Over half those surveyed felt overwhelmed and close to burnout (Carers UK, 2020). Professional carers have also been affected. A survey by the Health Foundation found that 80% of paid carers reported increased workloads since the onset of the pandemic and almost half (47%) said their general health had worsened, with social care workers reporting feeling more depressed, gloomy or miserable (58%) and also more tense, uneasy or worried (81%) as a result of their job (Hussein, 2020).

Impacts on project delivery

Reading is Caring was designed to be delivered in a pre-Covid environment. It was originally intended to deliver Reading is Caring workshops to small groups of participants in face-to-face settings (e.g. a community centre or care home). A small number of taster sessions were, in fact, delivered via this approach in the early stages of the project (see [section 4](#)). Of course, with the arrival of Covid-19 in the UK in the early stages of the project, this plan needed to be revised and it was decided to continue with the project by delivering the workshops online, until a time when it is deemed safe to meet face-to-face again. This meant a number of significant changes to the project as described below.

1. The project co-ordinator circulated the information to a variety of networks by providing a leaflet about the offer attached to an email and followed this up with individual phone calls.
2. Workshops and taster sessions were redesigned so they could be delivered online using Zoom.
3. Delivery time was changed to being a one-hour taster session followed by (for those who wanted more in-depth support) two half-day online workshops or one full-day online workshop.
4. The project team wrote and published a Reading is Caring handbook and a Reading Diary that was sent in the post to all participants in advance of attending the online workshops so they could work through the activities in front of them alongside the online real time support to

adapt the materials to their specific circumstances and in addition they now had the handbook and reading diaries to refer back to in the future.

5. The handbook included a 'how to sign up and use Zoom' section to support those less familiar with online delivery, in addition to phone call support when logging in and setting up where needed.

The limitations on face-to-face interaction meant it took longer than had been anticipated to build relationships. Both care staff and family care partners wanted to know more about how the approach worked before they signed up and some had concerns or limited capacity around communicating online. This has resulted in a much longer lead in time to establish trust and rapport with family care partners and care staff before they signed up to take part. Adaptations made to support relationship building with potential workshop attendees included the following:

1. A frequently asked question and answer page to accompany the sign up/ information sheet 'About Reading is Caring'
2. The creation of an online taster session so participants could experience the approach first hand before they signed up to the more in-depth workshops
3. Evidence from research papers of the potential of this approach as part of the course materials (acknowledging the fact that there are limited academic studies in this area)
4. Feedback quotes from participants who attended the initial online workshops sharing their experiences of the workshops in the information email being circulated to supporting networks to encourage them to take part in the future workshops.

3. Evaluation methodology

Just as the Reading is Caring project itself had to adapt in light of the coronavirus pandemic, the way in which the evaluation was conducted also had to change from our original plans. The original methodology, designed pre-Covid, included:

- Observation of a limited number of face-to-face workshops (representing a variety of group and setting types), including informal conversations with attendees
- Video ethnographies of shared reading sessions with a cross section of reading partners being asked to record at least one of their reading times
- Short follow-up telephone interviews with carers asking them for their reflections on the session(s)
- Impact stories gathered through visits to reading pairs in their home or another location to share some of the things they have been reading and observe their reactions.
- Attendance at a Celebration Tea to observe participants and activities; speak to participants informally about their experiences; and distribute feedback postcards
- Documentation analysis of written material related to the project delivery (e.g. recruitment flyers, workshop training materials, workshop attendance numbers).

With the change in project delivery and the wider implications of Covid restrictions, many of these approaches were not possible in practice. We therefore worked with Scottish Book Trust to revise the evaluation methodology to take account of the new circumstances in which the project was being conducted. The data collection methods used in practice are described below.

Observation of online workshops (via recordings)

As the majority of sessions have taken place online, it was possible to 'observe' more workshops than was originally planned. All online workshops were recorded (with the permission of participants) and the recordings shared with the evaluation team. It was therefore possible to observe in greater detail a) how sessions were adapted to meet the needs of different participants and b) how the facilitator developed the sessions over the course of the pilot in response to feedback and suggestions from participants.

In addition, a member of the evaluation team attended the online Celebration Tea event at the end of the pilot phase.

Feedback forms returned by workshop participants

Participants were asked to complete short online or emailed feedback forms following each workshop. In total, 33 forms were received. Table 2 shows the number of feedback forms received for each mode of delivery. Where quotes from the feedback forms are used in this report, we indicate whether they relate to Phase 1 (face-to-face) or Phase 2 (online) delivery.

Delivery mode	Number of feedback forms
Taster session	6
Full day	1
Workshop 1 Online	12
Workshop 2 Online	13
Not provided (incomplete)	1
TOTAL	33

Table 2: Feedback forms received

Informal feedback from participants provided via email

The project co-ordinator collated feedback from participants sent by email throughout the year to share with the evaluation team.

Interviews with a selection of participants

Interviews were carried out with a selection of workshop participants. All participants who agreed to be followed up were contacted and a total of 11 interviews were conducted. This consisted of:

- 6 interviews with care partners
- 5 interviews with care staff (3 social care and 2 NHS).

All interviews took part in Phase 2 of the project. Interviewees had all taken part in the half-day online training option, with the exception of one member of care staff who had co-ordinated taster sessions for a dementia support group. Where quotes from interviews are used in this report, we indicate whether they relate to a care partner (family member) or care staff (paid carer).

It was hoped to gather a number of video ethnographies of shared reading activities by asking interviewees to record one or more of their reading sessions as part of the evaluation. However, this was not possible in practice. The most common reason for this was the person with dementia experiencing ill health, or in some cases being hospitalised. In other cases, there were ethical barriers, for example, if the person concerned had not been informed they had dementia. Of course, due to Covid, it was not possible for a member of the evaluation team to visit people in their homes,

or to visit care homes, to carry out an in-person observation of shared reading activities as had originally been planned.

Reflections (written and verbal) by the Scottish Book Trust project team

Throughout the pilot period, members of the Reading is Caring team were in regular contact with the evaluation team to share feedback and reflections about successes, challenges faced etc. both verbally and via email.

Statistics and documentation provided by the project co-ordinator

The project co-ordinator regularly provided the evaluation team with updates on numbers of workshops delivered, participants reached etc., as well as written material related to the project delivery (e.g. recruitment flyers, workshop handbook).

Reflections on the evaluation process, and lessons learnt from conducting the evaluation during this challenging time, are included in [section 6](#).

4. Workshop delivery

This section reports on the delivery of Reading is Caring workshops, and feedback received throughout the pilot from participants.

Over the whole pilot project, approximately **150 carers** received Reading is Caring training (workshops or taster sessions) and **at least 175 people living with dementia** received shared reading sessions with the person who cares for them or through Reading is Caring workshops and/or taster/ introduction sessions.

- **78** people received hour-long Reading is Caring **face-to-face taster/ introduction** sessions
- **67** people received hour-long Reading is Caring **online taster/ introduction** sessions
- **2** people received **8-hour full-day** Reading is Caring **online** workshops
- **22** people received **4-hour half-day** Reading is Caring **online workshop 1**
- **19** people (who previously attended workshop 1) received the follow-up **4-hour half-day** Reading is Caring **online workshop 2**.

Phase 1: Face-to-face taster sessions (November 2019 to March 2020)

Prior to the national lockdown in March 2020, the following face-to-face Reading is Caring workshops were delivered.

- x62 Family care partners and care staff **one-hour taster/ introduction** session during Book Week Scotland (Nov 2019)
- x8 Care partners/ staff and those living with dementia — **one-hour taster/ introduction** session (Dec 2019)
- x2 Care staff **one-hour taster/introduction** session (Feb 2020)
- x6 Care staff **one-hour taster/ introduction** session (Mar 2020)

Total: 78 people received hour-long face-to-face Reading is Caring taster sessions during Phase 1.

Phase 2: Online sessions (June 2020 to March 2021)

Workshops resumed from June 2020, but taking place online rather than in person. Table 3 summarises the number of participants for each delivery format.

Type of online workshop	Care partners (family)	Social care staff (e.g. care homes)	Health care staff (NHS)	People with dementia	Funders	TOTAL
Taster session/introduction ²	45	5	-	17	-	67
Full-day workshop (8 hours)	2	-	-	-	-	2
Half day: workshop 1 (4 hours)	10	7	2	-	3	22
Half day: workshop 2 (4 hours)	10	6	1	-	2	19

Table 3: Phase 2 sessions delivered

The data presented in this report include both the Phase 1 face-to-face and Phase 2 online sessions. It is worth noting that many of the suggestions made by participants during Phase 1 were, in fact, included in the delivery of Phase 2 (where they were appropriate for online delivery).

Organisation of workshops

Of course, Reading is Caring does not take place in isolation. Many care homes already run book groups or similar activity sessions; however, one-to-one reading experiences are much less common. As a care home activity group facilitator who attended the training in the early stages of the pilot commented about a resident:

You can tell she still enjoys the reading during the group but she struggles to remember the storyline from week to week. So it would be good to have help to try different approaches to get round this (care staff interview).

It is precisely this more tailored, or person-centred, approach that Reading is Caring is designed to provide.

During the earlier stages of Phase 2, most of the online sessions were with family care partners; engaging with care homes and healthcare settings was, understandably, challenging in the earlier stages of the pandemic in particular. However, there has been increasing engagement in the later stages of the pilot, perhaps as health and social care facilities gradually return to a more 'normal' way of operating. It has, inevitably, been harder to bring groups of people together online than it would have been if it had been possible to deliver sessions face-to-face, for example, in a care home. In practice, many sessions have been delivered one-to-one, although some have included two or three participants.

Organisation of the Reading is Caring workshops has presented a number of challenges. It requires a long lead in time and has proved more time-consuming than was originally envisaged. The journey

² This includes a recurring activity run on a monthly basis from January 2021 with an established dementia support group.

to a participant taking part in a workshop can be a long and complex one, involving finding the right person to speak to in an organisation; several stages of follow up; providing information to allow individuals to decide whether the course is for them; and once again following up, taking account of disruptions that those caring for people with dementia inevitably face (e.g. medical appointments). On occasions, people who appear interested stop communicating and it is difficult to decide to what extent to chase them up, especially given the challenging circumstances they may be dealing with.

In the later stages of the pilot, referrals from people who had already completed the Reading is Caring workshops started to become a more important route to identify new participants. After several months delivering workshops, a critical mass is starting to build and word of mouth is likely to be an important recruitment tool in the next stages of the project. This referral process has included care staff who have taken part recommending the course to family members of people they support, as well as to other care staff. For example, a member of NHS staff felt that it would be difficult for ward staff to get time to attend, but she recommended Reading is Caring to community-based staff and to family care partners.

The project co-ordinator has been extremely flexible in arranging workshops – offering a wide choice of dates and both full-day or half-day options. Nevertheless, finding time to dedicate to taking part in a Reading is Caring workshop could be challenging, especially for family care partners. Scottish Book Trust offers support for respite care if required, but arranging this might still be challenging emotionally and practically. In this context, the move to online delivery has some advantages as it means people can take part from their home and do not need to travel. (See below for more reflections on online delivery).

Another challenge was potential participants thinking the workshops were not for them. There might be many reasons for this. A significant factor is likely to be the fear that still surrounds dementia that can lead to an element of denial. In particular, those caring for someone who is currently at an early stage of dementia might feel the course was not relevant for them at this point. Another factor might be people not feeling that reading with a person with dementia was part of either their role as a care partner or their relationship with their relative. For example one care partner commented:

[my husband] is a really keen reader always has been but he would not want me to read to him. I am his wife not his carer like that. Maybe when he needs a professional carer they could do this (care partner).

The taster sessions have proved successful in giving people a flavour of what the full Reading is Caring workshops involve and in persuading people that they may benefit from the course.

Whilst it has sometimes been challenging to engage participants who may well benefit from the workshops, on the other hand, there has been some interest from people for whom the course is not really intended. In particular, publicising Reading is Caring through libraries led to interest from people who were not currently caring for someone. This highlights the importance of finding the right communication channels and partners to publicise the workshops.

Feedback on Reading is Caring workshops

Delivery of workshops

All 32 completed feedback forms, returned by 22 participants (including taster (5 Phase 1; 1 Phase 2), full-day (1) and half-day (25) sessions), indicated that they were happy with the approach taken to the workshops. In particular, they praised the workshop facilitator for her organisation and clarity, as well as her passion and enthusiasm. They also commented that the sessions were well-paced, relaxed and informal:

...the session was well paced, the leader well prepared and the video items clear and informative. (Phase 2 half-day – part 2 feedback)

... it was relaxed and informal and we had lots of opportunity to feedback (Phase 1 Taster session feedback).

This praise was echoed in informal feedback received via email:

I cannot praise you enough for the way you delivered the workshops - honestly it was an absolute privilege and joy to be involved... (Phase 2 participant)

I've gained a great deal from today more than I'd expected given our current situation, it's been excellent. Thank you (Phase 2 participant).

One of the key strengths of the programme is the workshop facilitator's knowledge of, and enthusiasm for, literature and ability to work with participants to think about possible resources and different ways of reading with the person they care for. This came through strongly in interviews conducted:

[The workshops facilitator's] enthusiasm comes across, way she delivers the training is not boring and she brings life to it (care staff feedback)

I loved her manner and her warmth and her enthusiasm and her understanding of...my situation (care partner feedback)

I think that [discussion with the workshop facilitator] was the big thing about it for me...during the conversation, I thought, "Oh, I could put that in [the life story book box] as well' (care partner feedback).

Participants spoke about the value of this sharing both during the session, but also through follow-up emails or conversations with the workshop facilitator.

Participants also commented on the usefulness of the written materials – slides, handbook and reading diary – to support the workshops:

Reading is Caring handbook is a great resource - one that can be readily drawn upon when needed (Phase 2, half-day feedback)

The video items [were] clear and informative. The handbook and reading diary have left me with a complete aide memoire of the workshops (Phase 2, half-day feedback).

However, as a participant commented, there was added value in attending the training and interacting with the facilitator, which went far beyond the face value of the written materials:

Having read quite a bit of the booklet beforehand, I was amazed how much more was achieved with [the workshop facilitator's] help (Phase 2 half-day feedback).

Furthermore, attendees valued the opportunity to try out shared reading examples during the session:

The example reading was particularly helpful way to get an idea of the practice (Phase 2 Taster session feedback)

As mentioned above, Phase 2 participants were offered various attendance options (full day, or 2 half days). As most participants opted for two half-day sessions, there is limited feedback on the one day option, but a participant who had taken part in a one-day workshop commented:

... I think it is best delivered over two sessions. Love the 'homework' after the first session (Phase 2, 1-day feedback).

For those who attended two half days, the timing between first and second sessions was discussed in interviews. Overall, interviewees felt that a gap of 2 to 3 weeks was probably about right to give them time to try out activities from the first session, but not too long so as to lose momentum. In some cases, this was not possible in practice however, and a participant who had attended sessions just a few days apart commented that a longer gap between would have been useful.

Whilst some interviewees were happy with the length of the course, others commented that it could be shortened a little. Indeed, towards the end of the pilot phase, the project co-ordinator had started to explore ways in which the content could be adjusted for different audiences; for example, care staff with a background in dementia care may not require so much introductory material about the condition.

Online delivery

As suggested above, there are pros and cons associated with the move to online delivery in Phase 2, necessitated by the Covid pandemic. Some care partners commented that this made it easier for them to attend the workshops as they did not have to arrange respite care or leave their home. Furthermore, as more people have become used to using Zoom, for example, to attend dementia friends groups, some of the technical barriers that might otherwise have existed have been reduced. At the start of the workshops, the project co-ordinator helped participants with any technical issues and gave detailed instructions about what do should they lose connection. However, there were, of course, still some people who are likely to benefit from the course, but were unable to attend via online delivery. A dementia support group organiser commented:

I felt at that stage, [joining the course] was a step too far, probably, for group members who had just recently...had the confidence to join Zoom meetings. (Dementia support group organiser interview).

Another potential disadvantage of online delivery pointed out by one interviewee was that the "protected nature of going somewhere else" might, in fact, make it easier for a care partner to

attend a face-to-face session in comparison to an online one, provided they knew respite care would be in place and they were guaranteed time away from caring responsibilities.

The majority of the workshops in Phase 2 have been delivered one-to-one. Some sessions have been delivered to up to three people, but the workshop facilitator feels that it would be difficult to deliver to larger groups effectively online and maintain the ability for people to interact in a natural way. An interviewee agreed that the one-to-one session went more smoothly than a large group was likely to online. This means that, whilst online delivery may reduce travel time, it is still likely to be more time-consuming to deliver than would have been the case if larger face-to-face groups were possible.

One-to-one online delivery meant that workshops were able to be highly tailored to the specific needs of an individual participant as an interviewee described:

...because she'd kind of understood, you know, the situation that I was specifically in...So we'd get to a bit where she'd say, "Well, I'm guessing this isn't really very relevant in your situation?" And I say, "No, probably not". And then we'd move on (care partner interview).

One-to-one workshops may encourage some participants to share more freely than they would do within a larger group as an interviewee commented:

I didn't feel a need to hold back a bit because there's other people that might want to contribute, you know, so from that point of view, it was good (care partner interview).

It is also interesting to note that an interviewee whose husband had only recently shown signs of dementia commented that she may have been reluctant "to be pushed forward into the future" by joining a session with people caring for those with more advanced dementia.

Following feedback from interviews, in later stages of the pilot, yet more emphasis was placed on the personal connection in one-to-one sessions by finding out a little more about the person and their situation at the start. However, group interaction and peer learning is inevitably missing to an extent; as an interviewee commented:

...there were parts where it might have been good to have someone else's take... (care partner interview).

In a session attended by three people, for example, participants were able to share ideas for texts and approaches to try. To try to replicate this within the one-to-one sessions, the workshop facilitator made efforts to cascade information from previous sessions so sharing still takes place, despite the fact that people do not actually meet. However, interviewees spoke about the potential disadvantages of not being able to take part in group sessions:

...there's a nice sharing when you've got a group and you know, quite a sort of camaraderie, really, and getting ideas from other people as well as from the presenter. So, obviously, I missed that part of it (care partner interview)

I probably will just prefer to be with someone else. And I think it's slightly less intense. And it's also bouncing ideas around as well...it's always good. It's always nice to pick someone

else's brain, isn't it?...you know, bouncing ideas around and experiences and things like that (care staff interview).

The workshop facilitator pre-recorded videos to convey the main areas of content in the workshops. This has the advantage of making the sessions less tiring to deliver – a widely acknowledged problem with longer online delivery. A potential disadvantage is that it is more difficult to adapt aspects of the sessions in response to feedback or to tailor to individual circumstances. However, this is not a major issue as the mix of 'live' and pre-recorded segments mean the workshop facilitator could easily add further explanation or instructions during the workshop as an interviewee described:

I really liked the fact that you kind of watch the short video and then it stopped and then you could discuss it...and give thoughts and you know go over it again...I quite liked that way of doing it (care staff interview).

Workshop content

All the feedback forms (including taster, full-day and half-day sessions), indicated that participants had found the information provided in the Reading is Caring workshops helpful. In particular, taster session participants commented that the workshops had highlighted the potential benefits, both of reading and of adopting a person-centred approach when caring for someone with dementia:

...it reminds you to bring the 'activity' back to being person centred, allowed us to mentally see the benefit for the people we support (Phase 1 Taster session feedback)

I found it really powerful and raising awareness of the benefits that reading can bring to the carer and someone living with dementia – can bring them back together again and help to build a positive relationship. (Phase 1 Taster session feedback).

Additional comments from participants in the full-day/half-day sessions indicated that these provided many ideas and practical tips and examples:

It gave me plenty of ideas for themed shared reading sessions, as well as practical tips on how to approach these in a sensitive, non-challenging way, and some super poems and short stories to use / start off with. (Phase 2 half-day feedback)

...there were very practical examples that could use immediately, lots of good tips and also reasons for why these approaches would work. Made me think about why it would be good to start earlier (planning memory box etc) (Phase 2, 1-day feedback).

As this was a pilot project, the workshop facilitator constantly adapted the workshop content in response to feedback. It was noticeable in observing sessions throughout the pilot period that she added to her bank of ideas – sharing texts mentioned by earlier participants with those who attended later workshops. However, as an interviewee pointed out, it may be good to find a way to share these additional ideas with those who had attended in the earlier stages of the pilot so will not have benefited from hearing them.

Despite the fact that workshop participants are already caring for someone with dementia (and might therefore have been expected to have a reasonable level of knowledge), they appeared to find the general information about dementia provided during the sessions valuable. For example, a

care partner commented that the idea of asking one question and waiting for the person to answer was one of the most valuable things she had taken from the sessions. However, for care staff – especially those in the health sector – an interviewee suggested that this basic level of information about dementia was probably less necessary.

Several participants made positive comments about the person-centred nature of Reading is Caring workshops:

Love the idea of facilitating person centred approach especially around reading not aware of this ever being done before, currently using play list for life effectively (care staff feedback)

I like the approach to honour the spirit of the person living with dementia (care staff feedback).

Timing

One of the challenges the project has faced is addressing the question of when is the best point for a family care partner to attend a Reading is Caring workshop. It is not unusual for people with dementia, and their carers, to be unwilling to want to look forward and to think about what the future may hold due to the fear and stigma surrounding the condition (e.g. Kevern, 2017). As mentioned above, some people felt that the course was not for them because the person they were caring for was still at an early stage of dementia. However, a participant whose husband was at an advanced stage of dementia commented:

I think the entire concept is lovely and just wish I had it in use at an earlier stage of my husband's dementia (Phase 2 half-day feedback).

It was also interesting to note that a community-based member of care staff interviewed had used the Reading is Caring approach with someone at the very early stages of dementia and had found it helpful. Furthermore, as a family care partner participant pointed out, finding time to attend the workshops might be more challenging if she was caring for someone at a later stage of dementia, and a further participant whose husband was also at much earlier stage commented:

...somethings aren't going to apply at the moment, but others are definitely appropriate (care partner interview).

However, this led to a challenge in gathering data for the evaluation as a number of workshop participants were not yet ready to put what they had learnt through the workshops into practice:

...we're not quite ready for it yet, but I can see it will be useful [in the future] (care partner interview).

5. Impact of Reading is Caring

Reading is Caring aims to have an impact both on people living with dementia, and on their care partners or care staff.

Impact on people with dementia

For people living with dementia, the project aims to evoke memories or imagination and to support better one-to-one relationships with their care partners/care staff, and as result, promote improved feelings of connectedness and personhood, through which they can contribute to their caring relationships in a more meaningful way. The impacts of Reading is Caring for people living with dementia evidenced during the pilot project are discussed below using Kitwood's (1997) model of psychological needs as a framework.

Comfort

Care partners and care staff described how they had witnessed the shared reading process appear to bring comfort to the person they were caring for, often in particularly distressing situations. For example, in a workshop observation, a care partner described how her mother needed an ambulance, so whilst they were waiting she read a few poems from a familiar poetry book and her mother became less agitated:

I found it helpful to have a focus sitting there for that length of time...and I think she did too (care partner workshop observation).

A care partner who was interviewed commented that reading together acted as a form of stress-relief on days when both she and her husband were finding things difficult:

It's more for the days when...somehow it just doesn't seem to be going right. You know, things seemed to be going on. And we're both getting a bit stressed by it. And I think it's a really good de stressor (care partner interview).

Similarly, a member of care staff reported how reading had appeared to help someone suffering from chronic pain by acting as a distraction:

...she just really suffers from chronic pain. It was just the delight that she'd found something to do to take her mind off...and get completely caught up in the story (care staff interview).

Shared reading was also reported to bring comfort and aid relaxation in more everyday situations that were not as noticeably stressful:

I have used [a particular book] more with four patients as an aid to relaxation. One person in particular loves birds so loves pictures with gold finch and some of the poetry and he looks at the pictures and part way through he fell asleep as he was so relaxed (care staff interview)

I do read with our granddaughter, and Malcolm enjoys that. He likes listening to the children's books... So that's quite nice. Sometimes he'll just doze off to sleep. It's like a bedtime story. But he, you know, he enjoys seeing her listening to them (care partner interview).

Often this effect appeared to last long beyond the reading period itself:

And then, you know, he really had a good morning and it just kind of totally changed the mood and changed, you know, how he was... he couldn't cope with even the littlest things to being, you know, feeling much happier and more contented (care partner interview).

Inclusion

Another benefit of Reading is Caring is the way in which it helps people living with dementia to feel more included and able to play a valued part in activities and relationships. For example, in a taster session attended by people with dementia as well as their carers, one of the people with dementia went to the bookshelf and took down a book he was interested in to show the rest of the group onscreen. According to his care partner, and the group organiser, it was very unusual for him to engage with activities in this way.

Through trying out techniques suggested in the Reading is Caring training, care partners and care staff witnessed the people they care for becoming more involved and more responsive than they had been previously:

[Before the workshop] we were reading to people. [The workshop facilitator] said that some people would like to read for themselves. And there was a lady and I said "I'll start the story off". And we paused, so I asked if she would like to carry on with the story and she said, "Yes, yes" and she read the whole lot. It was just fantastic! (care staff interview)

...the thing about, you know, finding the subject that interests them...I see that now. I see that, you know, when a friend comes and speaks to Tom and says something that he's interested in...you can see the connection there...rather than just them rambling about, you know, COVID or something (care partner interview).

Identity

In the workshop observations and interviews, it was clear that care partners and care staff had become increasingly aware of the importance of tailoring the reading materials and approaches they use around the identity of the person they are caring for. For example, some people may respond to things they were interested in the past, but others might be more focused on things that were important to them in the present:

I got out this child's nursery [book] and as she was brought up on a farm, she picked out a story that had all the cows in it. I thought I would read out one line of it, and the reaction of her face, and she knows what she was looking at and what you were talking about. It has really brought home to me, the importance of reading. (care staff interview)

So you have to try and find out what each person remembers now. Which I began to realise lately, because I did things with my mum...but I found out that she wasn't interested. She was like, "No, not that. That's not mine...that's not me". So I've got to get things that she's interested now (care partner interview).

An interviewee described how shared reading might help a person with dementia to share aspects of their identity with a carer – particularly a member of care staff who had not known the person earlier in their life:

...in sharing some reading it's possible that I might find out more about them because it comes from the reading. You know, you might be reading something about gardening and all of a sudden they start telling you about, you know, the things they love to do in the garden and that kind of thing (care staff interview).

It was interesting to note that some materials could work when they chimed with a person's identity in a particular situation, but might not be appropriate in other circumstances. For example, a care partner described how children's books worked when her father was in a situation where his identity as a grandparent was in focus, but not on other occasions:

When I have their great grandchildren, dad would sit and love the picture story. But when I tried to share something with him [he wasn't interested in a children's book] (care partner interview).

This theme also highlighted a potential barrier identified by a member of care staff: whilst people who saw themselves as 'a reader' may be easy to engage with Reading is Caring, those who had struggled with reading or had not had opportunity to read earlier in their life might find it difficult to relate to books and other reading materials as part of their own identity:

...certainly won't be for everybody. Basically, because not everybody reads. Some people don't even like, read the newspaper...It's sort of like embedded in them, that they're not readers...very hard to break through that (care staff interview).

Occupation

Occupation is one of the themes where there is strongest evidence through the pilot that Reading is Caring can make a difference to the everyday lives of people with dementia. It offers people an enjoyable, stimulating and accessible activity. For some people, this was particularly important during the coronavirus lockdown when many usual activities were closed:

[During lockdown] just to have something is a bit of a relief for me (care partner interview)

...I'll certainly spend time preparing my 'Life Story Book Box' after today.... I feel sorry for him sitting there doing nothing hour after hour. I wish I'd taken part in this course 6 years ago! (care partner feedback).

For those who had enjoyed reading earlier in their lives, in particular, shared reading provides options to allow that activity to continue beyond a time when a person with dementia might be able to read for themselves:

I just think it's opened up a whole world, really...George does read because he loves reading. But I see that he's reading less and less, you know, he'll sit for longer periods without reading. And it takes him longer to get through a book and things like that. So, you know, I think being able to either me or someone else read with him is just, it's just really good (care partner interview).

Shared reading is also an activity that is easy to implement, requiring minimal resources, and able to take place easily alongside other activities, such as cooking or eating. In addition, reading materials

can be useful as a focus for conversation and interaction. This can be particularly useful for care staff who may not know all the people they care for well and initially find it difficult to find a connection; the activity of reading could help to stimulate conversation:

...you're not asking them to have a conversation that like just a normal conversation you've got something to focus on that you're sharing together and you can just chat about it (care staff interview).

Even amongst care partners who know a person with dementia well, shared reading – as well as being a stimulating activity in itself – could lead on to further discussions, reflections and other forms of stimulation:

...when you get a connection, and he starts just talking about things it's lovely...And he enjoys reminiscing and various things. And you know, it stimulates thoughts and ideas for him, which is lovely (care partner interview).

Attachment

Reading is Caring also has the potential to support people living with dementia in being able to have relationships based on genuine partnership and to feel close to others. For example, a care partner interviewee described how she and her husband talked about incidents from his childhood he had never previously told her about after a memory was sparked during shared reading:

I was cooking. And I said, "Oh, we could look at one of these [stories from the Reading is Caring handbook]". And George actually started to read a bit of it himself out loud to me, which was nice. And I enjoyed that, because I was cooking, he was reading...And then we chatted because it made him think about when he grew up in the west of Scotland...And it got to him talking about his cousins and a lot of childhood memories. And it was, it was very relaxing for both of us. And it was it was just nice talking about his childhood and him talking about it (care partner interview).

Another interviewee spoke about how, through poetry, she and her mother were able to become closer:

...she quite often does connect with it especially if it's something that sparks a memory for her, you know. Some poems obviously do and she'll occasionally produce a line, or really wake up, or even the name of a poet that she likes...just that lovely connection when you can see that she's understood and that gives her pleasure that she really looks at me and engages, you know, you get that contact in a way that if I'm just sitting there droning on about my day... (care partner interview).

The same care partner went on to describe how reading had helped to place their relationship on a more equal footing (rather than being based on carer and cared for):

...occasionally I'll say, "Oh I don't know this poem"...and she'll say, "Take the book". And...that's what our life always used to be like in terms of reading so that's a really special thing you know and it gives her the ability to be part of that relationship in an equal way, you know, it's really lovely (care partner interview).

Impact on carers

Reading is Caring also aims to have an impact on care partners and care staff themselves. The following section sets out the main impacts in terms of carers' confidence using shared reading; impact on caring relationships; and ability to manage their own mental health and wellbeing.

Confidence using shared reading as an approach to create and maintain their relationship with a person with dementia

The act of reading aloud can be intimidating at first and several care staff and care partners commented on how taking part in the Reading is Caring workshops had helped them to overcome their initial hesitancy:

...it just gets you over that fear of reading out loud as well when you're when you start doing it you know in a small group like that and everybody's in the same boat (care staff interview).

In particular, several interviewees said that they had found the advice to read more slowly particularly helpful:

I've maybe been more conscious of the speed and perhaps slowing down even more...or at least leaving gaps...leaving a pause for her to absorb the information and that's possibly something that I've noticed I've been doing better I think since the course...I quite often read poems twice with mum...I'll sometimes read it very slowly the first time and then the second time I'll read it with the rhythm...once she's already familiar with what we're talking about (care partner interview).

Another tip from the course that participants said they had started to use was pre-reading material before they shared it:

I'm realising that death is a difficult subject from now, which it didn't used to be. And there's a horrible number of poems that, you know, suddenly lead off into that kind of world...it sounds so obvious when...somebody says, "Check this stuff before you read it". But yeah, I was guilty of not doing that before...I'm better at doing a very quick scan... (care partner interview).

The importance of illustrations was another aspect of the training participants said they found helpful and were starting to make more use of:

...I think probably the idea of...looking for and separating out illustrations and maybe giving mum those to look at while I read...there's a couple of books with pictures or illustrations which she does often enjoy but...I think the idea that I could maybe just photocopy those and have them separate or look for pictures that go along with whatever I'm reading and because I think it works that mum's quite often distracted by trying to read the words and then not being able to and so I think that for me feels like quite a sort of lightbulb moment and that's that feels really quite a strong thing for me (care partner interview).

In another case, an interviewee said they had been prompted to use non-fiction books, such as sport, for shared reading, whereas before they would only have considered using fiction.

Several interviewees said the sessions had acted as a prompt or reminder that had stimulated them to start, or to do more, reading activities:

...several folks have said to me, "I've picked up poetry books again"...the poem that [the workshop facilitator] did was a great kick-off, and for sure. The short story as well...great foundation points for people to start thinking about (taster session group organiser interview).

Although not all participants had started to create a life story book box by the time of the evaluation interviews, a number commented that the course had been useful in giving them an opportunity to think about the different types of resources and themes that might appeal to the person they were caring for. For care staff, the links between the Reading is Caring approach and life story work made it easier for them to think about ways of integrating shared reading with the usual approaches they might adopt when working with someone with dementia.

Furthermore, many interviewees described how attending the Reading is Caring workshops had given them increased confidence, or "permission" as one put it, to try different approaches. Indeed, there were several examples of care staff in particular adapting and building on the techniques from the workshops. Examples included:

- creating a box of books that had inspired someone throughout their life
- linking reading into care home theme weeks e.g. Easter, 1950s week
- integrating Reading is Caring with a hospital-based reminiscence and sensory group.

Impact on caring relationships

Workshop participants described how Reading is Caring has the potential to impact on caring relationships as members of the family came together to support the shared reading process. This might involve a person with dementia and their care partner creating a life story book box together, for example, or involving children or grandchildren in the creation of life story book boxes. It could also be an activity a professional carer and person with dementia could do together to help the member of care staff to better understand the person:

...if I could use that course in that way to help get a conversation going so I could talk to them about what they liked and we could maybe make a box together (care staff interview).

Interviewees described how life story book boxes and the reading diary could help to provide continuity of care and also enable a wider range of people to get involved in shared reading. For instance, a life story book box, or favourite books, could be shared with care staff to help them to understand the life and interests of the person with dementia, or to help other relatives to engage more effectively:

...if it came to the point of carers, [a life story book box] would be incredibly useful. Because ...then carers would know something about the person rather than just not knowing a thing. I thought that was incredibly good idea (care partner interview)

I think it might be quite a good idea...to start getting a few boxes, so that, you know, if his son or his daughter in law comes...they can use that...Paul might like to read to his dad, but

he doesn't know what he likes...I could suggest it to him. And he may even bring something of his own because they have very similar interests, you know (care partner interview).

She absolutely loves it [poetry book suggested in the Reading is Caring workshop] and has really formed an attachment to it already, which is amazing. Her carers have picked it up and read it with her and so has her art companion (care partner feedback).

The workshops also helped some participants to see new ways of engaging with the person they were caring for that suited their current situation:

...my ambition was every night you'd have a little bit of story and we would recap and move on. And you know we're passed that...but not to panic about what I can't do and just accept things that I can (care partner interview).

Some interviewees spoke about the challenge of fitting shared reading into an already busy caring schedule, but others saw it as a means of finding space to escape from day-to-day difficulties:

... if things are difficult or if you're having a difficult day; if the person's having a difficult day; if you feel you're not coping terribly well actually sit down and read something together. And it will take you right away from the here and now and into some other world. And, you know, that you can share and talk about, and I would say, that's, that's a big thing for me... (care partner interview).

Similarly, another interviewee commented that shared reading felt like one of the more positive aspects of her role as a care partner:

...this is actually one of the more positive elements of my role as a carer you know is that that reading thing and here's a way of making it even more positive and hopefully being able to keep it going for much longer than it otherwise might have been able to...that feels like a lovely experience ...to think about the positive bits and opposed to dealing with problems (care partner interview).

Ability to manage their own mental health and wellbeing by using reading for pleasure.

There was also evidence from the pilot phase that Reading is Caring has positive benefits for care partner and care staff mental health and wellbeing. A number of interviewees spoke about a slight sense of guilt as a carer taking time for themselves, so it helped to be reassured during the course that it was okay for the activity to be enjoyable for them, as well as for the person they were caring for:

...that's really nice just to be kind of reassured that it can be partly for you as well (care partner interview)

They appreciated the suggestion of finding reading materials that were of interest, not only to the person with dementia, but for them too:

Choosing books and magazines that are of interest to both people would be quite important I think (care partner interview).

Interviewees spoke about the shared reading experience being a relaxing one for both parties. This could be true in everyday situations, but also in more distressing circumstances:

George had a fall in the house...he couldn't get up. So I called the ambulance...And so we're sort of just sitting waiting, and I thought I could maybe read to him. He had a book for Christmas...it was about a Tiger Moth flying over the Himalayas. So I started reading that. I didn't get all that far, but I think the thing that was good was that...we were in a difficult situation, we were just waiting for the ambulance, we're both worried about, you know, what was going to happen and him having maybe having to go up to a hospital and so it just kind of took us both to a different world for a while till the ambulance came. So that, you know, that was good...I definitely get taken into another place as well. I mean, certainly, that day, was it waiting for the ambulance, I think it was good for both of us... (care partner interview).

As another interviewee explained, it was not simply the act of reading itself that was relaxing, but also the knowledge that, as a care partner, she was doing something that might help the person with dementia:

...if she's quite anxious so for me it's helpful to have...I mean, it's not just about the pleasure of reading for me - I get that - but it is it is also a pleasure to have a way of thinking this might help because that helps my anxiety too if she's in...a bad way (care partner interview).

A member of care staff echoed this sentiment when describing how she felt shared reading might be helpful for the wellbeing of people caring for a relative with dementia. Shared reading activities could reduce family members' sense of helplessness and allow them to feel they were doing something positive:

...it's something that I think I can share with family members... I have two gentlemen...they both had wives in local care homes who have dementia...both gentlemen are in their 80s. And both come back really quite upset every day when they've sat there and have not been able to have any kind of conversation with the person. And they find it really upsetting and really demoralising...maybe it's something that I can help them with. Maybe we could, you know, do come up with the boxes together for them to take down to the care home... it would be something that they could gather together themselves and work on themselves. So it would give them a focus as well. And they'd really feel like they were helping (care staff interview).

Case study

Although the evaluation team was not able to collect video ethnographies as we would have liked in order to create case studies, a participant in one of the workshop sessions vividly described her experience of reading with her husband who has dementia. Her description from the recorded workshop is presented below to provide a wider contextual view of the potential benefits of Reading is Caring.

It was last week there was a day when Ron was really not good at all and the carer said he wasn't good as well it wasn't just with me and he came through for breakfast and just sat and looked at it and so I put some porridge on a spoon and left it for him and he said your making me do the hard bit so I thought oh right, ok, so I said do you want me to feed you so he did and I said well I could read as well so I got "Sup" out...because [the Reading is Caring handbook] was there it was handy...So I read that whilst I fed him his porridge [because he was] very sleepy and also grumpy. That was very unusual I've never had to do that before so he was really not in a good place, but it was a good experience. But not as I expected; I thought Ron would talk about hill walking, but when I said to him, "What does it remind you of?" he said, "Climbing a pit bing³".

I should have tried to get him to say a bit more [but] I was just so surprised because he's never ever said anything about climbing pit bings to me before but that was obviously a childhood memory. I've spoken to him about it since and he said he did climb; he wasn't supposed to, but he did once. His mother had said not to. It was about a mile away and he did climb one when he was younger because they lived in a mining area so that was interesting and we did have a bit of a discussion about that.

We did talk about walking and talked about climbing a particular Munro⁴ he's very fond of...he used to go on a walk called the John Smith memorial walk in memory of John Smith, you know, the Labour leader who died...We then talked about politics.

After we finished all this he went and sat in this reclining chair and said he was going to sleep but he didn't and he listened to music, and he was tapping his feet and he was singing along and he actually had a very good morning and by lunchtime was bright and I thought this is amazing because it's just taken him from this mode of being totally down and not happy with the world and in on himself to coming out and for me it was good because it allowed me to focus on the reading and the story whereas if I hadn't had that it would have been focusing on why am I feeding him and what's wrong and a very negative kind of thing where this was a nice thing to do, and we were both...I felt more relaxed and I think Ron did and listened and it obviously triggered, I think that's quite remarkable that he said this about the pit bing that he's never said before because he quite often talks about his childhood and different things from it but not that.

I thought, "This is amazing," because we never would have got to that place without it. It just made me realise how important reading is; it gives you something else to focus on rather than the interaction between you and the kind of mood that's around.

³ Heap of waste from a coal mine

⁴ A mountain

Further developments

This section outlines a number of issues raised during the evaluation that may help to inform the future directions of Reading is Caring beyond the pilot phase.

Peer-to-peer support

Pre-Covid, the plan was to deliver Reading is Caring training in small group face-to-face sessions. As NICE (2018) points out, carer interventions are likely to be most effective when provided as group sessions. Whilst the move from face-to-face to online delivery had some advantages, a significant disadvantage was the reduction in opportunities for peer-to-peer support, both during the session and on an ongoing basis. As an interviewee commented:

...in normal times, it would be lovely to continue to come and share opportunities to meet up every few months and just talk about with other people to share experiences (care partner interview).

The majority of sessions were delivered one-to-one, but even where there was more than one participant, natural interaction and informal discussion was more difficult to facilitate in an online environment.

Whilst this issue will be reduced once it is possible for face-to-face sessions to resume, some online sessions may continue to meet the needs of people who find it difficult to attend face-to-face. It may therefore be useful to build in ways of providing a greater element of peer-to-peer support for those who attend online training. An interviewee suggested a Facebook group as an option to provide ongoing peer-to-peer support:

I wondered if there was any real value in like a Facebook group for people that have been on the course...if there was a place where someone could say, "I'm struggling to do this," or "This hasn't worked." Then get any suggestions, or "Oh my goodness, I've just come across this book or this magazine or whatever," you know. Or even, "I've got a load of books; does somebody want them?"...might be a nice way to share...other people's brilliant ideas... (care partner interview).

Off-the-shelf materials

A suggestion made by several interviewees was for Scottish Book Trust to provide more 'off-the-shelf' materials suitable for shared reading. Interviewees felt that some people might experience difficulties in finding materials themselves and would appreciate extra support in identifying texts or putting together life story book boxes. This might particularly be the case for people who did not read widely themselves:

...maybe there could be an accompanying booklet with lots of poems and reading material in it or something (care partner interview)

If they put some kits together that had, you know, a complete kit that we could start off with so that they could see how it works...maybe if they had one...to share with the person it would give them an idea of how to put one together themselves...(care staff interview).

However, it is important to balance the provision of generic materials with the value of tailoring materials to the specific needs of the individual. For example, an interviewee described how they

would want to tailor materials to the individual rather than simply present them with more 'neutral' reading material:

...the reading material that we went through it's...very neutral isn't it? It's not going to offend anybody or clash anybody's cultures or anything like that. I totally get that that's how it's meant to be. Whereas...when we go and speak to somebody then we could like tailor it to that person and their thoughts, beliefs whatever... (care staff interview).

What is 'shared reading'?

The project co-ordinator has adapted the project publicity materials throughout the pilot in response to feedback. However, even towards the end of the pilot there was still some ambiguity reported by interviewees about either themselves or other people being initially unsure exactly what Reading is Caring or 'shared reading' involved:

...first of all, I thought it was just a list of titles, and it obviously wasn't that (care partner interview)

...one person on Facebook didn't understand what the course... "Is it like a book group or is it...?" So she didn't feel there was particularly clearly described... (care partner interview).

A suggestion to help overcome this ambiguity was to film short videos of people engaged in shared reading to show what it involved and, hopefully, convince potential participants that the approach might be helpful for them:

...one thing that might be lovely...if there was some video clips of people doing it with somebody, that would be amazing...may be just to give people the confidence that... it might be just very, very lovely to see a couple of clips of those things (care partner interview).

Continuity of care

As Reading is Caring started to gain more interest within the healthcare sector in the later stages of the project, another theme that emerged was the potential use of shared reading to support continuity of care between hospital and community (and also social care) settings:

...to have it out in the community it really important so when they come in here [to the hospital ward] I can carry it on, so I thought it was very important to get it out in the community (care staff interview).

The project has begun to engage with community healthcare staff, so this is likely to be a theme that is taken forward into the next stages of the project.

Use with other conditions

Finally, it is worth noting that several interviewees pointed out that the Reading is Caring approach was likely to have value beyond people living with dementia. Parkinson's disease and anxiety were other conditions mentioned where elements of, or lessons from, shared reading could be helpful. This may be useful to bear in mind particularly for care staff who may be supporting individuals with comorbidities:

I think this actually works really well for people that suffer with things like anxiety disorders because I've met people in the past that have been avid readers that literally cannot read...because you know the anxieties...that'd be quite interesting to see if I could get this to sort of work...not maybe just a book but to like start off with, but maybe magazines little bits rather than facing them with a whole book...and finding techniques that work for them and it's a very individual thing. So this could work for people like that... (care staff interview).

6. Summary

The following section summarises the main findings from the evaluation of the Reading is Caring pilot phase, and makes suggestions to help inform the future development of the project.

Impact of Reading is Caring

1. Reading is Caring offers **comfort** to people living with dementia. It promotes relaxation in everyday situations and relieves stress in more challenging circumstances.
2. Reading is Caring supports the **inclusion** of people with dementia in activities as they become more involved and responsive than may usually be the case.
3. Reading is Caring provides people living with dementia a means to share aspects of their **identity** and validates the things that are important to them and that have shaped who they are.
4. Reading is Caring offers an enjoyable, stimulating form of **occupation** for people with dementia. It also provides a focus for further conversation, reflection and discussion – and potentially other activities.
5. Reading is Caring supports **attachment** and feeling close to others as readings can prompt people living with dementia to share memories they have not done previously; play a more equal part in caring relationships; and make connections at a deeper level than is often possible through everyday conversation.
6. Reading is Caring workshops have helped care partners and care staff to feel more **confident in engaging in shared reading**, particularly in reading aloud and slowing down their reading when appropriate (which may feel unnatural at first), but also using different types of text and integrating shared reading with other activities.
7. Reading is Caring impacts on **caring relationships** in a variety of ways, in particular, in bringing together the wider family and support network of the person with dementia in a shared endeavour. Shared reading is seen as a highly positive aspect of caring relationships.
8. Reading is Caring also has an impact on the **mental health and wellbeing of care partners and care staff**. It can be useful, not just to the person with the dementia, but also to the care partner/care staff in stressful situations, and can help care partners/care staff to feel they are making a positive difference.

Workshop delivery

Due to the Covid pandemic, plans for promotion and delivery of Reading is Caring workshops had to be adapted to enable the project to continue in an ongoing changing and uncertain environment. The project co-ordinator has demonstrated a great deal of flexibility in dealing with this situation and adapting the delivery of the project and learning lessons along the way.

1. The workshops have been extremely well-received. In particular, the organisation, clarity and pace of the sessions were praised by participants, as was the enthusiasm and knowledge of the workshop facilitator.
2. There is evidence that family care partners and professional care staff attending increase their knowledge of why a tailored bespoke shared reading approach works for those they care for who are living with dementia, and increase their confidence in using shared reading approach.
3. Organisation of the workshops has required a long lead in time – and patience following up potential contacts. However, there is evidence that momentum has started to increase during the later stages of the pilot as word about the project has begun to spread more widely.
4. It can be tricky to identify suitable participants – in particular, some people who may well benefit feel the workshops are not for them. The reasons for this are likely to be complex, but a reluctance to look forward along the dementia journey may play a part.
5. Taster sessions are valued and a successful way to convey information to allow someone to decide if the course is for them as well as providing those who are, perhaps, less confident to engage with the project.
6. Online workshops may be off-putting for some potential attendees. However, they can make it easier for some participants to attend (e.g. no need to arrange respite care). Online delivery may, therefore, still be considered as a potential delivery option when social distancing measures are no longer needed to meet the specific needs of some participants.
7. There are both positive and negative aspects to one-to-one workshops. They can reduce opportunities for direct peer interaction and be time-consuming to deliver. However, they can also have important potential benefits, such as allowing for greater personalisation and openness.

Suggestions for further development

The following are suggestions for ways in the project might be developed in response to some of the issues identified in the evaluation.

1. It may be worth considering slightly different approaches for professional care staff and family care partners. For example, even when it is possible to deliver effectively in person again, online delivery is likely to offer more advantages for some family care partners (especially those in more remote locations) compared to professional care staff who can attend a session in their workplace. There may also be scope to tailor the workshops for different audiences (e.g. reducing the amount of information about dementia for healthcare staff).
2. The impacts of Reading is Caring on the identity of the person with dementia is a complex topic. However, it may be helpful to stress the value of the approach for those for whom reading has been a big part of their life – and which Reading is Caring can allow them to continue albeit in different ways – but also for those who do not identify as readers, but may still be able to connect strongly to alternative forms of text (e.g. cartoons, scripts, lyrics).
3. If online delivery is to be considered an element of the Reading is Caring programme in the long term it may be worth considering ways in which additional support can be provided to compensate for the lack of direct peer-to-peer support during the sessions (e.g. Facebook group or other online community where people can share ideas, suggest texts etc.).

4. Whilst the Reading is Caring handbook has been very well-received, there is some evidence that care staff/care partners would appreciate further examples of shared reading materials. However, it could be difficult to balance this 'off-the-shelf' approach with the emphasis on tailoring to the needs of the individual. One option may be to encourage more peer-to-peer sharing through, for example, a forum where both those who have attended the training and Scottish Book Trust staff could suggest materials for particular topics.
5. The pilot phase has had a slow build, but the level of activity in the later stages demonstrates the need to develop a 'critical mass' that can start to generate further interest through word of mouth. It may, therefore, be worth focusing on a defined target population (e.g. a geographical area) in the next stages.
6. Practical demonstrations of Reading is Caring (e.g. through videos of shared reading in practice, or people discussing their life story book boxes) may help those who are unsure whether the course is for them to understand what it involves and the potential benefits.
7. The way in which the pilot project has developed suggests that greater administrative support may be valuable in any future roll out (e.g. in the early stages of identifying participants) to allow the project co-ordinator to devote more time to delivery and ensure demand can be met.

Reflections on evaluation approach

As described in [section 3](#), the evaluation methodology had to be adapted in response to the arrival of Covid-19 in the UK and subsequent changes to the Reading is Caring project itself. It is hoped that, as the risk from Covid-19 reduces, some of the original evaluation approaches will again be possible (e.g. visiting people in their homes to observe Reading is Caring activities in practice). The last year has been a particularly difficult one for people living with dementia and their carers, and issues such as care staff workloads and illness amongst people with dementia have had an even greater impact on evaluation activities than would be expected in 'normal' times.

Whilst the post-training feedback forms allowed basic information to be collected, as the project scales up, it may be useful to develop these to include more quantitative information to further explore the reach and potential impact of the project (whilst also bearing in mind that carers will have limited time, so such feedback should be as light-touch as possible). In addition, as the scale of the project increases, it may also be possible to add a follow-up survey (e.g. 3 months later) to ask about the impact of the training and any challenges around its implementation.

The model of psychological needs (Kitwood, 1997) appears to be a useful one through which to explore the impact of Reading is Caring. It is an approach which shares a very similar ethos to the project and is widely used. It would seem to offer an appropriate framework for further evaluation going forward.

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