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**A “novel” reading therapy programme for
reading difficulties after a subarachnoid haemorrhage**

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A “novel” reading therapy programme for reading difficulties after a subarachnoid haemorrhage

ABSTRACT

Background: Although several treatments for acquired reading difficulties exist, few studies have explored the effectiveness of treatment for *mild* reading difficulties and treatment for reading difficulties associated with cognitive impairment.

Aims: This study explored the effectiveness of an individual strategy-based reading treatment of 11 sessions given to a female participant (IW) who had mild reading difficulties following a subarachnoid haemorrhage (SAH). The impact of treatment on reading ability, confidence and emotions associated with reading were investigated.

Methods & Procedures: Treatment focussed on the use of strategies to support IW’s memory when reading books, the use of a checklist to select appropriate reading materials, and increasing IW’s confidence in discussing the book she was reading with others. A person-centred approach and personally relevant materials were used throughout the treatment. Reading ability was assessed using the Gray Oral Reading Tests (GORT-4; Lee Wiederholt & Bryant, 2001), and IW’s perspective was obtained using the Reading Confidence and Emotions Questionnaire (RCEQ; see Cocks et al., 2010). Pre-treatment, post-treatment and maintenance (7 weeks post) assessments were undertaken, with an additional exit interview at the final time point.

Outcomes & Results: Gains were noted in reading rate, accuracy, comprehension, and confidence, with parallel increased pleasure gained from reading and reduced negative emotions and frustration. Self-reported gains included conversing with

others about material read, verbal communication, and re-engagement with the identity of being a reader.

Conclusions: Strategy-based treatment resulted in positive gains in reading for pleasure, conversation, and identity, for an individual with mild chronic reading difficulties. Participant self-report and interview reveal the true value of this treatment for the individual. The positive results suggest that further research is warranted that investigates the effectiveness of strategy-based reading therapy approaches for others with acquired reading difficulties.

MAIN TEXT

While text-level reading difficulties are common after stroke and head injury, most reading therapy protocols that have been published have focused on reading single words (e.g., Beeson, Rising, Kim, & Rapcsak, 2010; Nickels, 1992). While these may be appropriate for clients who have more severe difficulties, or difficulties with specific aspects of reading e.g. grapheme-to-phoneme conversion, they are not appropriate for clients who have more mild reading difficulties associated with an underlying cognitive impairment.

Those studies that have explored the effectiveness of reading therapy programmes that target the text-level, suggest that therapy can be effective (Beeson, 1998; Beeson & Insalaco, 1998; Cherney, 2010; Cherney, Merbitz, & Grip, 1986; Cocks et al., 2010; Coehlo, 2005; Lynch, Damico, Damico, Tetnowski, & Tetnowski, 2009; Mayer & Murray, 2002; Sinotte & Coehlo, 2007; Wilson & Robertson, 1992). These

therapy programmes have taken a number of different forms and have targeted either the underlying impairment or encouraged the use of strategies to aid in reading.

The effectiveness of the multiple-oral reading technique (MOR) was explored by Beeson (1998) and Beeson and Insalaco (1998). With this therapy approach, participants were required to repeatedly read pre-selected passages during therapy sessions and at home. Gains reported from both studies included a faster reading rate while maintaining a high level of comprehension.

Mayer and Murray (2002) built on the work by Beeson and Insalaco (1998) and compared a modified version of MOR with a treatment that focussed on working memory for a participant (WS) who had reading difficulties and aphasia. There was evidence to suggest that both approaches were effective. Treatment resulted in increased decoding speed, more efficient processing speed, enhanced reading comprehension and increased lexical-semantic working memory abilities. There was no difference between treatment type with regards to rate of improvement or extent of improvement.

The Oral Reading for Language in Aphasia (ORLA) therapy, that was developed by Cherney and colleagues (2010; 1986), also uses a repeated reading approach. First the person with aphasia repeatedly reads sentences and then paragraphs in unison with the clinician. They then do this independently. Improvements in reading and other aspects of communication including verbal expression and comprehension have been demonstrated. These benefits have been found to be robust even if the ORLA

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programme was delivered by a computer, as opposed to face to face therapy with a speech and language therapist.

While there have been many gains reported in relation to these repeated reading approaches, the effectiveness of these approaches has been tested with individuals who have reading difficulties that were not primarily due to cognitive impairment. For example, in Beeson (1998) the case description was consistent with a diagnosis of pure alexia. It is therefore unclear whether these reading approaches would be helpful for an individual whose reading difficulty was primarily due to difficulties with memory and/or attention. Furthermore, the treatment approach of repeated reading of the same passages may be counterproductive in terms of aiming to increase attention. Finally, it is unclear how these approaches would aid in supporting memory of reading texts other than the one that is repeatedly read. Alternative therapy approaches are therefore needed for individuals who have reading difficulties primarily due to impaired memory and/or attention.

Coehlo (2005) and colleagues (Sinotte & Coehlo, 2007) have explored the benefits of a reading therapy approach that specifically targets attention. They used single case study designs to explore the effectiveness of this approach. The participants, MH (in Coehlo, 2005) and AN (in Sinotte & Coehlo, 2007) both had mild reading difficulties associated with attention difficulties. MH received sixteen sessions of therapy over an eight week period and AN received sixteen sessions of therapy over a five week period. It was not clear how long each session was for. Therapy in both studies focused on increasing sustained attention, rather than specifically on reading. Positive

outcomes included an increase in reading comprehension (MH and AN) and reduced variability in comprehension task performance (AN only). Gains relating to language and attentions skills were also reported for AN. Further qualitative improvements were noted by MH in her reading log. MH reported that reading felt less effortful, that she was less distracted when reading, and that she could concentrate for greater periods of time. Additionally, she reported increased participation in reading activities including reading the daily newspaper, portions of magazines, reading short novels, and participating in a monthly book discussion group.

Another therapy approach that specifically targeted attention was described in Wilson and Robertson (1992). They also used a single case study design. The participant in this study had attention difficulties associated with reading as a result of a head injury. The training consisted of two different phases. The first phase (Training A) focussed on increasing concentration when reading and the second on increasing concentration when reading when a background distraction was present. The second phase consisted of two parts (Training B1 and Training B2). In Training B1 the goal was to read for five minutes without a slip of attention. Due to poor performance, this goal was modified in Training B2. The modified goal in Training B2 was instead to have no more than two slips of attention within a three minute period of reading. Training A consisted of 160 sessions (four sessions per day for 40 days). Training B1 consisted of 44 sessions (four sessions per day for eleven days) and Training B2 consisted of 156 training trials (six trials per day for 26 days). A particular strength of this study was that the reading material used was chosen by the participant (a novel) and so was motivating and also had high face validity. The therapy however

was high intensity. Following the first phase of therapy the participant had less frequent attention slips when reading the novel which was used in the training but this improvement did not generalise to reading a text that was not used in therapy.

Following the second phase, the participant had less frequent attention slips when reading the novel used in therapy and this improvement also generalised to texts not used in therapy. The participant also reported that following therapy he now read for pleasure.

Similar to the study by Wilson and Robertson (1992), Lynch et al. (2009) also used material selected by the participant in their reading therapy study. This study also used a single case study design. The participant, Ms A, had reading comprehension difficulties and Broca's aphasia. She received therapy twice a week over an eight month period with the exception of a five week break. In the approach described in this study, the focus was on obtaining meaning from the text rather than reading accurately. Complex texts were used as reading material. This was to ensure that the reading material was motivating and also had contextualised vocabulary and concepts. In this approach, the therapist also read and wrote aloud in the presence of Ms A. The participant was then encouraged to read and write along with the therapist. The strategies used by the therapist included modelling, foreshadowing, and employing meta-literacy comments. Ms A's comprehension improved following the intervention.

As individuals' therapy goals span the full spectrum of the International Classification of Functioning, Disability and Health (ICF) model (World Health Organisation

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(WHO), 2001; Worrall et al., 2011), it is essential that both assessment and therapy consider impairment, activity and participation (Kagan et al., 2008). Most of the reported gains in the previous research on reading therapy could be classified as impairment gains. For example, the only non-impairment measure reported in the study by Wilson and Robertson (1992) was that the participant reported that he now read for pleasure. There is therefore a need to consider all aspects of the ICF framework both when designing reading therapy approaches, and also to consider gains across the entire ICF spectrum when determining the effectiveness of any reading therapy approach.

Unlike previous research, Cocks et al. (2010) used a strategy-based reading therapy approach. The effectiveness of strategy-based reading therapy was explored with four participants with mild reading difficulties as a result of traumatic brain injury. The participants received 5-7 therapy sessions focusing on learning functional reading strategies, in order to be able to read reading matter of their choice (e.g. novels, magazines, and newspapers) independently. Strategies included highlighting key words and using prompt sheets to recall what was read. A range of measures, considering all aspects of the ICF framework, was used in order to determine whether gains had been made. These included extracts at the start and end of the therapy block that had been designed by the researchers, in order to assess accuracy, comprehension, and recall. Participants usually read only 2-5 extracts of a specific difficulty level, determined by either the SMOG (McLaughlin, 1962) or the Gunning-Fox Index (Gunning, 1952) as appropriate for their abilities and difficulties. A confidence and emotions questionnaire was also completed at the start and end of the

therapy block. Gains were reported in relation to reading accuracy, comprehension and recall. Three of the four participants had increased confidence following therapy, and two of the participants had a reduction in negative emotions associated with reading. Unfortunately, only one final assessment was carried out and there was no maintenance testing. While the addition of measures that explored gains that could be classified as activity and/or participation was a strength of this study, these gains could have been explored in more detail. For example, a detailed interview with participants could have been carried out. This interview could have explored participants' views regarding the reading therapy that they were given and the gains that they felt they had made.

In the clinical-outcome research model, used widely in the research community and adapted by Robey for use with clinical disorders (Robey, 2004; Robey & Schultz, 1998), there are five phases of intervention research. In the first phase of this model (Phase I) the intervention approach is identified and the effects are hypothesised. This involves the recruitment of single cases or small groups of participants. In Phase II, the clinical viability of the intervention approach is determined. At this phase it should be possible to hypothesise the magnitude of efficacy. Phase II research should also further refine the population and the treatment protocol. In Phase III, the efficacy of the treatment approach is determined through studies which have a tighter experimental design. Comparisons between treatment and no treatment conditions are made. At this stage, small group studies are still appropriate. In Phase IV, the therapy approach is directly compared to alternative therapy approaches or with a no

treatment condition but with larger group sizes than Phase III. In Phase V, a cost-benefit analysis is carried out.

The current study investigated whether a strategy-based therapy approach was effective for IW, who had mild reading difficulties associated primarily with a cognitive impairment, following a subarachnoid haemorrhage. The study used a similar design to that of Cocks et al. (2010). The study was considered a Phase I/II study for determining the effectiveness of strategy-based reading approaches for people with reading difficulties associated with cognitive impairment. Whilst the direct attention training approach used in Coelho (2005) and Sinotte and Coelho (2007) is clearly effective, and is likely to have been an appropriate treatment approach for the participant in this study, a different approach was taken. In order to maintain IW's motivation, the therapy approach needed to (1) Utilise relevant stimuli, like the studies by Wilson and Robertson (1992) and Lynch et al. (2009), in the form of personally-chosen novels), (2) focus on text-level tasks (page and book chapter), and (3) be motivating for both IW and her conversation partners who discussed material read each week. We deemed this approach would be more amenable to IW than repetitive drill-like component tasks of direct attention training and repeated reading. We employed a whole-task performance and practice approach, which is similar to Lynch and colleagues (2009), who used whole texts rather than "fragmented tasks that focused on splintered skills" (Lynch et al., 2009, p227). As limited service provision was available, the therapy approach needed to be less intensive than in the study by Wilson and Robertson (1992), and to occur over a short duration, contrasting with the eight month treatment period described in Lynch et al. (2009). The therapy

approach therefore used was similar to that described by Cocks et al., and was designed with the aim of increasing functioning, activity, and participation.

IW attended 11 sessions of therapy focussing on using strategies to help her to read books of her choice. The study differed to Cocks et al., in that more formal pre- and post- therapy measures were used, and a maintenance assessment was carried out seven weeks after therapy had ceased. Similar to Cocks et al., gains in confidence and negative emotions gains were measured using a questionnaire. Unique to this study, IW was also interviewed at the maintenance assessment in order to determine her thoughts on the therapy process and to determine whether additional activity/ participation gains had been made.

METHOD

Participant

IW was a 49 year-old right-handed British female, who was married and had two adult daughters. Her first language was English and she was university educated with 17 years of schooling and further education. She had a subarachnoid haemorrhage (SAH) two years prior to taking part in this study, incurring frontal lobe damage as indicated on a CT scan. IW had mild aphasia characterised by anomia, with an Aphasia Quotient of 89.5 on the Western Aphasia Battery-Revised (WAB-R) (Kertesz, 2006; tested two months prior to participating in the study) . Whilst she was classified as having anomia according to the assessment, the most impaired subtest was comprehension, specifically the aspect requiring following multi-part instructions, which may link to memory skills (See Table 1 for scores on subtests).

-----Insert Table 1 about here-----

Information taken from a neuropsychology assessment report completed 18 months prior to her taking part in this study indicated impaired executive functioning. Unfortunately, specific test scores were unavailable but the report indicated that in particular, IW had difficulties with multi-tasking, thinking flexibly and abstractly, sequencing, problem solving, and being able to plan and initiate a course of action. Her performance on memory tests suggested that weak attention and variable concentration impacted on her memory. Furthermore, the assessment results suggested that her speed of processing had also been affected by her SAH. These difficulties would be considered by the WHO ICF coding system as impairments in Specific mental functions (b140 Attention functions, b144 Memory functions, and possibly b164 Higher-level cognitive functions). IW was not receiving speech and language therapy services at the start of the study, and indeed, was deemed ineligible as her impairment was considered too mild by services she had previously approached. She had no visual or mobility difficulties. She was referred to a university clinic that specialises in reading difficulties after stroke and head injury by a researcher involved in another study.

IW reported that reading had always been very important to her both professionally and for leisure. At the time of the SAH, IW managed the catalogue division of a well-known private collection of books and art work, and had previously managed independent book shops, and worked as a book reviewer. One year after the SAH, IW wanted to return to her full-time position following a 6-month “phase in” process.

However after two months, she realised that this was not possible, due to difficulties with multi-tasking, attention, and memory that were necessary for the position. During the study, IW returned to this place of work one day per week in a staff training role. After the SAH, IW had attempted to read novels for pleasure, but had managed only two “chicklit” novels, which she reported were difficult to read, and she could not retain information or enjoy reading them. As an alternative, IW started reading factual books, such as biographies, which were easier for her to follow, due to being written in a way in which events are presented sequentially. Although she was experiencing some success with biographies, her goal that motivated her contact with the university clinic was to be able read novels for pleasure.

Assessment Procedure

IW’s reading ability, reading confidence, and emotions associated with reading were assessed pre-treatment, post-treatment (one week), and at maintenance (seven weeks post-treatment). Two assessments and an exit interview were used to measure baseline performance, capture change, and identify user perceptions of the treatment.

A formal, standardized assessment, the Gray Oral Reading Tests (GORT-4; Lee Wiederholt & Bryant, 2001), was used to assess reading rate, accuracy and comprehension. The GORT-4 is a text level reading assessment, with two equivalent forms (Form A & B), each containing 14 stories or single paragraphs of increasing length and complexity. The participant reads each story aloud, and then answers five multiple-choice questions that assess literal, inferential critical and affective comprehension of the text. Each story is scored for reading rate (in seconds), accuracy

(number of deviations from print), and comprehension (number of questions correct). A basal is obtained when the participant obtains the maximum score of five for comprehension in one story (and credit is given for all stories below the basal), and a ceiling is obtained when the participant answers three questions or more incorrectly in one story. Maximum comprehension score is 70 (5 correct answers for 14 stories). The GORT-4 yields a range of scores: a total comprehension score and a total fluency score for the test; an overall Oral Reading Quotient (ORQ) and percentile); and rate, accuracy, fluency, and comprehension scores for each story that are summed and averaged for the test. Standard administration and scoring instructions were followed, including using the GORT-4 conversion tables. The GORT-4 is an education assessment designed to identify reading difficulties in school-aged children, and not for adult neurological populations. Furthermore, it is an American test with American content and spelling, and standardized on American children and teenagers. Despite these limitations, it was selected for use, providing a comprehensive range of stories that would be suitably discriminating for this high-level participant, and has been used in aphasia reading research previously (e.g. Beeson & Insalaco, 1998; Coelho, 2005). Alternative assessments within speech and language therapy had only one or few paragraphs at the text level to assess reading ability. For IW, Forms A and B were administered pre-treatment, with an average score being obtained for baseline. Form B was used immediately post-treatment and Form A at maintenance testing. As post-treatment and maintenance testing were only six weeks apart, different forms were used in order to reduce gains made simply because IW remembered the texts.

The Reading Confidence and Emotions Questionnaire (RCEQ: see Cocks et al., 2010) was used to assess self-report of confidence and emotions associated with reading in different contexts. The RCEQ contains 22 questions (see Appendix 1) and is completed by the participant, with interviewer support available to read aloud the questions or clarify where needed. Both premorbid reading and current reading are assessed, with the majority of questions focussing on the latter. Two thirds of the questions pertain to confidence, and one third to emotions associated with reading. The RCEQ acknowledges that subjective evaluation is important for holistic assessment and compliments the objective information gathered using the GORT-4. The RCEQ reflects elements of the WHO ICF dimensions of Activity and Participation, focusing on the individual's reading in contexts with others, and can be linked to various Activity and Participation domains and codes (d1 Learning and applying knowledge – *d140 Learning to read, d166 Reading*; d3 Communication – *d350 Conversation, d355 Discussion*; and d9 Community, Social and Civic life – *d920 Recreation and leisure*). The RCEQ also links reading with quality of life, focusing on the psychological dimension or the individual's perception of their affective state (The WHOQOL Group, 1995). In the RCEQ, this is specific to reading, and is manifest in the concepts of confidence, pleasure, feeling upset, anxiety, worry, frustration, and anger. All questions are rated on a 10-point scale, from 1 (not at all confident) to 10 (completely confident), or 1 (none/not at all) to 10 (a lot/extremely) for emotions. Scores are not summed but rather treated as individual items to inform goal setting and treatment planning.

The RCEQ was devised in 2007 by five student researchers working in collaboration with two authors on the current paper (Cocks and Cruice), and slightly modified in 2008 by three further student researchers. Those involved in the development of the RCEQ are recognised in the RCEQ footer (see Appendix 1). It was modelled on the 12-item Communication and Readiness and Use Index (CRUI), developed by Lyon and colleagues (1997) to measure outcomes of communication partner training for volunteers working with adults with aphasia. Similar to the CRUI, the concept under study is considered in relation to different partners or contexts. For example, the RCEQ considers reading in the contexts of reading by one's self, with a family member or friend, and with a stranger. Again, similar to the CRUI, the RCEQ considers different stages of communicative interaction. For example, starting a conversation about something read versus maintaining a conversation about something read (see items I – L). The first section of the RCEQ focuses solely on confidence, which is partially represented in the CRUI, but is now a popular concept in its own right (see for example, the Communication Confidence Rating Scale for Aphasia (CCRSA) by Babbitt, Heinemann, Semik, & Cherney, 2011). Although the CRUI employs a 100mm visual analogue scale, which is viable and acceptable, the response format was modified to a 10-point likert scale for the RCEQ. This modification was deemed to be more helpful in enabling clients to select a point on the continuum, and discuss their perceptions and future desires over different time points.

Finally, to gather IW's perceptions of the treatment and her progress, a structured exit interview was conducted at the maintenance session. Research by Worrall and

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colleagues (2011) and Hersh (2009) on goals and discharge practices with clients with aphasia informed the selection of the following questions:

- How have you found coming to the reading clinic?
- Have you noticed any changes with your reading or your communication since you started coming?
- How do you feel you've gone with your goals?
- What did you like, or what was good, about the therapy?
- Was there anything about the therapy that you didn't like or that could have been better?
- Do you have future goals for your reading? If so, what are they?
- Is there anything else you wanted to comment on that we haven't covered?

Treatment Procedures

IW's goals for treatment were: to remember more when reading (including to use strategies more frequently to help with reading; and to be able to identify texts that are appropriate to read given her reading difficulties and strengths); to feel more confident with reading and to enjoy reading more; and to be able to talk about what she had been reading with confidence to family/friends and strangers. These goals were established in a discussion with IW integrating the results of the GORT-4, RCEQ, and her own views. Treatment consisted of 11 one-hour sessions (four sessions over five weeks; nine week break due to university holidays; seven sessions over eight weeks). Texts of IW's choice were used as therapy materials. Reading and home-practice tasks outside the clinic treatment sessions were integral to the programme of treatment.

Treatment initially targeted a novel (*The Return* by Victoria Hislop), however after four sessions and the holiday period, IW reported not enjoying the novel, and goals were reviewed to focus on factual text. Treatment then continued with a focus on an autobiography (*Journey Through a Small Planet* by Emanuel Litvinoff), and the final treatment session focussed on reading extracts from three different books: a graphic novel (*Persepolis* by Marjane Satrapi) and two novels (*Room* by Emma Donaghue; *The No. 1 Ladies' Detective Agency* by Alexander McCall Smith). Pre-holiday treatment was delivered by two student speech and language therapists (SSLTs) under close supervision of a qualified speech and language therapist (SLT); post-holiday treatment was delivered by a qualified SLT. This occurred because IW returned to work one-day per week during the study, and needed an alternative day for treatment to accommodate this, necessitating also a change in therapist. In addition to the texts focussed on in therapy, IW reported independently and spontaneously reading other factual books between sessions, including a book about the Isle of Skye, and one about the holocaust, with her interest in the latter sparked when reading *Journey Through a Small Planet*.

Treatment aimed to improve IW's ability to read and retain information through the utilisation of strategies including:

- Using a card to block text above and below the line she was reading
- Stopping at the end of each paragraph and verbally summarising the main points
- Highlighting main character's names (for fiction books) and key words

- Writing important plot developments in the margin of the book (for fiction books), and other things she thought may be important to remember
- Creating mind-maps to track who, where and what happened in the text
- Writing summaries at the end of each chapter

The highlighting, summaries and mind-maps helped IW revise and focus on the important aspects of the plot, and also acted as an aide memoire of text previously read. Some of these strategies, highlighting and writing summaries, were used in Cocks et al. (2010) and found to be effective. The addition of the use of mind-maps was inspired by adult education literature which suggests that creating mind-maps aids memory of text based material (e.g. Farrand, Hussain, & Hennessy, 2002). The use of a card to block text is a strategy applied frequently in clinical practice, despite the lack of published evidence for its use, to focus clients who have reading difficulties associated with cognitive difficulties.

Sessions also involved discussion about the book and verbal recall, in which IW was required to verbally recall what she had read that week; what had happened in the book so far; and the last two paragraphs read in the session. Initial summaries (those at *start* of treatment) contained a significant amount of detail and were poorly structured, necessitating a further treatment target of extracting key information only about each passage such as the characters involved, the setting, and the event that occurred. In the final two treatment sessions, IW additionally gave verbal summaries to two unfamiliar listeners (other researchers working at the university), which were then reflected on in a discussion with the treating SLT. Discussions during treatment

also focused on awareness and problem solving, for example identifying aspects of types of text that were more difficult and thereby selecting more appropriate reading materials; identifying shifting time frames within text (in one section of *The Return* the plot moves forwards and backwards in time) and thereby re-reading to understand plot development.

Results

GORT-4 Results

Rate and Accuracy

Rate and accuracy scores are reported on a scale of 0-5, and raw scores are then converted using GORT-4 tables. Pre-treatment, IW's rate of reading was fairly slow, obtaining an average score of 1.86/5 (see Figure 1 for details). Post-treatment, her rate improved to the maximum score of 5/5, and this was maintained (4.87/5). Pre-treatment, IW rarely made errors when reading aloud and obtained an average score of 3.93/5 for accuracy. Post-treatment, this improved to the maximum score of 5/5, and was maintained (4.87/5).

-----Insert Figure 1 about here-----

Comprehension

Pre-treatment, IWs total comprehension score was low (47.5/70, Standard Score = 8, Percentile = 25; see Figure 2 for details) and her comprehension varied between stories. This variability was not always related to the complexity of the text, for example, IW scored 1/5 on a story in Form A, and yet scored 4/5 on a later story in

Form B. IW reported more personally meaningful texts were easier to remember, or texts that drew on experience. Immediacy also appeared to impact on reading comprehension and memory, as IW reported that if the initial questions related to the last sentences read, she could remember and answer correctly. Analysis of her GORT-4 scores pre-treatment indicated that this was the case for the easier stories but the pattern was more complicated for the more difficult stories. Post-treatment, IW's comprehension score improved (65/70, Standard Score = 11, Percentile = 63), and the variability in her scores reduced with scores ranging from 3-5 (as opposed to 1-5). Improvement continued and at maintenance, IW obtaining a maximum score for all but one of the stories (69/70, Standard Score = 12, Percentile = 75).

-----Insert Figure 2 about here-----

Fluency and Oral Reading Quotients

Pre-treatment, IW's total fluency score was 94/140 (Standard Score = 8, Percentile = 25) (see Figure 3 for details). Post-treatment, her fluency was at ceiling with a maximum score (140/140, Standard Score = 16, Percentile = 98), and this was effectively maintained six weeks later (138/140, Standard Score = 15, Percentile = 95). Summed standard scores for comprehension and fluency over the three time points were calculated, in order to compute IW's Oral Reading Quotient (ORQ) and percentile. IW achieved an ORQ of 88 pre-treatment (in 21st percentile; Standard Error of Measurement (SEM) = 2), and an ORQ of 121 post-treatment (in the 92nd percentile; SEM = 2), which remained stable at maintenance testing, yielding a difference score of 33 (minimum difference score specified by the GORT-4 must be 9

points). Following the GORT-4 manual, her pre-treatment ORQ is interpreted as *below average*, and her post-treatment and maintenance ORQ is considered *superior*.

-----Insert Figure 3 about here-----

Confidence

IW rated her premorbid confidence in reading at ceiling (10/10). Pre-treatment ratings of reading silently were all low (3/10), and pre-treatment ratings of reading aloud to family/friend or stranger were similarly low (3/10 and 1/10 respectively; see Figure 4 for details). Reading aloud to herself alone, however, was rated at ceiling (10/10). Pre-treatment, IW was not confident in remembering what she had read (1/10) but more confident in understanding what she had read (5/10). Post-treatment, IW rated herself as more confident in all areas, with one exception (pre-treatment ceiling for item reading aloud alone sustained). Gains of five to seven points were achieved, with post-treatment scores ranging between six and ten. Gains were generally maintained, improved slightly or fell only slightly at maintenance testing.

Pre-treatment confidence in conversing with family and friends about what she had read was higher than pre-treatment confidence in conversing with strangers (Figure 5) and reading ability (compare Figures 4 and 5). Post-treatment, IW rated herself as more confident in all areas, with higher scores in conversing with family and friends, but greater gains in conversing with strangers. Gains were maintained or enhanced at maintenance.

The opportunities in the final two treatment sessions to verbally summarise reading to strangers were important to IW's perception of herself. IW reported that she had been worried about talking about her reading with a stranger, but that overall it was an experience she was proud that she had taken up. The second time she gave a verbal summary, the stranger asked her if she would recommend the book and if she had read anything similar. When reflecting on this activity, IW reported that it made her feel she could still discuss, review, and give opinions about books, and that this was something that was an important part of her pre-SAH life.

-----Insert Figure 4 about here-----

-----Insert Figure 5 about here-----

Emotions

IW rated her premorbid pleasure in reading at ceiling (10/10) but rated her level of pleasure in reading at pre-treatment substantially lower at (2/10). High levels of negative emotion (feeling upset, frustration when reading to self, and anxiety) were noted pre-treatment (see Figure 6). Some degree of worry and frustration when reading aloud was present pre-treatment, but only minimal anger was reported. IW commented that anger was not the right emotion, saying she felt "more hopeless than angry".

Substantial gain in pleasure from reading was evident post-treatment (change score 6-7 points), accompanied by substantial reduction in feeling upset and frustration when

reading to self (changed scores between 7-8.5 points), which were generally maintained. There was no change in anxiety and anger, and only minimal reduction in worry and frustration when reading aloud, at post-treatment, but with the latter emotion decreasing further at maintenance.

-----Insert Figure 6 about here-----

Exit Interview

In the exit interview, IW commented on how her confidence had improved, that she was reading more, and that she was regularly using the strategies she had worked on in therapy.

“more importantly it’s.... made me realise that I can read cos I had it stuck in my head that I couldn’t read I can read and it’s made me face up to the reality that I can’t read the sort of things that I used to read but there’s still some great books out there that I can read and I think if I hadn’t come to this I would have just stopped reading I think I would have become extremely depressed about I mean generally people are a bit depressed but to become very depressed about that because it was like being snobby and it was part of my identity as a bookseller”

“for two years... I only read one book and in the last six months I’ve read at least four books and I’ve tried at least half a dozen other books so... the change I’ve noticed is that my confidence and my determination is there and the belief is there erm and I also think about how I read, I don’t just try to do it because that failed. So

I'm actually thinking about what I read, how I read, when I read it and I was upset by having to do that at first but I'm not now and I enjoy it"

"I've read two [books] in the last three weeks cos I went on holiday. Two in ten days which was incredible for me to read. My future goal is to read more and to stop being snobby about books [laughs]. You know. I can do the same things but in different ways. And for me now, that means still reading and still enjoying reading but using our strategies and reading different you know kinds of things... Not necessarily what I think I 'should' be reading."

"I actually realise that I could read, just different stuff. I've gone out and actively looked at different stuff whereas before I was a bit stuck in like... 'Er, no, I only read literary fiction' and now I have learned that there's lots of stuff which interests me and I recently read a crime novel which I'd have never read before but I really enjoyed it. So that goal has been well achieved."

[In relation to the goal of using strategies] *"Well that, I've practised every week for a long time. I feel just about like that they're in my head now so that's good. I can use them."*

IW commented that she did not feel as confident with talking to people about what she had read. Although, it is important to note that this is in contrast to the change in her self-ratings for confidence, which indicate her confidence did improve in relation to this goal. Perhaps this reflects that although her confidence with talking to other

people improved, it did not improve as much as her reading or as much as she would have liked.

[in relation to talking to others about what she had read] *“I don’t feel as confident in that one erm but I think I have done it a little bit... I mean we did it here with you and then with that... Erm, that other person yeah and then I think back and I have spoken to my daughter about what I’ve read and she did understand it and we did have a chat and I didn’t feel embarrassed. I’m happier about that. So we’ve done it a bit but the idea of it... Looking, I don’t think oh yeah, you know, I could do that. A bit of a uh... work in progress I suppose.”*

Interestingly, in addition to improvements to her reading, IW reported that her verbal communication had also improved.

“And I think I’m brought new words to the front of my head. I said to you before I think I’m using the words I thought I’ve lost... the language that isn’t so simple. They’re there because I’ve been reading them so I remember that I can use them. It’s... All erm my talking is less blunt and the words come easier and more quickly. I used to choose a simple word or sit for a little while and have to think about it. And that feels like reading for learning.”

She reported that she found the structure and the routine of attending therapy beneficial.

“I liked how regulated it was.”

“I have found it being a good routine that it’s every week because I think many times I could have given up but because it wasn’t a big gap between times. It sort of kept me going. If it had been once a fortnight or once a month I think I would have dropped out”

“I liked the aspect of it that was like giving me homework to do cos I did feel that I needed slight rigidity like ‘do this, come back, tell us how you did’, rather than it just being where I could bluff it so I like the combination of everybody like compassionate and encouragement but with a structure. Yeah, I liked that”

The encouragement from the therapist and the acknowledgement that for her, even though her difficulties were mild, they had a big impact on her life, were considered positive aspects of the clinic.

“I’ve found coming to the reading clinic greatly encouraging”

“I found the person doing the class, erm you and the others, felt like somebody who was on my side backing me and understood me and thinking about me and that meant a great deal to me... Because I’m living a life of people telling me how lucky I am and this... centre... The people I’ve encountered here and you seem to acknowledge that what my issues is is still a big deal to me and erm”

“It has been great to have a place to come that understands.”

“I’ve found the whole experience erm learning-wise and emotional support wise extremely positive and I can’t thank you enough and I don’t think I would be reading if I hadn’t attended”

“I liked the fact that there was time at the beginning to tell my story. And I felt I liked the fact that there was a very compassionate approach from all the people I’ve interacted with.... Erm I found it was a very supportive approach everybody made literally made encouraging noises all the time. Everybody acknowledged that it was hard there was no sense of ‘oh, you can do it, move along, move along’, very well based around the individual person, there was really all about that and I really liked that. I’m just interested to notice that I’ve not felt guilty coming here at all when sometimes when I’ve used therapies in the hospital there was a sense of guilt that there were people worse off than me who need it but in this therapy I’ve been made to feel by everybody to feel legitimate.”

“I’m someone who’s high functioning but I was really finding it difficult because reading was really important to me. I hope that this project carries on because the emotional side of stroke and brain injury is not very addressed by medical if you can walk or clean your teeth that’s it but actually investing in the emotional outcomes of stroke, the ones that you’ve seen me have crying about like not being able to read or not being able to speak... like I want to. It makes sense cos then people don’t get

depressed and don't get sick cos that's what happens so I do hope that this centre that it can make a big difference to quality of life for people with stroke and brain injury."

The negative aspects she identified about the therapy she received were that she did not like completing the GORT-4, and she did not like having different SLTs involved in her management.

Discussion

The objective and subjective findings of this study indicate that a strategy-based treatment approach was effective in increasing IW's ability, confidence and pleasure in reading, and reducing the negative emotions associated with reading difficulties post-SAH. Gains were reported in relation to all aspects of the ICF framework. Similar gains in ability and confidence have resulted from strategy-based reading treatment approaches in individuals with head injury (Cocks et al., 2010).

As demonstrated here and in other studies, people with chronic difficulties can improve regardless of whether it is weekly (this study; Cocks et al., 2010) or intensive/other treatment (Code, 2012; Code, Torney, Gildea-Howardine, & Willmes, 2010). This study provided substantially less treatment than is recommended for people with aphasia in terms of total hours, frequency, intensity and duration (see Code, 2012). It also was less intense than the reading therapy approach described in Wilson and Robertson (1992) and occurred over a shorter period of time than the therapy approach described in Lynch et al. (2009). Comparison between reading treatment studies, however, is not straightforward. Optimal intensities may vary with

different approaches (Cherney, 2012), and determining the appropriate dose of therapy is complex (Enderby, 2012). The question of how manipulating intensity and dose would impact on the outcomes of this treatment approach could be explored in future research.

Participating in this treatment reportedly changed IW's approach to reading, with her reporting that she regularly used the treatment strategies (potentially now internalised and automatic). Interestingly, IW did not apply any treatment strategies such as verbally recalling what she had read, writing notes on GORT-4 post-treatment and maintenance assessments. It is possible that she only required strategies for longer texts such as books or that she had internalised her use of strategies and was using them automatically. Alternatively, IW might not have felt that using such strategies within a testing context was appropriate (particularly given her university background). The lack of strategy use in the final testing phase was unexpected, and unfortunately the participant was not asked why she was not using her strategies. Future research should include more robust monitoring, measuring and investigation of strategy use during the treatment, and at post-treatment and maintenance assessment points; and the process of how such strategies become internalised should be explored. Regardless of interpretation, IW made substantial gains in comprehension. Treatment also altered IW's reading consumption, wherein since treatment she had read at least four books and attempted an additional "half a dozen or so".

Two important features of the approach used in the current study, were the use of texts of IW's choice and the encouragement of verbal discussion about reading. The use of personally chosen texts was also a key feature of the reading approaches described by Lynch et al. (2009) and Wilson and Robertson (1992). Like these studies, the use of texts of her choice ensured that IW's interest was maintained throughout the therapy process. It is also valuable for connecting treatment to real life (Worrall et al., 2011).

An important aspect of IW's life prior to her SAH was being able to discuss books she had read, and this therapy approach resulted in an increased confidence in discussing books that had been read with family, friends, and strangers. The explicit person-centredness of this approach and the consideration of activity and participation goals in addition to those related to impairment, resulted in substantial benefits for IW. Activity and participation goals were not considered in previously published reading therapy approaches, other than that by Cocks et al. (2010), nor were they explicitly measured.

Unlike Cocks et al. (2010), IW's views on the therapeutic process and her reading gains were also explored. IW's reflections illustrate a clear attitudinal change towards reading books of different genres, and re-engagement with the identity of "being a reader", with not only multiple references to the quantity of books read, but the obvious pleasure she gains from doing so after therapy. On a broader level, the clinic's acknowledgement of her difficulties as worthy of treatment with legitimate need also contributed to her sense of identity. This acknowledgement can be

31 Author's version of Cocks, N., Pritchard, M., Cornish, H., Thompson, N., & Cruice, M. (in press) A "novel" reading therapy programme for reading difficulties after a subarachnoid haemorrhage. *Aphasiology*

considered an ICF environmental facilitator, and may be understood in terms of Attitudes (Chapter e4) especially the *Individual attitudes of health professionals* (code e450), or Services, Systems and Policies (Chapter e5) specifically *Health policies* (code e5802) which refers to eligibility for services.

The exit interview with IW highlighted that treatment can still be incredibly important even for someone who has such mild difficulties. Often, services prioritise clients who have more significant impairments. As a result clients with mild difficulties, like IW, are not able to access SLT services. This was acknowledged by IW, who reported that often she felt guilty for accessing services when she knew there were other people who needed the services more because they were “worse off”.

Reflection on self in comparison to others in terms of accessing services has been noted previously in the aphasia literature (Hersh, 2009). For IW, reading books was such an important part of her pre-SAH life and her identity. She reported in her interview that one of the positive things about attending the clinic and receiving reading therapy was the acknowledgement that her reading difficulties were “*a big deal*” to her. It is important to note that IW reported that she had not been eligible for local SLT services and this is particularly concerning given that she suggested that if services were not offered to clients who had mild issues they may become depressed. IW’s comment is unlikely to be based on factual experience, but is rather a personal expression highlighting the dissociation between levels of functioning and subsequent impact on mood in her situation. This has however been noted previously in Coelho’s study (2005) with MH. Furthermore, a recent large-scale study provides evidence for no correlation between mood and level of language impairment in aphasia (Cobley,

Thomas, Lincoln, & Walker, 2011). This is an important consideration when determining access to services. At first, a simple solution to this issue of service access could be that the client is offered fewer sessions. It is possible that IW could have made similar gains with just a few therapy sessions. For example, IW could have been taught the strategies in fewer sessions, and then continue independently. In her post-therapy interview however, IW discussed the importance of regularly attending therapy and having the encouragement of the therapist to continue with the strategies and to work towards her goals. Often the role of the SLT when working with clients who have higher-level difficulties, like IW, is somewhat like a “personal exercise trainer” and the routine of therapy is not unlike a “regular exercise class”. While IW knew what strategies she should be using, without the encouragement of the therapist and student therapists and the regular attendance at therapy, she may not have made the gains that she did. Using the ICF codes, this can be considered a facilitator in e3 Support and Relationships - *e355 Health professionals*. However, the degree to which this support was a facilitator (mild, moderate, substantial, or complete) would need to be determined by IW. As identified in other studies, the quality of the relationship and interaction between client and clinician are important to individuals with aphasia (Hersh, 2009; Worrall et al., 2011).

Unexpectedly, IW also reported gains in relation to verbal communication and her comments imply access to more sophisticated language (*I’m using the words I thought I’d lost...the language that isn’t so simple; my talking is less blunt*). While this was not directly measured in the current study, other studies have found that linguistic ability did improve as a result of reading therapy (Cherney, 2010; Cocks et al., 2010;

Coehlo, 2005). The relationship between increased print exposure and linguistic improvements is not surprising. If we consider the reading behaviours of people who have not had a stroke, we know that increased print exposure has been associated with better vocabulary in children (Cunningham & Stanovich, 1991), young adults (Stanovich & Cunningham, 1992), adults (West, Stanovich, & Mitchell, 1993) and second language learners (Kim & Krashen, 1998). Similarly, while the current study did not measure changes in cognitive ability, it could be that the strategies focused on in therapy e.g., memory strategies, could have been generalised to other non-reading related activities. It is also possible that the stimulation of regular sessions and engagement with others has influenced IW's verbal communication.

This study had a number of limitations regarding the measures used. GORT-4 has not been standardised on British adults, and is not designed for use with people with aphasia. Therefore the use of basals and ceilings may have meant that this assessment may not have reflected IW's true reading level at pre-treatment testing. For example, IW reported that she felt that text difficulty was more influenced by whether the topic was familiar or not, rather than the complexity of the text. The results of the exit interview should also be interpreted with caution. While the interview gave an important insight into IW's experience of the therapy process, the interview was carried out with the treating therapist, which may have biased IW's report. Similar caution should be given in relation to the confidence and emotions questionnaire, as this was also completed in the same manner. More detailed cognitive assessments could have been carried out at the same time as the initial reading assessments in order to determine current level of cognitive impairment.

As already indicated, while the participant reported language and cognitive gains, these were not directly measured. Re-administration of the WAB-R (Kertesz, 2006) and cognitive tests following therapy could have also aided in the interpretation of treatment outcomes. Gains in comprehension of multi-part instructions may have occurred due to improved memory and attention skills, which would be reflected in both these assessments. However, IW's self-report clearly indicates a *qualitative* change in the words she now accesses and uses, which is unlikely to be reflected in her already high WAB-R naming and spontaneous speech scores. Alternative measures such as discourse might therefore more appropriately have captured this improvement.

This study demonstrated that there were many benefits of a “novel” reading therapy programme for a lady who had cognitive-based reading difficulties after a subarachnoid haemorrhage. However it is important to note that this study was a single case study. Therefore the experiences of the therapy process, and the gains made, are in relation to just one therapy experience and one person. It is also important to note that IW returned to work during the study and this may have also impacted on the results. For example, increased life activity may have (1) provided IW with more opportunities for reading and strategy application, in contexts that were meaningful to her, enabling transfer of therapy and simultaneously provided IW with more opportunities to reflect on her progress made; or (2) lifted IW's general mood having an overall positive effect on her appraisal of her life situation. Additionally, a

stable baseline was not established which meant it was possible that the gains were not due to therapy.

This study was as a phase I/II study of the clinical-outcome research model (Robey, 2004; Robey & Schultz, 1998). Additional studies at phases II, III, IV and V are now needed which will help determine the effectiveness of this strategy-based approach. Studies at these phases will include a tighter experimental design and a greater number of participants. The inclusion of a larger number of participants and a tighter design will overcome the issues discussed previously, such as the impact of returning to work during the study. Future studies should also include comparisons with non-treatment conditions and/or other reading approaches. An exploration of whether strategies become internalised would also be useful. Ultimately the cost-benefit ratio of this approach can be determined. This Phase I/II study suggests that there is potential for a strategy-based reading therapy approach to be effective for participants with reading difficulties associated with impaired cognition. Particular strengths of this study were the consideration of the ICF framework in the design of the therapy and in the measurements used to determine its effectiveness, and in the person-centredness of the approach especially reflected in treatment materials and stimuli. These strengths should be maintained in future research on this topic.

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Table 1. Western Aphasia Battery-Revised (Kertesz, 2006) subtest scores

| Subtest | Score |
|--------------------------------------|----------------|
| Spontaneous Speech | 18/20 |
| Information Content | 9/10 |
| Fluency | 9/10 |
| Auditory Verbal Comprehension | 8.65/10 |
| Yes/No questions | 54/60 |
| Auditory word recognition | 59/60 |
| Sequential commands | 60/80 |
| Repetition | 9/10 |
| Naming and word finding | 9.9/10 |
| Object naming | 60/60 |
| Word fluency | 19/20 |
| Sentence completion | 10/10 |
| Responsive speech | 10/10 |

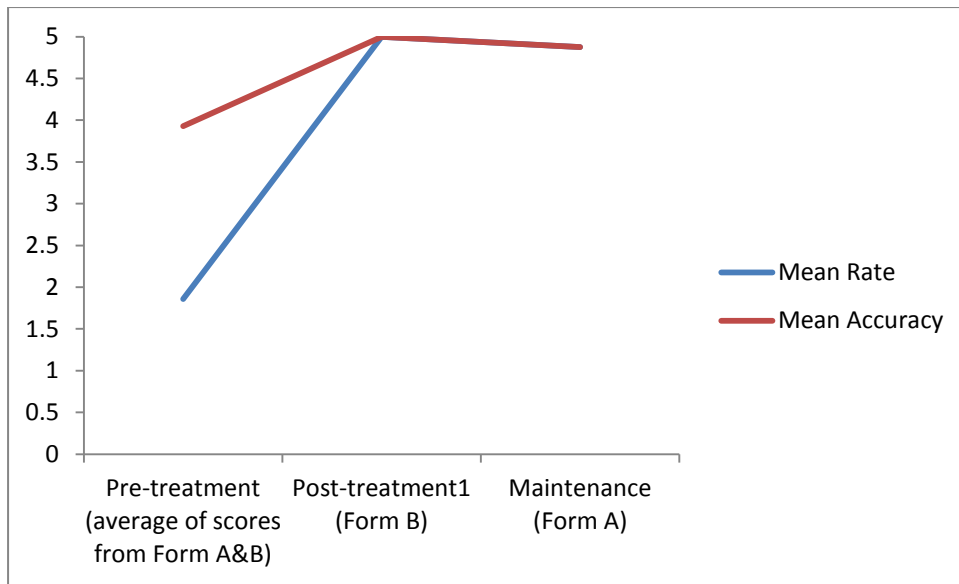


Figure 1: IW's mean rate and accuracy scores on the GORT-4 pre and post treatment

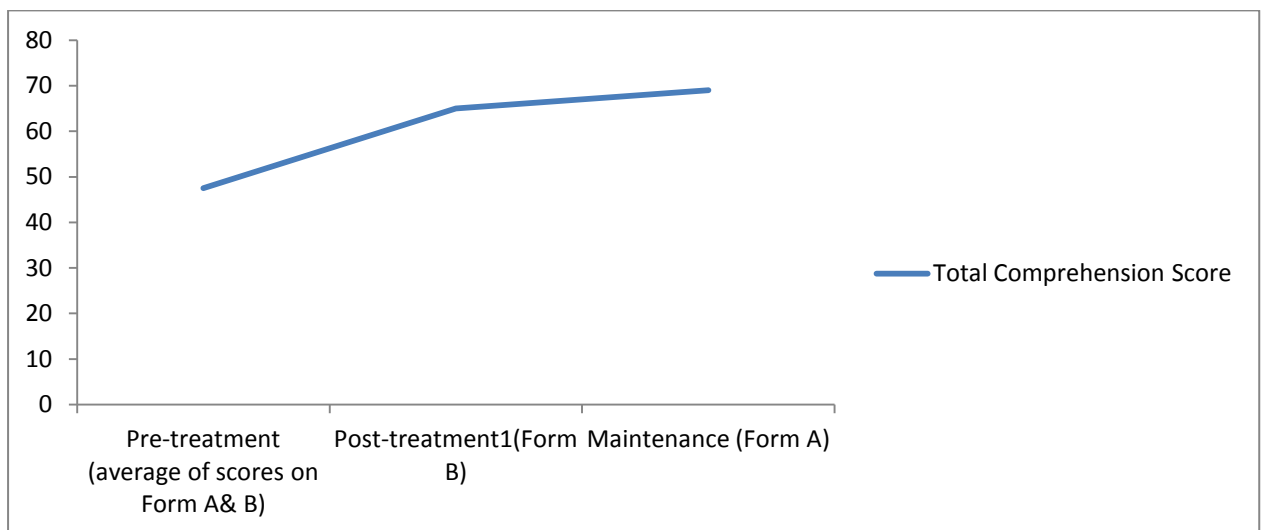


Figure 2: IW's total comprehension scores on the GORT-4 pre and post treatment

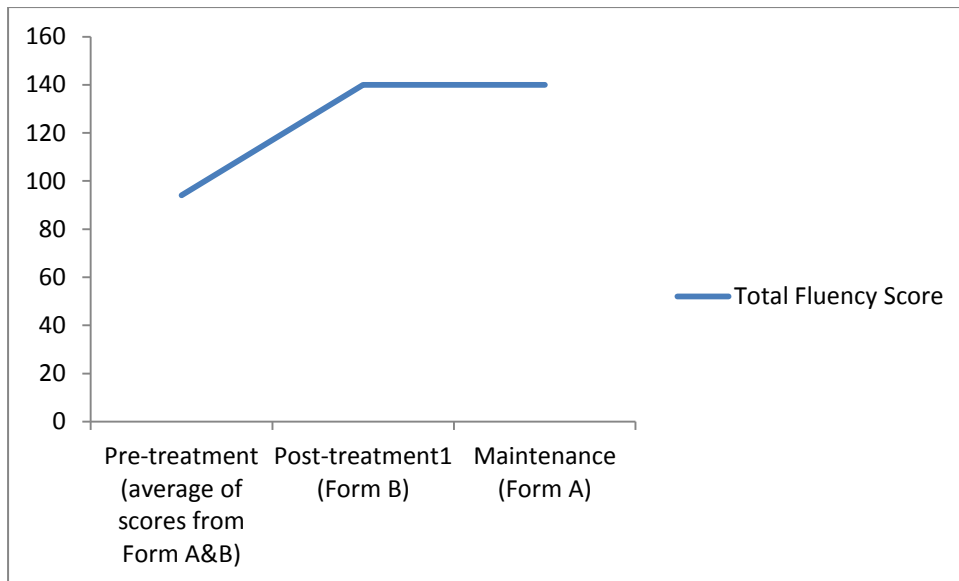


Figure 3: IW's total fluency scores on the GORT-4 pre and post treatment

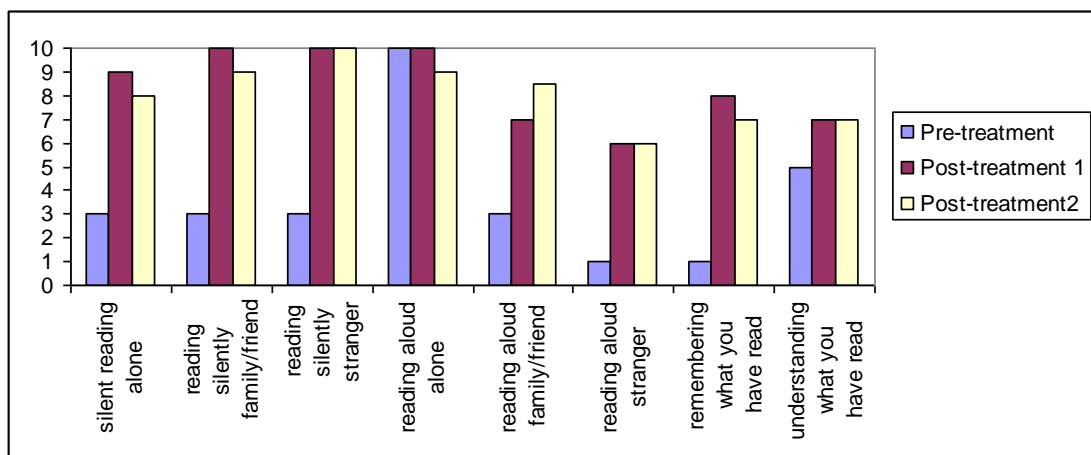


Figure 4: Confidence with reading before and after treatment (ratings are given out of 10 where 10 is completely confident)

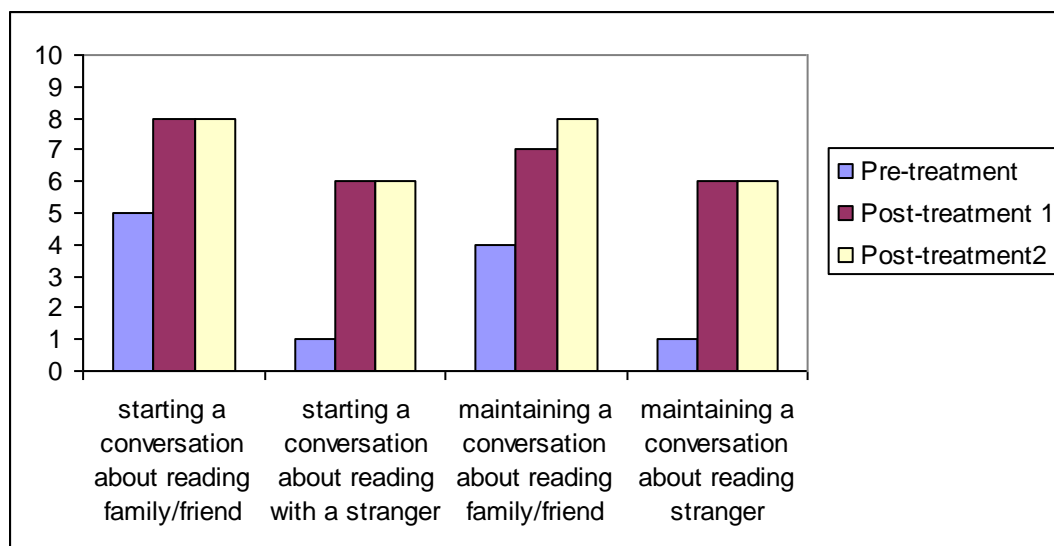


Figure 5: Confidence with talking about what she had read before and after treatment (ratings are given out of 10 where 10 is completely confident)

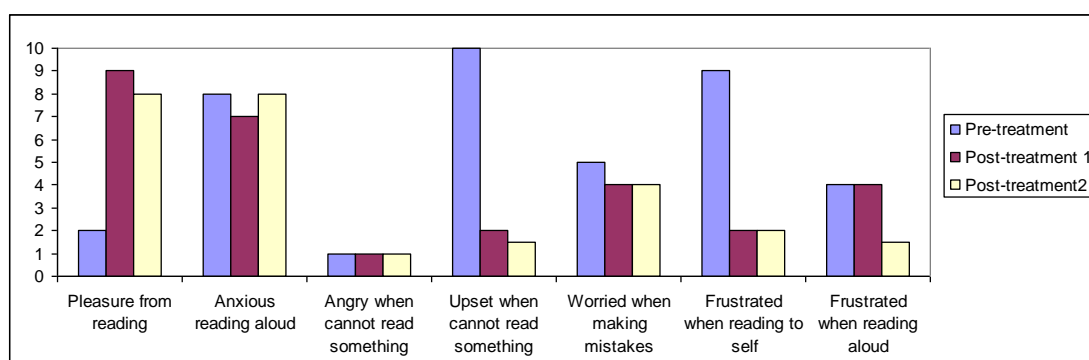


Figure 6: Emotions associated with reading (where 1 is “not/none at all” and 10 is “a lot/extremely”)

Appendix 1

The Reading Confidence and Emotions Questionnaire (RCEQ)¹

Rating Scale

Name:

Date:

This rating scale helps to make a comparative measure of your strengths and areas of need before and after the stroke/head injury.

Confidence

This first section relates to how confident about your reading skills, before and after the stroke/head injury.

Circling 1 means that you are “not confident at all”. 10 means you are “completely confident” at all times.

1 = Not at all confident 5 = somewhat confident 10 = completely confident

A. How would you have rated your overall confidence to read silently before your stroke/head injury?

1 2 3 4 5 6 7 8 9 10

B. How would have rated your overall confidence to read out loud before your stroke/head injury?

1 2 3 4 5 6 7 8 9 10

C. How confident do you feel about reading to yourself (silently) now?

1 2 3 4 5 6 7 8 9 10

¹ This rating scale was the collective effort of the following: Dr Naomi Cocks and Dr Madeline Cruice, and speech and language therapy students Emma Phillips, Lisa Barnett, Niina Matthews, Ruth Middleton, Joan Gregoire-Clarke, Derryn Henning, Chloe Selby, & Sarah Worgan whilst at City University London.

D. How confident do you feel about reading (silently) in front of a family member or friend?

1 2 3 4 5 6 7 8 9 10

E. How confident do you feel about reading (silently) in front of a stranger?

1 2 3 4 5 6 7 8 9 10

F. How confident do you feel about reading out loud, alone, in your own home?

1 2 3 4 5 6 7 8 9 10

G. How confident do you feel about reading out loud, in front of a family member or friend?

1 2 3 4 5 6 7 8 9 10

H. How confident do you feel about reading out loud, in front of a stranger?

1 2 3 4 5 6 7 8 9 10

I. How confident do you feel about starting a conversation with a family member or friend about what you've read?

1 2 3 4 5 6 7 8 9 10

J. How confident do you feel about starting a conversation with a stranger about what you've read?

1 2 3 4 5 6 7 8 9 10

K. How confident do you feel about maintaining a conversation with a family member or friend about what you've read?

1 2 3 4 5 6 7 8 9 10

L. How confident do you feel about maintaining a conversation with a stranger about what you've read?

1 2 3 4 5 6 7 8 9 10

M. How confident do you feel about remembering what you've read?

1 2 3 4 5 6 7 8 9 10

N. How confident do you feel that you understand what you have read?

1 2 3 4 5 6 7 8 9 10

Emotions

This section relates to how much you enjoy reading, and how you feel when you have difficulties reading.

In this case, circling 1 means “not at all” or “none at all”, and circling 10 means “a lot” or “extremely”.

1 = None at all

5 = Somewhat

10 = A lot

A. How much pleasure did you gain from reading before your stroke/head injury?

1 2 3 4 5 6 7 8 9 10

B. How much pleasure do you currently gain from reading?

1 2 3 4 5 6 7 8 9 10

1 = Not at all

5 = Somewhat

10 = Extremely

C. How anxious do you feel when asked to read out loud?

1 2 3 4 5 6 7 8 9 10

D. How angry do you get when you cannot read something that you want to?

1 2 3 4 5 6 7 8 9 10

E. How upset do you get when you cannot read something that you want to?

1 2 3 4 5 6 7 8 9 10

F. How worried are you about making mistakes when reading out loud in front of a family member or friend?

1 2 3 4 5 6 7 8 9 10

G. How frustrating do you find reading (silently) to yourself?

1 2 3 4 5 6 7 8 9 10

H. How frustrating do you find reading out loud?

1 2 3 4 5 6 7 8 9 10