

“The brain can’t cope”

Insights about reading from people with chronic aphasia

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Background: Reading difficulties are a common feature of aphasia. There has been limited in-depth investigation of how individuals perceive their difficulties and the impact of their reading difficulties on everyday activities.

Aims: This study explored the reading experiences of people with aphasia, asking them to describe pre- and post-morbid reading, considering aspects relevant to the different components of the International Classification of Disability and Functioning (ICF) (World Health Organisation (WHO), 2002). It also considered the relationship between use of technology (computers and mobile phones) and reading.

Methods & Procedures: Ten people with chronic, mild to moderate aphasia participated in the study. A semi-structured interview was carried out. Responses were transcribed verbatim and then analysed using the framework method. Themes were identified for pre-morbid reading, current (post-morbid) reading and for questions related to technology.

Outcomes: The results highlight the complexity of factors influencing reading and the individual variation in reading ability, the importance and frequency of reading and reading activities. Post-morbidly, there was a perceived decline in reading ability, with multi-faceted reading difficulties reported. Importantly, changes in reading activity reflected changes in role (for example, employment status) as well as change due to the reading difficulties. It was difficult to determine the influence of reading difficulties on the use of technology.

Conclusions: The implications for the assessment and treatment of reading in aphasia are explored.

Key words: reading, aphasia

Introduction

Reading is an important skill that allows participation in a range of work, social and leisure activities. Reading difficulties are common in people with aphasia but there has been quite limited investigation about how individuals perceive their difficulties and the impact they have on their everyday lives, including the use of technology.

Studies of reading ability in aphasia initially focused on single word reading, with exploration of the different routes involved in reading comprehension and reading aloud (see Whitworth, Webster, & Howard, 2014 for a review). Treatment studies similarly concentrated on single word reading, with minimal consideration of whether treatment influenced functional reading activities. There has now been more investigation of paragraph level reading, which is a closer approximation to everyday reading. Research has examined the nature of the reading difficulties, with characterisation of the influence of different types of information (Brookshire & Nicholas, 1993; Meteyard, Bruce, Edmundson, & Oakhill, 2015; Webster, Morris, Howard, & Garraffa, 2018) and the relationship between reading and other cognitive skills, for example, memory and executive function (Chesneau & Ska, 2015; Meteyard et al., 2015). Treatment studies at paragraph level have considered the impact of training oral reading or teaching various reading strategies on reading speed and reading comprehension (see Watter, Copley, & Finch, 2016 for a review of treatment for reading difficulties following acquired brain injury, including aphasia). There is, however, debate about what constitutes improvement: change in performance on reading assessments, change in reading speed, change in everyday reading activities or change in perception of reading ability (Webster et al., 2013). This highlights the need for a greater understanding of the reading difficulties experienced by people with chronic aphasia and the complex relationship between reading ability, feelings about

reading and impact on reading activity and participation. Consideration of reading in relation to the International Classification of Disability and Functioning (ICF) (Organisation, 2002) framework facilitates that in-depth investigation.

There is extensive variability in normal adults in the importance of reading, reading ability and preferences (Parr, 1992). Parr found that literacy activities (reading and writing) vary with a person's social network and roles, with delegation of some tasks to other people. Literacy activities cannot be predicted or typified (Parr, 1992), emphasising the need to explore pre-morbid reading when considering the impact of aphasia on reading. Over recent years, there has been an increasing reliance on technology to perform traditional reading and writing tasks (Dietz, Ball, & Griffith, 2011) and the Internet is used extensively for communication (Menger, Morris, & Salis, submitted). As the increase in the amount of digital information has influenced what and potentially how we read (Liu, 2005), it is also important to consider the role of reading in a person's use of technology. People with aphasia may struggle with technology-based communication due to their reduced ability to understand and/or create written messages (Dietz et al., 2011; Menger et al., submitted). As with reading, individuals differ in the extent to which they are motivated and/or need to use a variety of technology (e.g. computers, mobile phones) and their ability to access and use technology within communication. It is, therefore, important to consider pre-morbid use when exploring the potential impact of aphasia. These factors underline the importance of understanding reading from the perspective of the person with aphasia, using a holistic and client centred approach.

There are a small number of studies exploring reading from the perspective of people with aphasia. Parr (1995) carried out semi-structured interviews with 20 participants with mild to moderate aphasia. The interviews explored current and pre-

morbid roles, the literacy activities (both reading and writing) associated with those roles and the current use of social networks and strategies to support literacy. The study identified complex and variable factors that influenced literacy needs and practices, including patterns of premorbid literacy and reorganisation of domestic, work, recreational and social roles. Individuals (both pre- and post-aphasia) had the same variation in the range and variety of literacy activities as healthy adults, with delegation of some activities e.g. managing finances both pre- and post-aphasia. Parr (1995) contributed significantly to the field; however, the focus of the study was both reading and writing, with many of the specific examples provided referring to writing. In addition, as discussed above, literacy practices have evolved considerably in the period after this research, given the massive advances in technology.

A more recent study (Kjellén, Laakso, & Henriksson, 2017), considered literacy post-aphasia, with an increased focus on the literacy demands imposed by technology and the potential value of technology in supporting literacy; this study again focused predominantly on writing. Twelve participants with chronic, mild to moderate aphasia were interviewed about their current experience of reading and writing, their feelings about literacy, changes in their literacy skills due to the aphasia and then across their recovery. The study emphasised individual differences in the frequency and type of literacy activities both pre-and post-stroke. Aphasia resulted in impaired reading and writing skills, changes in reading and writing habits and feelings of frustration, dissatisfaction and loss. However, individuals wanted to improve their reading as it was necessary in everyday life and they felt it could still be enjoyable and interesting. They reported that their reading was constantly improving. People mentioned reading strategies including re-reading, reading aloud, choosing easy to read books, listening to audiobooks and using text to speech software.

Other studies have focused on specific aspects of reading, for example, reading material or the strategies used to aid reading. Knollman Porter et al. (2015) used mixed methods to explore the pre- and post-aphasia reading experiences of six people with chronic reading comprehension difficulties. Participants completed a written questionnaire that probed materials read, reading frequency and duration and strategies which aided reading. A semi-structured interview was then carried out with an opportunity to review the information in the questionnaire and with questions about post-aphasia reading experiences. Participants were also asked to bring and discuss examples of pre-and post-aphasia reading materials. Participants reported a decline in reading ability following aphasia with a variety of difficulties e.g. decoding words, reading speed, reading efficiency. As in the Parr studies (Parr, 1992, 1995), there was individual variation in the type of reading material they had read pre-aphasia and were choosing to read post-aphasia. Post-aphasia, participants expressed a continued desire to read but were reading a reduced range of materials and were reading less frequently. Three categories of support and strategies were identified: material characteristics, use of self-directed strategies and external aids, particularly the role of partners in supporting reading. All participants commented on technology but with varied interest and only one person was using technology (text to speech) on a regular basis. The study (Knollman-Porter et al., 2015) highlights some of the changes in reading ability post-aphasia and provides an in-depth analysis of the changes in reading material. Unlike the Parr (1995) study, it does not consider the potential reasons for the changes in terms of changes in role or participation. There is also limited exploration of how people feel about their reading difficulties.

Lynch and colleagues (Lynch, Damico, Abendroth, & Nelson, 2013) explored the use of reading strategies by three people with aphasia. This ethnographic study used

a combination of methods: recording and analysis of oral and silent reading of texts, interviews about pre- and post-aphasia reading practice and observation in a naturalistic setting. Across the three individuals, 28 strategies were identified which served different functions, either aiding efficiency, contextualisation, comprehension or socialisation. Individual participants varied in terms of the combination of and effectiveness of different strategies.

There is a need for an in-depth and comprehensive study of reading in people with aphasia. Other studies have combined consideration of both reading and writing or have focused on specific aspects of reading e.g. reading material, strategies. This study draws together aspects explored in the previous studies in relation to the ICF (World Health Organisation, 2002), with comparison of pre- and post-morbid reading, consideration of reading activity and how this relates to a person's roles and social participation, environmental factors that influence reading and feelings about reading.

Aims

This study explored reading from the perspective of individual people with aphasia, comparing pre-and post-morbid reading and considering reading within the components of the ICF framework (World Health Organisation, 2002). It investigated reading ability and reading difficulties (body function), reading activities (including use of technology) and participation (as related to specific social roles), feelings about reading (personal factors) and potential barriers and facilitators within the environment, including strategies to aid reading.

Methods

Participants

Ten participants with chronic aphasia (at least 9 months post brain injury) were recruited via an aphasia support centre (see table 1). Participants indicated interest following a presentation about the study and informed consent was obtained. During recruitment, it was emphasised that the researcher was interested in interviewing people with varied interest and ability in reading both pre- and post-aphasia and recruitment criteria were broad with the aim of capturing diversity. Participants were recruited with mild-moderate aphasia (as rated by clinical judgement), with adequate hearing and spoken comprehension to understand the questions and adequate verbal expression to be able to respond in some way within the interview, with support provided. However, it is important to note that participants did have significant verbal difficulties; all participants had word retrieval difficulties that sometimes made it difficult for them to get their message across. Some participants were non-fluent and relied on short phrases and sentences.

Participants included eight men and two women, with mean age 72.2 years (range 52-85 years) and mean time post-onset 7.7 years (range 15 months to 18 years). Eight had aphasia following a single, left hemisphere stroke. P1 had aphasia post-surgery to clip an aneurysm. P9 had experienced a traumatic brain injury, with aphasia as the most significant presentation. None of the participants were in employment at the time of the interview; most had retired prior to their stroke. P5 and P9 were working at the time of their stroke/head injury. P10 had just finished his job as a miner and was about to start new employment at the time of the stroke. None of the participants reported a history of pre-morbid dyslexia although P2 said he was not a good reader.

Table 1: Background information about participants

Participant	Age	Gender	Time Post-Onset	Previous Occupation	Severity of Aphasia*	Fluency of Speech*
P1	71	Male	8 years	Retired Printer	Moderate	Non-fluent
P2	81	Male	2 ½ years	Retired Soldier	Mild/ moderate	Fluent
P3	75	Male	10 years	Retired Teacher	Moderate	Non-fluent
P4	85	Male	5 years	Retired Engineer	Mild/ moderate	Fluent
P5	63	Female	11 years	Nursery nurse	Moderate	Non-fluent
P6	77	Male	15 months	Retired Factory worker	Moderate	Fluent
P7	72	Male	3 ½ years	Retired Lorry driver	Mild	Fluent
P8	81	Male	12 years	Retired Plumber	Moderate	Non-fluent
P9	52	Female	6 years	Pharmacist	Mild/ Moderate	Fluent
P10	65	Male	18 years	Miner	Moderate	Non-fluent

* Clinician ratings based on judgements from participation in interview

Interview

A semi-structured interview was carried out with each individual, video-recorded to allow transcription and reference to non-verbal communication (as advocated by Luck & Rose, 2007). The interview lasted for approximately one hour and took place at the support centre. The interview was carried out by a researcher who was experienced in

communicating with people with aphasia. An interview schedule was developed, with broad open questions for each topic. The interviewer then used follow up questions to clarify and expand on the participant's response and probe specific areas not initially covered. Luck and Rose (2007) found the traditional, non-directive approach with purely open-ended questions yielded limited information from a person with aphasia; the follow up questions provided support for participants with more limited verbal output, enabling them to provide relevant information. The interview schedule can be found in Appendix 1. The interviewer used supported conversational techniques (Kagan, 1998) to aid comprehension (e.g. repetition, rephrase and non-verbal support), facilitate production and clarify responses (e.g. suggesting words, probing, paraphrasing); these interviewer strategies were consistent with those described in Luck and Rose (2007).

The interview was designed to consider both pre- and post-morbid reading abilities, activities and preferences and the use of technology. Questions captured the different components within the ICF, asking individuals to describe their reading ability and reading impairment (questions 1, 9 & 10), the impact on activity and participation (questions 3 to 6 and 13 to 17) and the effects of the environment in terms of barriers (what makes reading more difficult) and facilitators (strategies used to aid reading) (questions 11 and 12). For personal factors, there were questions about the importance of reading (questions 2 and 11) and people were asked about how they felt about changes in their post-morbid reading. Questions about participation were structured around themes (reading for pleasure, hobbies and interests, occupation and day to day family life) as these related to roles a person may fulfil (as in Parr, 1995) and activities they may participate in. Broad questions in these areas were followed by specific prompts about the type of reading material, reading frequency and importance of

reading. Final questions in each section focused on the use of computers and mobile phones, probing purpose and frequency of use, with consideration of any change in use post-morbidly.

Analysis

The interviews were transcribed verbatim, with notes regarding any significant non-verbal communication e.g. pointing, gesture. The transcripts were then analysed using the framework method (as described in Gale, Heath, Cameron, Rashid, & Redwood, 2013). The researchers listened to the interviews and read through the written transcript to gain an overall impression of responses. Initial transcripts were coded by one of the researchers (the interviewer) and draft themes were identified for part 1: pre-morbid reading and part 2: current (post-morbid) reading and for the questions related to technology. These themes were then considered by a second member of the research team. There was a high level of agreement about themes, possibly due to the structured nature of the main questions and follow-up. Themes, however, emerged across questions. For each theme, a matrix was produced which summarised relevant comments from each participant and included illustrative quotations. The matrix for each theme was then analysed, with a focus on similarities and differences across participants.

Outcomes

Pre- and post-morbid reading themes included reading ability, reading frequency, importance of reading, feelings associated with reading, reading activities and materials and support from other people. For post-morbid reading, reading ability was subdivided into reading ability, nature of reading difficulties and adapting to reading difficulties. Within technology, participants' pre- and post-morbid use of computers and

mobile phones was considered, with characterisation of changes in use. Themes are illustrated using direct quotes from participants or paraphrased responses where themes emerged across responses and/or needed clarification from the interviewer. Illustrative quotes are provided, with reference to participant number (with ... indicating the presence and approximate duration of pauses (in seconds) within the response).

Pre-Morbid Reading

Reading ability

Participants (except P2) reported that they were competent (good or capable) readers before they had their stroke. In contrast, P2 said his reading was poor, “I wasn’t very good actually reading at the best of times” and made reference to being “poor” academically.

Reading frequency

Reading frequency differed across participants. Six participants (P1, P3, P5, P7, P8, P10) described themselves as frequent readers and would read the newspaper or a book on a regular (usually daily) basis. P5 said that on holiday she would read “all day”.

Three participants were more occasional readers; P6 described himself as an “on and off reader” whilst P4 and P9 reported they had limited time to read (see below). P2 was the only participant who reported he “didn’t do much reading at all”.

Reading importance

Reading was important within two broad areas of participants’ lives, their personal and work lives. Participants reported that reading was an important part of their personal life, linking it to hobbies and interests and to frequency e.g. reading “every day” (P7) and “always read” (P5). P4 said he rarely read at home, “you’re at work all day and... by

the time you get home...you say look I just want to go to bed". Similarly, P9 juggled her job around her four children and said she didn't have time to read as she was busy looking after her family. P2 did not see reading as an important part of his life before his stroke; reading did not play a significant role in his hobbies, interests or employment. He reported "I wouldn't say it was a good thing to have like". He said his wife had always managed all the household finances, meaning he had never read any bills or bank statements. Participants (with exception of P1 and P2) stated reading was an important part of their working life, and even essential to their job e.g. P4 "I couldn't do the job without it". P1 did not mention reading in relation to his job as a printer.

Feelings associated with reading

Pre-morbid reading was generally associated with positive feelings, with participants referring to reading as a pleasurable experience and linking it to enjoyment of hobbies and interests e.g. P3 reported that reading made him feel "wonderful"; he read aloud in church every Sunday and was part of the operatic society with his wife. Some participants linked reading with their intellectual abilities and a sense of pride. P4 spoke of his job as a skilled engineer and said "mathematics was nothing to me". P6 spoke of his ability to come back to a book months later and still remember the contents, "it was still in there (points to head) so I . I could pick up where I left off". P7 linked reading directly with intelligence, saying "I knew all sorts of clever things". When the interviewer clarified if his reading was good, he responded "I was very bright . very bright yes ah huh", making reference to reading and learning new information on a daily basis, "every day... I read something somewhere doing something". As highlighted above, P2 was less positive about reading although he did report reading books.

Reading activities and materials

Discussion of reading materials emerged across the interview, with specific materials linked to reading for pleasure, hobbies and interest and employment. All participants mentioned reading books, with specific reference to specific genres of fiction by some people e.g. westerns (P2, P8), war thrillers (P10), comics (P8) and historic novels (P6). All participants (except P5 and P10) referred to reading a newspaper. P9 also read magazines. Reading materials related to hobbies and interests varied extensively across participants:- betting slips (P1), hymns and the bible (P3), knitting patterns, recipes and poems (P5), DIY manuals (P6), quizzes (P7), maps (P8) and football scores (P10). There was similar variation in the reading required to support their work: factual documents (e.g. reports, text books) (P3, P4, P5, P8 and P10), road signs and maps for navigation (P7), technical measurements for machinery (P6) and computer based medical notes (P9).

Support from other people

Three people referred to relatives supporting them with reading pre-morbidly. P10 said his wife would help him if he struggled to understand bank statements. Similarly, P1 said “my daughter used to help us”. P2 relied heavily on his wife to read things for him.

Current (Post-Morbid) Reading

Reading ability and reading difficulties

There was a significant reduction in participants’ perception of their reading ability post-aphasia, with only two people (P5 and P7) now describing themselves as capable readers. P5 said her reading had been affected “a little bit” but not enough to stop her from being able to read anything. P7 said of his reading “not too bad take my time”, although it later emerged he was experiencing considerable difficulties in some areas.

The remaining participants spoke of their poor reading ability e.g. “I cannot” (P1), “I don’t fully understand what I’m seeing” (P4). The reading difficulties described by participants were many and varied. In response to the specific questions about linguistic difficulties, direct responses highlighted problems with single words (everyone except P5 and P8), difficulties at sentence level (P8 & P9) and problems reading aloud (P2, P4 and P6). P9 recalled a time when she thought a leaflet stated “once a month” but it actually said “once a week”. P6 said there were some words that he knew the meaning of, but he “just cannot pronounce them”. P4 explained “generally I know the sentence what it’s about” but suggested he could not read it aloud or explain to someone what he had read; he described this as “like a block or something in you”. Specific difficulties were reported reading function words “even little words like it is a nice day today . it . when I try to r-read it . it what’s it what’s it” (P4). P6 said “although I can see the words I keep going over the same lines”.

Comments about reading difficulties emerged from descriptions of post-aphasia reading and in response to the question about current barriers to reading. There were some global descriptions of the apparent cause of the reading difficulties. P5 reported “well the brain can’t cope”, P4 said “just the problems really in me head” and P8 described it figuratively “there’s somebody there that doesn’t want me to read”. Some participants alluded to focus or concentration e.g. “I have to sort of focus a lot more” (P6) , “I can’t concentrate” (P3). Participants also made reference to memory, e.g. P10 said he occasionally encountered words he can’t remember the meaning of, despite knowing he knows the word. P4 reported he sometimes had to read back over sentences “to try and figure out” what he had read. For other participants, their difficulty seemed to be in remembering what they had read, “that’s the most annoying thing, memory” (P10). P6 used to pride himself on having an excellent memory for

what he'd read, but now he said "they're not going in", reporting he couldn't remember what he had read even minutes afterwards. P7 also used to pride himself in being able to remember all sorts of facts he'd read about, but now he reported "I don't remember everything quite that much". It is not clear what is being referred to here: specific difficulties with memory and concentration, the impact of the linguistic difficulties or a combination or interaction of these skills.

Comments were not restricted to linguistic or wider cognitive issues; P6 made reference to mobility issues impacting his reading, "I'm not happy with reading a book 'cos er what happens is I'm reading and this hand comes... (indicated hand slipping)". Participants also referred to visual difficulties, with a combination of age-related visual decline/use of glasses (P10, "well me eyes, gettin' worse like") and post-morbid visual difficulties e.g. P9 "double vision" since her head injury. P8 reported that when he got to the end of a page, things were "bobbin over place" and said that this stopped him from continuing.

Participants reported that their reading was slow and effortful and this stopped them accessing materials they used to enjoy. When the interviewer asked P7 how he felt about reading a novel, he responded "I won't live that long". P4 had read two books in the five years since his stroke "and I've just finished the other one this year it took me a long time to read". He reported that he had to keep re-reading information to ensure he had understood it. P3 reported "I wouldn't have time" to read a newspaper saying it would take half an hour to read a small article.

In response to the question about what makes reading easier, participants talked about adapting to and compensating for their reading difficulties. Strategies included following the text along with their finger to compensate for visual difficulties (P3), having greater spacing between the text (P6) or buying books with larger print (P10). P3

explained how he found it easier to read short passages of simple information with visual support. Other techniques involved adapting the environment to make reading easier e.g. P10 found it difficult to concentrate on his reading if there was a lot of background noise, and so he made sure he went somewhere private “I go upstairs in me bedroom like”. P9 had found alternative ways to achieve the same goal, so whereas she used to read the newspaper to catch up on current affairs, she now watched the news on the television. P7 said “you have to set yourself up that’s right yes” so he wore his glasses and made sure he had plenty of time.

Reading frequency

P10 read as frequently as pre-morbidly, saying that he still enjoyed reading his war thrillers, reading for an hour despite it being “hard work”. P2 said he read more frequently than before his stroke, reading his novel each night before bed. Others read less than they used to, either in terms of frequency or quantity e.g. P5 reported he still read a lot, but for less time, “I put it down and then I pick it up”. P6 had given up reading novels because as reading was more effortful and frustrating, it was no longer a way of “winding down”. P3 no longer read a paper every day; he said he got one 3 times a week, and instead of reading the full text, he just read the headlines.

Reading importance

There was a noticeable shift in the level of importance participants placed on their reading post aphasia, with many reporting that it was no longer important in their lives. P6 reported that “talking is taking over the priority” as his reading wasn’t making “any advances”. P1 who struggled to read, said that reading “used to be (important)” but now “it’s a waste of time”. P4 reported “I want to be able to read again but I say to myself it’s left me behind sort of thing”. The other participants still reported that reading was

important despite the barriers they faced. When asked if reading still played an important part of his life, P7 said “oh yes yes please . yes oh yes I know I don’t do very much work about it because I can’t do very much I know it’s it should be just right”. P8 said reading was important as he needed to understand his bills.

Feelings associated with reading

Participants reported mixed feelings regarding their post-morbid reading. Participants said they still got pleasure from reading, particularly when reading something they were interested in e.g. “reading the instructions how to fix an electric kettle, ooh” (P6). In contrast, participants described their reading as “difficult” “frustrating” “horrible” “rubbish” and “hard work”. P3 said “I have to force myself to read”. P9 said “to me it’s annoying (reading) but I always said well there’s a lot worse than myself”. Despite this, participants were generally trying to read e.g. “bit by bit have a look” (P7). P4, having completed two books said “I persevere and I got it ... and I finished”.

Reading activities and materials

None of the participants were in employment at the time of the interview and reading activities had, therefore, changed due to changes in role and demands. As a result of their aphasia, participants had also given up reading the materials they used to enjoy in their leisure time. P8 didn’t read westerns anymore, a source of sadness as he used to enjoy them on a daily basis, “I miss them now”. P1 said he was unable to read anything at all. P9 also said she did not read much anymore.

Support from other people

More participants were now seeking support from other people when they were finding it difficult to read e.g. P9 said she would ask her partner or her son to help with her reading if she was struggling and reported that her sisters were very supportive “me two

sisters are brilliant”. P10 said his wife helped when he got lost or forgot a word “she tells where I was like”. P8 struggled with his bills after the stroke so he took them to the bank and they helped him. P4 and P1 both described a period of speech and language therapy intervention targeting their reading. P4 found this was a very positive experience, “...she’s a lovely girl and she made me made me... do, cheque, the cheque cause I couldn’t do cheque”. P1, on the other hand, said it was a “waste of time”.

Use of Technology

Computer

Pre-morbidly, four participants used a computer, with three people using them frequently at work. Four participants did not use a computer either pre- or post-morbidly. P1 said “I couldn’t be bothered”. Then when he tried he “couldn’t do it” concluding “it’s a waste of time”. P10 said he was “not interested”, P8 said “I just never need it” and P2 said “everything in my day was telephone”. Of the four who were computer users pre-morbidly, P3 used to be a teacher and would often present his classes via the computer and taught students how to use them. P6 told the interviewer how good his IT skills were “I used to do all my own invoices er tax and that yeah and always they had to be right”. P9 said she used a computer “8 til 4” every day during her job at the pharmacy. She said “I was er supervisor erm and so I had four people computer .. ringing so all connect so I could do computer and ring and things like that so easy”. These three participants (P3, P6 and P9) also used a computer at home. P3 would browse the internet and used the computer to write a book about his family history. P6 liked to upload his photographs onto the computer and P9 was the organiser out of her group of friends, booking their trips away on the internet (“me and me 2 sisters and 3 friends... we went on holidays like for weekends and I do it all on the

internet”). P4 had used a computer before his stroke but said “I wasn’t very pleased with it”. He only used it to keep in touch with his grandchildren and “apart from that...I couldn’t be bothered”.

Post-morbidly, P3 and P4 had stopped using a computer. P3’s reason for stopping was “can’t think”. P4 said he found it difficult to type or read on a computer screen, so instead of sending emails, he wrote letters by hand, even though this took him a long time, “all day it would take all day for one little thing”. People had suggested he use a computer but he said “I cannot . I look at the thing and what have I got to put”. P5 had learnt how to use a computer since her stroke. She used the computer to engage in hobbies such as designing greetings cards, using the internet to “get the verses off it”. Before the stroke, P5 reported that she was “not interested” in using a computer, but she said “I thought a long time ago what can I do”. She was also using social networking sites such as Facebook. P6 still used his computer but not to the same extent as before. He reported “I switch it on read the news and check the emails . that’s it”. P9 had an iPad which she used to browse the internet but had stopped using it because she had made mistakes when buying things online.

Mobile Phones

Three participants mentioned texting regularly before their stroke, particularly P6 who said “I had I had a girlfriend at the time” and texted daily. P8 and P9 used their mobiles to keep in touch with their children. P9 would text and ring but P8 did not like texting, preferring to speak to people. Two participants (P1 and P2) had never had or used a mobile phone, “no I haven’t nah” (P1).

Post-aphasia, participants generally reported using their mobile phones less than they did previously. P3, however, used his regularly to keep in touch with his family, sending and receiving an average of two text messages per day. P7 reported he only had

a mobile phone so that his family can contact him. “phwah ah I’ve got one of those don’- I don’t know what the bloomin thing...” and that he “very rarely use that”. Since his stroke, P6 had stopped sending daily messages, and instead only used his mobile phone to send short messages to his family. P10 very rarely sent text messages anymore and was more likely to ring people.

Discussion

The interviews provide valuable data about the ‘insider’ perspective (Parr, 2001) on reading in people with aphasia. Questions were framed around the components of the ICF (World Health Organisation, 2002), allowing a holistic consideration of personal perception of reading. There was exploration of reading function (ability and difficulties), reading activity, the role of reading within participation in social/vocational activities, personal factors including feelings about reading and environmental factors including self-directed strategies and the role of other people. As in previous studies (Kjellén et al., 2017; Knollman-Porter et al., 2015; Parr, 1995), extensive individual variability was seen in reading ability, preferences and practice.

Perception of Reading Function

Participants (except P2) reported that they were proficient readers pre-morbidly. Participants reported a decline in their reading ability due to the aphasia, with difficulties reported in understanding words and sentences, problems with reading aloud, reduced reading speed and having to re-read. Reading difficulties were, however, multi-faceted reflecting the linguistic difficulties associated with aphasia but also additional factors including vision and mobility. People also referred to memory and concentration, although there was ambiguity about the difficulties people described and whether they reflected the aphasia, other cognitive issues or a combination of factors.

The complex nature of the reading difficulties emphasises the need for in-depth, objective assessment of both reading and other related cognitive abilities.

Reading Activity and Participation

As in previous studies (Knollman-Porter et al., 2015; Parr, 1992, 1995), a variety of factors influenced reading practice and preferences. Reading frequency varied across participants, with one participant (P2) reading more post-stroke. For individuals, reading activities were linked to and important for different aspects of their social (hobbies and interests) and work lives. Post-morbidly, reading activities changed; these changes were sometimes a consequence of the reading difficulties and sometimes appeared to reflect changes due to shifts in role (as in Parr, 1995). In some cases, changes in role had preceded the aphasia, for example people had retired. It is important to recognise the influence of role changes on reading activity, whatever the underlying reason for the change. Like other studies (Knollman-Porter et al., 2015; Parr, 1992, 1995), participants were accessing a wide range of reading materials, with minimal overlap between individuals.

Personal Factors

Within the interviews, participants were able to convey how they felt about their reading. Pre-morbidly, people associated reading with pleasure and often linked it to intellectual ability. Post-aphasia, most people were still motivated to read and were finding pleasure in reading but also reported some negative feelings, for example, frustration, finding it difficult. These mixed feelings are consistent with the findings of other studies (Kjellén et al., 2017; Knollman-Porter et al., 2015). The reported feelings seem to reflect the chronic nature of the participants' aphasia, the time they had had to adjust to their difficulties and attempts to resume some reading activities. There was a contrast between P1 who repeated "it's a waste of time" and other individuals who

expressed hard work, perseverance and commented on what they had achieved. This determination may emerge from the need for hope and positivity, particular character traits or strengths (Brown, Worrall, Davidson, & Howe, 2012) or perceived improvement (Kjellén et al., 2017).

Strategies

Individuals described a number of strategies they were using to aid their reading. Strategies varied across individuals (as in Lynch et al., 2013) but the range and variety of strategies mentioned were significantly less than were observed in the Lynch study. In contrast to Knollman-Porter et al., (2015), participants did not generally describe the different characteristics of the materials they were reading post-stroke. These findings may suggest that people are not always aware of or able to articulate strategies they are using to aid their reading. Participants, however, did report relying on external support from family, friends and the wider community. There is some debate as to whether independence in reading should be the focus of intervention. Some participants in this study delegated activity before having aphasia and this delegation of literacy activities is a normal part of life (Parr, 1992). Parr argues that autonomy not independence should, therefore, be the primary goal (Parr, 1996). This study and others have shown that individuals seek more support from others post-morbidly. Participants in the current study did not express how they felt about doing this. However, other people with aphasia have expressed a desire for greater independence in reading (Knollman-Porter et al., 2015). It is also reported that individuals want to gain a sense of independence and that people with aphasia describe independence in terms of being able to do everyday activities by themselves (Brown et al., 2012). The level of independence the person desires and their views regarding support may differ, emphasising the importance of individual discussion.

Technology

For these participants, use of computers and mobile phones varied both pre- and post-morbidly. Half of the participants were regular computer users pre-morbidly and there was some decrease in current use, reflecting changes in role and post-morbid difficulties. Mobile phone use also decreased post-morbidly. None of the participants in the current study reported using technology to support their reading. The restricted use of technology by some participants may reflect the influence of age, with older adults and retired people using technology less (Czaja & Lee, 2007; Dutton & Blank, 2011; Dutton, Blank, & Grosej, 2013; Menger et al., submitted). For example, 25% of UK sample of retired adults did not use the Internet (Dutton et al., 2013); use may decrease following aphasia, with an increase in the percentage of non-users (Menger et al., submitted). It is likely that a complex range of factors contribute to this reduced post-morbid use of technology, with reading difficulties being one potential factor. Greig, Harper, Hirst, Howe, and Davidson (2008) provide a comprehensive discussion of barriers to mobile phone use. Menger, Morris, and Salis (2016) discuss factors influencing Internet use. As with reading, the delegation of activities related to technology and the use of the Internet is common in older adults so independent use may not be the desired aim of intervention (Menger et al., submitted).

Clinical Implications

When considering the assessment and treatment of reading, this study has reinforced that people have unique motivations for reading, read a unique range and type of materials and develop and use a unique set of strategies to aid reading. This reinforces the point made by Parr (1996) who suggests “assessment must be designed to be sensitive to, and delineate, the pre-morbid and current needs, practices and interpretations of the aphasic individual” (p472). Clinicians need to find a way of

obtaining information about current needs and preferences about reading alongside detailed assessment of linguistic and wider cognitive skills. All of this information will then ultimately feed into collaborative and functional goal setting (see discussion in Parr, 1996). Whilst exploring pre-morbid reading may provide an overall context, it is current needs and feelings which are likely to influence intervention. Intervention should focus on activities which are meaningful and enjoyable (Brown et al., 2012); ‘mechanical’ reading exercises may not be motivational enough (Kjellén et al., 2017). People may be “more interested in the meaningfulness of their reading experience than in the frequency or amount of time spent reading” (Knollman-Porter et al., 2015, p1463).

This study highlights that use of technology differs and, like with reading, we need to consider pre-morbid preferences and ability. Computer use declined post morbidly, but given the complexities of using technology, what role reading difficulties per se play is difficult to disentangle (see Menger et al., 2016 for comprehensive discussion). What we do know is that with an increasing reliance on technology, it is likely that people with aphasia will find it difficult to access online information and to use technology-based communication (Dietz et al., 2011; Menger et al., submitted) and this needs to be explored within assessment and in planning intervention.

Future Directions

The study used broad criteria in recruitment and as a result, a wide variety of participants were included; people differed in age, reading ability, reading preferences and use of technology. Participants were involved just in the interview; no assessment of their reading was carried out. In future studies, it would be interesting to investigate the relationship between client perception and performance on assessments of reading ability. When exploring technology, it may be beneficial to consider younger

participants where use is likely to be more prevalent and to include specific questions about the impact of reading difficulties on the ability to access information and read communication from others (e.g. emails, posts on social networking sites etc.).

The interview format, with a sole focus on reading, allowed in-depth exploration of each individual's experience. There were similar challenges in carrying out interviews with people with language difficulties as reported in other studies (Luck & Rose, 2007). Within the interview, there was a balance between using initial open questions which allowed people to explore issues from a very personal perspective and follow up questions which by necessity shaped responses. The recruitment criteria excluded people with more severe language difficulties but some participants were still only able to respond with short phrases and word finding difficulties; this influenced their ability to formulate and communicate complex ideas (Luck & Rose, 2007).

The participants in the study all had chronic aphasia, meaning that they had had time to adapt to their language difficulties and resume some normal activities. It would be interesting to contrast these findings with views from participants earlier post-onset. Within the current study, people did not discuss in detail the strategies they were using or the characteristics of the materials they were choosing to read. This emphasises that it might be useful to explicitly discuss examples of post-stroke reading materials (Knollman-Porter et al., 2015) and potential strategies.

Conclusion

This study considers reading from the perspective of people with aphasia, considering the different components of the ICF (World Health Organisation, 2002). It highlights that reading ability, activity and preferences differ pre-morbidly and these differences may influence post-morbid reading. Reading difficulties in people with aphasia are

variable, complex and multi-faceted. It is, therefore, important to explore reading from the perspective of the person with aphasia alongside any assessment of the nature of the reading difficulties.

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Appendix 1

Initial context: **‘I’m going to try and build up a picture about your reading. The first set of questions are about before you had your stroke/head injury’.**

- 1) How good was your reading in general?
- 2) How important was reading in your life, and why?
- 3) In your spare time, did you ever read for pleasure? Please expand.
- 4) What were your hobbies and interests? Did any of these involve any sort of reading?
- 5) What was your job? Did you read things as part of your job?
- 6) Who did you live with? Was reading a part of family life?

Additional questions following 3-6 probed materials read, frequency and importance of reading. Following question 6, there was also discussion of reading related to managing finances.

- 7) Did you use a computer?
- 8) Did you send and receive text messages?

Additional questions following 7 and 8 probed frequency and purpose of use.

‘Now I will ask you about your reading now – so after your stroke/head injury’.

- 9) How good is your reading now in general? Do you have difficulty reading single words, sentences and paragraphs? Do you have difficulty reading aloud?
- 10) What changes (*in reading*) have you noticed since your stroke?

Additional questions probed about reading that was difficult and feelings about reading and reading aloud.

- 11) How important is reading in your life now, and why? Has this changed since before your stroke?

12) Are there any barriers to your reading now? Things that make it more challenging or difficult?

13) Is there anything that makes reading easier for you? Do you use any strategies to help?

14) Do you still read for pleasure? If not, why not?

15) Do you have the same hobbies and interests? If not, why not?

Additional questions probed new hobbies, materials read and frequency of reading.

16) Are you still working? If not, why not?

Additional questions, if not working, probed reasons and feelings about change.

17) Would you say your role in the family has changed since your stroke?

Additional questions probed about reasons and feelings about change, materials read, frequency of reading and discussion of reading related to managing finances.

18) Do you use a computer? Has this changed since before your stroke?

19) Do you send and receive text messages? Has this changed since before your stroke?

Additional questions following 18 and 19 probed frequency and purpose of use.