Research Report

Aphasia and literacy—the insider’s perspective

Emma Kjellén, Katja Laakso and Ingrid Henriksson
Institute of Neuroscience and Physiology, Unit of Speech and Language Pathology, The Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

Abstract

Background: Few studies have investigated how people with aphasia (PWA) experience literacy skills. Taking the insider's perspective is a way to increase understanding of the individual experiences of literacy among PWA, which may have clinical implications.

Aims: To describe how literacy, i.e., reading and writing, is experienced in everyday life by PWA and to gain insight into the part played by literacy skills in their lives.

Methods & Procedures: A qualitative descriptive research approach was taken. In-depth interviews were conducted with 12 PWA (six women and six men) who had all lived with aphasia for at least 6 months post-stroke. The interviews were analysed using qualitative content analysis.

Outcomes & Results: One overarching theme emerged from the data: literacy as an ongoing recovery process. Based on this overarching theme, two subthemes were identified: changes in conditions for literacy (experiences of reading and writing initially post-onset compared with experiences at the time of the interview); and facing expectations about literacy (participants' own and other people's expectations of them in terms of literacy).

Conclusions & Implications: The findings are important at a general level in that they indicate that PWA are able to articulate their individual experiences and thoughts about literacy, i.e., reading and writing. Specifically, PWA in this study experience literacy as playing an essential part in their lives and the findings imply that personal experiences are important in the design of reading and writing interventions in speech and language therapy.

Keywords: aphasia, literacy, insider’s perspective, qualitative content analysis, interviews.

What this paper adds

What is already known on the subject:
Previous research has shown that people with aphasia (PWA) are able to express their experiences of everyday life post-onset, but few studies have concentrated on PWA's experiences of literacy, i.e. reading and writing. Previous research findings indicate that PWA may experience loss and frustration at not being able to read and write like they did pre-onset.

What this study adds:
The current qualitative study provides rich descriptions of how PWA experience literacy in everyday life and its strong link to their individual recovery. When asked to describe individual experiences of literacy, the participants were focused on the progress made and the ongoing recovery process. However, practising reading and writing was not only described as a way to achieve improvement, but also as an important way to obtain information and to
communicate, and was experienced as something the participants did out of interest and for pleasure. The findings indicate that taking the insider’s perspective means that clinicians need to carefully design or adjust their assessments of literacy and intervention plans to the PWA’s individual experiences of literacy. Furthermore, a conclusion drawn from the findings is that literacy intervention should be involved in daily life in a meaningful context for the PWA.

Introduction

In today’s high-tech information society, the importance of written language is increasing, even though written language is not seen as the primary method of human communication (Mortensen 2004). The European Union’s High Level Group of Experts on Literacy has stated that literacy is necessary, and more important than ever before, because written language plays an essential role in societies like those of modern Europe:

> Literacy empowers the individual to develop capacities of reflection, critique and empathy, leading to a sense of self-efficacy, identity and full participation in society. Literacy skills are crucial to parenting, finding and keeping a job, participating as a citizen, being an active consumer, managing one’s health and taking advantage of digital developments, both socially and at work. (EU High Level Group of Experts on Literacy 2012: 21)

In this article, in which people with aphasia (PWA) describe their experiences of reading and writing, we will use the term ‘literacy’ (i.e., reading and writing) in line with the view of literacy as a social practice rather than merely technical skills used for reading and writing (e.g., Street 1984, UNESCO 2016).

Impaired literacy is usually one of the integral symptoms of PWA (Beeson and Henry 2008). Processing written language is a complex activity that consists of several simultaneous sub-processes and demands great cognitive resources (e.g., Kellogg 1987, Ellis 1993, Torrance and Galbraith 2006). The severity and nature of language impairments vary, as do their consequences for everyday life (e.g., Parr 2007, Hilari 2011). Theoretical models for reading and writing emerging from cognitive neuropsychology are well established and used for diagnostic purposes as well as for planning of therapy (e.g., Beeson and Henry 2008). Parr (1992, 1995) suggested a sociolinguistic perspective on literacy and concluded that reading and writing should be taken into account in any evaluation of PWA’s functional communication needs. There are also reasons to believe that using written language for communication may be advantageous over spoken language to PWA. Using written language for communication through assistive technology such as text-to-speech software (Harvey et al. 2013), voice-recognition software (Estes and Bloom 2011) and smartphones (Brandenburg et al. 2013) can open up new opportunities for PWA to enhance their reading and writing skills and interact with others. Knollman-Porter et al. (2015) found that one participant in their study was using text-to-speech software as support in order to maintain independence when performing reading tasks and that several participants showed great interest in exploring text-to-speech software. It has also been found that written stories produced by PWA were in fact rated, in some respects, as richer and more comprehensive than their spoken versions of the stories (Behrns et al. 2009).

Qualitative research into aphasia has focused mainly on gaining insight into the experience of having aphasia (Simmons-Mackie and Lynch 2013). The majority of the studies included in Simmons-Mackie and Lynch’s (2013) literature review investigated experiences from an insider’s perspective, i.e., experiences as reported by PWA, and there are a few existing studies applying this perspective when studying reading and writing. Parr’s (1995) ethnographic research showed the importance of including different environmental and personal factors such as social class, education and marital status in the analyses of literacy, since pre-morbid and current roles have an impact on an individual’s reading and writing experiences. The findings revealed further that involvement in social roles was individual, dynamic and affected by aphasia, but also by other factors related to the stroke (changes in family circumstances, material factors and emotional factors), and that all these factors need to be taken into consideration when planning for intervention strategies targeting reading and writing (Parr 1995). Strategies were also analysed by Lynch et al. (2013) using a transactional socio-psycholinguistic model of literacy (Goodman 1994) studying authentic reading of three PWA in their natural settings. Findings showed 28 reading strategies across the participants with four different functions, where several were not specific to PWA but applied to the general reader as well. Again the focus on the individual is emphasized together with the importance of studying reading in a meaningful context. Individual variation in strategies for overcoming impaired reading ability, although commonly shared themes existed, was also found in a phenomenological study by Knollman-Porter et al. (2015) together with the finding that reading ability post-onset had a negative impact on several activities in daily life for the PWA. Interviews in Behrns (2009) showed that losing the ability to read and write may represent a radical change in a person’s life. The participants said that pre-onset they had done a great deal of reading
and writing at work, and that reading and writing had been a pleasure for them. Post-onset, however, they wrote mainly for rehabilitative purposes (Behrns 2009).

Not only may PWA experience substantial difficulties with the technical skills needed for reading and writing, but literacy may be affected in other ways as well, such as PWA's emotional experiences due to the changes in reading and writing skills. To increase our understanding of how PWA experience literacy, interviewing is an appropriate and powerful method since PWA are the true experts when it comes to their personal experiences. A qualitative research method allows us to capture the insider's perspective.

The aim of the present study was to enhance further our understanding of the insider's perspective on experiences of literacy, i.e., reading and writing, by PWA and to gain insight into the part played by literacy in their everyday lives, given that reading and writing are essential activities in today's information society.

Methods

Study design

The present study is a qualitative descriptive study (Sandelowski 2000) using a qualitative content analysis method (Graneheim and Lundman 2004). The interview is a powerful qualitative method for capturing experiences from people's everyday lives (Kvale and Brinkmann 2009) and allows the interviewer to explore a person's subjective experience (Wengraf 2001). Semi-structured interviews were selected for this study to obtain the qualitative data required and provided the participants with the opportunity to share as many illustrations and explanations as they wished. Ethical approval was obtained from the Regional Ethical Review Board of Gothenburg, Sweden. All names of participants have been changed to protect confidentiality.

Participants

Twelve participants with post-stroke aphasia, six women and six men aged between 39 and 76 years (mean = 62 years, SD = 10.1 years), who had lived with aphasia for between 1.5 and 25 years (mean = 7.2 years, SD = 7.8 years), participated in the study. As is appropriate for qualitative studies (Patton 2002), an effort was made to ensure that the sample included variation in terms of age, gender, time post-onset, amount of speech and language therapy received, and previous occupation. The participants were recruited from a number of centres for speech and language therapy and two local aphasia associations. To ensure the participants would be able to take part in an audio-recorded interview in Swedish, the researchers chose participants with a diagnosis of mild-to-moderate aphasia with the exception of one participant (Laila), who had been diagnosed with severe aphasia but was nevertheless able to take part in the interview and contributed to the descriptions, and was therefore included in the study. Two of the participants (Ingeborg and Laila) were not native speakers of Swedish but spoke it fluently and were able to participate in an interview in Swedish. All the participants were at least 6 months post-onset of aphasia to ensure that they were not in the initial phase as well as to enhance the possibility that they had a range of experiences of reading and writing post-onset. Three participants (Eva, Kjell and Gunn) had continued working post-onset though not in their previous occupations (table 1). However, Eva and Gunn were retired at the time of the interviews.

The participants' detailed scores on any language assessments (including reading and writing assessments) were neither of specific interest nor an inclusion criterion since the aim of the study was to explore the subjective experiences of the participants regardless of their actual ability to read and/or write post-onset. However, the fact that the participants had been diagnosed with aphasia was of interest and information about diagnosis was obtained from a prior assessment made by one of the researchers (participants 1–3) and the participants' speech and language therapists (SLTs) (participants 4–12). Details of the participants are summarized in table 1.

Data collection

Each participant took part in an individual semi-structured interview. The place for the interview was chosen at the participant's convenience. Each interview was recorded on a digital voice recorder (H2 Handy Recorder) and lasted for 20–50 min. The participants were interviewed by two SLTs (interviewers A and B) (table 1), with no significant others present.

The interview protocol consisted of questions that were open in such a way that the participants' responses might lead to follow-up questions that had not been prepared in advance (Wengraf 2001). The questions in the interview protocol were constructed with the aim of capturing the participants' experiences of reading and writing in everyday life post-onset. For information about questions used, see appendix A (the exact wording used in each interview depended on how the interview progressed). It turned out that the three initial interviews did not capture the participants' emotional experiences to the extent desired and some adjustments were made, e.g., follow-up questions such as 'How does it feel?' were used to a higher degree to encourage the participants to tell their stories (see appendix A). Additionally, at the beginning of the interviews with participants 4–12...
the words ‘Reading’, ‘Writing’ and ‘Aphasia’ were written down on a piece of paper as visual support and as a reminder about the theme of the interview. These interviews then started with the open question ‘What do reading and writing mean to you?’. Previous research has shown that interviews with PWA can yield valuable data, provided that both the interviewer and the method used are aligned with the PWA’s way of communicating (Luck and Rose 2007). Owing to the varying level of communication difficulties among the participants, the interviewers were aware of the possibility of misunderstandings, and frequently repeated questions, asked clarifying questions and summed up the participants’ responses. All participants were encouraged to take all the time they needed to formulate their answers so as to avoid any time pressure during the interview. In order not to interfere with the interview situation and since the participants mainly communicated verbally, a voice recording was used instead of a video recording. The interviewers attempted to be aware of any non-verbal communication (such as pointing, gestures etc.) and verbally interpreted this non-verbal communication during the interview for the purpose of capturing it on the recording as well as confirming their comprehension of the participants’ non-verbal responses.

All interviews were transcribed verbatim by the author who conducted them, and field notes were made. The quotations from interviews included in this article are English translations of the original Swedish statements. An attempt has been made to reflect the structure of the original, including deviations from language norms, but only to the extent that this would not impair comprehension.

**Data analysis**

The interview transcripts and field notes were analysed using qualitative content analysis (Graneheim and Lundman 2004). Qualitative content analysis was chosen as a method of analysis, since it gives a broad as well as an in-depth understanding of the phenomenon. Graneheim and Lundman (2004) have linked qualitative content analysis to Watzlawick et al.’s (1967) axioms of communication theory. The analysis can be performed with various focuses and various degrees of interpretation. Both manifest messages and latent meanings require some degree of interpretation, but the interpretations may vary in depth and level of abstraction (Graneheim and Lundman 2004). The following concepts will be described: unit of analysis, meaning unit, code, category, subthemes and theme (Graneheim and Lundman 2004). In this study the units of analysis are the interview transcripts.

The authors first read the transcripts and field notes to immerse themselves in the data. The next step was to divide the text into ‘meaning units’, i.e., words, sentences or paragraphs dealing with aspects that are related to each other through their content and context (Graneheim and Lundman 2004). The subsequent steps in the content analysis were to condense the data, which

| Number | Name | Gender | Age (years) | Previous occupation (occupation post-onset) | Time post-onset (years) | Aphasia type | Severity | Interviewer |
|--------|------|--------|-------------|---------------------------------------------|------------------------|-------------|----------|-------------|
| 1      | Eva  | Female | 67          | Secretary (limited secretarial duties)       | 21                     | Broca’s     | Mild     | A           |
| 2      | John | Male   | 67          | Graduate engineer                            | 2                      | Mixed       | Moderate | A           |
| 3      | Kjell| Male   | 53          | Engineer (assistant in information technology support department) | 8                      | Mixed       | Moderate | A           |
| 4      | Benny| Male   | 64          | Stock foreman                                | 3                      | Mixed       | Mild     | B           |
| 5      | Ingeborg| Female | 74          | Self-employed                                | 2                      | Wernicke’s  | Mild-to-moderate | B         |
| 6      | Ragnar| Male   | 76          | Butcher                                      | 1.5                    | Mixed fluent | Mild     | B           |
| 7      | Lars | Male   | 54          | Graduate engineer                             | 5                      | Wernicke’s  | Mild-to-moderate | B         |
| 8      | Gunn | Female | 65          | Social counsellor (assistant in a rehab department at a hospital, informing people about aphasia) | 25                     | Anomic difficulties | Mild | B           |
| 9      | Laila| Female | 60          | Graduate engineer                             | 2                      | Mixed       | Severe   | B           |
| 10     | Birgit| Female | 65          | Secretary                                    | 9                      | Broca’s     | Mild     | B           |
| 11     | Henrik| Male   | 39          | Driver                                       | 3.5                    | Broca’s     | Mild     | B           |
| 12     | Monica| Female | 56          | Teacher                                      | 4.5                    | Conduction aphasia | Moderate | B           |

Note: All names of participants have been changed to protect confidentiality.
Table 2. Example of data analysis: from meaning unit to overarching theme

| Meaning unit | Condensed meaning unit | Code | Category | Subtheme | Overarching theme |
|--------------|------------------------|------|----------|----------|------------------|
| Interviewer B: What’s difficult? R: Eh, well [laughter] I was thinking there what I wrote, I couldn’t write my name properly, huh | It is bad that he cannot write his name properly | Negative experience of impaired writing ability | Literacy as an emotional experience | Facing expectations about literacy | Literacy as an ongoing recovery process |

Involves shortening the text while retaining its core meaning, and to code the data. All data were condensed, but data that did not relate to the aim of the study were not further analysed. A research assistant (a master’s-level student of speech and language therapy) transcribed a random sample taken from four interviews, divided the data into meaning units and condensed them. The research assistant’s condensation corresponded well to the authors’. However, when any differences occurred, these were discussed until a consensus was reached. The process of coding, which involves raising the condensed meaning units to a higher level of abstraction, offers an alternative and new way of thinking about the data. The next step, grouping the codes into categories, is a way to describe the manifest content of the data (Graneheim and Lundman 2004). All codes for each participant that had something in common were grouped into the same category. The categories were further grouped into subthemes, with one overarching theme, which is a way to express the latent content of the data that runs through codes and categories (Graneheim and Lundman 2004). See table 2 for an example of the analysis process.

The work on categories and themes was carried out jointly by the authors, who met regularly to discuss the data and the analysis. During these discussions, some categories and themes were merged, new ones emerged, some were found to overlap and some evolved in the process of moving from the particular to more general aspects, always with reference to the interview transcripts. A preliminary analysis was performed after the first seven interviews had been conducted, but the authors estimated that data saturation (Saumure and Given 2008) had not yet been achieved since each of these interviews provided new and relevant information related to the aim of the study. Five additional interviews were therefore conducted and a second analysis was carried out.

**Results**

A single overarching theme emerged from the data: literacy as an ongoing recovery process, relating to how literacy is associated with the recovery process and how literacy skills may improve over time. Two subthemes were also identified: changes in conditions for literacy; and facing expectations about literacy.

**Overarching theme: literacy as an ongoing recovery process—‘You can improve throughout your life’**

In the participants’ descriptions of literacy, we distinguish a focus on the recovery process and on the improvement—or lack of improvement—of their literacy skills. The participant who had lived the longest with aphasia (25 years) stressed that continual improvement is possible by practising reading and writing alongside talking and listening: ‘You can improve throughout your life’ (Gunn). The emphasis on how the participants’ literacy skills had progressed and were progressing, and on the participants’ experiences of this process, reappeared in both of the subthemes. All the quotations used in headings and subheadings in the sections below reflect the overarching theme. When describing the changes in conditions for reading and writing, the participants focused on the fact that their reading and writing abilities had certainly changed but were still improving. In relation to expectations with regard to literacy, the participants emphasized that they had experienced loss, frustration and disappointment because of their present reading and writing difficulties, but they also expressed a desire to improve. The participants reported several motivations for reading and writing, e.g., as a way to communicate, to be informed and to remember things. The primary reason that the participants practised reading and writing (both in speech and language therapy and on their own) was to meet the need for functional reading and writing abilities in their everyday lives. They had also developed strategies for reading and writing, i.e., re-reading texts, reading aloud and using assistive technology such as spell-checkers and voice-recognition software. All the above-mentioned findings will be further presented in the following sections.
The participants did say that their literacy skills had been impaired since onset, but they also emphasized that their skills had improved to a greater or lesser extent and that they were still improving in some areas, such as reading. The participants’ literacy skills were not the only thing to have changed: there were also differences in what, when and where they read and wrote. The reasons for reading and writing included some of those that had existed pre-onset, but a new reason had been added: reading and writing to improve their literacy skills. The subtheme of changes in conditions for literacy consists of the three categories described below, covering specific aspects of how conditions for reading and writing have changed.

Changes in reading and writing habits—’[What did you used to read?] All kinds of things’

Pre-onset, the participants had read and written to a varying extent. Furthermore, the participants did not read and write only in Swedish but also in other languages, such as English. This, however, had changed post-onset: ‘I don’t tackle it either; I’m so terrified of English’ (Monica). There were participants who mentioned frequent reading of fiction and non-fiction pre-onset as well as reading related to their previous occupations: ‘Reading books is something I’ve always done. I used to read documents at work, well, I don’t any more, do I?’ (Lars); ‘[What did you used to read?] ’All kinds of things, yes, yes, this book, it eh, I [did not have] TV’ (Laila).

There were participants who still read and wanted to do so despite their reading difficulties: ‘I read every day’ (Gunn); ‘Reading every day’ (John). They mentioned reading newspapers (online and on paper), magazines, fiction, non-fiction, encyclopaedias, e-mails, messages in social media and information on websites (regarding banks, pharmacies, hobbies etc.): ‘I get [a Swedish daily newspaper], you know, and read it very carefully’ (Eva); ‘I actually did read for a while from last summer and it really was a nice story too, but over time, you know, I haven’t got any further’ (Ingeborg); ‘Yes, well, it’s [I use] Google’ (John). However, there were also participants who did not read at all post-onset or who just tried to re-read texts that they had read pre-onset.

According to the participants, they read more frequently than writing post-onset. Their writing was often restricted to short messages such as postcards, notes, e-mails and word puzzles: ‘I write here, in my calendar’ (Eva); ‘[What do you write nowadays?]’ ‘Letters, postcards’ (Birgit). One participant wrote short news articles and reminders to attend meetings. Those participants who received speech and language therapy wrote home assignments, such as the alphabet, words and longer texts: ‘[I write] the alphabet [laughter], well so it’s, and a few words, so it’s, otherwise’ [‘What are those words?’] ‘Well, car and boat and stuff like that’ (Henrik).

Constantly improving reading ability: ‘I’m improving, that’s absolutely clear’

When talking about the time immediately post-onset, several of the participants reported that at first they could not read at all. Even at the time of the interviews, they still found reading to be time-consuming and effortful. Some of the challenges associated with reading included difficulty keeping up when reading subtitles on television as well as when reading long sentences, long texts or entire books. The participants also mentioned that they would sometimes get stuck when reading aloud: ‘[Reading] is a bit slower, it still is’ (Monica); ‘I’ve started reading books as well now, there are also problems, like, I have to say, you need to take a long time and then, [ask yourself] “What did you read just now?”’, after a while now you have to go back’ (Ingeborg).

The participants reported that complicated texts were especially challenging and that remembering what one had just read could be difficult. However, the participants also emphasized that their reading ability was improving with time: ‘I’m improving, that’s absolutely clear’ (Lars); ‘I can read eh eh quite well [now]’ (Gunn); ‘It [reading] goes quite well’ (Laila). One participant explained that he doubted that he would ever be able to read a complete book because of his difficulties remembering the words he read. However, after some reasoning about this, he reached the following conclusion: ‘But it might improve because I practise, I do / . . . / like crazy, but I’ve been doing it for five years’ (Lars). The participants had noticed that short words and sentences were now easy to read. The experience of improvement was a great feeling, according to the participants, who expressed expectations of further progress: ‘It’s going to work out, actually, because it’s coming more and more, I think / . . . / It’s damn nice, actually, so it’s, it’s going to work out’ (Henrik); ‘When I retire for real, then maybe I can read properly, so I have another ten years’ (Lars).

Slowly improving writing ability: ‘Yes, I believe [my writing is developing], but very slowly’

Not only did the participants describe how their reading ability was severely impaired immediately post-onset, but many of them also stated that they could not write at all at the beginning of their recovery. The participants characterized their writing ability as having improved since onset, and said that it was still slowly improving. However, they also said that writing could be demanding and time consuming: ‘I can write, but
there are mistakes, you know’ (Ingeborg); ‘It’s eh not hard but it takes so long, it takes so long’ (John).

The participants mentioned specific difficulties with spelling, sentence construction, writing long sentences and the flow of writing, and also problems using their left (non-impaired) hand when writing: ‘[Spelling] is kind of difficult too, difficult sometimes’ (Ragnar); ‘I was going to write with my left hand and it came out so wrong, so wrong’ (Eva); ‘Well, most [aspects of writing are] difficult [laughter]’ (Kjell). However, some of the participants said that their spelling was quite correct and that writing their names was easy: ‘Spelling now nowadays works fairly well’ (Lars); ‘[Writing] my name is a piece of cake’ (Henrik).

The participants’ narratives reflected a fairly positive view on improvement. They highlighted the importance of practice even though some participants found the recovery process to be long and slow: ‘I’ve had to go through the alphabet and stuff like that the first time [in speech and language therapy] then we’re going to put the words right and so on so it’s going to, it’s going to work out I think’ (Henrik); ‘Yes, I believe [my writing is developing], but very slowly’ (Monica).

Subtheme 2: Facing expectations about literacy—’Everybody reads’

The interviews reflect the view that literacy is something that is expected of an adult in present-day society: ‘Everybody reads’ (Gunn). The participants described internal and external expectations on their literacy skills. This subtheme can be broken down into four categories relating to how the participants face expectations about literacy and how they deal with their difficulties in that context.

Literacy as an emotional experience: ‘[Writing] was tiresome, so I stopped, but now I’ve started again’

The participants expressed mixed emotions about reading and writing. They considered it to be a loss that they were not able to write as they used to, and hence that (in some cases) they could not continue working. Their impaired reading and writing ability aroused emotions of disappointment, surprise, annoyance, frustration and dissatisfaction: ‘It’s frustrating that writing and reading don’t work’ (Henrik); ‘Yes, it’s become a bit irritating, [I’m] a bit sad that it’s like this’ (Monica). The negative emotions about writing related to impaired motor functions as well as impaired language functions. The participants’ former writing skills were not reflected in their current texts, and they pointed out that it was an obstacle not to be able to express themselves in writing as fluently as before: ‘I’m a bit, I feel a bit disabled in writing and, that I can’t write properly or write with my name properly’ (Ragnar); ‘I think I’m saddest about the language, because I think it’s like, I think it’s like a child when I’m writing, oh God I think, like an idiot, myself, annoyed that I can’t get it out’ (Monica).

The participants expressed how they missed being able to read and write at their previous level of proficiency: ‘Well [I would like to write] all kinds of stuff, just write like nothing had happened’ (Henrik). They also pointed out that they wished to develop their literacy skills: ‘[Writing] was tiresome, so I stopped, but now I’ve started again’ (Monica). Having time to read and write and having functional reading and writing abilities was something that aroused positive emotions of inspiration and enjoyment: ‘[E-mail] is a darn good thing, it’s fun / . . . / to send e-mails, [to] write’ (Lars); ‘Before the ‘bang’ you didn’t have that much time for it [writing e-mails] but then suddenly tons of time’ (Lars); ‘Now I’m retired, so now I read the newspaper, I didn’t have the time before / . . . / it’s interesting to be able to read the newspaper properly’ (Benny).

Motivations for reading and writing: ‘[I read to] discuss’

Participants without jobs pointed out that even though they did not need to write every day at work, they were still required to possess the skills of writing and reading: ‘You should know how to do it [how to write]’ (Ingeborg). Reading was characterized as something that everybody does; hence, the participants should also be able to read.

Further, the participants explained that writing could be a mnemonic strategy and an effective communication tool. Some participants wrote e-mails because they found this to be enjoyable and practical. They also reported how other significant others had asked them to be more elaborate in their texts, which represented another reason for writing: ‘When I’m writing a message, I’m very brief; they often say, can’t you write a bit more, [not] just facts’ (Ingeborg).

Reading was not just something that the participants did to develop their reading ability as such. They also read texts because they were interested in the subject and for pleasure: ‘No, well, I don’t read for practice any more, but I, yes, [for the] experience’ (Monica). Further, the participants described reading as important for participation in the community: ‘[I read to] remember / . . . / [I read to] discuss’ (Birgit); ‘I have to read about all the things that are happening’ (Lars).

Developing strategies: ‘If I don’t understand, I read aloud’

The participants described a number of reading and writing strategies that they had developed. They
mentioned strategies that helped them to understand a text, such as re-reading, reading aloud, choosing easy-to-read books or listening to audiobooks: ‘If I don’t understand, I read aloud’ (Gunn); ‘When I’m going downtown on the tram, I can’t read the signs as they pass me, because I have to read more slowly, read two or three times before I remember, you know’ (Lars); ‘[I listen to audiobooks] every night’ (Birgit). They also reported that studying pictures associated with a text improved their understanding of the text. Re-reading was a strategy that the participants used when correcting a text that they had written themselves.

Some of the participants had tried, and were using, assistive technology—low-tech as well as high-tech, including reading rulers, post-it notes, text-to-speech software, audiobooks, voice-recognition software, electronic dictionaries, word processors, spellcheckers and word-prediction software. Many of the participants found it helpful to write on a computer, but their experiences of computer software differed: ‘[Writing on a computer] is the only thing I do, it’s the best. [Interviewer: ‘Why?’] Because I [write] faster’ (Monica); ‘[It’s] easier to write by hand’ (John). For some of the participants, using computers, computer software and the Internet was experienced as too complicated and not suited for PWA: ‘[Speech-to-text software] is difficult, you know / . . . / they run [a word-prediction software], I think it’s difficult’ (Kjell); ‘Often I forget to do a particular thing, recently from [a customer-to-customer website] I was going to [laughter] get something and I’m not sure, you know how do I get in there and so on’ (Ingeborg); ‘There is some computer stuff [assistive technology] which could improve / . . . / I don’t think I’m the only one who needs a little, even slower machine [refers to the reading pace in audiobooks]’ (Lars).

The participants were also supported by significant others, personal assistants and interpreter services provided by the county council: ‘Yes, I do [write e-mails], but rarely, [it] is my wife [who] writes [laughter]’ (John); ‘So when my wife comes [to visit] she’s got the newspaper with her, usually sits down and reads it [out loud]’ (Ragnar).

Finally, trying to avoid reading and writing was another strategy mentioned by the participants. For example, one participant reported that she preferred making telephone calls to writing.

### Practising reading and writing: ‘A positive spiral’

In order to live up to the above-mentioned internal and external expectations on their literacy skills, the participants practised reading and writing. The approach they used was to practise all communicative abilities constantly and concurrently. They believed that improvement was possible through practice: ‘Eh I believe you have to eh read and write, I believe it goes together, reading and writing go together and you can improve throughout your life / . . . / reading and writing and talking, then it becomes a positive spiral, I think [laughter]’ (Gunn).

Nearly all participants described their experiences of speech and language therapy during the recovery process: ‘The speak, speech and language therapist, she started reading with words and stuff / . . . / so then in a way I got to learn how to read’ (Lars):

We went to see this woman, I’ve forgotten her name but we went there for two years, and there you learned how to spell and everything that I wrote I have it, it is, I have it at home, those books that I wrote a long time ago.

(Eva)

The participants’ narratives indicated that their experiences of speech and language therapy differ—some were happy about the amount that they received while others wished for more speech and language therapy in general, and more reading and writing therapy in particular: ‘Yes it [speech and language therapy] was good too’ (Laila); ‘No, I haven’t really received [reading and writing therapy], it’s something I would like’ (Benny). They found practising their reading and writing skills to be important and rewarding, but also time-consuming and demanding. The participants argued that therapy should be meaningful, continuous, varied, stimulating, fun and ‘a treat’: ‘No, like going, like writing things just to learn / . . . / but you have to do it for a reason so to speak / . . . / I did that [crosswords] for a while too, but it, no, it was no fun’ (Lars); ‘I see that difference now, you have to feel like it as well or else it’s not real, you know’ (Ingeborg). However, the participants pointed out that it could be difficult to find interesting material, that the practice could be perceived as repetitive and that their home assignments had sometimes not been at an appropriate level of difficulty.

Some of the participants said that they were practising reading and writing on their own, for example using computer software focusing on specific language processes or just by reading or writing in daily life: ‘Yes, I tried [practising writing before starting group therapy] a bit sometimes’ (Kjell). Practice was found to lead to improvement and even to prevent negative thoughts: ‘And I think my practice, I think it’s good, you don’t get as depressed when practising regularly’ (Monica).

### Discussion

**Literacy as an ongoing recovery process**

The aim of this study was to present an insider’s perspective on literacy among PWA. To sum up, the
overarching theme revealed in this study provides an understanding of how the PWA in this study experience literacy, i.e., reading and writing, as an ongoing recovery process. The findings show that literacy is strongly linked to the participants’ individual experiences of their recovery. When asked to tell their personal stories about how they experience reading and writing in everyday life, the participants tended to talk in terms of improvement and/or lack of improvement, both retrospectively and prospectively. The participants had lived with aphasia for varying periods of time but they all described the ongoing process of recovery and the progress made. Their experiences indicate that PWA may need to engage in lifelong learning in order to maintain and improve their literacy skills.

The view of literacy as a social practice (Street 1984, 2003) rather than merely the technical skills necessary for reading and writing seems to fit well with the findings of the present study. As Parr (1995) suggested, changes in PWA’s living conditions in terms of work and social roles influence their literacy experiences and activities: the PWA in the present study do not discuss literacy only in terms of impaired and/or improving reading and writing skills, but also refer to other levels of literacy, for example literacy as a (re-)learning process involving the practice of reading and writing as well as the finding and learning of new, individually adjusted strategies for reading and writing. Further, the findings demonstrate how important literacy is in modern society; the PWA studied place literacy in relation to participation in the community, personal identity, employment opportunities and communication possibilities. Hence, the findings are in line with the account of the EU High Level Group of Experts on Literacy (2012), where it is emphasized that literacy enables, among other things, participation in society and self-efficacy. Below, the findings are further discussed in relation to the two subthemes.

Changes in conditions for literacy

The participants differed from each other in terms of age, prior occupations, time post-onset and how stroke and aphasia had affected their lives. However, it is clear from the findings that all PWA in this study shared post-onset experiences of impaired reading and writing skills and changes in reading and writing habits. The PWA reported that their literacy skills had been particularly strongly impaired initially post-onset. Some of them had not been able to read or write at all or had only been able to read and write single letters of the alphabet. However, these experiences were accompanied by a focus on actual and prospective improvements of their reading and writing skills. Many of the PWA felt that their reading ability was constantly improving while their writing ability improved more slowly.

There were differences among the participants in how often, how much and what they had read and written pre-onset. This is in line with previous research, which has found that typical everyday reading and writing practices cannot be predicted among normal adults (Parr 1992). The findings of the present study demonstrate that post-onset, there continues to be variation in the extent to which the participants read and write, in what activities they use literacy and in which literary genre they choose to read and write. As in Knollman-Porter et al. (2015) the participants reported that the material they read contained less text and less complicated text. Reading and writing abilities were most often described in a certain context and in relation to a certain type of literacy activity, i.e., the ability to read and write was described as depending on the personal and social context, and each PWA had his or her own individual profile, which is a finding that confirms earlier research (Parr 1995, Lynch et al. 2013, Knollman-Porter et al. 2015). Changes in roles post-onset, however, did not always have a negative impact on literacy activities, also confirming earlier findings (Parr 1995) that suggest that PWA will not necessarily find the change in his or her living conditions to be negative—in fact, PWA have also described positive changes in their roles in the fields of social and leisure activities. For example, one of the participants in the present study said that he had more time for writing e-mails to friends and family post-onset than pre-onset.

One reason for reading and writing mentioned by the participants related to their hope for and expectations of recovery and improvement. This corroborates previous research, which has found that PWA write mostly for practice and to improve their writing skills (Behrns 2009). However, many of the PWAs in the present study did not read and write only for recovery. The practice of literacy for pleasure, to obtain information and/or to communicate had been, and still was, an important part of the PWAs’ lives.

Facing expectations about literacy

The participants revealed mixed emotions about the expectations on literacy faced by them. They expressed emotions of frustration, dissatisfaction and loss at not being able to read and/or write like before. Some participants explicitly referred to not being able to write like before—perhaps not even their own names—as a ‘disability’. The self-images of some of the participants had changed radically. For instance, one participant had worked as a teacher pre-onset, and reading and writing had thus been natural activities for her. Post-onset, she claimed to feel like ‘an idiot’ or ‘a child’ when writing and she was not able to go back to work. These findings
provide further evidence in support of those of previous studies: that impaired reading and writing ability can lead to feelings of loss and frustration (Behrns 2009, Knollman-Porter et al. 2015), that aphasia may lead to a renegotiation of identity for PWA (Shadden 2005) and that PWA experience a sense of loss at no longer being able to perform activities perceived by them as important (Parr 1995).

One shared motivation for reading seemed to be that functional reading and writing ability was perceived as necessary in life and as something one should know how to do. Previous research has found that PWA wish to be ‘useful, meaningful and part of the community’ (Dalemans et al. 2010: 545) and that PWA are at risk of being socially excluded (Parr 2007). In everyday life, people encounter texts and are thus called upon to read. When talking about the need for functional reading ability, the participants mentioned reading signs, newspapers, websites, e-mail and regular mail—everyday activities which are central in a community.

When discussing improvement in reading and writing, many of the participants expressed optimistic and positive emotions, such as a conviction that lifelong improvement was possible and that a positive spiral is created by practising talking, reading and writing. Furthermore, the participants were of the opinion that reading could still be interesting and enjoyable. Previous research has also indicated that PWA believe that practising reading and writing is important for achieving improvement (Cruice et al. 2006) and that one key to living successfully with aphasia is activities, such as reading books and magazines, completing word puzzles, studying and working (Brown et al. 2010). The importance of a positive attitude, as stressed by the participants in the current study, is also in line with the findings of a study exploring personal perspectives on factors supporting recovery after stroke (Jones et al. 2008). Brown et al. (2010) also found that striving for a positive way of living was important for living successfully with aphasia, and findings in a study by Cruice et al. (2010) indicate that taking a positive view on life is likely to improve the quality of life for older PWA.

The PWA in this study found both speech and language therapy and practising on one’s own to be important. However, they also considered that ‘mechanical’ reading and writing is not motivating enough: therapy has to be meaningful and interesting in order to be stimulating. This is in line with Parr (1995), who argues for ‘functional, ecologically valid therapy’ (233) and Knollman-Porter et al. (2015), who found that PWA preferred meaningful reading experiences over reading frequency or time spent reading. Furthermore, Jones et al. (2008) assume that PWA would be more motivated and would experience their recovery as more effective if therapists designed treatment in collaboration with patients, taking account of the patients’ personal goals and their views on recovery. That assumption is borne out by our findings.

Some participants found it easier to write on a computer than by hand, and some of them had tried writing-support software. However, the participants pointed out limitations in the computer software; for example, in one participant’s experience, audiobooks were read out too fast and word-prediction software was difficult to use. Earlier research has shown that external support such as the use of assistive technology could be both compensatory tools and tools to improve one’s reading ability (Knollman-Porter et al. 2015) or writing ability (Behrns 2009). The findings in the present study support earlier findings (Lynch et al. 2013, Knollman-Porter et al. 2015), which stress the importance of individual adjustments and continuous support when it comes to computerized aids for reading and writing.

The participants also felt reading and writing support and assistance from significant others to be essential. Support from significant others has been acknowledged as being of great importance for PWA in earlier studies as well (e.g., Brown et al. 2010, Worrall et al. 2010, Knollman-Porter et al. 2015). It is evident that the participants’ social roles have changed, for instance needing help post-onset to read the newspaper. Accepting help was, however, experienced as crucial for the recovery process, rather than a social defeat. It is also important to point out that the ultimate goal for a PWA is not necessarily to become independent but to become autonomous, in this case regarding literacy, and to find strategies that allow the individual to be in control of the current situation (Parr 1995).

**Strengths and limitations of the study**

A strength of the present study lies in the careful analyses of data. Work on various aspects of trustworthiness (Lincoln and Guba 1985) was carried out and documented throughout the study. To achieve credibility (confidence in the ‘truth’ of the findings), the authors jointly analysed and discussed the data on a regular basis. Throughout the analysis, the interview transcripts were read several times to ensure that the codes, categories and themes were in line with the content of the interviews and to evaluate/re-evaluate the interpretations of the latent content of the data. In addition, a research assistant’s (a master’s level student of speech and language therapy) condensation of a random sample taken from four interviews corresponded well to the authors’. To promote dependability (showing that the findings are consistent and could be repeated), the research process was well documented and the authors have made an attempt to be as detailed as possible in order to make it possible to
replicate the study. To enhance transferability (showing that the findings have applicability in other contexts), details of the participants are provided (table 1) and the reported findings are extensively described, including a large number of quotes from the participants, in order to provide the reader with enough information to decide if the findings are appropriate in different context.

Possible limitations of the present study relate to the authors’ professional background, the method of data collection, the limited size of the materials and the decision not to use respondent validation. First, the authors have a background as SLTs. This may have influenced the analysis of the data in that they had too great a preconception of how literacy is affected for PWA, which could have had an impact on the interpretation of the data—but on the other hand, being SLTs may also have facilitated the conducting and interpretation of the interviews since the interviewers had knowledge about aphasia and experience of communicating with PWA. Second, audio-recorded interviews were used so as not to interfere with the interview situation. Video-recorded interviews would potentially have captured any non-verbal communication in a more accurate way. However, the interviewers systematically asked for clarifications during the interviews and made careful notes. Third, the material would have been larger if there had been more participants, but the sample was felt to represent variety in terms of age, gender, previous occupation and time post-onset and the authors chose to continue recruiting participants until the new interviews did not contribute any new information. Finally, qualitative studies sometimes use respondent validation, i.e., including an opportunity for the participants to confirm the authors’ interpretations of their statements. However, there are some limitations to this as a check on credibility (Mays and Pope 2000). For example, individual participants may interpret their own utterances differently when seeing them in the context of other participants’ utterances.

**Conclusions and clinical implications**

The PWA in this study were well able to articulate their thoughts and experiences of literacy in daily life and literacy was described as playing an essential part in the lives of the participants. The findings of the present study may have implications for clinicians, indicating that intervention and assessment of PWA’s reading and writing abilities should have a broader focus going beyond the technical aspect of literacy. In fact, the overarching theme of this study, Literacy as an ongoing recovery process, and the subthemes, Changes in conditions for literacy and Facing expectations about literacy, could provide a framework for designing or adjusting clinical intervention. Such an intervention would take the PWA’s experiences of changes in reading and writing habits, as well as experiences of a constantly improving reading ability and a slowly improving writing ability, into consideration. The findings also indicate that taking the insider’s perspective means that clinicians also need to consider the PWA’s emotional experience of literacy, their motivations for reading and writing, their experiences of developing strategies and/or practising reading and writing when designing or adjusting literacy assessment and intervention plans. One important element in literacy intervention is to involve it in daily life in a meaningful context for the PWA. In line with previous research (Parr 1995), there are however no ‘typical’ daily reading and/or writing activities that suit all PWA for the clinician to choose from. Hence, developing individual and meaningful intervention means that planning has to be carried out in cooperation with the PWA and that his or her individual experiences of literacy have to be taken into account.

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Appendix A: Questions from the interview protocol (the exact wording used in each interview depended on how the interview progressed)

What do reading and writing mean to you?

How do you experience reading/writing today?

Do you read/write today?

What do you read/write today?

Have your literacy skills changed because of your aphasia?

How did you experience your writing/reading skills initially post-onset?

Is there anything you used to read/write that you do not read/write today?

Have you received speech and language therapy?

How does it feel?

Please tell me more about . . .

Can you give an example . . .

What is your opinion about . . .?