

HOW THE APHASIA PATIENT REGAINS THE ABILITY TO READ INDEPENDENTLY WHEN MAKING USE OF A SCANNING PEN



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Abstract

A predominate focus of those studying stroke patients has included the practical/clinical aspect of the type of support offered after discharge from hospital, and the consequences of a stroke on a patient's self-identity. Studies have included the importance of care packages and strategies/programmes (Ellis-Hill et al. 2009) aimed at promoting independence and the opportunities to regain a sense of who you were, before a stroke (Code & Herrmann, 2003).

To date, many of my studies have focused on gaining insight into how the use of a Scanning Pen can support learners with dyslexia or reading difficulties. Therefore, keeping to the research theme involving those with reading difficulties, I turned my attention to a different category of need, those who have aphasia, specifically as a result of a stroke.

My research method was to seek a suitable aphasia patient who wished to regain the independent reading skills that they had experienced before their stroke. Furthermore, I wished to gain insight into the stroke patient's psychosocial identity, for example, the concept of how a stroke patient identifies with 'fitting' into social environments and how this affects their mental well-being. I therefore sought to introduce a suitable candidate to a Scanning Pen, and wished to record their thoughts and views on regaining a capacity to 'read' independently in a video interview.

Introduction


My thoughts and questions were based on the frustration an aphasia patient may experience when no longer able to read. According to research undertaken by Ellis-Hill et al. (2009) a vast majority of stroke patients will strive to reacquire everyday skills and will need support, after discharge from hospital, to independently achieve their hopes and aims. I, therefore, wished to add the goal: regain an ability to 'read'. I hoped this would help to promote feelings, such as success and enrichment, empowering emotions which may have been impacted upon since their stroke.

Identifying who would benefit from the chosen method was of upmost importance. Aphasia is akin to dyslexia; in that it takes on many different forms. Subsequently, those who have experienced damage to their comprehension levels would not benefit from being asked to partake; our participant would require the ability to understand the spoken word but would not be able to read for themselves. The loss of speech ability, was not a significant factor in this study. Our participant would need to be able to comprehend the information in the text being read and then be able to communicate, in any given way, their understanding of that information or text.

An accidental crossing of paths with a volunteer support worker from The Stroke Unit at Queen Elizabeth Hospital, Norwich, created an opportunity to discuss undertaking this study. The following hypothesis was put forward;

“Some aphasia patients will gain confidence and a sense of achievement, when given a Scanning Pen to enable them to ‘read’ documentation for themselves.”

Aphasia is the symptoms a person will experience due to the language areas of their brain being damaged or not developing correctly; this will often impact on speech, reading and the comprehension of language (The Tavistock Trust For Aphasia, 2019). It is thought 250,000 people in the UK have aphasia.



Method

The volunteer support worker put me in touch with a Communication Support Worker, (Gemma). Gemma identified a participant she felt would benefit from partaking in the study.

The participant: Ted* was 66 years of age when he was approached, his stroke had occurred in the Spring of 2016 and he had spent 2 months in hospital recovering and awaiting suitable re-housing. As a result of the stroke Ted had some difficulties with his verbal language and was no longer able to read, however his comprehension levels were exceedingly good. He lived with his partner, who spoke little English, as this was not her first language, therefore reading letters and accessing information was a difficulty for both.

Ted had left sided weakness, limited mobility and expressive aphasia. Expressive aphasia or Broca's aphasia is very slow speech, difficulty with reading, some sight problems, difficulty with spelling and writing. Some difficulties had been overcome due to speech and language therapy, but Ted continued to experience ongoing long-term problems.

Ted was enjoying and making use of audio books and an iPad, with apps, to help with communicating and understanding numerals and time. However, as well as his continued speech difficulties, Ted had identified displeasure at no longer being able to read important correspondence or to read for pleasure. Ted would await visits from Gemma to ask her to read his appointment letters and other important information; relevant to his ongoing treatment and recovery. Ted was also missing out on community news and accessing information of interest and importance to him.

Ted's stroke occurred in the right hemisphere of his brain, giving left sided weakness, his predominant side. In addition, his language skills were affected. This is of interest as the processing of language occurs within the left hemisphere of the brain. Neuroscientifically Challenged (2019) offer explanations as to the effects a stroke has on the human brain, including difficulties with fluency of speech, which occurs in the 'Broca's area' of the left frontal lobe. Gemma explains in her interview, that Ted had slowness of speech, which indicates damage to the Broca area of his brain, alongside the diagnosed extensive damage to the right side of his brain.

Further information pertaining to left hemisphere functions, which is worth noting, is the recognition of words occurs in the left temporal lobe, or Wernicke area, the ability to understand the written word occurs in the left parietal lobe and the ability to visually identify letters occurs in the left occipital lobe (Minnesota Brain Injury Alliance, 2019).

Gemma approached Ted to ask if he would agree to being part of the study. He would be given the use of a Scanning Pen to enable him to read his own mail and other materials of interest to him. Ted indicated he would be interested and consented to participate in the study. It was explained to Ted that he could withdraw his consent at any time, however if he continued with the study his experience and verbal feedback would be gathered via an interview at a date and time suitable to his needs. Studies pertaining to the skills required when interviewing aphasia participants were used as a reference (Luck & Rose, 2007), and were used when meeting with Ted, to record his feedback. Therefore, questions were of a conversational style to enable the flow of ideas and to create a reciprocal relationship, which were then videoed to enable the nuances and meaning to be clearly defined.

*Ted. Name changed to protect the identity of the participant.

Results

Ted shared, in his interview, his experiences when using the Scanning Pen. Ted told us how important it is to him, to be able to 'read' and the capacity in which the Scanning Pen enabled him to do so. He was able to demonstrate he was more than capable of achieving the skills required to use the Scanning Pen independently. In this phase of the study, Ted was introduced to the ExamReader, as the user interface offered the essential function of text to speech without the complication of additional menus and functions.

It soon became apparent that we had underestimated Ted's ability to explore, navigate, control the Exam Readers functions. He was able to use a Reader Pen with more functionality. We learnt that reviewing the aphasia patients use of the technology, as they become more familiar and confident, greatly helps in providing the most appropriate Scanning Pen for their needs.

Subsequently, due to Ted's abilities, we introduced him to a Scanning Pen and the enhanced functionalities of saving text to a file and an audio recorder. Ted was able to record conversations with medical professionals in meetings and then listen to them in the comfort of his own home. He could see the benefit of being able to review what had been said, that it would help him remember the things that he had been asked to do. Ted also understood that he could make his own recorded notes as a prompt for the questions that he wanted to ask at his appointments.

Ted moved beyond scanning single words. He wanted to scan whole sentences or paragraphs to gain a better understanding of the letters and articles he wanted to read. When recommending strategies for adults or children who are learning how to read, the strategy of single word reading is the starting point. This is because the pen helps to validate the meaning of a word in a sentence. We realised that the approach for the aphasia patient would be different as our aim was not to 'teach' reading but to provide access to the written word. Ted helped us to understand the importance of teaching and encouraging the scanning of blocks of text to support comprehension and give access to reading enjoyment of larger amounts of text.

Gemma was able to share with us, some other experiences that she had when introducing the ReaderPen to other aphasia patients. One lady used her pen to read books, this supported the findings we had with Ted. She particularly wanted to scan and listen to large bodies of text and regain her reading independence.

Stroke can have an impact on dominant hand use, this can present the challenge that the patient needs to use their less favoured hand to scan text. All Scanning Pens can be changed from right to left-handed. This switch is a feature in the pen's wizard and settings. Gemma recorded that this switch was helpful for three of her clients who set up the pen for their non-dominant hand. They also experienced success in learning to scan with that hand.

Finally, our results enabled us to gain insight as to the importance of the care and support packages offered to the aphasia patient. Not only was Gemma able to identify her own experience and knowledge in aiding her client's recovery, but Ted recognised how important it had been for him when taking his first tentative steps to join the Communication Support Group. The concept of a sense of who you are before a stroke, and the impact this has on your behaviour and confidence afterwards is explored in a study conducted by Hole et al, (2014). Therefore, Ted's first reluctance to attend the group is due to how he identifies himself after the stroke. Subsequently he is then conflicted with a characteristic of himself before his stroke, which he explains as "manners", which persuades him to give the group a go. During our interview Ted explains what it was like to meet with peers, seeing them laugh and explore hopes and dreams which gave him a sense of acceptance and belonging. This need was explored in a case study by Kessler et al. (2014), to feel validated due to belonging to a like-minded group and how this can aid recovery.

Discussion

Aphasia is a complex and unique condition in that each person who experiences aphasia will have their own experiences, difficulties and symptoms. Therefore, as Gemma indicated, finding the right support, questions and understanding of the aphasia patient's hopes and needs, may sometimes be overshadowed by clinical concepts. Clinicians may assume they understand the client's wishes without realising the influence of their own sense of self, the very nature of their job of wanting to help, and how these personal experiences can dictate outcomes. For example, strategies identified by the medical professional as the client's clinical targets may not prioritise some of the client's personal goals; to get back some of the person they had been before the stroke, their sense of loss, identity and social interactions. Studies from Worrall et al. (2011) suggest a percent of those with aphasia wish to return to how they were before their stroke. For Gemma, and those working in a similar capacity, this clearly indicates the importance of gaining insight as to what their client's life was before the stroke. Gemma achieved this by spending time and communicating with Ted about his hopes and needs.

The limitation of our research, is that there were only a small number of patients with aphasia who wanted to regain access to reading text in the sample group. Gemma identified in her video interview, that the patients who wished to have information read to them was limited. However, the Scanning Pen was an appropriate technology where patients were able to 'have a go' at reading for themselves, and that it brought joy and independence to those capable of trying. Additionally, Gemma then went on to consider other approaches and technologies where the dexterity required to manipulate a Scanning Pen was not achievable. She identified the importance of having an extensive knowledge of all the products and services that may be of use to those with aphasia.

From this study, I would recommend that organisations like The Stroke Association could greatly benefit from exploration of assistive technologies that aid and support communication and reading. We have seen that this can contribute significantly to developing independence and improving the patient's wellbeing. A Scanning Pen initially may appear to be outside the 'norm' of rehabilitation support where walking aids, gripping aids and speech therapy are more commonplace. The impact, of using a Scanning Pen however, has been significant for those taking part in this research.

The aphasia patient benefits from the tailored support package identified at discharge, to get them back on their feet and live independently, but just as importantly is the ability to regain their long-established qualities, those of which they possessed before their stroke.

Consequently, if reading or accessing important paperwork was something, they were successful at before the stroke, then having access to a ReaderPen, or similar device, should be considered part of their care package. Code & Herrmann, (2013) explored the concept for aphasia patients improved independence, joy and social interactions with peers being linked to mental health and well-being. This link is known as a psychosocial perspective and is advocated in a variety of treatment, including those with aphasia and anxieties. We recommend further research exploring and expanding reading capabilities within group-based programmes; using some of the positive methods we deployed in this study would ensure aphasia patients experience socially active lives and an increase in their emotional well-being as we identified and saw occurring for Ted.

Post script. Gemma recently contacted us to inform us of the family of an aphasia client who purchased a ReaderPen, at Christmas. The aphasia patient had rediscovered the joy of reading novels when shown the ReaderPen by Gemma during our study. As this brought so much joy to the aphasia client her family wished to encourage and support these feelings and the direct impact this had on family cohesion. From a clinical perspective using the ReaderPen was encouraging the use of the right hand, the side which was damaged due to the stroke, improving dexterity and movement. From an emotional well-being perspective the lady was doing something she identified as being 'her', an ability to enjoy a good read.



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