Menger F, Morris J, Salis C.

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Aphasiology 2016, 30(2-3), 112-132.

Copyright:

DOI link to article:

http://dx.doi.org/10.1080/02687038.2015.1109050

Date deposited:

07/03/2017

Embargo release date:

07 November 2016

Aphasia in an Internet Age: Wider Perspectives on Digital Inclusion.

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Shortened title: Aphasia in an Internet Age

This is an Accepted Manuscript of an article published by Taylor & Francis in *Aphasiology* on 7 November 2015, available online: http://dx.doi.org/10.1080/02687038.2015.1109050

Abstract

Background:

Aphasia is likely to impact adversely on ability to use the Internet successfully, as linguistic skills are important for many aspects of Internet use. Despite this, there exists limited evidence on how best to support people with aphasia to benefit from the Internet.

Whilst linguistic impairments in aphasia will have an impact on Internet use, there are other important factors such as other cognitive or physical impairments. There are also differences in digital skills between social groups in the UK, creating inequalities. People with aphasia and those who support them are likely to have varying levels of Internet use. These aspects are relevant in improving our understanding of factors relevant to supporting people with aphasia to use the Internet.

Aims:

The main aim is to discuss the key areas related to supporting people with aphasia to achieve equality of access to and use of the Internet. The paper focuses on three questions related to Internet use: 1) What do we know about access and use of the Internet by populations who share characteristics with people with aphasia and may experience similar disabilities?, 2) Based on that knowledge, what types of difficulties with Internet use might be predicted for people with aphasia?, and 3) How has Internet use or support with Internet skills been studied in relation to people with aphasia. If not directly studied, what does relevant related work tell us?

Main Contribution:

This paper discusses factors which might act as barriers or facilitators to Internet use by people with aphasia, viewed from within the conceptual frameworks of the International Classification of Disability and Functioning (ICF) and the Communications Consumer Panel Framework on Digital Participation. It considers relevant literature on digital exclusion in the wider population and on aphasia and technology, in order to present a wide perspective on the range of issues involved in mitigating digital exclusion.

Conclusions:

The interrelationships between the complex demands imposed by aphasia, and factors thought to contribute to digital exclusion are complex and multifactorial. Literature directly relating to aphasia and technology, and from wider evidence on digital exclusion all contribute to understanding of key barriers and facilitators to Internet use. Consideration of these wider factors and of the contributions from a range of disciplines, historically not involved in aphasia rehabilitation, is helpful in understanding the needs of people with aphasia in a digital age, and to develop future interventions.

Introduction

The Internet offers many benefits for individuals across the lifespan, improving access to education and employment, providing consumer benefits such as savings on purchases and increased choice (Koss, Azad, Gurm, & Rosenthal, 2013) and opportunities for inter-personal communication. However, not everyone is equally able to access such benefits; the term 'digital divide' describes differences between those more and less equipped with the knowledge and skills to access and use the Internet (Van Dijk, 2012). People with aphasia represent one such group, who have the potential to be digitally excluded with regard to access to and use of the Internet. In order to understand the possible risk factors and the evidence around solutions to digital exclusion in aphasia, this paper address the following questions:

1) What do we know about access and use of the Internet by populations who share characteristics with people with aphasia and may experience similar disabilities?

2) What types of difficulties with Internet use might be predicted for people with aphasia?

3) How has Internet use or support with Internet skills been studied in relation to people with aphasia. If not directly studied, what does relevant related work tell us?

These questions are addressed by first discussing the concept of digital exclusion within the UK; what is known about groups within the UK who share characteristics with people with aphasia, and who are also potentially at risk from digital exclusion and difficulties using the Internet. Frameworks provided by the Communications Consumer Panel on Digital Participation (Communications Consumer Panel, 2010) and the International Classification of Disability and Functioning (World Health Organisation, 2002) are then used to explore how people with aphasia may experience difficulties with using the Internet. Following this, findings from the literature relating aphasia and technology are discussed.

Cultures of Internet Use

The Internet is used by most people in developed countries (Lebo, 2013). However, Internet use varies within the UK population, not only in amount of use, but also in types of use, and attitudes towards its role in our lives. Regular surveys conducted by the Oxford Internet Institute, a world centre for the study of the Internet and society, provide valuable insights into Internet use in the UK. Their most recent survey (Dutton, Blank, & Groselj, 2013), described a spectrum of cultures of Internet users, ranging from those who embrace all aspects of the Internet to those who are sceptical and hesitant users. Groupings of sub-cultures, and the recognition that not everyone holds similar views on the Internet, or uses it in the same way, highlights the heterogeneity of Internet users. People with aphasia are likely to belong to some of these sub-cultures. Although Dutton et al.'s survey was based in the UK, other countries may have similar or different patterns of use.

Digital Exclusion: Vulnerable Populations

Certain social groups have been identified as being at increased risk of digital exclusion. Amongst these groups are several which potentially share characteristics with people with aphasia. These include healthy older adults, people with disabilities, those with lower levels of education, and those experiencing social deprivation (Helsper, 2008; Helsper & Reisdorf, 2013). Given that aphasia is a complex condition, often co-existing with other stroke related or medical difficulties, people with aphasia may fit into one or more excluded groups, making the factors related to their ability to access the Internet complex.

Use by Older Adults

Koss et al. (2013) recognised the importance of encouraging older adults to use the Internet, stating that digital technologies and the Internet can help reduce social isolation and improve mental health. However, Dutton and Blank's (2011) found that older adults and retired people are the least likely to use the Internet, and the most fearful of technologies failing, or being unable to understand them. In their survey, retired people were less confident of their Internet skills than students or employed people. This may be due to the fact that current

cohorts of older adults have been living at a stage of Internet evolution that has seen relatively sudden

popularity and change. Although Internet use amongst retired people increased from 2011 to 2013 (from 36-

45%), use in older adults was considerably lower than that of younger adults (e.g. 100% of students and 94% of

young people) (Dutton et al, 2013). Hanson (2009) suggests that many of the difficulties faced by older adults

are related to the physical changes associated with ageing (e.g. reduced perceptual skills, decline in cognitive

function). Some of these changes are also relevant in people with aphasia who are often older adults (Bhatnagar,

Scarborough, Smeeton, & Allender, 2010), either as a consequence of their medical aetiology (e.g., stroke) or

age-related cognitive changes.

Use by People with Disabilities

Dutton et al.'s (2013) survey findings also suggest that people with disabilities are less likely to use the Internet

than people who consider themselves not to have a disability (51% compared to 84%). The survey did not

examine disability further by medical aetiology or severity. To our knowledge, specific figures on Internet use

by type of disability do not exist. Having a better understanding of the influence of different disabilities would

be helpful in considering the likely differences between those with physical, sensory, or cognitive impairments.

This is because of numerous innovations which make computer access possible for physical and sensory

disabilities (e.g. screen readers and haptic adaptations for blind users, or adapted keyboards or navigation

methods for people with hemiplegia). However, for each type of disability, as with aphasia, there are likely to

be co-occurring factors impacting on levels of use, for example, some people with disabilities may be high level

users relying on technologies as aids to inclusion while others may be unable to benefit from these technologies,

afford specialist software, or obtain appropriate support. Jaeger (2012), expressed concerns about lack of focus

on issues specific to disability, and warned of the Internet emerging as a potentially marginalising environment

for people with disabilities, suggesting a "risk of segregation of people with disabilities as permanent second-

class citizens of the information age" (Jaeger, 2012, p. 34). Jaeger argued that people with disabilities have

already faced barriers to equality of access to other aspects of everyday life, and the rapid growth of the Internet

adds another exclusionary aspect. Highlighting the needs of people with disabilities in relation to the Internet is

important, especially in the context of recent government drives towards 'Digital Britain', with the government aiming for 'digital by default' services that are universally simple (Cabinet Office, 2013).

Although there is a clear need to make the Internet accessible, the current situation is one where compliance to existing web content accessibility guidelines (Web Accessibility Initiative, 2015) in both the UK and the USA is poor (Hanson & Richards, 2013). Easton (2013), describes how, in many cases of web design, accessibility issues have been addressed only after initial ideas and designs have been developed. Easton argues this is in conflict with the principles of universal design, which stem from the social model of disability (Oliver, Sapey, & Thomas, 1983). The social model is based on the premise that disability is created by society, rather than from impairments experienced by an individual. Easton argues that a more favourable approach should consider the accessibility of web design at the very onset of the process. This allows for well-integrated inclusion, and moves focus "away from difference and towards the universal" (Easton, 2013, p.106).

However, making Internet content accessible to all is not easy. Jaeger (2012) acknowledged the difficulties faced by web designers and developers, outlining the need to incorporate all possible adaptions that people with disabilities may find useful (e.g. text to speech, alternative means to input text, Braille, magnification, or text description of images). Blanck (2014) considered the needs of people with cognitive disability, acknowledging that they may have multiple needs, and that barriers are likely to be structural (e.g. resulting from reduced expectations of others or lack or educational opportunities) as well as technological and environmental. Given the range of disabilities, coupled with the range of technical aspects for facilitating accessibility, it is not surprising that bridging the digital divide presents a major challenge.

Use by Socially Disadvantaged Groups

Helsper (2008), on discussing the link between digital and social exclusion, concluded that individuals who experience isolation in life are unlikely to also engage with social aspects of the Internet. Helsper also argued that those who face disadvantage in society are at most risk of failing to access aspects of technology that could be of most benefit to them. There is also a concern that the current drive towards digitisation of government

services might compound social exclusion, with a significant section of the population unable to access services without support (Low Incomes Tax Reform Group, 2012).

There is recognition of the relationship between social and digital disadvantage, and initiatives such as Go-On UK (go-on.co.uk, 2015) are working to increase awareness of reasons behind exclusion, and to promote the development of basic digital skills for those who lack them. Examples of initiatives include self-appointed 'digital champions' who sign up to share skills, classes at all levels of ability, company initiatives to support employees, and promotion of free Wi-Fi hotspots.

The Internet and Aphasia

We currently know little about how the population of people with aphasia use the Internet. Finch and Hill (2014) surveyed computer use by 34 Australian people with aphasia pre- and post-stroke, and found that the nature of computer use changed following the onset of aphasia, with a reduction in frequency of what they defined as 'work' related use in favour of use for a general interest, entertainment, and therapy (Finch & Hill, 2014). This raises questions around what aspects of stroke and aphasia have contributed to the change. Given the role of the Internet in inter-personal communication, and, in particular, the demands for processing written and spoken information, aphasia could make a major contribution to digital exclusion. For many people with aphasia, there are likely to be co-occurring factors such as physical, cognitive, or sensory disabilities, or difficulties associated with ageing. As mentioned earlier, stroke is more likely in older adults (Bhatnagar et al., 2010); people who have had strokes are also most likely to report severe disabilities such as physical weakness, increased levels of dependency, visual or hearing problems, or cognitive impairment beyond language (Adamson, Beswick, & Ebrahim, 2004). Given the potential impact of aphasia and the wider complexities of digital exclusion, understanding the overlapping factors is likely to be important when considering the needs of individuals with aphasia. There are a variety of social, cultural, or personal factors which might impact on Internet use, as well as the recognition that individuals will have different levels of skills and use prior to stroke.

Identifying Barriers to Inclusion for Aphasia

The potential factors related to digital inclusion for people with aphasia will be discussed with reference to two existing frameworks. The first is the Communications Consumer Panel (CCP) (2010) framework, which considers what people need to get online and to get the most out of the Internet, outlining the essential skills needed to engage with the Internet (see Figure 1). Each section (of the framework) describes skills inherent to Internet competence, making it possible to identify areas of potential difficulty for individuals or groups. This provides a useful starting point for understanding possible barriers to successful Internet use for people with aphasia. Given that many skills listed in the framework are language-dependent, a person with aphasia would experience multiple difficulties (see Figure 1 for examples).

Figure 1 about here. Reproduced with permission of the Communications Consumer Panel.

The second framework is the International Classification of Disability and Functioning (ICF) (World Health Organisation WHO, 2002) which has a focus on health and functioning, considering the description of body function and structure alongside impact on activity and participation, and takes into account personal and environmental factors. WHO (2002) suggests possible application of the ICF at the social level, for identifying the "needs of persons with various levels of disability – impairments, activity limitations and participation restrictions" (p. 7). This makes it an ideal framework for viewing how and why people with aphasia might experience difficulties using the Internet successfully.

Considering aphasia and the Internet within these two frameworks (in combination) enables a more thorough understanding of potential barriers to Internet use. Table 1 lists the CCP categories and considers how difficulties caused by aphasia could be mapped onto the CCP framework. The examples suggested under each grouping of skills are illustrative rather than exhaustive. In order to consider the complexity of potential barriers and facilitators (to Internet use) the ICF classification scheme codes have then been applied (using the guidelines outlined by Cieza et al., 2002), allowing consideration across ICF domains. Table 1 demonstrates that whilst many codes are directly related to language impairment (body structure and function), there are also

codes associated with environmental and personal factors. Consideration of each of the different ICF domains is expanded in the sections below.

Table 1 about here

Body Function and Structure

Considering the domain of body function and structure allows for focus on the language and other difficulties people with aphasia experience in relation to the Internet. Reading is the most important skill needed for understanding Internet content, and writing for many online interactions; impairment of these (in aphasia) is therefore likely to have major impact. Impairment of spoken comprehension or expression is also likely to affect ability to use aspects of the Internet, as it is a multi-media environment, with the ability to listen to/view and interact with audio-visual content. Furthermore, language and other cognitive functions are prerequisite skills across many other areas (e.g. negotiating broadband contracts, or reporting and describing problems). Beyond language, the possible impact of impaired cognitive (non-linguistic) skills, such as attention, memory, visual perception, problem solving and integration of cognitive processing abilities also needs consideration. In addition, there are other possible stroke-related impairments which are likely to have an impact, for example, hemianopia, or hemiplegia. There may be other physical impairments associated with either normal ageing (e.g. presbycusis, deteriorating vision) or with other physical conditions. These could have bearing on the ability to physically access computer equipment, or to achieve unfettered access to Internet content.

Activity and Participation

In considering activity and participation, the important role the Internet plays in inter-personal communication becomes crucial. The Internet has developed in recent years from a vast source of information one passively searches to an interactive source of communication, sharing, and social media. Changes in the level of online participation continue to grow, creating new communication environments with their own unique features and challenges. Many everyday activities either have an online equivalent or are exclusively online (such as finances, voting, job applications, purchases). The Internet has become a mirror of daily life comprising a range

of environments in which people with aphasia may be excluded from because they cannot access or use the Internet for the first time, or because they have lost required skills as a result of aphasia. Within table 1, there are several activity and participation areas of the ICF classification system which directly relate to the CCP section on ability to enjoy the benefits of the Internet. Examples include learning and applying knowledge (online courses/education), general tasks and demands (paying bills, registering to vote, applications for housing), communication (social media connections with friends, contact with people with similar interests), domestic life (shopping, banking), interpersonal interactions and relationships (email, social media, photo sharing), major life areas (making a will, buying a home) and community, social and civic life (local events, council information, campaigning). Whilst language and cognition underpin many of these areas, there are some aspects of online interactions which could be less demanding and enabling. For example, video calling allows individuals to use alternative means (e.g., facial expression, gesture) to convey a message, and activities such as photo sharing or clicking a 'like' button require no verbal or written expression.

Environmental Factors

Environmental factors are likely to contribute (either as barriers or facilitators) in various ways; this includes the provision of support. Examples might include content and/or design modification specifically for aphasia, provision of assistive technologies, or appropriate one-to-one facilitation and training. Modifications to online environments is considered by Elman (2001), who suggested that disability advocates might have a poor awareness of aphasia, and that when issues around policies or content guidelines were in discussion, aphasia was unlikely to have been considered. Elman argued that creative thinking around the use of commercially available products might be helpful for individuals with aphasia. She acknowledged that independent use may not be feasible for all, but suggested supported access might be the way forward for some individuals, using trained communicators to facilitate tandem viewing of information. This concept is crucial with regard to considering environmental factors, in that the source and nature of this support has yet to be defined. While speech and language therapists (SLTs) have knowledge about language impairment and its impact on

participation, they may experience barriers or exhibit varying levels of confidence when providing support with technology. The experiences of SLTs in this area is not described in the recent literature. However, Johnson, Menger, and Morris (2014) surveyed SLTs on their use of technology with people with aphasia and found client suitability, cost, availability of trials, and awareness of what is available amongst the most cited barriers to using technology with their clients. Other professionals are also likely to provide valuable skills (e.g. occupational therapists regarding environmental modifications to facilitate Internet use, or technical officers to give advice on appropriate access to devices and or software). Friends and family of people with aphasia (if willing to provide support) may have varying levels of skills and abilities, and/or understanding about the nature of the problem. Finally, community provision such as courses or drop-in sessions for help with digital skills and hardware problems could be intimidating for people with aphasia, or operated by staff without skills in communicating with people with impaired language.

Personal Factors

We can extrapolate from literature on Internet use (e.g. Dutton et al., 2013) that prior to aphasia, individuals' Internet use and skills will differ widely, and such diversity would also apply for those in a caring or therapeutic role with people with aphasia. Although these factors are not included in the ICF coding system (and so do not appear in Table 1), they are important to consider. Differences may relate to factors such as personal preference, age, gender, educational levels or linguistic/cultural origin; the person with aphasia and carer, or person with aphasia and professional offering support may have dissimilar views about or patterns of use of the Internet. This type of mismatch could lead to differing views and opinions on what is important and worthy of priority in terms of support and/or rehabilitation. This could have consequences for the type of support a person receives.

The loss of previous Internet skills has the potential to cause distress to a person with aphasia, particularly if the Internet was used daily. Aphasia contributes to social exclusion (Parr, 2007), a problem which access to communication and interaction via the Internet could ameliorate (Van de Sandt-Koenderman, 2011). For those who have never engaged with the Internet before the onset of aphasia, it has the potential to reduce the mental and physical health consequences of isolation and loneliness (Independent Age, 2010).

In summary, considering Internet use by people within aphasia within the two frameworks outlined above demonstrates that success is reliant not only on efficient functioning of language and ability to use language to participate and interact, but also on a wide range of other factors from across ICF domains of body functions, activities and participation, environmental and personal factors. Consideration of the potential barriers linked to each domain helps us to consider the need for interventions and wider service provisions targeting a number of areas.

Digital Technologies and Aphasia

In addition to considering potential barriers and risks around Internet use, it is useful to consider how facilitation might be provided. Research into supporting people with aphasia using the Internet is a relatively new domain. However, it is possible to draw upon work from related literature on aphasia and technology, to understand where people with aphasia have been supported to use computers for a variety of reasons.

To identify the literature relevant to aphasia and technology initial searches were carried out using PsychINFO and Linguistics and Language Behaviour Abstracts (LLBA) databases by entering the terms (aphasia or dysphasia) and (computers or technology) or (internet or human computer interaction) into search fields. Searches were from January 1990 until June 2015. In addition, the terms 'aphasia', 'aphasic', 'dysphasia', 'language impairment', and 'speech and language therapy' were entered into the Association for Computing Machinery Digital Library (dl.acm.org, 2015) which yielded further results from the field of computing science. We then screened the titles of papers which related aphasia to technologies or the Internet. These results were further screened by titles and abstracts, in order to focus on literature directly relating to the use of technology or the Internet by or with people with aphasia. We did not consider unpublished work, or papers over five years old with less than five citations on Google Scholar™. A few key well-cited or recent papers known to the first author which did not appear in search results were also included as it was felt their exclusion was not reflective of the literature. Papers from the same authors on the same topics were refined in favour of the most recent version. From this final bibliography, papers were identified which focused on the following themes: Internet

use, delivery of computerised therapy, design of technology for aphasia, use of specialist software with aphasia, mobile technologies and accessibility of text.

The following discussion summarises the literature found via searches as detailed above. Given the amount and diversity of the literature found, we do not claim to have included all literature, nor to have systematically reviewed the quality of the work within each area. Rather, we discuss the key themes emerging from this research with representative examples. We also considered how they illustrate methods and approaches that have been used to support people with aphasia in the use of technology.

Internet Use

There is a small body of literature directly related to facilitating Internet use by people with aphasia. Specific aspects of use such as email have been addressed, for example, work by Al Mahmud and Martens (2013) whose research involved collaboration between computer scientists, SLTs and people with aphasia to design and initially evaluate 'Amail', a simplified and accessible email tool. An accessible social media tool for aphasia was explored by Miller, Buhr, Johnson, and Hoepner (2013) using a participatory design approach to develop the software and provide initial evaluation.

Researchers have also developed and evaluated broader programmes aimed at teaching basic computer and Internet skills to people with aphasia. These are based on the premise that individuals with aphasia may need training to enable them to access the Internet, but that any training available in the wider community may be inaccessible for them. Egan, Worral, and Oxenham (2004) evaluated a computer skills training package designed for people with aphasia, citing the availability of appropriate training as a considerable barrier to people with aphasia accessing the Internet. In order to support aphasia related difficulties they helped with supported access to written instruction, and encouraged learning at an individualised pace. Prior proficiency with computers was not required. Participants favoured and needed access to 1:1 tutoring. Although not all were successful in achieving independent use, the authors point out that this did not necessarily equate to a measure of success, as some were happy with the experience of using the Internet while supported by others.

The effectiveness of group training of computer skills has also been appraised in the context of facilitating social engagement and self-management. Kelly, Kennedy, Britton, McGuire and Law (in press) worked with people with diverse pre-stroke experience with computers and expanded on Egan et al.'s study. They were able to facilitate interactive and social use of the Internet, demonstrating the potential to increase engagement and improve quality of life. Kelly et al. discuss and reflect on the difficulties of measuring and sustaining change for this type of intervention, and on creating bespoke interventions for individuals with a range of skills. Further research is needed on supporting people with aphasia with Internet skills, for example, by examining the impact of 1:1 versus group training, by comparing interventions between groups of people with aphasia who have never used the Internet and those who have lost previously held skills, or by considering how mainstream support might be made more accessible.

Computer Therapy

Therapy delivered via computer can be seen as a way to increase efficiency of service delivery, as an alternative to face to face treatment, and as a means to allow clients to work in their own homes at their own pace and at a time convenient to them (Palmer et al., 2012). Work in this area provides information about the acceptability and usability of interfaces for people with aphasia. One consideration is accessibility of hardware; the ability to use means to navigate and select items on a screen. Research suggests that this does not seem to be a major barrier to access. For example, Crerar, Ellis and Dean (1996) assessed their participants' ability to use a mouse prior to commencing computerised treatment and found nearly all participants could access the software in this way. More recently, Palmer et al. (2012) did not consider a physical disability to be a barrier to inclusion to their study, and enabled those with upper limb impairments or difficulties with a mouse to use a trackball or a touchscreen alternative to enable them to access therapy software. Considering usability for people with aphasia and recognising the need for simplicity, Mortley, Wade and Enderby (2004) used a simple interface, with icons such as a telephone to send completed data to a therapist. These examples show how simple modifications to both hardware and software can facilitate access for aphasia.

There are examples where computer software has been developed to be personalised to a person's needs, (e.g. exercises containing vocabulary that can be changed to suit the level of impairment of an individual (Mortley et al., 2004)). This type of adjustment illustrates how bespoke content can be created for aphasia, modifying provision of therapy to best fit each person.

There are also examples in the literature of innovative design and development in producing therapy software such as the use of digital pens to create interactive paper materials or photographs (Piper, Weibel, & Hollan, 2010, 2011, 2014), delivery of gesture therapy using sensors to read participant gestures (Marshall et al., 2013), and the development of a virtual gaming environment for people with aphasia to practice communication skills (Galliers et al., 2011). Such innovations have the potential to broaden the ways SLTs provide treatment. They demonstrate thinking beyond the more traditional means of 'screen plus keyboard and mouse' access, opening up possibilities for ways to engage with computers and the Internet that are potentially less intimidating, more accessible, intuitive and motivating.

Finally, the attitudes of those who support people with aphasia on use of computers for therapy is also worthy of consideration when considering acceptance and adoption of technologies. Wade, Mortley and Enderby (2003) found that partners could influence access to therapy in a positive way through intuitive knowledge of the needs of the person with aphasia. However, demands on and/or preferences of the partner should also be considered; Wade et al. also reported one partner who found providing support with therapy very taxing. Palmer, Enderby and Paterson (2013) also reported that some carers preferred not to provide help with computer therapy, and were happier with an external volunteer providing this support. This may relate to the issue of burden of care. These findings help to appreciate factors which may be relevant to the provision of assistance to access and use the Internet. Carers in some cases may provide effective support but their needs should be considered, particularly in relation to pressures on their time alongside other demands. In other cases it may be more appropriate to enlist specially trained volunteers, the effectiveness of which would need to be evaluated.

Design of Technology for Aphasia

The design and development of technology for aphasia is seen most in the production of alternative augmentative communication devices (AAC) and demonstrates collaborative design efforts between speech and language therapists, computing scientists and, in some cases, users. Examining factors related to success or failure of AAC use has great relevance to adoption or use of other types of technology. Van de Sandt-Koenderman (2004) argued that intervention for aphasia in the field of AAC needs to be tailored to individuals, and that factors influencing success are similar to those affecting the use of low technology alternatives (such as gesture/drawing/communication books). She also argues that factors likely to influence outcome include non-linguistic cognitive functioning, level of acceptance or expectations of an alternative means of communication, limitations of available vocabulary, type/amount of training given and skills of communicative partners.

Multi-disciplinary collaborations and user involvement are dominant in AAC. For example, early work by Waller, Dennis, Brodie and Cairns (1998) developing "TalksBac", an AAC system for aphasia, involved a speech and language therapist, and participants with aphasia in its development and evaluation. Davies, Marcella, McGrenere and & Purves (2003) used ethnography to inform the design of a communication aid and found that their method, although time intensive and demanding for participants, informed production of an AAC device. Boyd-Graber et al. (2006) utilised speech-language pathologists as proxies to support design, and describe in detail how they progressed from early paper prototypes to a working AAC device for trial with people with aphasia. Description of process of design is invaluable in demonstrating how developments can be made through collaborations with those who know and understand aphasia. This is also seen in studies involving people with aphasia and their partners at various stages of design and redesign (e.g. Koppenol, Al Mahmud, & Martens, 2010). More recent developments have produced increasingly bespoke and user-sensitive AAC for aphasia, e.g. by the use of portable cameras to capture life experiences and share stories (Al Mahmud, Gerits, & Martens, 2010), the combination of low-tech with high-tech communication support (Al Mahmud, Dijkhuis, Blummel, and Elberse, 2012) or by GPS technology to provide context-aware support and access to vocabulary (Demmans Epp, Djordjevic, Wu, Moffat, & Baecker, 2012; Kane, Linam-Church, Althoff, and

McCall, 2012). Collaborative multidisciplinary work with a focus on aphasia and technologies was carried out by the Aphasia Project (McGrenere et al., 2003). This research group discussed the challenges of designing technology to suit the intended end users and stressed the importance of having people on a design team who are able to communicate with a population with impaired language. Work from the Aphasia Project produced several innovative and bespoke technology designs, including a sound and image enhanced daily planner (Moffat, McGrenere, Purves, & Klawe, 2004), a visual recipe book (Tee et al., 2005), and 'Photo Talk', a digital image communication application (Allen, McGrenere, & Purves, 2008). Galliers et al. (2012) discussed the process of involving people with aphasia in the design of a gesture therapy tool, describing challenges they faced when consulting with people with aphasia and reflecting on the experience.

The projects described above share a common theme of the ability to demonstrate and evaluate potential uses of new technologies for aphasia. There is much to learn here regarding facilitation of Internet use. Collaboration between end users, those who support them, and experts in human computer interaction reveal how it is possible to use innovation, creativity, and intelligent design to identify solutions to difficulties faced by people with aphasia. The experiences of researchers reporting on these types of multidisciplinary collaborations are important, as is the vital contribution of people with aphasia in any design or development of technology which takes into account the end user from the beginning of the digital technology design to its end.

Use of Existing Software for Aphasia

Several researchers have taken a different approach, using existing software and applying its use to aphasia. As people with aphasia are a relatively small and heterogeneous population it seems sensible to utilise widely available tools where possible. This can be helpful in supporting Internet use as it has the potential to maximise opportunities for participation without the need for bespoke software which may be expensive to design and produce and runs the risk of dating quickly. Voice recognition software (originally designed to support physical disability causing difficulties with typing) is an example, which was investigated as a possible tool for people with aphasia by Wade, Petheram and Cain (2001). Initial results from six participants showed poor levels of acceptability at single word level but the authors made suggestions for how specific training and support might

improve accuracy and therefore usefulness. The technology has since been evaluated in single cases studies as an aid to writing (Bruce, Edmundson, & Coleman, 2003; Estes & Bloom, 2011), and most recently by Caute & Woolf, (in press). Caute and Woolf present the case of a client with aphasia who made significant improvements in writing following training to use voice recognition software. Gains in quantity and quality of writing also led to increased social participation for their client. Thiel, Sage and Conroy (2014) provide a review of the literature on interventions for functional writing, which included eight therapy studies using assistive writing technologies as part of treatment. The authors suggest these types of technologies appear to have some use for people with aphasia and acknowledged the large gap in the literature on this area. To date, research in this area is in its infancy and, consequently, it is not yet clear which types and presentations of aphasia are best suited to using voice recognition software, or how it could be adapted to improve its utility for people with aphasia. Voice recognition software is now a fairly standard feature on modern devices, so as a relatively affordable and easy to access tool, it warrants further investigation. Text to Speech reading support (originally developed for the visually impaired) may also be used to help people with difficulties with reading. As with voice recognition software, the evidence is based on single case studies; for example, Harvey, Hux and Snell (2013) present a case on using text to speech to support an individual with mild aphasia and cognitive impairment, with cautious results as to the positive benefits for the individual concerned. Strategies to support literacy on computer applications were outlined and reviewed by Dietz, Ball and Griffiths (2011), who concluded that more research is needed in this area.

Mobile Technologies

Accessibility of mobile phones, now a frequent means by many to access the Internet (Dutton et al., 2013) is largely unexplored in aphasia. Greig, Harper, Hirst, Howe and Davidson (2008) addressed potential barriers and facilitators specific to mobile phone use with aphasia. However, the internet connectivity of phones and tablet computers has changed considerably. Smartphones raise new issues around accessibility, while the rapid influx of available software for mobile devices is difficult to continually evaluate and appraise in a systematic and comprehensive way (Brandenburg, Worrall, Rodriguez, & Copland, 2013). There has been a vital resource

development in the form of the Aphasia Software Finder (Tavistock Trust for Aphasia, n.d.) which compiles general software and apps for aphasia as well as therapy software. There are also recent descriptive reports on current practice using tablet devices (e.g. Kurland, 2014). Similar to work on computerised therapy for aphasia, this area of research can provide valuable insight into accessible interfaces for people with aphasia; what they find motivating and easy to use, and what facilitates digital participation.

Although general guidelines and descriptive accounts of therapy-related applications for mobile technologies are available (Holland, Weinberg, & Dittelman, 2012; Hoover & Carney, 2014; Ramsberger & Messamer, 2014; Szabo & Dittelman, 2014), the surge in apps 'for aphasia' therapy has not been met with the same level of critical evaluation as conventional face-to-face therapy studies or work on mobile devices within the field of AAC. However, evidence is emerging. Kiran, Roches, Balachandran and Ascenso (2014) investigated the effectiveness of continuation of therapy using an iPad app, and Kurland, Wilkins and Stokes (2014) designed and evaluated the use of personalised iBooks software to deliver home practice as part of naming therapy. Specific to Internet use, this area of research can help us evaluate which features and uses of mobile technologies are the most beneficial for people with aphasia; which types of interface are the most motivating and easy to use, and which applications can facilitate digital participation.

Accessibility of Text

Research on reading is highly relevant to Internet use, considering the level of literacy competence needed for many aspects. Improvement of reading skills could improve Internet use in a number of areas. However, the potential differences between computer and paper based tasks must be considered, recognising that the two are not directly equivalent. On-screen reading is slower than paper based reading (Noyes & Garland, 2008) but technology allows us greater flexibility for adaptations to screen based text. Research on the facilitation of paper based reading may therefore need adaptation to be relevant for understanding of online content.

There are existing guidelines for written information for aphasia (Stroke Association, 2012), but these would not directly apply to content which is ever changing, multi-media, and interactive, and which should seek to

comply with web accessibility standards (Web Accessibility Initiative, 2015). However, the recognition that people with aphasia often find it difficult to process written information on screen has been considered by researchers examining issues around accessibility of the web; Ghidella, Murray, Smart, McKenna and Worrall (2005) examined websites with content related to aphasia in relation to their degree of accessibility of textual information. They investigated the views of both SLTs and people with aphasia on the accessibility of several websites about aphasia. Their conclusions showed lack of agreement, which highlights the importance of consulting and including people with aphasia in the design of websites aimed for them. Similarly, Kerr, Hilari and Litosseliti (2010) used card-sorting techniques and examined how to structure preferred written information about stroke for people with aphasia on websites, demonstrating one way of including people with aphasia in the web design process. Availability of accessible information is vital, but not only in finding out about aphasia and stroke since people with aphasia are likely to be interested in accessing information across other areas of the Internet. Devlin and Uthank (2006) addressed this regarding access to news and current affairs, with work on text simplification of online newspaper stories. There is of course a disadvantage of only being able to access environments which have been specifically modified, the virtual equivalent of a wheelchair user having to stay on the ground floor of a building where there are no lifts. Full and equal access to all online information for people with aphasia presents considerable challenges, not just related to literacy skills, but also to multimedia formats (e.g. understanding of audio and video content).

Discussion

This paper has considered internet use for people with aphasia, discussing key areas related to supporting people with aphasia to achieve equality of access to and use of the Internet. In doing this, we have brought to the fore wider, relevant perspectives beyond aphasia. People with aphasia may be vulnerable to digital exclusion, not only because of their aphasia but also other concomitant factors, faced by other social groups. We have therefore considered the evidence about digital exclusion of older, disabled and socially excluded groups. There may also be additional factors for the individual such as other cognitive skills, physical disability, type

and amount of therapy intervention available to them, alongside personal goals, motivation and support from family, carers and friends.

Using the CCP framework allows for careful consideration of the many skills involved for successful Internet use. The ICF illustrates how body structure and function, activity and participation, the environment as well as personal factors may all interact and contribute not only to potential barriers but also facilitators. Both frameworks highlight potential areas of difficulty, ranging from communication and negotiation around the provision of Internet services to the ability to request support and understand the issues causing problems. These can be viewed alongside the potential impact of aphasia on the more directly interactive aspects of Internet use as well as spoken comprehension and production, reading and writing.

The literature related to aphasia and technologies has also been explored, illustrating factors relevant to Internet use by people with aphasia from diverse disciplines and research paradigms.

Digital literacy and Internet use will differ considerably among people with aphasia, just as they do in the wider population. This suggests differing needs, for example, initial engagement of people with aphasia who are not users of the Internet contrasted with support for those who were Internet users, and for whom aphasia has impaired this aspect of their communication. In the same way that SLTs may address a person's goal to read a newspaper or novel, goals may now be related to reading online news or emails, broadening the scope of clinical practice. Other examples include as well as attending support groups, people with aphasia may now wish to access support with living with a long-term condition from online forums or groups. As an alternative to using the phone, they may want to engage with video calling services such as Skype or FaceTime.

The on-line environment is a potentially enabling one, yet as Jaeger (2012) discussed, as the digital world becomes more and more dominant and essential in activities of daily living, there is additional risk of exclusion. Environmental factors such as support provision may be key for some. However, there is likely to be variability in accessing support. This may be due to the fact that those who are likely to provide support may have their own difficulties with Internet use, or not know how to provide specific support for aphasia. Access to training or

exposure to the Internet pre-stroke may influence use, as may financial implications of cost of broadband/phone contracts/Internet enabled devices. Viewing the Internet as a mirror of the real world, and as a potentially excluding environment, it is possible to see barriers for people with aphasia not solely related to making devices work and navigating their content, but arising from difficulties accessing training or support, or from previously limited skills.

If barriers are experienced across ICF domains, interventions designed towards change in a number of areas are likely to be of benefit. Regarding Internet use, this means approaching the problem from several directions. To give examples: at the individual level, interventions targeted at improving reading might be accompanied by training on use of text to speech software, but also on ensuring a support system is in place to guarantee that updates to software or changes of equipment do not negatively impact on future use. When working with aphasia support groups, training aimed at introducing or improving Internet skills could look beyond the supportive environment of a group setting and consider how newly acquired skills can be developed, used, and maintained in participants' homes.

A number of successful projects in the literature involved working in collaboration with people with aphasia, viewing them as experts within the research process. There is an ongoing call for people with aphasia to be involved in research (Brady, Frederick, & Williams, 2013). In the case of technology and the Internet, this means ensuring that their voices are heard in a future which will undoubtedly involve further rapid developments. Technologies have much potential for aphasia, e.g. Blanck (2014) presents one view of a potential future where web equality is achieved via bespoke design of Internet content for individuals. He argued that developments in technology should give us the ability to personalise the web to meet a variety of needs of those with cognitive impairments. Such personalisation would reduce cognitive load for the individual and facilitate access. So, content would be bespoke rather than uniform.

Conversely, the consequences of failing to support people with aphasia with digital skills could lead to inequalities of access to a number of essential areas of daily life which now require Internet skills. Despite rapid technological change influencing the way we communicate, the potential for breakdowns to online

communication and interaction have not yet been fully addressed. Nor has the likelihood that people with aphasia already and might continue to face exclusion in an increasingly digital world. For many people, aphasia will significantly impair ability to participate in aspects of internet use which frequently form an essential part of daily interaction. As the online environment constantly evolves, there will be an ongoing need to develop means to assess how aphasia can impact on every day Internet use. In addition, interventions are in order to understand the best ways to both facilitate change and to provide acceptable and effective levels of support. This issue is a complex one, likely to involve the expertise of SLTs, occupational therapists, human computer interaction specialists, accessibility experts, web designers, web developers, charitable organisations, and users themselves. Other groups may also provide helpful insights such as those with cognitive, visual, or sensory disabilities. Further work in this area might focus on a closer examination of work produced for and in collaboration with these groups and how this might benefit aphasia. There is also likely benefit for researchers in these fields to learn about work specific to aphasia.

The motivation to address these issues comes from the ability of the Internet to increase social participation, reduce isolation, increase independence, save money, and improve access to current information. There are likely to be considerable benefits for aphasia of further research in this field. A vital consideration is to understand the complex interrelationships between factors already known to contribute to digital exclusion, and any additional demands imposed by aphasia.

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Table 1: Barriers to Internet Use for Aphasia: Communications Consumer Panel Categories Linked to the International Classification of Disability and Functioning

CCP Categories: Skills Needed to Get the Most out of the Internet	Possible Barriers for People with Aphasia (in relation to category)	Classification of Barriers using ICF Coding B = body functions, D = activities and participation, E= environmental
To get interested	Obtaining accessible information on uses and possible benefits	→ B210 seeing functions, B230 hearing functions, B167 mental functions of language, E535 communication services, systems and policies
	Access to basic introductory courses appropriate for aphasia	→ B210 seeing functions, B230 hearing functions, B167 mental functions of language, E5850 education and training services
	Ability to communicate interest to others	→ B167 mental functions of language
To get online	Ability to understand and retain information on new equipment or upgrades	→ B167 mental functions of language, B144 memory functions
	Difficulties with money/numbers when understanding cost or equipment or software	→ B167 mental functions of language, B1720 simple calculation
	Ability to negotiate purchases/broadband contracts	→ D620 acquisition of goods and services
	Access to broadband in care homes	→ E5350 communications services
To make it work	Ability to understand and follow instructions on paper and on screen	→ B210 seeing functions, B230 hearing functions, B16701 reception of written language, B164 higher-level cognitive functions
	Difficulties with direct access (e.g. motor, visual, sensory)	→ B760 control of voluntary movement functions, B210 seeing functions, B230 hearing functions, B265 touch functions
	Remembering/entering passwords	→ B144 memory functions, B16711 expression of written language
	Inputting information needed to search for information	→ B210 seeing functions, B16711 expression of written language, B1672 integrative language functions D175 solving problems
	Access to appropriate support	→ E3 support and relationships
	Understanding and negotiation of control settings	→ B164 higher-level cognitive functions, B167 mental functions of language, D175

CCP Categories: Skills Needed to Get the Most out of the Internet	Possible Barriers for People with Aphasia (in relation to category)	Classification of Barriers using ICF Coding B = body functions, D = activities and participation, E= environmental
To manage the risks		solving problems
	Ability to read and understand possible fraudulent information ⟶	B210 seeing functions, B16701 reception of written language
To enjoy the benefits	The ability to use all aspects of online communication and interaction – e.g. education, shopping, social media, booking appointments, email, photo sharing, local and national government information. ⟶	B210 seeing functions, B230 hearing functions, B164 higher-level cognitive functions, B167 mental functions of language, D1 learning and applying knowledge, D2 general tasks and demands, D3 communication, D6 domestic life, D7 interpersonal interactions and relationships, D8 major life areas, D9 community, social and civic life
	Interaction with and creation of verbal/written content – e.g. status updates, video diaries, comments on news/blogs/recipes etc ⟶	B210 seeing functions, B230 hearing functions, B167 mental functions of language