INNOVATIVE HEALTH TECHNOLOGIES PROGRAMME

Inclusive Internet Technologies for People with Communication Impairment

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RESEARCH FINDINGS

KEY FINDINGS

Using participative and action research methods, this study explored the issues of access to the Internet for people with communication disability: those who struggle to use written and spoken language. A group of people who have aphasia (a communication impairment that commonly follows stroke) scrutinized a number of health and disability related websites and documented the barriers to accessing information and support. The study also investigated the potential and pitfalls of the Internet as a means of expressing identity and sharing narrative, when talking and writing is difficult. A website was built to demonstrate accessible design for this group.

- People with aphasia encounter many barriers when using the Internet. These include busy site design and layout; multi-tasking demands; font-size, colour and background; complex navigation; formal, abstract language; elaborate sentence structure; overwhelming or obscure imagery.
- Other barriers concern the social interface between site and user. These include 'tone of voice'; priorities and balance; inconsistent language; site narratives; and users' own purposes and perspectives in seeking support or information. The sense of exclusion from sites is often consolidated by feelings of panic, inadequacy and fatigue.
- Participants engaged with the personal stories found in disability, stroke and aphasia related sites. They were critical of some aspects: text-based, sanitised or ghost-written accounts and predominantly heroic, tragedy or restitution narratives.
- Purposes in constructing personal pages were diverse, and the outcomes idiosyncratic. Participants first used a range of non-text methods and favoured non-standard writing. As the process developed, many opted to standardise their pages, oversee their editing, and render them more text-based.
- The Internet has enormous potential as a vehicle for authentic, flexible, non-standard narrative. If barriers to access can be overcome, it offers a means of contacting and supporting others for whom verbal communication is a struggle.

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Barriers and facilitators to Internet access for people with communication impairments

People with aphasia encountered numerous barriers to Internet access. Design aspects included long sentences and paragraphs, acronyms, jargon, metaphor and abstraction. Search facilities were problematic, particularly the retrieval and spelling of search terms, detecting and remedying spelling mistakes and understanding the scope and conventions of querying.

Consistently designed navigational tools and page layout enhanced usability. Websites that distinguish navigation from content enabled participants to make rapid judgements without over-burdening language processing skills. Many people with aphasia have had strokes affecting their right visual field: one- or two-column layouts were helpful.

Images that support written text facilitate understanding and act as a 'break' to reading, but need to be chosen carefully. Gratuitous use of animation distracts from meaning, and ambiguous or unrelated imagery should be avoided. Difficulties with reading mean that first impressions of a particular website are commonly formed from the home-page imagery: and this can express alienating narratives.

People with aphasia commonly have physical impairments associated with stroke, particularly right-sided paralysis. Despite the availability of assistive devices, many participants experienced problems using the mouse and keyboard, scrolling and windowing.

Barriers and facilitators emerged that were unrelated to the interaction between user and website. Those with PCs at home struggled to negotiate access to the machines, and family time and support. The jargon and slang surrounding the Internet, and the complexity of cultural conventions of Internet use serve to disempower those with communication disabilities further.

Many of these barriers and facilitators are similar for other groups of disabled people. Consequences for people with aphasia are arguably more severe, as alternative strategies are often not available. Disabling barriers are not simply a matter of distracting icons, obscure language or unclear, cluttered design. They are also socially situated, relating to the priorities of the web-provider and the social interface between provider and user. In addition, personal narrative determines information-seeking priorities.

The Internet as a means of expressing identity, hearing and telling illness narratives, and negotiating the meaning of aphasia

Inaccessible design made participants feel excluded. Sites were felt to be about people with aphasia, not for them. Family members, carers and healthcare professionals were perceived as the intended audience. Participants felt alienated by websites demanding a protracted search for information; explanations using medical imagery, terminology and jargon; and suggestions that people contact organisations by phone (a formidable prospect for people who struggle to talk). Such sites precipitated dependence on the support of others.

Obscure language and jargon were even more excluding when they occurred within sites that made some gestures towards increasing accessibility. Inconsistency of style and language provoked strong reactions:

> *'It makes you feel even more foolish because you're trying to understand and they're not letting you in on it. The rug is pulled from under your feet. You feel you're doing something by logging on, gaining control; this is almost like a big sign saying 'no, you can't come in here.'*

Disability-related organisations, that should prioritise access, failed to accommodate communication impairment in their websites. Commonly, an aspirational tone led participants to think sites were intended, not for them, but for young people with motor impairments. Clashing with participants' pragmatic life-views and accounts of disability, this met with some cynicism.

Restitution narratives, prominent within charitable aphasia and stroke-related websites, provoked strong reactions. Some were inspired and encouraged, others found the approach simplistic and patronising. Engagement with sites was often contingent on subscribing to a specific perspective on aphasia, stroke and disability.

They're all so upbeat': Personal stories of people with stroke and aphasia

Group members were interested by the personal accounts of people with stroke and aphasia, many attached to some charitable websites. One website was singled out and applauded for its use of emboldened key words, short sentences and icons, and its attention to appropriate pacing of information. But many individual accounts mirrored the organisational narrative: most were inaccessible. Participants were taken aback the length, density and complexity of these personal accounts of stroke. They suspected that people with aphasia had been excluded, or their accounts ghost-written or sanitised.

A number of accounts emphasised perseverance and determination to recover, provoking mixed reactions. Even if participants did not agree with representations, however, these accounts prompted them to define their own perspective in response. For some with little language, this was a rare opportunity to express and share their life-view.

Participants pointed out a failure to acknowledge the emotional, social and financial impacts of aphasia. While they did not simply want to hear stories of hardship, a balanced recognition of difficulties, together with strategies developed, would be welcome.

'Pick me up and not a down down. Up up!': construction of personal web-pages

Participants were invited to construct their own personal web-pages as part of the project site. Pages varied enormously in scale, format, content and style. They offer idiosyncratic combinations of text, poetry, photographs, diagrams, and drawings. The production of written text raised the issue of whether or not non-standard, 'different' language should be edited. A minority elected to construct their pages without editing.

A number of paradoxes emerged. One participant decided to avoid writing difficulties by speaking aloud while a researcher typed verbatim. This would provide a first-hand personal account, preserving word-finding difficulties and grammatical anomalies. However, hearing the text read back proved a distressing experience. To the embarrassed participant, this sounded 'stupid.' She instructed the researcher to clarify the message then to 'translate' it into standard English. Construction of the web-page proceeded in this way, with the participant using a mixture of spoken keywords and phrases, drawing, gesture and writing, and the researcher making verbal suggestions. This participant determined vocabulary, and the perspective, order and structure of the page. Even though it is an authentic personal account, controlled by the person who generated it, the communication impairment is not apparent.

Participants' personal narratives started to replicate some of the stylistic traits of which they had been critical: tidied-up language and the production of inaccessibly long, text-based accounts.

Participants varied in terms of thinking about the purpose and content of their site. Some wished to pass on wisdom and help others negotiate emotional and practical obstacles. Others aimed to inspire and encourage: 'Pick me up and not a down down. Up up!' Others saw a chance to reflect on their past, present and future. Some focused on giving an intricate account of the event of stroke itself and details of the hospital experience. One participant elected not to refer to stroke and aphasia at all but focused entirely on his current family life. Another, a former journalist, positively celebrated his aphasia in his page. His insights, comments and poems, unedited and idiosyncratic, are laid out in a newspaper format.

Can the Internet provide a virtual community for people isolated by aphasia? The answer to this question seems to be, not surprisingly, yes and no. People with aphasia were transfixed by others' accounts and by the websites that related to their experience ('Fascinating! Fascinating! Wow! Yes!'). On several occasions, the group elected to make contact with different organisations and individuals. But there are many barriers to community building. If they were not excluded by design or alienated by narrative and decided to make contact, people with aphasia often fell at the first hurdle when they had to register, fill in a form, type a password and provide some information about themselves.

In summary, the Internet has enormous potential as a source of information, contact, support and self-expression for people with aphasia and other communication impairments. However, this group encounters many design-related and socially mediated barriers in attempting to access and use the Internet. This results in a potentially empowering technology consolidating their social exclusion. Identifying and removing these barriers will enable this group to cross the digital divide.

About the Project

Participants

Thirteen people with aphasia took part in this project, recruited through Connect, the Communication Disability Network. Participants were purposively selected to represent a range of Internet experience, age and severity of aphasia. Most group members could speak fairly fluently and follow discussions when facilitated, but three people with little verbal output and limited comprehension also joined the project. They used a variety of means to communicate including drawing, some writing, gestures, facial expression and prosody. Comprehension was facilitated by gesture, repetition, key words, writing and frequent verification. Following the development of the prototype website, a number of speech and language therapists in the UK, US, Canada and Australia were asked to recruit local groups of people with aphasia to evaluate the site. In the event, five groups of virtual volunteers undertook to meet and record their discussions. The project was monitored by an advisory group, comprising people with different communication impairments, and experts in computer and assistive technology.

Procedures

Following initial in-depth interviews probing their experience and expectations of the Internet, participants met weekly over a one year period. The first part of each session was spent collectively surfing the web. Discussions, comments and insights were probed, audio-recorded and documented. Participants then surfed individually or in pairs. Detailed field notes were made, documenting methods, difficulties, strategies and reactions. Researchers provided assistance when requested, using Total Communication methods throughout.

Participants explored the scope of the Internet, visiting a selection of websites including sites relating to shopping, auctions and local and personal interests. However, most group surfing time was spent exploring nine aphasia, stroke, disability and health-related websites. Data from the group and individual sessions were analysed. A taxonomy of barriers and facilitators to Internet access was developed. In addition, responses to personal stories and web-pages of disabled people were scrutinised, and data analysed for themes regarding the expression of identity and the negotiation of the meaning of illness.

Work began on constructing a prototype accessible website (www.aphasiahelp.org). The web-designer involved participants in carrying out usability trials and individual and group consultations concerning content and design.

Personal web-pages, to be included in the prototype website, were constructed. Participants worked first in groups and then one-to-one with the research assistant who scanned pictures and images brought in by participants and supported elaboration and clarification of content.

During the closing phases of the project, home visits were made to four participants, documenting the social context of Internet use within the home and family.

Sessions ended with a group meeting in which the new website (including web-pages) was reviewed. Participants took part in closing interviews. Interview data were transcribed. Interview, field-notes and discussion data were transcribed and analysed using the Framework method (Ritchie and Spencer, 1994).

Inclusive research

The project was designed to be inclusive of people with aphasia. Consent materials, project information, agendas, minutes, briefing notes and other documentation were adapted to be aphasia-friendly (streamlining information, simplifying expression, enlarging font-size and adding illustrations, headings, key-words and bullet-points). Meetings and discussions were facilitated and conducted slowly, with frequent re-caps. Researchers were trained in supporting communication and were supervised. Participants were co-researchers in the project. Paid for their contribution to the working group, they took a number of additional roles, for example joining the advisory group and interviewing candidates for the research posts.