

Project report

What facilitates communication between people with little or no speech and general practitioners? A research project underway in Melbourne, Australia

Louise Greenstock and Brendon Wickham

Louise Greenstock is a Research Fellow at the Australian Health Workforce Institute, The University of Melbourne, Melbourne, Australia.
Brendon Wickham is a Program Consultant (eHealth Support) at the General Practice Victoria, Carlton, Australia.

Abstract

Purpose – *This paper seeks to provide an overview of research that is currently underway at The University of Melbourne, Australia, exploring the ways in which people with little or no speech communicate with general practitioners (GPs).*

Design/methodology/approach – *The project aims to explore the potential role of internet technology and high speed broadband in facilitating communication between people with little or no speech and GPs. A literature review was conducted which aimed to draw together existing literature on several topics surrounding the health care communication needs of people with little or no speech and their GPs and to summarise the findings of previous research in these areas. This overview of existing literature informed the development of an exploratory research project.*

Findings – *Existing research shows that people with little or no speech are at risk of receiving sub-optimal health care and experiencing significant barriers to communication in health care contexts. The exploratory research project is still underway at the time of writing but this aims to conduct a simple needs analysis with a small group of people with little or no speech and a small group of GPs, through the use of reference groups and participant engagement.*

Originality/value – *This project seeks to explore the potential of internet technology to meet the communication needs of patients with little or no speech and their GPs.*

Keywords *Communication, General practitioners, Health care, Internet, Patients, Speech*

Paper type *Research paper*

Introduction

How can we improve access to high-quality health care for all patients? What barriers to accessing health care do people with communication disabilities face? And how empowered do they feel in making choices about their own health and the care they receive? Most people take it for granted that they can use the phone to make an appointment with a GP, or walk into a clinic and ask to make an appointment. However, for many people with speech, language or communication difficulties, this process is more complex. The authors are part of a team of researchers who are now exploring the role of communication in health care and the consequences for patients with disabilities whose communication needs are not being met in these contexts.

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Speech Pathology Australia separates communication disability into five categories, speech, language, pragmatics, fluency and voice (Speech Pathology Australia, 2011). Although individuals with communication difficulties in any of these categories may face challenges in communicating in health care contexts, this research relates to those with expressive speech and language difficulties. These individuals have physical or cognitive difficulties producing speech due to an acquired or innate physical or neurological impairment. These individuals may have cerebral palsy or have experienced acquired brain injury or stroke. In this paper, these individuals are identified as having little or no speech.

In the literature surrounding disability and health care delivery, there is evidence to suggest that people with little or no speech are at risk of receiving sub-optimal health care and experiencing significant barriers to communication in health care contexts (Addington-Hall and Kalra, 2001; Aulagnier *et al.*, 2005). In particular, persons with little or no speech appear to experience barriers in accessing health care (O'Halloran *et al.*, 2008). Many people with little or no speech use communication aids and systems that enable them to communicate effectively in everyday life but it is not always possible for them to use these systems in health care contexts. Not being able to access and use a preferred mode of communication is likely to cause frustration in any context but is potentially dangerous in a health care context. Communication in health care is a right and research has shown alarming consequences of communication breakdown in health care contexts (Greenberg *et al.*, 2007; Smith, 2009).

This paper provides an overview of a piece of research which is currently underway in Melbourne, Australia. The research is funded by the Institute for a Broadband-Enabled Society (IBES) at the University of Melbourne. The research is led by the Australian Health Workforce Institute (AHWI) and General Practice Victoria (GPV), the peak state-based organisation for the Divisions of General Practice. AHWI is a research institute dedicated to exploring the long-term sustainability of the health workforce with programs of research addressing new models of care, workforce planning, access to health care and health literacy. AHWI has partnered with GPV to address the concern that people with little or no speech are sometimes disempowered when communicating in health care contexts. Communication Rights Australia (CAUS), an organisation providing specialist advice and advocacy for people with little or no speech are also involved in the project.

In June 2010, IBES provided seed funding for an exploratory project exploring the ways in which people with little or no speech communicate with general practitioners (GPs). The project aimed to identify challenges for people with little or no speech in making contact and interacting with GPs in accessing primary health care. The project also aimed to explore whether new technologies and high-speed broadband had any potential to address these challenges and/or enable people with little or no speech to use their preferred mode of communication in these contexts. The researchers are also exploring whether assistive technology or software already exist or could be developed to facilitate communication for people with little or no speech in health care.

Findings from the literature review

A narrative literature review was conducted which aimed to draw together existing literature on several topics surrounding the health care communication needs of people with little or no speech and their GPs and to summarise the findings of previous research in these areas. In particular, the reviewers sought to explore the contribution of several key corpuses of literature in explaining what is currently known about communication between people with little or no speech and GPs and the extent to which internet technology might have the potential to act as an enabler/facilitator of communication in this context. A selection of this literature will now be explored.

The literature presented findings in relation to communication between patients and health professionals, the utilisation of health care by people with disabilities, environmental barriers to communication in health care contexts, and a poorer standard of care for people with disabilities (O'Halloran *et al.*, 2008). The literature surrounding assistive technologies and telehealth was also explored. A general overview of this literature is presented below.

There is a range of evidence to suggest that people with disabilities receive sub-optimal care and that communication in health care contexts is often challenging for this population. Research has shown that persons with disabilities are at “an increased risk of experiencing ineffective patient-physician communication, compromising current health status and increasing the possibility of secondary health conditions” (Smith, 2009, p. 206). People with disabilities have been found to access health care less frequently than other patient groups. Hwang *et al.* (2009, p. 28) reported the finding that people with disabilities “use primary preventive health services less than general populations [...] have poorer overall health outcomes [...] more preventable emergency room visits and hospitalisations [...] and they report more unmet needs and dissatisfaction in the services they do receive”. Disabled patients may be most at risk of “injury through neglect, delayed diagnoses, or inadequate treatment” (Kirschner *et al.*, 2007). Disabled patients themselves report a poorer standard of care (Balandin *et al.*, 2007; Nieuwenhuijsen *et al.*, 2008).

Many of the issues identified in the provision of the health care for disabled patients are related to various forms of barriers and constraints within health care environments. These barriers were found to be associated with the attitudes of health professionals and issues that constrained or inhibited channels of communication in these environments. People with communication disabilities are particularly at risk of “not being able to communicate effectively with their healthcare providers and this might directly compromise their health, healthcare and their right to participate actively in decisions about their healthcare” (O’Halloran *et al.*, 2009, p. 601).

Patients with little or no speech may experience barriers to communication in many health care contexts. Patients with cerebral palsy who may find unaided speech challenging have reported difficulties communicating with nurses and in some cases this has had “serious negative health consequences” (Balandin *et al.*, 2007, p. 56). Communication breakdown was linked with the patient’s difficulties in initiating communication about wants and needs and gaining attention in the health care setting.

People with little or no speech use assistive technology and various forms of communication aids to support two-way communication in their daily lives. The latter stage of the literature search focused on the utilisation of assistive technology and communication aids in health care and explored the role of assistive technology as an enabler of communication in health care contexts. Though these technologies exist, in a health care context the communicative preferences of the patient may be met with a lack of appropriate infrastructure and varying levels of willingness and adoption of these communication methods among health professionals and administrative and operational staff. This must be explored more fully.

While access to high-quality care and appropriate opportunities to communicate with health professionals may be variable, new models of care are emerging around the world which may offer potential solutions to bridge some of these gaps. Initially, telehealth developed as a collection of technological solutions in relation to providing health care and access to health services via telecommunications. While not primarily designed for people with disabilities, the systems and services that telehealth models of care can provide may hold potential for addressing the needs of patients who have additional or unique communication needs. The first stage of the literature review indicated that sub-optimal care and access to health care is a concern for people with disabilities and those with communication difficulties in particular. Although telehealth has not yet been clearly linked with disabled patients in existing literature, it seems logical to explore new ways to improve care and communicative channels for this population due to the innate potential of technology to be a facilitating medium in this context. There is a need for exploratory research, which involves analysis of the needs of patients and the population as a whole and then investigates possible solutions and tests these out. Researchers must engage with consumers/patients and the population as a whole.

This brief overview of the existing literature informed the development of an exploratory research project due to be completed in June 2011. This research aims to conduct a simple needs analysis with a small group of people with little or no speech and a small group of GPs. Reference groups were selected as the medium for this process as close conversation

with participants was considered as the most effective method because it allows the researchers to guide the conversation with prompts. Participants can also engage with each other and explore their responses to questions raised. Reference groups will be organised to accommodate the needs of participants and will be video-recorded so that all communication attempts will be picked up.

Two reference group events are planned for early 2011. The first of these reference groups will involve four participants who are currently living in Melbourne or surrounding areas and who consider themselves as having little or no speech. During the reference group the participants will be invited to discuss their experiences of communicating with GPs and accessing primary health care and what they feel are the challenges when communicating in this context. They will also be asked about their preferred media and/or techniques for communicating with health professionals and whether the internet plays a role in this.

The second reference group will involve four GPs who currently live and work in Melbourne and have some experience of using the internet. The GPs will be encouraged to discuss their experiences of working with people with communication disability, particularly those with little or no speech. They will also be questioned about the use of internet technology in their practice and communication with patients. Half way through the second reference group, the researchers will distribute summarised notes from the first reference group, which provide an overview of the comments made by the participants with little or no speech. Participants will then be given the opportunity to discuss the comments made by participants with little or no speech and share their opinions about the preferences for communication mediums expressed by the participants in the first reference group. Full ethical approval was received from the University of Melbourne Human Research Ethics Committee before the sampling and data collection began.

The primary objective of this research is to explore the perspectives of patients with little or no speech on their communication with GPs.

Conclusion

As technology continues to develop at an ever-increasing pace, it is important that we increase our understanding of the ways in which new technologies might be harnessed to enable different population groups to participate more in everyday life, particularly if their choices are limited and improve their access to opportunities around them. This means exploring new ways to use existing technology and developing new technology with the needs of different groups in mind. This project seeks to explore the potential of internet technology to meet the communication needs of patients with little or no speech and their GPs. It does not, however, assume that technology will necessarily provide a solution. This is something that can only be answered if those that design the technology take care to understand different needs, and if technologists, patients and GPs come together to identify opportunities for improvement.

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Corresponding author

Louise Greenstock can be contacted at: lgreens@unimelb.edu.au

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