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CASE STUDY

Bedside computer access for an individual with severe and multiple disabilities: A case study

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Abstract

Purpose. This case study documents the process of designing a custom-tailored bedside computer access solution for a 20-year old individual with quadriplegia and reports the effects of computer access on her participation in life activities.
Method. We adopted a person-focused approach to match the individual to an access solution. Two months after the access solution's introduction, we measured its impact using a 2-dimensional Fitt's Law test and questionnaire from the ISO 9241-9 standards document, typing tests, a usage log and a semi-structured interview. The Canadian Occupational Performance Measure was also administered pre- and post- access, focusing on the client's perceived ability to use the computer.
Results. After 2 months, the individual was spending an average of 8.4 h per day on the computer, engaging in electronic communication, recreational, and educational activities. She learned single-switch typing with a throughput of 1.03 bits/s and targeting accuracy of 87.5%. The questionnaire revealed that the client was thoroughly satisfied with the interface. These results were interpreted as positive gains in the International Classification of Functioning, Disability and Health domains of communication and social interaction.
Conclusions. By addressing individual goals, abilities and relevant environmental factors, a bedside computer access solution can be developed for individuals in long-term care. The introduction of a computer access solution augmented the participant's communication, leisure and educational activities, as well as perceived independence.

Keywords: *Computer access, severe and multiple disabilities, person-focused approach*

Introduction

Computer access for individuals with severe and multiple disabilities

Computers pervade nearly every aspect of life in the 21st century, playing key roles in activities such as communication, information retrieval, and education. However, compared to the general population, individuals with severe disabilities are less likely to own a computer and to use the internet [1]. To use a computer, these individuals typically require an access method, whereby the user's intention, manifested either motorically or physiologically, is translated into a useful input to the computer. Computer access methods can be categorized by the requisite level of voluntary physical movement [2]. Access technologies range from mouth sticks, tooth-click devices [3], head pointers, eye-activated mice and forehead/eyebrow twitch switches [4] for those with some voluntary motor control to electroencephalography, electrocorticography, and intracortical recordings, for those with no functional movement. The interested reader is referred to [2] for a comprehensive review of these and other access technologies. Generally, as an individual's level of controlled, voluntary abilities becomes more limited, there are progressively fewer viable computer access options. At present, those who are unable to reliably control at least one physical movement typically cannot engage in computer-based activities because they lack an access pathway.

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The benefits of computer access

Computer access can have a significant positive impact on academic, communication, and recreational activities [4]. When conditions completely prohibit communication, as is the case for individuals with locked-in syndrome (LIS), computer access can have a liberating effect. Computer access can facilitate otherwise impossible tasks, such as initiating dialogue and preparing questions and other messages [5]. An 11-year cohort study of individuals with LIS reported that access to the computer drastically changed their lives, not only by increasing the amount of communication with family and friends, but also by changing the patterns of communication, giving individuals with LIS some control and independence [6]. In addition to affecting social interaction and communication, computers give individuals with disabilities the ability to independently access information about their health, providing a readily accessible forum for individuals to further educate themselves about their condition, resulting in a positive impact on their overall health [1]. In brief, computer access can have a multifaceted impact on the lives of individuals with severe and multiple disabilities, giving them greater independence [7,8], enhanced quality of life [9], improved psychological well-being [10], and broader employment opportunities [11].

Barriers to computer access

While the benefits of computer access are well-documented, the challenges of finding an access pathway for individuals with severe disabilities can be so overwhelming that efforts frequently cease after a few iterations [10]. These often insurmountable barriers include the need for reliable motor control to operate conventional mechanical input devices (e.g., mechanical switches and adapted keyboards), the health professional's limited awareness or experience of the diverse collection of available devices [12] and the prohibitive cost of customized solutions [4,7]. Another major barrier is the lack of a universal and comprehensive computer access assessment [13]. Although many different systematic assessments for computer access have been proposed [8,14–16], none have been widely adopted. In many instances, finding a successful access solution for a particular individual remains a trial and error process, because of the 'lack of a valid predictive model' to guide device selection [10].

This case study describes the development of a bedside computer access solution tailored to the needs of a young lady with severe disabilities and within the constraints of the specific hospital environment. Through a mix of qualitative and quantitative data, we demonstrate the effects that bedside computer access can have on enabling participation in life activities.

Methods

Description of the participant

The participant, who we will refer to as Kate, was a 20-year old female who experienced an incomplete C1-C4 spinal cord injury at birth resulting in incomplete quadriplegia. She received constant mechanical ventilatory support via a tracheotomy. She did not exhibit any cognitive impairment and could speak. At the time of writing, Kate had completed her high school education and had aspirations to enter college. The majority of her time was spent lying supine in her hospital bed with her neck laterally rotated and slightly flexed to the right. She had extensive motor impairment with the exception of minimal voluntary movement in her thumb, which could not be dissociated from involuntary activity of her fingers. Kate had voluntary control of her eye gaze, eyebrows and eyelids with no evidence of ptosis. She resided in a complex continuing care unit with 24-h nursing support. Nursing staff assisted her with operating the television and the telephone. She received attendant care at school and on outings from the hospital. Kate was medically fragile and frequently transferred to an acute care hospital.

At the time of writing, Kate had amassed 6 months of experience with a voice recognition system for environmental control that enabled her to use her telephone, fan, and music player. Voice recognition had been limited to the switching of these selected environmental controls due to Kate's variable voice quality, largely attributed to her mechanical ventilation. The voice system also required caregivers to initialize software and to position the microphone. Kate had also used a sip-n-puff switch for 5 years to drive her powered wheelchair. However, the sip-n-puff device had been implicated in multiple oral infections in the past. Kate and her health care providers were eagerly seeking an alternative access modality to complement and potentially replace the voice recognition system. In particular, they hoped that a single switch for computer access could be established. Consent was obtained, and approval to conduct the study was granted by the research ethics boards of the pediatric and adult centers involved in her care.

Finding an access site

The initial challenge of creating a computer access solution involved finding a reliable, voluntary movement to operate a binary switch. Criteria for successful switch design included easy set up and removal by caregivers who may not be technology savvy, and accommodation of the participant's fixed positioning on the bed.

Initial assessments by an interdisciplinary research team (nurse, occupational therapist, rehabilitation engineer) indicated that mechanical switches (Tash Big Buddy Button, Tash Leaf Switch, and a Touch Switch) on her chin and thumb were impractical access alternatives. Because of limited strength and confounding involuntary finger movements, she was unable to voluntarily activate any of the three switches consistently using her thumb. The chin switch could be more repeatedly triggered but challenges of unobtrusive placement and mounting precluded its usage. Additionally, Kate expressed fatigue and frustration with both the thumb and chin switches.

A novel vibration switch was developed to capture the upward movement of her eyebrows. This custom switch consisted of a dual axis accelerometer strategically mounted in a plastic hair band to sit above the right eyebrow. A microcontroller was programmed to discern voluntary eyebrow raises from other facial gestures with both positive and negative predictive values exceeding 88% over 214 trials. Unfortunately, Kate reported that it was fatiguing to consistently lift her eyebrows, and requested an alternative access solution.

Finally, a switch was introduced that took advantage of Kate's voluntary tongue movement. The switch was mounted on a microphone stand that was placed directly behind her bed, on the end of a flexible arm that could be easily adjusted in all three dimensions. This mounting allowed Kate to talk freely without involuntarily activating the switch, while simply requiring a tongue protrusion to lift and depress the switch. After an initial trial period, Kate expressed satisfaction with this access site, as it was comfortable, and did not require undue effort on her part to operate. Subsequently, the switch was adapted such that depressing the switch activated the call bell in her long-term care facility, and lifting the switch completed the circuit in an adapted computer mouse, thereby creating the equivalent of a left-mouse click. The solution is illustrated in Figure 1. The mouse was connected to a computer system, and thus, by moving her tongue, Kate was able to reliably and reproducibly generate a mouse click on command.

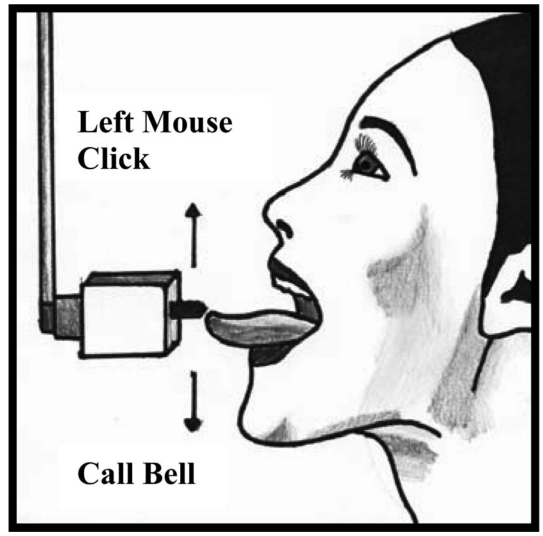

Figure 1. The final tongue-switch access site. Using her tongue, Kate could lift the switch to generate a left-mouse click, and depress the switch to activate her call bell.

The software solution

There is a high rate of abandonment and non-compliance of assistive technologies. Research focusing on user perspectives has concluded that the primary reason for abandonment is device ineffectiveness in helping individuals attain their personal goals [17]. Consequently, before we chose software to interface with the binary switch, we interviewed Kate to determine her goals. Her top three priorities were: (1) to e-mail her friends and family, (2) to use the word processor to read and write school assignments, and (3) to surf the internet.

Many commercially available software systems use single-switch scanning to facilitate the selection of letters from an onscreen keyboard. Kate's needs were more diverse – her wide range of desired activities, in addition to her desire to independently select and switch between them necessitated the introduction of a full software platform. To this end, QualiWORLD, a comprehensive and fully integrated software platform developed by QualiLife, was introduced. QualiWORLD's user interface arranges the various applications, and the desktop operations (e.g., opening and closing a program), in a manner that enables the user to easily access all options, while accommodating a variety of inputs, including a single binary switch.

QualiWORLD provides different mouse emulation strategies to navigate and select icons on a computer screen using a single, left-mouse click. Examples of these include XY-mouse, which scans the computer screen in a horizontal, then vertical direction; radial-mouse, which scans the computer screen in a counterclockwise, then radial direction; and auto-scan mouse, which sequentially highlights each icon available to the user. The user is able to navigate all available options by pressing the switch to select the currently highlighted item. These three options were presented to the participant, who immediately discarded the radial mouse on the grounds that it was not intuitive. In the subsequent training phase, both the XY-mouse and the auto-scan mouse were made available to the user so that she could test and evaluate both options.

Finally, QualiWORLD comes with a number of modular applications, each enabling access to a different interface. Possible interfaces include the telephone, the radio, the television, and the DVD player. To target the goals of the user, three modules were purchased: QualiWORD, an accessible word processing program; QualiMAIL, which enables sending and receiving e-mails, and QualiSURF, an interface which creates an accessible environment through which the user can surf the internet with any of the adapted mouse options presented above. Each of the above modules was accompanied by an on-screen keyboard, which the participant accessed through row–column scanning.

The physical setup

In order for an assistive technology to be accepted, many believe that it is vital that the device be compatible, not just with the needs of the individual, but also with the environment in which the device will be utilized [18]. Consequently, great care was taken to clarify the expectations of all stakeholders at the long-term care facility regarding an assistive device intended for daily, long-term use by the participant, and to comply with the constraints introduced by the facility and the immediate space around Kate's bed. The most pertinent constraints are discussed below.

Since Kate was fully dependent on her caregivers for all of her physical needs, unobstructed access to her bedside was required at all hours of the day and night; it was essential that no part of the computer access solution restrict freedom of caregiver movement around her bed, or impede access to any medical equipment located on the walls. This physical space included that which was necessary to bring her power wheelchair beside her bed, and the ceiling space necessary to operate the lift that transferred the participant from her bed to her chair. Additionally, the process of setting up the tongue switch could not be onerous or require precise positioning, as the staff had limited time and were responsible for many patients. In the case of an emergency, it was necessary that Kate's bed be made mobile at a moment's notice; no part of the access solution could be secured or attached to the bed in any manner, and the pathway to the door had to remain barrier free. Finally, Kate might be transferred to another room as the needs and available spaces of the long-term care facility evolved; thus, no part of the solution could be mounted on the walls or ceilings of the room. The computer screen had to be mounted in a position where Kate could easily read text from a supine position, and wires had to be secured in a manner that they did not present a safety hazard to the other occupants and/or visitors of the room.

Several solutions were attempted to address these constraints. The first was to mount the entire computer access system on a Mobile WorkStand by Ergotron. Using this system, the LCD monitor was placed on the end of an articulated arm that could be adjusted so that the contents of the screen were within Kate's field of view. The entire system was mounted on wheels, and therefore easily moved around the bedroom according to the current needs of the individuals in the room. However, over the course of several months, many problems became apparent. In constantly needing to move the system to and from the bedside, the tower containing the central processing unit was knocked out of its bracket on two occasions, damaging the hard drive and necessitating the purchase of a new computer. The height of the WorkStand was in level with the ventilator system mounted on Kate's wall, and on several occasion as the workstation was moved, the systems collided, spilling water over the entire contents of the system. Given the financial and safety consequences of these events, this solution was abandoned.

The next solution exploited a cylindrical mount designed to support an intravenous (IV) pole. The mount was positioned at the foot of the bed, on the right side. An LCD monitor pole with monitor arm was fit into this mount, enabling the participant to see the contents on screen. The tower for the computer system was set up in a corner away from Kate's bedside. This solution was abandoned after 1 month, as the wires running from the tower to the monitor posed a safety hazard. Furthermore, the mounting system constrained the diameter, and therefore the strength of the pole supporting the monitor; after several weeks, the pole had bent to an alarming angle towards the participant.

Subsequently, the LCD monitor was removed, and the visual output of the computer was displayed on Kate's bedside television. The tower was set up in an unoccupied corner of her bedroom, and wires connecting the tower to the television were secured along the wall. The final layout of the bedside access solution is illustrated in Figure 2. After several months of testing, this system was informally evaluated and approved by all stakeholders, as it satisfied both the constraints of the physical space, and Kate's preferences.

Measurement

System and human factors

To evaluate system and human factors of the access solution, we adopted measurement tools from the International Organization for Standardization (ISO) 9241-9 standards document for 'requirements for non-keyboard input devices' [19]. These tools, which gauge the performance, comfort and effort of computer input devices, were previously deployed in the evaluation of computer access solutions for students with quadriplegic athetoid cerebral palsy [4].

The first part of the ISO 9241-9 evaluates system factors, namely, the movement time (MT) and the accuracy that a user is able to achieve with a non-keyboard pointer interface system. On the basis of the Fitt's Law, the test combines measures of distance to the target (D) and effective width of the target (W_e) with MT to produce a measure of throughput (TP) according to the relationships outlined in Equations (1)–(3) [19], where SD represents the standard deviation of the selection coordinates, and ID_e represents the task's effective index of difficulty.

$$TP = \frac{ID_e}{MT} \quad (1)$$

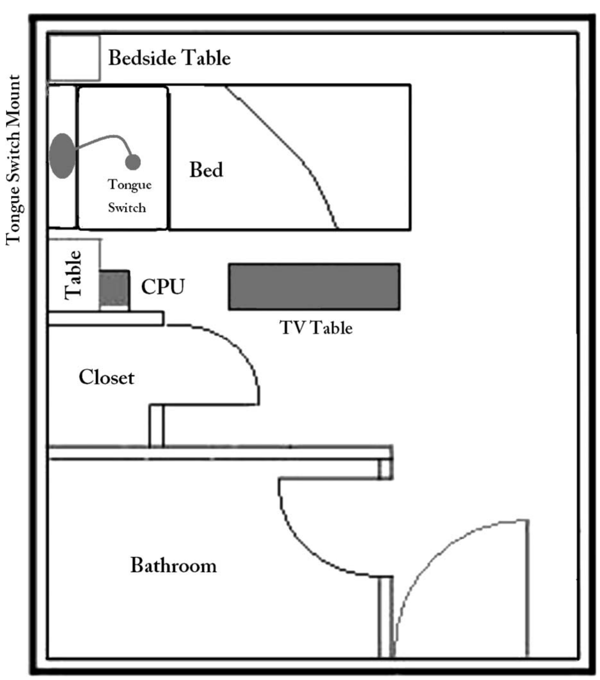

Figure 2. Layout of the participant's bedroom. The components of the access solution are shaded – the CPU was under the table beside her closet, and the computer display appeared on the television on the mobile table by her bed.

$$IE_e = \log_2\left(\frac{D}{W_e + 1}\right) \quad (2)$$

$$W_e = 4.133 \times SD \quad (3)$$

In a study evaluating the effectiveness of the different parts of the ISO 9241-9, MacKenzie et al. determined that the one-direction task did not yield significant results [19]; Consequently, in this study, we focused only on the multi-directional tasks to evaluate system factors. To this end, a two-dimensional array of targets was created to test the system performance for the participant; an example of these targets is depicted in Figure 3.

Eight different circles were presented to the user, who was told to use her computer access solution to click on the highlighted circle. The XY mouse began scanning the screen at the point marked (X) in Figure 3, and Kate used her tongue switch to stop the mouse when it reached the highlighted circle. The eight circles spanned a range of distances required for Equation (2); varying widths were achieved by presenting four different sized circles, for a total of 32 trials. Within the 32 variations of the two-dimensional systems test based on Fitt's law, eight different effective widths were presented to the user, as calculated with Equation (3). These widths were representative of typical navigation requirements on a computer screen displaying the Quali-World Software, and are presented in Table I.

Kate used the XY-mouse to complete this part of the assessment. Consequently, all distances were measured with the start point at the top left corner of the screen where the XY-mouse began scanning, and with the end point being the coordinates that the participant finally selected. These trials were

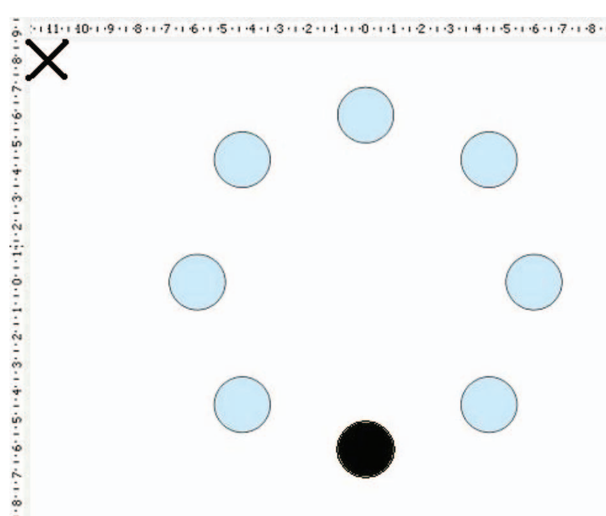

Figure 3. An example of the targets created based on the ISO 9241, Part 9 Standard to test system performance. The individual was asked to target the shaded circle.

presented in a random order; Kate's MT and accuracy (0 = did not hit the target, 1 = clicked on the target) were recorded.

Human factors were evaluated using the ISO 9241-9 questionnaire that is comprised of questions about the subjective levels of comfort with and requisite effort in actuating a computer access solution. Responses were measured on a 7-point interval scale [20].

The Canadian occupational performance measure

The Canadian Occupational Performance Measure (COPM) is designed to detect changes in a client's self-perception of occupational performance over time [21]. The tool measures users' perceptions of their performance at an occupation, and their level of satisfaction with this performance ability. Changes in performance and satisfaction scores of two or more points between assessment and reassessment are considered clinically significant [22]. In Kate's case, we used the COPM to measure her performance and satisfaction with her use of a computer. An occupational therapist conducted the COPM at two times; we define Time 1 to be the time just before the computer access solution was introduced, and Time 2 to be 2 months after the solution had been introduced to Kate. Between Time 1 and Time 2, she was given the opportunity to use her computer access solution as often as she wished.

Frequency and type of computer usage

At Time 2, Kate was also asked to record how often she used her computer and for what purposes, over the course of a typical week. This information was gathered to capture her patterns of computer usage, and to compare these with her original goals for the computer access solution. Kate's primary caregiver logged this information at the end of each day over a 1 week period.

Typing speed and accuracy

At Time 2, Kate's typing speed and accuracy were also tested. She had become comfortable with a row–column scanning [23], with a scanning speed of 1.5 s. She was asked to type the sentence 'My computer's name is Bubbles' complete with capitalization and punctuation, and also to type out the letters of the alphabet, in order, with a space between each letter. The number of switch activations and the time required to select each letter, the number of 'missed' selections, and the number of selection errors were recorded.

Table I. Effective widths (W_e) presented to the participant.

0.66
0.99
1.69
1.82
2.03
2.73
3.67
4.22

Semi-structured interview

Finally, at Time 2, Kate was asked to participate in a semi-structured interview to assess her level of satisfaction with the solution, and to garner her opinions on what she liked and what could be improved. The interview questions encouraged her to compare the computer access solution to those that she had previously tried, and to reflect on the importance of computer access, possible improvements and desirable features of the system, and the perceived impact on her lifestyle.

Results

System and human factors

In the two-dimensional Fitt's Law test from the ISO 9241-9, the participant achieved an average TP of 1.03 bits/s and an average accuracy of 87.5%. The values and ranges of the variables calculated during this assessment are presented in Table II.

On each of the questions evaluating the level of comfort and effort associated with the computer access solution, Kate consistently chose the highest rating. Specifically, these ratings indicated that she was very comfortable with the force required for actuation, and that she perceived the operation as very smooth and very low effort, very accurate and acceptable in operation speed, and very comfortable and very easy to use. Kate also indicated that there was no fatigue of the finger, wrist, arm, shoulder, or neck. Given the specific nature of her access solution, the questionnaire also assessed the level of fatigue in her tongue; she indicated that there was none at this site either.

Table II. Results of ISO 9241-9 system assessment.

Variable	Average	Minimum	Maximum
Distance to target (D)	30.1 cm	21.8 cm	38.9 cm
Index of difficulty (ID)	19.6	7.57	38.9
Movement time (MT)	19.9 s	14.2 s	27.5 s
Throughput (TP)	1.03 bit/s	0.34 bit/s	2.62 bit/s

The Canadian occupational performance measure

The results of the pre- and post- COPM measures of the participant's performance and satisfaction with her computer access solution are presented in Table III.

At Time 1, Kate reported that she was unable to use the computer, and not satisfied at all with her level of ability. At Time 2, she reported using the computer almost everyday for e-mail, internet and writing, that she was extremely happy about her current computer use and that she had developed an interest in learning about her computer. The changes in performance and satisfaction scores between the pre and post measure are considered clinically significant [22].

Frequency and type of computer usage

The daily documentation of frequency and type of computer use at Time 2 are summarized in Table IV. On average, she used the computer for 8.4 h per day.

Typing speed and accuracy

It took Kate 74 clicks, and a total of 7 min and 30 s to type the phrase 'My computer's name is Bubbles'. During the typing process, Kate took advantage of the built-in word prediction of the onscreen keyboard to minimize the number of clicks required to type each word, enabling her to select a letter with an average of 2.6 clicks. Without the word prediction, each letter required three clicks to select, and Kate was able to type the alphabet in 2 min and 35 s. Given system constraint of a 1.5 second delay between scanning options, the minimum possible time needed to complete this task was 2 min and 32 s. Although these numbers demonstrate her proficiency in accessing the individual letters of the alphabet on her keyboard, the time she required to type out the full sentence is more representative of her typical typing speed, as it accounts for format, punctuation, and spelling.

Semi-structured interview

During the semi-structured interview, Kate expressed a preference for her new tongue switch over the switches that she had previously tried. She reported that the sip-n-puff left her short of breath, and she remembered experiencing significant fatigue using the forehead and chin switches, both of which were non-issues with the tongue switch.

According to Kate, the most important reasons for having an access solution were: (1) to communicate and (2) to learn new things. She expressed interest in using her computer to do school work, to e-mail friends and family, and to 'learn new things on the internet'. Asked about improvements that she would make to the system, she said that she would 'make it more cool' and expressed interest in learning to use online chat rooms. Finally, she was asked about her overall impressions of the system, to which she replied 'It's a wonderful program. Very easy to work with. I like it a lot. It makes me more independent'.

Table III. COPM results.

Subscale	Time 1	Time 2
Performance: Ability to use a computer	1	5
Satisfaction: Ability to use a computer	1	10

Discussion

Within the International Classification of Functioning, Disability and Health (ICF) framework, the computer access solution is an environmental factor that may facilitate participation in life activities. In the following sections, the impact of the computer access solution on Kate's well-being is interpreted in terms of the ICF domains. The numbers appearing in parentheses are the relevant ICF codes.

Expanding communication

The results of the speed and Fitt's law tests indicate that computer access expanded Kate's communication activities, specifically, writing messages (d345) and receiving written messages (d325). Prior to computer access, Kate's participation in these activities was completely restricted. Indeed, enhancement of communication has been noted as a primary impact of access solutions for individuals with severe disabilities [9].

At first glance, Kate's typing performance appears low. Using the multidirectional Fitt's law test presented in the ISO 9241-9, able-bodied individuals were able to achieve an average TP of 2.15 bits/s using a joystick, in comparison to Kate's average TP of 1.03 bits/s [19]. In addition, the majority of able-bodied individuals would be able to type a five-word sentence in less than 1 min whereas Kate needed 7 min and 30 s to complete this task. However, these numbers must be interpreted in the context of an individual who has never had any form of computer access. Assessments of Kate's level of satisfaction with her access solution reveal that the speed she achieved was in fact, acceptable to her, and that it did not negatively affect her impression of the system. In

Table IV. Frequency and type of computer use over a 1-week period.

Day	Did you use your computer today?	For what purpose?	For how long?	Total time
1	Yes	Checking e-mail	N/A	n/a
2	Yes	Writing e-mail, arranging transportation	7:45–11:05	3 h 20 min
3	Yes	Checking e-mail Music	7:15–10:00 13:00–15:00	4 h 45 min
4	Yes	E-mailing Bible study	9:00–22:00	13 h
5	Yes	Checking e-mail	9:00–13:00 13:30–17:00	7 h 30 min
6	Yes	Checking e-mail	9:00–13:00 13:30–17:00 18:00–22:00	11 h 30 min
7	Yes	Writing e-mail	9:00–13:00 13:30–17:00 19:00–22:00	10 h 30 min
				Average daily time: 8.4 h

response to the ISO 9241-9 question concerning the operation speed of the computer input device, Kate ranked her access solution '7' on a 7-point scale, indicating that the TP was acceptable. Her satisfaction with the system, in spite of these seemingly-low speeds was also reflected in the results of the COPM; at Time 2, she rated her satisfaction as '10' on a 10-point scale, whereas at Time 1, before she had developed competency on the computer, her satisfaction level was a '1'. During the semi-structured interview, the speed of the access solution did not arise as an issue; even when asked about possible improvements, Kate suggested more 'coolness', rather than greater speed. Finally, Kate's typing rate of approximately 3.5 letters per minute is on par with rates documented for typing by single-switch scanning of QWERTY on-screen keyboards [24].

New opportunities for interpersonal interactions and relationships

Prior to the access solution, the only way that Kate could connect to her social network was to wait for a nurse or her personal care worker to put the telephone by her head and dial a number for her. Furthermore, if the phone rang, she would not be able to answer the call unless there happened to be someone at her side. Thus, social interactions with family and friends could not be spontaneously initiated. The access technology however created new opportunities for Kate to nurture family relationships (d760), and informal relationships with peers (d7504) and friends (d7500). From the week long log of computer usage and the qualitative interview, it is clear that the solution allowed her to initiate and sustain interaction with family and friends through email. She was able to independently compose and send e-mails, and to open and read the replies she received. This enhanced interaction with family and friends echo the findings of Drainoni et al. [25], who report significant associations between social integration scores and internet usage in individuals with SCI.

Over the course of a typical week, Kate's one consistent daily activity was to check and compose e-mail. She reported: 'I've been on it [the computer] all day, every day, checking my e-mail, writing back. If I didn't have the computer, I'd be bored'. Kate's high frequency of computer usage and primary activity of emailing is consistent with recent studies examining the pattern of computer and internet usage by individuals with spinal cord injury [1,25].

Facilitating educational, leisure and spiritual activities

Prior to the access technology, Kate learned only what others chose for her to learn, and what others believed that she might find interesting. Computer access gave Kate the unprecedented ability to search for things of interest to her, and to direct the process of learning. When asked what she wanted to use her computer to do, she responded: 'I want to learn new things on the internet'. In this way, the access technology facilitated opportunities for informal education (d810) at the bedside. This observation resonates with previous research that has identified new educational opportunities for people with disabilities as a key benefit of internet access [25].

Kate used her computer access for independent leisure activities (d920) such as reading and surfing the internet, the latter being a key activity identified by Houlihan et al. [26] in patients with SCI once granted internet access. Kate's competence in surfing the internet is reflected in her unrestricted response to the question of what she went online for: 'Searching for different places to live, different schools . . . anything!' Her access technology even created an accessible setting for spiritual development (d930) as she reported using her computer for Bible study.

When she was asked about the specific things she liked about the system, she reported: 'It drags, and I can type, and I can save, and I can change the font, format, color and underline . . .', indicating her growing proficiency in using the word processor. Evidence from other studies of individuals with SCI (e.g., Kruse et al., 1996 [11]) suggest that Kate's newly developed computer skills would facilitate her participation in higher education (d830) and her opportunities for eventual employment (d850), although these benefits had yet to be demonstrated at the time of writing.

In summary, the access technology expanded Kate's activities and participation in life situations, leading to an overall growth in independence. This heightened independence was not simply due to a change in functional ability, as often measured by professionals, but also attributable to the expansion of her personal and social freedoms [27]. Kate recognized this effect, commenting that 'It [computer access] makes me more independent'.

Environmental factors

Prior to the access technology, the demands of the environment outweighed Kate's functional abilities, such that she could not perform the tasks of typing, reading emailing or surfing the internet. From an occupational science perspective, one can interpret the introduction of the access technology as a change in the physical environment which redresses the balance between the person, environment and occupation [28]. From an ICF perspective, the access technology is an environmental factor which reduced the gap between performance and capacity and is thus a facilitator of the aforementioned activities.

It is important to note that the ICF concept of environmental context is much broader than just the physical environment. In a recent, ICF-inspired review of communication between patients with communication disability and healthcare providers, O'Halloran et al. [29] identified a host of environmental facilitators and barriers, including, caregiver knowledge about disability and communication strategies, caregiver attitudes, physical factors in the hospital environment, and, hospital services, systems and policies. Likewise, from their interview of 136 patients with SCI, Lysack et al. [30] implicated the natural (physical) environment, government policies, transportation and health services as the chief barriers to community integration after SCI whereas Whiteneck et al. [31] pinpointed the natural environment, transportation, 'help at home' and 'available information' as barriers to participation after SCI. Therefore, Kate's access technology only directly modulated one component of the environmental context, namely, the physical elements of the hospital environment.

Access development approach

The development of Kate's computer access solution followed a person-focused model of matching an individual to an assistive technology as opposed to the traditional people-focused model [32]. From the initial stages, Kate was consulted regarding her goals, expectations of the access solution, and her personal preferences. The client-focused process of establishing computer access allowed Kate to exercise her personal choice and to imprint her 'personal touch' on the final solution, affordances described by Scherer in transitioning from a medical to a social model of service delivery [32]. Other person-focused case studies relating to the provision of access have also been detailed in the literature (e.g., ref. 7]).

Sparks emphasizes that the only 'viable' measure of success of an assistive technology intervention is the ability to function successfully in 'real world' situations [33]. In this particular case study, the constraints of Kate's physical environment (i.e., hospital room) required the utmost attention to minimize the risk of abandonment. In fact, many elements of the ICF personal and environmental context – the access site, the software, the positioning of hardware within the room, the configuration of furniture, appliances and medical equipment, Kate's posture, her motor ability, hospital building and safety policies, the level of computer proficiency of her caregivers, her financial resources – all had to be mutually compatible to achieve a usable solution. With the person-focused approach, we are more likely to ensure that individuals with severe disabilities are outfitted with assistive technologies that fit their individual needs and lifestyles.

Need for access research

Before the introduction of computer access, Kate was not without the ability to communicate; she had the ability to speak clearly and to express her needs and preferences. Computer access dramatically augmented her opportunities for participation in life activities. How much more profound the impact would be for an individual without a similar baseline communication ability? At present, clinically available access pathways depend largely on somatic muscle activation, leaving many individuals without a means of communication [2]. This population includes individuals who are locked-in as a result of late-stage amyotrophic lateral sclerosis or brain stem strokes, as well as individuals with excessive involuntary movement (e.g., athetoid cerebral palsy), general hypotonia, or severe muscle spasticity (e.g., spastic quadriplegic cerebral palsy). The results of this study encourage the hastening of access research and development for this often-invisible population.

Limitations

The positive findings of this case study must be interpreted in light of the limitations of its design. Although a large range of both objective and subjective measures are employed in attempts to maximize the internal consistency of the study results, it is possible that the results are inflated due to Kate's desire to give positive feedback to the researcher's efforts to outfit her with an access solution. Future work examining the impact of introducing computer access to other individuals with severe and multiple disabilities, in different environments and at various stages of life must be conducted to assess the external validity of these study results.

This research was conducted as a case study of one specific intervention. While utilizing a single subject research design (SSRD) would have increased the rigor of the results, none of the range of SSRD options was suitable for this particular situation. As there was only a single subject and a single, binary intervention, multiple baseline design, alternating treatment design and changing criterion design [34] were all not feasible. The remaining option was reversal design, which the researchers decided not to use for ethical reasons.

Finally, this study only takes into account Kate's experiences and perspectives on the introduction of a computer access solution. As computer access has been demonstrated to affect an individual's social interaction and communication, and as Kate's top priority in acquiring computer access was to communicate with her social network, further insights into the effects of this solution could be garnered by interviewing Kate's friends and family. Gathering data from this source may also address any bias introduced into the reported results by Kate's subjective experience of the solution, and provide further understanding of how computer access affected her interpersonal relationships and participation in life activities.

Conclusion

This article presented a case study of a 20-year-old female with quadriplegia who was outfitted with a computer access solution realizing a tongue-driven binary switch to access the internet, word processing and e-mail. The participant's goals and the constraints of her real-world environment were considered throughout the design process. Two months after the introduction of the access solution, qualitative and quantitative measures indicated the acquisition of a functional level of single-switch typing, the expansion of everyday activities, particularly in the areas of communication, leisure and education, and a perceived, significant increase in independence.

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