© Med Sci Monit, 2004; 11(1): RA32-39
PMID: 15614204

Received: 2003.12.22
Accepted: 2004.07.29
Published: 2005.01.01

The efficacy and benefits of environmental control systems for the severely disabled

Ashley Craig, Yvonne Tran, Paul McIsaac, Peter Boord

Department of Health Science, University of Technology, Sydney, NSW, Australia

Source of support: This study was supported by grants from the Australian Research Council (Project ID: C00106683; C4992001) and by a competitive research grant from the Motor Accidents Authority, NSW, Australia.

Summary

Background: People living with a severe disability suffer substantial personal and social consequences that reduce quality of life (QOL). One potential negative impact on the QOL of a disabled person is the loss of the ability to control devices in their immediate environment (such as the television, computer, telephones, lights, doors, etc.). Consequently, research and development has been conducted on technology designed to restore independence by providing some means of control over these devices. Technology that allows a severely disabled person to gain this type of control has been called an environmental control system (ECS). The aim of this review was to evaluate critically the status and efficacy of ECS technology for the severely disabled.

Materials/Methods: To achieve this, a comprehensive database search was conducted for relevant material on technical and clinical aspects of ECS control.

Results: The review demonstrated that there is an abundance of work conducted on ECS technology, resulting in a number of creative control systems that are designed to be used by the severely disabled. These include switching systems that utilize voice, muscle, brain activity, head motion, eye blink, breath, chin, and so on. However, the review also established that rarely has the efficacy of these systems been scientifically established.

Conclusions: Severely disabled persons need access to ECS technology that has been shown to be efficacious. While the severely disabled gain benefits from using ECS technology, challenges still exist before ECS technology for the severely disabled can provide highly reliable and user-friendly device control.

key words: **environmental control systems • severe disability • switches • assistive technology • spinal cord injury**

Full-text PDF: http://www.MedSciMonit.com/pub/vol_11/no_1/4469.pdf
Word count: 4808
Tables: –
Figures: –
References: 98

Author's address: Professor Ashley Craig, UTS, PO Box 123, Broadway, NSW, Australia, 2007, e-mail: a.craig@uts.edu.au

Background

Severe disabilities are generally low incidence and prevalence disorders with high-cost implications. Examples include cerebral palsy, spinal cord injury (SCI), muscular atrophy, multiple sclerosis, amyotropic lateral sclerosis and so on. These types of disorders are high cost due to the essential dependence on medical and personal care. For example, the cost of SCI includes primary costs related to hospital care and the cost of dealing with physical complications. Loss of prior work productivity and lowered quality of life (QOL) are often extreme and this is compounded by severity of the disability [1–8]. Quality of life is defined for this paper as a person's state of well-being, encompassing aspects of life that contribute to the person's degree of comfort, independence, enjoyment, choices and so on. Costs for the first year of a quadriplegic person have been estimated to be almost half a million dollars (estimates in 1992 US dollars). Ongoing costs are high (up to $US100,000 pa in 1992). These figures were based upon direct costs and did not take into account indirect costs due to loss of productivity and lowered QOL. In 1992 US dollars, it was estimated that the aggregate annual cost of new cases of SCI in the USA would be $7.2 billion, with $3.1 billion due to direct costs and $4.1 billion due to indirect costs [2]. In addition to the high medical costs associated with severe disability, difficulties that may be experienced include:

a) significantly reduced opportunity for ongoing employment resulting in possible financial hardship and insecurity [2];

b) increased tensions in family/partner relationships as a result of an almost complete dependence on the carer [9]. For example, this is reflected in divorce rates in people with spinal cord injuries and the difficulties in finding partners post injury [10–12];

c) increased risk of experiencing social isolation and discrimination. Recent research indicated that almost 50% of severely disabled people experience some form of social discrimination [12]. These figures are concerning, as social support has been shown to be positively associated with life satisfaction [13];

d) increased risk of medical complications such as pain and infection. Ongoing pain in the long-term has been shown to be associated with depression [14] and QOL [1,15]. In addition, risk of serious illness is very much higher in severely disabled populations. For instance, risk of death from septicemia has been estimated to be 82.2 times more likely in SCI, while risk of death from pulmonary emboli was estimated to be 46.9 times more likely [16]. Self-neglect is also a problem in those with severe injury and this can result in physical complications such as infections, especially when depressive illness or lowered self-esteem is involved (17,18];

e) increased risks of being depressed and anxious [3,6–8,14,19–25]. For example, results from controlled longitudinal research suggested that up to 30% of SCI persons have raised levels of anxiety and depressive mood which does not diminish significantly over time for up to two years [19,20] and this has been shown by researchers using either prospective or retrospective designs [19]. Furthermore, suicide is also a potential threat for the severely disabled, with, for instance, SCI persons having four to five times the risk for age-sex-specific rates in the community [16,26].

Solutions that can Raise QOL of the Severely Disabled

While many with severe disability can enjoy an acceptable QOL [27,28], the above demonstrates the substantial needs of people with severe disability. The abundance of negative life indicators strongly suggest the need for effective strategies that can help to raise QOL. It stands to reason that providing state of the art medical treatment and rehabilitation is essential to achieve this, and given the psychological distress that can be associated with severe disability, it would also seem necessary that psychological therapies be made available to the severely disabled and their carers/families. For example, cognitive behavior therapy (CBT) has been shown to be effective in lowering anxiety and depressive mood in SCI persons who were previously anxious and depressed [19]. Furthermore, the CBT group had lower rates of hospitalization, less drug intake and higher levels of adjustment in comparison to the controls [12]. Additional solutions could include promoting strategies to enhance entry to the workforce (e.g. improving access), and encouraging participation in leisure and sporting activities [2].

An alternative solution for enhancing rehabilitation outcomes of the severely disabled is to reduce the level of their dependence or conversely, enhance their independence. There are at least two ways of potentially achieving this. First, this may be achieved through functional electrical stimulation (FES). Limited hand and leg use imposes substantial restrictions on the capability of people with SCI to perform basic living activities such as eating, drinking and standing. FES involves electrical stimulation applied to appropriate muscles in order that specific behaviors can be performed [29]. FES is a developing technology that has the potential to help the severely disabled to achieve greater independence. For example, FES has been used successfully to restore hand grasp and release in people with tetraplegia [30,31] and standing and stepping in people with paraplegia [32]. However, FES still remains an experimental procedure and clinical trials investigating its utility and efficacy have not yet been conducted.

A second strategy involves the provision of assistive technology that permits a disabled person to regain some control over their living environment that they have lost due to their impairment. This type of assistive technology has been called an environmental control system (ECS) and it is basically a switching device that allows disabled persons to activate and control aspects of their environment that the disability prevents them from controlling [33–35]. Controlling a television with their hands using a remote is not possible for most severely disabled people. The use of ECS technology provides the switching interface assistance they need to activate the television, using alternative means that they are capable of performing. For instance, a tetraplegic person may not have fine finger movement to activate a television remote control, but they usually have chin or eye movement that can be used as a switch with the assistance of the

ECS technology. Devices commonly controlled include domestic appliances such as a television, radio, air conditioners and lights; vocational devices such as a computer and telephone; and security devices such as doors, alarms and so on. ECS technology incorporates a control unit that activates these devices by means of electrical fixed wiring or remotely by infra-red or radio frequency control. The disabled person is interfaced with the control unit allowing them to switch the unit in order to activate a selected device. For example, they can use voice control to switch on the ECS, and then they choose a device from a menu by switching again.

Aims of the Review

The aim of this review was to analyse critically the development of ECS technology with specific emphasis on evidence for benefits and efficacy of the technology with severely disabled persons. Greater emphasis will also be given to work conducted over the past 15 years. To ensure an adequate coverage of the ECS literature, a comprehensive review was conducted using database searches such as Medline, PsychINFO, ENGINE (engineering database) and IEEE sources. The search concentrated on engineering/electronic development as well as experimental and clinical applications of ECS technology.

POTENTIAL BENEFITS OF ECS TECHNOLOGY

Platts and Fraser [35] very sensibly suggested that just as psychological rehabilitation has been shown to assist the severely disabled to cope with the impairments arising from the disability [12], so its seems reasonable to assume that a severely disabled person will learn to cope better with their disability if they can gain some control over their physical limitations using ECS technology. Providing the newly severely disabled with as much independence as possible is regarded an important component of rehabilitation and ECS technology is considered valuable in this regard [36]. While the benefits of ECS technology have not been widely or robustly examined, existing evidence suggests that such systems do enhance the QOL of the disabled, most likely by increasing their independence in their home environment, decreasing the load of the carer and increasing the self-esteem of the disabled individual. [33–35]. For instance, 29 severely disabled users (tetraplegic) of ECS technology were interviewed for their beliefs about perceived benefits [36]. The majority believed that (in order of importance) ECS technology improved their (i) ability to communicate, (ii) their security and health, (iii) recreational capacity, (iv) control of household appliances and (v) employment capability. Preliminary evidence based upon a survey of seven severely disabled ECS users and 13 non users, suggested that ECS users were more independent [37]. Furthermore, when ECS technology is used in hospitals or nursing homes, not only does evidence suggest the user will be more independent, but also the nursing staff have been shown to have reduced work related demands [38]. The subjects in this hospital based study included people with SCI, muscular dystrophy and multiple sclerosis. Furthermore, successful ECS technology may also allow the severely disabled to stay home for longer, reducing risks of them being institutionalised [39]. Smart wheelchair integrated control systems have also been suggested to raise motivation, assertion and communication skills in child users [40–42]. The above research suggests that ECS technology can be very beneficial and potentially enhance QOL, but clearly, well designed, evidence based studies still need to be conducted on the potential benefits of ECS technology for the severely disabled.

ECS TECHNOLOGY FOR THE SEVERELY DISABLED

Improvements in ECS design have occurred since the first ECS technology (called the POSSUM, or patient operated selector mechanism) was developed in the 1950s for people with poliomyelitis and cerebral palsy [34,43,44]. According to Wellings and Unsworth [34], much of the early ECS technology was cumbersome and as would be expected, shadowed the development of electronics and computer systems. However, in the past 15 years, substantial advances have occurred in the area of medicine, neuroscience, electronics and computer systems, and this has led to sophisticated advances in the quality and a simultaneous increase in the quantity of ECS technology. This has been especially true in the development of the interface between the user and the ECS technology [45].

It is important to note that for ECS technology to be truly functional, it should provide control over multiple functions, such as mobility, manipulation, communication and control of devices in the environment [35]. The severely disabled have limited capacity to control all these functions [35]. Therefore, it is desirable that ECS technology be built around the individual user, in some cases as they proceed through rehabilitation [35]. It is also important that ECS technology look attractive and have aesthetic appeal, as attractive technology may encourage usage [45]. To achieve many of these goals, ECS technology has been developed that can control multiple functions, such as the system referred to as the 'multipurpose interfacing device' [46] and other systems that use either fixed wiring or remote control [47,48]. Nisbet [42] argues for the provision of 'distributed' versus 'integrated' control. "Distributed' control involves multiple control using varied types of switches, for example, using a hand operated joystick to drive the wheelchair, another type to operate a telephone, another to control a computer and so on. Benefits of this system include ease of use and speed. However, 'distributed' control systems are usually not possible for use by severely disabled users [42]. "Integrated' control systems are preferred by users with very limited switching capability [42,49], and involves the control of multiple functions with say a single switch (e.g. a motor reflex touch switch or a head movement switch). However, even in an integrated system, it is believed preferable to provide several switches as for example, driving a wheelchair will naturally require different controls to operating a computer [42]. Communication systems for severely disabled persons who have limited speech capacity have also been developed, and these have been developed to operate as a communication device (eg. synthesized speech) as well as an ECS [50].

Many of the above assistive technologies rely on the disabled person having some control over their legs, arms or neck [36,51]. For instance some systems incorporate a remote control unit similar to those used for television sets and require finger or hand movement to operate a touch or mechanical switch [34,45]. However, in a clinical discussion paper, Wellings and Unsworth concluded that the weak link in ECS technology is the method used for switching (ie. the type of interface used between the person and the ECS), and this is especially true for those who are severely disabled [34]. Unfortunately, by definition, most severely disabled persons have very limited capacity to use their arms, hands and legs. To overcome this, specialized switching techniques have been developed such as "suck-puff" techniques, chin operated control sticks, mouth sticks, eye movement and eye blink switches, and head movement and voice control switches [34,45,52]. Latest experimental interface systems include brain computer interface approaches (BCI) [53,54]. BCI involves brain activity, usually electroencephalography (EEG) or evoked potentials, being used as the control in the interface between the user and the ECS.

ECS technology developed for the severely disabled can usually be interfaced with a variety of switching options, commonly with breath control (suck and puff), mouth sticks and chin operated control, and it is preferable that the ECS technology is developed with individual user specifications in mind [42,55–57]. "Suck and puff" provides a binary switch where a breath in or out can be used to perform various functions. Mouth sticks and chin-operated switches have also been used widely, and these type of switches allow the user to control devices, for instance, selecting and activating from a menu. Lawrence and Horne [57] conducted an evaluation of factors influencing typing performance using ECS technology, of 14 moderately to severely disabled persons (including those with cerebral palsy, muscular dystrophy, tetraplegia, poliomyelitis etc). In comparison to able-bodied subjects, the disabled group were consistently slower on performance measures. Results suggested that able-bodied performance was not applicable to the performance of the disabled users. The performance of the disabled users was enhanced by providing a variety of control options [57]. Pollak and Gallagher [50] evaluated the efficacy of using ECS technology to control electrical devices. Switching interfaces consisted of either a joystick or a simple pressure switch for the more severe. A small group of disabled users was tested over 1–2 days and results suggested that the system was able to be used effectively, though there were no results reported, with the authors stating that results "seemed favourable" [50].

Newer developments in switching types include voice activated systems, head movement switches, eye blink and movement switches and switches based upon electromyography activity or some other physiological function such as skin conductance [34]. Automatic speech recognition was believed to be one of the most promising developments for users who are severely disabled [58–60]. The advantage is clearly one of being able to instruct the unit freely by talking to the system, rather than having to select from a menu using some alternative switch. In addition, improvements in speech recognition have led to its inclusion into many types of ECS integrated systems [58,61,62]. Users are required to train the system to recognise their speech, though some newer voice recognition systems may not need training [63]. For reliability, it is important that users give clear short voice commands [61]. Speech recognition technology mostly employs "word" recognition rather than "continuous" speech recognition given the difficulties associated with reliability in recognising all words in continuous spoken sentences [64]. However, as up to 40% of the severely disabled have difficulties with speech production [33], it is important that users have a selection of switches in their ECS technology. An example of a voice recognition system is the Voice Activated Domestic Appliance System or VADAS, which allows the user to control up to 16 appliances by voice [58]. Results from pilot efficacy research for 12 able bodied subjects (6 female) using the VADAS unit 15 minutes a day over 10 days, showed relatively low recognition rates, suggesting that difficulties with recognition accuracy exist [58,65].

Head movement switches have also been used in cases where the disability is severe [66]. Earlier head movement technology restricted the user's head motion and were not always reliable, as with mercury tilt switches [67]. Later technology has employed a self-adjusting accelerometer tilt switch that is small enough to be attached on a band that sits around the head, and that is very sensitive to change in head movement. In order to minimize user inconvenience, the switch has been adjusted so that the accelerometer only reacts to head nodding [67]. Preliminary work with a small number of users suggests this switch could be successfully used by severely disabled persons to communicate and control devices [67]. Alternative approaches employ movement of the head and eye as a positioning signal in order to control a cursor on a screen [68]. The system requires the user to wear an optical sensor mounted on a head band and gazing position provides control of the cursor [68]. This type of switch was believed to be superior to using eye movements detected by image processing of the eye as light intensity can negatively influence reliability [68,69]. Eye movement switches require a camera to be placed in front of the user in order to detect eye movement. In one system, the user moves their eyes to position the cursor and then breathes in or out to switch [69]. Other systems based on eye movement have also been developed [70].

EMG has been investigated for its utility as a switch for the severely disabled [71–73]. For example, a touch switch placed upon a user's cheek detects changes in surface muscle activity (when the user tenses their cheek) which then acts as a single switch that allows selection of options from a menu [71]. Initial evaluation suggests this technique could be a viable alternative switch for the severely disabled. More experimental switch types include skin potential response [74]. The choice of this switch type is based on the assumption that skin conductance is less influenced by severe disorder (such as cerebral palsy) than is muscle activity or eye movement [74]. Research suggests that skin conductance switches hold some promise, though low hit rates raise the need for further research and development [74].

BCI Switches

BCI switches have been the subject of intense research and development over the past 15 years as there is a belief that they may be potentially viable alternatives to the abovementioned switches for people with very limited movement capability [53,54,75]. A BCI interface has the advantage of being totally "hands free", allowing it to be used by severely disabled users, and BCI control does not rely on voice control, as many who are severely disabled have problems with voice production [33]. However, most BCI switches are still experimental and very few, if any, have been made available commercially. BCI switches have been mostly based upon mental motor imagery (MMI) brain activity and involve subjects learning to control brain activity in the 8-13 Hz (mu wave) range of the EEG [76–78]. The mu wave is measured from the sensory and motor cortex with surface electrodes, and MMI involves EEG activity responding to some imagined movement, say imagining a particular finger moving [76]. People learn to increase or decrease the mu wave in order to control a cursor on the screen. Using this BCI strategy as a switch, the hit rate accuracy can be above 70% [76,78,79]. Using similar strategies, the Graz Brain-BCI obtained hit rates of 90-100%, though training times to achieve this accuracy can be high (for one subject over 60 training sessions over 5 months) [77]. Work is continuing on improving detection of the EEG changes [80] and some success has been demonstrated with able bodied subjects and one severely disabled subject in controlling devices using an imagery BCI to select devices with ECS technology [81]. Subjects were able to perform 12 actions taking up to 30 seconds per switch with only a few errors [81]. Other types of BCI switches are being researched and developed [82,83].

Almost all the above work has been carried out on able-bodied subjects using surface electrodes, and usually substantial training times are necessary to achieve accurate control of brain waves using MMI [75]. Latest experimental work has involved invasive neural-based electrodes in animals such as monkeys, and results have demonstrated impressive control of a cursor or robotic arm with reduced training times [84,85]. Other work is concentrating on developing microchips that can be inserted in the brain, and which can communicate with brain tissue, assisting the animal's control of a prosthesis [86]. Invasive electrode work (electrodes placed within the motor cortex) in humans suggests that the severely disabled (e.g. those with amyotropic lateral sclerosis) can learn to control a cursor in order to communicate. Subjects learned to control the firing rate of the neurones in the cortex by, for example, imagining movement. Using this technique, they formed words by selecting letters, and they were able to select correctly up to three letters per minute [87].

A recent non invasive study (electrodes placed on the scalp at a central site) showed that two severely disabled (advanced amyotropic lateral sclerosis) persons were able to be trained to communicate through selecting words on a computer through voluntary control of EEG (slow cortical potentials). However, the subjects made many errors (from 20 to 30%) in selecting letters, many hours of training were involved (at least 30 hours) and it took 16 hours for one subject to write a 10-line message [88]. There are some BCI devices available commercially. For example, the Mind Controlled Switch (or MCTOS; info@mctos.com) is claimed to enable severely disabled people to communicate or control devices by muscle or eye activity via an electrode placed on the forehead. It is also claimed that the disabled user can control or communicate by manipulating mental states. However, to date, the authors have not sighted scientific evidence for these claims, nor have field trials been conducted to test the efficacy of the MCTOS.

BCI ECS technology developed by the authors utilizes increases in alpha wave signals (8–13 Hz) contingent with eye closure (EC) as the switching mechanism [89–93]. This ECS device has been called the "Mind Switch" and it operates by detecting the conscious control of brain signals in the alpha wave frequency band (8–13 Hz) of the EEG [89]. The increase in alpha waves following EC has been shown to be quick (1–5 seconds) and reliable for the majority of disabled and non-disabled persons [89–91]. Able-bodied persons have been shown to employ this ECS very effectively in order to activate and control up to six devices in the laboratory [92] and the time taken to select an option and errors made in selecting the correct option were shown to reduce significantly over four days of using the device [92]. The Mind Switch BCI has also recently been applied as a switch for FES control that allows a paraplegic person to stand or perhaps walk [94].

Severely disabled persons have also been shown to use the Mind Switch ECS technology effectively [53]. Ten severely disabled participants consented to participate in a field trial to test the efficacy of the Mind Switch ECS. Eight were men and two were women and their mean age was 42.9 years (SD=8.9 years). Six were spinal cord injured with breaks ranging from C2 to C5/6. The remaining four had profound disability, one resulting from polio, one from muscular atrophy, one from multiple sclerosis and the last from cerebral palsy. None of the 10 subjects had been introduced or had experience with the ECS prior to the study. The trials were conducted in the homes of the severely disabled, and before they began, each participant had EEG electrodes attached in bipolar configuration on EEG sites $T4\text{-}O_2$. The objective of the trial was to test whether severely disabled persons would be able to activate their television without making substantial errors within a reasonable period of time (say within 1-2 minutes maximum) using the Mind Switch ECS technology [53].

All participants were able to switch and consequently activate their televisions without making substantial numbers of errors, and within a reasonable time of around 30–60 seconds per correct activation. In terms of improvement with practice, the time taken to select an option decreased slightly over the three occasions, and the mean number of errors made in selecting the correct option reduced significantly over the three trials [53]. All subjects were also able to operate the Mind Switch ECS without becoming frustrated and the majority believed that the ECS would be a very useful technology to use in their homes [53]. Improvements in the Mind Switch ECS technology continue [95], and further study of the brain activity of the severely disabled is occurring [96] in order to provide better EEG signal capture, reduce switching times and increased hit rates.

Efficacy of ECS Technology with the Severely Disabled

For ethical and professional reasons, it is essential that ECS technology be shown to be effective in providing user-friendly functional control. While many environmental control systems have been used in hospitals and in the community over the past 30 years by the disabled [97], it is unfortunate that little scientific evidence of substance exists to demonstrate efficacy. This emphasis upon demonstrating evidence for efficacy in a scientific and rigorous manner is a major goal of evidence based health care (EBHC). In an editorial of the British Medical Journal, EBHC was defined as the "conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients" [98]. Sackett et al, [98] suggest that clinical experience should be integrated with the best available clinical evidence from systematic and rigorous research. Neither is sufficient by themselves, and both are absolutely necessary when assisting the severely disabled. The authors go on to discuss how clinical evidence should invalidate and therefore replace previously accepted diagnostic techniques and treatments with more powerful and efficacious intervention (or rehabilitation) strategies. In this way, the health professional becomes more effective in providing care for their clients [98].

Providers that claim that certain ECS technology can be successfully used by the severely disabled to control devices should support their claims with scientific evidence. It is not sufficient to claim efficacy by merely stating that the system was effective, or by trialling the ECS technology on a few able bodied subjects. Ideally, steps necessary to demonstrate efficacy should at least include the following: (i) the ECS technology should be initially developed with the needs of the severely disabled in mind, (ii) it should then be trialled on able-bodied subjects under laboratory varied conditions, even though there is some evidence suggesting that able-bodied performance is not always of relevance to the performance of the severely disabled [57], (iii) appropriate technological and aesthetic adjustments made, (iv) followed by a controlled field trial on a reasonable number of severely disabled of varying ages using objective outcome efficacy measures, and (v) results reported in relevant conferences and published in refereed journals. With this sort of rigorous evidence base, ECS technology could be commercialized and then confidently recommended and used by severely disabled people. and health professionals would have confidence in recommending ECS products for severely disabled use.

Conclusions

The aim of this paper was to review ECS technology suitable for the severely disabled and its potential benefits in improving QOL. Results showed a number of systems have been used over the past 50 years. However, exciting new developments in ECS technology has occurred concurrent with improvements in microelectronics and computers. Furthermore, a range of switches are being researched and developed that maybe capable of being used by those with severe restrictions in motor ability. This variety is important given the individual needs and capabilities of the severely disabled, and it is essential that they have access to functional ECS technology and switching methods that they can use to gain some independence. Preliminary evidence suggests that ECS technology can improve QOL. Notwithstanding the above, it is disappointing that robust scientific evidence for the efficacy of many of these ECS technologies is lacking. It is hoped that researchers and technicians in this area will devote time to scientifically evaluating the efficacy of assistive technology designed to enhance the ability of severely disabled to control their environment.

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