Environmental control systems: recommendations based on users’ experience

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Abstract

Purpose:
This paper translates research findings from an exploration of the users’ perspective on living with Environmental Control Systems (ECS) into real world implications and recommendations.

Method:
The experiences of ECS in Irish people with high spinal cord injuries (SCI) were explored in a qualitative multiphase study. The studies included three focus groups (n=15); a single pilot study and an 8-week ECS trial involving six in-depth interviews. Findings from each phase are summarised and combined.

Findings:
Cumulative findings from all phases provide seven practical implications. 1) ECS need to be made available to people with SCI. 2) Barriers to provision and unrealistic expectations need to be addressed. 3) ECS use must be established as an early habit. 4) ECS are an occupational therapist’s responsibility. 5) An ECS starter pack is viable. 6) ECS cannot be considered in isolation of other technology. 7) Non-use is a realistic and expected outcome for some.

Conclusions:
Exploring the users’ perspective has produced seven practical implications, which provide the basis of recommendations for improved provision and sustained ECS use. Recommendations span both rehabilitation and community living settings. This paper overtly translates research findings into useful clinical information.

Key words
Environmental Control Systems (ECS), Electronic Aids to Daily Living (EADL), tetraplegia, qualitative, non-use, Users’ perspective
1. Introduction

Environmental Control Systems (ECS) enable people with significant physical disability to control and access everyday electronic devices such as navigating televisions and making telephone calls (Ripat, 2006). Such access and control is an essential requirement to enable participation in modern digital society. Documented benefits of ECS use include increased independence (Croser, Garrett, Seeger, & Davies, 2001; Judge, Robertson, Hawley, & Enderby, 2009; Ripat, 2006); autonomy and choice (Verdonck, Chard, & Nolan, 2011a); decreased dependence on carers and positive psychosocial impact (Harmer & Bakheit, 1999; Jutai, Rigby, Ryan, & Shone Stickel, 2000; Ripat, 2006). Despite the clear value of such devices those who can benefit from the use of ECS may be living without such technology as is common in Ireland (Verdonck, Steggles, & Chard, 2009a).

Occupational deprivation is “the deprivation of occupational choice and diversity because of circumstances beyond the control of individuals or communities” (Wilcock, 2006, p. 343). Using ECS enables people with severe physical disabilities to participate in everyday tasks such as navigating television channels and making telephone calls. These task become choices for those who without ECS have less autonomy (Verdonck et al., 2011a). People who have to live without ECS suffer occupational deprivation as they are unable to participate in activities which are meaningful to them.

This paper translates the research findings of a 3 phase study (see Table 2.1), which investigated the lived experience of ECS use for people with high cervical spinal cord injury, into real world implications and recommendations for ECS use and provision.

Phase 1 findings described ECS user and nonusers ECS expectations, experiences (Verdonck et al., 2009a) and meanings (Verdonck, Steggles, & Chard, 2009b). Phase 3 showed ECS use to involve an interplay of hassle and engagement in getting used to using ECS (Verdonck, Steggles, Nolan, & Chard, 2014). This last phase also illustrated how living with ECS allowed users to feel enabled and to reclaim a little doing (Verdonck, Chard, Nolan, & Steggles, 2012).

2. Method

The experiences of ECS for Irish people with high spinal cord injuries (SCI) were explored in a qualitative multiphase study. The studies included three focus groups (n=15); a single pilot study and an 8-week ECS trial for six persons and involving six in-depth interviews. Data where analysed using a phenomenological approach. The research methods have been described in greater detail elsewhere (Verdonck et al., 2011a; Verdonck, Chard, & Nolan, 2011b; Verdonck et al., 2014). The findings from all stages when considered together have real-world implications which are presented here.
2.1 Summary table of study findings

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3. Findings
Cumulative findings from all phases when integrated together provide seven practical implications.

3.1 ECS need to be made available to people with SCI
Having ECS enables users to live rather than to just exist through actively participating in everyday occupations (Stead, 2002). Users in both this study and in other studies have referred to ECS as ‘essential’ and ‘indispensable’ (Palmer & Seale, 2007; Ripat & Strock, 2004). The positive effects of living with ECS obliges service providers to ensure that ECS are integral to living with a high tetraplegia and to ensure those who require ECS are able to do so. ECS should be available to those who can benefit from their use but should not be prescribed as mandatory with a one size fits all approach (Verdonck et al., 2014). Phase 2 and 3 illustrated how an ECS starter pack was customised for each participant through a collaborative approach between the user, their family members and an occupational therapist (Verdonck et al., 2011b). Customisation of ECS for each user provides choice and improved autonomy. Collaboration is intended to empower the users to make independent adjustments to their ECS.

3.2. Unrealistic expectations and barriers to provision need to be addressed.
Poor knowledge of ECS was revealed during Phase 1 focus groups and consequently Phase 3 participants were pleasantly surprised by their ECS experiences (Verdonck et al., 2014). Their surprise related to their successful adoption of ECS as well as the new abilities offered by ECS. This indicated that their experience did not match their expectations. Expectations included that ECS would not suit their needs and that ECS would be difficult to use and to incorporate into existing lives (Verdonck et al., 2014). These inaccurate expectations suggest that Irish participants had not had access to accurate information about ECS. It follows that there is a need for realistic information for both service providers and potential ECS users during rehabilitation, in outpatient services and in the community. Potential users can learn that ECS can be simple, fun and can be customised (Verdonck et al., 2014). In addition realistic information would be best shared through actual real experience with ECS use including trials of ECS both in rehabilitation at home.

Exploring barriers to ECS provision in Ireland was not a focus of this multi phase investigation. Findings did however indicate barriers such as poor funding, limited opportunity and a lack of realistic ECS information. The absolute need for ECS as a tool to combat occupational deprivation must be highlighted and funding needs to be actively sought to begin to address to inadequacies of ECS provision.

3.3. ECS use must be established as an early habit.

Living with high SCI was described in Phase 1 as acquiring habits that are not easily given up and are in fact essential to enable those living with high SCI to do some things for themselves (Verdonck, 2012). If ECS are introduced after these habits have been established the challenge involved in both undoing some of these habits and becoming used to using ECS, are more likely to be not worth the effort. However if ECS are introduced early enough this could make the ECS a habit, as echoed by expressions of ‘couldn’t be without it now’.

People with high SCI need to be offered the experience of ECS use early in their rehabilitation so that they become an integral part of their decision making and total rehabilitation. This means that people with high SCI should be offered a starter-pack as early as possible.

However allowances must be made for individual differences described as a timing issue. A starter-pack needs to be available at different times for people so that they can experience ECS when they are ready. This means offering a starter-pack at the start of rehabilitation, as well as: during rehabilitation, on discharge from hospital and when living in the community. This may be difficult to achieve as bureaucratic processes and systems that govern rehabilitation service will challenge this concept favouring the identification of one uniform ideal time for introduction to ECS. Healthcare systems tend to favour bureaucratic simplistic systems rather than person-centred services as recommended by his study.

3.4. ECS are an occupational therapist’s responsibility.

Occupational therapy interventions are occupation-focused and centred on meaningful doing, being and becoming (Hammell, 2004). Occupational therapists facilitate people to do what they want to including controlling audio visual and
electronic devices. The occupation of being includes time alone without others something that is possible through ECS use. ECS users can feel safe alone. Having an ECS facilitates people with high cervical spinal cord injuries to feel enabled and by feeling enabled they may feel worthy of having an ECS. Prior to hands-on experience participants did not consider the availability of ECS to be realistic or necessary. Subsequently participants reported that they felt worthy of having their own ECS (Verdonck, 2012).

Neither those with high SCI, who lack ECS experience, nor services providers can understand what it is like to live without ECS or to live with ECS. Occupational therapists therefore have to be advocates for those who have become accustomed to living without ECS. We need to advocate for ECS use and provision based on the experiences of using an ECS and their meaning as uncovered in this study.

In addition to advocating for ECS provision, occupational therapists also have a role to play in supporting new ECS users. Acknowledging the challenges involved in establishing ECS use as a habit while also overcoming frustrations with learning to use ECS can facilitate successful use (Verdonck et al., 2014). Understanding the possible resulting good feelings, fun and humour and surprise that can result from ECS use may offer some motivation for continued ECS use. Phase 3 described the reality of getting used to ECS in contrast with the previously well documented benefits with little acknowledgment of challenges involved.

3.5. An ECS starter pack is viable.
Phase 2 of this study involved developing an ECS starter pack (Verdonck et al., 2011b). The specific components of the starter pack were less important than the functionality of the pack and how it was customised. A starter pack required control of audio visual equipment, telephones and some simple on off appliances. The pack allowed single or multiple function and was considered to provide a building blocks allowing further functional expansion. Providing a supporting booklet and DVD facilitated a collaborative approach by providing the users with information on which to base their choices. Installation was enhanced by using a collaborative problem solving approach. This starter pack was a viable way to provide a practical introduction to ECS. Such a pack may be provided on a loan basis as a precursor to supply and thus allow an informed choice in future ECS use. Alternatively it may be a stepping stone to a more complex set up that could include door openers and intercom systems. Using a starter pack can enable a non-specialised occupational therapist to provide the first realistic introduction to ECS.

3.6. ECS cannot be considered in isolation of other technology.
Although the focus of this multi-phase investigation was on the use of ECS it is also important to considering other assistive technologies (AT). Findings from Phase 1 and Phase 3 included discussions of powered mobility and mouthstick use and the integration of these AT with ECS. This novel inclusion was an unexpected finding resulting from providing people with the freedom to discuss ECS on their own terms in this qualitative investigation. The powered wheelchair, mouthstick and ECS triad uncovered in Phase 1 highlights the need for the integration of assistive technologies as advocated by Ding et al. (2003). Both high and low technology assistive technologies are equally valuable (Scherer, 2000). The identification of the value of
mouthsticks for people in his study highlights the need for their inclusion in rehabilitation in conjunction with electronic technologies.

3.7. Non-use is a realistic and expected outcome for some.
Using an ECS involved an interplay of hassle and engagement. The hassle included having to change habits along with dealing with pragmatic and service provision frustrations. Engagement is possible for those able to overcome the hassle of getting used to using an ECS. On the other hand the hassle itself may not be worth the effort to others and they may never engage in the use of ECS. The choice to not use ECS is an expected outcome and is acceptable if based on realistic trial and adequate realistic information (Verdonck et al., 2014). If people are provide with an opportunity to trial ECS and then decide not to become ECS users this should be viewed as a positive outcome in contrast with the negative associations of non-compliance and abandonment.

4. Conclusion
Exploring the users’ perspective has produced practical implications, which provide the basis of recommendations for improved provision and sustained ECS use. Potential ECS users need to be provided with opportunities to trial using ECS. This can be achieved using starter packs in addition to providing support to both acknowledge and overcome the challenges of using ECS. Individuals need to be permitted to select to not use ECS as an acceptable choice if based on adequate information and experience. The opportunity to have ECS is essential for people with high cervical spinal cord injuries as their use can limit occupational deprivation.

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References


**Summary**

The experiences of ECS in Irish people with high spinal cord injuries were explored in a qualitative multiphase study. Cumulative findings from all phases are summated and combined to provide seven practical implications and recommendations for improved provision and sustained ECS use. These span both rehabilitation and community living settings.