

## Taking back a little of what you have lost: the meaning of using an Environmental Control System (ECS) for people with high cervical spinal cord injury

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## **Taking back a little of what you have lost: The meaning of using an environmental control system (ECS) for people with high cervical spinal cord injury.**

### **Abstract**

Purpose: Assistive technologies have deep and personal meanings for people with disabilities.

This study sought to provide an in-depth exploration of the subjective meaning of

Environmental Control System (ECS) use for people with high cervical spinal cord injury.

Materials and method: Interpretative Phenomenological Analysis (IPA) was used to explore the personal meaning of ECS. In-depth interviews with five participants were analysed according to recommended IPA guidelines to produce a rich phenomenological account of lived experience.

Results: This study identified two overarching themes, one of which was the subject of an earlier publication. This paper focuses on the second theme “Taking back a little of what you have lost” and its two main components “Reclaiming a little doing” and “Feeling enabled”. Doing everyday things, being less dependent on others and feeling safer and less needy all contributed to participants’ experience of regaining something important of what had been lost.

Conclusions: A nuanced range of meanings, demonstrating how “a little can mean a lot” emerged from this study. For those with high cervical spinal cord injury, “reclaiming a little doing” resulted in subtle, but subjectively significant, improvements in identity, relationships and well-being, while “feeling enabled” was both enjoyable and empowering and led to an increased sense of safety and reduced neediness. The potentially powerful impact on individuals with life altering injuries of reclaiming a little of what they had lost supports the value of more widespread access to and provision of ECS.

## **Introduction**

Assistive technologies (AT) are personally meaningful for users for a wide variety of reasons as indicated by a growing body of qualitative evidence [1, 2]. Successful integration of such technologies, including Environmental Control Systems (ECS), is related to the individual and specific meanings ascribed to these devices by users [3]. This paper provides an in-depth exploration of the meaning of living with an Environmental Control System (ECS) for users with high cervical spinal cord injuries (SCI). Considerable non-use of assistive technologies has been identified by practitioners, although specific studies on the use of ECS report a low rate of abandonment [4, 5]. An enhanced understanding of the personal importance of ECS to users may clarify the higher utility rate and provide support for the ongoing provision of this particular AT. It may also contribute clinically valuable information to improve the beneficial impact of ECS and other assistive technologies for people with high level physical disabilities.

ECS are assistive technologies that enable people with severe physical impairments to control electronic devices by activating customised switches which communicate with control units capable of sending signals to televisions, radios, lights and door openers [6]. ECS are potentially useful for people with significant physical limitations arising from conditions including, but not limited to, SCI, motor neuron disease, multiple sclerosis, acquired brain injury, and cerebral palsy. The SCI population, the specific focus of this study, are frequently represented in ECS research [6, 7, 8, 9, 10, 11]

High levels of satisfaction with ECS, as well as positive psychological outcomes have been reported using standardised and ECS-specific outcome measures. The Measurement of Control Using Electronic Aids to Daily Living [MCEADL][8], Lincoln Outcome Measures for Environmental Controls [7, 8] and the Psychosocial Impact of Assistive Devices Scale [PIADS] (10), have been used to demonstrate positive, psychological outcomes[6, 7, 12].

ECS use has been linked to increased independence, choice, and quality of life [6, 13, 14]. Others have linked ECS use to increased autonomy which, in turn, was linked to changed relationships and an increased capacity to spend time alone [9]. A descriptive phenomenological study of ECS prescription and use also identified increased user autonomy and highlighted the important, positive effect of user training and user-readiness to engage with ECS [10].

A review of qualitative ECS literature, including grey literature, indicated a thematic focus on the practical and technical benefits of using ECS [9]. Two grounded theory studies revealed some of the complexity of what it means to live with ECS [15] [16]. Stead's study [16] was one of the first to identify "meaning" as a major theme but did not expand on this theme in any depth. Palmer and Seale's [15] study of ECS use identified two themes, "utility transcended" and "utility denied" suggesting richer and more personal benefits in addition to the more obvious practical, task related benefits. Although literature has provided some qualitative insights into ECS use, findings are descriptive rather than interpretative in nature. An understanding of the deeper meanings of assistive technology to the user may provide subjective insights that will, ultimately, facilitate long term successful incorporation of ECS into everyday life. An in-depth understanding of the lived experience of using ECS, beyond a focus on functional benefits, will better equip clinicians and suppliers to facilitate meaningful occupation, incorporating ECS use, for individuals with significant impairments.

An in-depth, interpretative phenomenological study was therefore conducted. Its aim was to provide a deeper understanding of the subjective meaning of ECS beyond the merely descriptive. It sought to build on previous grounded theory and descriptive phenomenological studies, using Interpretative Phenomenological Analysis (IPA). Phenomenological inquiry was used to gain an understanding of the lived experience of ECS use for five people living with high cervical spinal cord injury in Ireland. IPA can produce rich findings such as those reported in a

single participant case study by Eatough and Smith (2006) [17, 18]. The findings of this single participant IPA study were shared in two separate publications to allow adequate coverage of the findings. Similarly, another IPA study exploring relationships for people with intellectual disability shared its findings in two separate publications, in order to do justice to the depth of analysis produced by IPA [19, 20].

IPA in this study produced a rich understanding of the lived experience of ECS. One overarching theme explained the learning process and practical benefits that arose initially from the dynamic interaction between hassle and engaging with ECS, detailed in an earlier publication[21]. The current, companion paper provides a focus on the second overarching theme, that focuses on the personal meaning of living with ECS for five Irish people with high cervical SCI. Together the two papers provide a deep understanding of the practical and personal significance of ECS to individuals with significant physical impairments.

## **Methods**

IPA was chosen as an appropriate methodology to explore the lived experience as it involves rigorous, qualitative analysis of the complexity of lived experience in a homogenous sample [22]. In IPA, the researcher makes sense of the participants' making sense of their own experience in a double hermeneutic. The researcher is active in the analytical process and brings personal and professional insights to bear on participant data [22]. In this study, the researcher lens was that of an occupational therapist and reflexive journaling was conducted throughout the study to clearly acknowledge and delineate this influence [23]. IPA differs from other methodologies as it seeks to understand the individual lived experience and comparisons between individuals only occurs once all individual experiences are comprehensively analyzed and individual themes identified. This aspect of IPA allows for both the identification of nuanced

individual differences and commonalities between people [24]. The small sample size, allows for in-depth individual analysis which facilitates a subsequent comparison across participants [22].

### **Participants and procedures**

The sample for this study has been described in detail in the associated publication [21]. Recruitment was facilitated by the national support organization, Spinal Injuries Ireland. The final homogenous sample included 1 female and 4 male participants with high cervical spinal cord injuries. Participants did not own an ECS and were all unable to use a standard remote control or feed independently. Participants' ages ranged from 22 to 55 years of age and all had been discharged from rehabilitation for at least 3 years. Sample size in IPA is typically small, and therefore often contentious. However, the value of IPA is the focus on "thick" interpretative accounts from a small number of participants as opposed to "thinner" accounts from a larger group [24, 25].

Full ethical approval was granted by the National Rehabilitation Hospital application number ECM4(h)05/05/09. Participants provided informed consent and selected a pseudonym (used throughout this paper). Participants were provided with an ECS starter pack described elsewhere in detail [26]. The pack was fitted in each participant's home and customised to each participant's usage preferences. Following the trial, each participant completed an individual, in-depth interview in which they were asked to describe life with an ECS and the meanings they ascribed to the experience. Unstructured interviews in the style of a free-flowing conversation were conducted by the first author, an experienced qualitative researcher and interviewer, using a broad questioning route comprised of open questions exploring "what is it like to use ECS?". The interviewer sought depth in individual answers through iterative questioning and prompting such as "can you tell me more about that?". Field notes, reflexive journal notes and a detailed audit trail were maintained throughout the study to enable the interviewer to enrich data obtained at interview and to record researcher influences on data collection. Each interview was conducted in

the person's own home and lasted between 41 and 56 minutes. Interviews were audio and video recorded and transcribed verbatim.

### **Data analysis**

Data analysis was conducted according to the six steps described by Smith et al. : 1)reading and re-reading, 2)initial noting 3)developing emerging themes, 4)identifying connections across emergent themes; 5)moving to the next case and repeating first four steps then 6) looking across cases [22]. Analysis of transcripts and recordings was aided by the use of ATLAS.ti, a computer assisted qualitative data management programme [27]. The use of software allowed comparison between data sources and themes as well as continual linking back to the primary data (transcripts) to validate emerging findings [28]. This process was lengthy and required several months of analysis and re-analysis despite the small sample size. Yardley's guidelines for ensuring quality and rigor of analysis including: sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance were applied throughout the study [29]. Sensitivity to context was based on substantial clinical experience in spinal cord injury and awareness of potential researcher bias and recognition of the time limited nature of the trial. Commitment and rigor was established by an extensive literature review, formal training in IPA, in-depth and lengthy data analysis process and lengthy debate and discussion. Transparency was ensured through reflexive journaling, field notes; a detailed audit trail (available on request) and integration of verbatim excerpts. A clinical expert in assistive technology for people with SCI, working outside of Ireland also reviewed and confirmed the coherence of the findings based on her clinical experience. Impact and importance was established by validating and disseminating findings through user organizations in Ireland, including publication in user's magazines, academic peer reviewed conference presentations and unsolicited guest presentations.

## **Findings**

Two major themes were identified: Getting used to using ECS and Taking back a little of what you have lost. The first theme (previously reported in a companion paper) describes the practical experiences of using ECS as a complex interrelationship between “hassle and engagement”. Engaging with, and enjoying the benefits of, ECS meant grappling with the “hassle” of new learning for participants. [21]. This paper explores the second major theme of “Taking back a little of what you have lost”, providing a deeper understanding, beyond the merely functional aspects, of the underlying meaning of living with ECS. “Taking back a little of what you have lost”, consists of two subthemes: “Reclaiming a little doing”, capturing the personal meaning for participants of being able to “do” things again and “Feeling enabled” exploring further psychological consequences of increased activity.

### **Reclaiming a little doing**

“Taking back a little of what you have lost” described the subjective importance of reclaiming or doing previous occupations again:

Oh I think it is because if you can do all those things for yourself you are taking back a bit of your dependency like. Taking back what you lost. You are getting something back. I know it’s only to turn on a television or put on a light but it is something a person does every day (James).

Although the actual activity “reclaimed” through ECS use was described as small, this was only in the context of having no or almost no ability prior to using ECS: “They are only small things. They are like tiny things to people who are able to do them but they are big things to people who aren’t, you know?” (Emily). Therefore, while the change may have been “small”, the difference that it made to their lives was “huge” or “big”: “It would make a huge difference... it obviously would make a huge difference” (Matthew).



“Reclaiming a little doing”, reflected the pleasure in doing everyday things, enjoying one’s own company and being less physically dependent. A person with high SCI can do very little physically, and “doing” is often reduced to a cognitive task or one involving verbal requests. Returning to “doing” everyday things pleased and surprised participants.

Participants mentioned a range of simple everyday tasks facilitated by ECS: turning on the light, the television, the stereo, closing the curtains, picking up the phone and, more importantly, “having a chat”. Browsing television channels was a popular pastime as it made selecting TV or DVD programmes possible:

I started watching box sets (of DVDs)... I’d go to bed every night and I’d have this (ECS) and I don’t think that dad would have appreciated coming in every 40 minutes or every hour or something for a new episode... if I missed something... I can just flick back (James).

Linking participants’ landline telephone or mobile phone to the ECS made it possible for them to use a telephone independently and privately. Being able to carry out simple everyday activities had huge personal significance, beyond the action itself, as vividly described by Bridget:

You are not actually confined to a bedroom ... You can forget who you are and the way you are because you are looking at the outside world the same as everybody else is... there are a couple of million people looking at the same thing (on television) and I am actually one of them

The increased ability to make preferred, spontaneous choices was simply expressed by Emily; “It gives you an option as well, if you want the light turned on, if you want the TV turned on or off”.

ECS enabled participants to experience the pleasure once again of being able to do things for themselves without having to call anyone. Participants acknowledged that they had become accustomed to being unable to “do” and the simple ability to do something independently was frequently mentioned by participants: “Just to be able to do something” (Emily); “It’s to be able to, the independence to do it yourself like, to be, to be able to do all these things” (James); “I can actually do it myself” (Bridget); and “It’s just good to be able to do things yourself” (Emily). James explained how he felt when the ECS was returned for a replacement battery:

When I sent it back ... it was frustrating because not to be able to do what I wanted to. Like I still do what I want to but I’d have to get somebody else to do it for me, which was frustrating (James).

The capacity to “do it for themselves”, thereby reducing dependence was clearly identified as both important and pleasurable for participants.

The enjoyment of one’s own company was identified as an important component of “Reclaiming a little doing”. Participants’ capacity to spend time alone and to enjoy one’s own company was novel for participants. It became possible because of the ability to call for help and therefore manage without a physical presence. Having an ECS reintroduced the experience of being alone: “I suppose I didn’t realise what it’s like anymore to be on your own because I am so used to having somebody there... I actually had forgotten what it’s like just to kind of have nobody here or nobody in the room”. (Matthew). Being alone provided “space” in contrast to having constant company: “Just to have my own space because I never have my own space, but just to have your own space and quiet”. (Matthew).

Being physically dependent on others limits the opportunity for privacy and using an ECS enabled participants to relish privacy once more. Emily frequently referred to her

enjoyment of doing things for herself in private: “I’d have the privacy to do with the environmental controls things that I wanted to” (Emily). Others talked about time alone being an opportunity to just enjoy their own company – a rare occurrence for those with high SCI: “Ah I’d love it!! I like being by myself... It’s just peace and quiet. People don’t irritate you and everyone likes being alone ... Everyone likes their own space and to do what they want as well. I get, I don’t like people around me the whole time. I like my few hours by myself” (Peter).

### **Feeling enabled**

The second sub-theme, “Feeling enabled”, encompassed the emotional impact of what it feels like to be able to take back a little of what has been lost. It encompassed experiencing pleasure in doing; feeling safe alone; and feeling less needy. ECS also evoked an emotional response of feeling good and feeling better about oneself: “You feel better about yourself because you are doing it yourself”. (Emily). Bridget’s new found ability to do something was a source of pleasure for her and she described her joy at being able to do things she thought she would never do again:

You get a great kick out of it. You get a great feeling that “I can do this on my own” you know. I can do something that I wasn’t able to do, um, that I could only do 36 years ago; to think that you can... do something for yourself... mentally it means an awful lot

Emily echoed this sentiment:

It’s just nice to be able to do something especially when you, when you physically can’t do it. So it’s nice to just be able to have something to help you do it... It makes you feel good

ECS enabled participants to enjoy their own space because they felt safe. Feeling safe and enjoying your own company were closely interlinked. Feeling safe represented the emotional

feeling of safety when alone, as distinct from the pleasure of simply “choosing” to be alone. Such nuanced differences within the themes highlighted the richness and complexity of the lived experience of having an ECS. However, while participants valued being alone, feeling safe required more than just an ECS.

All participants reported having someone either close by or whom they could call, either by means of their ECS or by calling out. ECS helped participants and their families feel relaxed and reduced feelings of vulnerability:

I am more relaxed, more relaxed at night. I sleep better. I am more relaxed during the day because I know that I am only within a whisker of calling somebody and they will (come)... (The sound-switch is) like a person, another person in the house being able to walk around, if I got in distress or if somebody was coming to the door ... I was not afraid because I could call for help so quick (Bridget).

Peter valued the ECS for the security it offered and sought to buy his own ECS following the trial period: “If I needed I could cut back on (carer) hours some places, if I felt more secure with the ECS”. Emily, like Peter, considered being left alone more in the future. However, neither of them expressed much conviction about this possibility or voiced it as a priority, despite it being physically possible. The participants were all accustomed to physical dependence on others and technology alone was not viewed as a safe substitute. They had no experience of this possibility and were unaccustomed to feeling safe alone: “I am so used to having somebody there” (Matthew); “There is always somebody around... there is always someone in this house” (Emily); “I would never perceive being ever left on my own in the house, you know” (Bridget). Bridget described the interplay of mental and physical states: “So that’s where something like the switch comes into play believe me it has a lot of uses mentally... to me it means an awful lot because once I am mentally stable I am OK. By having it I physically feel better” (Bridget).

Participants also reported, “feeling less needy”. This was expressed as more than feeling independent, it included feeling less frustrated, less annoyed, and less of a burden. In consequence, participants felt less indebted to others and less obliged to show constant gratitude. Bridget talked about no longer needing full-time assistance as she: “Can do that now (myself). I don’t need somebody standing beside me all the time having to actually physically do everything for me”. (Bridget). This had been frustrating for Bridget who felt that her constant requests were annoying to others. She described the internal conflict between not wanting to call for help which can be “annoying” and the frustration of “doing without it” or “putting up with it”. Bridget admitted that she sometimes chose not to call for assistance to avoid putting a carer under pressure. Using an ECS provided some relief from the sense of being a burden on others. One of the benefits of using an ECS was a decreased burden of care. James commented on the freedom of not being a burden on others when using ECS:

I feel that every time I call someone I am putting a burden on someone now getting them back here to stick on something (change a TV programme) even if I am half way through a programme and I don’t like it I got to bring them back in again so... I can watch five minutes of a programme turn it off, go watch another programme turn that off if I don’t like it... that’s what I like about it. That’s what; I think it’s the freedom and the independence of it (James).

Matthew expressed this as feeling “more comfortable” when not constantly asking for help: “It makes me feel a bit more comfortable... makes it easier ... I don’t like just constantly asking and asking”.

The range of meanings identified by participants in the overall theme “Taking back a little of what you have lost” provides a vivid illustration of how “a little can mean a lot”. While participants experienced ECS use for only a little time and were thereby enabled to just

do a little bit more, they all identified a spectrum of positive consequences, from the practical to the deeply meaningful, resulting from the small but significant recovery of ability and meaning lost to them as a consequence of sudden, acquired spinal cord injury.

## **Discussion**

Although these findings are consistent with much of the available literature, this study offers a more in-depth understanding of the subjective meaning of ECS use by highlighting intrinsic meanings rather than just describing overt experiences. A focus on experience usually provides detailed observations and descriptions of events and outcomes associated with using an ECS, whereas meaning is expressed or felt internally by the individual. This subtle difference has not previously been emphasised or explored in the ECS body of evidence: namely the pleasure and value of doing everyday things and the feelings associated with ECS use. An explicit focus on the intrinsic meaning of using ECS reveals how “a little” can in fact mean “a lot” to people who have lost considerable autonomy and agency. Small changes from a practical point of view (turning on a device) is more than simply “doing something”, it also means something and creates feelings of pleasure, safety, and an enhanced sense of self. Previous evidence focused largely on the objective enablement that results from using an ECS, rather than the individual, subjective, lived experience that makes doing something, being someone and exercising autonomy through action a unique personal event. The current study highlights the crucial importance of being able to reclaim a small amount of ability in the context of severe functional limitations and participation restrictions. The use of IPA enabled this nuanced understanding to become apparent and offers valuable insights into the lived experience of ECS use for people with significant physical impairment.

We live in a technological age with daily activities mediated by technology, we ‘do technology’ or ‘do through technology’. Doing is a core concept within occupational therapy and a crucial dimension of the meaning of occupation [30]. ECS enabled users to ‘do’ despite

significant physical impairments. Life lived with high SCI and without an ECS presents many barriers to ‘doing’ everyday occupations. While doing simple things such as telephoning someone or choosing what to watch on television may appear to be mundane occupations, they have significant, personal meaning [31]. Being able to use an ECS facilitated ‘doing everyday things’

“Doing” by using an ECS has been described as being independent, or enabled to do things without assistance [6, 14]. In the current study, participants referred to “doing things on their own” or “reclaiming a little doing”, which is different to being independent. “Taking back a little of what you have lost” implies an emotional complexity far beyond functional independence, which is not only unrealistic, but irrelevant, to these participants. While not explicitly linked to quality of life in this study, the ability to engage with and enjoy simple normal living by “doing everyday things” is a prerequisite for quality of life for people with high SCI (25).

The meaning of “Feeling enabled” incorporated “doing” of ordinary, everyday things which most of us take for granted. Furthermore, ECS enabled “being”. Being alone and being safe alone were discussed by participants repeatedly throughout the interviews. “Being” is a phenomenological concept, described by Heidegger as “Dasein” [28]. Being is harder to conceptualise than doing, but in a phenomenological sense being is central to who we are. It involves being true to ourselves, being able to think, to reflect and to simply exist [32]. The findings of this study suggest that being, in both an occupational and phenomenological sense, is facilitated by using an ECS. Hammell described “Being alone” as “meaningful use of time beyond doing” (25) including spending time in nature, listening to music, appreciating art or spending time with special people.

“Time alone” has been identified in previous ECS studies, as a component of meaning and autonomy [9, 10, 16]. Being alone can be considered in terms of fewer care hours and

less expense rather than “being” for its own sake: as an occupational and phenomenological concept.

A fuller understanding of the lived experience of time alone results from considering the psychological benefits as well as the practical and safety aspects of ECS. Feeling safe alone is something able-bodied people take for granted. It was only when exploring descriptions of feeling unsafe when living without ECS that the value of feeling safe for people with high SCI became more clearly apparent.

On the basis of a systematic review of qualitative literature, and an IPA study of five men’s experience of SCI following discharge from rehabilitation, Nolan concluded that “a challenge to identity is at the core of the lived experience of SCI” [33,p.121] and that continuity is of crucial importance to a re-establishment of self. This re-establishing of identity is likely to be easier if the person “feels enabled” and can reclaim former activities. ECS have a role to play in facilitating positive self-perception and re-evaluation of self [34]. If an ECS can enable doing and being, as the findings from this study suggest, then it is clear that using an ECS facilitates much more than turning electrical appliances on and off and providing some breathing space for carers and users. It is likely that having greater confidence and feeling less needy helps facilitate a new or renewed positive self-perception and continuity of being.

Life with SCI, or with any significant physical disability, has been described as a state of being continually indebted. Galvin [35] describes reliance on others as living with “perpetual obligation” that requires “irrevocable gratitude” which involves constant apologising and thanking of others. Findings from this study indicate that having an ECS has the potential to create subtle, but significant, alterations in interpersonal dynamics as users are less likely to feel permanently apologetic and under obligation to others. Both parties may consequently be less irritated, resulting in a decreased burden of care and a better quality of communication.



[6, 9]. The effects of ECS on relationships with family and close friends were noted by participants. ECS use did more than simply facilitate better communication, it changed relationships by increasing the repertoire of abilities and thus reducing the extent of physical and psychological demand placed on others.

### **Study Limitations**

The study was based on the experiences of five people with high cervical SCI, living in their own homes in [country] and therefore generalizability to other populations is unknown. The resulting themes do however resonate with clinical experiences of the multinational research team and a larger study is recommended. Advances in technology have resulted in ECS being integrated into smart devices such as smartphones and tablets. The participants of this study all used stand-alone ECS devices that were not integrated with smart devices. The findings of this study are likely to apply to ECS use in general but may be specific to older technologies. Clinical experience also indicates that the use of non-smart device ECS remains widespread for people with SCI.

. The richness and complexity of the findings have been described in two separate, complementary publications which when read together provide insights into understanding of the outcome for these participants. While this could be considered a limitation, it may also be considered a strength and a means of giving adequate voice to the substantial findings from the larger study. The lived experience of ECS is captured in this combination of papers highlighting firstly the interaction of hassle and engagement and then the deeper subjective meaning of the experience once the initial “hassle” had been overcome.

### **Conclusion**

This study provides an example of the complexity of the personal meaning of assistive technology use. The in-depth phenomenological analysis using IPA provides insights into the

multiple and multi-layered subjective meanings of ECS use as described by five people with high SCI. The value of reclaiming some ability to do ordinary, everyday things as well as insights into the meaning of using an ECS are highlighted. The meaning of living with an ECS resulted in “small” differences with a “big” impact for participants. An ECS enabled them to do everyday things, to enjoy their own company and to feel less physically dependent while experiencing pleasure in doing, feeling safe alone and feeling less needy. The personal and occupational benefits clearly outlined by participants reinforces the clinical importance of providing ECS to those with high cervical spinal cord injuries.

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**Declaration of interest**

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