

The Meaning of living with or without Environmental Control Systems for People with Tetraplegia: an Irish Focus Group Study

Michèle VERDONCK^{a,1}, Elizabeth STEGGLES^b and Gill CHARD^c

^a*National Rehabilitation Hospital, Dun Laoghaire, Co Dublin, Ireland*

^b*School of Rehabilitation Science, McMaster University, Ontario, Canada*

^c*Department of Occupational Science & Occupational Therapy, University College Cork, Ireland*

Abstract. Interpretative Phenomenological Analysis was used to analyse four focus groups that explored the lived experience of life with and without environmental controls (ECS) for persons with high cervical spinal cord injury. Findings revealed themes of *autonomy, freedom, safety, time alone, and relationship*. These experiences offer useful insights for both users and practitioners in the field of assistive technology.

Keywords. Environmental controls, domotics, electronic aids to daily living EADL, interpretative phenomenological analysis, qualitative research, spinal cord injury.

Introduction

Environmental Control Systems Environmental Control Systems (ECS) also know as Electronic Aids to Daily Living (EADL) can enable a person with physical limitations to control a wide range of electronic devices. By using ECS they can open doors, answer phones, turn on lights and surf TV channels. Accordingly ECS are important and useful for persons with high cervical spinal cord injuries [1-4]. Perceived benefits of ECS include functional independence, personal autonomy and psychological well being [3, 5, 6]. These perceived impacts are stable over time [6, 7]. In addition ECS users have reported a high level of satisfaction with their ECS [8, 9].

The body of literature on this topic is predominantly quantitative despite the fact that the users' personal perspective is valued by researchers. Accordingly mixed methodologies have been used to add qualitative findings to outcome measurement [7]. While qualitative studies of ECS are scarce, two studies explored the adaptation process of new ECS users with traumatic brain injury (n=12) and spinal cord injury (SCI) respectively (n=2) [10, 11] and a third English study investigated the attitudes of users to their ECS[12].

Despite evidence to support the use of ECS for persons with SCI the lived experience of the use of environmental controls by persons with spinal cord injury has

¹ Corresponding Author. Michèle Verdonck, National Rehabilitation Hospital, Rochestown Avenue, Dun Laoghaire, Co Dublin, Ireland; E-mail: great.sci@gmail.com

not been explored. The provision of ECS for this client group in Ireland is inconsistent and people living in the community with spinal cord injury may or may not have access to ECS.

1. Methodology

Interpretative phenomenological analysis (IPA) was selected to explore the lived experience of life with or without ECS. Focus groups were selected to encourage discussion between people with high cervical spinal cord injuries (injury level C3-C5) in similar situations to uncover rich descriptions of their shared experience. Groups were designed to be led by group members (rather than researcher-led) in an attempt to focus on users' experiences rather than researcher expectations, theories or outcomes.

Fifteen people with cervical spinal cord injuries attended four focus groups that were video recorded, transcribed and analysed. The users group described living with ECS while the nonusers described life without them. Participants without ECS were also asked to envisage life with ECS.

2. Findings

Data analysis uncovered homogenous themes for both user and non users groups. These themes were organised into three categories: a) *utility and usage*, b) *desires* and c) *meanings* of living with ECS. This paper will explore the third theme *meanings of ECS* including autonomy, freedom, safety, time alone, and relationships. These five subthemes are interrelated as illustrated in figure 1. The first two themes, *Utility and usage*, and *desires* have been discussed in a separate publication. Pseudonyms have been used throughout this paper.

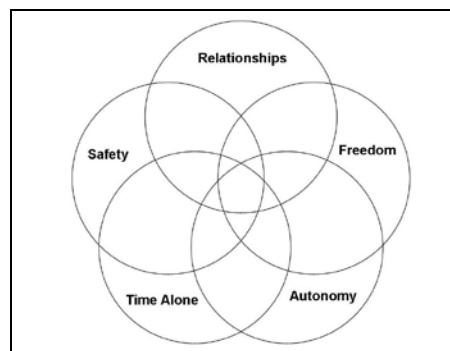


Figure 1. Themes of the meanings of living with Environmental Controls.

2.1. Autonomy

The ability to *do something yourself* [James] was the dominant perceived value of having ECS. *That's the whole idea of an environmental control system, you aren't relying on people.* [Dave]. *(I)t has changed so many things for me ... it's like giving a*

quadriplegic arms and hands that work. [Jane]. Even those without ECS predicted that they would, *be able to do what you want* [Peter]. ECS improve autonomy and *it feels like you're living your life instead of hanging around waiting for other people to help you live your life.* [Dave]. Similarly it, *gives you the choice to choose what you want to do* [Jim]. *It's great to be able to do something without asking someone, all along you ask enough people to do things* [Michael]. Richard echoes this, *by having the environmental controls I don't need help, (I don't need) someone to do anything.* Accordingly those with ECS said that they would find it hard to be without their technology. Autonomy as a result of having ECS was also considered to contribute to individual and family confidence and independence. *For me, just even the confidence to do a lot of things yourself without anyone needing to be around, just self reliance* [Paul].

2.2. Freedom

For many persons with high tetraplegia 24/7 care is a reality and having ECS can reduce the feeling of dependence. Participants discussed the fact that carers may sit around doing nothing but waiting in case they may be needed. This is unpleasant for both parties. It is more satisfactory to ask a personal assistant to be there when they are needed instead of them feeling that they *'have to be there for you'* [Dave]. This gives carers their own freedom. They can feel secure leaving the person alone with an alarm or call system. Freedom, from the burden of care, affects both the users and their carers or family members. Those without ECS predicted that ECS could help with *lightening the load* [Jane]. ECS provide the freedom for carers so that, *they can go on and do their own thing and not have to worry. You know, worry about you.* [Emily]. For persons with no ECS simple tasks like changing TV channels or turning pages of a book could only be carried out with carer assistance. In contrast, *if you had these things in your house, you wouldn't have to bother your family all that much* [James].

2.3. Safety

Not being able to rely on one's body to relieve pressure, to prevent falling over, to control bladder function, and the added danger of life threatening autonomic dysreflexia make people with high spinal cord injury vulnerable if left without constant care. Personal safety is essential to keep these people out of hospital and medical compromise. ECS has to offer both personal and physical safety. This means that the system has to address fire, theft or other danger, as well as provide assistance to the user to prevent ill health or personal risk. *I think the security thing is a huge part of it, is that people are leaving hospital to come home, you have to provide them with a level of security and one of those is communications, the other one is being able to get in and out of house, rooms and that, unassisted. You can't be 100% reliant on somebody else* [Paul]. The ability to summons help using an alarm system or telephone was considered to be the most important dimension of personal safety. Secure door closure and locking was another safety concern as some ECS users described dissatisfaction with door installations.

2.4. Time alone

Members all spoke passionately about enjoying solitary time. Those without technology could only anticipate this time alone, *(I)t would be nice to be on your own too* [James]. *I think that's very important. You could spend much more time on your own* [Jerry]. The ability to spend time alone was a new experience for people when first introduced to ECS. *It's not being babysat 24 hours a day anymore* [Dave]. *It's just great to get away you know like, without all people around you* [Ciara]. *Just having space* [Richard]. Being able to be alone was attributed to having both ECS and a powered wheelchair. This combination facilitated entire days away from carers and away from home for some. *I'd often work at home for 6 or 7 hours without anybody being around* [Paul]. *There's nothing better, I have my own shadow behind me, I have all these hours of PA's, ... it's just that I hate them being around. I hate having people around. Go off on my own, open the door. Go out anywhere* [Michael]. *I might just go out the door and could be gone for 2 hours and just head off to the middle of nowhere* [Dave].

2.5. Relationships

Living with a severe physical disability necessitates a considerable amount of assistance from others. This need for help makes it difficult to experience equitable relationships, as one party is always dependent on the other. *(If you are completely dependent, then obviously that is your relationship with them. That becomes the relationship and it becomes a major dynamic in the relationship, whereas if you can be a lot less reliant or calling on people then it takes some of that out of the way* [Joe]. Both parties have to consider the other and it is difficult to have a spontaneous relationship when interactions require such careful planning. Both users and non users discussed how they always have to ask for help and thus spend much time apologising for being a burden. *It's always, 'I'm really sorry, but would you mind?* [Jane]. Both, asking for help and having to provide that help, imposes a particular dynamic on a relationship. Users agreed that ECS offered some respite from the strain that dependency places on relationships. It became possible to act independently without the necessity of involving others at every stage. *It (ECS) definitely helps in a relationship of any sort, it just means you contribute more. Give, give, or take, take, take* [Michael].

3. Discussion

This description of the lived experience of ECS, and the benefits that result for users, adds a rich perspective to existing literature. The meaning of living with ECS, both in reality and as anticipated, illustrates valuable benefits for this population. Lessening caregiver burden, or freedom as we have termed it, has been previously considered although not proven [2, 9]. Safety features of ECS have been considered a high priority [2, 9, 13, 14]. This facilitates psychological confidence for both users and carers.

Novel themes such as being alone and relationships were explored within this chosen methodology as it allowed free discussion rather than being based on existing theory. These themes are novel in terms of the existing ECS literature. In contrast, qualitative inquiry about quality of life for persons with high spinal cord injury

revealed similar themes such as autonomy, relationships, being alone [15, 16]. ECS may thus contribute to improved quality of life.

All five themes are closely related. The provision of increased safety with the assistance of ECS in turn facilitates being able to spend time alone. Time alone allows some freedom from carers, which in turn affects interpersonal relationships. The autonomy afforded by ECS allows safe, time alone, free from carers.

4. Conclusion

These findings have implications for social inclusion, independence, and autonomy. ECS provides people with severe and significant disability the means to regain the potential to feel safe, have time alone, be free from carers, do things for themselves and experience independent relationships. This suggests that the provision of ECS should be seen as a fundamental human right. This exploration of the lived experience of people who utilise ECS reaffirms the need to address the right to access to such technology and emphasises the inequalities that exist between those who do and those who do not have access to such valuable life-enhancing equipment.

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