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Electronic Aids to Daily Living: Be able to do what you want.

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Abstract

Purpose. This study explores the experiences of Irish people with high cervical spinal cord injuries living with electronic aids to daily living (EADL) and the meaning attributed to such systems in the context of participation in everyday life.

Method. Qualitative methodology using a phenomenological approach was used to explore the phenomenon of living with EADL. Data were collected using four focus groups of users and nonusers of EADL (n¼15). All participants had high cervical spinal cord injuries (C3-5). Groups were video recorded, transcribed verbatim and analysed using descriptive phenomenological analysis.

Findings. Findings revealed key elements of the meaning of living with EADL. Two key themes, time alone and changed relationships are described. These contribute to the super ordinate theme of autonomy. Findings suggest that participants perceived improvements in both anticipated and actual lived experiences with EADL. Themes are interrelated and together represent a summary of the experience of living with environmental controls. The themes described are similar to those found in other spinal injury studies relating to quality of life.

Conclusions. Findings highlight differences in life experiences for those with and without EADL and provides motivation to address this difference. Such insights are valuable for both users and providers of EADL.

Keywords: *Environmental control systems (ECS), electronic assistive technology (EAT), qualitative inquiry, occupational therapy, cervical spinal cord injury*

Introduction

Electronic Aids to Daily Living (EADL) or Environmental Control Systems (ECS) offer significant benefit to those with high cervical spinal cord injury as they make possible a degree of independent control over a range of standard and specialised devices. EADL are used to control television, satellite and stereo as well as door and window controllers and telephones. In recent years technological developments have improved the features of EADL so that they can be totally wireless, have dynamic colour displays and be speech operated. More broadly, assistive technology including EADL is a rapidly growing field of interest both clinically and academically with research interests focused on use and non-use (or abandonment) [1,2], user satisfaction[3-7], and quality of life [8,9]. While acknowledging the broader developments in the field of assistive technology, this study focused on EADL specifically rather than AT in general as AT has a broader scope ranging from simple devices such as eye glasses to technologically advanced items such as communication aids.

Early EADL research was largely descriptive and based on case studies, surveys and anecdotal evidence from the user's perspective[10-15]. The subsequent introduction of outcome measurements indicated overall satisfaction with EADL and some subjective evidence of psychosocial benefits [7,16-18]. Comprehensive summaries of these early EADL applications were provided by Ripat (2006) and Rigby (2005) [16,17]. Recent EADL research favours qualitative investigation which is consistent with a Matching Persons with Technology model used in the field of assistive technology, and advocates the adoption of a user-centred perspective [19]. The shift to qualitative inquiry began with the inclusion of some quotations in

quantitative and descriptive studies. Mixed method studies followed with qualitative findings used to substantiate quantitative results [20,21]. Recent studies have focused primarily on the users' perspective using qualitative methods. A summary of EADL studies that use qualitative methodologies is presented in Table 1.

(Table 1 here)

Qualitative findings

A number of qualitative research methodologies have been adopted including narratives[21], grounded theory[22,23], phenomenology[24,25], framework analysis [26,27] and naturalistic inquiry[28]. The data produced through qualitative inquiry are intended to be rich, deep and descriptive. However, it can be challenging for researchers to articulate findings and for readers to interpret them, as they are presented in a wide range of formats including codes, themes, sub themes and categories. Judge et al (2009) presented 5 main themes with 5 to 17 sub themes within each. Palmer and Seale (2007) found 8 categories, Buxton described 8 codes, Erikson discussed 4 stages when first using EADL and Verdonck et al. (2009) described 2 categories with four to five themes within each (see Table 2). The themes that emerged ranged from practical and technical ones, to those describing the benefits and deeper meanings of living with EADL. These qualitative investigations are an important contribution to the knowledge base as they focus on users' opinions, attitudes and views of EADL and therefore may offer insights as to why some environmental controls are embraced by some users and others are not.

(Table 2 here)

Practical and technical themes included: supply, support and training issues[25] such as access to information about EADL[22], upgrading of EADL[22], reasons for success or failure of EADL[26], that EADL does not suit everyone[22], EADL has good points and bad[23], desired features of EADL [25], unhappy users[22], attitudes of professionals[22], users background and experience[26] and interface features[26]. Benefits of EADL included: cost savings[22], care giver benefits[22,29], independence[22,26,29], improved quality of life[22], risk management, security[26,29], very helpful[23] and useful[23]. Stead (2002) described 'meaning' using sub-themes such as time alone, freedom and decreased burden of care (resulting in more balanced relationships)[22]. Buxton (2002) also described meaning using themes such as 'I am in my glory now' and 'the EADL is my friend'[28]. In an exploration of users' attitudes to EADL, Palmer and Seale (2007) used *codes* such as: 'part of me', 'changed my whole outlook' and 'indispensable'. Findings from these studies (themes or codes) indicate the deeper psychological meanings of EADL for users compared to traditional (quantitative) results that focus on physical and functional benefits.

Qualitative inquiry yields both expected and unexpected findings. While most EADL research focuses on the positive aspects of EADL, Palmer and Seale (2007) offer a more balanced perspective with themes that included 'good points and bad' and 'extremely limiting'. These negative aspects could be attributed to outdated EADL equipment (Steepers fox, Possum PSU6, Possum companion) that were used in this study [23]. Similarly Stead found that EADL are 'not for everyone'[22].

Existing literature is expansive, making the true meaning or essence of the experience of using EADL from a user perspective difficult to uncover. In Ireland there is no clear system of EADL supply and no formal pathways for persons with

spinal cord injuries to acquire a personal EADL. Limited funding for EADL is provided both publicly and privately[25], potential users typical acquire EADL through independent fundraising initiatives or through waiting for special funding from already stretched community occupational therapy budgets. There is no known study in Ireland that has explored EADL use or its impact on users with high cervical spinal cord injury. Thus the purpose of this study was to explore the experiences and the deeper meaning of l[Orton, 2008 #315]iving with EADL from both users' and potential users' perspectives. This study is the first part of a larger study that seeks to explore the experience of using EADL from the users' perspective.

Method

Qualitative methodology within a phenomenological tradition was selected as the most appropriate means of understanding the lived experience of participants. The purpose in phenomenology is to study how people make meaning of their lived experience[30]. Descriptive phenomenology generates a rich description of the phenomenon under investigation, which in this instance was the experience of living with and utilising EADL[31]. While semi-structured interview is the traditional phenomenological data collection method, focus groups have also been found useful [32,33] and were selected for this preliminary study. Focus groups are useful tools in both disability and AT research [34-37]. Focus groups encourage free conversation between group members thus allowing participants' own words to be heard. Group members themselves generate the discussion, uncovering content that is important to research participants rather than to researchers[38]. A moderator facilitates active participation of all members[39], using key phrases to keep the discussion moving rather than leading it. The researchers anticipated that the utilisation of EADL by

persons with quadriplegia in Ireland would be highly variable but of interest to potential users. This variety of experience with EADL was expected to generate broad and rich group discussion thus having the potential to yield more information than individual interviews. It was hoped that the data would reflect issues of importance to the group participants rather than reflect predetermined topics based on the existing literature and the clinical experiences of the researchers. It is however, impossible to negate the influence of the moderator, who kept a reflexive diary to record her thoughts and perceived influence on the groups[40]. Open ended questions from an interview guide (see Appendix 1) were designed to provoke thoughts and reflections on using EADL and generate rich discussion. Ethical approval was granted from the relevant research ethics committees and all participants provided informed consent including consent to the use of video and audio recordings.

Participants

Potential research participants were invited to participate in the study by Spinal Injuries Ireland (SII), a charity and support service for people with spinal cord injuries living in Ireland. A spinal cord injury at level C3 to C5 constituted the inclusion criterion. Injuries at this level result in paralysis of all four limbs and an inability to carry out most activities of daily living. Fifty potential recruits were identified by SII who invited them to participate by letter which was followed by a phone call. Ten of those identified did not respond to postal or telephone invitation and three declined to participate, leaving a potential sample of 37. Purposive sampling was then used by the researchers to select 16 participants for two focus groups. Participants included those with experience of EADL as well as those without. Non-users were

included because, in Ireland, persons with high cervical spinal cord injuries often do not have EADL as a result of circumstance (not choice), and many of these people would be interested in acquiring EADL. In addition previous studies have shown that non-users have accurate perceptions of the anticipated psychosocial benefits of EADL [20,21]. The final sample was based on participant availability and physical ability to attend the focus groups at scheduled dates and times.

Fifteen participants were recruited, eight with EADL and seven without. Participants consisted of 11 men and 4 women who ranged in age from 20 to 57 years and who had been discharged from rehabilitation for periods ranging from 1 year to 31 years. All were quadriplegics with injuries at the C3, C4 and C5 level with no active hand movement. Most were powered wheelchair users (n=13), six by chin control, six using a joystick and one with a switch control. None were able to feed themselves. Twelve participants lived at home; two lived in a nursing home and one lived in a university residence. All participants selected their own pseudonyms which are used throughout this paper (see Table 3).

Procedures

Fifteen people with high cervical spinal cord injuries participated in the focus groups. Group membership was assigned to two groups based on telephone recruitment and participants' self report of having or not having EADL. Each group met twice, over a two week period, making four focus groups in total (two attendances per participant), although some participants were unable to attend both meetings, (see Table 3). Seven people attended focus group 1, six attended focus group 2, six attended focus group 3 and seven attended focus group 4. All participants in focus group 2 and 4 were EADL users. Participants in focus group 1 and 3 were intended to be non-

users. However, one person in each group revealed that they did in fact have EADL and were thus not non-users. Both remained in the groups as they were actively involved in the group discussion. Participants traveled across the Republic of Ireland to attend groups which were held at a rehabilitation centre in Dublin. Each group was moderated by the first author, and an assistant moderator with group experience took research notes and operated an audio recorder. All groups were video recorded. A Therapy Aide attended each group to attend to individual participant needs such as positioning changes. Care-givers were not invited to attend the groups as their views were not the focus of this study and their presence was considered a potential limitation on the freedom of expression of participants. Discussions from each group were transcribed verbatim. A verbal summary of group content was presented by the assistant moderator at the end of each group and at the start of the second group meeting. This allowed participants to validate the discussion and provide an opportunity for them to expand or amend the summary.

(Table 3 here)

Data analysis

Data were analysed according to Giorgi's four stages of descriptive phenomenological analysis as outlined by Langdridge (2007)[31]. The first stage involved a close reading of transcripts and repeated viewing of the video recordings of the groups to gain an overall sense of the content. Meaning units were subsequently identified which were then assessed for significance by the research team. In this step some meaning units were excluded as peripheral to the research question, while others were merged or renamed. The final stage was to synthesize the meaning units into an overall structural description.

Results/ Findings

As it was not possible to compare users and non-users, and as themes in all groups were similar, all data were merged. Several meaning units were identified and organized into three broad categories: 'desired features of EADL', 'use and utility of EADL' and 'meaning of EADL'. The first two categories have been presented elsewhere. The latter category is the focus of this paper as it represents participants' interpretation of their experience of EADL and the meaning that they ascribe to the phenomenon. Within the category '*meaning* of EADL', three themes were identified as follows: 'time alone' and 'changed relationships', both of which were linked by a third super ordinate theme of autonomy which reflected the overall meaning of the lived experience of EADL for participants. A summary of themes and sub-themes is presented in Table 4.

(Insert Table 4 here)

Time alone – 'not a shadow with you'

Having EADL means that users have the choice to spend some time alone. Time spent alone allowed increased psychological space, privacy and, for some, the ability to be away from home. Time alone was discussed as a valuable experience by those with access to EADL, and expected to be such by non-users.

> *(It) 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].*

Users reflected on their ability to enjoy solitary time when they first acquired EADL.

> *I can now be on my own and it just makes such a huge difference. [Jane]*

It's just great to get away you know like, without all people around you [Ciara].

It's nice to have some time on your own, even if it's only an hour, or half an hour, just somebody not, not asking someone to do anything [Jim].

This time alone appears to be more than a physical experience.

It's not being alone its (interrupted) [Michael]. Just having space [Richard]. It's just not people you know. Wherever I go there is usually someone I can ask to pick up the water bottle if I drop something, but its people, it not a shadow with you, a PA or something [Michael].

While accustomed to having high levels of care, participants found the necessary dependency and the lack of privacy difficult.

I know other friends of mine like having their (personal assistants) there always beside them all the time. That can freak me out [Paul].

Despite having high cervical spinal cord injuries that traditionally require long care hours, some users were able to spend long periods away from care givers and possibly even away from home. This ability to spend time alone was attributed to the combination of having EADL and the independent mobility offered by a powered wheelchair.

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, they are grand people like. 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].

That's what I do as well you know, I do the same thing. I might just go out the door and could be gone for 2 hours and just head off the middle of nowhere, the sea, down the lake. [Jim]

<u>Changed relationships - 'not being babysat'</u>

EADL changed the relationship dynamic between people with spinal cord injury and their family and care givers. Changes included less apologising, reduced annoyance and a decreased burden of care.

People with high cervical spinal cord injuries can be constantly physically dependent on others. For several participants the reality of having a high spinal cord injury meant needing 24 hour care.

> *Before your accident you didn't rely on people to do so much for you. You might say to your friend give us a lift here or give you a lift there on occasion, not every single day on every aspect of your life having to ask someone to help you [Dave].*

Dependency on friends, family and caregivers can then define the relationship in a fixed dynamic consisting of the one always requiring help and the other who always has to provide it.

> *It definitely changes relationships. As it is, 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].*
>
> *It (EADL) definitely helps in a relationship of any sort, it just means you contribute more. Give, give or take take take [Michael].*

Caregivers have to do whatever the person is doing for example.

> *If I spend two hours reading, my carer spends two hours reading as well [Jane].*

Participants spoke of always having to ask for help and thus always apologising. Despite the familiarity and regularity of the constant need for assistance, it violates expected interpersonal dynamics and frequently results in the adoption of a persistently apologetic manner.

> *It's so nice not having to call someone all the time.[Jane]. Absolutely, they are going to get fed up. You know? They are absolutely going to get fed up.*

They'll say, not again ... they've only just sat down and I realise I've forgotten this. [Jerry]. It's always, 'I'm really sorry but would you mind'…[Jane]. I think that's important though, that relationship thing is really important in that situation because it changes the dynamic of every relationship you have. I'd absolutely agree with Jane that's its important.[Joe]

In addition, the nature of this care was described as being annoying for both parties because the caregiver had to be constantly present.

I just live with my mother; she's a bit old. There's nothing good about getting her up [Jerry].

You don't need to be annoying people then you know. That's what you feel like, you keep asking someone to do something, thats what I feel, like I'm annoying them or interrupting them or when they are doing their own thing you know watching TV or something and you have to say to them that "you wouldn't mind lifting my bag", when they are well in watching something, you feel a xxxxxx like . [Jim].

(It)must be fairly annoying for somebody to be called just to open a door.[Dave]. It's even annoying having them there [Michael]. Half the time there is nothing to do [Jim].

The alternative, made possible by the use of EADL is to have help on request.

It makes a big change 'cause then again the people that are used to doing everything for you have time on their own, and they are not thinking I have to go and make sure that Dave can get in or out, or he can do this or that, it is not being babysat 24 hours a day anymore you know and people are only there when you actually ask them to be there they don't feel they have to be there for you.[Dave]

Thus EADL reduced the burden of care for the caregiver, even leading on some occasions to a reduction in the number of care hours needed.

It really eases the load for families and carers, really [Jane].

What you would say is that I will need less PA hours 'cause of these controls [Michael].

I mean 6 hours now is not an issue. I used to have 105 hours PA down to 70 hours [Paul].

Participants also discussed the concept of burden of care when talking about the commonly experienced cycle of worry. Caregivers and family members worried

about the person with a spinal injury who in turn often worried about the care giver worrying about them.

> *They can go on and do their own thing and not have to worry. You know, worry about you. Don't have to change the channel, I know I keep going back to the TV but just to change the channel or turn on the light if it gets dark outside or anything. They don't have to worry about getting right in before you need them straight away [Emily].*
>
> *I can make phone calls which is great because it means I can be on my own in the house, and I mean, that is a complete change of life experience, instead of having people worrying - oh Jane is on her own if the house goes on fire. I can now be on my own and it just makes such a huge difference [Jane].*
>
> *Before like they can't go to the shop cause they are worried to leave you for 5 minutes cause you can't do anything on your own, and now it's not a problem to go away for an afternoon or a morning or whatever you know.[Dave]*

They also referred to increased individual and family confidence and independence. This was facilitated by the enhanced sense of safety and security afforded to participants by having reliable EADL to raise an alarm or call for help.

> *From a security point of view I'd stay on my own but I don't think anyone would let me. My parents would never go away or anything like that. [Michael].*
>
> *And security, as long as you know it's going to work and they know its going to work, well [Dave].*

Autonomy – being able to do what you want

The two themes discussed above can be considered as separate aspects of the over-arching theme 'Autonomy'. Each theme relates directly to this central concept of being able to, *'do something yourself'* [James] or *'do what you want'* [Peter]. This autonomy results in an ability to spend quality time alone and the transformation in relationships that occurs as a consequence of proficient and regular use ofEADL. In addition autonomy encompassed issues relating to active participation, independence and choice.

Users described the change in active participation since acquiring the EADL.

> *It has changed so many things for me … it's like giving a quadriplegic arms and hands that work [Jane].*

Accordingly those with EADL said that they would now find it hard to be without EADL technology.

> *'I couldn't be without it now, you know. I can't sleep until I know I have it there with me'. [Susan]*

Without EADL simple tasks like changing TV channels or turning pages of a book could only be carried out with caregiver assistance.

> *… if you had these things in your house, you wouldn't have to bother your family all that much [James].*

Non-users were also able to predict the autonomy that could result from having EADL.

> *If I had it (EADL), I'd feel more independent. I wouldn't have to rely on my PA for everything. Independence, even if it's only a tiny bit of independence because I don't have any independence at home. [Emily]*

This independence meant less reliance on others.

> *For me, just even the confidence to do a lot of things yourself without anyone needing to be around, just self reliance [Paul].*
>
> *By having the environmental controls I don't need help, someone to do anything. [Richard]*

There was increased freedom for the EADL user and caregiver. Being able to use EADL meant that users were less reliant on care givers and that reciprocally caregivers had more freedom from the demands of the users. In contrast to the traditional concept of giving independence to the client, Dave referred to this freedom as giving caregivers more independence which in turn changes the dynamics of the caregiving relationship.

EADL users described the increased choices and options made available through EADL.

> *Gives you the choice to choose what you want to do. [Jim]*
>
> *When I got the controls there was far more that you could do for yourself , so it feels like you're living your life instead of hanging around waiting for other people to help you live your life.[Dave]*

Discussion

Autonomy

EADL are considered to provide increased independence [10,15,17,41-43]. This is further supported in qualitative studies with independence as a theme [22,26,29]. In this study we chose to use the term autonomy instead of independence in an attempt to avoid the 'ideological preoccupation with physical independence' as suggested by Hammell (pg 129) [44]. The theme of autonomy encompasses choice and control of one's life and better suits the participants' descriptions of life with EADL. This is articulated in themes such as, 'control over personal space and activity'[29] and 'Now I can do what I want, when I want!'[28] and 'being able to do what you want' [Peter].

Autonomy is considered a primary goal of rehabilitation[45]. Cardol et al. (2002) describes two types of autonomy – 'executional' and 'decisional'. Decisional autonomy is the ability to make decisions while executional autonomy is the ability to execute such decisions. This executional autonomy is limited by physical disability, but can be facilitated in part through EADL. Van de Ven et al. (2008)[46] refers to four types of autonomy in a study of people with high cervical spinal cord injuries: 'Independence in daily life' or executional autonomy; 'self determination' or decisional autonomy, participation and identification. Participation is the organizing of one's own social roles, affairs and relationships[46]. This supports the link between the

themes of autonomy and changed relationships. Identification is 'the degree to which individuals feel comfortable with their way of living and feel that their way of living befits the person they are' [46] p.250.

Quality of Life

Improved quality of life is cited as a benefit of EADL [12,14,22]. The Psychosocial Impact of Assistive Device Scale (PIADS) explores psychosocial wellbeing using three scales: self esteem, competence and adaptability. High PIADS scores have been found for both EADL users and potential users and authors suggest that EADL has a role to play in improving quality of life and enhancing autonomy [16,17,20]. The overlap of themes in an associated qualitative study such as 'control over personal and physical space', 'value of independence' and 'changes in interpersonal relationships' provides support for the findings in the present study (see Table 2)[29]

Ripat & Strock (2004) used mixed methods to explore quality of life using the Lifestyle Performance Model. Findings suggest that the use of EADL enhances autonomy, individuality, volition, predictability and self efficacy which contribute to an improved quality of life. EADL offer the user choices and alternatives and the ability to control occupation [21]. This provides support for the concept of autonomy, encompassing choice and independence found in the present study.

The themes in this study namely autonomy, time alone and changed relationships are closely related to themes found in a study of quality of life for people with high cervical spinal cord injury rather than of EADL utilsation[47]. Hammell (2004) also found that quality of life was enabled by social policy, physical resources and technical resources including EADL[48]. Three similar primary themes where found to

contribute to perceived quality of life for people with high spinal cord injury living in the community: autonomy, meaningful use of time, and relationships [47]. Autonomy included the ability to make choices and to be in control of one's life through community living. The second primary theme, 'strong relationships with special people was identified by the participants as contributing to the experience of life's quality and also comprised an important resource in reconstructing a life worth living and in re-affirming one's value' p.614. This confirms the potential role of EADL in enhancing the quality of relationships as discussed by participants in each focus group in the current study. For Hammel (2007), meaningful use of time included being alone, as well as engaging in other aesthetic experiences such as art, music, sunshine, nature and being with special others.

Time alone

In other EADL studies time alone, surprisingly, has only occurred once as a subtheme of meaning[22]. This may be because time alone could be considered as an aspect of the broader category of independence with its implication of being left without care. This dimension has been reported in some studies by caregivers who confirm that they can leave users alone for longer periods of time due to EADL [12,49]. This is an aspect of decreased burden of care which we have included within the theme of relationships thus indicating the link between the themes of time alone and improved relationships. It may be possible to quantify this decreased burden of care in terms of the reduced care hours that could result. Such reductions would in turn lead to significant financial savings. Two participants in our study (Michael and Paul) offered examples of such savings. Similarly, Harmer and Barkheit found that 13 of 16 research participants reported using reduced care hours as a result of having

EADL[15], while McDonald et al. found reduced caregiver hours in only two of 29 EADL users[49]. No study to date has found clear evidence of cost savings or potential savings suggesting a need for further investigation [7,41]. However Ripat & Strock (2004) suggested that the main benefit of EADLs may not be financial but may relate more to improved subjective quality of life for users[21]. Such improved subjective quality of life for our participants includes the ability to have time alone which is more meaningful than having mere physical space. Similarly, Stead's (2002) theme of 'meaning' included the sub theme of 'time alone' which was distinct from the theme of 'benefits for carers' supporting the importance and meaning of this theme to EADL users.

Relationships

EADL have the potential to alter the dynamics of a relationship as users are less likely to feel permanently apologetic, both parties may be less annoyed, and there is a decreased burden of care for both parties. One of the previously recognised benefits of EADL is the facilitation of communication, socialisation and relationships [15,17,42,49]. Participants in this and another study[29] discussed the effect that EADL has on actual relationships as opposed to the physical facilitation of communication. Having an EADL can change relationships by increasing the repertoire of abilities and thus reducing the extent of physical demand placed on others. This is important as meaningful relationships have been found to contribute to improved quality of life for people with high spinal cord injuries[47]. People with paraplegia have described the delicate balance between their enforced reliance on others and not being an imposition so that they can be 'equal contributor(s) in their relationships' p215 [50].

Support from care-givers and family members can be viewed by people with spinal cord injury as negative when perceived as 'over assistance' contributing to increased feelings of dependence[51]. It follows that EADL can be a substitute for such assistance. In contrast, two participants in Palmers study consider EADL to be a social barrier [23], highlighting the need to maintain a person-centred approach and to remind ourselves that EADL are 'not for everyone'[22].

Security

For persons with high quadriplegia the physical risks associated with being left alone results in the provision of constant care and attention. The security and sense of trust offered by the utilisation of EADL means that the user may be 'free' of the caregiver in both a physical and psychological sense. Using the language of participants this means a reduction in 'worry' where both parties are caught up in a cycle of worrying about each other. (The caregivers are worried about the person and the person worries about how the caregiver is worried). This issue has been identified in another study as 'reduced carer workload and worry'[29]. EADL can reduce overall worry by providing an element of safety for both parties in the care-giving relationship. Safety and security is well documented as a benefit of EADL [7,17,18,42] and as a theme in qualitative studies[22,26,28,29]. Our study highlights that safety and security is a psychological construct as well as a physical construct.

A review of the personalised meanings attributed to AT suggest that successful integration of AT is dependent on the individual meaning ascribed to the AT which in turn is influenced by psychosocial and cultural issues[52].

Limitations

The high positive recruitment of 37 out of a potential 40 responses in our study suggests a high level of interest in EADL. Attendance rates at groups was high despite the fact that attendance was difficult for several participants due to challenging travel arrangements, personal care schedules, caregiver arrangements and health issues. Individual interviews in participants' homes would have avoided many of these issues. A criticism of focus group method is a lack of depth in comparison with individual interviews. However, we believe that the discussions that took place in the focus groups, particularly between users and non-users, provided insights and shared views of living with EADL that would not have been possible with individual interviews. Further investigation through in-depth qualitative interviews would build on the findings of this study. This study was conducted on a small Irish sample and generalisability to other cultures or groups warrants further exploration. The inclusion of non-users can be considered a limitation as some of the findings are based on anticipated lived experience. However the inclusion of non-users also added a positive dimension as they provoked discussion and evoked greater clarity and richness of expression from users. Further investigation could be used to compare users and non-users' experiences of EADL. It is not known if the use of video to record the focus groups limited discussion or contributions of participants, but this did not seem evident when reviewing the video recordings.

Conclusion

This qualitative study contributes to an understanding of the phenomenon of living with EADL for persons with high cervical spinal cord injuries. The meaning of living with EADL is captured by three key themes. As similar themes have been found in previous studies it is likely that these themes are an accurate reflection of the lived

experience of this small group of Irish people with spinal cord injury. Direct comparisons between studies are difficult as ascribing labels to themes is considered to be a personal or even a controversial undertaking.

Increased autonomy emerged as the core meaning of life with environmental controls for this sample of Irish people with quadriplegia. Autonomy encompasses the increased active abilities, increased independence and increased choice that result from access to EADL. Two strong sub themes of autonomy are the ability to spend time alone and the changed relationships that are facilitated by EADL. These three themes: autonomy, time alone and changed relationships, have been previously linked to enhanced quality of life for persons with high cervical injuries indicating that EADL contribute significantly to quality of life. Both users and non-users attribute the same meaning to EADL which highlights the gross inequality of the current lack of access to EADL for many. Future studies need to explore the barriers to acquiring EADL as well as reasons for their limited use by people with spinal cord injury. It is essential that users' needs and desires are identified so that EADL are both available and suitable to all those with high cervical spinal cord injuries.

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Appendix 1 Focus Group Questioning Route

Focus group 1 and 2

Welcome

Moderator: Thank you all for making the time today... I am ... an Occupational therapist ... researching environmental control systems use for persons with high quadriplegia.... I am interested in your personal experiences and opinions about EADL.

You may wonder why I did not choose to ask you all individual questions and why you all have to be here at the same time. This is more of a discussion group between yourselves, as you are the experts here and I don't want to guess your opinions or ideas or force mine on you... There are no right or wrong answers and you are most welcome to not all agree. You can speak freely and ask each other related questions if you like...

Assistant moderator: I am here to help ...keep ... time ... I will be switching this tape recorder on and off and taking a few notes.

Moderator: I will be recording this discussion on video. ... It's not a professional video and will only be used for this research.... We plan to be finished by 4pm.

Opening question

Please introduce yourselves, give us your name and where you are from. Then tell us about any gadgets or useful devices that you use?

Introductory Question

What does environmental control systems mean to you? Do you use any other names for these things?

Transition Questions

How could/ do you use an EADL? What things can you do using these remotes?

Where could/ do you use them?

Who do you think should have EADL?

Key Questions

How would your life change for you, if you did/ did not have EADL?

How would it impact on others around you, if you did/ did not have any EADL?

How do your carers/ family friends feel about EADL?

How would you explain the importance of EADL?

What do you think are the benefits of using EADL? Can you give me any examples?

What difficulties are there with using EADL?

Ending Questions

I am going to ask (assistant moderator) to summarise what has been discussed.

How well does this capture what has been said today?

Is there anything that we have talked about that is unique to Ireland?

Is there anything we should have talked about but did not?

Are there other thoughts or feelings you'd like to share with me to help us understand how not having/ having an ECU has influenced your life?

We are learning through these groups. Do you have advice for how we can improve them?

Focus group 3 and 4

Welcome

Moderator: Thank you all for making the time today and two weeks ago. To remind you, I am interested in your ideas about EADL, not things I can read in books, ... I am interested in your personal experiences and opinions about EADL... there are no right or wrong answers ...you can speak freely and ask each other related questions if you like...we will record the group on video for research purposes.

Opening question

Remind us who you are.

Do you have any new thoughts ideas about EADL since last group?

Recap

I'd like to begin by summarising what we took to be the main ideas from last time. Please feel free to comment as I go along. The purpose of this is to see that I have an adequate idea of your thoughts not my own interpretations.

Summary of focus group 1 and 2 contents

Introductory Questions

What are the EADL needs for a high quad like yourselves?

What are your carers desires for EADL for you?

Transition Questions

Discuss the possibility of a starter pack for all people with (C4) high quadriplegia?

What are the important features of an EADL?

What do you like best about an EADL?

Like least?

Key Questions

How could the design of EADL be improved. How would you like yours improved?

If I design a starter pack for all people with C4 (high) quadriplegia

What should it have in it?

What should it do?

What should it look like?

How should it be controlled?

What scanning options should it have?

How should it be mounted?

Who can programme it?

Ending questions

Summary of group discussion

How well does this capture what has been said today?

Is there anything that we have talked about that is unique to Ireland?

Is there anything we should have talked about but did not?

Are there other thoughts or feelings you'd like to share with me to help us understand how having/ not having an EADL has influenced your life?

Table 1 – Summary of literature of qualitative electronic aids to daily living studies

Study	Sample	Methodology	Topic
Rigby, P., Renzoni, A.M., Ryan, S., Jutai, J., & Stickel, S. (2000)[29]	19 EADL users and 19 non-users	Qualitative -semi-structured interviews (associated with a quantitative study)	Impact of EADL on daily life
Stead (2002)[22]	6 users	Qualitative – grounded theory, semi-structured interviews	Users' perspective of use of EADL - impact of quality of life
Ripat, J., & Strock, A. (2004)[21]	7 users	Mixed – PIADS outcome measure and open ended questioning	Acquisition of EADL
Erikson, A. ,Karlsson, G., Soderstrom, M., &Tham, K. (2004)[24]	11 traumatic brain injured users	Qualitative - empirical phenomenological psychological method, interview	Acquisition of EADL
Palmer, P. & Seale, J. (2007)[23]	14 users	Qualitative - grounded theory, semi-structured interview	Attitudes to EADL
Buxton , J.C.(2007)[28]	2 users	Qualitative -semi-structured interview	Acquisition of EADL

Judge, S., Robertson, Z., Hawley, M., & Enderby, P. (2009)[26]	12 users	Qualitative - framework analysis, semi-structured interview	Users' perceptions of Speech EADL
Verdonck, M., Steggles, E. & Chard, G. (2009)[25]	8 users & 7 non-users	Qualitative – descriptive phenomenology, focus Groups	Experiences and desires of EADL
Judge, S., Robertson, Z. & Hawley, M.(2009)[53]	Users & professionals	Qualitative - framework analysis, semi-structured interview	Use of EADL

Table 2 Wide range of formats used to present Qualitative Research Findings

Paper	Research focus	Category	themes/ codes
Rigby, P., Renzoni, A.M., Ryan, S., Jutai, J. & Stickel, S. (2000) [29]	Impact on daily life	Being	Reduced physical dependence
			Do things for personal health and safety
			Value of independence
		Belonging	Control over personal space and activity
			Change in interpersonal relationships
		Becoming	Reduced carer workload and worry
			Increased opportunities in daily life
			Greater access to computer
Stead, A. (2002)[22]	Value of EADL		Independence
			Quality of life
			Meaning
			Cost benefits
			Benefits for carers
			Risks and safety
			EADL
			Not for everyone
Erikson, A., Karlsson, G., Soderstrom, M., & Tham, K. (2004)[24]	Lived experience in an EADL training apartment		'Plunging into' an EADL equipped environment
			'Landing' and feeling comfortable
			Incorporating the 'new' into daily activities
			'Taking off' in the future
Ripat, J. & Strock, A (2004)[21]	Users' perceptions of the impact of electronic	Narratives from users (Themes were not reported)	'Feel safer… more independent and make things simpler.'
			'the (EADL) was not going to help me get up and walk; it's not a 'cure-all.''

	aids to daily living		‘Easy to use.’ ‘I don't want to be without it…don't like to ask nurses to do too much’ ‘Do things on my own, can do what I want, when I want it.’
Palmer, P. & Seale, J. (2007)[23]	Users attitudes to their EADL	Part of me	Utility transcended
		Indispensable	Utility denied
		Changed my whole outlook	
		Very very helpful	
		Useful	
		Good points and bad	
		Extremely limiting	
Buxton, J. (2007)[28]	Users’ perceptions of EADL		The excitement of anticipation
			The long wait was worth it
			A feeling of safety
			Spreading the word
			I am in my glory now
			The EADL is my friend
			Hearing yourself constantly asking for help
			‘Now I can do what I want, when I want!’
Verdonck, M., Steggles, E. & Chard, G. (2009)[25]	Lived experience of users and non-users of EADL	Utility and usage	Assessment supply support and training
			Abandonment
			Powered wheelchairs
			Mouthsticks
			Devices
		Desires	Voice activation
			Simplicity

			Robust and foolproof
			Unobtrusive a aesthetically pleasing
Judge, S., Robertson, Z., Hawley, M. & Enderby, P. (2009)[26]	Users perception of speech-driven EADL	Failure	Human issues
			Reliability
			Technical issues
		Success	Determination
			Resilience
			Simplicity
			Speed of operation
			Use of voice
			Personalising the device
			Compensation tactics
		Background	Cognitively able
			Computer literature
			Tolerant
			Computer voice recognition experience
			History of long term EADL use
			Support from carers
		Interface	Aesthetics
			Microphone
			Feedback and interaction
		Usage	Risk
			Security
			Independence
Judge, S., Robertson, Z.	Professionals and users	History of EADL use	
		Assessment	

& Hawley, M.S. (2009)[53]	perceptions of EADL	Risk assessment
		EADL use
		Provision of EADL
		Perception of current EADL

Table 3 – Demographics of Participants and Focus Groups Attended

Pseudonym	Gender male/female	Age yrs	Injury Level	Years since discharge	EADLs	Living	FG1	FG2	FG3	FG4
Joe	m	48	C4	31	no	home	*		*	
Emily	f	27	C3/4	1	no	home	*		*	
Peter	m	20	C3/4	1	no	nursing home	*			
James	m	26	C4/5	6	no	home	*			
Jerry	m	55	C3/4	22	no	home	*		*	
Mathew	m	34	C4/5	7	no	home			*	
Frank	m	43	C4/5	6	no	nursing home	*		*	
Jane	f	37	C4/5	12	GEWA prog	home	*			*
Susan	f	32	C4/5	6	GEWA prog	home			*	
Jim	m	24	C4/5	1	GEWA prog	university residence		*		*
Michael	m	22	C4/5	2	Protector Keo	home		*		*
Ciara	f	57	C4	29	GEWA prog	nursing home		*		*
Dave	m	38	C3/4	3	Protector Keo	home		*		*
Richard	m	44	C4/5	1	Protector Keo	home		*		*
Paul	m	43	C3/4	23	X-10	home		*		*

Table 4 - A summary of Themes and sub-themes

Category	Super ordinate theme	Sub ordinate theme	Components
Meaning	Autonomy (Active participation, Independence, Choice)	Time alone	Space
			Privacy
			Away from home
		Changed relationships	Less apologising
			Reduced annoyance
			Decreased burden of care