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Experiences and Desires of People with Tetraplegia living with and without Electronic Aids to Daily Living: an Irish Focus Group Study

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ABSTRACT

This qualitative descriptive study explores the lived experience for persons with a high cervical spinal cord injury who have Electronic Aids to Daily Living (EADLs), and for persons who have no EADLs. Fifteen people with cervical spinal cord injuries attended four focus groups. Data analysis uncovered a novel framework of several themes that were organised into three categories: experiences, desires and meanings of living with EADL. Users' and non users' groups revealed homogenous themes. Experiences and desires are explored further in this paper. Themes within the category of experiences included: EADL devices, supply support and training, abandonment, mouthsticks and powered wheelchairs. Desires included: simple stuff, reliability, aesthetics and voice activation. Findings offer valuable personal insights about life with EADL to be considered by all involved with EADL.

KEYWORDS

Environmental Control Systems (ECS), focus groups; tetraplegia/quadriplegia, qualitative, Electronic Aids to Daily Living (EADL)

BACKGROUND

A high cervical spinal cord injury disrupts both the body and the self thus leading to activity limitations and participation restrictions. Bladder, bowel and sexual function changes accompany losses of mobility and roles. Modern advances in technology offer some benefit for these people in terms of Electronic Aids to Daily Living (EADL) also know as Environmental Control Systems (ECS). These can enable a user to open doors, answer phones, turn on lights and surf TV channels.

In Ireland the use and provision of EADLs is varied. "As useful as technologies are, we still do not know enough about how they affect the individuals who use them" pg.160 (1). Craddock

(2002) advocates a partnership between providers of assistive technology and persons with disabilities to facilitate mutual learning(2). It is important to explore what such technology, or lack there of, means to such people. This can inform future plans for access to electronic assistive technology and EADL in particular. Exploring the opinions and expectations of potential and current EADL users is essential to limit abandonment (1).

EADLs are important and useful for persons with high spinal cord injury (3-6) . People with spinal cord injuries have been represented in several general EADL studies (7-11). The existing EADL literature is varied and includes case studies (3, 12) reviews of practice (13), audits (4, 8, 9, 11, 14), trials of EADL (15-19), and comparisons of users and non users (5, 10, 20-23). Recent work has focused on the development and application of outcome measures to evaluate use, satisfaction and perceived benefits of EADLs (5, 7, 10, 18, 21, 23, 24).

The body of literature on this topic is predominantly qualitative despite the fact that the users' personal perspective is valued by researchers and clinicians. Direct quotations are included in some findings(12, 17, 23, 24). In addition mixed methodologies have been used to add qualitative findings to studies based on outcome measurement(22, 24). Qualitative studies of EADL are scarce (6, 19, 25). Two studies explored the adaptation process of new EADL users with traumatic brain injury (n=12) and spinal cord injury (n=2) respectively (6, 19) In an English study a grounded theory approach based on semi structured interviews was used to investigate attitudes of users to EADLs (25). No study has investigates the lived experience of the use of EADL by persons with spinal cord injury.

METHODOLOGY

Research questions and design

Qualitative enquiry was selected to uncover meanings and descriptions from the participants' perspectives based within a phenomenological tradition. Focus groups were selected to encourage active discussion using personal language to describe the lived experience for persons with high cervical spinal cord injuries who have EADLs, and persons who have no EADLs. (26) This study aimed to describe what these people think of EADLs from their own perspective rather than being researcher lead.

Participants

Focus group participants were selected using purposeful sampling from Spinal Injuries Irelands' national database (n=15). Selection criteria included cervical spinal cord injury at neurological level C3-C5 with resultant bilateral upper limb paralysis, and the ability to attend focus groups. Participants were divided into EADL users and non EADL users groups to create two groups of six or seven. These groups each met twice resulting in a total of four focus groups.

Insert table 1 here: Biographical Details of Participants

Data Collection and Analysis

Focus groups were digitally recorded using a video camera and an external microphone. Themes identified by research team, transcriptions, assistant moderator's research notes, and group summaries were all analysed according to a phenomenological tradition based on the data analysis spiral described by Creswell (27). This is an ongoing process of analysis of reading and memoing, then describing, classifying and interpreting.

Validation, reflexivity of the researcher

Summaries of groups were validated by participants. Analysis of data and emerging themes or were validated by the second author. The researcher, who is also the and primary author kept a reflexive diary, throughout the planning, execution and analysis stage to record her personal perspective and her influence on the study.

FINDINGS

Emerging themes were arranged into three major categories: experiences, desires and meanings of the lived experience of EADL. Content analysis revealed no difference between users and non users of EADL and thus data were merged.

Insert diagram 1 here: Overview of Themes

This article briefly discuss the first two categories namely experiences and desires. Meanings will be discussed in a separate publication

Experiences

EADL devices: Users had control of a variety of appliances and control units. Both users and non users had a balanced view about what is possible and what is necessary and that applications must be realistic to avoid an over-supply of technology. How EADLs were used depended on both individual physical ability and participant positioning. Some accessed technology directly using a mouthstick or a knuckle while others relied on switches. All reported increased reliance on indirect switch access to technology when in bed

Supply, support and training: EADL was supplied by a variety of agencies. These were funded both- privately and publicly with no apparent guidelines or policy for supply or maintenance. Time delays for repairs ranged from one day to several months. Those who been introduced to EADLs during their rehabilitation reflected that this was useful when in the community as they had some knowledge of the equipment upon which to base decision making. This helped them to be active participants in the assessment. In contrast others had relied on commercial suppliers for information and training. In contrast others had relied on commercial suppliers for information and training. They felt that information on how to use technology was scarce and successful use relied on the ingenuity and perseverance of the individual. Users expressed frustration at the limited knowledge of the agencies and suppliers. Three felt that they had been over-supplied. The possibility of a loan system was viewed as a advantageous as it would enable potential EADL users to learn how systems worked before they made a private purchase or where supplied with an unsuitable system.

Abandonment: Both users and non users referred to items that they had abandoned. Reasons given included the equipment being too complicated, unnecessary, non functional for the user. One user had abandoned a door operator after equipment failure and because she lived in residential care did not see the need for it. Two other users cited difficulties with the reliability of door operators. Two EADL controllers had been abandoned as they were considered too complicated for the users.

Mouthsticks: Use of mouth sticks, while not anticipated, was a strong theme throughout groups, particularly for non users and MK strongly recommended that mouth stick education should precede any technological training. Despite being proficient users of EADLs two of that group were also proficient mouthstick users. They used a mouthstick both to access EADL and as an alternative to it.

Powered wheelchairs: A powered wheelchair can help position a mouthstick user close enough to switch on a light or to push a swing-through door open. It can also adjust seating positions in order to facilitate successful switch use.

Desires

Reliability: Reliability is an expected feature for any technology. Participants felt that if EADLs are unreliable that this results in vulnerability, decreased confidence, and abandonment. Suggestions for improved reliability included making controllers heavy duty and water proof, and having an appropriate battery life. Other desires related to EADL support services that included the loan of back up equipment during repairs. Independent management of technology could be facilitated by having technology that is simple enough for mainstream repair. The researcher was concerned about several descriptions of unreliable alarm and call systems and unreliable switch access.

Aesthetics: All prefer assistive technology to look pleasing, and to be as small as functionally possible. Even one of the smallest control units was considered by Dave and Michael to be too large to be mounted on a wheelchair. This concern about appearance extended to the home as well. Participants talked of their own homes with large boxes, holes and wires as being unnecessary and favoured neat subtle designs and mountings, expressing some frustration with their own technology.

Simple stuff: The desire to keep things as simple as possible was a dominant theme throughout groups but was balanced by the necessity of reliability. Both users and non users discussed how they manage without specialised technology and how they used simple things aside from their assistive technology.

Participants extended the concept of simplicity to physical set up of EADL, the EADL controller, and choice of appliances. Simpler control units with fewer options can be sufficient in some cases.

Voice activation: All participants were aware of the possibility of voice activation to control technology. While they were optimistic about its possible application they were sceptical about how reliable it was. Previous experiences of voice recognition software were varied and one participant abandoned a voice controlled EADL.

Insert Table 2: Quotations

DISCUSSION

Previous studies have tended to evaluate satisfaction and benefits of EADLS, while this study uncovered desires for EADL which had not been discussed previously. This exploration of the personal perspectives and experiences of persons with spinal cord injuries' living with and without EADL has resulted in a novel framework. Living with EADL has been described in terms of the practical **experience** of using EADL, people with spinal cord injuries' **desires** of EADL and their ascribed **meanings** to this assistive technology. This has been independent of prescribed outcome measures or survey tools and thus focused on the users experience rather than the researcher's expectations or existing theory or models.

Participants were concerned about delays in repairs, over-supply of EADL, and scarcity of information and training in the area of EADL. The inclusion of EADL in rehabilitation was viewed as positive by participants and has been recommended previously (6). As with most assistive technology abandonment is a concern. Reduction of EADL abandonment may be facilitated by considering the themes within the category of desires uncovered in this study. Scherer's list of

assistive technology design features related to high rates of use includes ease of use, reliable and attractive (1). These are similar to themes of simple stuff, reliability and aesthetics.

Both high tech and low tech assistive technologies are equally valuable (1). Findings highlight the need to consider the interplay of other assistive technology such as mouthsticks, powered wheelchairs and voice activation in relation to EADL.

This framework is new and should be explored and adjusted based on further qualitative inquiry and in light of existing theory. These findings do however offer some insights and highlights several considerations for users of EADL and clinicians working in the field of EADL.

REFERENCES

1. Scherer, M.J.,(2000). *Living in the state of stuck: how technology impacts on the lives of people with disabilities*. 3 ed., Cambridge, Massachusetts: Brookline Books.
2. Craddock, G.M.,(2002), *Partnership and assistive technology in Ireland*, in *Assistive technology: matching device and consumer for successful rehabilitation*, M.J. Scherer, Editor. American Psychological Association: Washington. p. 253-266.
3. Van Laere, M. and Duyvejonck, R.,(1986). *Environmental control and social integration of a high-lesion tetraplegic patient: case report.* Paraplegia. **24**(5): p. 322-325.
4. McDonald, D.W., Boyle, M.A., and Schumann, T.L.,(1989). *Environmental control unit utilization by high-level spinal cord injured patients.* Archives of Physical Medicine and Rehabilitation. **70**: p. 621-623.
5. Rigby, P., Ryan, S., Joos, S., Cooper, B., Jutai, J.W., and Steggles, E.,(2005). *Impact of electronic aids to daily living on the lives of persons with cervical spinal cord injuries.* Assistive Technology. **17**(2): p. 89-97.
6. Buxton, J.C.(2007) *Electronic Aids to Daily Living: Their Impact on the Quality of Life and Daily Occupations of People with Spinal Cord Injury*. in *RESNA 2007: Many Discplines, one AT family* Arizona Biltmore Resort: RESNA.
7. Ripat, J.,(2006). *Function and impact of electronic aids to daily living for experienced users.* Technology & Disability. **18**(2): p. 79-87.
8. Harmer, J. and Bakheit, A.M.,(1999). *The benefits of environmental control systems as perceived by disabled users and their carers.* British Journal Of Occupational Therapy. **62**: p. 394-398.
9. Maguire, S.M., McCann, J.P., and Swallow, M.,(2001). *An audit of the provision of environmental control systems in Northern Ireland, 1992-1997.* Clinical Rehabilitation. **15**(3): p. 320-323.
10. Tam, C., Rigby, P., Ryan, S., Campbell, K.A., Steggles, E., Cooper, B.A., and Goy, R.,(2003). *Development and the measurement of control using EADL.* Technology and Disability. **15**(3): p. 181-190.
11. Novak, S.A.,(1998). *Environmental control systems - an audit of existing provision in three inner London districts.* Clinical Rehabilitation. **12**(1): p. 88-93.
12. Bonner, S.G. and Auterson, R.,(2003), *Utilising building control systems and environmental controls to enhance ADL - A Scottish Case study*, in *Assistive Technology - Shaping the future*, G.M. Craddock, et al., Editors. IOS Press: Amsterdam. p. 601-605.
13. Wellings, D.J. and Unsworth, J.,(1997). *Fortnightly review: Environmental control systems for people with a disability: an update.* BMJ. **315**(7105): p. 409-412.

14. Cowan, D.M. and Turner-Smith, A.R.,(1999). *The User's Perspective on the Provision of Electronic Assistive Technology: Equipped for Life?* British Journal Of Occupational Therapy. **62**(1): p. 2-6.
15. Hawley, M.S., Enderby, P., Green, P., Cunningham, S., Brownsell, S., Carmichael, J., Parker, M., Hatzis, A., O'Neill, P., and Palmer, R.,(2007). *A speech-controlled environmental control system for people with severe dysarthria.* Medical Engineering & Physics. **29**(5): p. 586-593.
16. Croser, R., Garrett, R., Seeger, B., and Davies, P.,(2001). *Effectiveness of electronic aids to daily living: Increased independence and decreased frustration.* Australian Occupational Therapy Journal. **48**(1): p. 35-44.
17. von Maltzahn, W.W., Daphtary, M., and Roa, R.L.,(1995). *Usage patterns of environmental control units by severely disabled individuals in their homes.* IEEE Transactions on Rehabilitation Engineering. **3**: p. 222-227.
18. Vincent, C., Drouin, G., and Routhier, F.,(2002). *Examination of new environmental control applications.* Assistive Technology. **14**: p. 98-111.
19. Erikson, A., Karlsson, G., Soderstrom, M., and Tham, K.,(2004). *A training apartment with electronic aids to daily living: lived experiences of persons with brain damage.* American Journal of Occupational Therapy. **58**(3): p. 261-271.
20. Efthimiou, J., Gordon, W., Sell, H., and Stratford, C.,(1981). *Electronic assistive devices: their impact on the quality of life of high level quadriplegic persons.* Archives of Physical Medicine and Rehabilitation. **62**: p. 131-34.
21. Jutai, J., Rigby, P., Ryan, S., and Shone Stickel, M.,(2000). *Psychosocial impact of electronic aids to daily living.* Assistive Technology. **12**(2): p. 123-31.
22. Rigby, P., Renzoni, A.M., Ryan, S., Jutai, J., and Stickel, S.(2000) *Exploring the impact of electronic aids for daily living upon persons with neuromuscular conditions*. in *Tri-Joint Congress 2000*. Toronto, Ontario, Canada: The Canadian Association of Speech-Language Pathologists and Audiologists, The Canadian Association of Occupational Therapists, The Canadian Physiotherapy Association.
23. Stickel, S.M., Ryan, S., Rigby, P.J., and Jutai, J.W.,(2002). *Toward a comprehensive evaluation of the impact of electronic aids to daily living: evaluation of consumer satisfaction.* Disability and Rehabilitation. **24**(1-3): p. 115-25.
24. Ripat, J. and Strock, A.,(2004). *Users' perceptions of the impact of electronic aids to daily living throughout the acquisition process.* Assist Technol. **16**(1): p. 63-72.
25. Palmer, P. and Seale, J.,(2007). *Exploring the attitudes to environmental control systems of people with physical disabilities: A grounded theory approach.* Technology & Disability. **19**(1): p. 17-27.
26. Kitzinger, J.,(1994). *The methodology of Focus Groups: the importance of interaction between research participants.* Sociology of Health & Illness. **16**(1): p. 103-121.
27. Creswell, J.W.,(1998). *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. London: Sage Publications.

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Table 1 Biographical Details of Participants

Bibliographic details of participants (n=15)

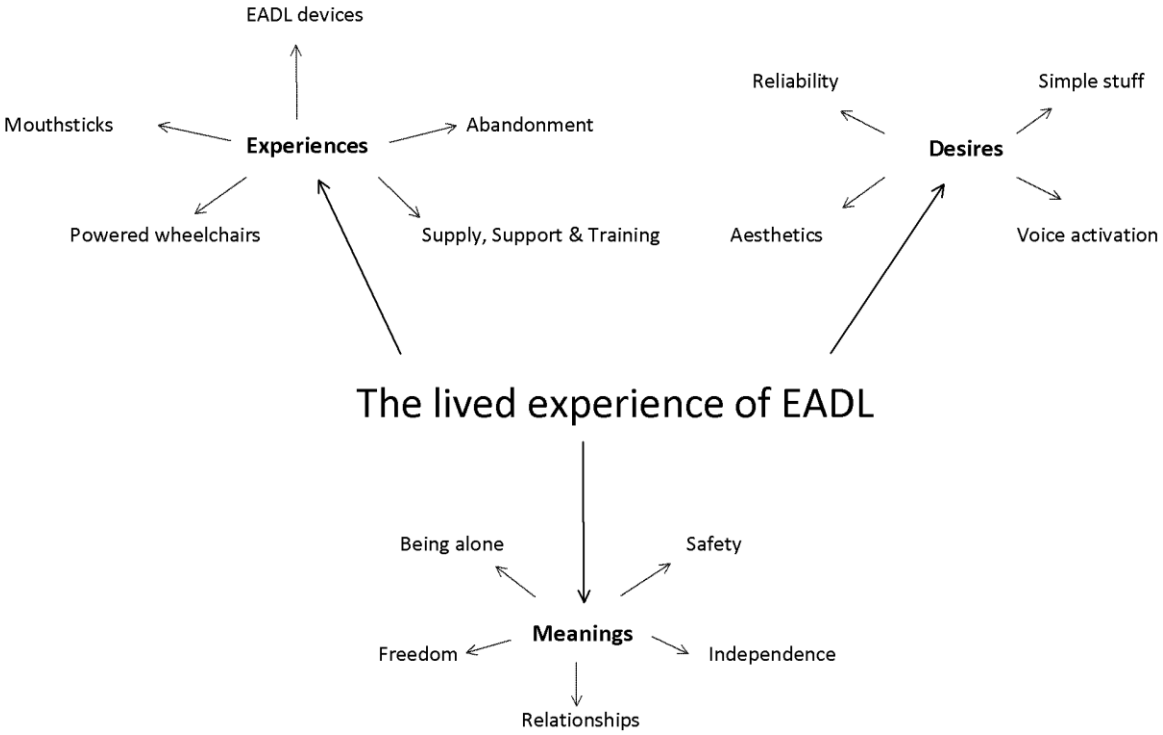
Pseudonym	Gender male/ female	Age yrs	Injury Level	Years since discharge	EADLs	Living
Joe	m	48	C4	31	no	at home
Emily	f	27	C3/4	1	no	at home
Peter	m	20	C3/4	1	no	in nursing home
James	m	26	C4/5	6	no	at home
Jerry	m	55	C3/4	22	no	at home
Mathew	m	34	C4/5	7	no	at home
Frank	m	43	C4/5	6	no	in nursing home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

Paul	m	43	C3/4	23	X-10	at home

Alternative Text Description for Table 1: Biographical details of participants

List of participants to indicate gender, age, living situation, time since discharge from rehabilitation and EADLs.

Diagram 1: Overview of focus group findings: The lived experience of EADL



Alternative Text Description for Diagram 1: Overview of focus group findings: The lived experience of EADL O Biographical details of participants

Diagram shows three categories of themes: Experiences, Desires and Meanings and the corresponding themes. Category - Experiences contains themes: EADL devices, supply support and training, abandonment, mouthsticks and powered wheelchairs. Category- Desires: simple stuff, reliability, aesthetics and voice activation. Category – Meanings: being alone, freedom, safety, relationships, and independence.

Table 2 Experiences – quotations

Experiences - quotations

Theme	Quotation	Participant
Supply support & training	*Often you see something that will work for you, and you go to the so called experts and they've not got a clue about what's available in the first place.*	Dave
Supply support & training	*Dave's case and my case of you know doing an initial over supply of sophisticated complicated systems and that you now find that 70% of it is wasted money.*	Paul
Supply support & training	*a company come out and say we can do this and that, and it all sounds good. It's in now, and it costs money and I don't use it all*	Michael
Supply support & training	*He is a salesman, he's not an OT or a physio, he doesn't really know what you need, but he does know how much he wants to sell you, so he's going to push for the biggest most expensive thing rather than what you actually need.*	Dave
Supply support & training	*I think the idea of the technology loan thing would be a really good idea, if you were coming out of rehab you would have a number of systems on trial for a month or two, not just a week or two, a decent trial length, would be useful.*	Paul
Supply support & training	*Just say my door doesn't open properly, that could take 2-3 months before somebody comes out to fix that door, so that is 2-3 months where you are relying on somebody to do things for you that could be an electronic motor or a button, they are the only 2 things that are on the door.*	Dave
Supply support & training	*You just have to adjust it to suit yourself basically. No-one does it for you.*	Frank
Supply support & training	*just to be able to have the language to be able to talk about it to someone. It's all right saying to look something up but you can't look something up unless you know what you are looking up*	Joe
Abandonment	*An awful lot of it is about timing too. When you hear about something at the right time.*	Joe
Abandonment	*I did have a control for the door. It's just too much of a nuisance really, because people are coming in and getting you up anyway like, you know. There was no point; I got it taken out all together. The door closed one day and I couldn't open it and carpenters had to come up and break the door down.*	Ciara
Mouthsticks	*My mouth stick is my hands for the last 25 years, and it doesn't require batteries.*	Paul
Mouthsticks	*Stuff that you can do with a mouth stick to keep your mind ticking over.*	Peter
Powered wheelchair	*I find the power chair isn't just there to get me from A to B. It helps me eat, helps me work the TV, closing doors, it's so much more than just a means of transport.*	Dave
Powered wheelchair	*She said she doesn't need a power chair (to Jane), but even if I wanted to go to the television or the computer I'd need someone to push me, by having the environmental controls I don't need help someone to do anything .*	Richard

Desires - quotations

Theme	Quotation	Participant
Reliability	*...unless they work really well, all the time, early on.*	Paul
Reliability	*The last thing you want to do, is to be reliant on something and it doesn't work (laughs) that's not nice .*	Frank
Aesthetics	*so mountings, like even the chin control with this chair, the mounting that came with the chair, was terrible. So I actually sourced my own and just got it mounted in a far more reliable and neater sort of way.*	Paul
Simple stuff	*The maximum effort should be made to do things without assistive technology, and learning to become just self managing, weather it is turning the pages with your finger or work using the phone with your own hand, and then those that aren't satisfactory I think that then after that, then assistive technology.*	Paul
Simple stuff	*not too complicated to set up hassle free as possible … anything I'm using can be set up by someone or if I have to ask them its not a big deal like you know.*	Michael
Simple stuff	*One window(opener) should be enough - there are blinds, you don't really need it and with and someone coming into put you to bed at night they close the blinds.*	Richard
Voice Activation	*computer, voice recognition, is increasingly hopefully for high quads - becoming a viable option for high quads*	Paul
Voice Activation	*It would be great if someone did come along to sort these things out. Put them all on voice control, that's what I reckon anyway is the way to go.*	Jerry

Alternative Text Description for Table 3: Experiences - quotations

Selected quotations from focus group transcriptions that illustrate themes in the Experiences and Desires categories and who said these quotations.