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Users' Perceptions of Environmental Control Systems

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Abstract: This paper presents users' perceptions of the benefits and challenges of environmental control systems, the data having been collected as part of a project developing a new speech-driven environmental control system. The first stage of this project collected data from existing users of speech-driven environmental control systems and provided information for the specification for the new device. A secondary analysis of this data revealed perceptions about environmental control systems in general and the results are presented here. Independence and control emerged as a key aspect of environmental control systems. In addition it was possible to identify other themes around topics such as perceptions of service delivery and provision. It can be easy for a non disabled person to overlook the importance of being able to independently change the television channel or make a phone call and this data reinforces the importance of this to people who use environmental control systems.

Keywords: Environmental Control Systems; Qualitative Analysis

Introduction:

Environmental control systems were initially developed in the 1960's to enable people who had suffered a spinal cord injury to control equipment in their immediate environment: for example switching on and off lights, operating the television etc. There have been a number of studies auditing the provision of environmental controls, supported by a range of articles describing their use. For example: Palmer et al. [1] described the process of providing environmental control systems in one service in the UK. Novak [2]; Paul et al [3] described the demography of referrals to one UK service and Maguire et al. [4] audited provision of systems in different services. Craig et al [5] demonstrated that people with disabilities are able to use environmental control systems and a small number of studies have also aimed to study the effectiveness of environmental controls (e.g. Harmer and Bakheit [6]). Some studies have used qualitative research methods to investigate users' perceptions of the systems: Harmer and Bakheit collected some qualitative data on the perceived benefits to their participants and Palmer and Seale [7] used a grounded theory approach to represent attitudes towards environmental control systems. Eagle [8] notes the existence of unpublished data demonstrating the effect on quality of life measures on young men with Duchene Muscular Dystrophy; however there is little published data regarding the effect on quality of life of electronic assistive technology. A review of the literature by Craig et al [9] concluded that there was little work in demonstrating the efficacy of environmental control systems and to date there does not appear to have been extensive

evidence considering the benefits of these systems from the perspective of users or carers over any of the stages of the patient journey.

1. Method:

United Kingdom ethical approval was granted by North Sheffield Ethics Office. Participants for the study were identified by contacting health professionals involved in the prescription of environmental control systems via an assistive technology professionals' mailing list. Professionals were sought who could provide details of clients in their areas currently using speech-driven environmental control systems. Eleven professionals expressed an interest and contact was pursued with five for participant recruitment. The inclusion criteria for this opportunity sample of participants were that they should be: over 16 years of age; either be people who currently use or had tried speech-driven environmental control systems and have sufficient cognitive ability to take part in the interview.

Interviews were carried out at the homes of the users of environmental control systems by researchers experienced in assistive technology and trained in qualitative interview techniques. The interviews lasted approximately an hour in length and were designed to be open and free ranging whilst also drawing on a pre-defined topic guide. The topic guide was developed following a literature review and discussion between members of a small expert group. Involvement of professionals who prescribe environmental control systems was through two initial validation interviews and a subsequent focus group with six professionals.

Initial analysis was determined by the needs of the overarching project to develop a new speech-driven environmental control system and details of this process and the results can be seen in Judge et al [10]. This paper briefly reports the results of a secondary analysis of the data from both environmental control users and professionals looking at themes around the use of environmental control systems in general.

Framework analysis [11], a qualitative research approach, was chosen as the basis for interpretation of these data since it allows a focused analysis. Carrying out the secondary analysis involved re-reading the source material and coding data into a framework of themes relating to general environmental control system use. Researchers then jointly compared and consolidated the identified themes into an agreed framework. Consensus was agreed between researchers by discussing similar themes and referring to their definitions. In many cases themes identified were similar however each researcher had named them slightly differently. The coded data were then reviewed and the researchers discussed in detail extracts which had been coded differently in order to achieve consensus on their coding.

2. Results:

Themes that emerged can be related closely to a typical patient journey: from initial assessment for environmental control to provision and then long term use. The results of the analysis are described below, ordered according to this patient journey (words in square brackets are where person identifiable data have been replaced).

2.1. History of environmental control use

All of the user participants had had an environmental control system for at least six months with a majority having used them for 2 years or more. User participants were therefore a cohort of experienced and 'successful' users of environmental control systems. All participants used a speech-driven environmental control however almost all participants had trialed other systems and approximately half of the participants had alternative systems which they use in conjunction with or as back-up for the speech-driven system. Seven of the eight professional participants were Clinical Scientists or Technologists and had experience in provision of environmental control systems including speech-driven systems. The professional participants can thus be regarded as a cohort of experienced prescribing professionals with a wide range of knowledge.

2.2. Assessment

The process of assessment for environmental control was described by both users and professionals. Participants described the assessment appointment and appeared to be well aware of its objective and there was some reference to the patient-'expert prescriber' relationship:

User *- A [Professional] kind of assesses me to see what I needed. He had his little briefcase and he thought this was the best for me.*

Both the professionals and users commented about initially introducing systems with a limited number of functions and then adding to this as the user's experience, skills or requirements increase. Professionals commented on this trial element being a useful part of the assessment process:

Professional *- Sometimes the proof of the pudding is in the trying and the only way to prove a point is to show what you feel is the most appropriate option in an assessment, in a trial or whatever.*

There was some indication from users that not all of their environmental control needs had been met by the systems:

User *- No, he came with [a Professional] who gave me the system and they brought this system along and we spent a long time – it seemed like half a day I should think setting it up and putting it up but no, I didn't have a choice, this was what they brought.*

Professionals discussed some of the issues which arise during assessment and highlighted finding a method of access, for example a suitable switch, as one of the key challenges and influences on success. In addition they emphasised the need to demonstrate the operation of a system during an assessment and to allow the potential user to try it at this stage.

Professional *- generally we solve it by finding a suitable switch, we can prescribe a switch and initially, that's fine, but then with the deterioration in their condition, particularly MS and Motor Neurone Disease, that won't be the switch that they will always use, but once they know how the system works, finding the switch is probably the most difficult part for us*

Routes to provision seem varied in terms of referrers, sources of information and care pathways:

User - *I'd lost the use of my arms and I spoke to my nurses who said 'it's ridiculous, you need everything in here upgraded' so my doctor came out and he referred it back to [Mr X] and [MrX] got in touch with them and they all came out – social workers and everything. They just looked at it and went 'antiquated, this stuff was out of date when it was put in' so consequently it was all ripped out and put back in, the latest version according to them.*

2.3. Risk assessment

Professionals highlighted that risk assessment is a key part of assessing for an environmental control. It was also noted that the benefits of provision can outweigh the risk provided adequate measures to minimise the risk have been made:

Professional - *You've got to assess them, 'are they competent to take that decision on the risk?' and then they've got to insist, even if you just list the possible side effects of what could go wrong. I mean most people are well aware of those and if they insist you say 'sign here please'.*

The majority of these users of speech-driven environmental control systems do have some form of switch or direct access alternative as a back up and this was mostly instigated by their 'risk assessment' of the reliability of the speech-driven system.

User - *If I lived completely on my own, well it would have to be a telephone to ring out, especially at night times if my son went out*

2.4. Environmental control use

Users identified strong benefits to independence in the use of their environmental control systems. Professionals were aware of the impact on quality of life of such systems but highlighted that often the initial driver is on safety and security e.g. enabling the person to be able to call for assistance. Frustrations emerged around reliability of systems and the impact of problems, given the level of dependence these participants have on the systems.

User - *Life without it would be impossible, just about, but life with it sometimes can be hard.*

Difficulties with switch scanning as a method of access to environmental control systems was another notable theme with users describing difficulties and frustrations with scanning and professionals noting similar problems in appropriately prescribing scanning systems:

User - *I think for about 3 or 4 months but I got very frustrated with it and I felt like a budgie banging my head on a bell. Didn't just suit me at all like.*

Data in a number of themes emerged which highlighted that, although people with severe physical disabilities are often reliant on family and carers for a large number of functions, being able to carry out some functions independently is highly important and enables the person to have at least some level of control and privacy. The emphasis on

increased independence also showed in the participants' comments about the effect of the system on their carers:

User - *it's made life a lot easier and simpler, you know, because there'd be nothing worse than every time you wanted to do a channel change or something having to call your carer.*

2.5. Provision of environmental controls

The users of environmental control systems interviewed generally gave positive feedback about the provision process. NHS assessors (generally clinical scientists or technologists) were mentioned in a number of cases in a positive light as was some of the maintenance support provided by environmental control companies:

User - *I mean mine now, I've got [a Professional], I think he's rehabilitation or something, but [Professional], you can ask him and he'll do anything with it. He does help and I feel more at ease with him. So it does come into consideration, yes.*

There were also some difficulties and criticisms reported, including with interactions with environmental control companies:

User - *It was decided that perhaps a system, an environmental system would help me, it took them nearly 2 years to get round to actually sending some engineers round to have a look at the position and get some quotes, so in all the whole thing started 4 years ago, but I have had actually had an up and running system for 2 years now*

Interestingly some of the users seemed quite aware of the costs associated with such systems and the cost pressures within the NHS in relation to their provision:

User - *It would be nice to be able to control the curtains, but I guess it was decided for this system that that's too expensive to do and that I don't really need it, that badly.*

2.6. Perception of current environmental control systems

Both the users' and professionals' perceptions of current environmental control systems were that they are functionally sufficient and enhance independence but that they are not as advanced as they could be or do not perform as well as they could do. Professionals highlighted limited choice, lack of cross compatibility and along with users, had negative perceptions of the aesthetic appeal of the devices. Users also highlighted a lack of consumer power to increase the speed of development in this sector due to the systems not being something they could opt out of having.

User - *obviously they're getting more advanced, but they still use the same dull equipment and some people have got to use that because obviously they are so severely disabled that they've got to use that sort of equipment,*

3. Discussion

This study is covering the secondary analysis of data collected focusing on a different aspect of environmental control (speech driven systems) – this means that the data collected is peripheral and themes are not necessarily saturated. It was possible to

collect enough data from this analysis to develop a coarse but robust framework around general perceptions of environmental controls which could be used as the basis of further work.

Several biases exist in the data: user participants were experienced and successful environmental control users; professional participants were also highly experienced; user participants were all recruited from areas where there are clinical scientist or technologist led services – this is not the case in all areas; all user participants had a speech-driven environmental control system, hence there was a non-representative spread of environmental controls and installing companies and speech-driven systems are often perceived as less reliable.

The key outcomes from the analysis were user participants' emphasis on their increased independence and reduced burden on carers afforded by the use of these systems. In addition users' perceptions of the different stages of the patient journey have also emerged that could influence service development. This study has demonstrated that qualitative data can provide useful and rich information that may be difficult to obtain by a purely quantitative investigation. The combination of professional and user feedback also aids in giving a more complete picture of perceptions of environmental controls.

This work highlights the need for further work focused on investigating the perceptions and needs of users of environmental control systems over the various stages of provision of the systems.

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