

Essential EADL for persons with high level tetraplegia: A case series

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ABSTRACT

Electronic Aids for Daily Living (EADL) are a category of AT that provides individuals with limited physical function a means of controlling electronic or physical devices that are essential for safety, security, and control of one's environment such as operating lights, opening doors, and activating emergency call systems and mobile communication or computing devices. Reported benefits of using EADLs include decreased workload on family or caregiver, improving ability to be alone safely, improving social connections, and supporting autonomy. Since the 1960's, EADLs have transitioned from large, expensive stand-alone devices hardwired to the electronics they control, to small and portable devices controlled wirelessly. Recently, mainstream internet-based home control devices, including tablets, smart phones and WI-FI-enabled home devices, are becoming more widely used as EADL by people with disabilities. A recent environmental scan conducted by Canada's Drug and Health Technology Agency on access and funding available for EADLs concluded that each province uses different funding and service delivery processes for AT generally, and specifically that there is insufficient research relating specifically to EADLs to provide consensus on definitions of 'essential' items and to determine eligibility criteria.

To address this issue, we conducted a research study to determine how individuals with high level spinal cord injury (SCI) identify an essential EADL need, and whether the selected essential EADLs were effective in addressing self-identified goals.

We used a collective instrumental case study design and recruited three participants with C6 or higher-level motor-complete acute SCI from within a local in-patient rehabilitation hospital. Participants needed to require one or more home-based AT upon discharge and were not recipients of private payer funding/insurance (received public funding only). Participants were enrolled from the time they were in in-patient rehabilitation until 6 months post-discharge.

Participants were asked to identify home-based goals that used technology and related to the areas of safety/security, home access, or virtual access. Each participant was provided with \$5000 CDN to select and purchase the technology that they deemed to be essential. Over the study span, participants had unlimited access to an experienced AT provider for advice on selection, assistance with installation and set up, and for ongoing trouble shooting. Outcome measures related to performance and satisfaction with achieving functional goals, satisfaction with the selected essential technology and service delivery, and influence of the essential technology on feelings of competence, adaptability and self-esteem were administered.

Findings supported that while all individuals had sustained a high level SCI, their unique goals, circumstance and contexts influenced what they deemed to be "essential" technology. It was clear that essential technology was defined differently for each participant depending on their differing contexts; contextual differences included physical home accessibility, available social supports, and cultural or religious influences.

Our results suggested that it may be inappropriate to expect individuals to make decisions on the technology most essential to them in the early stages of rehabilitation following injury, as we found that supported decision-making on the technology most useful to achieve meaningful goals occurred over a six-month post-discharge period.

Despite the different selection of essential technologies, all participants reported positive effects were found in achievement of functional goals, satisfaction with the devices and services, and the impact on competence, adaptability, and self-esteem.

In this study, all essential technology items selected were common, readily available technology, supporting the need to utilize and fund a wide-spectrum of technologies, beyond dedicated EADLs. Low cost, readily available technologies may be preferable to standalone dedicated EADLs but effective use requires appropriate access or interface methods, integration with other technologies used (current and in future), and readily available support

and maintenance.

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