Research in Developmental Disabilities 35 (2014) 611–618

Contents lists available at ScienceDirect

Research in Developmental Disabilities

Technology to help persons with extensive neuro-motor impairment and lack of speech with their leisure occupation and communication

Giulio E. Lancioni [a,*], Nirbhay N. Singh [b], Mark F. O'Reilly [c], Jeff Sigafoos [d], Fiora D'Amico [e], Luigi M. Addante [e], Gabriele Ferlisi [f], Valeria Zullo [f], Doretta Oliva [f], Marisa Megna [a]

[a] University of Bari, Italy
[b] Medical College of Georgia, Georgia Regents University, Augusta, USA
[c] University of Texas at Austin, USA
[d] Victoria University of Wellington, New Zealand
[e] S. Raffaele Medical Care Center, Alberobello and Modugno, Italy
[f] Lega F. D'Oro Research Center, Osimo, Italy

ARTICLE INFO

Article history:
Received 2 January 2014
Accepted 2 January 2014
Available online 25 January 2014

Keywords:
Amyotrophic lateral sclerosis
Stroke
Neuro-motor impairment
Leisure occupation
Communication
Technology

ABSTRACT

These two studies were aimed at extending the assessment of technology-aided programs to enhance leisure occupation or communication with persons with extensive neuro-motor impairment and lack of speech. Specifically, Study I implemented the program for leisure occupation with two post-stroke patients. Study II implemented the program for communication with two persons affected by amyotrophic lateral sclerosis (ALS). In Study I, a computer system presented the participants with a variety of stimuli. The participants could select/access those stimuli by microswitch activation or could bypass them by abstaining from microswitch responses. In Study II, the participants used a computer-aided telephone system that allowed them to choose via microswitch activation the persons to call. On the computer screen, they also had words and phrases that they could activate during the calls to influence the conversation with the persons called. Data from both studies were largely positive. The post-stroke patients showed high levels of stimulus selection (access) and extended engagement. The patients with ALS were able to make phone calls and to select the words/phrases to influence the conversations. The relevance of technology-aided programs for leisure occupation and communication of persons with extensive multiple disabilities was discussed.

1. Introduction

Persons with extensive neuro-motor impairment and lack of speech, following severe neurological damage, remain largely dependent on caregivers for all daily functions including leisure occupation and communication (Aoun, McConingley, Abernethy, & Currow, 2010; Bauer, Elsaesser, & Arthanat, 2011; Brauer, Hayward, Carson, Cresswell, & Barker, 2013; Cameron, Naglie, Silver, & Gignac, 2013; Dijkers, Brandstater, Horn, Ryser, & Barrett, 2013; Geytenbeek,

* Corresponding author at: Department of Neuroscience and Sense Organs, University of Bari, Via Quintino Sella 268, Bari 70100, Italy. Tel.: +39 0805521410.
E-mail addresses: giulio.lancioni@uniba.it, g.lancioni@psico.uniba.it (G.E. Lancioni).

0891-4222/$ – see front matter © 2014 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ridd.2014.01.002

Heim, Vermeulen, & Oostrom, 2010; Lancioni et al., 2012; Trojano, Moretta, & Estraneo, 2009). Any effort to help them acquire some level of independent functioning requires the support of specific technology (Bauer & Elsaesser, 2012; Borg, Larson, & Östergren, 2011; Casey, 2011; De Joode, Van Boxtel, Verhey, & Van Heugten, 2012; Gibson, Carnevale, & King, 2012; Lancioni, Singh, O'Reilly, Sigafoos, De Pace, et al., 2011; Loureiro, Harwin, Nagai, & Johnson, 2011; Scherer, 2012; Wallace & Bradshaw, 2011).

For example, a computer-aided program presenting brief samples of environmental and social stimuli might be used together with a microswitch device to enable passive/isolated persons with extensive neuro-motor impairment and lack of speech to manage positive leisure engagement (Lancioni, Singh, O'Reilly, Sigafoos, Buonocunto, et al., 2011). Indeed, they could trigger the microswitch through a minimal response (e.g., minimal head movement) and, through this response, choose among the aforementioned stimuli and activate those that they prefer. Computer-aided telephone technology operated via a microswitch might enable persons with minimal response repertoire and lack of speech to place phone calls to relevant partners and have a basic contact and communication with them (Lancioni, Singh, O'Reilly, Sigafoos, Buonocunto, et al., 2013). The availability of a series of words and phrases that the persons could activate via the microswitch to ask the partners about specific topics (e.g., activities performed during the day) or answer their questions could largely improve the communication value of the call (Lancioni, Singh, O'Reilly, Sigafoos, Ricciuti, et al., 2013).

Preliminary versions of the first type of technology-aided program have been assessed with persons with congenital multiple disabilities and post-coma patients emerging from a minimally conscious state and affected by motor and communication disabilities (Lancioni et al., 2010; Lancioni, Singh, O'Reilly, Sigafoos, Alberti, et al., 2011; Lancioni, Singh, O'Reilly, Sigafoos, Buonocunto, et al., 2011). The second type of program with words and phrases usable to impact the conversation during the call has been assessed with a post-coma man who had recovered high levels of cognitive functioning but was isolated mainly because of his motor disabilities and lack of speech (Lancioni, Singh, O'Reilly, Sigafoos, Ricciuti, et al., 2013). Both types of programs were reported to be largely effective and to help the participants involved reach the skills targeted.

The present two studies were aimed at extending the assessment of the aforementioned types of programs with new participants. Specifically, Study I implemented the first type of program with two post-stroke patients who were in a medical care center due to the severity of their disabilities, which were made even more serious by their advanced age. Study II implemented the second type of program with two persons affected by amyotrophic lateral sclerosis (ALS) in an advanced stage, who also resided in a medical care center. Both these persons were involved in the use of technology resources to reduce their level of dependence and increase their active role. The outcome of these studies was considered important to determine the applicability/effectiveness of the two programs with new patients with different medical histories and characteristics compared to those previously involved.

2. Study I

2.1. Method

2.1.1. Participants

The two participants (Warren and Andy) were 88 and 84 years old, respectively. Warren had suffered an ischemic stroke involving the left middle cerebral artery about 18 months prior to this study. A CT scan showed expanded cortical and subcortical atrophy, particularly evident in connection with the periventricular areas. He presented with extensive motor impairment, which was aggravated by the fracture of several vertebrae (i.e., D4, D6, and L4). He spent his time in bed or in a wheelchair, wore a urinary catheter, and required assistance for all his activities. He had no speech, but he seemed capable of understanding verbal questions concerning his personal life (i.e., autobiographical events and personal needs) and could respond to them appropriately with minimal head movements.

Andy had suffered an ischemic stroke involving the right parietal-posterior area due to occlusion of the carotid artery about 6 months prior to this study. A CT scan showed extended hypo-dense areas in the right parietal-posterior region. He presented with extensive motor impairment, which was aggravated by fracture of his left arm, and spent his time in bed or in a wheelchair. He wore a gastrostomy tube for enteral nutrition and a urinary catheter and required assistance for any of his daily activities. He had no speech, but he seemed to understand verbal questions concerning his personal life (i.e., like Warren). He also responded to those questions with minimal head movements or eyelid closures. Both participants were reported by families and staff to like videos with music and films or with family scenes/events as well as caregivers' procedures, such as refreshing/grooming or massaging. Their families had signed a formal consent for their participation in this study, which had been approved by a scientific and ethics committee.

2.1.2. Position, response, and stimuli

Both participants sat in their wheelchair throughout all sessions of the study. The response selected for them was a small, downward head movement, which they already possessed (see above). The stimuli presented to them during the sessions consisted of video-clips with (a) music and song scenes, caregiver's procedures, such as refreshing/grooming, and family members talking to them (i.e., presumably preferred events; see participants' section), as well as (b) instruments emitting