Research in Developmental Disabilities 34 (2013) 2959–2966

Contents lists available at SciVerse ScienceDirect

Research in Developmental Disabilities

Technology-aided recreation and communication opportunities for post-coma persons affected by lack of speech and extensive motor impairment

Giulio E. Lancioni [a,*], Nirbhay N. Singh [b], Mark F. O'Reilly [c], Jeff Sigafoos [d], Francesca Buonocunto [e], Valentina Sacco [e], Jorge Navarro [e], Crocifissa Lanzilotti [e], Fiora D'Amico [e], Giovanni Sasanelli [e], Marina De Tommaso [a], Marisa Megna [a]

[a] University of Bari, Italy
[b] Medical College of Georgia, Georgia Regents University, Augusta, GA, USA
[c] Meadows Center for Preventing Educational Risk, University of Texas at Austin, TX, USA
[d] Wellington Victoria University, New Zealand
[e] S. Raffaele Rehabilitation and Care Centers, Ceglie and Alberobello, Italy

ARTICLE INFO

Article history:
Received 30 May 2013
Accepted 5 June 2013
Available online 29 June 2013

Keywords:
Post-coma persons
Consciousness
Technology-aided programs
Microswitches
Recreation
Communication

ABSTRACT

This study assessed technology-aided intervention programs for two post-coma men who had re-acquired consciousness, but were unable to engage in personally or socially relevant occupations, given their lack of functional speech and their extensive motor disabilities. The microswitches used for accessing the program contents consisted of (a) a pressure sensor fixed in the palm of the first man's hand that could be activated with a small hand closure movement, and (b) an optic sensor fixed under the chin of the second man that could be activated by mouth opening movements. The programs' content consisted of recreation and communication options, which involved activating music, videos, and basic requests, sending and receiving (listening to) text messages, and placing phone calls. The results showed that the men (a) used the technology-aided programs successfully to manage the recreation and communication options available and (b) showed consistent preference for the sessions with the technology-aided program over other daily events. Family and staff members interviewed about the participants' programs (seven members for each participant) thought that the participants enjoyed the intervention sessions with the programs and that the programs had beneficial effects for them. Implications of the findings are discussed.

1. Introduction

Recovering from coma subsequent to brain injury can follow many different directions across individuals, depending on the type of injury incurred and its neuro-motor and functional implications (Bruno, Vanhaudenhuyse, Thibaut, Moonen, & Laureys, 2011; Cattelani, Zettin, & Zoccolotti, 2010; Demertzi, Soddu, & Laureys, 2013; Estraneo et al., 2013; Lancioni, Singh,

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

0891-4222/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ridd.2013.06.006

O'Reilly, Sigafoos, Colonna, et al., 2012; Nakase-Richardson, Yablon, Sherer, Nick, & Evans, 2009; Taylor, Aird, Tate, & Lammi, 2007). A minimal (most unfavorable) form of recovery consists of the person entering a vegetative state and remaining in that state permanently with virtually insignificant rehabilitation opportunities (Giacino & Kalmar, 2005; Lotze, Schertel, Birbaumer, & Kotchoubey, 2011; Von Wild, Laureys, Gerstenbrand, Dolce, & Onose, 2012). A less unfavorable form of recovery consists of the person remaining in the vegetative state only temporarily and then advancing toward a minimally conscious state (Gosseries et al., 2011; Hirschberg & Giacino, 2011; Katz, Polyak, Coughlan, Nichols, & Roche, 2009). In this state, the person may learn the use of simple technology (e.g., microswitches or speech generating devices; see Lancioni et al., 2009; Lancioni, Singh, O'Reilly, Sigafoos, Olivetti, Belardinelli, et al., 2012) to access environmental stimulation and call for the attention of the caregiver in a successful and independent manner in spite of any level of motor impairment.

A third form of recovery consists of the person evolving through the vegetative state and minimally conscious state and emerging from this process (and from the last state) with a satisfactory level of consciousness, but with the inability to function within his or her context, due to lack of speech and extensive neuro-motor disabilities (Bekinschtein et al., 2005; Laureys & Schiff, 2012; Noé et al., 2012; Pistoia, Mura, Govoni, Fini, & Sarà, 2010). This person has the potential of being successfully engaged with environmental events and to perform socially relevant forms of communication only if adequate technology-aided programs are developed to help him or her realize those objectives (Lancioni et al., 2013; Lancioni, O'Reilly, Singh, Oliva, et al., 2011; Lancioni, Singh, O'Reilly, Sigafoos, Colonna, et al., 2012; Lancioni, Singh, O'Reilly, Sigafoos, Olivetti, Belardinelli, et al., 2012). In practice, the situation of this person could be considered similar to that of patients in a late stage of a neurodegenerative syndrome (e.g., multiple sclerosis or amyotrophic lateral sclerosis) or, to a lesser extent, to that of patients with a "Locked-in-Syndrome" (Bowen, MacLehose, & Beaumont, 2011; Chiò et al., 2011; Davis & Lou, 2011; De Carvalho & Swash, 2011; De Jong, 2013; Haase, Schultheiss, Kempcke, Thomas, & Ziemssen, 2012).

Technology-aided intervention programs for this last type of post-coma person with recovered consciousness (as well as for patients in a late stage of a neurodegenerative disease such as amyotrophic lateral sclerosis) are classified on two critical aspects, namely, (a) the access devices (i.e., microswitches) they rely on and, thus, the responses they require the person to use, and (b) the content (e.g., the recreation and communication opportunities they allow the person to enjoy once he or she has gained access) (Friedman, Wamsley, Liebel, Saad, & Eggert, 2009; Jumisko, Lexell, & Söderberg, 2009; Lancioni, Singh, O'Reilly, Sigafoos, Ferlisi, et al., 2012). Microswitches that rely on minimal responses that are available in the person's repertoire and easy for him or her to perform (e.g., optic microswitches under the chin to detect small chin movements) would be considered highly advantageous and preferable over microswitches that rely on gazing responses or brain waves, as the latter responses may be much more complex to control and perform reliably (Guger et al., 2009; Hennessey & Lawrence, 2009; Krausz, Ortner, & Opisso, 2011; Lancioni, Singh, O'Reilly, Sigafoos, Ferlisi, et al., 2012). The program's content can be judged on whether (a) it satisfies the person's occupation and communication requirements (i.e., the person prefers to have access to the program's content as opposed to other daily situations, such as watching a film) and (b) relevant raters such as family members and staff/caregivers consider it enjoyable and beneficial for the person (Gruis, Wren, & Huggins, 2011; Lancioni et al., 2006).

In line with the above, this study was an effort to develop and assess technology-aided intervention programs for two post-coma men who had re-acquired consciousness, but were unable to engage in personally or socially relevant occupations, given their lack of functional speech and their extensive motor disabilities. The microswitches used for accessing the programs' content consisted of (a) a pressure sensor fixed in the palm of the first man's hand that could be activated with a small hand closure movement, and (b) an optic sensor fixed under the chin of the second man that could be activated by mouth opening movements (Lancioni, Sigafoos, O'Reilly, & Singh, 2012). The programs' content consisted of recreation and communication options, which involved activating music, videos, and basic requests, sending and receiving (listening to) text messages, and placing phone calls (Lancioni et al., 2013; Lancioni, O'Reilly, et al., 2012; Lancioni, O'Reilly, Singh, Sigafoos, Buonocunto, et al., 2011; Lancioni, O'Reilly, Singh, Sigafoos, Oliva, et al., 2011; Lancioni, Singh, O'Reilly, Sigafoos, Ferlisi, et al., 2012). The assessment process consisted of verifying whether the participants (a) learned to access the programs' content and to use the options available successfully and (b) preferred the use of the programs to other daily alternatives (Lancioni, Singh, O'Reilly, Sigafoos, Ferlisi, et al., 2012). Interviews of two groups of seven family and staff people (one group per participant) were also carried out to determine their opinion on the impact of the programs (Callahan, Henson, & Cowan, 2008).

2. Method

2.1. Participants

The participants (Barry and Damien) were 55 and 56 years old, respectively. Barry had suffered a left total anterior circulation stroke about 2 months prior to the beginning of this study. A brain computed tomography scan had shown extensive left temporo-parietal ischemic lesions. By the time of the study, he presented with right hemiplegia, right homonymous hemianopsia, motor aphasia, ideomotor apraxia, and no functional activity engagement. He had minimal trunk control, relied on oral feeding with semi-solid diet, and was fitted with a urinary catheter. His cognitive/social behavior seemed to be consistent with the cognitive/social skills characterizing the seventh level of the Rancho Levels of Cognitive Functioning (see Hagen, 1998). His speech utterances were largely incomprehensible except for a few of them that concerned the "yes" sound and expressions of joy in relation to which smiles and underlying sound emissions were