



## Supporting self-managed leisure engagement and communication in post-coma persons with multiple disabilities



Giulio E. Lancioni<sup>a,\*</sup>, Nirbhay N. Singh<sup>b</sup>, Mark F. O'Reilly<sup>c</sup>, Jeff Sigafoos<sup>d</sup>,  
Marta Olivetti Belardinelli<sup>e</sup>, Francesca Buonocunto<sup>f</sup>, Fiora D'Amico<sup>f</sup>,  
Jorge Navarro<sup>f</sup>, Crocifissa Lanzilotti<sup>f</sup>, Floriana Denitto<sup>g</sup>, Marina De Tommaso<sup>a</sup>,  
Marisa Megna<sup>a</sup>

<sup>a</sup> University of Bari, Italy

<sup>b</sup> Medical College of Georgia, Georgia Regents University, Augusta, USA

<sup>c</sup> University of Texas at Austin, USA

<sup>d</sup> Victoria University of Wellington, New Zealand

<sup>e</sup> "Sapienza" University of Rome, Italy

<sup>f</sup> S. Raffaele Rehabilitation and Care Centers, Ceglie and Alberobello, Italy

<sup>g</sup> ISPE Medical Care Center, Mola di Bari, Italy

### ARTICLE INFO

#### Article history:

Received 7 December 2014

Accepted 9 December 2014

Available online 26 December 2014

#### Keywords:

Technology-aided programs  
Minimally conscious state (MCS)  
Emergence from MCS  
Leisure engagement  
Communication

### ABSTRACT

Post-coma persons affected by extensive motor impairment and lack of speech, with or without disorders of consciousness, need special support to manage leisure engagement and communication. These two studies extended research efforts aimed at assessing basic technology-aided programs to provide such support. Specifically, Study I assessed a program for promoting independent stimulation choice in four post-coma persons who combined motor and speech disabilities with disorders of consciousness (i.e., were rated between the minimally conscious state and the emergence from such state). Study II assessed a program for promoting independent television operation and basic communication in three post-coma participants who, contrary to those involved in Study I, did not have disorders of consciousness (i.e., had emerged from a minimally conscious state). The results of the studies were largely positive with substantial levels of independent stimulation choice and access for the participants of Study I and independent television operation and communication for the participants of Study II. The results were analyzed in relation to previous data in the area and in terms of their implications for daily contexts dealing with these persons.

© 2014 Elsevier Ltd. All rights reserved.

\* 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](mailto:giulio.lancioni@uniba.it) (G.E. Lancioni).

## 1. Introduction

Post-coma persons affected by extensive motor impairment and lack of speech, with or without disorders of consciousness, frequently fail to manage leisure engagement (i.e., occupation and regulation of their stimulation input) and interaction/communication with their context (Bruno, Vanhauzenhuysse, Thibaut, Moonen, & Laureys, 2011; De Jong, 2013; Eifert, Maurer-Karattup, & Schorl, 2013; Elliott & Walker, 2005; Giacino, 1996; Giacino, Fins, Machado, & Schiff, 2012; Katz, Polyak, Coughlan, Nichols, & Roche, 2009; Lancioni et al., 2010; Nakase-Richardson, Yablon, Sherer, Nick, & Evans, 2009). Given the severity of their situation and the importance of helping them achieve self-managed leisure engagement and basic communication, growing emphasis has been placed on the need to develop technology-aided programs for assisting them in these skill areas (Conneely, 2012; Frankoff & Hatfield, 2011; Lancioni et al., 2012; Lancioni, Bosco, et al., 2014; McGiltron et al., 2011; Müller-Patz, Pokorny, Klobassa, & Horki, 2013; Naci et al., 2012; Scherer, 2012; Seel et al., 2013; Wallace & Bradshaw, 2011).

During the last few years, a number of technology-aided programs have been evaluated. For example, Lancioni, Singh, O'Reilly, Sigafoos, Alberti, et al. (2011) assessed a program to enable three post-coma adults with multiple disabilities including pervasive motor impairment, lack of speech, and a minimally conscious state (MCS) to access environmental stimuli independently. In practice, the participants could access 10–15 s of preferred stimulation each time they activated a microswitch device via a full eyelid closure, a small change of fingers/hand position, and a protracted eyelid closure, respectively. The microswitches were a camera device, a touch pad, and an optic sensor. All three participants showed clear response increases (i.e., strengthening self-management of stimulation input) during the application of the program.

Lancioni et al. (2012) set up a program to enable three post-coma adults with motor impairment and lack of speech who were emerging from a MCS to choose among various stimulation events. A computer system presented them 5-s samples of the stimuli available (i.e., one at a time). If they activated a pressure microswitch placed into the palm of their hands within the 6-s interval after the sample, the computer ensured the occurrence of the matching stimulus event (song, video or caregiver procedure) for 20–25 s. If they activated the microswitch shortly after the end of one of such events, a repetition or extension of the event occurred. If they did not activate their microswitch after a sample or the end of a stimulus event, the computer entered a brief pause and then presented the next sample available in the programmed sequence. Data showed that the three participants had high frequencies of choice responses in relation to stimuli considered preferred for them.

Lancioni, Singh, et al. (2014) developed a program to enable two post-coma adults with motor impairment and lack of speech who had no disorders of consciousness to switch on music and videos, make requests to the caregiver, and send text messages to family members and friends. The participants were in front of a computer screen that showed pictorial images of the four options available. These options were automatically scanned (lit) and the participants could choose any of them by activating a microswitch (a touch/pressure device fixed inside their hands) when it was lit. Choice of one of the first three options caused the appearance of a new screen with six new images related to the option chosen (e.g., six singers/songs). Choice of one of those images led the computer to play the corresponding song or video or to verbalize the corresponding request so that the caregiver could satisfy it. If the messaging option was selected, the computer guided the participants to choose the person to whom the message should be sent, and the topic and type of message to send from a pool of available messages. Results were highly encouraging with both participants managing the leisure and communication options successfully.

Although the results of the aforementioned studies and other studies in the area appear quite encouraging, the number of participants involved in the research is relatively small (Lancioni, Singh, O'Reilly, Sigafoos, Buonocunto, et al., 2011; Lancioni, O'Reilly, et al., 2013; Lancioni, Singh, O'Reilly, Sigafoos, Buonocunto, et al., 2013; Lancioni, Bosco, et al. 2014). Given this situation, new research seems necessary to (a) extend the number of participants involved and add new evidence and (b) develop adaptations of the programs available to meet the needs of persons with different characteristics and interests (Barlow, Nock, & Hersen, 2009; Kennedy, 2005; Lancioni, Bosco, et al., 2014; McNaughton & Light, 2013; Posatskiy & Chau, 2012). These two studies pursued the aforementioned goals. Study I extended the evaluation of an existing technology-aided program for stimulus choice (i.e., Lancioni et al., 2012) with four new post-coma adults who were apparently in the process of emerging from a MCS and were affected by multiple disabilities. Study II assessed a technology-aided program, which was specifically arranged to enable three post-coma persons with multiple disabilities, but no consciousness disorders, to operate a special television device and make requests or statements.

## 2. Study I

### 2.1. Method

#### 2.1.1. Participants

The four post-coma participants (Janine, Thomas, Margaret, and Richard) were in rehabilitation or care centers and were diagnosed as borderline between the MCS and the emergence from such state. In fact, their performance on the communication subscale of the Coma Recovery Scale-Revised (CRS-R; Kalmar & Giacino, 2005) was clearly exceeding the requirements for a score of 1 (i.e., MCS) but remained somewhat short of the requirements for a score of 2 (i.e., Emergence

Download English Version:

<https://daneshyari.com/en/article/371212>

Download Persian Version:

<https://daneshyari.com/article/371212>

[Daneshyari.com](https://daneshyari.com)