



Occupation and communication programs for post-coma persons with or without consciousness disorders who show extensive motor impairment and lack of speech



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ABSTRACT

These two studies were aimed at extending the assessment of technology-aided programs for post-coma persons with extensive motor impairment and lack of speech. Specifically, Study I assessed a new program arrangement, in which stimulation access and caregiver attention could be obtained with variations of the same response (i.e., single- versus double-hand closure) by three participants who were diagnosed at the upper level of the minimally conscious state at the start of the study. Study II was aimed at enabling two persons who had emerged from a minimally conscious state to engage in leisure activities, listen to audio-recordings of family members, and send and receive messages. The responses selected for these participants were hand pressure and eyelid closure, respectively. The results of both studies were positive. The participants of Study I increased their responding to increase their stimulation input and caregiver interaction. The participants of Study II managed to successfully select all the options the program included (i.e., the leisure options, as well as the family and communication options). General implications of the programs and the related technology packages for intervention with post-coma persons with multiple disabilities are discussed.

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1. Introduction

Post-coma persons in a minimally conscious state or emerging/emerged from such a state, and affected by extensive motor impairment and lack of speech, are unable to manage any (satisfactory) interaction with their context and regulate their stimulation input (Bruno, Vanhaudenhuyse, Thibaut, Moonen, & Laureys, 2011; De Jong, 2013; Eifert, Maurer-Karattup, & Schorl, 2013; Elliott & Walker, 2005; Giacino, 1996; Katz, Polyak, Coughlan, Nichols, & Roche, 2009; Lancioni et al., 2010;

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Whyte, 2007). Adopting intervention strategies to avoid their likely isolation and impoverishment is a basic priority of any rehabilitation and care center, and of any family context responsible for them (Conneeley, 2012; Hirschberg & Giacino, 2011; McNamee, Howe, Nakase-Richardson, & Peterson, 2012; Müller-Patz, Pokorny, Klobassa, & Horki, 2013; Naudé & Hughes, 2005; Noé et al., 2012; Seel et al., 2013).

Technology-aided intervention programs (i.e., procedures based on the use of assistive technology to monitor responding and follow it with relevant stimulation and social or communication events/options) have been suggested as an advantageous approach to help these persons (Baxter, Enderby, Evans, & Judge, 2012; De Jooode, Van Boxtel, Verhey, & Van Heugten, 2012; Lancioni et al., 2010; Lancioni, Singh, O'Reilly, Sigafoos, De Pace, et al., 2011; Naudé & Hughes, 2005; Scherer, 2012; Wallace & Bradshaw, 2011). Indeed, those programs (a) focus on the use of technology to enable the person to develop an active role and self-determination with choice opportunities, and (b) thus depart from traditional stimulation approaches that treat the person as a largely passive recipient of therapy (Davieson, 2010; Di Stefano, Cortesi, Masotti, Simoncini, & Piperno, 2012; Georgiopoulos et al., 2010; Hirschberg & Giacino, 2011; Lotze, Schertel, Birbaumer, & Kotchoubey, 2011; Magee, 2005, 2007).

Research with persons at the upper level of the minimally conscious state or emerging/emerged from such a state, but affected by extensive motor impairment and lack of speech, has emphasized the potential of technology-aided programs for the persons' independent pursuit of (a) general stimulation and caregiver attention, (b) communication, or (c) combinations of multiple options (Lancioni, O'Reilly, et al., 2013; Lancioni, O'Reilly, Singh, Buonocunto, et al., 2011; Lancioni, O'Reilly, Singh, Sigafoos, et al., 2011; Lancioni, Singh, O'Reilly, Sigafoos, Buonocunto, et al., 2011). For example, Lancioni et al. (2009) used a program that included a microswitch for accessing preferred stimulation and a sensor connected to a speech-generating device (SGD) for calling the caregiver with two adults at the upper level of the minimally conscious state. Different responses were required to activate the two devices (i.e., microswitch and SGD-related sensor). Both participants learned to use the devices successfully and thus managed independent stimulation access as well as requests for caregiver attention. Lancioni, Singh, O'Reilly, Sigafoos, Buonocunto, et al. (2011) developed a technology-aided messaging program, which allowed two persons emerged from a minimally conscious state to choose the partner with whom to communicate, to select the message to send him or her from among a variety of messages available, and to have any incoming message read out to them. Lancioni, Singh, et al. (2013) assessed a program that expanded the aforementioned ones, and allowed two adults who had recovered consciousness but were limited by their motor and speech disabilities to engage in leisure and communication. In practice, the participants were enabled to activate songs and videos, to make requests, and to engage in messaging activities and phone calls on their own.

The two studies reported here were aimed at extending the assessment of technology-aided programs for post-coma persons with extensive motor impairment and lack of speech. Study I assessed a new program arrangement, in which stimulation access and caregiver attention were obtained with variations of the same response by three participants at the upper level of the minimally conscious state (i.e., at the start of the study) (Bruno et al., 2011). In practice, a single hand-closure response allowed them to access preferred stimuli while a double hand-closure response allowed them to add a request for caregiver attention. The technology for monitoring the responses was a combination of pressure and optic devices. Study II was aimed at enabling two persons who had clearly emerged from a minimally conscious state to engage in leisure activities, listen to audio-recordings of family members, and send and receive messages through a technology package that they could operate via hand or eyelid responses.

2. Study I

2.1. Method

2.1.1. Participants

The three participants (Adam, Walter, and Billy) were 51, 74, and 79 years old, respectively. Adam had suffered a rupture of aneurysm of the left middle cerebral artery with subsequent extended left fronto-temporal hematoma with midline shift and coma about 3 months prior to the beginning of this study. His coma lasted about 2 weeks and developed into a vegetative state followed by a minimally conscious state, which was still present before the start of this study, as documented by the Coma Recovery Scale-Revised (CRS-R) (Kalmar & Giacino, 2005). His CRS-R total score was 15, with partial scores of 1 on the communication and oromotor/verbal subscales, 2 on the arousal subscale, 3 on the auditory and visual subscales, and 5 on the motor subscale.

Walter had been involved in a road accident resulting in severe traumatic brain injury with left fronto-temporal subdural hematoma and diffuse axonal injury on the left temporal, corpus callosum and mesencephalic lesions about 3 months prior to this study. His coma lasted less than 2 weeks and then developed into a vegetative and eventually minimally conscious state. Prior to this study, his total score on the CRS-R was 16, with partial scores of 1 on the communication, 2 on the oromotor/verbal and arousal subscales, 3 on the auditory and visual subscales, and 5 on the motor subscale.

Billy had suffered a fall accident resulting in severe traumatic brain injury with left temporal cranial fracture, extended left occipito-temporal subdural hematoma with midline shift and coma about 2 months prior to the beginning of this study. His coma lasted 1 week and evolved into a vegetative and eventually minimally conscious state. Prior to this study, his total score on the CRS-R was 15, with partial scores of 1 on the communication subscale, 2 on the arousal, oromotor/verbal and auditory subscales, 3 on the visual subscale, and 5 on the motor subscale. The participants' families had provided informed consent for this study, which was approved by a scientific and ethics committee.

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