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Further evaluation of a telephone technology for enabling persons with multiple disabilities and lack of speech to make phone contacts with socially relevant partners

Giulio E. Lancioni [a,*], Nirbhay N. Singh [b], Mark F. O'Reilly [c], Jeff Sigafoos [d], Doretta Oliva [e], Francesca Campodonico [e]

[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] Lega F. D'Oro Research Center, Osimo, Italy

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ABSTRACT

This study assessed whether a girl and a woman with multiple disabilities could (a) make phone contacts with relevant partners through a special telephone technology, and (b) enjoy their telephone-mediated communication with them. The technology involved a net-book computer, a global system for mobile communication modem (GSM), an optic microswitch, and specific software. The technology was programmed to present the names of the partners available for contact, and the participants could choose at each presentation sequence the one they wanted to contact with a simple microswitch response. Such response triggered the computer to place a phone call to that partner. Both participants (a) learned to use the technology quite rapidly to contact relevant partners and maintained the successful use of it over the intervention and post-intervention sessions, (b) showed high levels of indices of happiness during the phone calls as opposed to pre-baseline control sessions, and (c) showed preferences among the partners. Implications of the findings are discussed.

1. Introduction

Persons with extensive multiple (e.g., motor, intellectual, visual, and speech) disabilities may find themselves in a condition of passivity and isolation and in need of intervention efforts planned to alleviate such condition (Bell & Clegg, 2012; Blain-Moraes & Chau, 2012; Holburn, Nguyen, & Vietze, 2004; Lancioni et al., 2008; Lancioni, Singh, et al., 2011; Leung & Chau, 2010; Mechling, 2006; Memarian, Venetsanopoulos, & Chau, 2011; Stainton & Clare, 2012; Taylor & Hodapp, 2012). Intervention efforts with these persons (a) need to establish forms of response engagement, enhance stimulation input and self-determination, and promote some level of communication and socio-emotional contact with relevant partners (e.g., family members and friends), and (b) require the support of technology (Borg, Larson, & Östergren, 2011; Chantry & Dunford, 2010; De Joode, Van Boxtel, Verhey, & Van Heugten, 2012; Lancioni, Sigafoos, O'Reilly, & Singh, 2012; Nicolson, Moir, & Millsteed, 2012; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013).

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

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For example, the persons might be taught to use microswitches connected to various stimulus sources to activate such sources in a direct manner, and thus regulate their level of stimulation input (Lancioni, Sigafoos, et al., 2012). The persons might be provided with samples of the environmental stimuli available and allowed to choose those that they prefer to experience through simple responses linked to computer systems and microswitch interfaces or camera-based technology (Lancioni, Bellini, et al., 2011; Lancioni, Singh, et al., 2012). The persons might be exposed to programs that allow them the use of speech-generating devices to make requests to their context (e.g., for attention, material items, and care procedures) (Achmadi et al., 2012; Sigafoos et al., 2009). The persons might also be provided with computer-aided telephone systems through which they can establish telephone contact with socially relevant partners, such as family members and friends, not always directly accessible for social interaction and communication (cf., Lancioni, O'Reilly, Singh, & Oliva, 2011).

This study assessed whether a girl and a woman with multiple disabilities could (a) make phone contacts with relevant partners via a computer-aided telephone system similar to that used by Lancioni et al. (2013) with two post-coma persons, and (b) enjoy their telephone-mediated communication. The system was programmed to present the names of the partners available for contact, and the participants could choose at each presentation sequence the one they wanted to contact with a simple microswitch response. Such response triggered the computer system to place a phone call to that partner. Partners were informed of the program and highly familiar with the participants, thus they also knew what form of conversation they could have with the participants. In particular, the girl's partners could talk warmly to her about their normal topics (e.g., food, pets, games, and trips), but could also change to a specific story/individual if the girl communicated such a desire through forms of verbal utterances that they understood. The woman's partners generally proceeded by telling her a simple story concerning them in a warm and/or excited manner. The woman could not change the topic through any utterance, but could confirm her enjoyment with laughter.

2. Method

2.1. Participants

The participants (Karen and Jessie) were 11 and 21 years old, respectively. Karen had a diagnosis of congenital encephalopathy due to complications during twin pregnancy and prematurity. Her condition was characterized by spastic tetraparesis, with extensive motor impairment that prevented her from functional interactions with her surroundings, optic atrophy with minimal residual vision, epilepsy partially controlled through medication, and lack of sphincteric control. Her vocal utterances were largely incomprehensible, but persons familiar with her could recognize "yes" and "no" sounds and a few words and names. At the receptive level, she showed the ability to follow simple conversations over familiar daily events and persons responding affirmatively (i.e., with "yes" sounds or combinations of smiles and matching sounds) when the conversation required those sounds and abstaining from any such sounds/responses or using "no" sounds in the other circumstances. She enjoyed direct and telephone-mediated interaction events with family members and other relevant persons (i.e., relatives and friends) talking with her and showed frequent and extended smile reactions. Her intellectual disability was estimated to be in the mild/moderate area, but no IQ scores were available, and caution was recommended given that her motor condition restricted her behavioral expressions drastically. Her daily program was largely focused on physiotherapy, interaction with other children, and occupation and communication activities.

Jessie had a diagnosis of encephalopathy due to perinatal intraparenchymal hemorrhage. Her general condition was characterized by spastic tetraparesis, with extensive motor impairment, minimal residual vision, epilepsy partially controlled through medication, and lack of sphincteric control. She had no verbal utterances, but emitted sounds of pleasure and laughter in conditions of happiness/excitement. She enjoyed the presence of familiar persons, liked listening to them also on the telephone, and could show frequent smiles and laughter. Her receptive ability was largely unknown, but it was obvious that she followed (paid attention to) the persons interacting with her carefully and seemed certain to recognize their names and the general tone of their messages/stories. Her intellectual disability was estimated to be in the severe range, but the cautionary note made for Karen applied to her also. Her daily program was focused on the use of general stimulation sessions (e.g., with music and vibratory inputs) and physiotherapy. The participants' families had provided informed consent for this study, which was approved by a scientific and ethics committee.

2.2. Setting, sessions and data collection

The study was carried out in a quiet room of the participants' daily contexts. During the sessions, they sat in their wheelchair. Baseline sessions were restricted to 5–10 min because the participants did not have the technology and were not expected to place phone calls via a standard phone device. Intervention sessions were planned to last 20 and 10 min for the two participants, respectively (i.e., based on staff and families' recommendations). Recording concerned (a) the frequency of calls made per session and whether they were answered, (b) the names of the partners called, (c) the length of the calls, and (d) the participants' mood during about 15% of the intervention sessions (i.e., over the time periods in which a partner was linked via phone and talked to them) and throughout three 10-min pre-baseline control sessions, in which the participants were provided with musical stimulation (see Lancioni et al., 2013). The first three measures were recorded automatically through the computer system. A research assistant recorded the mood, according to a momentary time sampling procedure with 10-s intervals. In practice, the research assistant watched the participants at the end of each interval and scored