

A woman with multiple disabilities uses a VOCA system to request for and access caregiver-mediated stimulation events

Giulio E. Lancioni,¹ Nirbhay N. Singh,² Mark F. O'Reilly,³ Jeff Sigafoos,⁴
Irene Ricci,⁵ Luigi M. Addante⁶ & Grazia Trubia⁷

Abstract

This study assessed a program involving the use of a voice output communication aid (VOCA), which was aimed at allowing a post-coma person with multiple disabilities to choose among stimuli/activities and ask for the mediation of the caregiver to access them. In response to the participant's choice (request) of a stimulus/activity verbalized by the VOCA, the caregiver could propose two alternatives of it and eventually provide the one that the participant seemed to prefer. Results showed that the program was effective in increasing the participant's successful requests and allowing her to access chosen stimuli/activities with a brief mediation of the caregiver. The practicality and implications of the program are discussed.

Keywords: VOCA, Multiple disabilities, Choice, Caregiver mediation

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¹ University of Bari, Italy. E-mail: g.lancioni@psico.uniba.it

² American Health and Wellness Institute, Verona, VA, USA. E-mail: nirbsingh52@aol.com

³ Meadows Center for Preventing Educational Risk, University of Texas at Austin, TX, USA. E-mail: markoreilly@mail.utexas.edu

⁴ Victoria University of Wellington, NZ. E-mail: jeff.sigafoos@vuw.ac.nz

⁵ S. Raffaele Care Center, Modugno, Italy. E-mail: irene.ricci1984@libero.it

⁶ S. Raffaele Care Center, Modugno, Italy. E-mail: luigi.addante@consorziosanraffaele.it

⁷ IRCCS 'Oasi' Troina, Italy E-mail: gtrubia@oasi.en.it

Address correspondence to G. E. Lancioni, Department of Psychology, University of Bari, Via Quintino Sella 268, 70100 Bari, Italy.

1. Introduction

A basic, preliminary objective of any programs for persons with severe multiple disabilities is to enable these persons to interact with the immediate context and control relevant stimulation events independently (Mechling, 2006; Lontis & Struijk, 2010; Borg, Larson, & Ostegren, 2011). The achievement of such an objective is largely connected to the availability of assistive technology and, in particular, of microswitches (Mechling, 2006; Lancioni, O'Reilly, Singh, Sigafos, Oliva, Antonucci *et al.*, 2008; Weightman, Preston, Holt, Allsop, Levesley, & Bhakta, 2010). Microswitches are devices that allow a person to activate stimulus sources with minimal responses that per se would not be adequate (sufficient) to handle those sources (Holburn, Nguyen, & Vietze, 2004). For example, a touch/pressure microswitch placed inside the palm of the person's hand may allow the person to activate a music box with a small hand closure response (Lancioni, O'Reilly, Cuvo, Singh, Sigafos, Didden *et al.*, 2007).

A subsequent objective of the programs may be that of extending the range of environmental stimuli available for the person and enabling the person to choose among them (Lancioni, Singh, O'Reilly, Sigafos, Buonocunto, Sacco *et al.*, 2011). With regard to this objective, a first approach may involve the use of multiple microswitches (each linked to a specific type of stimuli) that allow the person to choose among stimuli and to access those selected totally on his or her own (Lancioni *et al.*, 2011). One might also arrange an approach that entails a partial involvement of the caregiver, that is, the caregiver is called through the verbal request of a VOCA device to mediate the access to the stimuli (activities) that the person has chosen (Schlosser, 2003; Lancioni, Singh, O'Reilly, Sigafos, Oliva, & Cingolani, 2009; Sigafos, Green, Payne, Son, H., O'Reilly, & Lancioni, 2009; Rispoli, Franco, Van der Meer, Lang, & Höher Camargo, 2010). In this process, the caregiver can also present different alternatives of such stimuli/activities so that the person's choice opportunities increase. For example, the person may choose to watch video segments and call the caregiver to help with that through a VOCA request. The caregiver may intervene in response to that by allowing the person to choose between two different video segments (Lancioni, Olivetti Belardinelli, Stasolla, Singh, O'Reilly, Sigafos *et al.*, 2008).

This second approach would simultaneously promote the person's initiative in making requests/choices (seeking different stimuli/activities) and his or her opportunity to interact with the caregiver (increase his or her social contact and choice level) (Lancioni *et al.*, 2008; Kagohara, 2011). Given these social/emotional components, the second approach may be seen as highly attractive and, at the same time, as also relatively expensive in terms of caregiver's time (Mcintyre, Kraemer, Blacher, & Simmerman, 2004). To make such an approach realistic (affordable), one might need to ensure that (a) the mediation required to the caregiver for accessing the stimuli/activities amounts to a

momentary participation that is basically reconcilable with his or her regular duties, and (b) the sessions requiring the caregiver's mediation are part of a wider program that also includes technological solutions allowing the person to choose and access stimuli independently (Lancioni *et al.*, 2009, 2011).

This study was aimed at devising and assessing a basic application of the second approach (i.e., the one with caregiver mediation) for a post-coma woman with multiple disabilities. Although a relatively extensive literature exists on the use of VOCA for persons with severe/profound communication and multiple disabilities, this study was thought to add new evidence because it focused on an area (i.e., extended choice with social mediation) and on a type of participants that had attracted only a limited amount of attention so far (Lancioni *et al.*, 2009, 2011; Sigafos *et al.*, 2009; Rispoli *et al.*, 2010).

2. Method

2.1. Participant and Setting

The participant (Jenny) was 33 years old. She had congenital encephalopathy due to complications during pregnancy. Her level of intellectual disability had been estimated to be in the severe range, although no formal IQ scores were available. From her early childhood, she had been suffering from obesity and diabetes mellitus with respiratory problems, which could also be very severe. About 10 years prior to this study, she had incurred respiratory and cardiac arrest with subsequent coma. From that time she had been provided with a tracheostomy tube and artificial ventilation. This condition restricted her to bed or to a reclined wheelchair, and eliminated any form of productive verbal communication. Indeed, she tended to be isolated and only occasionally she resorted to eye-gazing or partial pointing as forms of requests concerning stimuli available in her immediate surrounding. These attempts could easily fail because they went unnoticed or were misinterpreted, particularly if the caregiver or other personnel were not directly watching her. This condition was considered very damaging in terms of communication and social-emotional interaction. In addition, it complicated her access to stimulation. Indeed, she would be allowed to access a few forms of stimuli directly through basic microswitch technology or would be provided with environmental stimulation determined by her caregivers rather than through her choice. Given this situation, the arrangement of a program that would allow her to request/choose stimuli/activities and access them through the mediation of the caregiver was thought to be a valuable goal. Moreover, Jenny seemed to be very interested in this approach. Her legal representative had provided formal consent for her participation in the study, which was approved by a scientific and ethics committee. The study was carried out in Jenny's room within the medical care center in which she was living.

2.2. *Technology, request/choice responses, and stimuli/activities*

The VOCA system used for allowing Jenny to request/choose stimuli/activities was a commercial (tablet-like) device provided with nine cells of 4.5 cm X 5.5 cm (Go Talk 9; Special Needs Products of Random Acts Inc., USA). Only five of those cells were used in this study. Each of these five cells was eventually provided with a pictorial representation of one of the stimuli/activities available (see below). Request/choice responses consisted of applying light pressure to any of these cells (pictorial representation). Each response made the system call the caregiver (research assistant) and ask her the possibility to access the stimulus or activity selected. The stimuli/activities included: songs, videos, ornamental material, paintings, and make-up items. Songs and videos included a variety of popular tunes and comedy or animated-film segments stored in a portable computer. Ornamental material included items, such as rings and bracelets, which could be tried on and worn briefly. Paintings included various series of picture cards representing persons and scenes that Jenny liked as well as coloring materials that could be used to complete drawings included in the series. Make-up items included materials such as a mirror, lipsticks, and creams. These sets of stimuli/activities were used for the study based on staff recommendations. That is, staff had confirmed that they were enjoyable for Jenny as shown by her smiles and active participation during their availability through time.

2.3. *Experimental conditions*

The study was carried out according to an AB¹BAB design sequence (Barlow, Nock, & Hersen, 2009), with the A representing baseline phases and the B¹ and B representing intervention phases. Typically, two or three sessions per day were carried out. Sessions lasted until an interval of 20-25 min had elapsed. A research assistant recorded the responses performed and the stimuli/activities selected within the sessions. Interrater agreement was assessed in about 20% of the sessions with a second research assistant recording the aforementioned measures independently. Agreement (i.e., availability of matching scores from the two research assistants) was reported in 38 of the 39 sessions targeted for the assessment.

Baseline (A) phases. Each of the two baseline (A) phases included four sessions. The research assistant who carried out the sessions (a) was in the room with Jenny, busy in settling away things around the room, or immediately outside her room and (b) could talk to Jenny but generally without watching her for any specific length of time. Namely, the research assistant simulated the common daily situation Jenny experienced at the medical care center. If no requests occurred that the research assistant could understand, she would (a) suggest one stimulus/activity option to Jenny, and (b) eventually (e.g., once Jenny had acknowledged with a smile that she liked it), she presented such stimulus/activity to Jenny.

Intervention (B¹) phase. This phase included 38 sessions that served to introduce the five pictorial representations used to indicate the five sets of stimuli/activities available (see above). Initially, a practice session was used with the representation of music. Jenny was guided (via verbal and physical prompting) to push such a representation on the VOCA tablet where it was attached. As soon as Jenny pressed it, a vocal request of listening to music was emitted (addressed to the research assistant) by the VOCA system. In response, the research assistant would present two music alternatives (e.g., the pictures and names of two singers) to Jenny and ask which alternative she wanted. Fixation/pointing of one alternative led the research assistant to turn on the file of that singer on the computer for about 2 min. Once, Jenny was requesting music appropriately, the intervention focused on the request of films. Only the pictorial representation of films was available on the VOCA tablet initially. Conditions matched those described above for music. Eventually, the pictorial representations of music and films were made available simultaneously on the VOCA tablet. Now, Jenny could request for both. Once she had shown that ability, the intervention focused on ornamental stimuli. Initially, only their pictorial representation was available. Subsequently, such a representation was presented together with those of music and films, and Jenny could request any of the three based on her preference. Once she had shown requests for any of the three stimulus options, the intervention continued with the introduction of the pictorial representation of paintings/images and drawings. The procedure was the same as that described above. Jenny could go through the set of images available and could also color some of the interspersed drawings. Then, this pictorial representation was made available on the VOCA tablet together with the three previously introduced. The same strategy was followed for the last pictorial representation (i.e., make-up). In this case, a request could be followed by the presentation of a mirror and a lipstick or a mirror and a cream. A stimulus/activity condition was made available for about 2 min at each choice occasion.

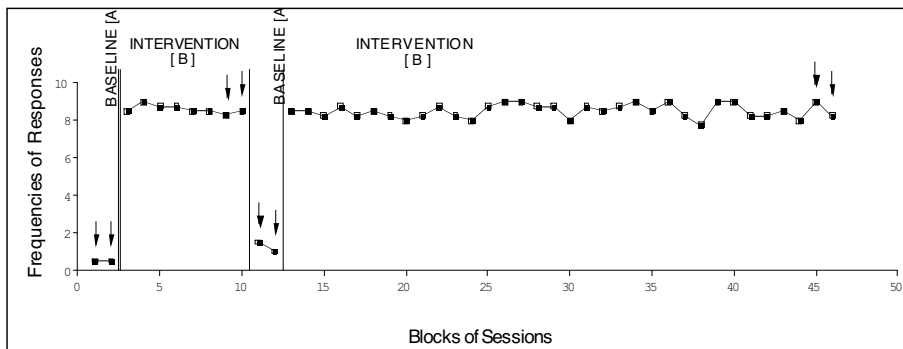
Intervention (B) phases. The two intervention (B) phases, which were separated by the second baseline (A) phase, included 29 and 134 sessions, respectively. The VOCA had all five pictorial representations (choice options) on its tablet and Jenny could choose among all of them as at the end of the B¹ phase. A stimulus/activity was available for about 2 min as during the B¹ phase.

3. Results

The results of the study are summarized in Figure 1, which shows the mean frequencies of requests per session over blocks of sessions through the baseline (A) and the intervention (B) phases. Blocks include four sessions except when an arrow is present. In that case, they include two or

three sessions. Grouping the sessions allowed a simplified presentation of the data without any apparent loss of information as to the participant's performance over time. The data of the B¹ phase were not reported in the figure, as different conditions were available across the phase (with sessions or part of them involving only one stimulus/activity representation on the VOCA tablet; see above). The data of the baseline phases indicated that only sporadic requests were made (understood) during those periods. The use of small numbers of baseline sessions was based on the view that (a) data changes could hardly occur under those conditions, and (b) a short baseline period would avoid an extension of a presumably frustrating situation. During the B¹ phase, Jenny was showing regular requests, with a mean frequency of about eight per session. During the two intervention (B) phases, Jenny's mean frequency of requests exceeded eight per session. The stimuli/activities more frequently requested were songs, videos, and make-up.

Figure 1 - *The data points represent mean frequencies of requests per session over blocks of four sessions (or blocks of two or three sessions if an arrow is present) during the A and B phases of the study*



4. Discussion

These results indicate that the participant was consistently active making requests and, with marginal caregiver mediation, succeeded in accessing forms of preferred stimuli/activities during the intervention phases. These data provide strong support for the possibility of successful intervention with persons who are rarely provided with such an opportunity and for the possibility of reconciling choice and caregiver mediation in a practicable way (Lancioni, *et al.*, 2007; Sigafos *et al.*, 2009; Rispoli *et al.*, 2010). Indeed,

the caregiver was involved in extending the participant's choice range and allowing the availability of the stimuli/activities, but this involvement was not continuous/massive so as to preclude other commitments.

In light of these findings, three considerations may be in order. First, the number of options available was relatively limited and probably could be extended in line with the characteristics/interests of the participant. Such an extension would pose questions about the new choice alternatives to introduce and the technology to use for that. The basic requirement for the new choice alternatives would be that they are feasible within the participant's situation (i.e., in addition to being interesting for the participant) (Brown, Schalock, & Brown, 2009). The technology could remain the same for the next few alternatives. Afterwards, one could decide whether to adopt a wider device or to divide the options into different groups and allow choice within a single group per session (Light, McNaughton, Weyer, & Karg, 2008; Sigafoos, Schlosser, O'Reilly, & Lancioni, 2011).

Second, some changes could be introduced in the program to make the caregiver mediation somewhat more economical in terms of time (i.e., more reconcilable with his or her regular duties). One way to pursue this goal could be that of extending the amount of time that the participant can deal with the stimulus/activity chosen (e.g., such time could change from about 2 min, as adopted in this study, to 3-4 min or more). Another strategy could be that of involving more staff personnel (and not only a specific caregiver) in the mediation process. In this case, the staff person more easily available could intervene at each of the requests.

Third, one should ensure that the VOCA-assisted choice sessions, which require caregiver mediation, are alternated with microswitch sessions in which the participant is autonomous in seeking environmental stimulation. This combination of sessions could prevent sensory deprivation or understimulation and, at the same time, could keep the time cost for the caregiver (staff) affordable in busy daily contexts (Parsons, Daniels, Porter, & Robertson, 2008).

In conclusion, this study extends the evidence available on the use and effectiveness of VOCA within an area only marginally investigated. New research in this area would be necessary to determine the generality of these findings and provide useful information for possible intervention improvements (Barlow *et al.*, 2009; Lancioni *et al.*, 2009). Research would also need to address (a) the feasibility of the changes suggested above to make the program more practical and affordable in terms of staff/caregiver time investment and (b) the issue of social validation of the reported approach involving caregivers as social raters (Callahan, Henson, & Cowan, 2008).

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