Research in Autism Spectrum Disorders 8 (2014) 1269–1278

Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

Journal homepage: http://ees.elsevier.com/RASD/default.asp

Comparing PECS and VOCA to promote communication opportunities and to reduce stereotyped behaviors by three girls with Rett syndrome

Fabrizio Stasolla [a,*], Claudia De Pace [b], Rita Damiani [b], Antonia Di Leone [b], Vincenza Albano [b], Viviana Perilli [c]

[a] Lega del Filo d'Oro, Research Center, Molfetta, Italy
[b] Department of Educational Sciences, Psychology, Communication, University of Bari, Italy
[c] Lega del Filo d'Oro, Research Center, Lesmo, Italy

ARTICLE INFO

Article history:
Received 12 June 2014
Accepted 23 June 2014
Available online 23 July 2014

Keywords:
Rett syndrome
Augmentative and alternative communication
Developmental disabilities
Indices of happiness
Quality of life
Stereotypies

ABSTRACT

We compared PECS and VOCA intervention strategies to promote communication opportunities for three girls with Rett syndrome and severe to profound developmental disabilities. The first aim of the study was to assess the effectiveness of both aforementioned strategies by enhancing request and choices of preferred items by the participants involved to a caregiver. The second goal of the study was to assess the effects of the intervention program by reducing stereotyped behaviors (i.e. body rocking and hand movements). Finally, the third purpose was to carry out the indices of happiness and monitor quality of life concerning the participants exposed to the intervention program. The study was carried out according to an alternating treatments design with a final preference check phase for each participant. Results showed an increasing of independent requested and chosen items as well as of indices of happiness during intervention phases for all participants. Moreover, two of them chose VOCA strategy during preference checks phase, while the third one equally chose both strategies. Furthermore, a decreasing of stereotypies was observed during intervention phases for the three participants. Clinical, educational and psychological implications of the findings are discussed.

1. Introduction

Rett syndrome (RS) is a progressive neurodevelopmental disorder, X linked, due to mutations in the methyl-cytosine phosphate guanine binding protein 2 (MECP2) gene, located on Xq28, largely affecting primarily females, first described by Andreas Rett (Rett, 1966). It is associated with severe to profound intellectual, communicative and motor impairments, beginning between 6 and 18 months old, preceded by a normal birth and an initial regular development (Didden et al., 2010). RS traditionally follows four stages: (a) stagnation, (b) regression, (c) stationary, and (d) motor deterioration (Stasolla and Caffò, 2013). The first one, *stagnation*, is characterized by a global arrest of child's development, generally starting near to 6 months. The second, *regression*, usually initiating between 1 and 4 years old, includes a loss of acquired adaptive and social functions (i.e. verbal language and social interaction), while gazing for communicative goals is preserved. The third stage,

* Corresponding author. Tel.: +39 3496635397; fax: +39 069384564.
E-mail addresses: f.stasolla@libero.it, f.stasolla@psico.uniba.it (F. Stasolla).

http://dx.doi.org/10.1016/j.rasd.2014.06.009
1750-9467/

stationary, is presented with stereotyped hand movements such as clapping, tipping and washing, in addition to breath irregularities (i.e. hyperventilation) and behavioral disturbances (e.g. nocturne crying and laughing). Apraxia, seizures, motor scoliosis appear during the third stage between 3 and 10 years old (Giebers et al., 2012). Finally, the *motor deterioration*, is introduced after 10 years old as a progressive physical decline, diminued motor abilities, reduced and stereoypies. Revised criteria by Neul et al. (2010) also encompass withdrawal and failing in ambulation responses.

Educational and rehabilitative programs for individuals with RS are consequently aimed at enhancing the aforementioned adaptive behaviors. Priority within those interventions is commonly assigned to communication skills, considered crucial, due to the early loss of the acquired speech abilities and the very limited communicative repertoire (Matson, Fodstad, & Boisjoli, 2008). To deal with this issue, augmentative and alternative communication (AAC) strategies are viewed as critical by researchers (Sigafoos et al., 2009; Sigfoos et al., 2011). AAC pursues the objective to improve individual's communication opportunities by augmenting his/her behavioral repertoire, finalizing it at fostering communication abilities, using alternative codes from verbal or writing language (Sigafoos et al., 2011). AAC strategies commonly include two different broad categories, that is (a) unaided, and (b) aided. The first category includes procedures such as manual signs that do not require any external equipment to individual's body. The second category refers to pictorial material and technological supports such as picture exchange communication systems (PECS) and vocal output communication aid (VOCA) (Bondy & Frost, 2001; Sigafoos et al., 2004; Lancioni, O'Reilly, Cuvo, et al., 2007).

The PECS consists of six different phases. During the first one, it teaches to exchange a picture for the preferred item available in full view but not accessible in any other way than by handing such a picture to the communication partner. The issue consists of learning by the individual to perform a basic request and to receive a positive consequence (i.e. reward) represented by the preferred item for such act. During the second phase, the PECS enables the individual to find a picture from a book that is not in front him or her and to hand it to the communication partner who is not near to him or her. The next third phase ensures the child to discriminate among pairs of items proposed by the communication partner of which one is high desirable (i.e. motivating item) and one is not (i.e. unpreferred item). The following three phases of the PECS are aimed at teaching the person to build sentences, answer to questions and perform comments, respectively (Bondy & Frost, 1998).

VOCAs are speech generating devices (i.e. technological tools) that translate into synthesized and digitized verbal outcomes (i.e. request messages) basic nonverbal behaviors such as press a picture or a lexigram on a device board (Sigafoos, Didden, & O'Reilly, 2003). The properties of such devices, opposed to manual sign or to picture pointing, are that the output verbal messages produced are easily understandable by parents, teachers, staff and caregivers (Sigafoos & Drasgow, 2001). The understanding occurs even if the aforementioned persons are not in the immediate proximity of the child (Lancioni, O'Reilly, et al., 2009). A number of studies comparing PECS and VOCA strategies enabling children with developmental disabilities to perform communication abilities have been carried in the last decade involving children with intellectual disabilities and motor impairments (e.g. post coma patients) or autism spectrum disorders (Lancioni et al., 2008a, 2008b), but it seems to be no studies comparing PECS and VOCA for promoting communication opportunities by individuals with Rett syndrome, neither assessing their effects on the quality of life of those participants (e.g. increasing the indices of happiness and reducing stereotyped behaviors) (Lancioni & Singh, 2014).

The present study pursues consequently five objectives, that is assess (a) the effectiveness of PECS to promote communication abilities, (b) the effectiveness of VOCA to enhance communication opportunities, (c) the comparison between both with a preference check phase (see Section 2.5) for three new participants with RS, (d) the effects on decreasing body rocking and hand movements related stereotypies, and (e) the effects on increasing their positive mood (i.e. indices of happiness).

2. Method

2.1. Participants and setting

The participants (Cindy, Diane and Tamara) were 9.2, 8.4 and 10.5 (mean age 9.36) years old and received a diagnosis of RS at 20, 16, and 18 months, respectively. They presented communication impairments (i.e. lack of speech, but some vocalizations), seizures, hyperventilation, withdrawal, stereotyped behaviors (i.e. body rocking for Cindy, hand tipping for Diane and hand washing for Tamara). None of the girls had awareness of the sphincteric control and all showed motor impairments, with failure in ambulation responses. In fact, they were all equipped with a wheelchair. Although no formal score of intelligence quotient was available, since no test was feasible, all children were estimated with severe to profound developmental disabilities from clinical observations. Cindy, Diane and Tamara were recruited by reporting from their neurologist to the research team and included in the study since they were unable (a) to interact constructively with the surrounding world (e.g. preferred items, parents and caregivers), and (b) to perform request and choice of needed items to their communication partners. They attended regular classes with special training and teachers.

The study was carried out at participants' homes with two research assistants. Cindy and Diane received physiotherapy sessions twice a week, while Tamara was exposed to logopedic and stimulation treatments once a week. They all presented very limited adaptive behaviors and social skills. All lived with their parents, who considered the rehabilitative intervention high desirable, and provided a formal consent for video-recording and data collection of their girls during the study, which was approved by a local ethic and scientific committee according to Helsinki Declaration and its later amendments.