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Promoting adaptive behaviors by two girls with Rett syndrome through a microswitch-based program

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ABSTRACT

We assessed a microswitch-based program to improve self-determination to access to preferred stimuli and to foster locomotor behavior by two girls with Rett syndrome and multiple disabilities. To enhance the first behavior (access to preferred stimuli) a wobble microswitch (sensitive touch sensor) was used while for the second behavior (step responses) optic sensors were applied. A second aim of the study was to monitor indices of happiness as consequence of the use of assistive technology. Finally, a third objective of the study was the reduction of hand washing and body rocking related stereotypies. The study was carried out according to a multiple probe design across behaviors for both participants, where the two behaviors were first learned independently, then combined together. Results showed an increasing of performance and of indices of happiness and a decreasing of stereotyped behaviors for both participants during intervention phases. Practical, psychological and clinical implications of the findings are discussed.

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1. Introduction

Rett syndrome (RS) is a progressive neurodevelopmental disorder caused by X-linked genetic mutations in the methyl-cytosinephosphate-guanine binding protein 2 (MECP2) gene located on Xq28, occurring primarily in females, first described by Rett (1966). It is characterized by a gradual deterioration in cognitive, communicative, and motor abilities, starting between 5 and 18 months old, after an apparent normal birth and initial regular development. RS usually follows four basic stages: (1) stagnation, (2) regression, (3) stationary, and (4) motor deterioration (Didden et al., 2010). The first stage (stagnation) presents a general arrest of child's development starting at 5–6 months. The second stage (regression) has an onset between 1 and 4 years old. In this stage there is a loss of acquired adaptive functions such as language (speaking) and/or social interaction, while eye contact for communicative purposes is relatively preserved (Sigafoos et al., 2009). During the third stage (stationary) stereotypical hand movements (i.e., clapping, mouthing, washing) as well as breathing anomalies (i.e., hyperventilation) and behavioral disturbances (i.e., laughing and crying attacks during the night) emerge (Giesbers et al., 2012). Apraxia, motor scoliosis, impairments, and seizures are also included in this stage, between 2 and 10 years old (Bartolotta, Xipp, Simpkins, & Glazewski, 2011; Young et al., 2011). The fourth stage (motor deterioration) starts after the age of 10 years old and is usually characterized by physical decline, reduced mobility, and a decreased stereotyped hand movements (Marschik et al., 2013). Criteria for diagnosing RS, as revised by Neul et al. (2010), include severe to profound intellectual disabilities, progressive decline of adaptive behaviors, withdrawal, failing locomotion.

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Persons with RS are often very isolated, have minimal opportunities to interact constructively with their environment, show reduced sensory input, very limited mobility, and usually experience low levels of quality of life (Felce & Perry, 1995; Gutowski, 1996; Ivancic & Bayley, 1996). In fact, they may be sedentary and passive, showing no specific interests for stimuli around them, with few opportunities of self-determination (Lancioni, Belardinelli, et al., 2008; Matson, Fodstad, & Boisjoli, 2008). The complexity of their situation makes it very hard to staff to apply conventional rehabilitation programs aimed at developing positive engagement, and improving their mood (Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005).

Besides to a large body of literature focusing on communication abilities in RS individuals (Fabio, Antonietti, Castelli, & Marchetti, 2009; Sigafoos et al., 2009; Sigafoos, Kagohara, et al., 2011; Sigafoos, Wermink, et al., 2011), a certain number of studies described the improving or re-gaining of lost walking ability in this population following intensive intervention (Lotan & Gootman, 2012; Lotan & Hanks, 2006; Lotan, 2007). For example, Lotan, Isakov, and Merrick (2004) employed a training program on a modified treadmill with four girls with RS. After two months of intervention, the girls' physical fitness improved significantly. Their general functioning abilities also improved with statistically significant changes reported for knee walking, going up and down stairs, and walking over short distances. Conversely, there is a lack of studies on object manipulation responses in RS individuals, employing assistive technology interventions. Microswitch-based programs have been already employed with persons with multiple disabilities (Lancioni, O'Reilly, et al., 2008; Lancioni, Singh, et al., 2008; Lancioni, O'Reilly, Singh, Green, et al., 2010) and they proved to be useful to increase adaptive behaviors and reduce stereotyped ones. The aforementioned positive outcomes suggest that such interventions are highly desirable in order to improve both object manipulation and locomotor behavior. Combining the latter ones through microswitch-based programs might foster relevant rehabilitative goals in persons with RS.

Next to the attention given to educational and/or rehabilitation goals of behavioral intervention for participants with multiple disabilities, there is a growing interest for quality of life of those participants (Felce & Perry, 1995; Ivancic & Bayley, 1996). The most distinct aspect of quality of life is happiness. This latter construct involves different components such as personal well-being, pleasure and contentment. These components are difficult to detect and quantify among individuals with non verbal behavior and low levels of functioning. To overcome this methodological problem, researchers have selected behavioral expressions already connected to possible conditions of pleasure and well-being, labeling them as indices of happiness (Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005). The indices of happiness are almost overlapping with those signs of positive mood which persons without any disability exhibit in similar situations. Thus, smile, laugh, excited body movements with or without vocalizations are considered as indices of happiness (Yu et al., 2002). The literature on indices of happiness in persons with severe to profound multiple disabilities is vast (Bat-Haee, 2001; Chambers & Rehfeldt, 2003; Lancioni, Singh, O'Reilly, La Martire, et al., 2006; Singh et al., 2004) and research studies on this topic vary extensively in terms of procedural conditions and methodological approaches, due to characteristics of participants and their daily contexts (Duker & Jutten, 1997; Gutowski, 1996; Helm, 2000).

The present study is aimed to pursue three objectives: (a) to provide a new set-up for two girls with RS exposed to a microswitch-based program, specifically promoting object manipulation and ambulation fluency (Lancioni, Singh, O'Reilly, Sigafoos, Didden, Manfredi, et al., 2009; Sigafoos et al., 2009), (b) to reduce the stereotyped behaviors of the participants (Lancioni, Singh, O'Reilly, & Oliva, 2005), and (c) to monitor the effect of the program on their positive mood (indices of happiness) (Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005).

2. Method

2.1. Participants and settings

Lucie and Emily were 12 and 17 years old and received a diagnosis of RS at 24 and 18 months, respectively. They presented lack of speech, hyperventilation, withdrawal, stereotyped behaviors (i.e., body rocking for Lucie and hand washing for Emily), scoliosis, seizures, epilepsy. They had no awareness of sphincteric needs and showed motor impairments with dystonic movements, although they were able of some step responses in their walker device. Although no formal intellectual quotient score was available and no regular test was feasible due to their general conditions, the clinical observations allowed to rate them in the range of severe to profound intellectual and developmental disabilities. They were recruited by reporting from their general practitioner to the research team and included since they were unable (a) to interact constructively within their environment, and (b) to walk independently.

The study was carried out with two research assistants, in a quiet room at participants' home, where they lived with their parents. They received physiotherapy sessions once a week, and attended regular classes with a special educational trainer and program. They were dependent on others for meeting their basic needs (e.g., feeding, dressing, toileting). They had some vocalizations, limited use of hands, profound deficits in adaptive behaviors. Their families considered the rehabilitation program highly desirable and provided a formal consent for video-recording and data collection of both participants during the study. The Review Board of the Institution approved the study protocol, and the whole study was performed in accordance with the Helsinki Declaration.

2.2. Selection of stimuli

Parents' interviews and a screening preference check (Crawford & Schuster, 1993) served to select preferred stimuli used in this study. Screening involved four to six sessions for both participants with a 10-s presentation of an item suggested by

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