



Technological aids to support choice strategies by three girls with Rett syndrome



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ABSTRACT

This study was aimed at extending the use of assistive technology (i.e. photocells, interface and personal computer) to support choice strategies by three girls with Rett syndrome and severe to profound developmental disabilities. A second purpose of the study was to reduce stereotypic behaviors exhibited by the participants involved (i.e. body rocking, hand washing and hand mouthing). Finally, a third goal of the study was to monitor the effects of such program on the participants' indices of happiness. The study was carried out according to a multiple probe design across responses for each participant. Results showed that the three girls increased the adaptive responses and decreased the stereotyped behaviors during intervention phases compared to baseline. Moreover, during intervention phases, the indices of happiness augmented for each girl as well. Clinical, psychological and rehabilitative implications of the findings are discussed.

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1. Introduction

Rett syndrome (RS) is commonly described as a progressive neurodevelopmental disorder associated with severe to profound developmental disabilities (i.e. intellectual, motor, and communication disorders). It is characterized by a significant loss of speech skills, hand functionalities, ambulation responses, starting between six and eighteen month old, after an apparent normal birth and an initial regular development (Didden et al., 2010; Rett, 1966; Stasolla & Caffò, 2013). RS is traditionally characterized by four main stages (i.e. stagnation, regression, stationary and motor deterioration) (Stasolla et al., 2014d). During stagnation, beginning at 5–6 months old, the child's development is affected by a global arrest. The regression stage, starting between 1 and 4 years old, presents a gradual loss of acquired adaptive functions (i.e. language and social interactions). The third stage (i.e. stationary), having an onset between 2 and 10 years old, emphasizes stereotypic hand movements such as mouthing, washing or clapping, added to breathing and behavioral disturbances (i.e. hyperventilation, crying and laughing). The fourth stage (i.e. motor deterioration) is characterized by a physical decline, decreased stereotypic hand movements, reduced mobility. Apraxia, seizures, scoliosis, general impairments are usually also included in RS' clinical descriptions (Giesbers et al., 2012; Marschik et al., 2013; Matson, Fodstad, & Boisjoli, 2008; Young et al., 2011).

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Children with RS, according to revised criteria by Neul et al. (2010), show severe to profound intellectual disabilities, progressive decline of adaptive behaviors (e.g. the aforementioned loss of speech and locomotion), withdrawal, isolation and passivity (Sigafoos et al., 2009, 2011). Moreover, they are often isolated, with minimal chances to interact positively with their environment and surrounding objects, reduced sensory stimulation, deprivation, with negative consequences on their quality of life (Felce & Perry, 1995; Ivancic & Bayley, 1996). Furthermore, the latter conditions (i.e. deprivation, isolation, passivity and withdrawal) may seriously hamper their social image and status (Lancioni et al., 2014b; Stasolla et al., 2014f).

One way to overcome the latter issue is the use of assistive technology (AT) (Lancioni, Sigafoos, O'Reilly, & Singh, 2012; Lancioni & Singh, 2014). That is, by using technological aids such as sensors and personal computer, one may envisage to improve self-determination, with the opportunity of enhancing occupation, constructive engagement and choice options, almost lacking among children with RS (Lancioni et al., 2014b). Specifically, once the child exhibits an adaptive response (e.g. manipulate an object) detected by the sensor (e.g. a wobble device), it brings usually 8–10 s of preferred stimulation, supplied by the computer, connected to the sensor through an appropriate interface. To design a choice/occupation rehabilitative intervention, the researcher should define at least two behavioral responses, in order to provide the participant with the possibility of varying and choosing among different stimuli, while constructively engaged (Lancioni & Singh, 2014).

The literature on this topic is encouraging, although studies on this field are still limited (Lancioni, O'Reilly, & Campodonico, 2001; Lancioni et al., 2014a,b; Stasolla & Caffò, 2013; Stasolla et al., 2014c). For example, Lancioni et al. (2001) worked on two men with severe visual impairments and profound intellectual disabilities, engaging them in a positive object manipulation, with beneficial outcomes for both participants, as those obtained by Lancioni et al. (2014b), who exposed two participants (a woman with RS and an adolescent with pervasive neuro-developmental impairments and profound intellectual disabilities) to a microswitch-based program, ensuring them with brief periods of positive stimulation (i.e. 10–15 s) contingently to the exhibition of the adaptive responses. Lancioni et al. (2014a) involved two participants (an adult and an adolescent) in a manipulation object program, providing them with the autonomous access to preferred stimulation, through the use of AT, with positive results. Stasolla and Caffò (2013) recruited two girls with RS for a microswitch-based program aimed at promoting adaptive responses (i.e. object manipulation and locomotion fluency), and demonstrated learning abilities for both participants. Recently, Stasolla et al. (2014c) worked with two boys affected by fragile X syndrome, involving them in an occupational/rehabilitative intervention, through the use of AT, with encouraging effects on stereotypic behaviors and positive mood concerning both participants.

The present study pursues three main objectives: (a) further extending (i.e. in terms of participants involved and adopted responses) the use of AT providing a new setup for three girls with RS and severe to profound intellectual and developmental disabilities, in order to attempt of supporting constructive engagement, occupation and choices strategies, (b) assess its rehabilitative effects by reducing stereotypic behaviors (i.e. body rocking, hand mouthing, hand washing), and (c) monitor the outcomes on positive mood (i.e. indices of happiness) of participants.

2. Method

2.1. Participants and setting

The participants (Angie, Lauren and Pauline) were 9.6, 12.4 and 10.5 years old (mean age 10.83) at the beginning of the study and received a RS diagnosis when they were 12, 15 and 18 months old respectively. They presented withdrawal, isolation, passivity, lack of speech, unawareness of sphincter control, stereotyped behaviors (i.e. body rocking for Angie, hand mouthing for Lauren, and hand washing for Pauline). All of them failed in the autonomous locomotion and were equipped with a wheelchair. Although no formal IQ score was available since no test was feasible, due to their characteristics, they were all estimated within the range of severe to profound developmental and intellectual disabilities from clinical observation. Moreover, although all participants exhibited hand-related stereotypic behaviors, they were still able to pick up familiar objects surrounding them, at least with one hand, if adequately interested and motivated to achieve this goal, as reported by their parents.

The participants attended regular classes with a special training. During the afternoon, Angie received speech sessions twice a week, Lauren was provided with stimulation session three days per week, and Pauline attended a rehabilitative center, where she followed a physiotherapeutic program twice a week. The study was carried out in a quiet room of participants' home, where they lived with their parents. Furthermore, during all sessions, the girls were sited in front of a 240 cm × 90 cm table, where three different squared wicker containers are available during the fifth intervention phase (see below Section 2.5). They were all recruited and reported to the research team by their neurologist. Their families considered the AT-based program high desirable for their children, in order to promote occupation, constructive engagement and choice strategies, added to prevent deprivation, passivity and saturation. In fact, they all signed a formal consent for the participation of Angie, Lauren and Pauline to the rehabilitative program, which was approved by a local ethic and scientific committee.

2.2. Selection of stimuli

Matched to an informal parents' interview, a formal screening preference of stimuli was assessed (Crawford & Schuster, 1993). That is, 4 to 6 10 min sessions were carried out for each participant. Thus, within each session, a 8–10 s presentation of

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