

ARTICLE

Using Sounds of Intent (SOI) to evaluate the impact of music therapy on girls with Rett Syndrome

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ABSTRACT

In this article, we discuss the importance of music therapy in the development and evaluation of skills in girls with Rett Syndrome. The intention of this study was to collect and analyse data in order to empirically contribute to a mapping of the individual sound-musical development profile of girls with Rett syndrome. The study proceeded with the translation, adaptation, and implementation in the Portuguese context, of a specific music programme, Sounds of Intent (SOI). It was intended to measure target distal, proximal, cognitive and emotional behaviours in girls with Rett syndrome. Longitudinal action research with multiple case-study methodology was carried out, assuming a qualitative nature. This article is focused on the two Rett syndrome case studies that were part of a larger sample with multiple diagnoses. An instrument for data collection was also used, namely matrices of development designed to evaluate this type of intervention and documental analysis process. The results suggest that it is possible to systematically observe and evaluate the development of girls with Rett syndrome over a given period of time through the manifestation of sound-musical behaviour using a programme such as SOI. The data collected through the grid and the concentric profile of the subjects demonstrated a wide variety of sound-musical manifestations throughout the intervention period. Both girls demonstrated different levels of progress with regard to their musical behaviours. The data analysis demonstrated that there was regression and development in the sound-musical behaviours of the clients, both clients showed consistency and high level of involvement during the sessions, sound-musical behaviours have been revealed mostly in the interactive domain and the sound-musical behaviours observed developed towards more complex musical behaviours over time.

KEYWORDS

music therapy,
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INTRODUCTION

Research has demonstrated that music has a direct relationship with, and influence in, the human body (Gordon, 2000; Sacks, 2008), making it possible, among other things, to evaluate the physical, psychological and emotional growth of the child (Pocinho, 1999). Music can also play an important role in the development of musical and non-musical skills in the child with special needs (Elefant & Wigram, 2005; Nordoff-Robbins, 1965; Ockelford, 2000; Raine, 2003; Welch, Ockelford & Zimmermann, 2001; Wigram & Backer, 1999).

Music therapy has a relevant role with girls diagnosed with Rett Syndrome. Joining a multidisciplinary approach with other important complementary therapies, music therapy not only provides complementary diagnostic and evaluation information but also facilitates and evokes behavioural manifestations in the individual, contributing to their communication and socio-relational processes (Chou et al., 2019; Elefant & Lotan, 2006; Yasuhara & Sugiyama, 2001). According to Wigram and Laurence (2005), the main direction of music therapy assessment (and treatment) is to develop communicative potential, attention, motivate, and develop functional hand use, social behaviour, and facilitate emotional expression.

The purpose of the research presented in this article was to understand how the sound-musical expression, through the use of a music therapy intervention, contributes to the evaluation, maintenance, and development of competencies, such as musical, cognitive and emotional behaviours, of children with Rett syndrome. This article presents the results of a longitudinal research study centred on the development and evaluation processes of two case studies of clients diagnosed with Rett syndrome through the use of music therapy sessions, using as an assessment instrument the Sounds of Intent (SOI) programme.

LITERATURE REVIEW

Rett syndrome is a rare (0.01%) girl-specific genetic developmental disorder severely affecting physical and mental abilities (Andziule, Aleksien & Lesinskiene, 2018). Rett syndrome has a genetic origin – mutations in the MECP2 gene, which is located on the X chromosome and is responsible for the production of a protein necessary to maintain brain development and functions (Andziule, Aleksien & Lesinskiene, 2018; Chahrour & Zoghbi, 2007; Percy, 2011). This syndrome is characterised by the deterioration of behavioural, social, cognitive, communicative, and functional skills to a profound level.

The development of Rett syndrome is characterised by four stages (IRSA, 1997):

- Stage I (Onset Stage): It appears after a seemingly normal to almost-normal period of development (from 6-18 months). This is the period when symptoms of Rett syndrome may arise, such as the delay in the normal development of gross motor frames. This period is quite short and can last from a few weeks to a few months.
- Stage II (Rapid Destructive Stage): During this period there is a rapid (or, in some cases, more gradual) regression in which the child loses acquired speech and deliberate hand movements. This stage appears between the ages of one to four years, and can last from a few weeks to several months.

- Stage III (Plateau Stage): This phase is long and fairly stable, and can last for many years. Seizures, apraxia, and motor problems are more prominent, but the child seems less irritable, more alert and interested. This is the period when the child may be more receptive to learning. The introduction and development of non-verbal communication strategies will become effective and useful from this stage.
- Stage IV (Late Motor Decay Stage): This period begins at the age of ten and is characterised by reduced mobility and loss of ambulation, but there is no decline in cognitive, communicative, or manual skills and scoliosis is a prominent feature

There is no cure to Rett syndrome, but a treatment provided by several therapies (music therapy, occupational therapy, physiotherapy, speech therapy, and hydrotherapy) seems to relieve and to improve the patient's symptoms (Elefant & Lotan, 2006; Hunter, 1999).

Andreas Rett (1966) noticed that music could break the barrier of difficulties, and at the same time revealed the hidden capabilities of patients with Rett syndrome (Chahrour & Zoghbi, 2007). Also, according to Hunter (2007), individuals with Rett syndrome are particularly fond of music. By using music as their strength, one can contribute to the smoother development and education of these patients, because learning new things is easier when the learning content is presented in an interesting way and the process is engaging (Hunter, 2007). Music helps individuals with Rett syndrome to understand and express themselves in the first place, as well as their surrounding environment and relationships with people (Merker et al., 2001; Trevarthen & Burford, 2001).

Music therapy nonetheless has an exclusive role in the list of therapies for individuals with Rett syndrome. It was recommended by Andreas Rett as a useful intervention for reducing stereotypic hand movements, shortening response time, muscle tension, arousing interest, and stimulating the sensory system (Andziule, Aleksien & Lesinskiene, 2018). Girls with Rett syndrome are sensitive, receptive to musical sounds, able to recognise and associate them with events, so music therapy can be particularly successful in promoting and motivating communication with the social environment (Elefant & Lotan, 2004). A doctoral study designed to investigate intentional communication in this population through the use of songs in music therapy demonstrated that individuals with Rett syndrome could be motivated to communicate and learn when therapeutically employed by a trained music therapist who is familiar with this group of clients (Elefant & Wigram, 2005).

According Andziule, Aleksien and Lesinskiene (2018), the results of an internationally conducted questionnaire survey indicate that the most often-applied and the most effective music therapy methods and techniques for patients with Rett Syndrome include: structured musical games using musical instruments of interesting texture, different timbre, and varying touch pattern; selection of songs and instrumental music pieces using pictures or other symbols; listening to songs or short instrumental pieces and motivating a child to purposefully fill in a pause with a musical instrument or to clap hands when a basic beat is heard, or the like. These music therapy methods are indicative, aiming at functional use of hands and strengthening of other motor skills; also an improvement of non-verbal communication and experiencing joy and pleasure. The music therapists' survey did not prove the hypothesis on the applicability/suitability of improvisational music therapy methods for the reduction of stereotypic hand movements.

Research has proved music therapy to have a positive effect in improving these children's capacity for social and preverbal skills such as initiative, response, imitation, vocalisation, and turn-taking (Aldridge, Gustorff & Neugebauer, 1995; Bunt, 1994; Edgerton, 1994; Elefant, 2002; Müller & Warwick, 1993; Oldfield, 2003; Plahl, 2000). Besides intensive research and findings about Rett syndrome over time, there is no known remedy that can repair the genetic fault of Rett syndrome. Some medical solutions have succeeded in alleviating symptoms connected to Rett syndrome during pre-, peri-, or postnatal periods, and subsequent medical treatment that will improve the physical condition and the functional abilities in this population (apart from the anti-epileptic medication for patients with seizure symptoms) (Elefant, 2002). However, different types of therapy are likely to be very important for any potential improvement, and even the slowing of deterioration (Elefant, 2002). Some researchers believe that knowledgeable therapy might change the course of Rett syndrome (Jacobsen, Viken & von Tetchner, 2001).

Music therapy has a relevant role with girls diagnosed with Rett syndrome, joining a multidisciplinary approach with other important complementary therapies. The inclusion of this type of intervention in multidisciplinary teams not only provides complementary diagnostic and evaluation information, but also facilitates and evokes behavioural manifestations in the individual, contributing to their communication and socio-relational processes.

The SOI programme

The Sounds of Intent (SOI) programme provides a curricular basis for planning which allows for evaluating the results and progress of sound-musical behaviours in children and youngsters with special educational needs (SEN) (Cheng, Ockelford & Welch, 2009). The programme consists of three domains of musical involvement (Reactive [R], Proactive [P], and Interactive [I]) that are presented through a series of concentric circles (Figure 1). In particular, the reactive domain corresponds to the ability to listen and respond to musical stimuli; the proactive domain denotes causing, creating, and controlling music and sound-musical instruments; the third dimension of the concentric frame, the interactive domain, concerns the ability to communicate and dialogue, to hear sounds and produce them together with other element(s) (Ockelford, 2008).

The SOI programme identifies six major success levels as key elements for the recognition and understanding of the musical development that children with multi-deficiency are prone to follow. The programme is based on the typical characteristics of early musical development, to map the structure of the SOI programme (Cheng, 2010).

Each domain has six levels to depict different levels of achievement, involvement, or experience, and to illustrate the important contingent relationships between them.

The SOI framework attempts to portray "[...] the notion of growth/development as a small inner core for a wider and more external world" (Ockelford, 2008, p.81). This idea is portrayed in the concentric frame of musical development and evaluation that the programme features. For each level (one to six), in each domain (R, P, I), there are four back elements (A, B, C, and D) that serve as examples for the researcher to identify various sound-musical relevant information.

SOI users can assess and measure levels of involvement and consistency of participants within each element of the SOI structure over a period of time. This process allows observing the evolution of the participant in each SOI element.

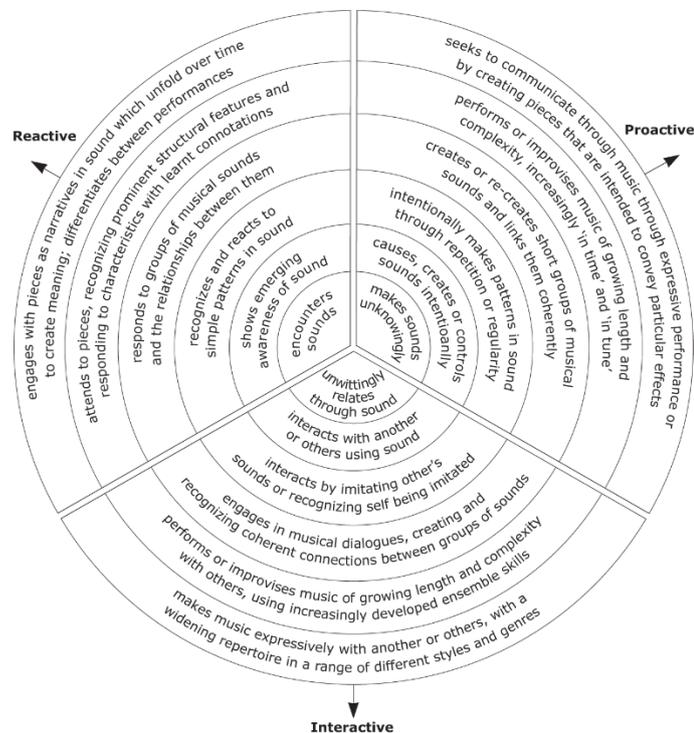


Figure1: Concentric frame for evaluation and development of the SOI programme (Ockelford, 2008, p. 393)

METHOD

Design and data

The research question of the present study was: How can the sound-musical expression, through a music therapy intervention, contribute to evaluation, maintenance and development competencies such as musical, cognitive, and emotional behaviours of children with Rett syndrome?

In this way, the SOI programme was implemented in music therapy sessions for the evaluation of skills and sound-musical development over a period of 23 weeks of intervention (this period was chosen according to the school-year calendar) in order to evaluate the musical, socio-relational, motor, and communicational behaviours in two girls diagnosed with Rett syndrome. Musical improvisational techniques were used, such as playing, vocalising, and singing traditional children's songs that were relevant to each participant.

The aim was to develop the following methodological approaches:

- a) In a theoretical dimension, implement the SOI programme in order to get answers to the questions asked;

b) Use a case-study approach, through the action-research method, with incorporated fieldwork, which focuses on the musical behaviours observed and the development and evaluation during a period of 23 weeks, allowing a descriptive and comparative analysis between the participants.

The present study adopted a qualitative research approach, focusing on the experience and the subjective outcome of the participants. The researcher was an active participant in the context of the research, becoming an active part of the observed field.

Action research was the methodology applied, due to the character and design of the research as a systematic, practice-oriented process. The action occurred on a realistic level and was always followed by a self-critical and objective reflection and evaluation of the results, based on the triangle: action, research, and training (Kember, 2000; McNiff, 2002; Zuber-Skerrit, 2005).

The technique adopted for the data-elaboration process was content analysis (Bardin, 1977; Bogdan & Biklen, 1994). The main sources of data collection on both case studies were based on fieldwork, school context, weekly observations, audio and video recordings; interviews with teachers and technicians from the multidisciplinary team; information obtained through the diagnosis reports and school documentation about the clients; a survey about the sonorous identity (Benenzon, 1985) of each client.

In the present research, the process of data collection and analysis of the case studies is performed in a systematic way. The design of the case studies is based on the theoretical and methodological orientation of the SOI programme, through the use of the evaluation frameworks and grids that register the evolution of the different subjects' behaviours during the 23 weeks of the intervention. The specific techniques used for the analysis of the case studies were the analysis of the development profile of each client, temporal analysis, the development of the client over time, as well as a comparison with data obtained through the grids and tables of evolution and development.

Participants and consent

The sample consists of four-year-old twin girls with Rett syndrome who attended a private Structured Teaching Unit (UEE), in Lisbon, Portugal. Both clients had several co-morbidities associated with their diagnosis, such as epilepsy, spasticity usually associated with muscle weakness and dystonia, respiratory dysfunction, hyperventilation, language and communication impairments (they are non-verbal), motor impairment, stereotypies, socio-relational, emotional, and hand-functional disturbances. The clients also attend other complementary therapies weekly, such as physiotherapy, occupational therapy, and hydrotherapy. The study was approved by the scientific committee of the Instituto Superior de Psicologia Aplicada.

CASE STUDIES

The two girls had individual music therapy sessions during the 23-week intervention period. The sessions occurred once a week, with a duration of 30-45 minutes for each participant. The interventions occurred in the same context, an educational context, with the same music therapist.

The assessment instruments used were the SOI programme instruments, which included the concentric frame, a session form (which evaluated the receptive, proactive and interactive behaviours of the clients in a quantitative way) and a registration form, (where the behaviours observed in every session were registered in a qualitative way). The data obtained throughout the 23 sessions were also collected through the use of a camera, which provided greater acuity of analysis of the session and the behaviours observed. The collected data were extracted by the music therapist.

The sessions had the same structure: introduction ("Hello song"), development and conclusion ("Goodbye song"). The music therapist used musical improvisational techniques; playing, vocalising, and singing songs that were relevant to the musical sonorous identity (ISO; Benenzon, 1988) of each participant.

Various sound-musical materials were used, selected according to the interest shown by the clients. In the sessions, a piano, an acoustic guitar, several Orff instruments (clubs, castanets, Chinese box, reco-reco, xylophone, shakers, maracas, tambourines), bells, drums, ethnic percussion instruments, an ocean drum, a rain stick, a microphone and a cajón were used with both clients. In the setting, there are also cards with augmentative communication images, some of which are personalised to each client, which are associated with moments, objects, people, and feelings.

The levels of involvement and consistency of the musical behaviours of each participant were also being evaluated in each session, through the use of a camera and the collecting of data later on. The intervention took place in an educational setting. The intervention space was a room with abundant natural light. The floor was cushioned with foam plates. There was a rectangular table for children and two chairs in a corner of the room. The researcher (first author) had the role of active participant.

Case study M

At intervention initiation, M was four years old. The social-relational area seems to be a strong area in M. In the sessions (session 1 to 23), M reveals herself to be very expressive and empathic, especially with eye gaze, relating and being musically with the therapist. Guitar and singing are facilitators of this process since they arouse great interest and curiosity in M. M did not show great interest in exploring and discovering the various instruments available in session, focusing and becoming fascinated only by the guitar, despite several attempts to introduce new and different sonorities. The guitar has been mediating the relation of M with the therapist, since it provides processes of socio-relational activation. The level of involvement of M, both in relation and in music, is total; concentrating during the entire music therapy session (30 to 45 minutes). With regard to the cognitive aspect, the expressiveness of M allows the possibility of recognising the positive and negative responses to the musical activities. M communicates through motor activation, facial and vocal expression, and sometimes through the triggering of stereotypy (as a way of communicating excitement or feelings of anxiety).

She shows intentional will and attempts to vocalise sounds and participation in musical dialogues through songs. She recognises known and already-sung songs, and there is physical activation in M when this happens. M carefully observes and listens to the musicality being played and sung. She easily engages and "requires", vocally, more rhythm or intensity.

In the start of the therapy, M already sang in question-answer mode, without delay, emitting vowel sounds (/ and // a // i // mmm /); recognises and temporarily identifies the sequence of actions in the songs as well as body parts (e.g., clapping, wiggling, singing, dancing). Currently, she has some delay in the corporal response and, sometimes, incapacity in the vocal response, despite the effort and visible intentionality. M effectively differentiates the singing from the speech in her tone of voice.

M does not associate the images of the songs with them, nor does she demonstrate the autonomy to choose what to sing in the sessions. However, her involvement in the process is total, being always in relation and visual contact with the therapist and with the music.

Regarding the motor aspect, M particularly likes to clap hands. In some songs, with enthusiasm, she claps of her own accord and likes it when others clap. There is a process of motor and relational activation with the songs "Hello M," "The Cat," "The Ball," and songs created/improvised about/with M. During the session, when she feels like it, she gets up alone to go dancing, later needing help to sit down. She presents stability and some balance, being able to differentiate dance/balance for a few minutes).

Profile of M

According to the data obtained through the application of the instruments, it is possible to verify M's sound-musical profile. Through the sound-musical behaviours manifested by M and classified in the respective domains (reactive, proactive, and interactive) it is verified that M mainly reveals sound-musical behaviours in the interactive domain. Her level of involvement is high, mostly at level 5; and the sound-musical behaviour of M shows some consistency, assessed between level 3 and 4.

M interacts with others through sound, and it is in this parameter that more of the same behavioural observations are recorded throughout the intervention period. The client finds herself developing the notion of the "I" and the "other" through sound, eventually occurring during a period of interaction between M and the music therapist.

M makes sounds in response to sounds produced by the "other." Her form of response is through vocalisation. She never resorts to musical instruments. Her expression and form of communication are essentially corporeal; through eye contact, body movement, stereotyping, and vocalisations. She likes to hear singing and to sing; easily engaging in what is happening at a certain musical-sounding moment.

Overall, data analysis demonstrated that there was regression and development in the musical behaviours of M in the three domains. However, two domains, reactive and proactive, showed progress in the musical behaviour of M in the final period of the intervention.

In the reactive and interactive domains, the musical behaviours observed in M moved towards more complex musical behaviours, with a regression to the manifestation of simpler musical behaviours from the fifteenth session until the end. The level of sound-musical behavioural consistency presented by M in the reactive, proactive, and interactive domains during the 23 weeks of intervention was on level 1 in the first two sessions. In the remaining sessions, it oscillated between levels 3 and 4 (on a scale of 1 to 5). It was in the interactive domain that the highest levels of sound-musical behavioural consistency were recorded. The levels of M's involvement were always high in all three domains.

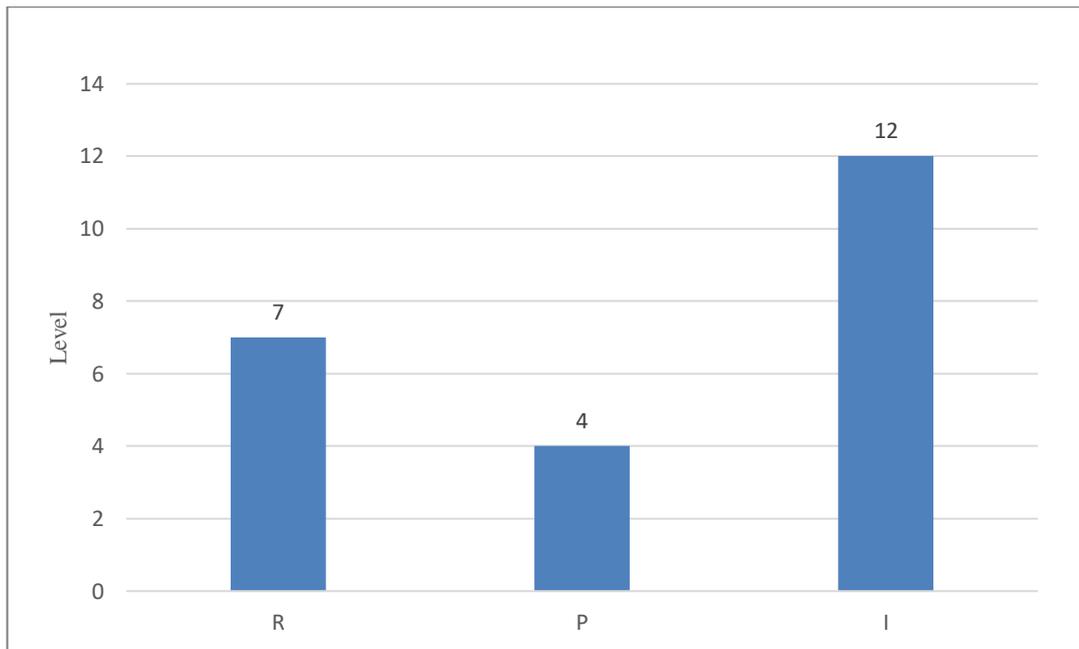


Figure 2: Sound-musical behavioural observations of M recorded in the reactive (R), proactive (P) and interactive (I) domains, during the 23 weeks of research.

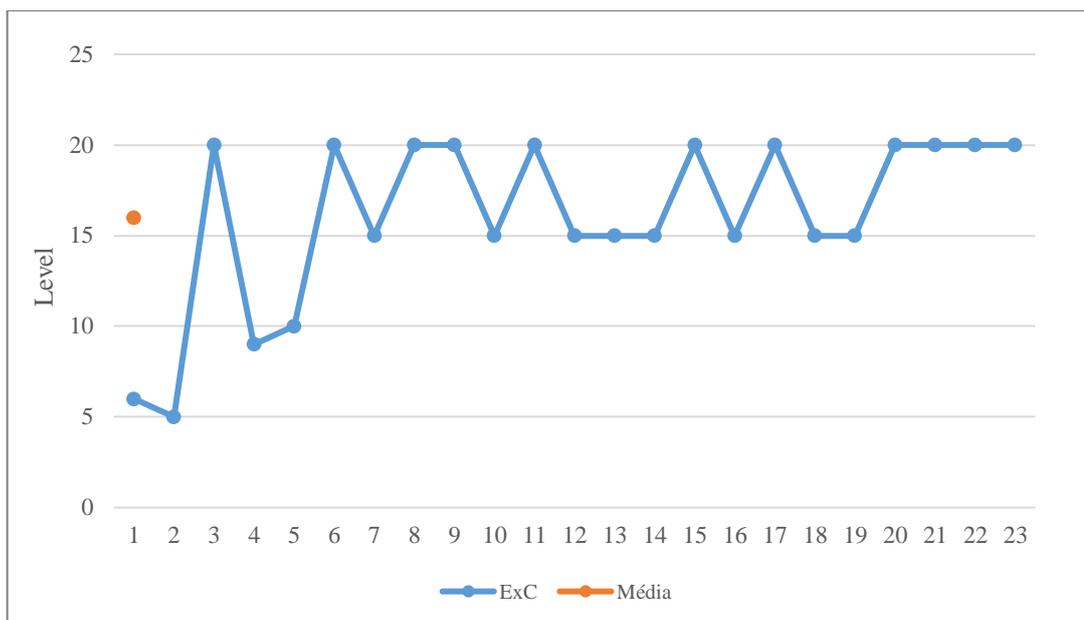


Figure 3: Chart corresponding to the measure (minimum score = 0 and maximum = 25) of the levels of consistency and sound-musical involvement of M (consistency level (C) x level involvement (E)), over 23 weeks of intervention.

CASE STUDY L

L was four years old. During the sessions, eye contact has increased in quantity and duration, albeit temporarily. In sessions, L engages in music, relates to, and interacts with, the other through the exploration of vocal singing, stories/sung jokes, and the musical game of question-answer. She emits

vocalisations, although currently less. This decrease can also be associated with growth and, as such, greater awareness and sound consciousness on the part of L. She manifests her musical preferences during the session, through motivation, vocalisation, and participation. These behaviours are associated with hand-stimuli increase, stereotypies, body, and leg movement. In the last weeks of the intervention period, L's involvement decreased, and the level of concentration became shorter. She was emotionally more sensitive, and that emotional state was transmitted through different kinds of vocalisations, so the session format and dynamic were slightly altered.

Regarding the cognitive aspect, the facial and vocal expressiveness of L allows the recognition of positive and negative responses to musical activities. L communicates through body activation, facial expression, vocalisation and sometimes the triggering of stereotypy.

She shows intentional will, attempts to vocalise sounds and participates in musical dialogues through songs. She recognises known songs, and there is a positive body response in L when this happens. The sessions with L have different sound dynamics throughout the session.

L temporarily focuses on the action but after a while loses interest and complains. Although she participates in the songs, showing understanding and learning competencies in a cognitive way (for example, in songs with sequential actions, clapping hands, identifying parts of the body), sometimes she shows an 'apparent' disinterest during the session.

At motor level, in some songs, L enthusiastically claps her hands in an intentional way and likes when others do it too. She also dances. There is an increase in her body movement. It is possible to differentiate the stereotypy of the intentional movement. She likes to have the freedom of her body to dance and to move around the room to the rhythm of the music. She has instability and motor imbalance. During the session, she rises alone from her chair to go dancing.

L presents strong stereotypies (clapping), and bites her hand in moments of greater insecurity and excitement. The intervention took place in the same space as the sessions of the M case study.

Profile of L

According to the data analysis, through the use of the instruments of analysis, it is observed that L reveals a profile with sound-musical behaviours manifested essentially in the proactive and interactive domain. Despite her non-verbal communication, communicative and relational sound-musical behaviours were observed.

The levels of involvement and consistency in the musical-sound behaviours manifested by L, throughout the intervention, are significant, at level 4. The sound-musical expression provided L an alternative way of communicating and expressing her intentions, a complementary form of communication and development resource in the work with L.

A developmental and cognitive evolution was observed regarding intentionality as, initially, the register of behaviours, which were essentially reactive to a stimulus, would, from the fifth session on, appear to be intentional manifestations on the part of L in the proactive domain.

Her instrument is the voice; using sound vocalisation to respond, whether intentionally or reflexively, to the therapist. Percussion instruments are used, but not on her own initiative. She likes to move around the room (also as a form of energy-channelling, given the stimuli she is receiving) during the sessions, instead of sitting. Her muscular tone still allows it, despite the imbalance. She

does not make eye contact many times, two to three times per session and during a short period, but "is" in the session.

On the scale of 0 to 25, her level of involvement and consistency in sound-musical manifestations is 16. Overall, data analysis demonstrated that there was some progression in the musical behaviours of L in the three domains. The proactive and interactive domains showed progress in the musical behaviour of L in the final period of the intervention. The musical behaviours observed in L developed towards more complex musical behaviours in the three domains. Levels of involvement and consistency remained high throughout the intervention period.

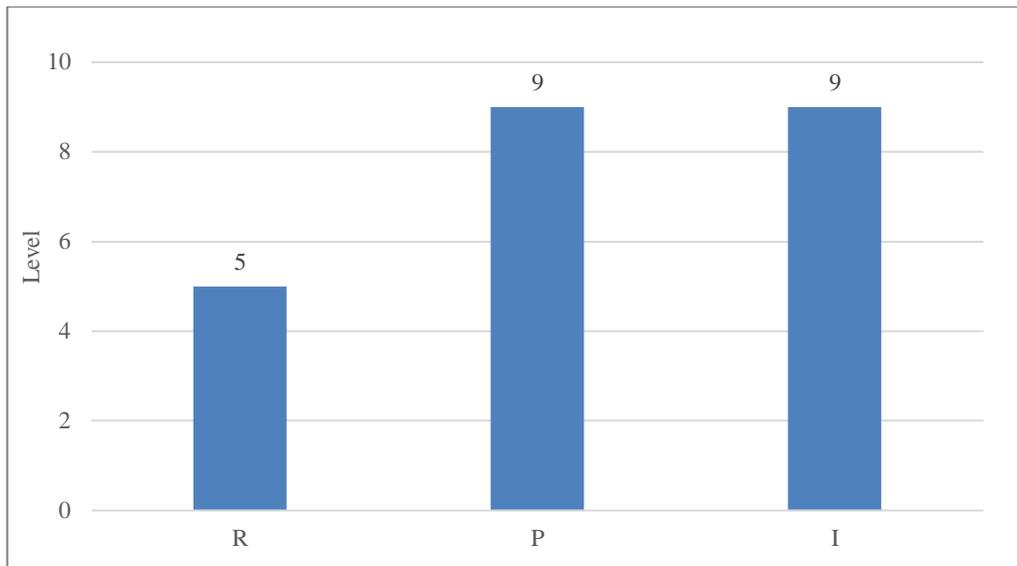


Figure 4: Behavioural observations of L recorded in the reactive (R), proactive (P) and interactive (I) domains, during the 23 weeks of research.

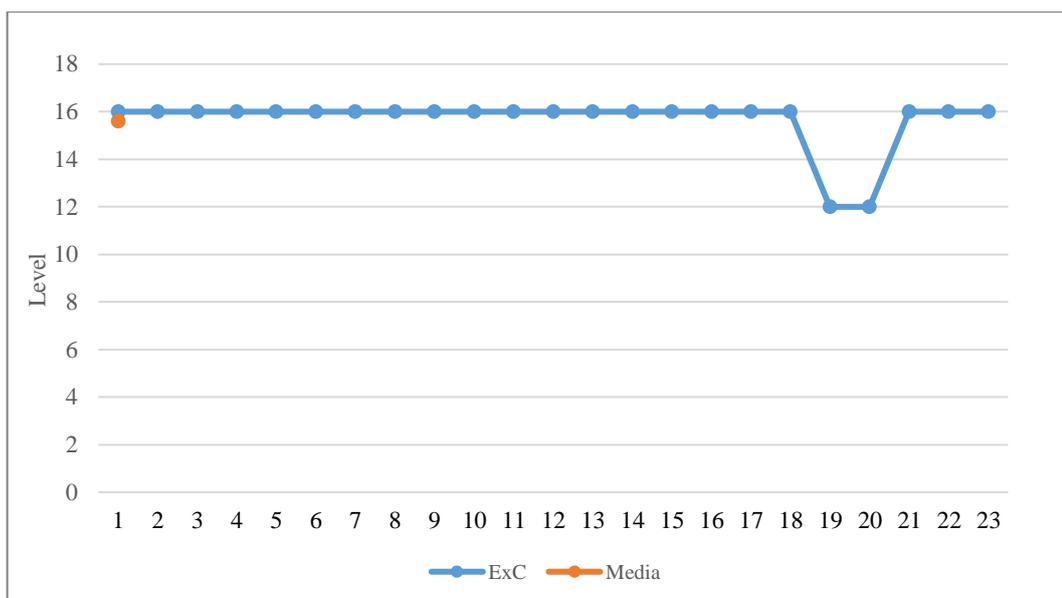


Figure 5: Correspondence frame (minimum score = 0 and maximum score = 25) of the levels of consistency and sound-musical involvement of L (level of consistency (C) x level of involvement (E)), over 23 weeks of intervention.

DISCUSSION

The research question of the present investigation was: How can the sound-musical expression, through a music therapy intervention, contribute to evaluation, maintenance and development competencies such as musical, cognitive, and emotional behaviours of children with Rett syndrome? Data analysis shows that the use of music and the sound-musical expression in children with Rett syndrome can contribute to the development, maintenance and evaluation of competences and sound-musical behaviours. It may also encourage intentional processes of verbal and non-verbal communication, motor, cognitive and socio-relational skills, as well as records of development in the behaviours of the participants, at the level of expressive and receptive communication. It was possible to verify indices of development in the sound-musical behaviours of the subjects as well as the maintenance of competences.

In this study, major findings suggest that it is possible to evaluate, maintain and develop skills in children with Rett syndrome, through the sound-musical expression and the use of the SOI programme. Demonstrations of reactive, proactive and interactive behaviours, closely related to areas of cognitive, motor, communicative and socio-relational development, were evolved and evaluated.

In conjunction with Sigafos' analysis (2000), all behaviours can be defined as non-conventional forms of communication, and as a form of "Potential Communicative Act." As the majority of individuals with Rett Syndrome are not verbal communicators, some information can be drawn from their emotional and physical behaviours (Elefant, 2002).

Elefant (2002) categorises the Rett syndrome behaviours by dividing them into three sections: emotional, communicative, and pathological.

1. The emotional behaviours can be categorised as smiling, laughing, frowning, crying, moaning, shouting, and vocalisation;
2. The communicative behaviours can be categorised as body movement (rocking), leg movement, eye contact, looking away, eye shifting, closure of eyes, leaving the seat, walking towards exit door, returning to seat, leaning forward, leaning back, pushing picture symbols away, leaning hands on researcher, putting leg on researcher, and opening/closure of mouth;
3. The pathological behaviours can be categorised as hand movement, teeth-grinding, and hyperventilation. Change in facial colour could fall into either pathological or emotional behaviour, depending on whether it reflected raised anxiety or raised excitement respectively.

In this research, the SOI programme analysed the sound-musical behaviours, which evaluated and developed the emotional and communicative abilities through sound-musical expression and, at the same time, allowed the analysis of the pathological behaviours from a receptive, proactive, and interactive perspective. The fact it is an instrument with the purpose of evaluating a client through his or her sound-musical behaviours and intent makes it accessible in the assessment of clients with non-verbal communication and with diagnoses of neurodevelopmental disorders. The possibility of verification, through the concentric grid, of the predominant pattern of the patient's development over a period of time is a useful tool in the evaluation and perception of the behavioural tendency of the patients. It also allows reflection and analysis of the behaviours observed in each session (through registration in session forms, concentric grid and video-viewing) and not only after a certain period of

time, or in the end of the intervention. The SOI programme contributes in a relevant way to a consolidation and perception of the evolution of the patients' development. The SOI programme also functioned as a continuous aid in training the technician, providing practical suggestions for intervention in the context with clients.

It was apparent from the findings of this research that both girls from the case studies improved their abilities over time. This finding has also been reported in previous research with Rett syndrome population (Elefant, 2002; Wigram, 1995). Due to repetition and practice, it is evident that abilities (after being achieved) can be sustained over periods of time (Elefant, 2002). According to the literature (Elefant, 2002; Wigram, 1995; Yasuhara & Sugiyama, 2001), it is suggested that music, and songs in particular, have an important role in revealing such potential in a population that until not long ago was thought of as uneducable, considered as mentally weak, and with pre-intentional communication.

In this research, it was interesting to observe the way that the girls intentionally and consistently (consciously or unconsciously) moved their body to indicate a communicative act or response to the stimuli. This happened during songs, especially favourite songs, through excitement behaviours and an increase of the hand-movement stereotypy as well as a change in breathing patterns (to hyperventilation). Sigafos et al. (2000) also noted that the girls in their study exhibited high levels of eye-gaze, hyperventilation, and stereotypical hand movements. These behaviours occurred during social interaction moments. Their findings are similar to the ones in this study. This behaviour is presented in other literature on Rett syndrome (Lindberg, 1991; Hunter 1999), suggesting that in this population stereotypical hand movement may represent inner feelings.

The eye contact during musical interaction coincides with Wigram's (1991) and Elefant's (2002) reports, where they mention that girls maintain very good eye contact during music therapy sessions.

The girls' emotional responses were reflected in their behaviour through excitement, laughing, increase of body movement, and vocalisation. These emotional responses coincide with Latchford (in Trevarthen & Burford, 1995) and Elefant (2002), who implied that even severely impaired children react appropriately by smiling and laughing when being joked with or teased. Despite the disability, they are left with some level of intact emotions at a subtle level.

One of the emotional responses is made through vocalisation. In this study, the girls reacted through vocalisation in an alternative way (Stern, 1975). It is curious to note that the vocalisation never/rarely occurred coactively (singing together at the same time). Instead, the girls were always focused on the therapist when she sang. One of the girls, M, always seemed to be concentrated and focused while hearing the songs (favourite ones or new ones). Silent moments were considered to be very important, giving the girls the space and time that was needed for them to have the initiative to start to vocalise. According to Elefant (2002), in order to enhance vocalisation, it is recommended to give ample space and time for the girl to respond either in pre-composed songs or in improvised activities.

Elefant (2002) had similar findings in her study and mentioned Clair (1996, in Elefant, 2002), who also reported identical findings in a study with the population of senile dementia. In that study, the participants kept quiet whenever the researcher was talking or singing, and initiated verbalisation only when there was silence. Elefant (2002) emphasises that, with an attentive cooperative child, a good rapport between child and researcher, a familiar situation, and strong motivational factors will facilitate positive outcomes.

CONCLUSIONS

The research literature (Elefant, 2002; Wigram, 1995; Yasuhara & Sugiyama, 2001) shows that it is important to identify emotional reactions and different behaviours that can be interpreted as communicative attempts. Recognition of these behaviours and understanding their intended meaning will increase shared understanding. According to Sigafos et al. (2000) and Elefant (2002), there is also a danger that when a child's needs and wishes go unrecognised, withdrawal or more problematic behaviours might appear.

This research showed intentional, emotional, communicative, and social behaviours from girls with Rett syndrome, manifested through sound-musical stimuli. Similar pieces of evidence were also found in previous research. Further research is needed in order to support theoretical fundamentals on music therapy intervention with this population.

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Ελληνική περίληψη | Greek abstract

Η χρήση του Sounds of Intent (SOI) για την αξιολόγηση της επίδρασης της μουσικοθεραπείας σε κορίτσια με σύνδρομο Rett

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ΠΕΡΙΛΗΨΗ

Σε αυτό το άρθρο συζητάμε τη σημασία της μουσικοθεραπείας στην ανάπτυξη και την αξιολόγηση των δεξιοτήτων κοριτσιών με σύνδρομο Rett. Σκοπός αυτής της μελέτης ήταν η συλλογή και η ανάλυση δεδομένων με στόχο την επίτευξη μιας εμπειρικής χαρτογράφησης του ατομικού προφίλ της ηχητικο-μουσικής εξέλιξης των κοριτσιών αυτών. Η μελέτη προχώρησε στη μετάφραση, την προσαρμογή και την υλοποίηση ενός συγκεκριμένου μουσικού προγράμματος, του Sounds of Intent (SOI), στην Πορτογαλία. Η έρευνα αποσκοπούσε στο να μετρήσει την απόκλιση από τους στόχους, την εγγύτητα και τις γνωστικές και συναισθηματικές συμπεριφορές κοριτσιών με σύνδρομο Rett. Η έρευνα που πραγματοποιήθηκε είχε ποιοτικό χαρακτήρα: πρόκειται για μια έρευνα διαχρονικής δράσης με πολλαπλές μεθοδολογίες μελέτης περιπτώσεων. Αυτό το άρθρο επικεντρώνεται στις δύο περιπτώσιολογικές μελέτες κοριτσιών με σύνδρομο Rett που αποτελούν μέρος ενός μεγαλύτερου δείγματος με πολλαπλές διαγνώσεις. Επιπλέον, ως εργαλείο συλλογής δεδομένων χρησιμοποιήθηκαν οι αναπτυξιακές μήτρες [matrices of development] που αποσκοπούν στην αξιολόγηση αυτού του είδους της παρέμβασης και της διαδικασίας τεκμηρίωσής της. Τα αποτελέσματα υποδεικνύουν ότι η συστηματική παρακολούθηση και αξιολόγηση της ανάπτυξης των κοριτσιών με σύνδρομο Rett σε μια δεδομένη χρονική περίοδο είναι εφικτή μέσω της εκδήλωσης της ηχητικο-μουσικής συμπεριφοράς τους όπως αυτή καταγράφεται με ένα πρόγραμμα όπως το SOI. Τα δεδομένα που συλλέχθηκαν μέσα από μια πλεγματική και ομοκεντρική σκιαγράφηση/προσέγγιση του προφίλ των υποκειμένων έδειξαν μια ευρεία ποικιλία ηχητικο-μουσικών εκφάνσεων καθ' όλη την περίοδο παρέμβασης. Όσον αφορά τις μουσικές τους συμπεριφορές, και τα δύο κορίτσια παρουσίασαν διαφορετικά επίπεδα προόδου. Η ανάλυση των δεδομένων έδειξε ότι υπήρξε παλινδρόμηση και ανάπτυξη στις ηχητικο-μουσικές συμπεριφορές των πελατισσών, ενώ οι δύο πελάτισσες έδειξαν συνέπεια και υψηλό επίπεδο συμμετοχής κατά τη διάρκεια των συνεδριών. Οι ηχητικο-μουσικές συμπεριφορές τους αναδείχθηκαν κυρίως σε διαδραστικό επίπεδο και εξελίχθηκαν σε πιο πολύπλοκες μουσικές συμπεριφορές με την πάροδο του χρόνου.

ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

μουσικοθεραπεία, σύνδρομο Rett, έρευνα δράσης, μελέτη περίπτωσης