Physiotherapy and music therapy for a girl with Rett Syndrome

- a dual treatment approach

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Introduction

Rett Syndrome (RS) is a neurological disorder diagnosed predominantly in girls (1). It is characterized by the deterioration of behavioural, social, cognitive, communicative and functional skills to a profound level, after a seemingly normal first six to 18 months of life (2). Its etiology is derived from impairment in an X-linked gene (3, 4). There is no known cure to RS, and care provided by conventional treatments (music-, physical-, occupational-, speech- and hydrotherapy) seem to relieve and improve

the patient's symptoms (1). The incidence of RS is between 1:10.000 (5) and 3.8:10.000 (6) in female births, and it is considered as the second most common cause for severe mental retardation in females after Down syndrome (5).

The development of Rett Syndrome is characterized by four stages:

Stage I - Onset

This stage appears between the ages six months to one year. This stage is usually overlooked as there are no evident neurological symptoms. The infant may show less eye contact and have reduced interest in toys. There may be delay in gross motor milestone, but at times the child may show an increase in refined hand use (i.e. handling a telephone dial, shifting pages of a book). This stage may take a few weeks and up to a few months.

Stage II - Destructive

This stage appears between the ages one to four years. This stage can have a gradual or rapid onset as purposeful hand skills and spoken language are lost. Stereotyped hand movements begin to emerge and may include: hand-wringing, hand-clapping, handwashing and hand-to-mouth movements. Breathing irregularities may be noticed and may include episodes of breath holding and

hyperventilation.

Some girls appear autistic-like with loss of social interaction and communication (behaviours which situates those children under the umbrella term of PDD on the DSM-IV). General irritation and sleep irregularities are typical. Slowing of head growth can be noticed from three months to four years when the girls' head circumference falls below the percentile chart.

Stage III - Plateau

This stage is usually detected from around the age of two and above and sometimes lasts throughout the individual's life. This is a more balanced period. Clear signs of RS are apparent at this stage and may include: reduced hand function, apraxia, ataxic gait, difficulty maintaining equilibrium, scoliosis, gravitational insecurity and seizures. However, improvement is seen in behaviour with less irritability and crying and less autistic-like features. The girls show more interest in their surroundings especially in people. Alertness, attention span and communication skills might improve.

Stage IV – Late Motor Deterioration
If this stage begins, it starts around the age of ten and is characterized by reduced mobility. Some girls stop walking (stage IV A) while others may have never walked (stage

Sammendrag

Fysioterapi og musikkterapi som en kombinert tilnærming for personer med Rett syndrom (RS) ble satt i gang som følge av lidelsens komplekse og utfordrende manifestasjoner. RS er en genetisk lidelse som i de fleste tilfeller rammer kvinner. Både fysisk aktivitet og fysioterapi er anbefalt som tiltak for pasienter med RS, men ofte blir behandlingsformen mislikt av pasientene selv. Musikkterapi er kjent som et effektivt og egnet tiltak og er svært godt likt av pasientgruppen. For å kunne imøtekomme RS pasientenes fysiske og medisinske behov, utvikle deres samarbeidsevne og anerkjenne deres emosjonelle og kommunikative behov, ble en kombinert behandlingstilnærming av fysioterapi og musikkterapi, prøvd ut. Behandlingen har et bredt terapeutisk

perspektiv og medfører at begge terapeutene oppnår de terapeutiske målene i behandlingssituasjonen, uten at pasienten motstiller seg behandling. Samtidig viser behandlingen å ha god effekt på barnets kommunikasjonsevner. Denne kasusrapporten gir et innblikk i den kombinerte behandlingen i et eksempel med en ni år gammel jente med RS. Hovedfokus er på de fysiske og motoriske aspektene ved behandlingsforløpet. Vi foreslår at lignende intervensjoner også kan introduseres i tilnærmingen til personer med andre alvorlige funksjonshemminger.

Nøkkelord: fysioterapi, musikkterapi, Rett syndrom, kombinert behandling.

IV B). There is no decline in cognition, communication or hand skills. Repetitive hand movement may decrease. Scoliosis is a prominent feature in about 85 percent of children with RS (3). Rigidity (stiffness) and dystonia are common characteristics (7).

Experts in the field of RS now believe that this fourth stage might be avoided under intensive appropriate therapeutic care (8).

Intervention for individuals with RS

The treatment of children with RS is essential in order to accommodate them with maximum level of functioning and to provide them and their families the best possible quality of life. Physical therapy and music therapy are two important forms of intervention for girls with RS.

Physical Therapy in the Treatment of RS Since life expectancy in RS is evaluated at 49-50 years of age (9) and due to the vast physical challenges experienced by children with this disorder, treatment, especially physiotherapy treatment, is essential. The secondary deterioration typical of adolescents with this disorder compels physiotherapy as one of the most important treatments for individuals with RS and is applied to almost 80 percent of girls with this disorder (10).

Despite the debilitating characteristics of RS many physical intervention programs have been found to yield positive results for this population:

Individuals with RS are less mobile than their peers. This leads to a sedentary life style, reduced cardiovascular abilities and low functional levels. Improvement of functional abilities and cardio-vascular capacities were found to be the result of a daily treadmill training program introduced to four children with RS (11).

Scoliosis is a severe problem for children with RS due to its frequency (up to 85 percent) and severity (an average increase of 14 degrees a year) (2). The reduction of scoliosis curve was found possible through an intensive intervention program with one child with RS (see picture 3). This intervention program was implemented through the use of various positioning postures of the child (12).

Additional complications of RS might be: limb deformity, fear of movement, improving hand function or loss of walking ability. Such complications might be reduced and even avoided through the use of hydrotherapy (13).

Many children with RS show neurological and sensorial difficulties such as: poor limb coordination during function, postural and equilibrium difficulties, diminished hand functioning, apraxia, ataxia, and other sensory and perceptual problems. Such complex issues might be improved through the use of Snoezelen (see picture 2), also known as the controlled multi-sensory environment (14, 15).

All those characteristics are commonly introduced by individuals with RS and are all apparent with the girl who will be described in this case example. The intervention was planned to address some of those issues.

Music Therapy in the Treatment of RS Music Therapy was recommended by Dr. Andreas Rett as early as 1982 as means of treating individuals with RS (16). It's potential to promote and to motivate their desire to interact and to communicate with their surroundings as well as in developing their cognitive, affective, sensory-motor and physical abilities has been revealed and reported by many (17-34).

Since girls with RS express and communicate their emotions and feelings through facial, bodily expressions and vocalization, the music therapist can create music that reflects and supports these expressions. By doing so the therapist creates a safe and a special enabling environment, consequently helping to broaden and to increase the girls' «circles of communication». Through these musical creations the music therapist can become familiarized with the way the child expresses her feelings, and with this knowledge the music therapist can build the base for a close intimate interaction (see picture 1).

The Dual Approach –Physical and Music Therapy

We have chosen to work in a dual approach with girls with RS who are in Stage IV as we found it beneficial for the girls, for the physiotherapist and for the music therapist. The dual treatment approach was implemented for several years and had positive results. The treatment plan was conceived in accordance to the child's physical and emotional state and was planned to answer the child's therapeutic needs in a comprehensive way. The initial plan was very structured (see table 1), but the actual implementation was flexible according to the child's state during each session.

The reasons which brought the authors to unify the physical and musical treatments were directly connected to the child condition and to the interaction with both therapeutic milieus.

Talia – a Case example

Talia is a nine year old girl with RS. She de-

veloped normally until the age one and a half years. She then stopped maintaining some acquired milestones that she previously had engaged in. Other diagnosis, secondary to RS include: mild scoliosis (stable at present) with no orthopedic support, and epileptic seizures (about two per week), despite her large dosage of anti-convulsing medication.

Talia walks with considerable support, sits with no support for limited periods of time (a few minutes). In order for her to be able to sit for long periods of time (as is expected during therapy sessions), external support is needed. When seated on the mattress she frequently falls from sitting to laying position without using protective extension. When this occurs, she cannot return independently to a sitting position and needs the help from others (stabilizing her pelvis).

Communicatively she did not use any alternative communication system before the beginning of the dual treatment and did not even show minimal choice preference.

Hand usage is extremely limited, and Talia is totally dependent on caregiver's support throughout all activities of daily living including feeding and self care.

Emotionally she is very capable and expresses her emotions through laughs, cries, body movements, teeth grinding and facial expressions.

Physical Therapist's Point of View Along the life span of females with RS's there are times where their ability to move independently decreases and their ability to maintain posture and stability (even while sitting) is deteriorating. These periods of deterioration are frequently temporary and the child returns to her former abilities. As a result, during these periods, they need to receive an increased dosage of movement and physiotherapy (35). Since physiotherapy is suggested as an important treatment against scoliosis (36-38) and since transfer abilities are usually the first functional capabilities to be lost in RS (39), physiotherapy is of extreme importance and even a vital treatment for individuals with RS.

In spite of its importance, physiotherapy can be unpleasant, and even penetrating. These facts may induce unpleasant feelings, which the girls are incapable of expressing. Individuals with RS function according to their emotional state, and when they dislike physical treatment (as in the case example), they might react by falling asleep and even by evoking a seizure. In this special case example (described below) we found it necessary to intervene by providing a positive mi-



Picture 1. Music therapy. Group music therapy with children with Rett Syndrome. Photo: Meir



Picture 2. Snoezelen. A child with Rett Syndrome in the Snoezelen room. Photo: Meir Lotan



Picture 3. Physiotherapy. A child with Rett Syndrome in a half kneeling position during physiotherapy session (right C shaped scoliosis). Photo: Meir Lotan

lieu for treatment and by helping to increase her motivation

Before implementing the dual intervention Talia's physical therapy program was implemented twice a week for half an hour sessions. During that time, Talia showed no will to cooperate, her physical performance was below her known abilities and she was mostly unhappy. In order to avoid total rejection by her, physical demands were lowered, and there was little hope for a change in her attitude or the intervention outcome. It was hypothesized that the use of music will help Talia to intensify her motivation and participation, thus achieving higher level of functional demands during physical therapy sessions.

Music therapist's point of view

Before the introduction of the dual intervention Talia received music therapy twice a week for half an hour sessions. Despite her obvious affection to music, the music therapist found it very difficult to provide music therapy while Talia was constantly occupied with maintaining her body positioning, thus not able to freely participate in any musical activity. It was clear that in order for Talia to attain concentration, communication, emotional expressions and to reduce hand stereotypic movement, she needed physical support.

Due to these problems, the need for joint treatment was aroused. It was hypothesized that through the dual treatment the music therapy will create an atmosphere that will enable the space necessary for the physical therapeutic process to develop.

The joint treatment

These conflicts paired with professional needs and the girl's preferences, made it nec-

essary to combine the physical therapist who presents the child with physical demands and the music therapist, who prepares, reflects, interprets, contains and structures the sessions. The combination of music and physical therapy raised Talia's physical performance while at the same time converted the treatment from being difficult and disliked by her, to a more complete and positive experience partially controlled by Talia.

The musical content was functioning as a vessel which provided freedom for expression for different emotions. Whilst there was a space for expression, the music created a clear structure for the treatment. By repeating the same structure every session, the child could anticipate every phase of the treatment. This created a sense of trust and security that helped Talia to build a positive feeling of suspense towards the next phase of the treatment.

Another important aspect was that the music created by the music therapist helped to motivate Talia. In such a positive milieu the physiotherapist was able to elevate therapeutic demands and to achieve maximal results without any resistance or any aversive behaviour by Talia.

Targets of treatment for Talia

The targets of physiotherapy intervention:

- To establish rapport and a positive atmosphere towards the intervention: This goal was established through gradual verbally preparing Talia before each session.
- Maintaining walking abilities, improving balance and equilibrium reactions: These goals were established by walking with Talia to and from the physical therapy room and by challenging Talia to maintain erect postures while walking and within the session.

- Proprioceptive preparation towards movement while improving body scheme:
 These goals were established by giving sensory proprioceptive stimuli to Talia's body and to different limbs.
- Maintaining spinal range of motion and centering Talia's midline perception:
 These goals were achieved through movement opposite to the child's natural scoliotic curve, and are in accordance with «over correction» therapeutic intervention for scoliosis developed by Susan Hanks (40) and prior work by the first author (12). Rolling on a mattress was planned to achieve similar effects.
- Acceptance of movement by an external facilitator (while practicing balance reaction and protective extension): Fear of motion, and as a consequence, the rejection to external manipulation, is common to many individuals with RS. A play like exercise on the green physiotherapy ball enabled us to overcome such resistance.
- Improving hand usage: This is achieved by massaging the child's hands and by supporting Talia's body while she was introduced with manual demands (playing the guitar, beating the ocean drum and communicating).
- Addressing educational goals: The physical therapist working in an educational setting needs to support the achievement of educational goals of each student. By supporting the child body the physical therapist helped to promote educational goals such as: communication skills, attention span, decrease stereotypical hand movements and enhancement of the child's vocalization.

Targets of the Music Therapy intervention

• To provide a consistent and relaxed treat-

Phases	Description	Physiotherapy (PT) goals	Music therapy (MT) goals
1. Assessing the child's condition.	Both therapists update on the childs physical and emotional condition.	The physical and emotional state of the child determines the nature and pace of the treatment.	
2. Verbally preparing the child for the treatment.	Both therapists verbally prepare the child for the transfer from her classroom to the therapy room.	The Rett Syndrome population has difficulty in sudden changes. Preparing the child for the treatment builds confidence an acceptance and relaxes the child.	
3. Walking to the physical therapy room.	Walking from the class room to the therapy room.	Maintaining walking ability. Improving balance. Improving equilibrium reactions.	Evaluating the childs emotional state. Interacting and building rapport. Enhancing vocalization.
4. Opening song.	The child stands close to a mirror. The PT is behind her maintaining balance. The MT in front of the child.	Improving equilibrium reactions in standing. Proprioceptive preparation.	Structuring the treatment by repeating the song at the beginning of each session.
5. Song about body parts.	Posture remains the same. PT gives sensory enhancement to body parts described by MT.	Improving equilibrium reactions in standing. Improving body scheme.	Framing and improving body awareness.
6. Rolling on a large red physical therapy ball.	The child is on her back on a large physical therapy ball. PT moves ball and the child according to music.	Centering the childs midline perception.	Creating a supportive and a calming atmosphere through the musical content. Preparing the child for the exercise.
7. Rolling on the mattress.	The PT facilitates rolling the child while MT describes the movement through singing.	Setting body boundaries through sensory stimulation. Maintaining spine and back range of motion. Defensive reaction to obtain weight bearing on hands.	Preparing for the exercise. Enhancing vocalization. Preparing and reflecting feelings and experiences.
8. Jumping and rocking on a (smaller) green physical therapy ball.	The child is seated on the ball and PT bounces the child. The MT accompanies with guitar and singing.	Practicing balance reactions and protective extension. Establishing body scheme through proprioceptive stimulation. Acceptance of movement by an external facilitator.	Preparing, mirroring and describing the exercise for the child. Assisting in accepting movement bye and external facilitator.
9. Playing the drum.	The PT supports the childs back so she is free to explore the drum. The MT holds the drum in front of child.	Massaging the childs hands in preparation for playing the drum. Improving use of the hands. Decreasing stereotyped hand movements.	Encouraging hand use. Decreasing stereotypical hand move- ments.
10. Listening to ocean drum.	The child lies on her back supported by the PT while MT plays gently on the ocean drum upside down so that the child can se the pebbles.	Decreasing stereotyped hand movements.	Enabling the child to be in a relaxed state. Increasing attention. Decreasing stereotypical hand movements.
11. Listing and playing the guitar.	The PT supports the childs back seated on the mattress. MT holds the guitar in front of her.	Bearing weight to the right. Achieving elongated torso. Providing support so that the child can play.	Encouraging individual hand use. Examining an other instrument.
12. Choosing songs to sing from picture symbols.	The child is seated at a side seating position to the right. PT helping the child to maintain the posture. MT presents the child with choices of song selection.	Elongating the childs right side (due to scoliosis). Stabilizing the child and enabling functional use of body (choosing songs).	Improving communication skills. Enhancing attention span. Providing expressive outlet.

Table 1. Step by step phases in the dual intervention approach of physiotherapy and music therapy involving a child with RS. The described treatment session can also be viewed on a video recording displayed on the NJMT website: www.njmt.no

ment setting.

- To provide a place for self control.
- To develop a sense of confidence and trust through the musical relationship.
- To provide a supportive environment where Talia could express her emotions such as: frustration and fear of movement.
- To enhance and to develop Talia's awareness of herself and of her surroundings.
- To enhance Talia's communication skills such as: non-verbal expressions, vocalization or verbal ability.
- To increase Talia's attention span.
- To reduce hand stereotypical movements and to increase hand functioning.

These general goals were implemented into different phases of the dual intervention. The basic plan for all treatment sessions with Talia is shown in table 1. The treatment session can also be viewed step by step on a video recording displayed on the Nordic Journal of Music Therapy website: http://www.njmt.no

Treatment Outcome

The dual treatment, described above, enabled us to shorten treatment time for Talia (two ¾ hour treatments per week instead of four ½ hour treatments). At the same time, the new treatment regime enabled therapy possibilities that were unavailable during past therapeutic arrangements.

The physical level of difficulty in the treatments was raised and became more complex than the individual treatments that preceded this approach (for instance asking Talia to use her hands without external support during music therapy sessions became possible during this intervention; or working with Talia on protective extension was done during individual PT sessions only slowly and from a seating position on a mattress, but during this intervention it was performed during swift movement changes on a physiotherapy ball).

Talia's communication choice making abilities advanced dramatically, from an inability to choose between objects (Honey and lemon juice), to choosing from picture symbols (Song names). These skills were immediately transferred to Talia's classroom and home. The development of such new skills for a disabled child has a dramatic effect on her independence, self esteem, self-confidence and quality of life. The outcome of this treatment correlated with the rational which initiated the dual intervention of music and physical therapy.

Conclusion

Individuals with RS are usually extremely disabled. Most are slow to react to external stimuli and dread movement by external facilitators. When physical therapy intervention is applied without atonement to the child's emotional state she might react with lack of cooperation and even obvious rejection. Such reactions can be avoided by introducing additional motivational factors such as: video films, food, animals and the assistance of the child's family members. While all such additions might help, music is surly the most motivational of all.

The introduction of music, which has been highly recommended for this population, has been found again in this case, critical in achieving cooperation and enjoyment from the child. Thus, on occasions where the physical progress of a therapeutic intervention comes to a halt, the introduction of dual intervention such as the one presented in this article might be considered.

We believe that the treatment described in this article can open up a window of opportunity to advance treatment possibilities for children with RS exhibiting multiple disabilities. We also believe that this treatment approach can be implemented with other children exhibiting a combination of movement, sensory, speech and motivation difficulties. By implementing this approach the results will reward the child and the therapists as one. This approach shows that even in a severe neurological disabling disorder, such as RS, there is always a possibility of excelling treatments and achieving additional functioning and less disability.

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Abstract

Physiotherapy and music therapy (dual intervention approach) for individuals with Rett Syndrome (RS) was initiated as a result of the complex and challenging features which characterizes this disorder. RS is a genetic disorder effecting mainly females. Due to its debilitating characteristics, physical activity and physiotherapy is highly recommended however often disliked by these patients. Music therapy has long been suggested as a preferred therapy intervention, highly effective and greatly loved by the patients.

In order to address the patients with RS's physical and medical needs and at the same time enhance their cooperation and take into consideration their emotional and communicative needs, a dual treatment program of music and physiotherapy was introduced. This approach augments a broad therapeutic perspective and thus establishes a better quality treatment. This intervention approach has enabled both therapists to raise physical requirements of the patient without rejection of the therapy program. At the same time the dual approach proved effective in improving the child's communication skills. This article presents a dual physical and musical treatment approach with the case example of a 9 year old girl with RS. The main focus is on the physical and motor skill aspects of the treatment. The authors suggest similar approaches might be introduced to other individuals with severe disabilities

Key Words: Physiotherapy, Music Therapy, Rett Syndrome, Dual intervention.

Tre masterstudier under utvikling

Universitetet i Tromsø, Høgskolen i Bergen og Norges idrettshøgskole har fått støtte fra Fond til etter- og videreutdanning av fysioterapeuter til utvikling av i alt tre nye masterstudier.

Av Heidi Johnsen hj@fysio.no

Dette gjelder mastere i neurologisk fysioterapi, idrettsfysioterapi og klinisk fysioterapi.

Fondets intensjon med denne typen tildelinger er å støtte planlegging og igangsetting. Målet er at studiene eller videreutdanningen senere skal overføres til institusjonens ordinære budsjetter.

Universitetet i Tromsø søkte om midler til utvikling av klinisk masterstudium i neurologisk fysioterapi og fikk tildelt 430 000 kroner høsten 2005. I 2003 ble Høgskolen i Tromsø tildelt inntil 300.000 kroner til planlegging av en videreutdanning i neurologisk fysioterapi.

Norges idrettshøgskole, NIH, søkte om midler til planlegging og igangsetting av et masterstudium i idrettsfysioterapi, to kull og evaluering. Våren 2005 ble NIH tildelt inntil 430.000 kroner til utviklingsarbeidet. Fondsstyret sier i vedtaket at de i prinsippet er positive til å bidra med inntil 4.869.000 millioner kroner. Dette skal kunne omfatte to kull studenter á 120 studiepoeng, samt en evaluering av masterstudiet i idrettsfysioterapi.

Høgskolen i Bergen har fått 164.500 kroner til utvikling av master i klinisk fysioterapi, med fordyping i ortopedi og revmatologi, samt lungelidelser. Studiet skal totalt gi 120 studiepoeng.