

# MOTOR TRAINING IN GIRLS WITH RETT SYNDROME

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## Abstract

The individuals with Rett syndrome display a lot of challenging difficulties in all areas of daily living. The aim of the research among girls with this type of combined disability was to conduct a survey to gain as much information as possible about the possibilities for motor training, movement activities and physiotherapy that can suppress regression and improve quality of life. The questions put to 14 mothers revealed that standard physical exercise is not possible given the girls' health and mental condition. Consequently, physiotherapeutic concepts and methods (Vojta reflex locomotion, the Bobath concept) and other complementary therapies (canistherapy, hippotherapy, music therapy, ergotherapy et al.) are applied, attended by the girls mainly as part of compulsory schooling. The exercise usually takes place several times a day, both in school or an educational facility and at home.

## Introduction

Rett syndrome (RS) is a neurodevelopmental disorder characterized by arrest of brain development caused by an X chromosome mutation mainly affecting females [3; 8; 30; 33]. RS ranks among the category of pervasive developmental disorders [6], but is not typical of this category. That is because it is a progressive illness characterized by normal early development in the first 6 to 18 months of life [38], with a known aetiology and, moreover, occurring mainly in girls, which is in itself highly atypical for autism [12].

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision [5] uses the following five criteria for diagnosing a child with RS: (1) slowing of head growth between the ages of 5 and 48 months, (2) loss of purposeful hand movement, (3) loss of social engagement, (4) poorly coordinated gait or trunk movements, and (5) significantly impaired expressive and receptive language development with severe psychomotor retardation. However, there are many other symptoms that may develop with age – the appearance of stereotypical hand movements (hand washing and hand-mouthing movements), irregular breathing with apnea or hyperventilation, bruxism, sleep disturbances with unpleasant awakenings at night, frequent seizures, scoliosis, dystonia, ataxia [for more details see e.g. 42]. Not all girls and women with RS display all of these symptoms, and individual symptoms may differ in their severity [40]. From the point of view of motor skills and the performance of movement activities, the following are regarded as the most serious: motor apraxia<sup>1</sup>; ataxia;

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<sup>1</sup> Apraxia is the inability to control the body and execute purposeful movements. Dyspraxia of the hands is a regression in the development of fine motor skills and is manifested in stereotypical hand movements. Girls with RS are not able to use their hands for ordinary tasks, which are also hindered by stereotypical movements (patting, wringing, clasping, releasing and hand mouthing). Many of them suffer from subtle quivering of the

poor gross and fine motor skills; loss of transitional movements; abnormal breathing (like hyperventilation or apnea), which is linked to blackouts; seizures; muscular hypotonia, spasticity and rigidity, which is reflected in poor posture; scoliosis. All of these potential medical issues can cause delays in the motor domain. Teachers, coaches, and recreation specialists must be aware of any medical precautions when working with children with RS [32].

Individuals with RS have been found to be at risk for developing sedentary lifestyle associated diseases, such as elevated risk for coronary artery disease and stroke. A physical activity programme might improve present and future health conditions. There have been very few studies on effects of physical exercise and RS [20].

Females with RS can be physically exercised with the use of a treadmill programme [24]. A low intensity, daily training programme could improve physical fitness/aerobic capacity. Such programmes can be performed in addition to physical therapy intervention and might enhance the results of such intervention. Improved physical fitness might be linked with the improvement of functional abilities in children with RS, thus enhancing the value of such programmes.

There are no available therapies that radically change the course and the natural evolution of RS. Interventions are generally aimed at preserving physical and psychosocial functioning, enhancing quality of life, and providing education and support to families. The efficacy of the adopted therapies is not well documented, most findings being based on single case studies and individual experiences rather than controlled experimental studies [41]. Most treatments are supportive and aim at addressing specific symptoms of RS rather than trying to take on the disorder as an entire entity. The goal of these treatments is to hold back the decline in abilities, enhance or maintain movement, and support social contact and communication. The best way to help reduce the effects of RS is a complex, mixed-bag method of attack that includes many diverse kinds of therapies. These therapies, which range from traditional approaches to new and experimental ones, may include physical therapy; speech-language therapy; occupational therapy (ergotherapy); physiotherapy (like massage and exercise) and alternative approaches such as hydrotherapy, hippotherapy [27], dolphin therapy and dog-assisted therapy; auditory integration training; hyperbaric chamber; manual therapy such as acupuncture/acupressure, aromatherapy, craniosacral therapy, Mayo facial release, Treager massage, chiropractor, and Reiki; mental modification techniques such as Lovas and cognitive rehabilitation; motor interventions, such as advanced biomechanical rehabilitation, patterning/Doman-DeLacato approach, and yoga [22].

Girls with RS mostly go to special schools and educational facilities that offer them individual treatment and a diverse programme to encourage acquisition, or reacquisition, of basic adaptive skills (e.g., expressing preferences, self-feeding, and achieving various motor skills). Besides individual and group tuition, according to Tupá [35] these are various auxiliary activities e.g. hydrotherapy, zootherapy, lying on a waterbed and basal stimulation activities, music therapy, aromatherapy, vision stimulation, training of self-service skills etc. All this is combined with physiotherapy, which is essential for girls with RS.

## **1 Aim of the research**

The aim of the research was to gain as much information as possible about motor training and physiotherapy for girls with RS.

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whole body and uncontrolled limb movements. Owing to apraxia, a loss of spatial orientation and own-body orientation tend to be customary [42].

In the context of the aforementioned aim, the following research question was formulated: What are the possibilities for motor training and movement activities for girls with RS?

## **2 Methods**

The sample consisted of 14 parents or mothers of girls with RS. Given that this disability is relatively rare, it is very difficult to find a sufficiently large sample of respondents. The sample is therefore considerably heterogeneous in age terms (the mothers' ages range from 30 to 60 and their daughters' from 3 to 31). The girls' degree of disability (both mental and physical) is also very varied.

It should be noted that it is relatively difficult to gain any information about girls with RS: there is currently no list of schools or educational facilities they attend; there are no detailed data about the number of individuals with RS in the Czech Republic; nor is there consistent diagnosis or records. The following organisations were therefore asked to assist: APLA (Association Helping People with Autism), the Autistik association, Rett Community, the Zahrádka primary school in Prague and regional coordinators for autism as a newly established institution that is responsible for coordinating counselling and educational services for clients with autism in the regions and is an important integration tool.

The research took place by means of a questionnaire that targeted families of girls with RS. It consisted of 19 open, closed and semi-closed questions [15] concerning the possibilities for motor training, movement activities and physiotherapy for girls with RS; four questions were multiple choice; the parents answered the others according to their experiences.

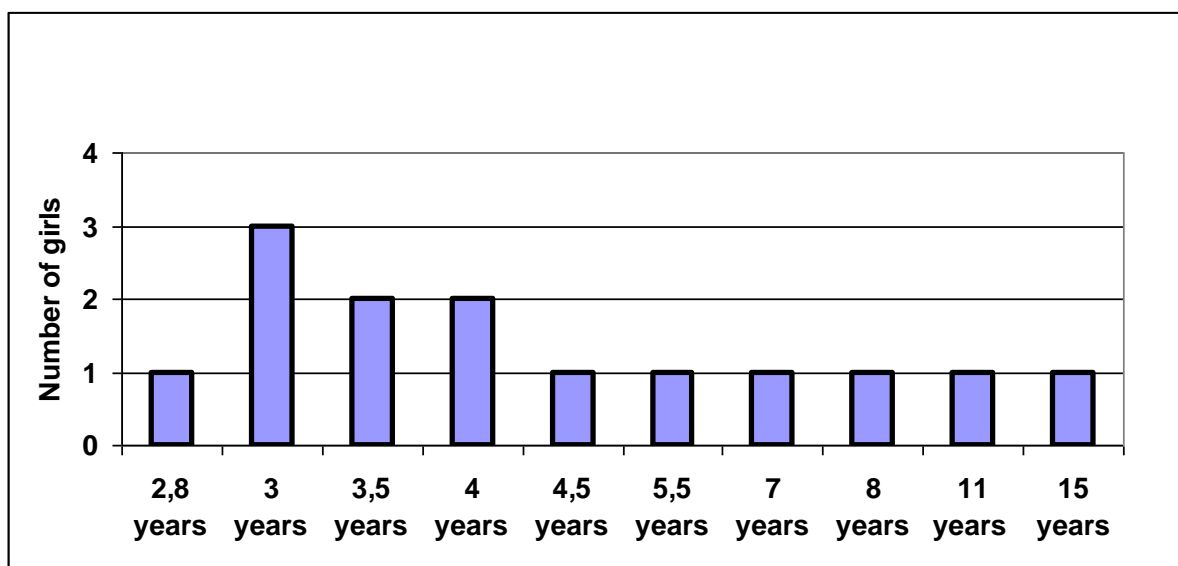
## **3 Results and discussion**

Given the chosen research method of a qualitative survey and, above all, the small sample of respondents, the research is not intended to be generalised. We regard it as a basic set of problems that could act as a stimulus for more in-depth and detailed research using quantitative methods.

We would also like to mention that the results of our research cannot be compared with any other similar studies, as none have been done in this area in the Czech Republic before. We attempted to make a comparison with sources from other countries, but these were not particularly successful either.

Parents' satisfaction with the levels of information about RS (and, by extension, about the possibilities of motor training in this group of the population) in Czech literature is low. According to 13 of them, there should certainly be more information; one mother regards it as totally insufficient. There is indeed very little information about the issue of RS in the Czech specialist literature; and that information is often merely linked to autism or other pervasive disorders. On this point two mothers stated that nobody knows anything about RS, often not even doctors (e.g. neurologists, orthopaedists). This is probably because it is a relatively young, little-known and rare diagnosis, estimated to number one case per 10,000–20,000 births [30]. In the Czech Republic 5–6 girls are born with this disability every year [34]; it has been confirmed in 48 girls, but according to probability there should be as many as 400 [12].

In addition, diagnosing RS is relatively problematic, as the wide range of diagnosis times in the girls in our sample bears out (Fig. 1). That is also a matter of the different ages of the respondents, however. For example, one girl, aged 18 at the time of the research, was only diagnosed with RS at the age of 15, even though regression began to appear in her at the age of 3½ years. By contrast, one girl aged 3½ was diagnosed at the age of 3.



Source: Own

**Fig. 1:** Age of girls when they were diagnosed with RS

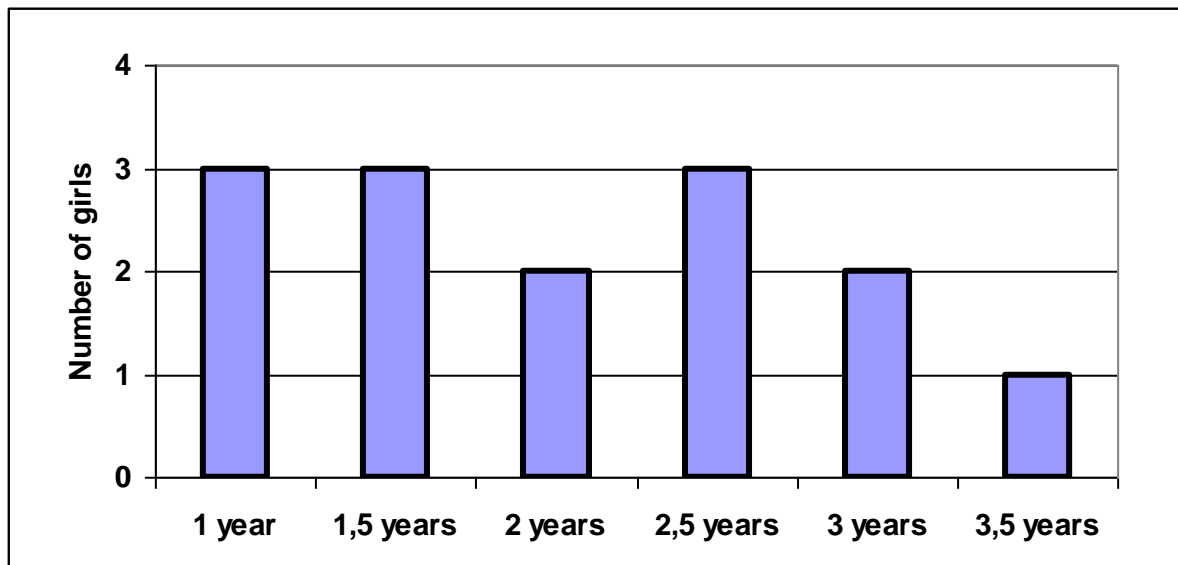
RS is often misdiagnosed, most commonly as infantile autism, infantile polio or non-specific behavioural retardation [16]. Misdiagnosis as autism takes place with girls who are mobile and do not have the typical hand wringing movements but only stereotypical movements at the time of diagnosis. When misdiagnosis as other developmental disorders occurs, parents have brought their child to an examination at a time when the full symptoms of the regressive period have not yet developed. The child is able to establish social contact [33].

The time when RS is diagnosed is linked to the start of regression, i.e. the deterioration of the girls' health. In our sample, according to the parents the start of the regression period ranged from 1 year to 3½ years (Fig. 2), but even so some girls were not diagnosed with RS until they were older. The typical manifestations of this regression are the cessation of psychomotor development, the emergence of stereotypical movements, epileptic seizures etc. [38]; the mothers mentioned symptoms such as dropping cups, spoons or toys. Motor training and physiotherapy are used to prevent a rapid deterioration in the health of girls with RS and delay this regression. So the sooner it is diagnosed, the sooner therapy can start. Intervention commenced shortly after diagnosis offers the best chance of achieving a positive impact on skills in later years. The sooner therapy begins, the better the chance of learning and also of coping with other problems linked to RS [27].

In addition, the manner of locomotion has a major influence on the motor training possibilities for girls with RS. Cross-sectional studies of subjects with RS suggest that most can sit independently, approximately half can walk, but not in a coordinated manner and on tiptoe [14; 21]. In our sample four girls move without support. Seven move with support and assistance, but four of them are unable to crawl on all fours. Three girls sit in a mechanical wheelchair; they are unable to control electric wheelchairs. Nor do they control the mechanical wheelchairs themselves: educational assistants, personal assistants, special teachers<sup>2</sup> or parents help them move about. Walking development disorders mainly depend on the phase of the girl's psychomotor development that regression occurs in; i.e. if the girl was already walking or just crawling and how far back in her development she regresses to [43].

<sup>2</sup> All the girls need a personal assistant, mainly for activities such as hygiene, getting dressed, eating, help playing etc. The degree of assistance depends on the severity of the mental disability and the degree to which the girls hands are affected – stereotypical movements mean that some cannot use their hands purposefully, which is a considerable handicap for certain types of movement activities.

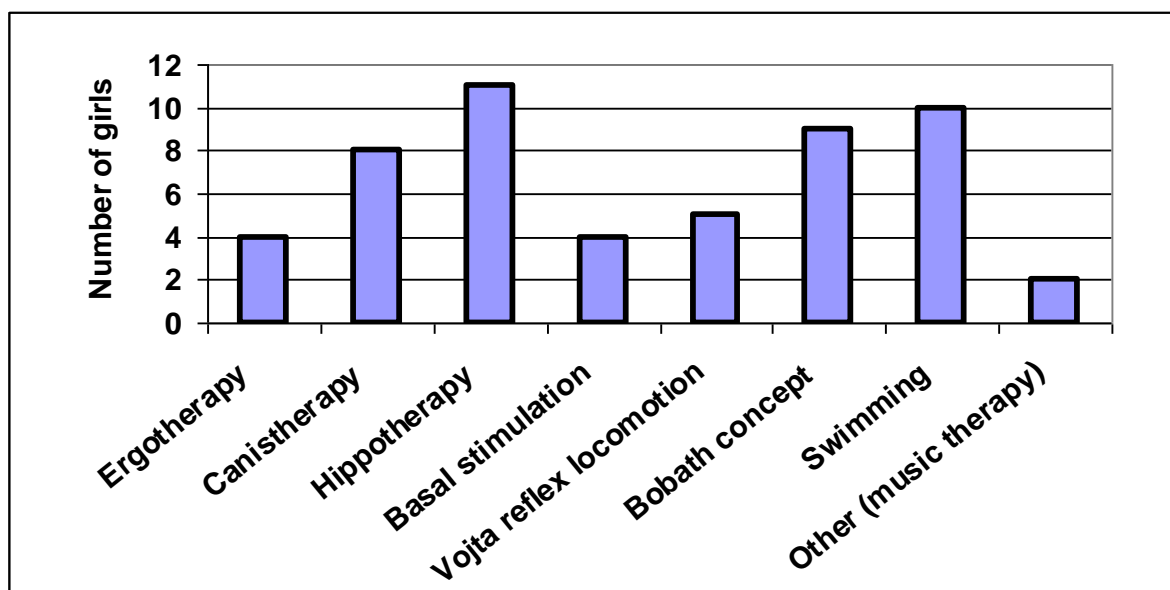
In the period of late deterioration of motor skills girls with RS who can walk suffer a worsening in the quality of their gait; some girls stop walking entirely [3].



Source: Own

**Fig. 2:** Onset of signs of regression in girls with RS

Fig. 3 shows the therapy and exercises the girls attend, often during school hours, sometimes in private after school. Girls who do not yet attend school or an educational facility go to therapy with their parents or do exercises with them at home (e.g. the Bobath concept, basal stimulation). They all try to ensure that the exercise is regular. Three mothers stated that they had replaced Vojta reflex locomotion with the Bobath concept, as this is more tolerable for their daughter. One of the respondents mentioned alternative methods: applied kinesiology (a method for eliminating physical and mental difficulties), reconnection (an energy healing method) and homeopathy (which is not classified as exercise, however). Two parents also used music therapy. The girls are often unable to perform the movement themselves; they are passive during therapy or exercise, so they have to be led through the movements by another person.



Source: Own

**Fig. 3:** Therapy and exercises attended by girls with RS

Two girls undergo all the seven types of therapy the respondents could choose from (ergotherapy, canistherapy, hippotherapy, basal stimulation, Vojta reflex locomotion, Bobath concept, swimming). Another three girls participate in five types of therapy; another three participate in four types. Four girls undergo three types of therapy; only one girl attends two types of therapy. One mother's response was surprising: she stated that as her daughter is relatively old (born in 1979) she did not attend and had never attended any type of therapy or exercise, as nothing was done with "these" girls in former times.

Nine girls had begun to attend the individual types of therapy and exercise as part of their compulsory schooling, i.e. aged around seven, even though some of them were not diagnosed with RS until a later age. The parents started to exercise with the girls at the first signs of regression. One mother practised Vojta reflex locomotion with her girl from the age of two months because she could only turn her head to one side, but at the age of two these exercises were replaced by the Bobath concept and the girl started going swimming from the age of six months. Physiotherapy (Vojta reflex locomotion or the Bobath concept) was the first therapy applied in the case of all the girls<sup>3</sup>. According to Felice [7, p. 2] "*the usual performance of physiotherapy with girls and women with RS does not necessarily guarantee the maximum result*", because (1) too much emphasis is placed on the developmental aspect and developmental progress, (2) excessive emphasis is placed on locomotive movements, (3) hand function is reduced, which prevents movement across floors and crawling, (4) difficulties with starting movement occur, and (5) the movement improvement goals differ from girl to girl. Nevertheless, physiotherapy for girls with RS is in our opinion extremely important, mainly to hold back regression.

Our questions also sought to ascertain how long the various types of therapy last and how many times a week girls with RS attend them. In the case of girls attending school or another educational facility, the parents often do not know how long the therapy lasts. It depends greatly on the girls' possibilities and, above all, mental and physical condition, so therapy times may change. However, nine girls attend different types of therapy at least once a week as part of school tuition, and this exercise is backed up with exercise at home, most commonly physiotherapy. Parents whose daughters (four) are not yet in school perform Bobath concept or Vojta reflex locomotion exercises every day for at least half an hour; they go swimming once a week for just under an hour; and attend hippotherapy once or twice a week for 10–20 minutes. They perform basal stimulation every day for around 10 minutes. Canistherapy and ergotherapy are done solely as part of school attendance.

There is no integrated system of care or exercise programme designed specifically for individuals with RS. The efficacy of the said complementary therapeutic procedures is not specific to RS<sup>4</sup> – they can help some girls' development and mental wellbeing just like various interest clubs and therapy for intact children. Reactions to these types of therapy tend to be highly individual and not every type is suitable for every child [39]. The therapy and exercises are therefore "prescribed" on a case-by-case basis depending on the girls' current state of health and the severity and type of associated difficulties (scoliosis, epileptic seizures etc.).

According to the respondents, swimming, which has a major physiotherapeutic significance for all disabled people, is the most popular therapy among girls with RS (Fig. 4). Through suitable and gentle movement stimulation it helps mitigate health problems by supporting

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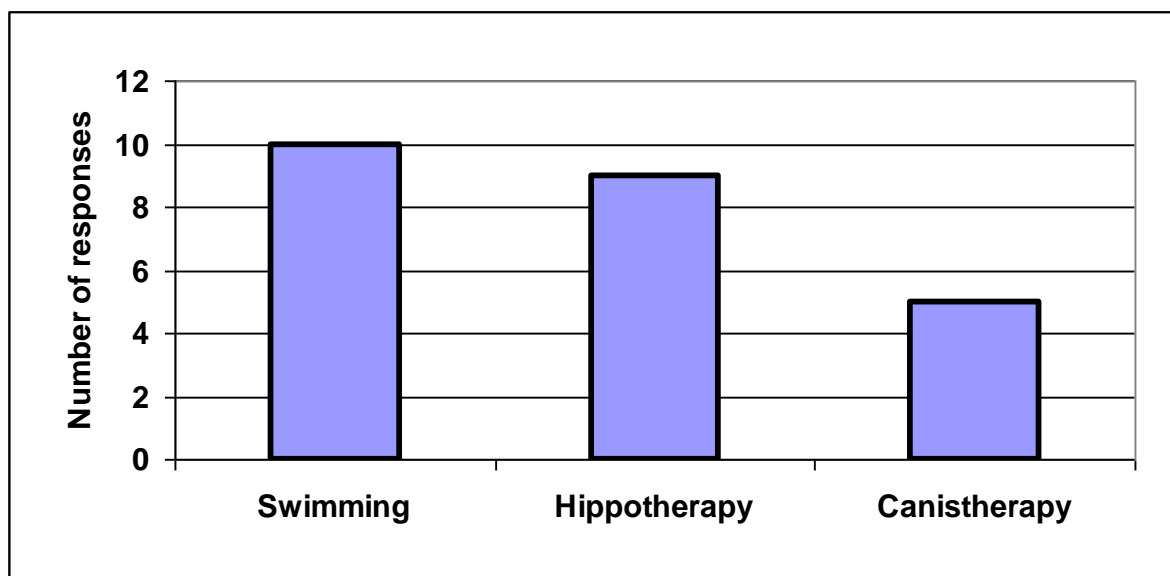
<sup>3</sup> One girl (the oldest, born in 1979) had never exercised and was therefore excluded from the assessment of the other questions.

<sup>4</sup> The same types of therapy are used for individuals with autism, intellectual disability, combined disabilities et al.

overall development – physical, motion, mental and social development [4]. Bunin et al. [1] confirmed by experiment the positive effect of hydrotherapy, and specifically the Halliwick swimming method, on improvements in coarse motor skills. However, positive effects seem to only last up to 8 weeks after the therapeutic sessions. According to the parents, moving in water is easier for girls with RS – the body feels lighter and is not as clumsy. Most of them have loved water from birth. The water should be warm, however (the action of warm water favours muscle relaxation and decreases body tension) – as it often occurs that the girls “go on strike” in cold water. Swimming, or rather bathing in the case of some girls, is great fun for them.

Other popular therapies include hippotherapy and canistherapy, where the girls are in contact with their favourite animals. Hippotherapy takes precedence over other methods in the case of autism spectrum disorders (and thus also RS), as it is far removed from the mental pressure and anxiety that can be aroused in educational and other medical facilities [29]. It is a simple and natural method, whereby one animal species influences the movement paradigms (gait, breathing, grip, speech abilities) of another animal species and which instinctively respects biological age, which is often fundamentally different from calendar age in the disabled. Želinová [44] states that if a girl with RS suffers from decompensated scoliosis that does not let her sit upright, for example, she rides the horse lying on her stomach. This position on the horse’s back is an alternative to the complicated “walking” mechanism that the girl cannot otherwise experience.

Canistherapy has a positive influence on motor skills, the cognitive sphere, motivation, sociability and social skills, on relationships with dogs and animals and nature in general, and contributes to mental support etc. [37]. The positive physical, psychosocial and emotional effects a dog has on a human’s health are mainly used in cases where other methods have failed or cannot be used [9]. According to Cicholesová et al. [2] the effect on a person’s physical health is secondary; it is more a case of motivation and rehabilitation, or possibly improving immunity via the mind. It is evident, then, that this is not treatment per se but rather an ancillary treatment method that can be successfully used in comprehensive rehabilitation.



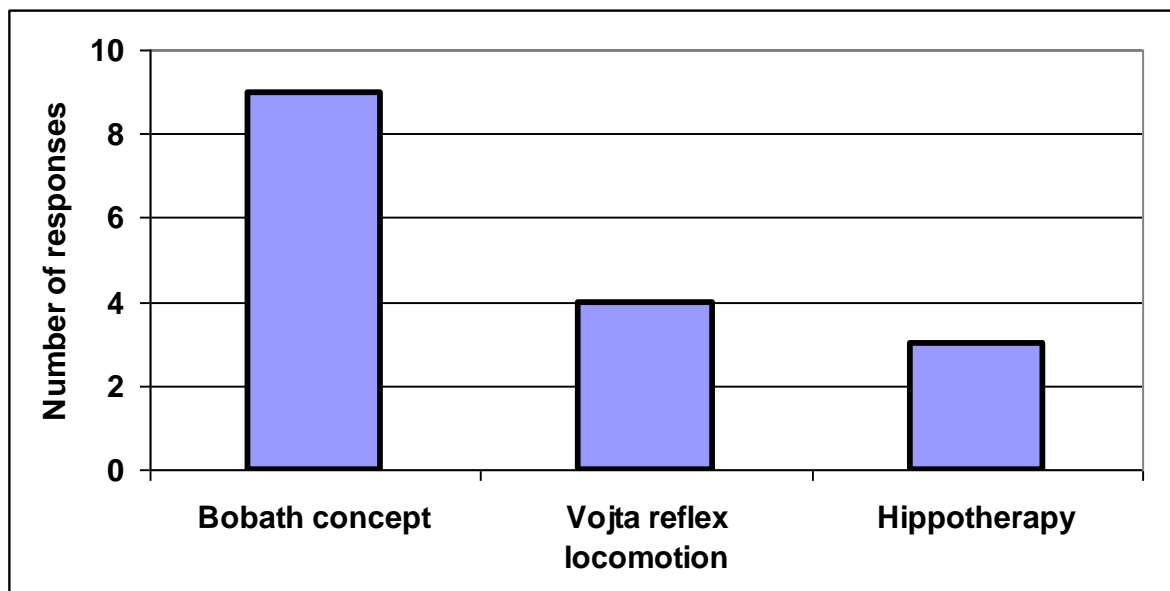
Source: Own

**Fig. 4:** Most popular therapies among girls with RS

When asked which therapies and exercises the girls do not enjoy and the probable reasons for this, most of the respondents replied that all the therapies are tolerable for their daughter and that at home they try not to do anything the girl does not like. If the parents had to pick a therapy that their daughter really does not enjoy, they often opted for physiotherapy (in nine cases), because during it the girl has to move and often engage muscles that are normally idle. Motivation is a key when attempting to involve a person with RS in a physical activity or motor skill setting [32]. Children with RS can become frustrated and/or become disinterested with an activity that is challenging for them, like motor activities [13]. Therefore, finding out what motivates the child (music, food, or social rewards) enables the child to stay more focused on the task.

In three cases, the unpopular physiotherapy was joined by ergotherapy, where the girls also have to work and be actively engaged. According to Klivar [18], there are large gaps between the currently used therapies for autism spectrum disorders, as ergotherapy is often overlooked. According to the author, clinical experiences have shown that this method is highly efficacious, mainly because it stimulates balance skills and the development of coarse motor skills and helps focus attention. Occupational therapy (ergotherapy) is used to promote and increase purposeful use of the hands in daily life activities in girls with RS [10; 13]. Although many emphasize the teaching of skills involved in daily routines, there have been few studies published on the use of occupational therapy in girls with RS [31].

According to the parents (Fig. 5), physiotherapy (Vojta reflex locomotion, Bobath concept) tailored to their daughter's needs has the biggest effect in terms of improved motor skills. Three parents also mentioned hippotherapy in their reply. An informed and intensely applied physical therapy regime can help the child and the family cope and even overcome the vast array of orthopedic and neurological difficulties (functional limitations, low cardiovascular capacity, hypotonia, ataxia, apraxia, loss of transitional movements, spasticity, scoliosis and/or kyphosis, loss of ambulation, loss of hand function, foot deformities, and spatial disorientation) and maintain or increase motor skills [23].



Source: Own

**Fig. 5:** Selected therapies from the point of view of motor skills improvement according to the parents

Another area of motor training for girls with RS is training coarse and fine motor skills, which is done by special teachers in school or by the parents at home. The family plays an



indispensable role in the education and upbringing of children with RS. As the people who know their child best, the parents often function in this process as both a basic source of information for the teacher and, above all, co-therapists and collaborators. The family should get involved in caring for the child as soon as possible and as intensively as possible. Their common goal is to help the child attain its optimal independence and adaptation in an environment that is as non-restrictive as possible.

As far as coarse motor skills training in the home environment is concerned, this takes place with all the girls (besides the exception mentioned above) regularly and several times a day. The choice of exercise naturally depends on the girl's age, the severity of her disability and what she can cope with. Here is a list of examples of home training to develop coarse motor skills mentioned by the parents: outdoor walking, walking up stairs<sup>5</sup>; training walking with support; training crawling on all fours; swimming; playing outside; bicycle, scooter riding; sledging in winter; jumping on a trampoline; squats; full-body stretching and relaxation; exercises at a rail (training walking sideways, alternate leg raising); exercise on a gymnastic ball (training stability, strengthening the stomach and back muscles, getting up from a seated position on the ball). According to Tupá [36], among girls with RS coarse motor skills are mainly drilled in the following positions and movements during physiotherapy: walking (including upstairs), standing, sitting, kneeling, positioning (ideal position - during relaxation, during activity, while eating); then also for alleviating the symptoms of scoliosis and hypotonia.

Children with RS tend to have significantly better gross motor skills than fine motor skills due to the distinctive physical characteristic of hand-wringing [13]. Training fine motor skills is very hard for girls with RS. Some are unable to use their hands at all and reject any activity involving their upper limbs. According to Tupá [36], fine motor skills are practised in the following areas: (1) mobility of the left and right arms – whether a girl can indicate a movement, whether she can complete it or can manage it in its entirety; (2) means of support – fixation, fixation of the other arm, elbow, wrist, start and completion of a movement; (3) grip – what kind of grip, what kind of support (does the child accept it or try to fight it?). Exercises in the home environment are also done several times a day. These are examples mentioned by the parents: playing with a ball; gripping e.g. crayons, laces, lentil-shaped sweets in a bowl; drawing; browsing through magazines and books; ordinary activities requiring the hands (e.g. laying the table); finger and hand massages; doing up buttons or zips; tying laces; using toys as motivation (child's piano, squeezing toys, toys emitting sounds and lights); there is often no problem with the mouth – giving kisses, sticking out the tongue.

Only one mother does not use any special or compensatory aids when exercising with her daughter. Nine parents mainly use balls of various sizes, types and materials. Five girls have at their disposal a specially equipped bicycle or exercise bike, and four girls have a specially modified ring for the swimming pool, which makes them feel safer. Other aids mentioned were rails (three times) and exercise mats (two times).

According to the parents, the biggest difficulty in terms of motor skills and movement activities among girls with RS is hand activity, specifically the targeted use of the hand for ordinary tasks, which is hindered by uncontrollable stereotypical movements (washing, wringing, pinching, clapping, putting the hand in the mouth or in the hair et al.). Repetitive hand movements seen in RS are non-functional and thought to be involuntary rather than self-stimulatory, which is more characteristic of classic autism [26; 28]. It is often difficult to redirect these children when they are displaying hand-wringing or other repetitive

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<sup>5</sup> Some professionals recommend walking as a preventive intervention that might hold back or diminish secondary damage [25].

movements, which in turn can hinder teaching and practising various motor skills [11; 17]. It has been shown to be effective that therapists or teachers fixate the hand in some way (splints, ties, placing the hand under the leg) so the girl does not perform the stereotypical movements that are considerably tiring and concentrates better on work with the dominant hand or pays more attention to a task or speech [33]. Implementing activities involving weight-bearing on hands, such as moving from sitting to standing, can encourage the child to use hands in more functional ways and aid in motor tasks requiring hand use [19].

The parents also find the greatest difficulties with fine motor skills (gripping items, doing up zips or buttons); the greatest locomotion difficulties are the act of walking itself, changing walking direction, walking up stairs, speeding up and standing without support. It often happens that the girl falls backwards and needs someone to hold her up from behind. Other problem areas include hygiene – teeth cleaning, washing, combing hair. Of course, these activities depend greatly on the girl's age, the degree of her disability and the actions she can manage.

According to the majority of mothers, motor training in school is sufficient. Some would wish for more physiotherapy, in which they would include reflex massage. Five mothers do not have sufficient information about school motor training, because their daughter does not yet attend school or another educational facility.

Although the possibilities for individuals with RS are limited, three girls attend a special-interest club. One girl is in the scouts; another girl goes with her mother to a civic association that offers leisure-time activities for parents with children in the form of educational, creative and sports courses. The third girl attends an exercise club at school.

Last but not least, we wanted to see whether the parents attend some educational courses or seminars concerning RS and, if they do, how they find out about them. Only one mother had attended several conferences on RS, including the international one held in Prague in 2005. She learnt about these conferences mainly by chance. The other parents do not attend any courses but are registered in the Rett Community civic association. Most of them find their own information on the internet.

## **Conclusion**

The survey-based research of 14 parents of girls with RS revealed that the girls' health and mental state make ordinary physical education impossible. There is no integrated system or care or exercise programme designed specifically for people with this disorder – each girl is unique and has her own therapy programme. Motor training is usually composed of physiotherapy (Vojta reflex locomotion, the Bobath concept) and supplementary therapies (canistherapy, hippotherapy, music therapy, ergotherapy, swimming et al.). The girls mainly attend these as part of compulsory schooling. The exercise usually takes place several times a day, both in school or educational facilities and at home. Both fine and coarse motor skills are practised.

In general, activities should focus on slowing the loss of motor and mobility skills occurring in RS as the syndrome progresses. The girls should therefore move all their lives, even if only passively and guided by another person.

We think that in this specific target group specialists should pay more attention overall physiotherapy, use more relaxation massage and pay attention to targeted fine motor skills training. Clearly, more research is needed on the efficacy of interventions for individuals with RS. It is fair to assume that research and development in medicine and special pedagogy will continue and will identify further ways to improve the comprehensive care for these girls.

## Acknowledgements

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## POHYBOVÁ VÝCHOVA DÍVEK S RETTOVÝM SYNDROMEM

Jedinci s Rettovým syndromem vykazují celou řadu složitých problémů ve všech oblastech denního života. Cílem šetření bylo u dívek s tímto typem kombinovaného postižení získat prostřednictvím ankety co nejvíce informací o možnostech pohybové výchovy, pohybových aktivit a fyzioterapie, které dokážou potlačit regres a zlepšit kvalitu života. Z dotazování 14 matek vyplynulo, že s ohledem na zdravotní a psychický stav dívek není běžná pohybová výchova možná. Aplikují se tedy fyzioterapeutické koncepty a metody (Vojtova reflexní lokomoce, Bobath koncept) a jiné doplňující terapie (canisterapie, hippoterapie, muzikoterapie, ergoterapie, plavání aj.), které děvčata navštěvují převážně v rámci školní docházky. Cvičení probíhá pravidelně několikrát denně, a to nejen ve škole či školském zařízení, ale i doma.

## DIE BEWEGUNGSERZIEHUNG BEI MÄDCHEN MIT RETTSYNDROM

Personen mit Rettsyndrom haben mit einer ganzen Reihe schwieriger Probleme auf allen Gebieten des täglichen Lebens zu kämpfen. Ziel der Untersuchung war es, durch diese Umfrage bei Mädchen mit diesem Typ der Mehrfachbehinderung möglichst viele Informationen über die Möglichkeiten der Bewegungserziehung, Bewegungsaktivitäten und der Physiotherapie zusammenzutragen, durch die sich die Regression unterdrücken und die Lebensqualität verbessern lassen. Aus der Befragung von 14 Müttern ging hervor, dass aufgrund des gesundheitlichen und psychischen Zustands der Mädchen eine normale Bewegungserziehung nicht möglich ist. Deshalb werden physiotherapeutische Konzepte und Methoden (Vojta-Reflexlokomotion, Bobath-Konzept) und andere ergänzende Therapien (Canistherapie, Hippotherapie, Musiktherapie, Ergotherapie, Schwimmen u. a.) angewendet, die die Mädchen überwiegend im Rahmen des Schulunterrichts absolvieren. Die Übungen werden regelmäßig mehrmals täglich nicht nur in der Schule oder der schulischen Einrichtung, sondern auch zu Hause durchgeführt.

## WYCHOWANIE RUCHOWE DZIEWCZĄT Z ZESPOŁEM RETTA

Osoby z Zespołem Retta borykają się z całym mnóstwem złożonych problemów we wszystkich sferach życia codziennego. Celem przedstawionego badania, prowadzonego wśród dziewcząt ze wspomnianym typem upośledzenia sprzężonego, było zdobycie w drodze ankiety jak największej ilości informacji na temat możliwości wychowania ruchowego, ćwiczeń ruchowych i fizjoterapii, które mogą zapobiec regresowi i poprawić jakość życia. Z ankiety przeprowadzonej wśród 14 matek wynika, iż zwykle wychowanie ruchowe nie jest możliwe ze względu na stan zdrowia i stan psychiczny dziewcząt. Dlatego stosowane są koncepcje i metody fizjoterapeutyczne (metoda odruchowej lokomocji wg Vojty, koncepcja NDT-Bobath) i inne terapie uzupełniające (kynoterapia, hipoterapia, muzykoterapia, ergoterapia, pływanie, itd.), w których dziewczęta uczestniczą zazwyczaj w ramach zajęć szkolnych. Ćwiczenia odbywają się regularnie kilka razy dziennie, nie tylko w szkole lub placówce szkolnej, ale również w domu.