International Journal of Applied Sciences: Current and Future Research Trends (IJASCFRT)

ISSN (Print) , ISSN (Online)

https://ijascfrtjournal.isrra.org/index.php/Applied_Sciences_Journal

Evidence Based Physiotherapy Management Guideline for Children with Down's Syndrome

Jemal Suleyman*

University of Gondar, College of Medicine and Health Sciences

Department of physiotherapy, Gondar, Ethiopia, Phone no.: +251 934 36 89 61+251 986 66 53 81

Email: jemsul950@gmail.com

Abstract

Background Down's syndrome is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21.Globally, as of 2010, Down syndrome occurs in about 1 per 1000 births and results in about 17,000 deaths In developing countries, many children with DS die in childhood from infections and congenital heart defects.

Objective to identify and compile feasible evidence based physiotherapeutic approaches for the management of Down's syndrome.

Method Full text RCT articles published from 2001 to 2013 in English language were searched and included. Studies which are exclusively for adults were excluded.

Result All the five articles that are included for this guideline supported different types of physiotherapy managements for the improvement of muscle tone, muscle strength and walking ability by using whole body massage, different strengthening and balance exercise, and treadmill training.

Conclusion The management of children with DS needs multidisciplinary approach to intervene in his/her body impairments, activity limitation and participation restriction. On physiotherapy, the articles I included supported different strengthening and balance exercises, treadmill training and massage when added to other exercises.

Keywords: Down's syndrome; motor development; physiotherapy intervention; children.

---

* Corresponding author.

1. Aim of the guideline

This guideline is written for physiotherapists to get quick physiotherapeutic approach for the management of children with Down's syndrome (DS).

Physiotherapy, being one of the multidisciplinary team in caring for children with DS, plays its role to improve functional activities and participation for the children.

The physiotherapy interventions for DS are simple and feasible to apply for Ethiopian situation by getting training with physical therapists.

2. Introduction

2.1. Definition

Down's syndrome is a genetic disorder caused by the presence of all or part of a third copy of chromosome21[1].

2.2. Prevalence

Globally, as of 2010, Down syndrome occurs in about 1 per 1000 births [2] and results in about 17,000 deaths In developing countries, many children with DS die in childhood from infections and congenital heart defects [3]. The annual mortality rate per 100,000 people from Down's syndrome in Ethiopia has decreased by 68.9% since 1990, an average of 3.0% a year [4].

2.3. Etiology

With most cases of Down's syndrome, the baby gets an extra chromosome 21, which gives him/her a total of 47 chromosomes [5].

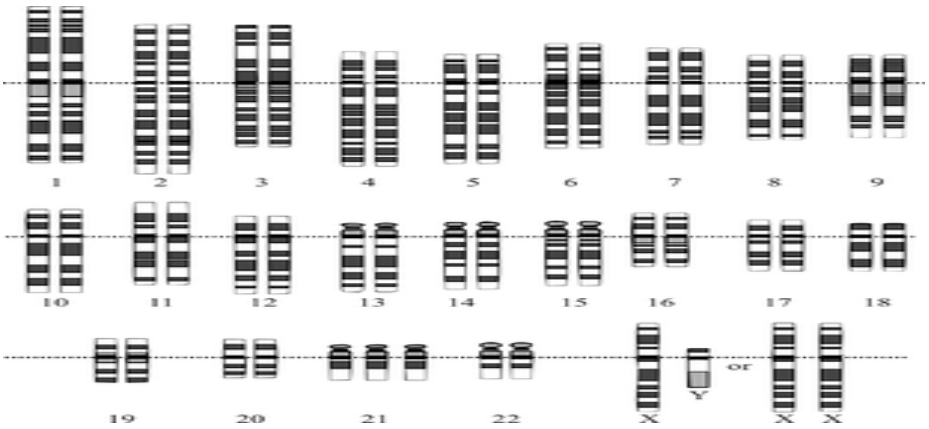

Figure 1: Karyotype for trisomy Down syndrome: Notice the three copies of chromosome 21.

Other causes of DS are: Robertsonian translocation which occurs only in 2-4% of the cases, the long arm of the chromosome 21 is attached to another chromosome (generally chromosome 14), and mosaicism (20-4%) some cells have the normal number of chromosomes, and others with an extra number 21 [6].

2.4. Signs and Symptoms

1. Developmental delay

The reduced size of the cerebrum, brain maturation disorders, and pathophysiological processes lead to motor development delay [7].

Hypotonia

- ✓ Hypotonia, which is nearly universal at birth tends to improve with age.
- ✓ Severe hypotonia in the first year of life leads to delay in reaching motor milestones; difficulty to learn turn over, sit, stand and walk. And also no head balance and incomplete Moro reflex.

2. Developmental Dysplasia of the Hip

- ✓ Acquired hip dislocation occurs in up to 30% of children with DS [8].

Figure 2: Dislocation of right hip examined (positive Galeazzi test).

3. Heart

The rate of congenital heart disease in newborns with Down's syndrome is around 40%.Of those with heart disease, about 80% have an atrioventricular septal defect or ventricular septal defect with the former being more common [9].

4. Respiratory disorders

Respiratory disease is a common cause of morbidity and mortality in children with Down's syndrome (DS). Causes range from those problems common to many children with DS, such as a narrow airway or impaired immunity, to rare structural lesions, such as tracheal bronchus [10].

5. Visual

More than half of children with DS have ocular abnormalities. In addition to ocular features related to DS such as epicanthal folds, narrowed or slanted palpebral fissures (the mongoloid slant) and Brushfield spots (38–85%) (Fig.4), these vision disorders include strabismus (20–47%), nystagmus (11–29%), congenital cataract (4–7%), acquired cataract (3–15%), blepharitis (7–41%), refractive errors (43–70%) and glaucoma (0.7%). Keratoconus is rare in childhood but develops later in life in individuals with DS [11].

6. Learning disabilities

Their Intelligence Quotient (IQ) level is always lower than their equivalent friends but the level of intellectual disability varies from moderate to severe. Their intelligence quotient decreases in the first of life. In adolescence, cognitive function may reach a plateau that persists in adulthood. Mental development shows a deceleration between the ages of 6 months and 2 years [12].

7. Behavioral changes

The most frequent problems are disruptive behavior disorders, such as attention deficit hyperactivity disorder (6.1%), conduct/oppositional disorder (5.4%) or aggressive behavior (6.5%). Epilepsy is seen in 8% of children with DS, with 40% occurring in infancy and often presenting as infantile spasms [13].

8. Appearance of the face

- ✓ A small, round, flat face
- ✓ Upward slanting eyes
- ✓ Small chin
- ✓ Microcephally (small head circumference)
- ✓ Small, malformed and low set ears
- ✓ Short neck
- ✓ Flat nasal bridge
- ✓ Protruding tongue due to small mouth

9. Appearance of the hands

- ✓ A single palmar crease on one or both hands (Simian crease)
- ✓ Brachydactyly -Abnormal pattern of fingerprint and short fingers.

10. Appearance of the feet

- ✓ Short and broad feet
- ✓ Sandal gap- wide gap between large and second toe

2.5. Prognosis

Efforts such as early childhood intervention, screening for common problems, medical treatment where indicated, a good family environment, and work-related training can improve the development of children with Down's syndrome.[14]

2.6. Problems according to ICF-CY with measurements to objectify in brackets

Table 1

Body structure and function	**Activity limitation**	**Participation restriction**
Low muscle tone (Amiel Tison) Syndromal signs: Upward slanted eyes, small stature and short neck, flat nasal bridge, protruding tongue, single, deep palmar crease, short and broad feet, large space between large and second toe(all by observation) Cardio respiratory problems (chart review+ huffing/coughing) Developmental dysplasia(Galleazi test) Learning disabilities (asking simple critical questions) Behavioral problems (asking the caregivers, observing)	Delayed motor mile stones (GMFM) Frequent falling (history) delayed side lying (GMFM) Difficulty to come from supine to sitting(GMFM)Difficulty standing from sitting(GMFM) Difficulty walking (6 min walk test) Low level of balance (observation, GMFM)	Unable to play outside (PEDI) Difficulty in ADL activities (PEDI)
Personal factors	**Environmental factors**	
Not motivated to do exercises (observation) Emotional stress (observation) Low level of IQ (asking simple age-related critical thinking questions)	Over care from parents (observation)	

3. Method

Searching strategy

PubMed database and PEDro by using search strategies such as "Down's syndrome AND children AND motor development", "Down's syndrome AND children AND intervention", "Down's syndrome AND children AND physiotherapy intervention" and others.

Inclusion criteria

Full text publications from 2001 to 2013 published in English language were included. Studies which are exclusively for adults were excluded.

Critical Appraisal

Randomized controlled trials that were included in this guideline were rated using a checklist called PEDro

scale. The scale contains a total of 11 items, of which 10 items assess the internal validity. The first criterion which eligibility criterion does not contribute to total score, so the maximum score is 10.

4. Results on search

In the following table, results of the five publications which were used for this guideline are described. The searches were done to have evidence based intervention for children with Down's syndrome. Out of the whole publications, the four articles focused on functional activities and the one is on body structure and function.

Table 2

Author/ year	level	Intervention	Results	recommendation
Shields and Taylor, 2010	RCT, level B	6 exercises using weight machines:3 for upper limbs -lat (latissimus dorsi) pull down, seated chest press & seated row and 3 for lower limbs -knee extension, calf raise & seated leg press	The exp'tal group demonstrated improvement in lower limb muscle strength	follow-up studies as to whether the effects of the intervention were maintained and any longer term outcomes
Gupta S and his colleagues 2011	RCT, level B	resistance exercise using sandbags and balance training using balance beam and trampoline for the lower limbs	Children in the intervention group showed significant improvement in lower limb strength and balance	follow-up studies with larger sample size and more objective measures of balance
Ulrich DA and his colleagues 2001	RCT, level B	stepping on a small motorized treadmill, 5 days/week, for 8 min/day in their own homes	The experimental group learnt to walk with help and without help significantly (73.8 days and 101days, resp.)	Future studies should focus on manipulating the treadmill training procedures in an attempt to reduce the delay in walking onset more dramatically and to evaluate the impact on the child's gait pattern.
Shields N and his colleagues 2013	RCT, level B	7strengthening exercises: 3 for upper limbs, 3 for lower limbs and one for the trunk) in 3 sets of 12 repetitions or until muscle fatigue	1.muscle strength= in favor of intervention group in UE (at week 11), LE (at week 11 & 24) 2.physical activity levels= in favor of intervention group(at week 24)	further studies with more established outcome measures
M.Hernandez-Reif and his colleagues 2006	RCT, level B	whole body massage therapy in addition to early intervention	Greater gains for the treatment group interms of fine and gross motor language dev't, arm and leg muscle tone	further studies with more established outcome measures

5. Conclusion of included studies

In developing countries, life expectancy of children with DS is lower than in developed counties. This is due to the fact that early medical attention and intervention is done in developed countries.

Physical therapy is very important for children with Down's syndrome to improve their motor learning abilities and their functional activities.

All the articles that are included for this guideline supported different types of physiotherapy managements. Three article of the articles [15,16,17], studied on strengthening exercises and the results were significant. The exercise can be done at home or in physiotherapy centers which is feasible to the local situation.

The other article is on treadmill training- Ulrich and his colleagues 2001, showed that involving treadmill training of infants with DS provides support for its use as an early intervention approach to facilitate earlier onset of independent walking. This exercise can been feasible in big hospitals.

The last article was on massage therapy- Hernandez Reifa & Moraa, 2006, showed that when added to an early Intervention program, massage therapy may enhance motor functioning and limb muscle tone for young children with Down syndrome. As a local situation these therapy is feasible to perform in physiotherapy centers.

As a physical therapist the interventions that are performed for children with DS are simple, which is feasible for the local situation and improves the child's fine and gross motor functioning. This can be achieved by instructing the parents to stimulate the child in daily activities.

6. Conclusion and summary

Down's syndrome is a condition which is occurred due to chromosomal abnormality which occurs by chance during fertilization. As a result, the child with this abnormality shows typical physical and mental features as well as cardiac problems. The most common features are typical face with protruded tongue and upward slanted eyes and also lower IQ than their peers. In developing countries, like Ethiopia, the life expectancy is lower than the developed countries. This is due to the presence of early intervention and better medical conditions in the developed countries. The management of children with DS needs multidisciplinary approach to intervene in his/her body impairments, activity limitation and participation restriction. Physiotherapy being one of the team plays its role to manage the activity limitation and participation restriction. The interventions are different according to age and level of development. For example treadmill training is given for those who could sit independently for 30 seconds and progressive resistance training for those who can, at least, walk. In Ethiopian situation, CBR workers are doing good jobs by assisting children home to home. So, physiotherapist should communicate with them how to manage children with DS by physiotherapy intervention techniques so that their quality of life in social functioning will be high.

7. General physiotherapy assessment of a child with Down's syndrome

Subjective assessment

- demographic details
- chief complaint
- pregnancy history

- investigation (if any)
- associated medical problems
- medication

Objective assessment

- observation
- vital sign
- examination (vision, communication)
- assessment tools- Amiel Tison , GMFM
- problem list
- diagnosis/differential diagnosis
- treatment
- evaluation

Progress note:

Subjective (S)-

Objective (O)-

Analysis (A)-

Plan (P)-

8. Physiotherapy assessment of a child with Down's syndrome

Subjective Assessment

Demographic details:

Request for help of child: What are you worried about? What do you hope to accomplish first in therapy?

Pregnancy history:

Did have pregnancy follow up?

Is there any abnormality told by your physician?

Medical history

Has your child been sick or hospitalized? When did your child last visit a physician or health care provider?

Developmental history

In what function do you suspect delay?

At what age he or she held the head upright?

At what age she/he rolled over?

At what age he/she sat unsupported?

At what age he/she crawled?

At what age he/she stood?

At what age she/ he walked?

Can he/she hold objects by his hands?

Can he throw a ball by one/both hands?

Can you understand his/her speaking?

How he/she is behaving at home?

Can he/she play outside?

- The above developmental milestone questions should beconsidered in objective assessment to observe the quality and how the activities are performed in addition to the quantitative tools.

Initial hypothesis

- ✓ Decreased tone (Amiel Tison)- due to floppiness
- ✓ Muscle weakness (RM, MMT)- due to difficulty in movement
- ✓ Developmental delay (GMFM, Child Development Poster)- due to floppiness, muscle weakness
- ✓ Developmental dysplasia of hip (Galeazzi test)- due to unable/difficulty of walking
- ✓ Low level of balance (GMFM selected items)- due to frequent falling
- ✓ Low IQ (asking simple critical thinking questions)- due to genetic factors
- ✓ Respiratory problems (huffing/coughing)- due to muscle weakness

Objective assessment

Observation

Physical examination: by using the tools- Amiel Tison, RM, MMT,GMFM, Child Development Poster,

Galleazzi test, asking simple critical thinking questions, huffing/coughing

Physiotherapy diagnosis – chief complaint+ activity limitation +participation restriction due to low tone/muscle weakness/low IQ

Problem list

- ✓ hypotonia
- ✓ muscle weakness
- ✓ developmental delay
- ✓ developmental dysplasia
- ✓ low IQ
- ✓ respiratory problems

Potential goals of Physiotherapy

- ✓ to be able to hold their head up on their own
- ✓ to be able to sit on the floor on their own without support
- ✓ to be able to take weight through their legs when placed in a standing position
- ✓ to be able to walk on their own
- ✓ To increase their balance
- ✓ to improve muscle tone
- ✓ to increase muscle strength
- ✓ to alleviate respiratory complications
- ✓ To improve their ADL activities

9. Management

A variety of therapies can be used in early intervention programs and throughout a person's life to promote the greatest possible development, independence and productivity.[18] The members of the team include:

- Physicians- to manage complications and medical problems
- Speech therapists- to improve communication skills and use language more effectively
- Occupational therapists- to adjust everyday tasks and conditions to match a person's needs and abilities
- Orthotic specialist- to adjust feet position
- Physical therapist- to perform activities and exercises that help build motor skills, increase muscle strength, and improve posture and balance.
- CBR workers- doing the interventions prescribed by physiotherapists in home to home way.

10. Physiotherapy Intervention of a child with Down's syndrome (from the identified articles)

I. Whole body massages (twice per week for 30min) - this can be done based on body regions such as face,

upper limbs, and lower limbs.

II. Exercises

1.Exercise to train walking-stepping on a small motorized treadmill, 5 days/week, for 8 min/day.[18]

2. Exercise to strengthen upper and lower limbs (**Shields and Taylor, 2010)(14-22years).[15] -** 3 sets of 12 repetitions, each for 10 weeks, twice a week.

Exercises using weight machines or sand bags

✓For upper limbs –

A/ lat pull down

B/ seated chest press

C/ seated row

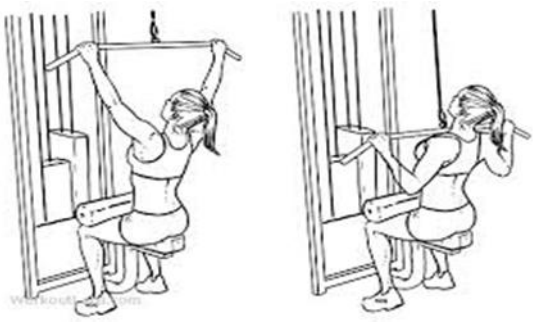

Figure 3: lat pull down.

Figure 4: Seated row.

✓For lower limbs –

A/ knee extension/flexion

B/ calf raise

C/ seated leg press

3. Exercise for balance (7-15 years of old) [19]

Initially 10 repetitions and increased by 5 rep, if easily done, for six weeks, 3 times a week.

- ✓ horizontal jumps,
- ✓ vertical jumps,
- ✓ one leg stance with eye open,
- ✓ tandem stance,
- ✓ walking on line,
- ✓ walking on balance beam,
- ✓ jumping on a trampoline

Referral to other services:

- ✓ for medical problems and other interventions

10.1. Evaluation of intervention

It is important to evaluate the interventions by using the tools described above in every follow up in SOAP (subjective, objective, activities and plan) progress note so that checking the progress of the child in activity and participation.

10.2. Follow-up

Children who did not finish developmental milestones need once in two months period follow up together with advice to his/her caregivers, but those who finished the milestones need follow up for the exercise at least twice a week.

Reference

[1]. Patterson, "Molecular genetic analysis of Down syndrome.". Human Genetics., 2009. **126(1):** : p. 195-214.

[2]. Weijerman, M.d.W., JP, Clinical practice. The care of children with Down syndrome. European journal of pedatrics, 2010. **12**(169): p. 1445–52.

[3]. Kliegma, R.M.t.e.P.p.C., Down Syndrome and Other Abnormalities of Chromosome Number. 19th ed.

2011: Nelson textbook of pediatrics: Saunders.

[4]. Global Burden of Disease Study (ghdx.healthdata.org). 2013.

[5]. Virji-Babul, A.E., D Kisly, J Down, RHA Haslam, Use of health care guidelines in patients with Down syndrome by family physicians across Canada. Paediatr Child Health, 2007. **12**(3): p. 179-183.

[6]. Liz Marder, o.C.M., Guideline for the Management of Children with Down Syndrome 2016.

[7]. Malak, R., et al., Delays in Motor Development in Children with Down Syndrom. Med Sci Monit, 2015. **21**: p. 1904-1910.

[8]. Hickey F, H.E., Summer KL, Medical update for children with Down's syndrome for pediatrician and family Practitioner Advances in Pediatrics, 2012. **59(1):**: p. 137-57.

[9]. Cowie, v.a., A study of the early development of mongols. . Oxford: pergamon press ltd. , 1970.

[10]. Rachel Watts, H.V., An overview of respiratory problems in children with Down's syndrome. BMJ Publishing Group Limited., 2013. **98**(10).

[11]. Stephen E et al., Dickson J, Kindley AD et al, Surveillance of vision and ocular disorders in children with Down syndrome. . Dev Med Child Neurol, 2007. **49**: p. 513–515.

[12]. Connolly, B.H.M., B.T, Performance of retarded children, with and without Down's syndrome, on the Bruininks Oseretsky test of motor proficiency. . Physical Therapy, 1986. **66**: p. 344- 348.

[13]. Block, M.E., Motor development in children with Down's syndrome: a review of the literature. Adapted Physical Activity Quarterly. 1991. **8**: p. 179-209

[14]. Cunningham, c.c., Down's syndrome: anintroduction for parents. London. souvenir press. , 1982.

[15]. Shields N, T.N., Wee E, Wollersheim d, O'shea Sd, Fernhall b, . A community-based strength training programme increases muscle strength and physical activity in young people with Down syndrome. Research in Developmental Disabilities. Journal of intellectual disability research, 2013. **34**: p. 4385-4394.

[16]. Gupta S, R.B., Sd K, Effect of strength and balance training in children with Down's syndrome. Clinical Rehabilitation, 2011. **25**(5): p. 425-432.

[17]. Taylor, N.S.a.N.F., A student-led progressive resistance training program increases lower limb muscle strength in adolescents with Down syndrome. Journal of Physiotherapy, 2010. **56**: p. 187-193.

[18]. Ulrich DA, U.B., Angulo-Kinzler RM Yun J . Treadmill training of infants with Down syndrome: evidence-based developmental outcomes. . Pediatrics, 2001. **108**: p. 84-90.

[19]. Gupta S, R.B., SD K Effect of strength and balance training in children with Down's syndrome. Clinical Rehabilitation, 2011. **25**: p. 425-432.