



Profile of physiotherapy intervention for Down syndrome children

Perfil do atendimento fisioterapêutico às crianças com Síndrome de Down

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Abstract

Introduction: Down Syndrome (DS) is a genetic disorder that causes global delay in development, including motor function, language and cognitive. Physiotherapy is offered from birth in order to stimulate the acquisition of motor skills. Early intervention presents most benefits, as neural plasticity is at its peak in the first months of life.

Objective: This study aimed to investigate the profile of physiotherapy intervention for children with DS during their first three years in specialized institutions. **Methods:** Data for this qualitative study were collected through semi-structured interviews, with 11 physiotherapists who worked in São Paulo coastal and metropolitan areas.

Results: Results indicate that, although most professionals use the internet as a means to being up-to-date, and doing specialized courses, not always in pediatric neurology, they felt safe to work in the area shortly after graduation, using the principles of Bobath Concept, characterized by 30-minute therapies, with a frequency of once to twice per week to guide treatment. **Conclusion:** Data should serve as a basis for parents' reflections, who must seek to know the experience of therapists who attend to their children, as well as institutions to encourage professionals to update their knowledge and search for appropriate expertise, in order to optimize therapy.

Keywords: Down Syndrome. Early Stimulation. Physiotherapy.

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Resumo

Introdução: A Síndrome de Down (SD) é um distúrbio genético que acarreta atraso global no desenvolvimento, incluindo funções motoras, linguagem e cognitivo. O tratamento fisioterapêutico é indicado desde o nascimento, visando estimular a aquisição de habilidades motoras. Quanto mais precoce for o tratamento, mais beneficiada poderá ser a criança, pois a plasticidade neural tem sua maior intensidade nos primeiros meses de vida.

Objetivo: Este estudo teve como objetivo investigar o perfil do atendimento fisioterapêutico às crianças com SD, nos primeiros três anos de idade, em instituições especializadas. **Métodos:** Tratou-se de um estudo qualitativo, sendo a coleta de dados realizada a partir de entrevistas semi-estruturadas, com 11 fisioterapeutas que atuavam em cidades do litoral paulista e da região metropolitana de São Paulo. **Resultados:** Os resultados indicam que, apesar da maioria dos profissionais utilizarem a internet como meio para atualização e terem cursos de especialização nem sempre na área de neuropediatria, sentiam-se seguros para trabalhar na área logo após a graduação, utilizando os princípios do Conceito Bobath para nortear o tratamento, caracterizado por terapias de 30 minutos com frequência de uma a duas vezes por semana. **Conclusão:** Esses dados devem servir como base para a reflexão dos pais, que devem buscar conhecer quais são as experiências dos fisioterapeutas que atenderão seus filhos, e das instituições especializadas, que devem incentivar os profissionais na busca de uma especialização adequada, visando melhor qualidade e aproveitamento terapêutico.

Palavras-chave: Síndrome de Down. Estimulação Precoce. Fisioterapia.

Introduction

Prevalence of Down syndrome (DS) is around 1 to 800 newborn babies, a ratio of 3:1 (male: female). There are 8.000 cases of DS a year in Brazil and incidence increases as maternal age increases, with a ratio of 1:350 at 35 years and 1:110 at 40 years. A 45-year-old woman is sixty times more prone to have a Down syndrome baby when compared to a 20-year-old (1 - 3).

Parents have to deal with different feelings at the birth of a DS baby, facing shock and fear, not always receiving much needed support and care. Physicians are not always prepared to break the news and parents are anxious facing the situation and especially when envisioning the child's future (4). Feelings of disappointment, rage, frustration and guilt are dominant and after a stage of shock, parents start to create positive prospects and provide care for the child to have a better quality of life, offering different interventions for her/his development. At this stage, the physiotherapist has to attend to and guide the family on specific procedures to stimulate child's development. Besides, there must be a concern to all professionals involved with the bonding between child and family (5 - 7).

It is fundamental that staff involved with families acquire more knowledge of the dynamics they go through, being able to understand them, allowing them the time to process information received. Parents must have their doubts solved, and must receive as much

information on disability as possible, for those factors will be prominent in their choice of procedures and resources to treat their children (8 - 10).

Interventions offered to DS children outdo the medical area only. Nowadays, therapeutic interventions aim interdisciplinarity, including physicians, psychologists, speech therapists, physiotherapists, occupational therapists and teachers. Teamwork will be effective only when all staff are regarded as having the same level of importance (7, 11).

After the disclosure of diagnosis to parents, health team must show the family the importance of starting early stimulation, referring the child to specialized programs made of occupational therapists, physiotherapists and speech therapists (7, 11, 12).

Early stimulation is a global, educational and empowering intervention, aiming to assist and stimulate postures supporting the disabled child's motor and cognitive development, using different stimuli that will have impact in the child's maturation. It is based in exercises according to the stage the child is in, targeting her/his development. The child must be referred to early stimulation preferably before three years, for that is the stage of greater neural plasticity. The more immediate the interventions, the higher the chances of minimize, or prevent, developmental modifications (13 - 19).

Physiotherapists normally view DS children and their families in intervention services, and plan treatment stemming from their knowledge and

specialization in different physiotherapy techniques, concepts and methods, all of them aiming to provide the DS child with more opportunities to acquire motor abilities, longevity and better life quality, enhancing the developmental process.

It is important to note that staff working in institutions are not always able to perform those interventions. Consequently, it is essential that they search for knowledge to assure effective interventions, because the most marked changes and acquisitions in motor behavior happen in the first three years of life. Those are the facts that justify the importance of this study that aimed to investigate how physiotherapists work in specialized institutions with DS children intervention, in the first three years of life. Specifically, it aimed to know the physiotherapist's perception of his/her academic formation to work in neuropsychiatry, to identify interests in further studies in child neurology, as well as the methods, techniques and concepts they chose from the therapeutic resources available.

Methods

The study was described as qualitative, with a convenience sample, as participants were selected from those who agreed to participate and were part of the institutions contacted. The group was composed by 11 physiotherapists, male and female, without age limits. Inclusion criteria were professionals, who graduated past 2 years, working in neuropsychiatry at least for one year, with 0-to-3-year-old DS children. After approval by the U. Presbiteriana Mackenzie Ethics Committee, process no 1253/06/2010, all participants received the information letter and signed the consent term, informed that they could leave the study at any time. Institutions also received the information letter and the people in charge signed the consent term, allowing the data to be collected in their premises.

Data were collected in five specialized institutions in São Paulo Metropolitan area (Barueri) and South Coastal area of São Paulo State (Guarujá, Mongaguá, Santos, and São Vicente). A semi-structured interview based in a model (Figure 1) was used and information were recorded, as well as a demographic questionnaire, containing participants' information. The participants received information about the aims of the study, as well as the relevance of each one for the profile of institutional intervention for DS children.

1. Why did you chose to work in neuropsychiatry?
2. What were your studies in neuropsychiatry at college? Did you feel able to work in the area just after graduation?
3. Did you attend to further courses (Less than 360 hours)?
4. Did you attend to specialization, Master, Doctorate (lato sensu: more than 360 hours and stricto sensu)?
5. What is the intervention resource you tend to use with up to three-year-old DS children? Comment your choice.
6. Have you been attending to congresses? How to you seek refresher courses? Does your institution support your attendance? How?
7. Your activity is focused in:
() kinesiotherapy () hydrotherapy () equotherapy () others
8. What principles from which concepts, methods, or techniques are the base for your work?
9. Concerning interventions, how long and how many times a week is therapy?
10. Which tests do you believe are fundamental to assess your DS patients in their first three years?
11. How do you involve the family in treatment?
12. How do you understand interdisciplinarity at that stage of development?

Figure 1 - Model for semi-structured interview.

Individual interviews conducted in the institutions lasted 30 minutes and participants appeared calm. All recordings were transcribed and the 12 questions grouped in 6 categories for data analysis. Categories and subcategories are described in Table 1.

Table 1 - Categories for data analysis

| | Questions | Categories | Subcategories |
|-------------------|-------------|---|---|
| Category 1 | 1, and 2 | Identification with neuropsychiatry | |
| Category 2 | 3, 4, and 6 | Further and refresher courses | |
| Category 3 | 5, 7, and 8 | Physiotherapy resources | - Methods and techniques - Instruments |
| Category 4 | 11 | Family | |
| Category 5 | 12 | Interdisciplinarity | |
| Category 6 | 9, and 10 | Frequency of therapy and tests required | |

Results and Discussion

Table 2 shows information on the participants, identified as P1 to P11.

Table 2 - Participants' description

| Participants | Age | Sex | Time since graduation | Time in institution | Town |
|--------------|----------|-----|-----------------------|---------------------|-------------|
| P1 | 33 years | F | 12 years | 09 years | Barueri |
| P2 | 40 years | F | 18 years | 10 years | Guarujá |
| P3 | 30 years | F | 07 years | 05 years | Guarujá |
| P4 | 48 years | F | 26 years | 19 years | Guarujá |
| P5 | 28 years | F | 05 years | 03 years | Guarujá |
| P6 | 27 years | F | 05 years | 03 years | Guarujá |
| P7 | 30 years | F | 09 years | 02 years | Mongaguá |
| P8 | 27 years | F | 05 years | 01 year | São Vicente |
| P9 | 32 years | M | 10 years | 03 years | São Vicente |
| P10 | 32 years | F | 10 years | 09 years | Santos |
| P11 | 32 years | F | 09 years | 07 years | Santos |

Analysis of Interviews:

Category 1 - Identification with neuropsychiatry

It can be noticed from the interviews that two from the 11 physiotherapists chose to work in neuropsychiatry due to having a disabled family member; six chose the area for identification with children since graduation, two due to being a job offer when they were not professionally defined, and one chose to work due to all those factors.

"I started Physiotherapy because I have a disabled family member; then I already wanted to work with child when I started" (P11).

"I chose this area because I always liked children, because I have an autistic niece in my family and it was also a job opportunity for me" (P9).

Concerning their ability to work in neuropsychiatry after graduation, eight participants reported being able to do it, due to their experiences at University, in supervised internship and having very competent lecturers, whose ability to teach led to the participants being confident at work. The others did not

feel completely skilled, as they had very basic, not complex information at University.

"As soon as I left University, I didn't have much skill and confidence to work with children, but when I attended Bobath classes, this changed, as I felt more competent and confident to work in neuropsychiatry" (P1).

"I consider the level of knowledge I received at University as excellent, as my lecturers had published book chapters. That gave me confidence to work as soon as I graduated" (P9).

Category 2 - Further and refresher courses

Among the participants, nine physiotherapists attended courses in neuropsychiatry, with less than 360 hours; one attended courses not related to neuropsychiatry and one did not attend to any course. Courses considered were within the areas of neuropsychiatry and neurology, as well as involving the swimming pool in treatment, and interventions using the ball.

Considering *latu sensu* and *stricto sensu*, four participants attended postgraduate studies in neuropsychiatry, two attended in neurology; two attended in different areas than Physiotherapy and three never attended postgraduate courses. Those three physiotherapists just attended courses with less than 360h and reported that would like to attend to a postgraduate course in neuropsychiatry. Table 3 shows the courses in detail.

Table 3 - Courses attended by the participants according to number of hours (To be continued)

| Participants | Courses with 360h | Courses with more than 360h |
|--------------|--|---|
| P1 | Bobath Baby Course Baby Motor Coordination Balance Postural Adequacy Sensory Integration Global Postural Reeducation Thoracic-Abdominal Rebalancing | Postgraduation in Neurophysiotherapy |
| P2 | Hydrotherapy | Post-graduation in Pediatric Physiotherapy |
| P3 | — | Post-graduation in Woman's Health |

Table 3 - Courses attended by the participants according to number of hours (Conclusion)

| | | |
|-----|---|---|
| P4 | Bobath Baby Course Hemiplegia Global Postural Reeducation | Post-graduation in Family Health Program Post-graduation in Traumato-orthopedics Refresher course in Neurology |
| P5 | Refresher course in Neurology Global Postural Reeducation | Refresher course in Neuropediatrics Advanced course in Neurology and Physiotherapy Intervention |
| P6 | Watsu WaterPilates Bad Ragaz Psychomotricity in water Neuropediatrics in water | — |
| P7 | Global Postural Reeducation Ergonomics and Preventive Physiotherapy | — |
| P8 | Postural Reeducation on ball Techniques of complementary treatments (shiatsu and bamboo therapy) | Specialization in Dermato-functional |
| P9 | Wii rehabilitation Postural exercises on Swiss ball | — |
| P10 | Pilates Hydro-kinesiotherapy Assessment according to Hunst Curres | Post-graduation in Pediatrics Course on Nervous System Neuro- functional Rehabilitation Course on Early Stimulation |
| P11 | Hydrotherapy Ground Pilates | Post-graduation in Neuropediatrics |

It is important to note that some of the participants were specialized in areas without relation to neuropediatrics, being an indication that those professionals not always have skills to strengthen DS child's development while in treatment.

When questioned regarding their attendance to courses, congresses, conferences, or meetings, and whether or not their institutions allowed and encouraged their participation, 9 physiotherapists answered that they looked for internet sites, or papers to update their knowledge and the others looked for courses. Ten participants reported that their institutions allowed them to participate in congresses, conferences, or meetings, although without financial support. However, when participating in congresses,

conferences, or meetings, they do not present papers, or posters, only attend as listeners.

"I normally tend to search for updates in internet sites, or papers in journals. Currently, I cannot go to conferences because I have a young son" (P3).

"This institution allows some days to participate in congresses, but only when it is possible. They allow five days, once a year" (P5).

According to data, the great majority of participants improved and updated their curriculum after graduation via courses shorter or longer than 360 hours in their areas. According to COFFITO (20) this search for improving their knowledge is fundamental to determine quality of intervention and the benefits offered to the children during treatment. Actually, according to Coury and Vilella (21), physiotherapy as a profession is recent in Brazil, having commemorated 40 years of recognition as an University level course in 2009, and there are very few Brazilian physiotherapists with the title of master and doctorate. That could justify the absence of physiotherapists with stricto sensu titles in this study.

Category 3 - Physiotherapeutic resources

This category was divided into two subcategories: Methods and techniques (incorporating principles of treatment based in courses and concentration areas, such as hydrotherapy, kinesiology, and equotherapy) and Instruments (materials used in treatment).

Subcategory 1: Methods and Techniques

The majority of participants used Bobath when treating DS children; from the sample, 10 used Bobath and one used swimming-pool based techniques (Bad Ragaz, Watsu). From the participants who used Bobath, 4 only used Bobath, 2 used Bobath and Kabat and 4 used Bobath combined with other techniques, such as sensory stimulation, Thoracic-Abdominal Rebalancing, Balance and Shantala.

Concerning the area of expertise, 10 participants reported kinesiotherapy and one, hydrotherapy as their main areas.

"Here, we normally use a lot of Bobath and sensory stimulation in those children at that age" (P2).

"I end up using a bit of each technique, Watsu for relaxation and Bag Ragaz, when I want to strengthen some muscle. I also use a lot of stretching inside the pool" (P6).

Data show that 10 of the participants used Bobath during treatment; however, when we compared with Table 3, only 2 had a Bobath course with less than 360 hours. The same can be observed with Kabat and Shantala, as Kabat is reported by 2 participants, but none had the course in Kabat and, although Shantala is reported by one participant, there was no Shantala course in the curriculum.

That might be an indication that the content related to those techniques was learned during University, without the need for further courses. Nevertheless, the knowledge obtained in graduation is related to a more generalist and there is expectancy that definition for a specific area be followed by further courses to deepen theoretical and practical issues.

Subcategory 2: Instruments

Participants reported the following instruments as the main used in treatment of DS children up to 3 years of age: balls, rolls, stairs, and light and sound toys. From the total sample, 8 physiotherapists used those instruments during treatment; 2 reported using all those instruments above plus balance board, texture toys and sensory stimulators (balance); and one physiotherapist used specific swimming-pool instruments (floaters, boards, dumbbells).

"On the course of treatment with children at that age, I use many playful exercises, such as light and sound toys. I treat the child through playing activities that will stimulate, without her noticing the treatment. And the child is calm during therapy" (P7).

"I use the ball a lot with the children I treat because I follow Bobath very much" (P9).

Category 4 - Family

When participants were asked to explain the ways they involve the DS children's families in treatment,

all of the physiotherapists reported that the family participate on physiotherapy treatment, receiving all information and guidance to continue treatment at home, stimulating the child to provide positive inputs to his/her development. Participants said that families are encouraged to verbalize their doubts concerning their children, and to have those doubts explained, which is important for development.

Professional attitude is fundamental to family acceptance and adaptation to a new routine, especially early stimulation, due to mothers' emotional reactions. Although the physiotherapists not always have technical and emotional training to deal with disability, he/she must be prepared to receive the family, as parents report that involvement in rehabilitation services is a major factor to improve adaptation to the new family situation (22).

"Parents always enter therapy. While I'm working, I give parents direction for them to do exercises at home. There are some parents that come here with acceptance issues, bonding issues; those I refer to the institution's psychologist" (P7).

"We treat children in dyads here. I direct parents to stimulate those children at home, for the treatment to continue, as time is short here. I explain them the aims and importance of exercises at home" (P1).

The presence of a family member during physiotherapy sessions and guidance offered are very important, as we know that those children spend much more time at home with the family, when compared with time spent on different therapies. According with literature, it is necessary that parents help stimulating children at home daily, because time spent on therapy is not always enough (23, 24). Some authors explain that the experience of having a DS child leads the family to face periods of uncertainty and doubts, requiring new attitudes to tackle the unknown. Weekly frequency of physiotherapy sessions sometimes seems not to attend to the child's needs and parents must learn how to stimulate the child at home (25). This attitude reinforces the idea that the carer must participate in the sessions, in order to feel safer and effectively help in the child's stimulating routine. However, other studies indicate that parents may feel less supported in maternities and not included in their children stimulation, as therapists not always consider relational aspects between them

and families. This is an alert for potential hindrances in communication between staff directly involved in stimulation and the families (26).

Category 5 - Interdisciplinarity

Concerning participants understanding of interdisciplinary interventions when treating DS children from birth to 3-year-old, all of them believe the interaction among different specialists very important, as different techniques may improve child's constitution, as well as advance cognitive and motor development. The importance of verbal communication among specialists was also stressed, as situations that happen in a specific treatment session may not be the same in others, and interaction will allow staff to know the interventions most needed in a given period of time. Those results are in accordance with Japiassu's (27) viewpoint on interdisciplinarity, as an exchange of knowledge among specialists from different areas aiming at the same purpose. That purpose is achieving a better result for the patient's treatment.

"In my viewpoint, interdisciplinary treatment is happening here at the institution, because there is a daily interaction of specialists (physiotherapist, occupational therapist, psychologist, and social assistant) during children's treatment as well as in monthly meetings" (P9).

Category 6 - Frequency of therapy and tests required

Concerning duration and frequency of physiotherapy sessions, 4 participants reported that institutions offer to DS children twice a week, 30-minute therapies; 2 participants, once a week, 30-minute, and 5 participants, once a week, 60 minute therapies.

Many different sorts of complementary tests were named as relevant by the participants, all of them to be checked in the beginning of treatment. Table 4 shows details of tests requested by participants.

Table 4 - Details of tests requested by participants
(To be continued)

| Participants | Tests |
|--------------|--|
| P1 | Karyotype, heart test, hip X-Ray, atlantoaxial X-ray, eyes and ear tests |
| P2 | Karyotype, heart test and metabolism tests |
| P3 | Heart test |
| P4 | Heart test and lower limbs X-ray |

Table 4 - Details of tests requested by participants

| | (Conclusion) |
|-----|---|
| P5 | Karyotype, metabolism tests, heart test and lower limbs X-ray |
| P6 | Heart test and lungs X-ray |
| P7 | — |
| P8 | Karyotype, heart test and metabolism tests |
| P9 | Karyotype, heart test and heel-prick test |
| P10 | Heart test, lower limbs X-ray, eyes and ear tests |
| P11 | Heart test and ear tests |

There is no reference in literature about duration and frequency of therapy considered more appropriate for positive treatment results. However, most authors seem to follow a mean duration of 60 minutes and one to three times a week sessions (28, 29). According with data of this research, only one of the institutions, where 5 of the participants work offers 60-minute sessions. Regarding the frequency of therapies, all of the institutions where the participants work are within the expected, although none of them offer three times a week sessions.

Only one participant does not require any kind of complementary tests before starting the treatment of DS children.

It is known that a DS child may manifest many clinical symptoms that present negative influence in cognitive or motor development. Therefore, it is important to require complementary tests before the beginning, or even in the course of treatment, depending on the child's age.

According to Mustacchi e Rozone (30) and Avery and Tausch (31), 50% of DS infants present some sort of cardiopathy, attesting the importance of examining those children's heart tests before starting any treatment. Thus ten participants consider it relevant to examine heart tests, according to literature.

Wang (1) explains that atlantoaxial instability is another clinical manifestation present in 15% a 20% DS patients moreover. That must be considered an important factor to determine the kind of treatment to be implemented with the child, in order to avoid further complications. The precise test assessing that orthopaedic anomaly was cited by only one of the participants and must be required from 36 months on (32).

Metabolic questions cited by three of the participants also must be investigated, as thyroid alterations, when early diagnosed and treated direct benefits for physical and intellectual development of DS children (33).

Tests for vision, hearing, heart, metabolic dosages, and orthopaedic anomalies are important to be considered by the physiotherapist, as means of minimizing developmental anomalies of DS children. Interdisciplinarity among health staff should provide all professionals with the results of those investigations, aiming the potentiating of global development stemming from health attention and education of DS children.

Conclusion

Concluding, professionals dealing with DS children in their early stages of development seem interested in that challenge, although not always searching for appropriate resources to work in the area. Family involvement during orientations, recognition of interdisciplinary work, and requesting of appropriate tests show the endeavour of some physiotherapists in the mission of potentiating child development. Institutions are also responsible for hiring competent professionals, motivating them in the search for specialization, creating favourable conditions in benefit of DS children.

It is also important for the parents to get to know the physiotherapists that will care for their children, showing concern for their experiences, knowledge on the syndrome, and their interests and possibilities for specialization and attendance to refresher courses. Staff that care for that population in specialized institutions also must be motivated to constantly search for knowledge and new research in the subject.

This research had some limitations, especially concerning theoretical foundations, as there are few studies available on this subject, although treatment of DS children from birth to 3 years of age must be reinforced, due to emergence of important motor beacons for development, as well as the high level of neural plasticity observed in that period.

As there are still few studies on this subject, which is relevant to an effective physiotherapy treatment for DS children up to three years of age in specialized institutions, further studies are suggested. Studies with a larger sample and discussion on responsibilities and needs for permanent specialization might lead to better prepared professionals to deal with DS children at that developmental stage.

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