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Therapeutic pathways in speech-language pathology care for Down syndrome

Itinerários terapêuticos no cuidado fonoaudiológico na Síndrome de Down

Vías terapéuticas en la atención logopédica para el síndrome de Down

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Abstract

Introduction: Down syndrome involves complex care demands, especially in communication, requiring continuous and coordinated speech-language therapy follow-up. Therapeutic itineraries allow us to understand the paths families take in accessing and maintaining care. **Objective:** To analyze the therapeutic itineraries in the speech-language care of children with Down syndrome, from the perspective of their families. **Method:** A qualitative, exploratory, and descriptive study was conducted with 20 mothers of children receiving speech-language therapy in public, private, or philanthropic services. Data were collected through semi-structured interviews and analyzed using content analysis. **Results:** There was a predominance of access to private services (75%) and variable initiation of follow-up, with 50% starting three months after diagnosis. Access occurred mainly through internal referrals (45%), in addition to external referrals and active outreach. All itineraries showed changes, mainly due to the search for better approaches. Challenges related to feeding, communication, and the scarcity of professionals, as well as interruptions in care, were highlighted. Family engagement and professional conduct were highlighted as facilitating factors. The evaluation was predominantly positive, valuing the bond and listening. **Conclusion:** The pathways are complex and non-linear, with weaknesses in access to and continuity of care, emphasizing family leadership and the need to strengthen networks and improve family-centered practices.

Keywords: Trisomy 21; Effective Access to Health Services; Child; Child Care; Speech-Language. Pathology.

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Resumo

Introdução: A Síndrome de Down envolve demandas complexas de cuidado, especialmente na comunicação, requerendo acompanhamento fonoaudiológico contínuo e articulado. Os itinerários terapêuticos permitem compreender os percursos das famílias no acesso e continuidade do cuidado. **Objetivo:** Analisar os itinerários terapêuticos no cuidado fonoaudiológico de crianças com Síndrome de Down, a partir da perspectiva de seus familiares. **Método:** Estudo qualitativo, exploratório e descritivo, com 20 mães de crianças em acompanhamento fonoaudiológico em serviços públicos, privados ou filantrópicos. Os dados foram coletados por entrevistas semiestruturadas e analisados por Análise de Conteúdo. **Resultados:** Houve predominância de acesso a serviços privados (75%) e início variável do acompanhamento, com 50% após três meses do diagnóstico. O acesso ocorreu principalmente por encaminhamento interno (45%), além de indicação externa e busca ativa. Todos os itinerários apresentaram mudanças, sobretudo pela busca por melhores abordagens. Destacaram-se desafios relacionados à alimentação, comunicação e escassez de profissionais, além de interrupções no atendimento. Como facilitadores, evidenciaram-se o engajamento familiar e a postura profissional. A avaliação foi majoritariamente positiva, com valorização do vínculo e da escuta. **Conclusão:** Os itinerários são complexos e não lineares, com fragilidades no acesso e continuidade do cuidado, destacando-se o protagonismo familiar e a necessidade de fortalecer redes e qualificar práticas centradas na família.

Palavras-chave: Trissomia do cromossomo 21; Acesso efetivo aos Serviços de Saúde; Criança; Cuidado da Criança; Fonoaudiologia.

Resumén

Introducción: El síndrome de Down implica necesidades de atención complejas, especialmente en la comunicación, lo que requiere un seguimiento continuo y coordinado de la terapia del habla y el lenguaje. Los itinerarios terapéuticos nos permiten comprender las rutas que siguen las familias para acceder y mantener la atención. **Objetivo:** Analizar los itinerarios terapéuticos en la atención del habla y el lenguaje de niños con síndrome de Down, desde la perspectiva de sus familias. **Método:** Se realizó un estudio cualitativo, exploratorio y descriptivo con 20 madres de niños que recibían terapia del habla y el lenguaje en servicios públicos, privados o filantrópicos. Los datos se recopilaron mediante entrevistas semiestructuradas y se analizaron mediante análisis de contenido. **Resultados:** Hubo un predominio del acceso a servicios privados (75%) y un inicio variable del seguimiento, con un 50% que comenzó tres meses después del diagnóstico. El acceso se produjo principalmente a través de derivaciones internas (45%), además de derivaciones externas y divulgación activa. Todos los itinerarios mostraron cambios, principalmente debido a la búsqueda de mejores enfoques. Se destacaron los desafíos relacionados con la alimentación, la comunicación y la escasez de profesionales, así como las interrupciones en la atención. La participación familiar y la conducta profesional se destacaron como factores facilitadores. La evaluación fue mayoritariamente positiva, valorando el vínculo y la capacidad de escucha. **Conclusión:** Los procesos son complejos y no lineales, con deficiencias en el acceso y la continuidad de la atención, lo que subraya la importancia del liderazgo familiar y la necesidad de fortalecer las redes y mejorar las prácticas centradas en la familia.

Palabras-clave: Trisomía del Cromosoma 21; Acceso Efectivo a los Servicios de Salud; Niño; Cuidado del Niño; Patología del Habla y Lenguaje.

Introduction

Down syndrome (DS), characterized by trisomy of chromosome 21, is the most common chromosomal abnormality associated with intellectual disability[1] and constitutes an important public health issue[2]. Its approximate incidence is estimated at 1 in every 650 to 1,000 pregnancies, highlighting its epidemiological impact and the need for systematic organization of care within the Brazilian Unified Health System (Sistema Único de Saúde – SUS)[3].

Care for individuals with DS involves multiple health needs, continuous follow-up, and the involvement of different healthcare professionals, including Speech-Language Pathology[4]. In this context, care should be provided comprehensively, considering clinical, social, and family-related aspects throughout the life cycle[5]. The organization of healthcare networks and interdisciplinary work are essential to ensure continuity of care and better therapeutic outcomes, in accordance with the principles of Public Health[6].

Within this context, the concept of the therapeutic itinerary has been used as an analytical tool to understand the pathways taken by individuals and families in their search for healthcare, including access to services, professionals, and care strategies[7]. The analysis of these itineraries makes it possible to identify barriers to access, patterns of organization of healthcare networks, and strategies employed by families to address their health needs[8].

The scientific literature has investigated therapeutic itineraries in different contexts and health conditions, such as among family members of children with Congenital Zika Virus Syndrome[9], children with Autism Spectrum Disorder[10], children with special healthcare needs[11], and individuals with hearing impairment[12], demonstrating the influence of service organization on care trajectories.

Despite these advances, studies specifically addressing the therapeutic itineraries of children with Down syndrome and their families remain scarce. In this context, investigating therapeutic itineraries in Speech-Language Pathology care is particularly important, as children with DS frequently present difficulties in communication and language, as well as alterations in orofacial structures and functions. However, access to and continuity of Speech-Language Pathology follow-up may be influenced by social and institutional factors, as well as by the organization of healthcare services[13].

Therefore, the present study aims to analyze therapeutic itineraries in Speech-Language Pathology care among children with Down syndrome from the perspective of their family members, seeking to understand the pathways followed to access, receive, and maintain continuity of care in Speech-Language Pathology services.

Method

The study was submitted to and approved by the Research Ethics Committee of the Institute of Health of Nova Friburgo, Fluminense Federal University, under approval number 8.236.276, in accordance with Resolution No. 466/2012 of the Brazilian National Health Council.

All participants were previously informed about the objectives, procedures, potential risks, and benefits of the study, and anonymity, confidentiality, and privacy of the information provided were ensured. Participation was voluntary and required the signing of the Informed Consent Form (ICF), with the right to withdraw from the study at any stage without any consequences or harm.

This was a qualitative study with an exploratory and descriptive design, grounded in the field of Public Health and based on the theoretical framework of therapeutic itineraries[7,8].

The study included female caregivers (mothers) responsible for children diagnosed with Down syndrome, aged up to 16 years, who were currently receiving or had previously received Speech-Language Pathology care in public, private, or philanthropic services. The inclusion criteria were being directly responsible for the child and having experienced the process of seeking and/or receiving Speech-Language Pathology care. Participants were excluded if they were not directly involved in the child's care or if they presented cognitive or communicative limitations that could preclude participation in the interview, as determined by a prior assessment conducted by the researchers.

Participants were selected through non-probability convenience sampling. Recruitment was conducted with the support of partner institutions, such as the Speech-Language Pathology and Dentistry teaching clinic of Health Institute of Nova Friburgo of Universidade Federal Fluminense (ISNF/UFF), healthcare services, and associations

supporting people with disabilities located in the mountainous region of the state of Rio de Janeiro.

Data were collected through individual semi-structured interviews guided by a previously developed interview script. The interviews were conducted by the researchers responsible for the study and lasted approximately 30 to 60 minutes. They could be conducted either in person or remotely (via videoconference), according to the participant's preference. With the participants' authorization, the interviews were audio-recorded and subsequently transcribed verbatim for analysis.

The data were analyzed using thematic Content Analysis, as proposed by Bardin[14]. Following the verbatim transcription of the interviews, an initial floating reading was performed, followed by an in-depth reading of the material, in order to identify units of meaning related to the study objectives. Subsequently, the content was coded and organized into thematic categories, considering the convergence and recurrence of meanings expressed in the participants' accounts. The categories were subsequently reviewed and grouped according to the emerging themes, while seeking to preserve the context and uniqueness of the participants' narratives. Frequencies of occurrence of the contents were used as a complementary measure to characterize the recurrence of specific themes, without replacing the qualitative interpretation of the data.

Results

Twenty mothers of children with Down syndrome participated in the study, with mothers accounting for the entire sample (100%) as the children's maternal caregivers. Most participants were aged 40–49 years (75%). Regarding educational attainment, a heterogeneous distribution was observed, with the highest proportions having completed secondary education (30%) and higher education (30%). Regarding the children, most were aged 3–6 years (50%). With respect to school enrollment, an equal distribution was observed between children attending public educational institutions (40%) and those not enrolled in an educational institution (40%). Regarding the type of Speech-Language Pathology service, care in private services predominated (75%). All children (100%) received interventions in addition to Speech-Language Pathology care (Table 1).

Table 1. General participant data

Variable	N (%)
Relationship of the person responsible	Mother – 20 (100%)
Age of the person in charge	30 to 39 years – 4 (20%) 40 to 49 years – 15 (75%) Over 50 years old – 1 (5%)
Education level of the person in charge	Ensino fundamental – 5 (25%) Ensino médio – 6 (30%) Ensino superior – 6 (30%) Pós-graduação – 3 (15%)
Child's age	Menos de 3 anos – 5 (25%) 3 a 6 anos – 10 (50%) 7 a 10 anos – 3 (15%) Maior que 10 anos – 2 (10%)
Type of educational institution	Pública – 8 (40%) Privada – 4 (20%) Não frequenta EI – 8 (40%)
Type of speech-language pathology service	Público – 5 (25%) Privado – 15 (75%)
Performs other interventions	Sim – 20 (100%) Não – 0 (0%)

Legend: N – total number of participants; % – percentage; EI – educational institution
Prepared by the authors

Most diagnoses were established during the perinatal period (55%). Regarding recommendations for Speech-Language Pathology follow-up, 70% of participants reported having received a recommendation to seek this type of care. The time elapsed before initiating Speech-Language Pathology follow-up varied among participants (Table 2).

Table 2. Baseline care pathway data

Variable	N (%)
Time of diagnosis	Prenatal (pregnancy) – 7 (35%) Perinatal (at birth) – 11 (55%) After birth – 2 (10%)
Was there a recommendation to seek speech therapy?	Yes – 14 (70%) No - 6 (30%)
How long does it take to start treatment with a speech-language pathologist?	Less than 1 month – 4 (20%) 1 to 3 months – 6 (30%) 3 to 6 months – 4 (20%) More than 6 months – 6 (30%)

Legend: N – total number of participants; % – percentage
Prepared by the authors

Access to Speech-Language Pathology care occurred primarily through internal referrals from healthcare services (45%). Participants (60%) reported changes throughout their therapeutic journey, either in the professional providing care or in the location where care was received. Among the reasons for these changes, the search for other professionals or therapeutic approaches was the most frequently reported (35%) (Table 3).

Table 3. Data on the speech-language pathology care pathway

Variable	N (%)
How did you come to receive speech therapy?	Internal referral – 9 (45%) External referral – 6 (30%) Self-initiated search – 5 (25%)
Have there been changes to the service location and/or the professional?	Yes – 12 (60%) No – 8 (40%)
What was the reason for the change?	No change – 8 (40%) Seeking another professional and/or therapeutic approach – 7 (35%) Internal change within the service itself – 3 (15%) Family and/or personal issues – 1 (5%) Financial issues – 1 (5%)

Legend: N – total number of participants; % – percentage
Prepared by the authors

Among the main challenges faced by the families, feeding-related demands were the most frequently reported (25%). Interruption of care was reported by a substantial proportion of participants, with the lack of available professionals being the main reason (30%). Regarding factors facilitating access to and continuity of care, family engagement was the most frequently reported facilitator (50%). Overall, the evaluation of Speech-Language Pathology care was predominantly positive, with 45% of participants rating the care as excellent. Most mothers (80%) reported that their opinions were considered throughout the therapeutic process. Among the aspects considered most important, the professional's performance was the most frequently valued factor (65%) (Table 4).

Table 4. Facilitators, challenges, and perceptions regarding speech-language pathology care

Variable	N (%)
Challenges in speech-language pathology care *("wanting him to communicate and eat properly is my biggest concern…")* *("since there are no SUS professionals here, I have to pay for it, and it's very expensive…")*	Feeding needs – 5 (25%) Communication needs – 4 (20%) Qualified professionals – 4 (20%) Child's adjustment – 3 (15%) Financial access – 3 (15%) Behavioral needs – 1 (5%)
Reasons for the interruption of service *("at the clinics, professionals keep changing all the time—that's really bad…")* *("I didn't have family or a support network to help, so I had to stop for a while…")*	Lack of professional – 6 (30%) None – 5 (25%) Child health issues – 4 (20%) Family demands – 3 (15%) Pandemic period – 2 (10%)
Access facilitators *("when we can get all the therapies in one place, it makes things much easier…")*	Family engagement – 10 (50%) Professional's demeanor – 8 (40%) Service location – 2 (10%)
Evaluation of speech-language pathology services	Excellent – 9 (45%) Good – 7 (35%) Fair – 1 (5%) Poor – 3 (15%)
Reviews validated by the professional ("I was always heard, even when they didn't agree…") ("I've been in places where no one listened to me—especially at the beginning, or when things were really tough…")	Yes – 16 (80%) No – 4 (20%)
Aspects considered relevant to the service provided *("the professional makes all the difference when it comes to care…")* *("we have to be involved in everything, there's no way around it… she spends most of her time with us…")*	Professional's performance – 13 (65%) Family participation – 6 (30%) Team integration – 1 (5%)

Legend: N – total number of participants; % – percentage
Prepared by the authors

Regarding the support desired throughout the therapeutic journey, the need for greater professional welcoming and active listening was the most frequently reported (40%). Regarding suggestions for improving Speech-Language Pathology services, the need for greater professional training and continuing education was highlighted (35%). With respect to future expectations, most participants (85%) expressed the desire for their children to achieve greater autonomy and communicative independence (Table 5).

Table 5. Expectations and suggestions regarding speech-language pathology services

Variable	N (%)
Types of support you didn't have *("having a professional who truly listens to us…")* *("having family closer by…")*	Professional reception and listening – 8 (40%) Nothing to declare – 4 (20%) Other therapeutic possibilities – 3 (15%) Family support/support network – 3 (15%) Psychological support – 2 (10%)
Suggestions for improving speech-language pathology services *("there are many professionals who don't know what they're doing; they need to update their skills…")* *("sometimes professionals focus only on their own area…")*	Professional development – 7 (35%) Increased frequency of sessions – 6 (30%) Holistic view of the child – 3 (15%) Nothing to report – 3 (15%) Greater integration with the family – 1 (5%)
Expectations regarding the child's future *("there are many questions and uncertainties about what is yet to come…")* *("my main goal is for him to be autonomous and independent, and able to live without me…")*	Autonomy and independence – 17 (85%) Socialization and interaction – 2 (10%) Insecurity and uncertainty – 1 (5%)

Legend: N – total number of participants; % – percentage
Prepared by the authors

Discussion

The findings of this study demonstrate that Speech-Language Pathology care for children with Down syndrome is constructed through complex therapeutic itineraries shaped by multiple factors, including the timing of diagnosis, access to services, the organization of the healthcare network, and the central role of families.

The predominance of mothers as those responsible for accompanying their children corroborates the literature highlighting the central role of mothers in child healthcare, particularly in chronic and developmental conditions[14,15]. This finding reinforces the need for healthcare services to consider the demands and burdens experienced by these women, recognizing them as protagonists of care while also acknowledging their need for ongoing support and welcoming.

Regarding the timing of diagnosis, the higher frequency of diagnoses established during the perinatal period, followed by the prenatal period, is consistent with advances in screening and diagnostic technologies[16,17]. However, the lack of guidance regarding the need to seek Speech-Language Pathology care in some cases reveals weaknesses in the care pathway, indicating gaps in communication among healthcare professionals and in the comprehensiveness of care. This aspect is particularly relevant given the importance of early intervention for communication development in children with Down syndrome[18].

The variable time to initiation of Speech-Language Pathology follow-up reinforces the notion that access does not occur in a linear manner, but is influenced by structural and organizational factors within healthcare services[19], as well as by families' ability to mobilize resources[20]. The substantial proportion of children who initiated care late (after three months) may indicate barriers to access, which is consistent with Public Health studies pointing to inequalities in the availability and distribution of specialized services[21,22].

The predominance of care provided in private services may reflect limitations in the public healthcare network's capacity to meet this demand, leading families to seek alternatives in the private or supplementary healthcare sector[23]. This pattern is also reflected in reports of changes in professionals and services, often motivated by the search for more appropriate therapeutic approaches. This finding reinforces the understanding that therapeutic itineraries are not fixed but dynamic, being continuously reorganized according to families' experiences and expectations[7].

The different pathways through which participants accessed care, particularly internal referrals but also recommendations and active searching, indicate that the care pathway does not depend exclusively on the formal organization of the healthcare network, but also on informal networks and families' social capital. This finding highlights the coexistence of different formal and informal care practices that shape therapeutic itineraries[24].

Among the challenges reported, feeding and communication-related demands were particularly prominent, both of which are widely described in the literature on Down syndrome[25,26]. In addition, references to an insufficient number of trained professionals point to the need for continuing professional development in Speech-Language Pathology, particularly in the care of populations with specific needs and in alignment with Public Health principles[27].

Interruptions in care, frequently associated with a lack of available professionals, reveal weaknesses in continuity of care, which is one of the fundamental principles of healthcare[28]. This finding is particularly concerning because discontinuity may negatively affect therapeutic gains, as well as children's development and prognosis.

Conversely, the facilitating factors identified—particularly family engagement and the professional's approach—highlight the importance of interpersonal relationships in successful care[29]. The value placed on listening, therapeutic rapport, and partnership between professionals and families was also reflected in the positive perceptions of care, indicating that relational aspects play a central role in the evaluation of healthcare services[30].

Despite the overall positive evaluation of care, the suggestions made by participants, such as greater welcoming, qualified listening, continuing professional development, and expanded availability of services, point to the need for ongoing improvement and qualification of healthcare services[31]. The demand for a comprehensive perspective on the child reinforces the importance of interdisciplinary and family-centered practices[32,33].

Finally, mothers' expectations regarding their children's future, strongly focused on autonomy and communicative independence, demonstrate

that Speech-Language Pathology care is perceived not merely as a clinical intervention but also as a means of promoting social participation and quality of life[34].

In this regard, the findings of this study reinforce the importance of understanding therapeutic itineraries as unique processes influenced by multiple determinants and point to the need to strengthen healthcare networks, expand access, and improve Speech-Language Pathology practices in the care of children with Down syndrome.

It is important to note that although Brazil has guidelines for comprehensive care for people with Down syndrome[3], the insufficient availability or absence of specialized services in certain geographic areas may constitute a barrier to timely access to Speech-Language Pathology care. Given the frequent demands related to language, communication, orofacial motor skills, and feeding, the limited availability of specific interventions within the public healthcare network may lead families to seek alternatives outside the public system. This finding suggests that inequalities in access are not solely related to professional training but also to the healthcare network's capacity to provide specialized, continuous, and geographically accessible care.

This study has several limitations. First, convenience sampling may have restricted participant diversity and limited the transferability of the findings to other contexts. In addition, the sample consisted exclusively of mothers, which, although reflecting the central role of mothers in caregiving, may not capture the perspectives of other family members, such as fathers or other caregivers. Another limitation is the predominance of participants receiving care in private services, which may have influenced the understanding of therapeutic itineraries, particularly regarding access to and continuity of care within the public healthcare network. Furthermore, because this was a qualitative study based on self-reported data, the findings may be subject to recall and interpretation biases.

CONCLUSION

Therapeutic itineraries in Speech-Language Pathology care for children with Down syndrome are non-linear and characterized by challenges related to access, continuity of care, and the organization of healthcare services. Families played a central role in navigating these pathways, often in the context of weaknesses in the public healthcare network and the need to seek care in the private sector.

Relational aspects, such as therapeutic rapport and professional listening, emerged as essential factors for adherence to care and positive evaluations of the services received. These findings reinforce the importance of strengthening healthcare networks, expanding access to Speech-Language Pathology services, and investing in professional training and continuing education, with the aim of providing comprehensive and family-centered care.

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