

Levels of Language Communication Abilities in Children and Adolescents with Down Syndrome Attending Three Selected Special Schools in Kigali as Perceived by Parents, 2024

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ABSTRACT

INTRODUCTION: Down Syndrome is a genetic disorder commonly associated with low cognitive development, oral motor anomalies, and hearing issues, all of which contribute to language communication challenges. This study aimed to determine the levels of language communication abilities, including comprehension, production, and pragmatics, among children and adolescents with Down Syndrome attending three selected special schools in Kigali as perceived by parents.

METHODS: A quantitative cross-sectional study enrolled 40 participants from three special schools in Kigali. Descriptive statistics summarized demographics and language abilities. Pearson's Chi-square and Fisher's exact tests assessed associations between age groups and pragmatics, comprehension, production, and examined gender differences across defined age categories in children.

RESULTS: The results indicate that the majority of children and adolescents (n=16, 40%) were classified at Level 1 (Mild) for language comprehension. In terms of language production, most 14 (35%) children and adolescents were at Level 4 (Moderate-Severe). For language pragmatics, most 17 (42.5%) children and adolescents fell into Level 5 (Severe). Statistically significant differences were observed in language production between the 5–12 and 13–17 age groups ($p=0.05$). Similarly, significant differences in language pragmatics were found between the 5–12 and 13–17 age groups ($p=0.01$).

CONCLUSION: This study highlights the varying levels of language communication abilities among children and adolescents with Down Syndrome. These findings underscore the need for targeted interventions to enhance language skills in individuals with Down Syndrome, mainly the need for speech and language therapy, as supported by evidence, to be an effective management strategy.

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INTRODUCTION

Down Syndrome is one of the most prevalent neurodevelopmental genetic disorders in children, and it is the most frequent genetic cause of intellectual disability [1]. The symptoms for children with Down Syndrome include developmental motor and language delay, specific verbal memory problems, and general cognitive deficiencies. Additionally, comorbidities are more likely to affect children with Down Syndrome, worsening their cognitive deficiencies [1].

Worldwide, there is an increase in the number of people with Down Syndrome, including children, where statistics show that the incidence of children with Down Syndrome is one in 1000 births [2]. There is, however, little information available on its frequency in Africa; Huete-García and Otaola-Barranquero [3], in a systematic review of Demographic assessment of down syndrome found that in South Africa and Nigeria 1 in 865 live births are impacted, with prevalence ranging from 1.33 to 1.8 per 1000 live births. The prevalence of Down Syndrome in Rwanda is underreported [4]. Children with Down Syndrome can have improved quality of life when the interventions are provided as early as possible [5].

Almost all people with Down Syndrome struggle to communicate normally due to low cognitive development, oral motor anomalies, and hearing issues [6]. Impairments in the development of nonverbal communication behavior may result in fewer opportunities for experiencing contingent relationships and are strong predictors of caregiver response. Thus, the parents may not view their children as social interaction partners [7]

There have been contradictory reports about the receptive vocabulary abilities of people with Down Syndrome. A study by Onnivello et al [8] emphasized that children and teenagers with Down Syndrome understand spoken words at a level similar to that of children typically developed without Down Syndrome.

However, the comparative study on nonverbal communication skills in children with Down syndrome showed that the Down Syndrome group revealed a significant impairment in the expressive language score but not in the receptive language measure [9]. Children with Down Syndrome may have trouble expressing themselves effectively in unfamiliar situations and with new people if they struggle to use context. This could be especially

difficult when they start school and are exposed to different contexts [10]. Furthermore, it is important to educate children with Down Syndrome on pragmatic communication skills in addition to language form and content [10]. A systematic review carried out by Seager et al. [11] highlighted that language proficiency at school entry is a strong predictor of future academic and psychosocial outcomes in typically developing children. Given this, limited language skills could similarly impact the educational and social outcomes of children with Down Syndrome. Despite the critical role of communication, there is a lack of data on this aspect in children with Down Syndrome in Rwanda. This study provided the baseline information on aspects of language communication abilities of children and adolescents with Down Syndrome in special schools. This will enhance the understanding within special school settings and inform targeted interventions to address identified challenges. The aim of this study was to explore the language communication abilities of children and adolescents with Down Syndrome attending three selected special schools in Kigali, as perceived by their parents. Specifically, it examined parental perceptions of language comprehension, expressive abilities, and pragmatic use of language. The study also investigated the relationship between age groups and language communication levels.

METHODS

Study Design

This was a cross-sectional quantitative study. The cross-sectional study is conducted at a single point in time and is a reasonably time and resource-efficient strategy [12].

Study Setting

The study settings were three special schools: Special school is defined as a school for children who have physical or learning problems [13]: Home of the Virgin of the Poor (HVP), Gatagara, Gikondo, Heroes Day Care Center, and Izere Mubyeyi Organization. HVP Gatagara Gikondo is the branch of HVP Gatagara located in the Kicukiro district that delivers medical and health services, but it also has special schools that have children with intellectual challenges and limitations in everyday activities, including class participation [14]. Heroes Day Care Center is a

special school for non-governmental organizations located in the Gasabo district. It delivers a variety of services to children with disability, including Down Syndrome [15]. Izere Mubyeyi is a non-profit organization in the community of Kicukiro district that gathers children with disability and provides special needs, including education and class participation [16].

Study Participants and Eligibility Criteria

The study included parents and caregivers of children and adolescents with Down Syndrome aged between 5 and 18 years, all attending the selected special schools. The age range of 5 to 18 years was chosen because children typically develop foundational language skills by age 5 [17], while age 18 marks the end of adolescence [18]. This criterion ensured that children and adolescents were within a critical developmental period for assessing language communication abilities. During the participant selection phase of the study, children and adolescents with Down syndrome were identified across all designated study sites. This identification process was conducted in collaboration with the school administration delegate. Once eligible children and adolescents were identified, the research team recorded the contact details, specifically the addresses of their parents or primary caregivers. This information was essential for establishing communication, obtaining informed consent, and data collection. The entire selection and recruitment process is illustrated in detail in the accompanying Figure 1 below, which outlines each step of the participant inclusion.

Sampling Approach

A total population sampling, also known as a

census, was employed, and this is a sampling technique in which all people who fulfill the inclusion criteria are recruited for the study, and is primarily used in situations where the cases being examined are limited [19]. Therefore, each participant who met the criteria and was willing to participate was included, making 40 participants in total.

Data Collection Tool

The Functional Communication Measure (FCM) tool was utilized as the primary instrument for data collection. “The tool comprises three key components: language comprehension, language production, and language pragmatics. It employs a seven-level rating scale to assess communication abilities, ranging from Level 0, which represents independence, to Level 6, indicating profound difficulty. The levels are defined as follows: Level 0 (Independent), Level 1 (Mild), Level 2 (Mild-Moderate), Level 3 (Moderate), Level 4 (Moderate-Severe), Level 5 (Severe), and Level 6 (Profound)” [20]. The researcher assessed each child's communication abilities based on the responses provided by their parents or caregivers and assigned scores using the grading scale of the Functional Communication Measure (FCM) tool. The Functional Communication Measure (FCM) tool demonstrates strong psychometric properties. Its internal reliability is evidenced by a high Cronbach's alpha of 0.90. The test-retest reliability, reflecting consistency over time, is supported by an intraclass correlation coefficient (ICC) of 0.94 with a 95% confidence interval. Additionally, the interrater reliability, indicating agreement among different raters, shows an ICC of 0.73 with a 95% confidence interval. Significant results were observed regarding validity between

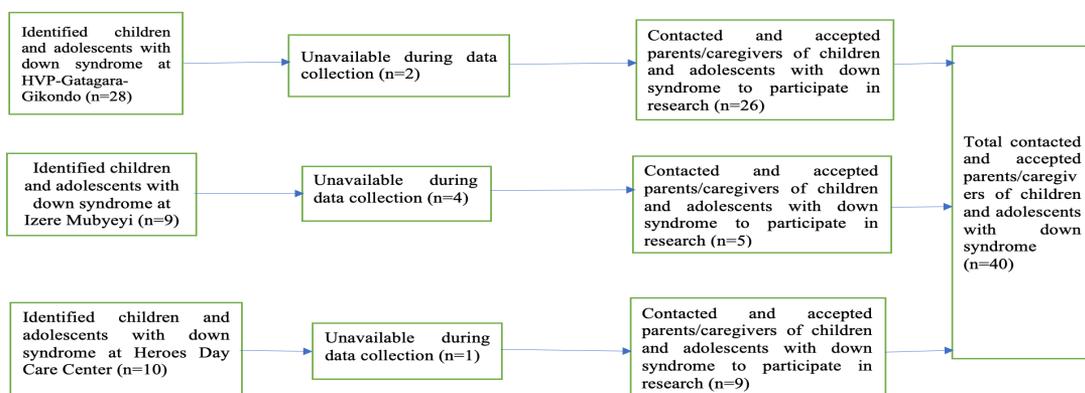


Figure 1: Flowchart for the selection process of participants

initial and repeat testing, meeting at least the 0.05 significance level [21].

Procedures of Data Collection

After obtaining ethical approval and permission from the identified study sites, the researcher received contact information for parents of children and adolescents with Down Syndrome from the schools' records. One available parent or caregiver per child was then approached, either in person or over the phone, with confidentiality maintained throughout. They were given consent forms to sign when they agreed, indicating their willingness to participate. Informed consent was obtained from all participants, either written or verbal. Following this, parents or caregivers were asked questions about their child's communication abilities based on the data collection tool.

Data Analysis

Data analysis was conducted using SPSS version 21 (IBM Inc., NY, USA). Descriptive statistics were used to summarize demographic data, including school, age group, gender, and three language communication components, namely: comprehension, production, and pragmatics. To evaluate statistical significance, Pearson's Chi-Square and Fisher's exact tests were applied to assess associations between age groups (5–12, 13–17 years) and language communication abilities (pragmatics, comprehension, production). The association of gender and language communication abilities was also determined. The level of significance was set to be $p \leq 0.05$.

Ethical Consideration

Ethical approval for the study was obtained from the Institutional Review Board (IRB) of the University of Rwanda, College of Medicine

and Health Sciences, under the reference number CMHS/IRB/142/2024. Permission to access contact information for parents or caregivers of children or adolescents with Down Syndrome was sought from the relevant study settings through formal request letters. Parents and caregivers of the children and adolescents were approached to take part in the study. The purpose of the study was clearly explained to them, and they were assured that their personal information would be kept private and confidential. Since the children and adolescents had cognitive impairments and could not give their own assent forms, the researchers asked for permission from their parents or caregivers instead. Participation was completely voluntary, and consent was given freely. The researchers made sure to treat all children and adolescents with respect and followed the principles of care, fairness, and protection throughout the study. Participants were encouraged to ask questions or share any concerns at any time before, during, or after the study. They were also told that they could stop participating at any point without facing any negative consequences. It was made clear that there were no direct benefits or risks from being part of the study. The study followed ethical guidelines based on the Declaration of Helsinki to ensure the rights and well-being of all participants were protected [22].

RESULTS

Demographic characteristics

Table 1 presents the demographic characteristics of children and adolescents with Down Syndrome. The majority of children and adolescents attended HVP-Gatagara Gikondo 26 (65%), followed by Heroes Day Care Center 9 (22.5%) and Izere Mubyeyi 5 (12.5%). The number of children 5-12

Table 1: Demographic information of children and adolescents with Down Syndrome

	Variables	Frequency (n)	Percentage (%)
Special Schools	Izere Mubyeyi	5	12.5
	Heroes Day Care Center	9	22.5
	HVP Gatagara Gikondo	26	65
Age range	5-12	27	67.5
	13-17	13	32.5
Gender	Male	18	45
	Female	22	55

Table 2: Parents' perceived response on language comprehension, language production, and language pragmatics of their children with down syndrome

	Variables	Frequency (n)	Percentage (%)
Language Comprehension	Level 0: Independent	4	10
	Level 1: Mild	16	40
	Level 2: Mild-Moderate	14	35
	Level 3: Moderate	2	5
	Level 4: Moderate-Severe	3	7.5
	Level 5: Severe	1	2.5
Language Production	Level 1: Mild	1	2.5
	Level 2: Mild-Moderate	5	12.5
	Level 3: Moderate	9	22.5
	Level 4: Moderate-Severe	14	35
	Level 5: Severe	5	12.5
	Level 6: Profound	6	15
Language Pragmatics	Level 2: Mild-Moderate	3	7.5
	Level 3: Moderate	10	25
	Level 4: Moderate-Severe	8	20
	Level 5: Severe	17	42.5
	Level 6: Profound	2	5

years old was 27 (67.5%), and adolescents were 13 (32.5%). The females accounted for 22 (55%), and the males accounted for 18 (45%) (Table 1).

Parents' perceived responses to language comprehension, language production, and language pragmatics

Table 2 summarizes the findings on language comprehension, production, and pragmatics among children and adolescents with Down Syndrome. The results indicate that the majority of children (n=16, 40%) and adolescents were classified at Level 1 (Mild) for language comprehension. In terms of language production, most 14 (35%) children and adolescents were at Level 4 (Moderate-Severe). For language pragmatics, the largest group, 17 (42.5%) children and adolescents, fell into Level 5 (Severe).

Association between age groups and language comprehension, production, and pragmatics

The study found no significant difference in language comprehension between age groups (5-12 years and 13-17 years), and in all language communication between male and female children. However, there was a significant difference in language production between the two age groups ($p=0.05$), and there was also a significant

difference in language pragmatics between the two age groups ($p=0.01$) (Table 3).

DISCUSSION

This study assessed the perceived levels of language comprehension, production, and pragmatic abilities among children and adolescents with Down Syndrome attending selected special schools in Kigali. The findings offered valuable insights into the language communication abilities of children with Down Syndrome and explored the associations between demographic information and language communication.

The results revealed that the majority 16 (40%) children and adolescents were classified at Level 1 (Mild) for language comprehension meaning that they comprehend 80-90% of conversation in broad contexts, minimal errors are noted in understanding of language structures (semantic, syntactic, morphologic, pragmatic), minimal errors are noted in phonological awareness and/or metalinguistic skills and is a full conversational participant. This is consistent with findings from Deckers et al. in a study titled 'Predictors of receptive and expressive vocabulary development in children with Down syndrome [23]. Receptive vocabulary (language comprehension) is often

Table 3: Association between language communication and demographic information of children and adolescents with Down syndrome

Variables		Language Comprehension							X ²	P-Value
		Level 0: Independent	Level 1: Mild	Level 2: Mild- Moderate	Level 3: Moderate	Level 4: Moderate-Severe	Level 5: Severe	Total		
Age,	Age 5–12	2	11	9	1	3	1	27	2.84	0.82
years	Age 13–17	2	5	5	1	0	0	13		
Sex	Male	2	7	5	2	2	0	18	4.37	0.56
	Female	2	9	9	0	1	1	22		
Variables		Language Production							X ²	P-Value
		Level 1: Mild	Level 2: Mild- Moderate	Level 3: Moderate	Level 4: Moderate- Severe	Level 5: Severe	Level 6: Profound	Total		
Age,	Age 5–12	0	1	6	10	5	5	27	10.41	0.05
years	Age 13–17	1	4	3	4	0	1	13		
Sex	Male	0	2	2	7	3	4	18	4.48	0.52
	Female	1	3	7	7	2	2	22		
Variables		Language Pragmatics							X ²	P-Value
		Level 2: Mild- Moderate	Level 3: Moderate	Level 4: Moderate-Severe	Level 5: Severe	Level 6: Profound	Total	Total		
Age,	Age 5–12	0	6	4	15	2	27	11.89	0.01	
years	Age 13–17	3	4	4	2	0	13			
Sex	Male	2	4	3	9	0	18	2.92	0.63	
	Female	1	6	5	8	2	22			

p<0.5: Statistically significant

relatively stronger compared to expressive language, but still significantly delayed compared to typically developing peers. This supports prior research indicating that spoken language comprehension in individuals with Down Syndrome is often comparable to that of typically developing peers matched for mental age [7,9]. However, a study conducted by Witecy and Penk [24], on language comprehension in children, adolescents, and adults with Down syndrome, has shown that on standardized tests of receptive vocabulary, children and adolescents with Down Syndrome tend to perform more poorly than younger, nonverbal, mentally age-matched peers. This aligns with the study findings, suggesting a spectrum of comprehension ability within the Down Syndrome population (some individuals perform on par with their mental-age peers, while others lag behind). Nonetheless, the majority demonstrate relatively strong comprehension skills, indicating that comprehension is less impaired than other domains of language. While comprehension challenges exist, they appear less pronounced than those related to language production. Regarding age-related differences, the study found no statistically significant difference in Language comprehension between children 5–12 years and adolescents 13–17 years.

Language production was found to be significantly impaired in the study population; most 14 (35%) children and adolescents were at Level 4 (Moderate-Severe), which means they communicate basic needs in routine contexts; Self-monitoring is evident approximately 25% of the time. These results are in agreement with prior research in a systematic review of speech, language, and communication interventions for children with Down syndrome from 0 to 6, showing that children with Down Syndrome often struggle across multiple facets of speech production [11]. Although children with Down Syndrome typically begin to babble at expected ages, they tend to experience delays in producing clear, intelligible single words compared to their typically developing peers [11,24]. Notably, there was a statistically significant difference in production abilities between children aged 5–12 years and adolescents aged 13–17 years. These findings suggest a trend of age-related improvement in language production among children and adolescents with Down Syndrome, further reinforcing the importance of ongoing

support and training throughout development. Pragmatic language skills were the most impaired domain, the largest group 17 (42.5%) children and adolescents fell into Level 5 (Severe) meaning the child can initiate and/or respond to communication approximately 25% of the time, even in familiar settings with a familiar communication partner; may whine or abandon topic and interaction if not immediately understood, requires encouragement to maintain interaction, maximum dependence on communication partner. These findings are consistent with those of Smith [25], who reported significantly lower pragmatic language scores among children with Down Syndrome when compared to typically developing peers across various subdomains. Particularly notable were difficulties in understanding social context and engaging in reciprocal communication. Significant differences were found in pragmatic abilities between age groups. Adolescents aged 13–17 exhibited stronger pragmatic skills than children in the 5–12 years groups. These improvements with age suggest a natural progression in social communication abilities. Older children were better able to interpret context, take conversational turns, and maintain dialogue. Moraleda et al. [10] noted that while language communication abilities in individuals with Down Syndrome may improve with age, early difficulties, especially in pragmatics, tend to persist. Smith [25] also found that pragmatic communication deficits are evident from early childhood, with distinct language profiles emerging by age six.

The systematic review by Moraleda et al. [26], on Language Intervention in Down Syndrome, found that speech and language therapy substantially improves communication skills among individuals with Down Syndrome. Therefore, the health institutions in Rwanda, especially RBC and concerned schools and their partners, need to establish and expand access to professional speech and language therapy services in Rwanda. This includes integrating speech therapy into special education programs, training more local speech-language pathologists, and developing context-specific intervention programs tailored to the needs of individuals with Down Syndrome. Additionally, promoting social interaction, early intervention, and inclusive educational opportunities should be prioritized within national policies to support holistic language development and enhance long-term communication outcomes.

This study is the first of its kind in Rwanda to investigate perceived language communication abilities in children and adolescents with Down Syndrome. It provides crucial baseline data to inform interventions and policy development. However, the findings are not generalizable to the national level due to the study's small sample size and limited geographic coverage. Additionally, data were primarily based on parent or caregiver reports, which may introduce reporting bias. Future research should include direct assessments of language abilities and involve larger, more diverse samples to capture a national perspective.

CONCLUSION

The study found that language production and pragmatic abilities in children and adolescents with Down Syndrome improve with age, particularly during adolescence. While comprehension appears relatively preserved, production and pragmatic skills remain areas of concern, especially during early childhood. Speech and language therapy is supported by evidence to be an effective management strategy, though it remains underdeveloped in Rwanda. The study emphasizes the pressing need for coordinated efforts among key stakeholders to enhance support for children and adolescents with Down Syndrome in special schools. It calls on the Ministry of Education to prioritize the development of speech-language pathology services through targeted capacity-building initiatives. At the same time, special school administrations are encouraged to adopt early, sustained, and holistic interventions encompassing social interaction and inclusive learning environments. Equally important is the active involvement of parents, whose consistent support and collaboration are vital in reinforcing language development and fostering meaningful progress both at school and at home. A national commitment to expanding these services is essential to address communication challenges and foster inclusive growth for individuals with Down Syndrome across Rwanda.

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Author's contributions

G.D and H.M, worked on the idea conception, overall supervision and final approval of the version to be submitted for publication, design, data analysis and interpretation, writing of the manuscript, and approval of the version to be submitted. N.J, B.P, N.P.M and N.F contributed to the manuscript writing and editing, and approval of the version to be submitted.

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