Communication difficulties in children with Down syndrome in Africa: A case study of Students attending Kampala School for Physically Handicapped, Uganda.

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Abstract

Background:[a]
Communication difficulties among children with Down syndrome are not only a problem in Uganda, but it's a worldwide problem. Such difficulties affect the child's ability to comprehend, detect or apply language and speech to engage in discourse effectively with others. Therefore, this study was done to assess the communication difficulties in children aged 3-13 Years with Down Syndrome Attending Kampala School for Physically Handicapped in Kampala District

Methodology:
The study was a descriptive cross-sectional study where quantitative and qualitative methods were employed in data collection. The study involved 25 respondents who consisted of male and female children aged 3-13 years who were selected by a non-probability Sampling design

Results:
A total of 25 children aged 3-13 years with Down syndrome were assessed in June 2016. 18 (72 %) children had communication difficulties and 7(28%) did not have any communication difficulties. 56 were males and 44 were females. The common communication difficulties in school-going children aged 3-13 with Down syndrome at Kampala School for Physically Handicapped included
Intelligible speech (25, 100%) and inability to perceive objects and communicate with others in their environment 14 (56 %) among others

Conclusion and recommendations:
The prevalence of communication difficulties was high and such difficulties impended children to communicate hence affecting their learning process. It was recommended that the government through the Ministry of Education should equip schools with more skilled manpower especially special needs teachers, speech and language therapists, and other multidisciplinary school team professionals, and school administration should design speech and language treatment programs for each child based on his/her communication pattern and needs.

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1 Background:

According to June Tham-Toh *et al.,* (2017), Down syndrome is a naturally occurring chromosomal arrangement that is being universally present across racial, gender, or socioeconomic lines, and affecting approximately 1 in 800 live births, Down syndrome usually causes varying degrees of intellec-

tual and physical disability and associated medical issues (Burgoyne *et al.,* 2012).

Communication is how people share information (including their thoughts and feelings). Often when people think about communication, they think about talking and listening (Bampoe *et al.,* 2021). However, people also send information by, the tone of their voice, the look on their face (facial expression), the way they use their hands (gestures), and the way they move and hold their body (Birkdale *et al.,* 2011).

A communication difficulty occurs when children have problems with; recognizing the emotions or intentions of others, speech sounds (saying the words clearly or correctly), speaking fluently (without hesitating too much or stuttering), using words and grammar (rules about word order and use), putting words together to let others know what they think or want, understanding what others say. Communication disabilities may affect a child's ability to speak (speech disorders/impairments) and/or the ability to understand and use spoken language (language disorders/impairments). Professionals talk about these as expressive and receptive communication difficulties (Birkdale, *et al.,* 2011).

Down syndrome usually causes varying degrees of communication difficulties and associated medical issues. Such kind of difficulties usually limits children's communication with the community (Burgoyne, *et al.,* 2012).

In every cell in the human body, there is a nucleus, where genetic material is stored in genes. Genes carry the codes responsible for all of our inherited traits and are grouped along rod-like structures called chromosomes. Typically, the nucleus of each cell contains 23 pairs of chromosomes, half of which are inherited from each parent. Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. It is universally present across racial, gender, or socioeconomic lines, and affects approximately 1 in 800 live births, although there is considerable variation worldwide. There are three types of Down syndrome: trisomy 21 (nondisjunction), translocation, and mosaicism. Down syndrome usually causes varying degrees of intellectual and physical disability and associated medical issues (Libby, 2006).

In 1959, the French physician Jérôme Lejeune identified Down syndrome as a chromosomal condition. Instead of the usual 46 chromosomes present in each cell, Lejeune observed 47 in the cells of individuals with Down syndrome. It was later determined that an extra partial or whole copy of chromosome 21 results in the characteristics associated with Down syndrome. In the year 2000, an international team of scientists successfully identified and cataloged each of the approximately 329 genes on chromosome 21. This accomplishment opened the door to great advances in Down syndrome research (Burgoyne, *et al.,* 2012).

Down syndrome occurs in people of all races and economic levels, though older women have an increased chance of having a child with Down syndrome. A 35-year-old woman has about a 1 in 350 chance of conceiving a child with Down syndrome, and this chance increases gradually to 1 in 100 by age 40. At age 45 the incidence becomes approximately 1 in 30. Since many couples are postponing parenting until later in life, the incidence of Down syndrome conceptions is expected to increase. Therefore, genetic counseling for parents is becoming increasingly important. Still, many physicians are not fully informed about advising their patients about the incidences of Down syndrome, advancements in diagnosis, and the protocols for care and treatment of babies born with Down syndrome (Libby, 2006).

Down syndrome is usually identified at birth by the presence of certain physical traits: low muscle tone, a single deep crease across the palm, a slightly flattened facial profile, and an upward slant to the eyes. Because these features may be present in babies without Down syndrome, a chromosomal analysis called a karyotype is done to confirm the diagnosis. To obtain a karyotype, doctors draw a blood sample to examine the baby's cells. They photograph the chromosomes and then group them by size, number, and shape. By examining the karyotype, doctors can diagnose Down syndrome. Another genetic test called FISH can apply similar principles and confirm a diagnosis in a shorter amount of time (Libby, 2006)

Communication forms the basis of human life and the complex ways with which humans can communicate and interact with each other. It also sets us apart from all other species. However, not all humans can communicate effectively due to a range of communication impairments (Birkdale, *et al.*, 2011).

According to the Uganda Bureau of Statistics (UBOS) census report of 2014, the total population of Uganda was 34.6 million people of which

12.5% are disabled people. However, it was estimated that people with communication difficulties were 1.5 million; this figure included those who were autistic, down syndrome, spine Bifida, hyperactive, and learning difficulties. Children with Down syndrome have a set of physical and mental abnormalities and also have strengths and challenges in the development of communication skills, including receptive (understanding) language and expressive (speaking and composing sentences) language skills and reading. This varies from person to person. But in most cases, it is mild to moderate. This can affect their ability to access education or employment and to be able to enjoy a reasonable standard of living (UBOS, 2014).

According to the Global Down Syndrome Foundation, "Many countries have at least one Down syndrome organization to support families and individuals with Down syndrome. In Uganda, the Down Syndrome Association of Uganda (DOSAU) is located at Kamwokya Education Centre Salaama Road, off Entebbe Road was sited out for Uganda's case.

It was estimated that 190.5 million people in low-income countries were expected to have communication difficulties by 2025 (Hartley 1998). This triggered the researcher to make further studies on the communication difficulties exhibited by children with down syndrome in an elementary school setting.

2 Methodology

Study site

This study was carried out at Kampala School for Physically Handicapped. This school is located in Kampala with a population of 150 pupils between 4 and 18 years. This is a mainstream school with both special needs children and typically developing children. Kampala School for the Physically Handicapped (KSFPH) is an elementary school with more than 900 special needs children and youth who have passed through the institution. This school has been in existence for over 45 years and it handles special needs children suffering from cerebral palsy, paraplegia, hydrocephalus, spina bifida, down syndrome to mention a few (Mwesigwa *et al.,* 2015).

Study design

This study was cross-sectional and descriptive.

Study population

The study population was children aged 3-13 years with Down syndrome and all staff in Kampala school for physically handicapped.

Sample size and selection

The non-probability Sampling design was used and specifically the purposive sampling technique.

The sample size was determined using Kish and Leslie (1965) to adopt a minimum sample size (n) as below.

$n = Z\ P\ (1\text{-}P)/d^2$

P = Proportion of children with communication disability including

those with down syndrome estimated as 13 % (UBOs, 2014).

d = Precision (set for 10 %)

Z = Score corresponding to 95% confidence interval which is equal to 1.96

(1.96) (0.13) (1-0.13) / (0.1) (0.1)

n = 22.2

Therefore, n is approximately 25

3 Method of data collection

Data was collected using a questionnaire that involved open and closed-ended questions and assessment forms for the identified children with down syndrome.

Quality and Reality of data

High-quality data was ensured by pre-testing the tool, pre-testing helped the researcher to check and confirm the validity of the data collection tool.

4 Data analysis

Data were examined to ensure completeness, accuracy, and uniformity before grading it for coding, and then it was entered into the computer program SPSS version 16 for analysis. Data was later be presented in form of tables, graphs and the rest narrated.

Ethical considerations

Permission was sought from the school of medicine through the ear, nose, and throat (ENT) department and SLT coordinator, plus IRB (institutional review board) and dean of the school of medicine to carry out the study. A written consent form was presented to the administration of Kampala school for the physically handicapped before collecting data. The participants were assured of confidentiality and the importance of the information.

5 Results:

This chapter consists of the results of the study findings. The study involved 25 school-going children with Down syndrome aged between 3-13 years at Kampala school for physically handicapped. Results were analyzed as follows.

6 Demographic Characteristics of Respondents

n=25

bove indicates that majority of the respondents 15 (60 %) ranged from 7-10 years, 14 (56 %) were male and the 12 (48%) were from a class of p1-p2.

7 Assessment/observation

n=25

showed assessment or observation of children in different activities. It is indicated thatmajority of them 24 (96 %) played appropriately, 18 (72 %) had limited attention, 23 (92 %) imitated properly, 12 (48 %) had good comprehension, 15 (60 %) struggled during expression, 17 (68 %) intelligibly spoke with struggle, 18 (72 %) had adequate eye contact, 17 (68 %) could request, 20 (80 %) shared with others and the 19 (76 %) took turns.

8 Results from key informant Interview Guide

9 Expressive communication

n=25

bove showed multiple responses were majority of the respondents (60 %) made their needs and wants known by gestures while 48 % of the children made their needs through body movements.

Figure 1: Responses whether child's expressive behavior appear to be intentional

n=25

Figure 2: Responses whether child's expressive behaviors is directed towards a goal

n=25

Figure 3: Responses whether children anticipate response to communication

n=25

Frequency of Child's communication

n=25

bove revealed that majority of the respondents (80 %) communicated for more than 3 times.

Figure 4: Specific messages or communicative functions expressed by children

n=25

Figure 5: Circumstances through which children are most communicative

n=25

Figure 6: Response whether children need prompting or support to communicate clearly or consistently

n=25

Ways children speak

n=25

Above revealed multiple responses on the ways children speak where majority of them (96 %) were stammering followed by 92% were not easily understood and the rest (80 %), were saying the same word differently at different times.

Expressive language

n=25

Above revealed multiple responses on the ways children express their language. All respondents found problems giving specific answers or explanations were the same as those who had difficulties joining sentences, problems with sequencing events and ideas appropriately, unable to retell a simple story and taking long time to organize words into a sentence.

Figure 7: Types of communicative behavior understood by children

n=25

n=25

Above shows that majority of the respondents (80%) understood greetings as a communicative function while the few (8 %) understood directives.

Responses whether children needed prompting and support to respond to a communication

n=25

Above showed that all the respondents (100%) needed prompting and support to respond to a communication.

Figure 8: People who communicate effectively with children

n=25

Particular activities in which the children seem most likely to respond

n=25

above indicates that majority of the respondents 23 (92%) stated that they were particular activities in which the children seems most likely to respond and of them, majority of them 14 (60.9%) stated physical education like running.

Table 1. Demographic Characteristics of Respondents

Age	Frequency (f)	Percentage (%)
3-6 years	6	24
7-10 years	15	60
11-13 years	4	16
Sex		
Male	14	56
Female	11	44
Class		
Pre-primary	2	8
P1-p2	12	48
P3-p4	7	28
P5-p7	4	16

Table 2. Assessment/observation

Assessments/observations	Frequency (f)	Percentage (%)
Play		
Appropriate	24	96
Inappropriate	1	4
Attention		
Attends	7	28
Limited attention	18	72
Imitation		
Yes	23	92
No	2	8
Comprehension		
Excellent	5	20
Good	12	48
Struggles	8	32
Expression		
Good	4	16
Struggles	15	60
None	1	4
Speech		
Intelligible with struggle	17	68
Intelligible with familiar people	6	24
None	2	8
Social Skills		
Eye contact		
Adequate	18	72
Inadequate	7	28
Request		
Yes	17	68
No	8	32
Shares		
Yes	20	80
No	5	20
Takes turns		
Yes	19	76
No	6	24

Table 3. Ways a child make his/ her needs and wants known

Ways a child make his/ her needs and wants known	Frequency (f)	Percentage (%)
Body movements	12	48
Gestures	15	60
Facial expressions	8	32
Vocalizations	6	24
Words	5	20
Sign language	1	14
Picture symbols	3	12
Object symbols	4	16
Others	0	0

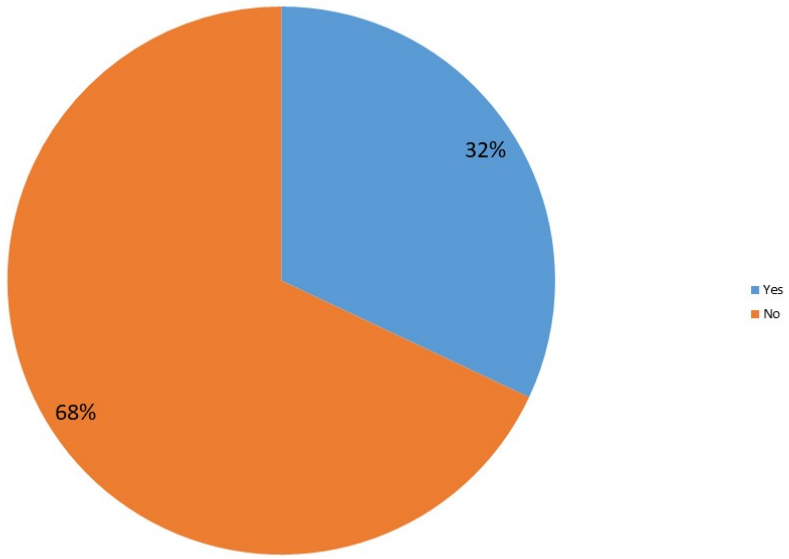


Chart 1. Above indicated that majority of the respondents (68 %), exhibited an expressive behavior appearing to be intentional while the rest (32%) showed no intentional expressive behavior.

Table 4. Frequency of Child's communication

Frequency of Child's communication	Frequency (f)	Percentage (%)
None	0	0
Once	1	4
Twice	4	16
More than 3 times	20	80

Table 5. Ways children speak

Speech	Frequency (f)	Percentage (%)
Speaks too quickly (words run into each other)	0	0
Not easily understood	23	92
Says the same word differently at different times	20	80
Stammers, that is hesitates, repeats sounds/words, and gets stuck	24	96

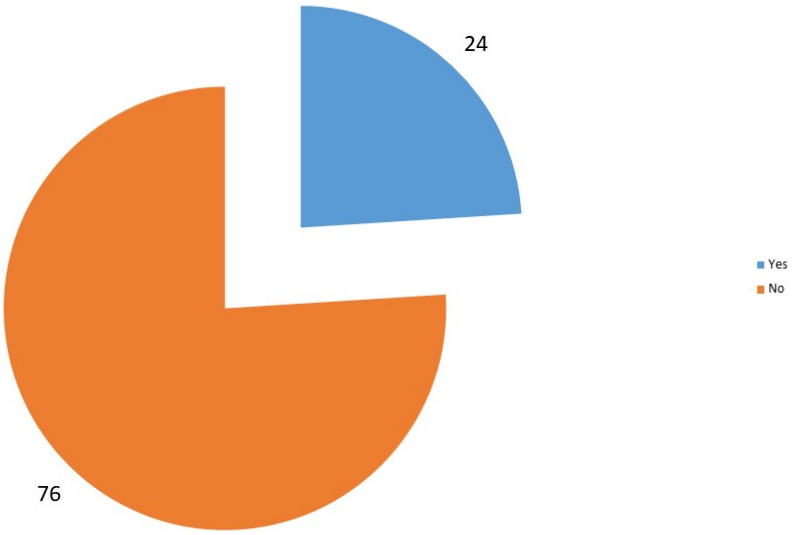


Chart 2. above revealed that majority of the respondents' (76 %) expressive behaviors were not directed towards a goal while the rest (24%) were directed towards it.

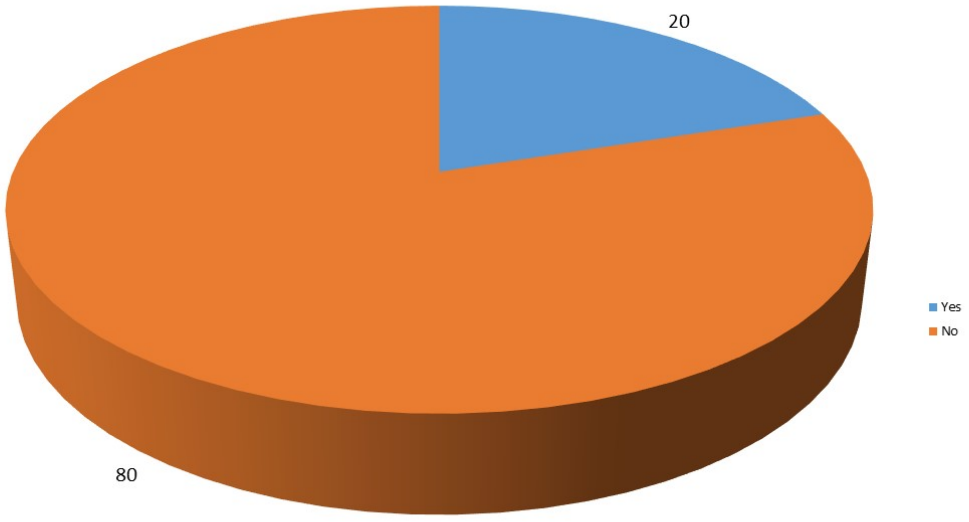


Chart 3. above showed that majority of the respondents (80 %), never anticipated response to communication while the rest (20%) did anticipate response to communication.

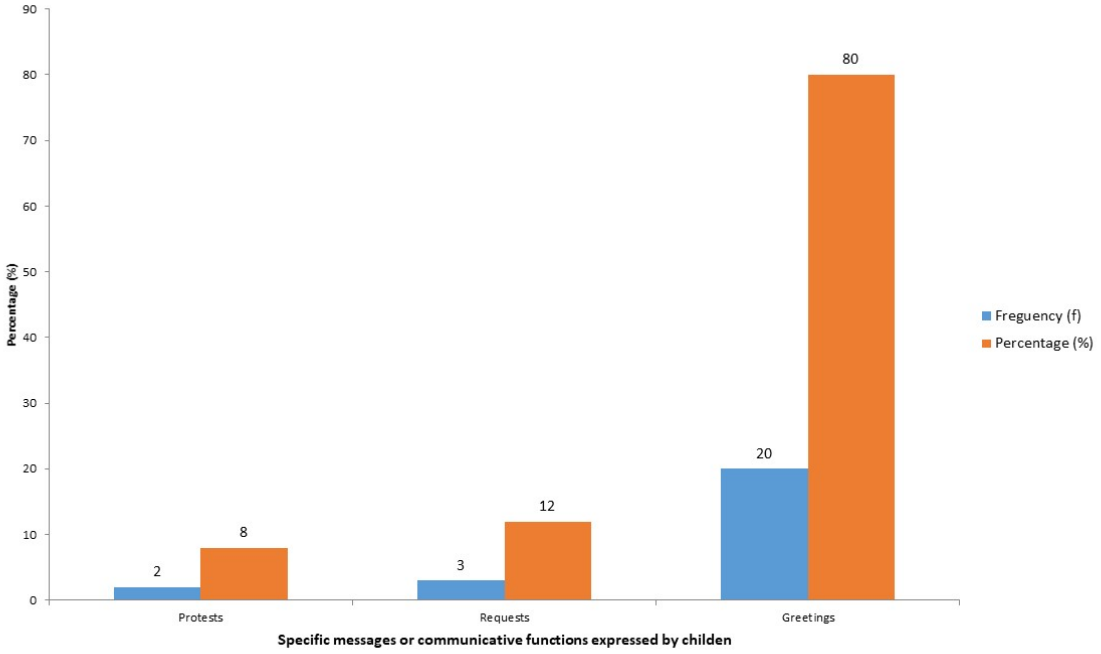


Chart 4. Above revealed that majority of the respondents (80 %) expressed themselves communicatively by greetings followed by request (12%) and protests (8%).

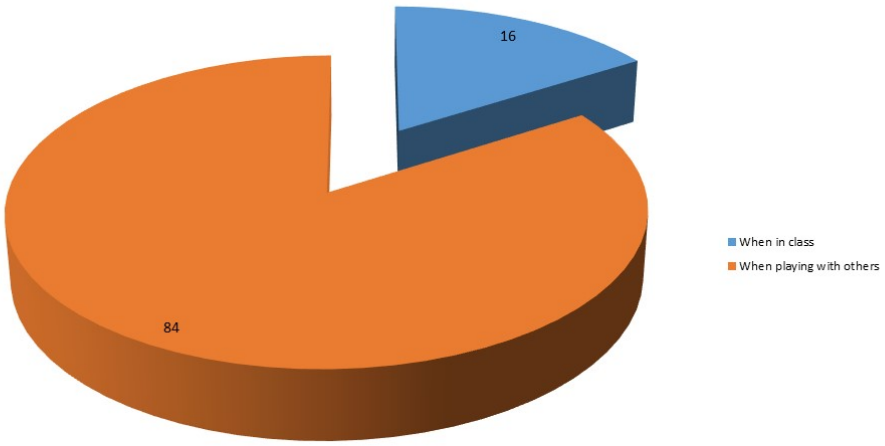


Chart 5. above indicates that majority of the respondents (84 %) were most communicative when playing with other while 16 % were communicative while in class.

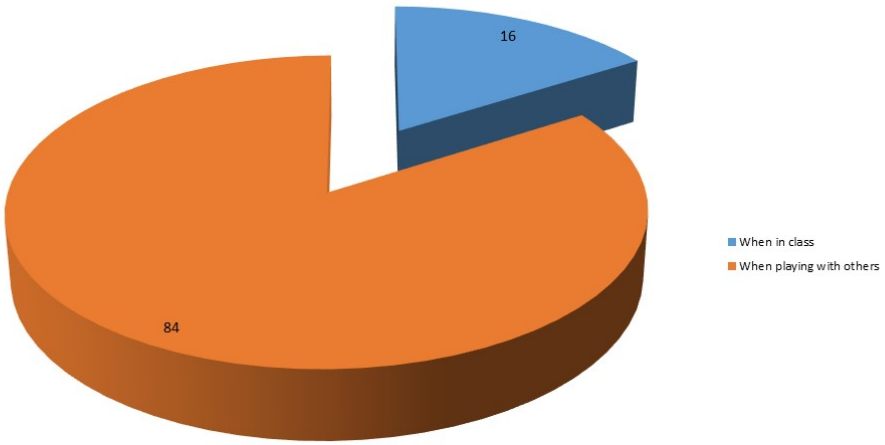


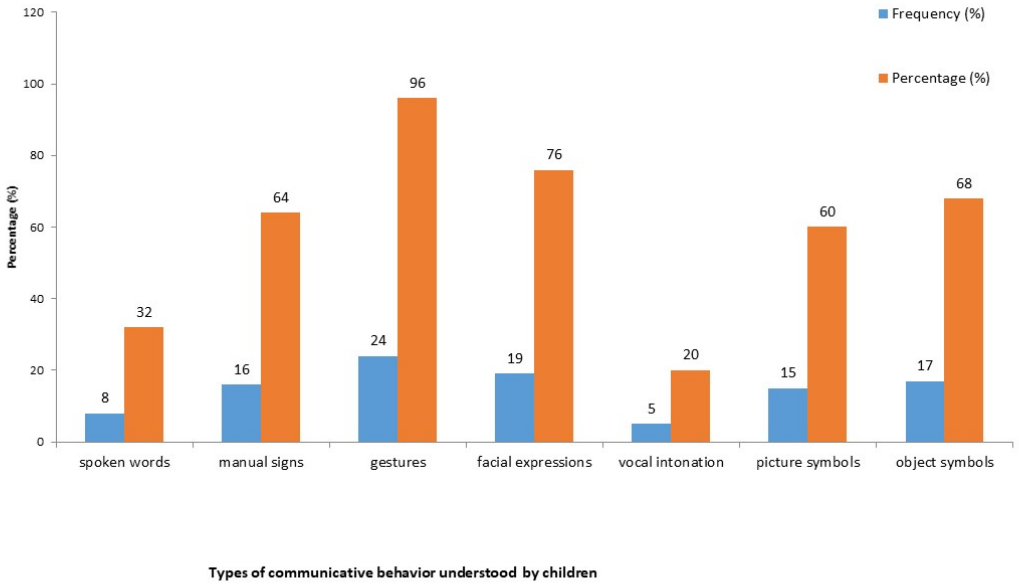
Chart 6. above revealed that the overwhelmingmajority of the respondents (96%) needed prompting or support to communicate clearly or consistently while only 4% never needed support.

Table 6. Expressive language

Expressive language	Frequency (f)	Percentage (%)
Limited vocabulary which could lead to excessive swearing	10	40
Finds it hard to express emotions verbally	19	76
Fluent clear speech which doesn't seem to mean much	0	0
Trouble learning new words, e.g. names of people and objects	15	60
Failure to provide significant information to listeners	20	80
Uses made-up words which are almost appropriate, e.g. 'window worker man'	2	8
Problems with prepositions (that is 'on', 'under', 'over', 'behind', etc.) or tenses	24	96
May take a long time to organize words into a sentence	25	100
Misses out words or puts them in the wrong order	21	84
Problems giving specific answers or explanations	25	100
Difficulties joining sentences with 'and', 'because' 'so', etc. or by using one of these words too much	25	100
Has problems sequencing events and ideas appropriately	25	100
Cannot retell a simple story	25	100

Table 7. Messages or communicative functions children appear to understand

Messages or communicative functions children appear to understand	Frequency (f)	Percentage (%)
Directives	2	8
Greetings	20	80
Requests	3	12

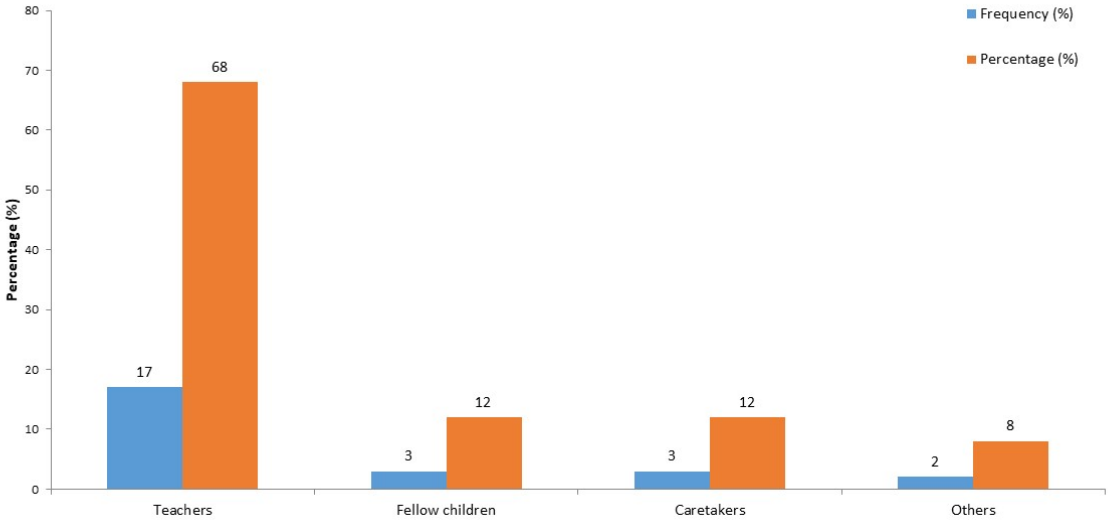


Types of communicative behavior understood by children

Chart 7. above indicates that majority of the respondents (96%) understood gestures as a communicative behavior while the least understood (20 %) was vocal intonation.

Table 8. Responses whether children needed prompting and support to respond to a communication

Responses	Frequency (f)	Percentage (%)
Yes	25	100
No	0	0



People who communicate effectively with children

Chart 8. Above indicates that majority of the respondents (68%) communicated effectively teachers while the fewest (8 %), communicated effectively with parents.

Table 9. Particular activities in which the children seem most likely to respond

Presence of particular activities	Frequency (f)	Percentage (%)
Yes	23	92
No	2	8
Activities		
Physical education	14	60.9
Co-curricular activities	9	39.1

Understanding language

n=25

above revealed multiple responses on the ways children understood language.All the respondents inappropriately responded to abstract language were the same as those who met problems understanding implied meaning, unable to vary language with the situation and unable to remember and recount last week's episode of a 'soap' on TV.

Social Interaction

n=25

above reveals that majority of respondents (96%) interacted with adults and of them, 62.5% interacted through greeting. And also majority of respondents (84%) interacted with peers and of them, 90.5% interacted through playing.

Figure 9: Challenges faced by children with communication difficulties due to down syndrome

n=25

10 Vision problems can interfere with a child's ability to balance

Ability to perceive objects and communicate with others in their environment

Intelligible speech

Slow physical response impact the child's ability to learn handwriting skills, cutting, manipulating objects with fingers, and grasping/releasing objects

Slow cognitive response in solving problems, remembering, sequencing, focusing, planning, completing tasks, and body awareness

Figure 9 above revealed that respondents gave multiple responses on the challenges faced by children with communication difficulties due to Down syndrome. At least all of them mentioned intelligible speech as a common challenge and the minority 56 %, could not perceive objects and communicate with others in their environment.

11 Discussions

The study found that the majority of the respondents (60 %) ranged from 7-10 years. This indicated that the majority of children with Down syndrome had grown. The majority of them (56 %) were male indicating that Down syndrome affects more males than females. This finding was in line with that of Stutter (1994) that indicated that males generally have more communication difficulties than females. Findings indicated that (48%) of children with Down syndrome were from a class of p1-p2.

According to the study findings, it was found that the majority of them (96 %) played appropriately, 72 % had limited attention, 92 % imitated properly, 48 % had good comprehension,60 % struggled during expression, 68 % intelligibly spoke with struggle, 72 % had adequate eye contact, 80 % shared with others and the 76 % took turns. It was observed that many of them (68 %) could request if needed assistance. Similarly, Mundy *et al.,* (1995) study indicated that children with Down syndrome usually requested attention.

The study found multiple responses on how children made their needs and want to be known were the majority of them (60 %) by gestures and 48 % by body movements. This finding was in comparison with Iverson) a study that indicated that children with Down syndrome seem to use gestures to make their needs and wants to be known. The majority of the respondents (68 %) expressive behavior appeared to be intentional. This implied that they focused on a goal. However, according to NYSDOH, 2008) study, it was indicated that the ability to focusing, planning, complete tasks, and body awareness was a problem. The study revealed multiple responses on the ways children speak where the majority of them (92 %) were stammering. This was in line with Abbeduto *et al.,* (2005) report that mentioned that children with Down syndrome have

Table 10. Understanding language

Understanding language	Frequency (f)	Percentage (%)
Difficulties following long or complex instructions	24	96
Better understanding in a one-to-one situation than in a group	23	92
Watches and copies others when instructions are given	20	80
Unable to remember and recount last week's episode of a 'soap' on TV	25	100
Tends to take things literally	19	76
Inappropriate response to abstract language, e.g. 'keep your hair on'	25	100
Repeats what you say rather than responding appropriately	16	64
Problems understanding implied meaning (e.g. 'I wouldn't take my shoes off now', meaning 'Don't take your shoes off')	25	100
Slow to learn new routines	17	68
Using language with others	15	60
Interrupts inappropriately	17	68
Avoids situations which require words	19	76
Unable to vary language with the situation	25	100
Attracts attention in inappropriate ways or without words	23	92
In conversation, moves from topic to topic for no obvious reason or finds it difficult to change the subject	17	68
Has problems taking turns in conversation	19	76
Does not ask questions or start a conversation	19	76
Does not say if cannot understand	22	88

Table 11. Social Interaction

Children interacting with adults		
Yes	24	96
No	1	4
Circumstances children interact with adults		
Greeting	15	62.5
Requesting	2	8.3
Playing	7	29.2
Children interacting with peers		
Yes	21	84
No	4	16
Circumstances children interact with peers		
Playing	19	90.5
Sharing	2	9.5

challenges in the development of communication skills like talking or language.

The study revealed child found problems giving specific answers or explanations and the same respondents mentioned that children with down syndrome found difficulties joining sentences, problems with sequencing events and ideas appropriately, unable to retell a simple story, and taking a long time to organize words into a sentence. This agreed with UBOS's report of 2014 that noted that children with Down syndrome challenges in speaking and composing sentences. According to the study findings, the majority of the respondents (96%) understood gestures as communicative behavior. This could be so because they could easily understand but could not express hence using gestures. This finding didn't differ from Chapman *et*

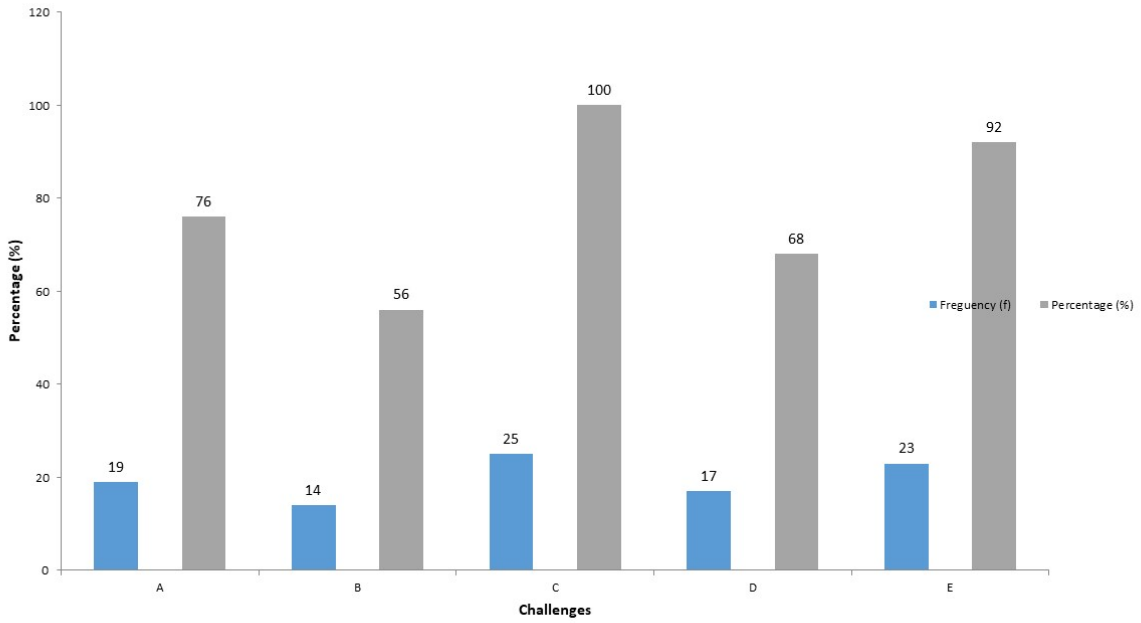


Chart 9. Challenges faced by children with communication difficulties due to down syndrome

al., (2000) study that noted that children with Down syndrome use gestures to express themselves

Majority of the respondents (68%) communicated effectively with teachers. This could be so because such teachers are well-trained in communicating with such children as compared to the rest of the people. Similarly, Price *et al.*, (2007) study also mentioned that children with communication disabilities have great difficulty in communicating with people who they don't know.

The study indicated that all respondents inappropriately responded to abstract language, met problems understanding implied meaning, were unable to vary language with the situation and unable to remember and recount last week's episode of a 'soap' on TV. Similarly, Chapman *et al.*, (2000) also noted that most children with Down syndrome can understand much more than they can express. As a result, their test scores for receptive language are higher than for expressive language. This is known as the receptive-expressive gap (Chapman *et al., 2*000).

The study found that the majority of the respondents (96%) interacted with adults and similarly, 84% of them interacted with peers. This implied that children with communication difficulties due to Down syndrome are social to all people of different ages. This finding was comparable with Dykens, *et al.,* (2006) findings that indicated that children with Down syndrome have good social interactive skills. The study revealed that respondents gave multiple responses on the challenges faced by children with communication difficulties due to Down syndrome and at least all of them mentioned intelligible speech as a hindrance to their academic progress. This finding did not differ from that of UBO (2014) that indicated that children with communication disabilities due to Down syndrome had less ability to access education.

12 Conclusions and Recommendation

13 Conclusions

According to the study, the communication difficulties in children with Down syndrome were speech difficulties as (68 %) speech was intelligible with struggle, expressive language as many of them (60 %) struggled to express themselves, receptive language difficulty i.e. listening and attention difficulties and as all of them were unable to vary language with the situation

The prevalence of down's syndrome was 16.7 %. The prevalence of communication difficulties in children with Down syndrome was 72 %.

The challenges which were faced by children with communication difficulties due to Down syndrome

included intelligible speech (100%) and inability to perceive objects and communicate with others in their environment (56 %) among others

Recommendations

- More skilled manpower especially special needs teachers, speech and language therapists, and other multidisciplinary school team professionals should be trained and also deployed in schools and in all other places where children with communication difficulties are so that they can be helped as early as possible.
- The school administrations should design speech and language treatment programs for each child based on his/her communication pattern and needs.
- The teachers, parents, and caretakers should be trained on how to help the child to explore more communication potentials he/ she has by prompting them to initiate communication so that child becomes more pro-active in the environment he/she leaves in.
- If teaching strategies are to be effective, they should build on the strength to minimize the weaknesses. Perhaps using visual channels as much as possible to augment and help overcome auditory processing deficit. For example use of visual aids.
- There should be general awareness to the public on conditions that bring about these communication difficulties so that the caretakers bring these children early for intervention.

Acknowledgment

I am indebted to extend my sincere appreciation to the following people whose support financially and morally enabled me to fulfill my academic requirements. Great thanks to my supervisors; Dr. Alunga Richard John, thank you so much for all the support and guidance offered in carrying out the research. The pupils, teachers, parents, and headteacher of Kampala School for the physically handicapped for their cooperation and understanding during the data collection phase. I am also immensely grateful to the department of Ear, Nose, and Throat surgery in particularly the Speech and Language Therapy Unit for giving us a chance to exploit our talent in the field of research.

Operational Definitions

Communication : is how people share information

Disability: is defined as a substantial functional limitation of daily life activities

caused by physical, mental, or sensory impairment and environmental barriers resulting in limited participation

Population: a group of things (people) having one or more common characteristics

Syntax: is the combination of words into phrases and sentences

Speech intelligibility: speech that can be easily understood).

LIST OF ABBREVIATIONS/ACRONYMS

DS : Down syndrome

KSFPH : Kampala School for the Physically Handicapped

MLU : Mean length of utterance

NYSDOH : New York State Department of Health

OME : Otitis media with effusion

PWD : People with Disabilities

TD : Typically developing

UBOS : Uganda Bureau Of Statistics

UNICEF : United Nations International Children Emergency Fund

VHT : Village Health Teams

WHO : World Health Organization

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