

Instructional constraints faced by learners with duchenne muscular dystrophy: A case study of Joy Town Special Primary School, Thika, Kenya.

Wang'ang'a Annerose Wanjiku¹, Francisah Wamocho², Paul Kioy³

¹Department of Special Education-Kenyatta University, Kenya; ²Francisah Wamocho-Department of Special Education-Kenyatta University, Kenya; ³Department of Medical Physiology-University of Nairobi, Kenya; ⁴Faculty of Education-Kigali Institute of Education, Rwanda

Abstract

The study is about the instructional constraints facing learners with Duchenne muscular dystrophy (DMD) at Salvation Army (SA) Joy Town special primary school, Thika, Kenya. Instructional constraints in this study are the academic challenges encountered by the learners that include: poor teaching methods, inappropriate curriculum, and lack of a modified learning and teaching environment among others. The study adopted a descriptive design because it aims at getting a true picture of a situation, behavior or attitude of individuals and the community at large. The target population was 43, and the study population was 23. The researcher used interviews and observation guide to collect data. Piloting was done at Dagoretti special school for the physically handicapped (PH), content-related validity was used as a measure to determine validity, and descriptive statistics where tables of frequencies and percentages were used in analyzing data. Results revealed that there were major instructional constraints facing learners with DMD.

Keywords: *Instructional constraints, Duchenne muscular dystrophy, learners with special educational needs.*

Background to the Study

Muscular dystrophy is a general term describing a number of genetically inherited disorders characterized by progressive muscle weakness and degeneration of skeletal muscles which control movement (Dubowitz, 1989). There are nine types of muscular dystrophy. They are Becker Muscular dystrophy (BMD), Congenital Muscular Dystrophy (CMD), Distal Muscular Dystrophy (DD,) Duchenne Muscular Dystrophy (DMD), Emery- Dreifuss Muscular Dystrophy (EDMD), Fascioscapulohumeral Muscular Dystrophy (FSH), Limble Girdle Muscular Dystrophy (LGMD), Myotonic Dystrophy also known as Steinert's disease, and Oculopharyngeal Muscular Dystrophy (OPMD) (Emery, 2000).

Becker Muscular dystrophy (BMD) is an X-linked muscular dystrophy with similar clinical pattern to Duchenne type but milder with slower progression. Congenital Muscular Dystrophy (CMD) is a rare form present from birth, symptoms usually progresses slowly and include general weakness and slow motor development. Distal Muscular Dystrophy (DD) Symptoms begin in middle age or later, and causes weakness in the muscles of the feet and hands. Emery-Dreifuss Muscular Dystrophy (EDMD) begins with muscle contractures and then progresses to muscle weakness and affects the shoulder and upper arm. Fascio Scapulohumeral Muscular Dystrophy (FSH) symptoms of FSH vary greatly, and most commonly begin in the early twenties. Symptoms begin with difficulty lifting objects above the shoulders. Limb – Girdle Muscular Dystrophy (LGMD) constitutes two forms, and the most commonly recognized one is the severe childhood form that is similar to DMD, while the second type appears in early twenties. Myotonic Dystrophy: most sufferers are severely disabled within 20 years of the onset of symptoms, but do

not require a wheel chair. Oculopharyngeal Muscular Dystrophy (OPMD) Symptoms of OPMD are confined to weakness in the muscles controlling the eyes and throat (Dubowitz, 1989).

Duchenne Muscular Dystrophy (DMD) is the most common and severe form of Muscular Dystrophy. It is caused by the absence of Dystrophin, a protein that maintains the integrity of muscle fibers. It affects boys almost exclusively because the mutated gene is on the X chromosome and boys have only one so there is no other X chromosome to counteract the defective gene (Tortora, 2002).

The researcher focused on DMD because it is the most common affecting school –age youths (Dubowitz, 1989, Emery, 2000, Tortora, 2002). The age of onset for DMD is between 2 to 6 years. DMD is named after Benjamin Amand Duchenne, a French neurologist since 1861; who described a boy with the form of muscular dystrophy that now bears his name. Duchenne was also the first to undertake any type of needle biopsy, a procedure by which a sample of tissue is removed with a needle. Duchenne designed the special needle for muscle biopsy. And in late 1985, researchers reported that it was possible to identify carriers of the Duchenne gene with about 98% accuracy.

Similarly, significant progress was also being made in an effort to identify the exact location of the gene (Kolata, 1985), and Xp²¹ was identified as the exact location of the Duchenne gene (Dubowitz, 1989). Dystrophin gene was discovered in 1987 and by 1990; first attempts were made to treat Duchenne muscular dystrophy patients with gene therapy (Tortora, 2002).

Globally, the disorder has no known cure; therefore, most effort in research as well as in practical medicine is concentrated upon its prevention (Ferri, 2005). Associations have been formed in developed countries like America, Britain, Ireland, Australia among others to combat neuromuscular disorders. For example, the Muscular Dystrophy Association was formed in 1950 in the United States of America by parents whose children had muscular dystrophy. The association established 85 out patients' clinics that provide diagnostic and follow-up services for affected persons (Weiner, 1973).

Doctors and teachers are specially trained to handle learners with muscular dystrophy. Doctors have specialized diagnostic equipment (Bauer, 1970). Teachers are trained on the kinds of adaptations required for learners with Duchenne muscular dystrophy (DMD) to enhance their learning. A model of adaptations is provided to the educator to select relevant adaptations to their needs. Systematic selections are made for learners suffering from DMD (Wolff, 1996). Specialized equipment used on these learners are dictated by the progressive nature of the disease, for example, some children have specially trained dogs to carry things for them like books or toys, while some are given drugs to delay muscle wastage (Alisa, 2004).

According to Bleck (1975), specialized equipment like the Hoyer hydraulic lifts are used, for they are valuable aids in bathing and toileting. Other specialized equipment includes auto vans, electric wheel chairs among others. Some learners are fitted with pacemakers when cardiac conduction defect occurs (Ferri, 2005). According to Dubowitz (1989), these learners are immobilized in calipers and swivel walkers after loss of ambulation. This enables

them to continue with their learning instead of dropping out from school. Learners with muscular dystrophy may attend main stream schools, integrated schools, special schools or residential schools with full assessment from the professionals and parents for appropriate placement (Stopford, 1987).

South Africa has researched on the disease and has established an association known as the Muscular Foundation of South Africa. It is a non-profit making organization that depends on the goodwill of donors. Donations assist with research, education, support groups and administration (Berge, 2005). In Kenya, no empirical research studies have been conducted on the disease despite having learners with muscular dystrophy in some of our schools. This was confirmed by a consultant neurologist/neurophysiologist, Paul Kioy who is the current chairman of Medical Physiology Department at Chiromo Campus University of Nairobi (personal communication, 2007).

Scarcity of information on Duchenne muscular dystrophy in the Kenyan context is regrettable because these learners' diverse needs may not be taken into consideration thereby denying them equal opportunities in their education as clearly stipulated in the Universal Declaration of Human Rights (1948) among other international conventions. Ominde Report (1964) advocated for teacher training to include a component of special education to enable the teachers to meet the needs of learners with special needs. Kenya is cognizant of the need to provide training on special needs. This is evidenced by several institutions that have been set up to offer special education training. These institutions include: Kenya Institute of Special Education (KISE), Kenyatta University, among others. The question is whether and to what extent the training given in these institutions is customized to the level or to the specific needs of learners with physical disabilities?

Salvation Army (SA) Joy Town Special Primary School was established by the Salvation Army in 1962, because the post-polio and cerebral palsy children were finding it difficult to gain admission to regular schools due to society's negative attitudes (Ndurumo, 1993). S.A Joy Town Special Primary School admits all categories of physical handicaps. Muscles of learners with DMD progressively degenerate, and their diverse needs may not be taken into consideration with the various groupings, since there is no special school for learners with muscular dystrophy.

According to the head teacher of SA Joy Town Special Primary School, the current number of learners suffering from DMD is 20 and many of them die at an early age due to respiratory and cardiac problems. The background information available points to the deficient efforts and information to mainstream the needs of learners with DMD in special schools in Kenya. In this context, the quality of instruction is a factor of interest. The study sought to find out the instructional constraints faced by these learners at SA Joy Town Special Primary School.

Theoretical Framework

The study was based on the Human Rights Model that builds upon the spirit of the Universal Declaration of Human Rights (1948) according to which; all human beings are born free in rights and dignity. In 1948 United Nations General Assembly adopted and proclaimed a resolution called the Universal Declaration of Human Rights. Education was considered a human Right and was clearly stipulated in Article 26 which emphasized that everyone has a right to education. This model emphasizes on viewing persons with disabilities as subjects not objects thus locating the

problem outside the disabled persons and addresses the manners in which the economic and social processes accommodate the differences of disability or not as the case may be.

The Human Rights model includes disability within a paradigm of rights that has been emerging since the United Nations Universal declaration of human Rights of 1948. This declaration recognized that all people have certain civil, political, economic, social, cultural and development rights, despite differences between individuals. From this perspective, a Human Rights model of disability perceives variation in human characteristics associated with disability whether in cognitive, sensory or motor ability, as inherent to human conditions. Thus a Human rights approach presumes that society is obliged to provide whatever mechanisms are necessary for individuals to realize their rights. In case of people with disabilities, this may involve the provision of support services and aids to enable social and economic integration, self, enjoyment of legal and social rights. The model is multifaceted in that it takes into account biological, psychological, social and spiritual aspects of function within the context of ethnic and cultural identities. .

The implication of this model to the study is that by providing special education among learners with disability, the government has been striving to ensure that all school-aged learners receive education which is a basic human right according to Article 26 of the Universal Declaration of Human Rights (1948). It also implies that failing to give adequate attention to the quality of education, many learners with special needs may fail to obtain meaningful schooling, or/and benefits of education in terms of cognitive development and independence.

Research Design

Research design is a plan to gather how and when to collect the data, and how to analyze the data obtained (Orodho, 2005). The study adopted a descriptive design. According to Gay (1973), the descriptive method of research is a process of collecting data in order to test the hypothesis or answer questions concerning the current status of the subjects in the study. According to Best and Kahn (1993), a descriptive study presents what is and interprets the nature of an ongoing event. It is concerned with conditions or relationship that exists, opinions that are held processes that are ongoing, effects that are evident, or trends that are developing.

It is primarily concerned with the present, although it often considers past events and influences as they relate to current conditions. It aims at getting a true picture of a situation, behavior or attitude of individuals and community at large. The study used grounded theory as a methodology. Grounded theory is a qualitative research method used to analyze social processes and human interactions. Ground theory is guided by theoretical sampling, which is an active process in which discoveries made during data gathering, observation and literature review direct the researcher to her next area of inquiry or potential data source (Glaser, 1992).

Target Population

According to Orodho (2005), target population is a large population from which a sample population is selected. In this study, the target population was 43 comprising of 20 learners, 20 teachers, 1 head teacher and 2 teacher aides

The study population was 23 comprising of 10 learners, 10 teachers, 2 teacher aides and 1 head teacher. These served a great deal in enabling collection of data on the instructional constraints faced by learners suffering from DMD at SA Joy Town Special Primary School.

Sampling Techniques

Purposive sampling is handpicking the cases to be included in the sample on the basis of one's judgment of their typicality (Orodho, 2005), and the goal is to select cases that are likely to be "information rich" with respect to purposes of the study. Ten teachers were purposively selected on the basis of previous experience with learners suffering from Duchenne muscular dystrophy (DMD). The teachers who had more experiences were picked from both the lower and upper primary.

Sample Size

Sample size was 23 comprising of 10 learners, 10 teachers, 1 head teacher and 2 teacher aides, selected on the basis of the information they would provide.

Research Instruments

The research used interview guides and an observation guide, which are a set of questions that an interviewer asks when interviewing respondents. It makes it possible to obtain the data required to meet the specific objectives of the study (Orodho, 2005). In this study, semi-structured interviews were used to collect data from respondents. Gall et al (1996) assert that semi-structured interviews involve asking a series of questions and then probing more deeply using open form questions to obtain additional information that is quite vital in a study. An observation guide is a tool that provides data through direct observation (Peil, 1995), and helps in gathering data concerning the status of the school facilities, equipment and in examining the general situation of the environment.

Results and Discussion

Table 1 Learners' responses on the academic difficulties faced by learners

Responses	Frequency	Percentages
Frequent absenteeism due to frequent ill health	7	21.9
Time given to complete their learning tasks is not enough and communication difficulties.	6	18.8
Some said they were poor in reading, writing, poor memory, spoken language and in mathematics	5	15.6
Slow in completing learning tasks	5	15.6
Not able to manipulate reading and writing materials	5	15.6
Poor posture and fatigue	4	12.5
Total responses	32	100.0%

As shown in table 1 above, the most reported academic difficulty faced by learners suffering from Duchenne Muscular Dystrophy (DMD) was constant illness (21.9%). This is likely that most of these learners spent most of their time in hospital leading to poor academic achievement since they were not able to catch up with the rest of the learners. In addition 18.8% of the learners responses stated that time given for them

to complete learning tasks was not enough. The Task Force (2005) noted that the extra 30 minutes given to learners with Special Needs (SNE) was not enough. They suggested that time was to be dictated by the severity of the disability. They may have communication difficulties due to weaknesses in speech organ muscles. They may require the services of speech therapist.

The regular curriculum poses academic difficulties to these learners because it was developed considering the average learner. The curriculum developers should diversify the regular curriculum to suit learners with DMD. In the same manner, it was reported that 15.6% of the learners were poor in reading, writing, poor memory, spoken language and in mathematics. This relates to an attribution given by Bushby (2001) who has stated that boys with DMD exhibit a range of intellectual deficit which are non-progressive.

The learners reported to be slow in completing learning tasks (15.6%). This implies that although it may be desirable to integrate DMD with other learners their kind of disability may not allow them to cope with the pace of the rest of other learners. This if not well managed, it may lead to frustration or an aversion to the instruction.

The curriculum should be designed in such a way that it accommodates the diverse needs of these learners. Learners with DMD will require a differentiated curriculum. According to Lewis (1981), a differentiated curriculum is an approach that one can use to identify the subjects in the curriculum that a learner should cover according to his or her needs and ability. It was also revealed that the physical disabilities were the basis of a wide spectrum of instructional learning constraints faced by learners with DMD.

It is likely that as their physical condition degenerated, these learners were unable to use their hands to write and hold the teaching learning aids. This shows that a great deal of innovation was required to aid these children get the best within their circumstances. In other countries, corticosteroids such as Prednisone and Deflazocort are given to learners with DMD to increase energy and strength and to defer severity of symptoms (Alisa,2004).

Another 12.5% of the responses cited fatigue caused by Scoliosis. At the advanced stages of the disease, the learners were fatigued due to the degeneration of their physical condition or because of the poor posture brought about by scoliosis or a secondary feature of muscle weakness resulting into curvature of the spine and severe physical dysfunctions.

Conclusion

The study revealed that there were major instructional constraints facing learners with Duchene Muscular Dystrophy (DMD) at Joy Town Special Primary School. The most reported academic difficulty was constant ill health leading to frequent absenteeism. Most of these learners with DMD spent most of their time in hospitals or in bed leading to poor academic achievement since they were not able to catch up with the rest of the learners.

Results have shown that learners with DMD in SA Joy Town in Thika faced many instructional constraints, including teachers' inadequate information about the ailment and how to manage it. The school was also faced with constraints in specialized resources and equipment. In some instances, the equipment was improvised but this did not help much in alleviating the conditions of the learners. The study revealed that the regular curriculum that was used in SA Joy Town lacked modifications on time, methodologies and in resources. The support staff was also found to be ineffective in their services to learners suffering from DMD. The study observed that much was needed to be done to make the lives of these learners bearable in order to achieve success in learning.

Recommendations

Following the study findings, the following recommendations have been made:

The government should deploy more teachers to special schools so as to enhance the teacher pupil ratio. This can improve the pupil teacher contact as well as the overall quality of instructional attention.

More human resource support staff should be deployed so as to improve their services to the learners suffering from DMD. A counselor should also be deployed to offer counseling services to learners with DMD. The environment should be made more barrier-free for learners with DMD. The training offered in specialized institutions should be customized to the level of the specific physical disabilities.

The learners with DMD should be given close supervision and encouragement in order to stay on the program for as long as they can. The curriculum for learners with DMD should be flexible enough and should be inspired by the fact that the physical condition degenerates irreversibly over time. They require a differentiated curriculum, or an approach that one may use to identify the subjects in the curriculum that a learner should cover and plan for each learner according their needs and ability. The curriculum differentiation would involve modifying the time, teaching methods and resources. The government should provide specialized facilities for learners suffering from DMD to enhance their mobility and independence.

Suggestions for further Research

- The study focused on only one type of muscular dystrophy DMD further research may be carried out in other types of dystrophies.
- Research may also be carried out in relation to other challenges facing learners with muscular dystrophies such as health factors, social factors, and emotional factors among others.
- A study should also be carried out to establish the prevalence levels of DMD. This can help establish the proportion of cases that are not taken to special schools, since every child has a right to education regardless of their disability.

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