



Understanding Muscular Dystrophy in a School Environment within an African Context

Nomusa Mlondo

Development Studies,
University of KwaZulu-Natal, South Africa

Mfundo Mandla Masuku

Development Studies,
University of KwaZulu-Natal, South Africa

Zamalotshwa Mncube

Psychology,
University of KwaZulu-Natal, South Africa

Xoli P. Mfene

Psychology,
University of KwaZulu-Natal, South Africa

Mashimane Njabulo Maphumulo*

Development Studies,
University of KwaZulu-Natal, South Africa
[*Corresponding author]

Maud Mthembu

Social Work,
University of KwaZulu-Natal, South Africa

Nontobeko Precious Angela Buthelezi

Psychology of Education,
University of South Africa, South Africa

Abstract

The paper reflects on the condition muscular dystrophy in African communities and the implications for inclusive education. It emphasizes the need for Afrocentric approaches to understanding disability and incorporating indigenous knowledge systems. It acknowledges that dearth of research on MD from an African perspective limits access to inclusive education. Information was obtained from literature on disability and indigenous knowledge systems from the African perspective. The dearth of research in MD from an African perspective compelled this study to utilise a comprehensive literature review, allowing the use of data sources across the globe. Afrocentric approaches that embrace African culture are the cornerstone of understanding issues of disability in the African context. The paper suggests that the Afrocentric lens is essential for achieving inclusive education in Africa by recognising the role of culture in the education system. The findings provide an understanding of the condition of MD from the Eurocentric and Afrocentric perspectives. Inclusive education should incorporate African indigenous knowledge systems to respond to disability in African school environments. Furthermore, the paper emphasizes the need to validate traditional practices in understanding and addressing MD.

Keywords

African perspectives, Disability, Eurocentric perspective, Muscular dystrophy, Symptoms

INTRODUCTION

This paper purports to shed light on how inclusive education in the African context accommodates learners with muscle weakening diseases that fall under the category of muscular dystrophy (MD). Muscular dystrophy research is ongoing and new types and sub-types keep emerging, yet there is a dearth of research that is informed by African epistemologies on MD in the school environment. Hence, the paper explores the Eurocentric and Afrocentric viewpoints on the condition and the implications thereof on accommodating learners with Muscular Dystrophy. Strategies for managing the condition at school will be looked into to assist parents, teachers, and health professionals in understanding the condition and gaining insight into the kind of support they can provide. The prevalence of MD in South Africa is not known as there is a lack of documentation on the historical and medical care of Africans, including under-resourced epidemiological data on the natural history of the disease on the continent. Epidemiological data is used to structure and assess interventions as a preventative measure and functions as a manual for the treatment of patients in which the disease has taken hold. The first MD Duchenne Muscular Disease registry in South Africa is that of DMD which was developed in 2017 using Research Electronic Data Capture (REDCap) (Jalloh et al., 2018). This is to categorize and document genetic information on South African patients with DMD that will serve as clinical research on children's illnesses which will be recognized internationally. The absence of epidemiological data on the local population is depriving it of better treatment approaches like gene therapy. The template developed by Jalloh et al. (2018) designed can be customized to conceptualise new disease registries and other types of MD. Theadon et al. (2014) who conducted a systematic literature review found that the prevalence of all muscular dystrophy studies with a low risk of bias ranged from 19.8 to 25.1 per 100,000 person-years. This means that there were, on average, 20 to 25 cases observed in 100,000 persons observed over a year. The most common types the study focused on were "Myotonic dystrophy (0.5-18.1 per 100,000), Duchenne muscular dystrophy (1.7-4.2) and facioscapulohumeral muscular dystrophy (3.2-4.6 per 100,000). Salzberg et al. (2018) established that DMD occurrence is remarkably higher in white males than in males of other races. The racial prevalence was confirmed in a later study titled "*Population-Based Prevalence Study of Genetic Muscle Disorders*" conducted in New Zealand. Theodon et al. (2019) found that the frequency of genetic muscle wasting diseases in Europeans was 24.4 per population of 100,000, which was twice the number observed in the country's other 3 main ethnic groups. For the Māori the prevalence rate was 12.6 per 100,000, for the Pasifika it was 11.0 per 100,000 and for the Asians, it was 9.13 per 100,000. The study also led to an observation that the crude prevalence of myotonic dystrophy was 3 times as high in Europeans than it occurred in Māori and Pasifika people.

Van der Walt et al. (2020), in an investigation titled "Prevalence of motor skill impairment among Grade R learners in the West Coast District South Africa", revealed that the frequency of significant motor skill impairment was at 14.5% and that the likelihood of children with difficulty in fine motor skills was at 24.6%. The frequency rate of children with steadiness complications was 18.1%, while that of children who struggled when aiming and catching was low at 4.3%. Interrelationship analysis led to the observation that the absence of play equipment and low weight and height are aspects related to the poor adroitness of learners. The study also revealed that poor manual dexterity and balance skills were associated with learners attending no-fee schools. That suggests a link between the late diagnosis of the condition and the low socio-economic status of the family. Van der Walt et al. (op cit) concluded their study by confirming the presence of undiagnosed muscular dystrophies in the region. The ones that were picked up in the study was because they were at school.

Nassoro et al. (2020) expressed a view that a lack of exposure to the symptoms of rare diseases like dystrophinopathies leads to a higher frequency of morbidity and mortality in Africa. Diagnosis of muscular dystrophy involves an all-inclusive medical record, highlighting how the weakness has spread, the age the disease started, heredity, and pathological characteristics. It has been noted that increased morbidity and mortality is caused by poor health care, lack of education, delayed detection and treatment. In the same study, Nassoro et al. (op. cit) refer to an article which analysed features of mutation in South African Dystrophinopathies patients and found that African patients had considerably more distal anomalies as compared to Whites and Asians. Wonkam-Tingang et al. (2020) in an article titled "DMD-related muscular dystrophy in Cameroon: Clinical and genetic profiles" noted that in Cameroon, as in other African countries, the detection happens in late adolescence, even though the initial manifestation of DMD cases appears during childhood. This confirms an underestimation of the number of cases of DMD not only in Cameroon but in Africa as Furthermore, the study argues that is not much documented information on the use of African traditional medicine for different types of diseases, let alone for muscular dystrophy. The scanty documentation available on African traditional medicine is the use of "*umhlabelo*" in Sub-Saharan Africa, which is an herbal mixture used for ailments like arthritis, injuries, muscle pain and for post-partum recovery (Ramulondi, De Wet & Ntuli, 2022).

In Africa the concept of disability is holistic, it is both spiritual and physical. A physical or mental disability is a manifestation of a spiritual source and the cause or spiritual source has to be addressed to cure the physical or mental disability (Etieyibo, 2022). In addition, Engelbrecht & Kasiram (2012); Clausnitzer (2021) argue that the prevalence of disability in some societies persists to perpetuate fatalistic beliefs about people living with Muscular Dystrophy as victims of bewitchment or suffering because of certain sacrosanct rites that may have not been observed. The study directly addresses muscular dystrophy, its focus on understanding the challenges faced by learners in a school setting, in accessing resources and opportunities in Africa. The study provides a critical discussion on the influence of South global ideologies that could be applied to analyse how education systems and policies address or fail to address the needs of learners with MD in Africa. While the study contrasts Eurocentric and Afrocentric viewpoints on MD. While the Eurocentric

perspective focuses on medical diagnoses and treatments, the Afrocentric perspective is holistic as it considers the social and spiritual dimensions of the condition, including traditional healing practices and community support.

METHODOLOGY

In pursuit of understanding Muscular Dystrophy in a School Environment within an African Context, this study employed a comprehensive literature review. The rationale behind this was that CLR is able to retrieve data from a wide range of scholarly and non-scholarly database sources.

Search criteria

The data search was based in focused on the six database sources because they demonstrated of having a relevant data on the MD in a school environment. The database sources were Google Scholar, Wiley, Springer Nature Link, Taylor & Francis, African Journal and Sabinet. The search terms used to retrieve the rich data on MD were; African perspectives and MD, Eurocentric perspective and MD, muscular dystrophy, and symptoms and MD. The search yielded 102 articles, after the discarding of irrelevant and duplications the study remained with 52 articles for analysis. However, it was only 19 articles that were included in the analysis which are contained in the below findings of this study.

Inclusion and exclusion criteria

The study included all empirical and non-empirical articles focusing on MD in a school environment which were written in English. In addition, they had to be within the 2003 to 2024 publication date, this was to trace the developments that have taken place regarding MD. However, articles that were not focusing on MD in a school environment, falling outside the search range date and were not written in English were excluded from the analysis.

Analysing and synthesising data

The data analysis and synthesis are forms part of the interpretive phase of the CLR, which deals with making meaning of the data extracted from the various utilised databases. The thematic analysis was employed to analyse data in this article about understanding muscular dystrophy in a school environment within an African context. The analysis of this article followed the six-step guidance by Braun & Clarke (2006). The six analysis steps entailed familiarising oneself with the data, generating initial codes, searching for themes within the data, reviewing the themes, defining and naming the themes, and producing the report.

The article's findings, based on data dating back to 2003, The study confirm that in Africa, not much scholarly information is available on the prevalence and types of MD. The suggestion is that a multidisciplinary approach is required to expand knowledge generation on MD.

FINDINGS AND DISCUSSION

Afrocentrism is a movement where the central tenets are around African values, beliefs, and perspectives in shaping the cultural image and human interests of the African populace. Furthermore, this study uses Afrocentricity as a foundation to challenge dominant Western perspectives on disability-related issues in a school setting and provide new contexts, insights, or reform inclusive education within Africa. Afrocentrism emerged from the recognition of the need for a corrective discourse and appraisal of the knowledge systems enforced by the West (Mekoa, 2018). This paper analyses the major gaps, inconsistencies, and contradictions in understanding the dynamics of MD in a school environment in the African context by focusing on African perspectives and Eurocentric prescripts.

Conceptualizing Muscular Dystrophy

Literature on Muscular Dystrophy is often described using a clinical lens and modern medical sciences, yet in the African context, the spiritual and cultural view of the disease is considered critical. MD largely affects muscle strength and function, it can also have psychological and cognitive implications as these are important, particularly in the schooling context. Numerous studies report on various areas of functioning that are impaired due to muscular dystrophy. Areas of executive functions that have been identified as impaired in individuals with MD include attention, speed of information processing, visuoconstructive abilities, visuospatial functioning, and problem-solving (Fujino et al., 2018). The area and severity of the impairment vary and therefore the quality of life is affected adversely.

In addition to vulnerability to experiencing executive functioning impairments, individuals with MD are susceptible to emotional challenges. Depression and anxiety are commonly found as psychological predictors of the quality of life of individuals with MD. The aforementioned psychological conditions contribute to social inhibition, apathy, and isolation (Fujino et al., 2018). The functional impairments that result from an individual having MD cause susceptibility to learning disabilities, reduction in implicit learning, immobility, cardio-respiratory complications, learning difficulties due to impaired speech and reduction in intellectual quotient (Vicari et al., 2018). As MD progresses, learners may fear losing independence and autonomy which would lead to social isolation, stigma, or bullying, thus impacting their ability to form relationships and participate in class (Wan et al., 2019).

Eurocentric and Afrocentric to Muscular Dystrophy

In this study, we explored the Eurocentric and Afrocentric viewpoints on the condition and its implications for accommodating learners with Muscular Dystrophy. In addition, the cause for MD in Africa goes beyond being medical;

culturally inclined sections of the continent perceive it as ancestral punishment for mischief. Ngubane-Mokiwa (2018) argues that in the ancient days, people with disabilities were socially eliminated to the point of being killed because were perceived as a curse from God and punishment from ancestors for their family's sins, which was contrary to the ethos and values of Ubuntu.

Some scholars argue that disability in the African perspective is partly associated with ancestors and witchcraft, while in modern medical science that view is almost non-existent (Mkize, 2003; Ajefu & Moodley, 2020). This has created a need for cultural restitution and indigenization to challenge Western empirical bias and decontextualized knowledge systems (Ntsoane, 2005). Although legislation acknowledging traditional healers highlights the significance of traditional medicine in South African cultural practices and enables the incorporation of indigenous healing methods into conventional healthcare systems (Shange & Ross, 2022). Thus, healing in traditional African medicine aims to bring back the balance between individuals, communities, and the spiritual world, offering a holistic health treatment that works alongside Western biomedical methods (Shange & Ross, 2022). This integration is crucial in addressing the complex health needs of South Africa's varied population. Indigenous African belief systems understand health and illness as being deeply rooted in spirituality and therefore what is seen in the physical is a manifestation of that which is happening in the spiritual realm. The harmonious relationship within the self, and between the physically living and those who have transcended to the spiritual realm (ancestors) is emphasized (Laar et al., 2021). Indigenous conceptualization of health and illness does not exclude the biomedical model, however, there are illnesses that are perceived as only curable through indigenous means.

Muscular Dystrophy in the School Environment

In educational discourse, children with MD encounter learning barriers, Nassoro et al. (op. cit) affirm that MD significantly reduces learning ability and socialization with peers. Amid the learning challenges, Botha & Mihai (2023) propound that learning should incorporate assistive technology to ensure smooth learning for learners with disabilities including MD. In accordance with the principles of Afrocentricity, people with disabilities especially MD should be well supported and cared for by their households and the school environment. In the community and school environment in which the underpinning life philosophy has to complement the way of life, the principles of Afrocentricity could be revived to enhance the integration of learners living with Muscular Dystrophy in society through instilling the culture of humanness in every aspect of life. In this context, caring for and supporting learners with Muscular Dystrophy is incumbent upon the school and the community at large to ensure safety and quality communal living in the spirit of reciprocity, harmony, shared world view and cooperation. This means that principles of Afrocentricity can add value to persons with Muscular Dystrophy illness and their integration into communal life (Engelbrecht & Kasiram, 2012). Our analysis depicts that educational facilities provide a safe haven for people with MD as opposed to society (Mubita et al., 2023). However, they are challenged but inadequate training of special needs educationists and educational facilities.

Ubuntu and Muscular Dystrophy

This confirms Ubuntu as an African moral system which in its literal sense means humanness (Metz, 2021). This entails that a person's being is intertwined with the connectedness and humaneness of relations with others. Africans view Ubuntu as what makes a person an authentic human because of the values that are enforced by upholding Ubuntu. The values of Ubuntu include embracing all humans, acknowledging those who have existed before and those who are to come, and embracing and caring for nature (Mugumbate & Chereni, 2020). Borrowing the values of ubuntu philosophy, social harmony enhances the belief in human dignity by calling human beings irrespective of their ability to be treated in a dignified manner that endorses their human value (Banda, 2019). Creating agency for learners with Muscular Dystrophy (MD) within an Afrocentric paradigm involves fostering empowerment, inclusion, and self-determination through culturally relevant and community-based approaches. This can be achieved by conducting cultural sensitivity training that promotes understanding and respect for diverse abilities through Afrocentric values such as ubuntu (humanity towards others). It is essential to incorporate indigenous knowledge systems by demystifying negative belief systems and enhancing relevant local knowledge and traditional practices that support learners with MD. Elders with similar conditions can serve as positive role models, enhancing the outlook for learners with MD.

Contribution to the field of inclusive education

The study contributes to the field by raising awareness about the challenges faced by learners with MD in inclusive education within an African context. The study is championing the grounding of treating learners with muscular dystrophy on Afrocentric principles, an approach that is rooted in African cultural values and community focused interventions. It is critical for professionals to meet the unique challenges of the communities they serve including a school environment, a drive amplified by the realisation that the current Eurocentric based education has limitations on the African way of life. It does not equip professionals with an understanding of the rich African narratives, traditions and culture, a situation which renders them non-responsive to the needs of their communities (Gray, Natchaba & Cole, 2024; Watson, & Wiggan, 2016). Upholding Afrocentric values such as respect and dignity for learners with disabilities does not only reflect on the humaneness and profound character of the educator, it also plants the same seeds of values to the able-bodied learners. The paper calls for a deeper understanding and appreciation of African philosophy, culture and spirituality in nurturing learners with disabilities. Continued pursuit of Eurocentric values at the expense of African values exposes the constraints of the former. It advocates for culturally sensitive approaches that incorporate indigenous

knowledge and community support to enhance the learning experience and well-being of these learners. It also emphasizes the need for further research on MD from an African perspective.

Schools, in collaboration with local mental health organizations, should lead community-based support networks to provide emotional and practical assistance to families and community structures, offering comprehensive support common in many African societies. Self-advocacy training sessions are critical, helping learners with MD express their needs, set goals, and make decisions about their education and life. Life skills and vocational training aligned with local economic opportunities will prepare learners with MD for independence and employment, addressing the high unemployment rates despite policies advocating for the preference of persons with disabilities. Peer mentorship and social inclusion programs, such as pairing learners with supportive peers, can foster healthy relationships, inclusion, and mutual respect.

CONCLUSION

The paper confirms that the African perspective can offer valuable insights and scientific solutions to address disabilities in a school setting. African perspective was used to describe broadly the condition of muscular dystrophy in the school setting. The study confirms that in Africa, not much scholarly information is available on the prevalence and types of MD. Therefore, it is important to adopt a multidisciplinary team approach where physiotherapists, occupational therapists, medical doctors, nurses, educationists, traditional health practitioners, teachers and parents are included in the planning, resourcing and execution of an inclusive school programme. Furthermore, the study suggests the development of a guide on health issues, emphasizing the nature and the morbidity that is associated with muscle-wasting conditions, and stressing the need for social, emotional and psychological support. Creating inclusive learning environments that value diversity and promote accessibility can help learners with MD feel more comfortable and supported. In addition, providing appropriate accommodations, such as extra time to complete assignments, use of assistive technology, and individualized support, can help affected learners to succeed academically. The study confirms that important communication skills are vital, such as active listening, flexibility and timeous responsiveness to the changing needs of the learners with disabilities. Although the mentioned difficulties are prevalent, they do not advocate for the exclusion of learners with MD from school but they underscore the importance of creating awareness amongst parents and educators about these negative effects of MD on the learning experience with a view of putting appropriate supporting measures in place. The study recommends that schools provide a supportive environment, accommodations, and resources to help learners with MD manage the psychological impacts and thrive academically and personally. This calls for relevant stakeholders to consider one of the African epistemologies based on ubuntu, which advocates for the sharing of resources and being sympathetic, caring, considerate and kind to learners with learning challenges. Key messages in the policies, plans should communicate the importance of respect, that human dignity is endowed or given to all individuals irrespective of ability, obligates others to respect that person, independently of material possessions. This further suggests that this can lead to an inclusive and nuanced understanding of MD.

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