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Ataxia and Pain Treatment with Onset of Disorder: A Case Study

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Abstract

A police constable who suddenly suffered Ataxia Spinocerebellar Ataxia type 3 was mobbed by his comrades because he misbehaved and walked strangely at the workplace. Initially, his comrades commenced to despise and confront him with insults until a proper diagnosis was made by a neurologist that he was suffering from Ataxia. Soon after that, the patient became bewildered and did not know what to do with his life. Moreover, he had neither heard of his family members nor extended family having been plagued by this neurological disorder. This longitudinal study, therefore, observed one 45-year-old patient with a wife and 4 children whose onset of managing ataxia disorder had been perceptually sanctioned and punished for his strange walking behavior. For the past three years, he had lived symptomatically, and now, he has been correctly diagnosed with spinocerebellar ataxia type 3 since the year 2022. He had wondered whether it was acquired or inherited Ataxia and characteristically found the situation unbearable, especially when he sat on a chair and felt waist pain. The experience of neuropathy and pain increased his problem of daily existence. The study utilized interviews, structured interviews, and WhatsApp videos to gather information which seems to give a high reliability and validity of data. The patient now receives a doctor's treatment and advice concerning medications and treatment with drugs. After initial help he had already received from other professionals such as nurses, psychiatrists, psychologists, social workers, and general doctors, he has come to associate with other patients suffering from Ataxia disorders and other neurological disorders. Local Ataxia Support Group, Patients, Caregivers, and family are very supportive.

Keywords: Ataxia; Chronic Pain; Coping strategies; Drugs; Pain treatments; Spinocerebellar Ataxia type 3

Abbreviations

SCA: Spinocerebellar Ataxia; NAF: National Ataxia Foundation; ILAE: International League Against Epilepsy; MDS: Movement Disorders Society; WFN: World Federation of Neurology; ASO: African Stroke Organization; AFAN: African Academy of Neurology.

General Background

Ghana and Ataxia Incidence

The disorder of Ataxia [1], as often exhibited by patients in Ghana shows inadequate muscle handling which results in awkward movements. This sharply influences walking and

balance, hand coordination, how to utter words in speech and swallowing, and the movements of the eyes.

There is a general comprehension among medical practitioners of this region (excluding traditional healers) that this had originated because of damage to a certain part of the brain called the cerebellum [2]. The damage influences the connections around this brain part. Muscle coordination is also controlled by the cerebellum. While certain conditions can originate ataxia illness, certain medicines or drugs can cause it. So far in Ghana, genetic conditions are less mentioned or attributed to as the cause. But stroke, tumors, multiple sclerosis, degenerative diseases, and alcohol misuse can cause ataxia, which the meaning may be attributed to an evildoer or magic, spiritual forces.

Most often stressed treatment given to ataxia patients determines the cause of ataxia [3]. If the patients and the family believe in the spiritually caused illness, they will consult a healer or shaman who deals with culturally provided mythology and their management systems. On the other hand, if the cause is understood to be biomedical then there are devices such as walkers and canes that might contribute to support or aid to maintain independence. The latter instruments are known as adaptive devices. In addition to this, physical therapy, occupational therapy, speech therapy, and regular exercise also might help to alleviate the excruciating pain that is often associated with ataxia.

In Ghana and West Africa, lack of coordination is not an uncommon outward manifestation of various neurological conditions, and these consist of stroke, brain tumor, multiple sclerosis, traumatic brain injury, toxicity, infection (including following varicella), and congenital cerebellar defects. And these cannot be exempted from being given spiritual connotations as regards the cause of these disorders. The genesis of this illness brings the experience to be acute, sub-acute, episodic, or chronic. Progressive ataxias frequently cause diagnostic uncertainty in general neurological practice, and many cases remain undiagnosed (or 'idiopathic') [4].

In the biomedical healthcare sectors, neurologists are the pathways for diagnosing and managing adults with progressive ataxias. Molecular genetics have also enabled many more cases with a genetic cause to be diagnosed. Autoimmunity may also be causing some progressive cerebellar ataxias [5]. Clinicians and researchers alike have no absolute treatments to stop the progression of most forms of chronic ataxia. However, there have been recent unique advances in disease-modifying interventions. Common to ataxia management is a multidisciplinary approach that calls for diverse experts such as nurses, physiotherapists, psychiatrists, psychologists, social workers, and general doctors.

Genetic versus acquired/degenerative Ataxia

Ataxia disorder is broadly divided into those that are genetic origination [6], which means this has a history or no family history connotation; and those that are acquired/degenerative. When ataxia is termed 'sporadic' it means there is no family history. Ataxia, that is, acquired progressive ataxias can be immune-mediated, and this is often denoted, as paraneoplastic spinocerebellar degeneration, gluten ataxia, degenerative (eg, a cerebellar variant of multiple systems atrophy (type C)), caused by deficiency states (eg, vitamin B12, vitamin E, and so on), toxicity (eg, alcohol-related ataxia, phenytoin), or associated with infections (HIV, sporadic Creutzfeldt-Jakob disease, progressive multifocal leukoencephalopathy, and so on). Inherited ataxias can have autosomal dominant, autosomal recessive, X-linked, or mitochondrial (maternal) inheritance. Metabolic disorders, such as Niemann-Pick type C, and Tay-Sachs disease, even though 'inherited', can present as late-onset ataxia with no family history, depicting the need for careful clinical scrutiny and comprehensive and appropriate laboratory testing concerning its diagnosis.

Clinical Symptoms of Ataxia

Ataxia patient usually complains of clumsiness, unsteadiness, incoordination, and slurred speech. Rarely, do they experience oscillopsia. At a consultation he may have one or more of the following signs: Gait ataxia and impaired sitting balance (usually late in the disease); Gaze-evoked nystagmus, jerky (saccadic) pursuit and hypo/hypermetropic saccades; Dysarthria; Intention tremor; Dysmetria; and Dysdiadochokinesis [7].

Ataxia patients may have numerous signs, which may be helpful reminders of the existence of the disorder [1]. The first ones are known as reflexes. Reflexes are usually reduced or diminished in Friedreich's ataxia, ataxia associated with vitamin E deficiency, ataxia with oculomotor apraxia type 2, and spinocerebellar ataxia (SCA) type 2 which we will discuss below in this investigation. These reflexes are present, even brisk, in patients with the most dominant SCAs and patients with multiple systems atrophy type C [2]. What consists of eye movements? How do they behave in Ataxia disorders? Eye movements or Oculomotor apraxia can appear in ataxia-telangiectasia and ataxia with oculomotor apraxia type 1 (although rare in this condition) and type 2. Slow saccades are typical of SCA type 2 [3]. *Postural hypotension*, which is often with impotence and urinary urgency/incontinence points towards multiple systems atrophy type C [4]. *Tendon xanthomas*, which are considered as early-onset cataracts suggest cerebrotendinous xanthomatosis [5]. Finally, what is understood to be *abnormal visually enhanced vestibular-ocular reflexes*, showing often pathological head impulse

test responses are characteristic of cerebellar ataxia with neuropathy and vestibular areflexia syndrome, which also has a sensory neuropathy [8].

The two most useful clinical features are *Age of onset and Rapid progression*. First, the ataxia disorder may appear in infancy reflecting a congenital or developmental cause. This usually develops genetically at the age of 20 years. This can occur in early-onset ataxia disorder. At the onset ataxias are genetic, which refers to autosomal recessive or mitochondrial inheritance. This has no family history. Dominant ataxias that are associated with SCAs tend to present later during the third and fourth decades onwards. One can emphasize that this rule does not always hold, as Friedreich's ataxia can have a late onset, characterizing intact or even brisk reflexes, and some SCAs form at the early onset. Despite recessive inheritance, CANVAS appears uncommonly late during middle age.

Second, *Rapid progression*, which can occur within weeks or months, is characteristic of paraneoplastic spinocerebellar degeneration and sporadic Creutzfeldt-Jakob disease. Multiple systems atrophy type C can also accelerate faster than other progressive neurodegenerative ataxias that consist of inherited types, which generally develop over many years [9].

To conclude this review, it can be asserted that there should be validated measures such as the 'scale for the assessment and rating of ataxia' to monitor the rate of progression serially. Therapeutic trials demand investigators to utilize rating scales that have as their endpoint the improvement or the stopping of the progression of ataxia [10].

Introduction

Preliminary investigation interviewed and observed Ataxia patients in Coastal Ghana concerning how they deal with and cope with the symptoms of this illness [11]. There is common knowledge about this illness in Ghana, and NGOs and several organizations offer support that educates the population and certain patients about their problems. Despite their efforts, awareness remains low. This study aims to improve awareness amongst students and the general public.

Aims

The two-year longitudinal study observed one 45-year-old patient with a wife and 4 children whose onset of suffering from this disorder had been wrongly understood by his coworkers. They quickly branded him a drunkard and asked that he should be sanctioned and punished for his strange walking behavior. The patient had lived symptomatically for some years now and had been correctly diagnosed with spinocerebellar ataxia type 3 in the year 2022. He wondered whether it was acquired or inherited Ataxia and found the situation unbearable, especially when he sat on a chair and felt waist pain. The experience of neuropathy and pain increased his problem of daily existence.

Review of Research

Akpalu, Adjei, Nkromah, Osei Poku, and Stephen Sarfo. (2021) "Neurological disorders encountered at an out-patient clinic in Ghana's largest medical center: A 16-year review", which was published in *eNeurologicalSci,* Elsevier, provided interesting data of 7950 patients that sought consultation over the period with 7076 having a primary neurological disorder. The mean age ± SD of patients included in the analysis was 43.0 ± 19.8 years with 3777 (53.4%) being males. The frequencies of the top 5 neurological disorders were epilepsy (23.0%), peripheral neuropathies (19.6%), movement disorders/Ataxia (14.7%), cerebrovascular diseases (11.1%), and headache disorders (7.7%). Neurocognitive disorders, autoimmune demyelinating disorders of the nervous system, and motor neuron disorders were infrequently observed [12] (Table 1).

Below is the information as categorized by these authors.

ICD code 11	Category of Neurological disorder	Number	Percentage
1	Movement disorders	1037	14.7
2	Disorders with neurocognitive impairment as a major feature	284	4
3	Multiple sclerosis or other white matter disorders	150	2.1
4	Epilepsy & other seizure disorders	1627	23
5	Headache disorders	543	7.7
6	Cerebrovascular diseases	784	11.1
7	Spinal cord disorders excluding trauma	240	3.4

8	Motor neuron diseases or related disorders	157	2.2
9	Disorders of the nerve root, plexus, or peripheral nerves	1384	19.6
10	Diseases of neuromuscular junction or muscle	286	4
11	Cerebral palsy and other neurodevelopmental disorders	67	0.9
12	Nutritional or toxic disorders of the nervous system	6	0.1
13	Disorders of cerebrospinal fluid pressure or flow	64	0.9
14	Disorders of the autonomic nervous system	17	0.2
15	Human prion diseases	0	0
16	Disorders of consciousness	8	0.1
17	Other disorders of the nervous system	164	2.3
18	Post-procedural disorders of the nervous system	5	0.1
19	Miscellaneous	115	1.6
20	Not classified	138	2
	TOTAL	**7076**	**100**

Table 1: Frequency of neurological disorders classified according to ICD 11 Coding Top blocks.

Adapted from Akpalu, Adjei, Nkromah, Osei Poku, and Stephen Sarfo, (2021) [12].

Method

As I continued for two years, observed and did daily interviews with him, it became apparent his pain where he could not sleep or do hard work. Due to constant advice and support, he was able to enable to cope. Moreover, WhatsApp videos by Dr. Susan Perlman, a UCLA expert regarding medications, current knowledge about causes of Ataxia illness, and how to deal with major symptoms appeared to offer support and coping. "Newly Diagnosed with Ataxia "videos prepared him to accept his life situation and boost his self-esteem. The National Ataxia Foundation (NAF) organized these conferences and videos to support global awareness and the fight against the disorder. This reminds us of the cost of the illness as a global one that needs to be shared [13]. This ushered the patient into the proper sick role that compelled him to seek leave from work and concentrate on his management of the disorder.

Results & Conclusion

The patient, who has come to terms with his disease, now seeks a doctor's advice concerning medications and treatment with drugs. This is after initial help he had received from other professionals such as nurses, psychiatrists, psychologists, social workers, and general doctors. Now he has been offered a neurologist. Moreover, he has come to associate with other patients suffering from Ataxia disorders and other neurological disorders: Local Ataxia Support Group and Other Patients and Caregivers. He asserted "My work has been impacted because of movement. My family is very supportive. Currently, my walking is awkward." Additional knowledge has encouraged him to attend the Annual Ataxia Conference organized by The National Ataxia Foundation (NAF) in 2024. Due to certain demands on him, he curtailed his intention to be at the conference.

He wishes that he would in the future be among the conference participants to share his illness experiences. As a police officer in a developing country where economic hardship and lack of awareness of Ataxia are rampant, he recognizes there is a responsibility on him to cope with and help others who are new sufferers of this neurological disease.

The patient reiterated he had been through enormous problems just like others in different hospital centers in Ghana since he discovered his illness and had to adapt, but "with regular exercise, my pain has been manageable." The family support and the forms of different help from them consist of "caring, love and everything." An important life lesson that I have learned since I suffered from this strange neurological illness is "I limit public appearances and my greatest admiration is when I see people walking." [14].

The conclusion of this research shows the need to train specialists particularly neurologists, and other health professionals such as nurses, psychiatrists, psychologists, social workers, and general doctors. These actionable recommendations are essential, especially now that it has become known that the multidisciplinary care approach can deal efficiently with these neurological disorders. Government and NGOs should raise awareness about ataxia through educational campaigns.

Discussion, Implication and Future Research

Ataxia is not a new neurological disorder in Ghana and West Africa though Ghana lacks adequate specialists to help with treatments. Economic stress has originated poverty in the country and this has contributed too to many people suffering the disorder. In addition to this problem, the nation lacks specialists with potent knowledge about the disorder. There is a serious problem with the economy of the government of Ghana as it deals with various disorders that require enormous financial investments in the training of its practitioners and the purchasing of drugs and medicines to be used. These have made it impossible to have well-equipped health centers and resources to handle these disorders [15-17].

The high and rising burden of neurological disorders encountered at diverse health centers and clinics suggests an urgent need to bolster the training of neurologists and to build the capacity of non-neurologists at primary healthcare hospitals to provide care for patients with neurological disorders. NGOs and private healthcare centers have recruited and organized several such training programs and outreach services and explored the potential for telemedicine as a promising avenue to support patients with ataxia. The government has recently organized training neurology specialists and practitioners to address the lack of medical officers and general practitioners across the country [18]. Various platforms from the International League Against Epilepsy (ILAE), Movement Disorders Society (MDS), World Federation of Neurology (WFN), Wessex Ghana Stroke Project www.wgstroke.org, African Stroke Organization (ASO), and African Academy of Neurology (AFAN) are being diligently utilized [19].

Neurological disorders are encountered in several hospitals and clinics in urban and rural areas, and there are reports that researchers in different centers in the country are meeting more. There must be urgent efforts to energize and build local capacity to grant optimal care to meet the demand of the rising burden of neurological disorders in Ghana and West Africa in general.

Conflict of Interest

There is nothing to declare.

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