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Guillain-barre Syndrome: The Life Experiences of a Woman Victim in Masvingo District, Zimbabwe

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Abstract

The presentation focuses on Guillain Barre Syndrome (GBS), the rare, neurological disorder, presenting a host of life threatening complications and the lived experiences of the young woman who fell victim to this autoimmune disease while pursuing her teaching career. A review of documents and researches was done to establish what GBS is, and how best it can be managed. In depth interviews were conducted to collect data from the forty six year old woman who painfully narrated her ordeal. The diagnosis of GBS may be challenging especially that in most cases, ascending weakness is the major symptom, yet it is not always viewed seriously to warrant the attention of the medical doctor. The young woman was unfortunate in that GBS is slightly more common in older people and in males. Despite her deteriorating health, the woman struggled to complete her professional training under very harsh conditions. Results show that she suffered double discrimination due to the impact of disability and gender. It has been observed that gender based violence has become a grave reality, existing in all societies regardless of class, culture or disability. The impact of GBS on the young woman's health doomed her career. It is recommended that the woman with disability must be supported fully to be able to fulfil her dreams. GBS is associated with a variety of viral and bacterial infections hence there is need to conduct further research on whether GBS may appear in COVID 19 patients. Practitioners should have GBS in mind as they manage COVID 19 cases because limited evidence suggests that GBS appears in COVID 19 patients after several days of onset.

Keywords: Guillain Barre Syndrome, Autoimmune Disease, Peripheral Neuropathy, Neurological Disorder, Paralysis.

Introduction

Guillain Barre Syndrome is a rare neurological disorder in which the body's immune system attacks part of its own peripheral nervous system (NINDS, 2018). The first and most common symptoms include varied degrees of muscle weaknesses or tingling that begins in the lower extremities migrating towards the trunk (Newman, 2017). These symptoms can increase until certain muscles cannot be used at all. The syndrome can affect the nerves that control muscle movement as well as those that transmit pain, temperature and touch sensation (WHO, 2018). Hence, the patient experiences numbness and muscle weakness in the legs and arms.

Occasionally symptoms start in the upper body moving down to the legs and feet. GBS may lead to weakness and paralysis that may last for months or years. The condition affects around 1 in 100, 000 people in the United States each year (Newman, 2017). GBS can affect anyone, although it is slightly more common in older people and in males. Both sexes are prone to the disorder but males are slightly more likely to contract GBS than women.

Symptoms

The weakness may first present itself posing difficulty climbing stairs or walking. However, the major symptom that prompts most people to seek medical treatment are weaknesses on both sides of the body (NINDS, 2018). Unexplained abnormal sensations such as pain, numbness and tingling in the feet that accompany or even occur before weakness are characteristic symptoms of GBS (Roberts, 2019). By tingling, a person experiences a sense of insects crawling under the skin called formication and pain (NINDS, 2018). Deep muscular pain may be experienced in the back and or legs. Symptoms may generally affect the arms, breathing muscles and even the face. In addition, symptoms may include difficulty with eye muscles and vision. Newman, (2021) elaborates that the patient has less control over facial muscles during activities such as chewing or talking. According to Hayward (2019) other symptoms include pricking or pins and needle sensations in the hands and feet, coordination problems and unsteadiness, abnormal heart rate or blood pressure and problems with digestion. The patient may lose control over the bowels or bladder and experience general instability. Young children may show symptoms with difficulty walking and may refuse to walk. These symptoms can increase in intensity until certain muscles can no longer be used. The severity of GBS ranges from mild weakness to total paralysis which can lead to death (Baxter et al., & The CISA Network, 2012)

Causes of Guillain Barre Syndrome

The real causes of GBS are still unknown. The condition is often triggered or preceded by acute respiratory tract infection or the stomach flu. Most cases usually start a few days or weeks following a respiratory or gastrointestinal viral infection (NINDS, 2018). In some rare cases vaccinations may increase the risk of one getting GBS yet occasionally, surgery may trigger the syndrome. Because it is a syndrome and not a specific disease, it presents different forms of health problems. It is not clear that a specific disease or causing agent is involved (mayoclinic.com). Researchers do not know why it strikes some people and not others. It is neither contagious nor inherited (NINDS, 2018). What researchers know is that the affected person's immune system begins to mistakenly attack the healthy nerves (NINDS, 2018). It follows that GBS is called auto referring to self since the body's own immune system itself does the damage to its own nerves (NINDS, 2018).

According to the NINDS, (2018), some countries world-wide reported an increased incidence of GBS following infection with the Zika virus. Zika is a mosquito- transmitted disease caused when a person is bitten by an infected Aedes species or tiger mosquito (Roberts, 2019). There are instances where Zika virus is said to be transmitted via sexual contact and blood transfusion. The Zika virus will remain in the human blood stream for a few days to a week, causing mild flu-like symptoms such as joint pains, fever, headache, red eyes (conjunctivitis) and skin rash. It can also present digestive problems such as diarrhoea, constipation and abdominal pain. The WHO (2019) reports that possible explanations from the available evidence from countries which suffered outbreaks of Zika virus infections and GBS is that Zika virus infection is a trigger of GBS. The WHO (2019) reports in the context of Zika virus

infections, that an unexpected increase in cases of GBS has been noted in affected countries. However, Roberts, (2019) reports that the Centre for Disease Control and other health experts have discovered a direct correlation between Zika virus and the development of a neurological disorder known as microcephaly. The infected new-borns and unborn babies have small heads and underdeveloped brains.

GBS is associated with a variety of viral and bacterial infections. In a systematic review of case reports done by Carrillo-Larco et al (2020), GBS is emerging as a disease that may appear in COVID-19 patients after several days of onset. The authorities further suggest that practitioners and investigators should have GBS in mind as they manage COVID-19 patients. In another report by Bueso et al (2020) it is indicated that the ill nature of many COVID-19 patients is a challenge to distinguish GBS from the critical illness. However, few COVID-19 patients with GBS have been reported. Early recognition of GBS is of vital importance with respect to the patient's recovery outcomes (Aljaafari and Ishaque, 2020). However, several disorders can be mistaken for GBS particularly in its early stages (Newswanger and Warren, 2004).

Treatment

There is no known cure for GBS. However, there are therapies that lessen the severity of the illness and accelerate the recovery of most patients. A number of ways are used to treat complications of the disorder (NINDS)

There are two treatment approaches commonly used to interrupt immune related nerves damage. One is plasma exchange or plasmapheresis. Plasma exchange is whereby blood is removed from the body through a machine inserted into the persons' veins. During this procedure, the machine removes the antibodies from the blood and finally returns the blood to the body. The body regenerates new plasma (Newman, 2021). This process removes some of the antibodies that attack healthy cells. It also reduces the severity and duration of the GBS episode (NINDS, 2018).

The other approach is high dose immunoglobulin therapy (NINDS, 2018). In immunoglobulin therapy, antibodies from donors are given intravenously (IV). Immunoglobulin are proteins that the immune system naturally makes to attack infecting organisms.

Hayward, (2019) emphasizes that donated blood with healthy antibodies removes some of these antibodies attacking nerves. The treatment seems to reduce the autoimmune response that occurs (Newman, 2017). Patients recover at different rates, and some experience incomplete or delayed recovery. One in 20 cases of GBS is fatal. According to Newman, (2017) immunoglobulin therapy shortens recovery time

Supportive care is very essential to address many complications caused by paralysis as the body recovers and damaged nerves begin to heal. All GBS patients should be monitored for complications which may include abnormal heartbeat high and low blood pressure, blood clots and infections (WHO, 2019). The hospital may use a ventilator to ensure continuous breathing, a feeding tube, a catheter as well as medication to prevent blood clots. There is need for further investigations to come up with novel treatment that are effective for such cases (Hayward, 2019).

In cases where muscle weakness persists after the phase of the illness, the patient may require rehabilitation services to strengthen their muscles and restore movement. Patients also benefit from services of the pathologist, occupational therapist and many others. Use of technology cannot be overemphasised (NINDS, 2018). GBS is a form of peripheral neuropathy. It does not cause damage to the brain or nervous system.

Case Study

Susan's Life and Medical History

Susan was born on the 25th January 1965 in the southern part of Zimbabwe. She was the fourth born of eight children. Being single at 46 years, Susan experienced various forms of discrimination and violence. However, she was very open and eager to talk about her life experiences. As a woman with disability, meeting her through an appointment was fairly easy and during the first and subsequent visits Susan shared many things including her family background and her intended career. She unfortunately had acquired the rare condition Guillain-Barre Syndrome, stroke and paralysis.

During her Primary education, Susan was physically weak. She repeated grade 4 and was not able to write the grade 7 national examinations due to illness. She had to repeat grades 6 and 7 at Goko mission. She attended Tsenzi Secondary School for one term then she transferred to Hove Mission where she sat for the Zimbabwe Junior Certificate (ZJC) examinations. She later moved to Zambuko mission where she did forms 3 and 4 and passed 3 'Ordinary' level subjects namely History, Geography and Shona. Despite her ill health, Susan supplemented 4 'Ordinary' level subjects and passed them all. In 1993 she enrolled in a Teachers' College for professional training.

On 22 February 1993, Susan reported that she felt numbness in the left leg and failed to walk. She was admitted at the District hospital and was quickly transferred to the Provincial and National referral hospitals respectively. A myelogram was conducted and the results indicated Guillain Barre Syndrome. The syndrome may cause sudden death, full recovery or the patient may become physically handicapped. Susan was physically weak and was sent to the National Rehabilitation Centre for treatment. She had a stroke which affected her left leg and had mobility problems. She was fitted in callipers and was expected to stay at the Rehabilitation Centre until recovery. Susan could not take that because she wanted to go back to College and complete her Diploma in Education. When she was finally discharged, she went back to college in 1994. Seeing Susan in callipers and crutches, the Principal at the Teachers' College indicated that the institution was not able to train students with disabilities. However, despite that, Susan got a lot of support from the lecturers who wanted her to proceed on teaching practice since she had passed the professional examinations.

Susan was deployed at a local school for teaching practice and external assessors were to follow her up in two weeks. Susan's mother assisted her in making class records and wall charts. Susan passed the evaluation exercise and the college lecturers continued to support her. Susan went back to college in 1995. Because she was unable to walk, she was re-admitted at the national rehabilitation centre in the capital city. Her urinary system collapsed and she had to use a catheter. When her bladder completely collapsed, she needed to undergo surgery for a replacement. She was referred to the major National Hospital in the capital city but found that doctors were on strike. Although she was admitted into hospital, she could not get the much needed treatment and was in great pain. She experienced two strokes due to high blood pressure and stress.

The symptoms of a stroke include sudden numbness or weakness especially on one side of the body. Sudden confusion or trouble speaking or understanding speech. The individual experiences dizziness or loss of balance or sudden problem in walking. The types and degree of disabilities that follow a stroke depend upon which area of the brain is damaged and the extent of the damage. Generally, stroke can cause five types of disabilities which are paralysis, or problem controlling movements, sensory disturbances including pain, problem using or understanding language, problem with thinking, memory and emotional disturbances. It

becomes apparent that GBS and stroke survivors need rehabilitation to regain lost functions (NINDS, 2018). Treatment focuses on improving functional skills as well as daily living skills. After staying at the rehabilitation centre for more than a year, she recovered and went back to college intending to complete her training in 1997. Susan finally completed her diploma studies after five years. She was offered a vacancy to teach at a special school for learners with physical challenges in the capital city. The Head of Office indicated that there was no accommodation for Susan at the school, yet the centre housed many individuals with physical handicaps who were on wheel chairs. Susan left the school because it was very difficult for her to rent accommodation and commute to the school using public transport daily. *"I was not able to board the bus or combi to work daily because I needed somebody to lift me and my wheelchair onto the vehicle as well as getting me off the bus."*

Susan went back to her home area and joined Kamba Primary school. She somehow felt out of place among the non-disabled teachers because she was on a wheelchair and had a catheter. However, she was taken aback by the warm reception she was given by the staff and Head of Office. This implies that the staff at the school might have done special needs education or it was mere sympathy. Everyone was very supportive and life became pretty good for her. When the Head retired and another one came into office, it was no longer rosy for Susan, who was asked to fill in forms each time she went to the hospital for treatment. The catheter which was tucked to her belly, needed to be cleaned every three months because the belly would become septic. She was later referred to a hospital in Pretoria in South Africa for further treatment and surgery. She had to continue visiting the hospital every three months for reviews and treatment. Meanwhile, she was struggling to raise money for transport and her upkeep in South Africa.

The new Head ceased Susan's salary and persuaded her to go on early retirement promising that she would get a lot of money as pension benefits. Having no choice, she left the school and was given a good send off by her colleagues but the hefty pension benefits never came. Susan reported that no follow up was made by the school community to see how she was coping. She moved into her brother's house in the high-density suburbs and was struggling to raise money for transport and treatment. The house did not have any ramps

In 2004 Susan lost speech several times after the death of her four brothers and her father. She suffered severe headache which resulted in sudden blindness. She was in great agony and needed counselling. She regained sight after going through an operation at the group of hospitals in the capital city.

She survived on hand outs from friends and the Christian community. Some local doctors provided counselling and some books to read. The same doctors assisted her in going to South Africa for treatment after every three months. She had since undergone 35 operations but she could still sit in her wheelchair and tell her life story. She suffered gender based violence and acquired a disability from a very rare syndrome.

Disability and Gender

Women with disabilities have been described as being doubly jeopardised on account of their disability and gender. They are often discriminated against for example in education and in the family. They may lack social, health and economic opportunities and they may be vulnerable to poverty and social exclusion (asksource.ids.ac.uk). Disability and poverty are intricately linked in a vicious cycle. Women with disabilities are more prone to live in chronic poverty which in turn can lead to disabling conditions. Disability movements world-wide advocate for a break in this link. (leeds.ac.uk). The Americans with Disabilities Act (ADA)

prohibit discrimination on the basis of disability in employment, accommodation, transport and so on. ADA emphasises that qualified individuals with disabilities should be accorded equal opportunities to enjoy the full range of employment related benefits that are available to others. It prohibits discrimination in recruitment, hiring, promotion, training, pay, social activities and other privileges gained from employment (unworkplace.uniaids.org). Being a woman with disabilities has real consequences in terms of education, employment, living arrangements, personal relationships, victimization and abuse. Susan suffered greatly during her school and college days due to the acquired disability. As this was not enough, she was unceremoniously dismissed from employment and had no consistent source of income to cover her needs. She attempted suicide.

Suicide

Suicide is the eleventh cause of death in the United States of America. People can consider suicide when they are hopeless and cannot see any other solutions to their problems. (ninds.nih.gov). Pressure, misfortunes such as financial difficulties, serious depressions or major stressful events play a significant role. The WHO, (2019) estimates that suicide is the 13th leading cause of death world- wide.

Susan benefited from the services of various specialists for example, physiotherapist, speech and language therapist, occupational therapist, the counsellor and many others. However, it was not easy for her to access the various specialists due to transport and financial problems. A few were seen in big hospitals but the rest were into private practice rendering the services more expensive. For Susan, rehabilitation was an ongoing process that is why her name continuously featured in the hospital's rehabilitation departmental register.

Evaluation and Critique

Susan toiled for five years to qualify for a Diploma in Education (Primary). After such a long period of suffering and perseverance, she was unceremoniously dismissed from the teaching profession because she was a woman with an acquired disability due to GBS. However, even if she might get another teaching vacancy, Susan would not be able to carry out her duties without an assistant because her body was weak due to the effects of GBS and stroke. She could not be at her place of work daily because she had to frequently visit the local hospital and go to South Africa for periodic checks on her artificial bladder. She however could not teach in a special school programme whose duties demanded an energetic teacher because she was confined to the wheel chair and was fitted with a catheter. She was a professional who depended on others and this lowered her esteem. The disabling conditions perpetuated by GBS and stroke were worsened by the loss of her supportive four brothers and her dear parents. She reported that she did not get much from the social fund, pensions and the Association for People with Disabilities in which she affiliated to. Having many responsibilities, for example, looking after her brothers' children and health care demands, Susan ended up having no choice but to attempt suicide. However, her good public relations enabled her to gain a lot of assistance and support from friends and relatives most of whom are non-disabled. Many thanks to all those who extended a helping hand, moral and financial support, free medical treatment from dedicated health professionals before Susan's departure.

Recommendations

It is clear from the discussion that Susan and many other women suffer the effects of disability and gender and that anyone can be a victim of the rare autoimmune GBS. Victims have to

endure the suffering and channel the meagre resources they get towards the much needed health services.

Below are the following recommendations:

- All health facilities to offer free investigation and treatment to people with disabilities especially women because most of them are not employed.
- Communities to make the necessary adjustments to accommodate people with disabilities so that they may also experience quality life
- Treatment sourced outside the country by people with disabilities to be fully funded by Government through its relevant ministries.
- Government, through the relevant Ministry should enforce legislation and policies that protect and advance the rights of people with disabilities
- Government, through the relevant Ministry, to facilitate infrastructural adjustments for PWDs as per need
- Government to provide consistent disability allowance for individuals like Susan who are not fit for work.
- Relevant skills training programmes to be put in place for individuals with disabilities to enhance self- reliance.
- Communities are urged to support PWDs especially women.

GBS is the most common cause of acute paralytic neuropathy. It is a form of peripheral neuropathy and it's the leading cause of acute non-trauma related paralysis in the world. The unfortunate woman fell victim to the life threatening autoimmune disease which affects more males than females especially those 50 years or older. She endured a lot of pain, frustration discrimination due to disability and gender. Adjusting to rapid paralyses that were wheelchair-bound and the dire need for help and family support was distressing. This case could not go unreported because it is very rare.

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