

Understanding the Health-Seeking Behaviour of Multiple Sclerosis Patients in Ghana Through Vignettes

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Abstract

Background: Autoimmune conditions occur when the immune system cannot differentiate between foreign substances and the body's cells. In multiple sclerosis (MS), the immune system attacks the central nervous system and causes debilitating symptoms. Various factors impact healthcare choices in Africa, including beliefs and social class.

Methods: This qualitative study explored the health-seeking behavior of five (5) purposively selected patients with MS in Ghana through in-depth interviews.

Results: The results of the study, as reported using vignettes, showed a lack of awareness about MS, and the high cost of treatment caused patients to seek non-biomedical forms of care, such as herbal remedies and divine healing.

Conclusion: This study highlights a lack of awareness regarding MS and how this affects the health-seeking behavior of patients. Desperation for an absolute cure to end suffering and the unending drain on their finances led patients to seek other modes of care. Public awareness is needed regarding the condition and alternative means of funding.

Keywords: Autoimmune conditions, multiple sclerosis, health-seeking behavior, religion, herbal remedies, vignette, Ghana

Introduction

Autoimmune conditions occur when the immune system, the body's defense against disease and infection, mistakenly attacks healthy cells, tissues, and organs (Ghazvini, 2010; Sompayrac, 2019). There are more than 80 different autoimmune conditions. These differences are as a result of the part of the body the immune system attacks which include the central nervous system (CNS), gastrointestinal systems, and connective tissues (Ercolini & Miller, 2009). When the immune system targets the CNS (brain

and spine) and optic nerves, the resulting condition is MS. Its symptoms include fatigue, numbness, loss of balance, muscle spasms, difficulty walking, vision problems, paralysis, vision loss, and cognitive issues (Compston et al., 2006; Dowd & Norton, 2014). Other symptoms include Lhermitte's sign, an electric shock-like sensation down the spine when the neck flexes, and MS hug, a tight, squeezing, and painful feeling in the trunk or abdomen (Racke et al., 2022). The cause of MS is unknown, and although there is no cure, patients

may experience periods of remission when the symptoms disappear for days, weeks, months, or years. Patients may also experience flare-ups when existing symptoms worsen and/or new symptoms appear. MS is managed with medications, including immunosuppressants, disease-modifying therapies (DMTs), and/or steroids. Women are twice as likely to develop MS than men (Chitnis & Khoury, 2022; Compston et al., 2006).

When people experience ill health, they seek ways to improve their health. Actions taken to resolve health issues are referred to as health-seeking (Olenja, 2003). The first point of call for the majority of participants in a study by Yarney et al. (2022) during ill health was faith-based healing and herbal sources because of benefits associated with cost, past experiences, or referrals (Asampong et al., 2015). Mbiti (1990) describes the African as “notoriously religious” (p. 1) and Pobee (1992, as cited in Quashigah, 2015, p. 2) describes the Ghanaian as “radically religious” to the extent that Africans and Ghanaians believe that some illnesses have supernatural causes such as curses, spells and witchcraft. According to Yarney et al. (2022), for Ghanaians, the cause of disease is either physical or supernatural. As such, it is believed that some illnesses cannot be treated with Western medicine but only by spiritual intervention or herbal medicine (Kahissay et al., 2017; White, 2015).

Conditions that result in disabilities such as MS are viewed by many African cultures as a curse or punishment because of traditional religious beliefs, resulting

in a mistrust of Western medicine as a solution (Aderinto et al., 2023). In Ghana, some autoimmune rheumatic patients report the sudden onset of symptoms as abnormal, leading them to believe that it had to be spiritual. Thus, they sought relief from prayer camps and spiritual healers. For those patients who initially went to the hospital for diagnosis and treatment, after finding out that their body was attacking itself and there was no cure, they chose to seek spiritual answers in addition to the orthodox treatment they were receiving in the hospital. Other patients tried herbal remedies when they saw no improvement from orthodox treatment (Amisshah-Arthur et al., 2022).

Inequalities exist in the healthcare coverage across Africa. Access to healthcare is skewed in favor of the socioeconomically advantaged. At the same time, the socioeconomically disadvantaged postpone care seeking because they do not see the need, cannot afford to, or both. The relatively wealthy understand the importance of good health because they are better educated and have the financial wherewithal to seek care. Additionally, the wealthy can seek treatment in private healthcare facilities, which tend to be well-resourced compared to public healthcare facilities (Aikins, 2005). Social class divisions thus determine access to health care, with those in the lower social class being underprivileged (Gordon et al., 2020; Karamangi, 2023). The situation in Ghana is not different; Boadu (2002) reports that better-educated people who are more knowledgeable about disease conditions

and invariably in a high social class are quicker to seek medical assistance than less educated people who are usually found in lower classes.

Similarly, Aikins (2005) found that the high cost of biomedical care determines cure-seeking behaviors and medical inaction. “The cost of diagnosing and managing MS is often prohibitive for the average African, making it difficult for patients to receive appropriate care” (Aderinto et al., 2023, p. 1774). A neurologist at the Korle-Bu Teaching Hospital in Ghana described the cost of diagnosing and treating MS as outrageous (Acquah, 2020).

To seek healthcare, one must believe in its efficacy and possess the resources needed to access it. Beliefs and socioeconomic status, an indicator of social class play a significant role in what an individual believes in and the resources one has respectively. These have the potential to affect health-seeking behaviors; however, there is no empirical evidence supporting this in Ghana for patients with MS. MS treatment is geared toward reducing severity and slowing disease progression (Humphries, 2012), and early recognition and early start of treatments reduce the rate of relapse and long-term disability (Makhani & Tremlett, 2021). How then can sufferers receive much-needed allopathic care if they believe in other sources of treatment or cannot afford allopathic care?

Autoimmune conditions have long been presumed to be rare in Africa. As the reportage of these conditions increased across the African continent,

suggesting that they had previously been unrecognized (Adelowo & Bello, 2014), some studies have also been conducted to examine the conditions. However, most of these studies focused on biomedical applications. Although Amissah-Arthur et al. (2022) examined the health-seeking behavior of autoimmune rheumatic patients in Ghana, there is no information on the health-seeking behavior of other autoimmune patients, including patients with MS. Thus, this study examined the health-seeking decisions of MS patients in Ghana by answering the following research questions:

1. What knowledge did patients have about MS before diagnosis?
2. What are the determinants of health-seeking decisions for patients with MS?
3. Does MS knowledge impact healthcare choice?

Literature Review

Religiosity has the potential to influence attitudes and preferences (Ayifah et al., 2022) and religious beliefs are a matter of choice. However, social class is not about choice but a matter of what one has or does not have, and it influences employment, income, literacy, education, health, and quality of life (Quansah et al., 2016). Beliefs and class have a significant impact on the lives of Ghanaians, including the choices and decisions they make about their health and healthcare options. Faith healing is popular in Ghana not only because of a belief in its thaumaturgical capabilities

but also because it is free (Senah, 2004). Additionally, herbal treatment is preferred over allopathic medicine because of the high cost of the latter as well as spiritual and cultural beliefs (Boateng et al., 2016).

Beliefs and Healthcare in Ghana

Religion permeates all facets of Ghanaian life and is at the heart of Ghanaian social structure (Busia, 2023). Giving further credence to this, the 2021 population and housing census in Ghana revealed that 98.8% of Ghanaians identified as belonging to one religion or another, with only 1.1% reporting having no religious beliefs (Sasu, 2023). Religion has been found to play a role in major decisions Ghanaians make, including politics (Takyi et al., 2010), education (Takyi & Addai, 2002), and healthcare (Takyi, 2003), and as such, determines how Ghanaians act.

Studies have investigated the effect of religion on Ghanaians' healthcare decisions. Investigating the health-seeking behaviors of autoimmune rheumatoid patients in Ghana, Amissah-Arthur et al. (2022) found that some patients sought help from spiritual healers and prayer camps. Their choice stemmed from a belief that the cause of their condition was not biomedical but spiritual. In a study examining healer shopping among Ghanaian diabetics, Aikins (2005) found that some participants believed that their condition was caused by witchcraft or sorcery and, as such, sought healing from either the Christian sphere (faith healing) or the traditional religious sphere. Kpobi and Swartz (2019) delineated the

traditional religious healing sphere as comprising herbalists, diviners, or fetish priests. Talismans and charms are used for spiritual protection, sacrifices are made to appease spirits and gods, and spiritual cleansing and exorcism are also used if the diviner perceives the cause of the disease to be spiritual. However, herbs are used if the cause is perceived as physical (White, 2015).

Similarly, religion has been found to influence the views and treatment of mental illnesses in Ghana. Abukari et al. (2021) found that some patients are sent to Christian prayer camps where prayer, holy water, chanting, and black seed oil are used as mediums to heal them, while Bible verses are recited to exorcise spirits. Read (2012) also found that families of mentally ill patients in rural Ghana doubt the efficacy of antipsychotic medication because of its inability to cure the condition permanently. This, coupled with the side effects of the medication, which rendered patients weak and interfered with their ability to work, supported the belief that the condition is spiritual and could not be cured biomedically. Additionally, a belief in the effectiveness of herbal medicine over orthodox medicine results in some Ghanaians preferring the former (Aziato & Antwi, 2016). This is especially the case in the treatment of chronic diseases that cannot be cured but are only managed (Stanifer et al., 2015).

Social Class and Access to Healthcare in Ghana

The differences in social classes are often based on what a group has and what

they have access to. In Boadu's (2002) study on social class and health status in Ghana, he placed his participants into three (3) classes based on certain indicators, including level of education and properties owned. While those in the upper class had the highest level of education, followed by those in the middle class, those in the lower class had little or no education. Members of the upper class owned their places of dwelling and owned modern household items such as cars; the middle class rented their place of dwelling and owned basic modern household items such as television sets; and members of the lower class owned no modern household items and neither owned nor rented their place of abode. Nyamah and Diko (2013) state that social class determines educational attainment, literacy, and income levels.

A high educational level and being gainfully employed influence health-seeking behaviors. Highly educated patients tend to understand their conditions better and seek biomedical care. However, the high cost of biomedical drugs places a significant financial burden on people in the low-income bracket, thus discouraging or preventing them from seeking biomedical care (Amissah-Arthur et al., 2022; Aikins, 2005) and pushing them to seek cheaper alternatives, such as herbal medicine, which is relatively cheaper (Pathak & Das, 2013).

Kuure et al. (2016) in a study on the health-seeking behavior of adults in a resource-poor setting in Ghana, revealed that educational attainment influenced the health-seeking behavior

of participants. Additionally, the study found that transportation costs to health facilities were a barrier to participants' ability to access health services when ill, even though they were enrolled in the National Health Insurance Scheme (NHIS), meaning they could access free healthcare. The poverty-stricken nature of their existence prevents them from accessing free services. In a study examining socioeconomic inequalities among pregnant women accessing antenatal services, which are accessible under the NHIS in Ghana, Ekholuenetale et al. (2021) also found that household wealth impacted the ability of pregnant women to attend antenatal clinics.

Methodology

Research Design and Sampling

Under a phenomenological research design that positions the researcher to study experiences from the perspective of others (Creswell, 2013), this study used a qualitative research approach in which purposive sampling was used to select five patients with MS from an MS support group in a national referral hospital located in Accra, the capital of Ghana. The researcher was a member of this group, and at the start of the study, five patients consented to participate. According to Creswell (2013), a sample size of 3 – 25 is adequate for a phenomenological study to achieve data saturation.

Data Collection

An interview guide was used to conduct in-depth interviews with selected participants to answer the

research questions. The interview guide consisted of topics and issues to be explored during the interviews. These were noted before the interview (Patton, 1990). Phone interviews were conducted from October 2, 2023, to October 14, 2023. Each interview lasted between 20 and 40 minutes and was recorded. One (1) of the participants was minor, and the father was interviewed to obtain additional information. Four (4) out of the five participants were female, which is understandable given that women are more affected by MS than men (Chitnis & Khoury, 2022). The youngest respondent was 16 years old, and the oldest was 56 years old.

Reflexivity

The researcher, aware of her position and connection to the research situation and the possible effects on it as an MS patient herself, used this connection to guide and direct the study by drawing on her experiences as an insider. This connection gave the researcher the advantage of access to participants, an understanding of the research situation, and a level of honesty from participants that an outsider would not have. While being able to conduct research sensitively, being an insider has disadvantages, such as making assumptions and conclusions based on prior knowledge or experiences and not necessarily on information provided by participants (Suwakhong & Liamputtong, 2015). The researcher overcame this challenge by reflecting on and questioning all assumptions and conclusions made at every step to give a

trustworthy, valid, and honest account of the research process.

Data Analysis

The recorded interviews were transcribed and presented as vignettes with excerpts. The vignette approach for presenting qualitative findings is narrative-based, in which data are presented as short stories. Vignettes vividly describe an event (Reay et al., 2019). While communicating valuable information, stories (vignettes) provide an emotional and deeper understanding of lived experiences (Jasinski et al., 2021). Patterns of meaning (themes) were also drawn from the data through interpretative phenomenological analysis (IPA), where the data were read again to gain understanding, make notes, and identify and connect themes from the notes (Smith & Osborn, 2007).

Ethical Considerations

Informed consent was obtained from each participant and the parents of the minor who participated in the study. The parents of the minor were present during the interview, and the call was on loudspeakers so they could listen. Participants were given the option to discontinue participation in the study at any point they desired and were not coerced or forced to be part of the study. Phone interviews were conducted at the convenience of the participants, who could participate in the comfort of their homes. Ensuring participants' comfort is of utmost importance because of the symptoms such as fatigue and pain experienced by patients. In presenting

the results, pseudonyms were used to protect the participants' identity, which was communicated to them before the interviews. All data were securely stored on a password-protected drive, to which only the researcher had access.

Results

***“We were told to pay GH¢1,000 [US\$ 75] before the ‘osofo’ [pastor] would attend to her... [and] listen to her problem”*: ADWOA’S STORY**

Adwoa is a 16-year-old senior high school (SHS) form 2 student and the second child of three children of a security officer and a caterer. She was diagnosed with multiple sclerosis (MS) in 2019. In 2018, when she was in junior high school (JHS) form 1, she started experiencing excruciating pain in her head and left eye and subsequently lost vision in her left eye. Her parents took her to a government hospital where she was referred to the Eye Clinic of a national referral hospital in the capital city, Accra. They were told that she had suffered nerve damage in her left eye and was put on some medication, but her condition did not improve. She was then referred to the Neurology Clinic at the same hospital. *“At that time... we didn’t know what to do and we were really disturbed and devastated so... we went to [a private] eye clinic... and the doctor told us that... nothing can be done about this situation because the nerve is completely dead... and he doesn’t know what to do... so... that’s the end of the left eye so we should just go and... I should continue seeing with my right eye because as for the left eye, nothing can*

be done about it.” From the private eye clinic, Adwoa’s parents sent her back to the Neurology Clinic of the national referral hospital where after a series of MRI scans of her spine and brain, blood tests, computerized tomography (CT) scans, lumbar punctures, and visual field tests of her eye, she was diagnosed with MS.

Due to her age, Adwoa was admitted to the children’s ward of the hospital where she received treatment from both the Neurology Clinic and the children’s ward. At the same time, family members started hounding Adwoa’s father about the need to act because the hospital was not helping. After constant prodding from an aunt, he took her to his aunt’s church for prayers. *“I don’t believe in such things but trust me... at that point, I have no choice... so we moved her from the hospital. She wasn’t discharged but I took her. That was when I realized that something that you say you don’t believe in... some situation can push you.”* The Bishop of this church, a popular Pentecostal church in Ghana asked for GH¢1,000 [US\$ 75] before praying for Adwoa. Adwoa’s father paid but he lost all faith in the Bishop when he demanded money. He saw the process as a business for Bishop and concluded that it could not be from God. The Bishop insisted that Adwoa would recover her sight after he prayed. *“So during the prayers... I was just observing. I was thinking immediately the eye will just come back.”* Adwoa’s eyesight remained the same.

Adwoa was subsequently sent back to the hospital, where she resumed treatment.

She sometimes experiences spasms that render her immobile until they pass. Whenever she relapses, the dosage of her medication is increased by about 1,000 times. Doctors spoke to Adwoa's father about a newer treatment that works to reduce the frequency of relapses but they also said it was expensive. *"I told them but what can man do... That means I need to... go to whatever... corner to... try and get the money to get this medication... At a point I asked the doctor... is it going to correct the eye for her to see once again... but I think they said... it's like managing it."*

Adwoa's father spent over US\$ 1,500 on tests for her diagnosis and has spent close to US\$ 6,000 on her treatment. The new treatment is an infusion, which costs approximately US\$ 900 every six (6) months. *"All my resources, I've depleted all my accounts... all the savings I've done has gone into this."* Although Adwoa's father is unsure about Adwoa's condition having a spiritual cause, he holds on to the hope that she will get better. *"What is going on... it's only God that can... If you ask them [doctors], from their explanation, you can see that they can't give you any concrete [answer]... that this will happen... so I'm just saying that... we know it's only God that's going to maybe speak one day... I am still not writing off that maybe it's some evil spirit working... but God is supreme."* After the experience with the Pentecostal Bishop, they now pray for themselves and have not tried any other treatment aside from what they receive in the hospital.

Aside from being able to perceive light and movements such as the blades of a moving fan and a waving hand when it is up close, Adwoa cannot see with her left eye. The vision in her right eye is 50%. Adwoa now attends school with her mates, but when the condition started while she was in JHS, her parents withdrew her from school and had her homeschooled. She sat for the Basic Education Certificate Examination (BECE) as a private candidate. *"In school, I use this device, the telescope for far distance and magnifier for smaller form."* She is given extra time during exams and her questions are printed in a font size larger than the size used for the other students. Before she was diagnosed, Adwoa and her parents had never heard of MS.

"I felt like... tomorrow someone thinks it's something, but they're not too sure... let me go and ask another... so I went to the States": ARABA'S STORY

Araba is the 43-year-old daughter of a retired business executive and owner of a popular luxury brand in Ghana. Araba holds a master's degree, is single, and lives with her parents. She vaguely remembers dragging her foot in 2002, which was after a friend reminded her of an episode she had when she complained to the friend about her current condition. She also remembered having some issues with her health when she lived in the United Kingdom (UK) some years after the 2002 incident, but the details were fuzzy. This was because these issues were not there constantly. In her words, *"They were on and off."*

In 2011 she was driving when suddenly she could not see clearly. She also started experiencing mobility issues, so she went to a private hospital where she was referred to a national referral center. After seeing a neurologist, she started physiotherapy at the hospital. She remembers taking a lot of pills every day. However, because of the uncertainty on the part of the doctors and the fact that she still experienced difficulties while on medication, she decided to go to the United States of America (USA) to seek another opinion in 2013. In the USA, she was diagnosed with MS, which was her first hearing about the condition. She was put on one of the newer treatments for MS, not available in Ghana. She remained on the treatment even after returning to Ghana. The medication was shipped from the USA whenever she ran out and requested. She, however, got tired of injecting herself thrice a week, which is how this medication is administered.

For close to two years, Araba was off any form of treatment and then relapsed. She returned to the national referral center and has since 2021 been on another one of the newer treatments for MS. The medication she takes is different from what Adwoa takes, and costs US\$ 1,350 every six months. Araba quit her job in 2019 and her parents foot the bill for her medical expenses. *“Right now, they’re on pension and... I’m siphoning their pension funds. It’s pricey... it’s expensive but does it help? Yes and no... There are days and times... I think I’m okay.”* However, she indicated that she does not always feel okay.

Regarding spirituality and her condition, Araba said, *“There’s no spiritual cause... we don’t know where it’s from. I read a lot.”* She also said no one has ever suggested a spiritual cause to her. *“Nobody would recommend that I go and see any pastor.”* Araba occasionally uses a Zimmer frame, depending on the distance she has to walk. She no longer drives and has had to give up her position as a lector in the Catholic Church. Araba has never tried any other form of treatment aside from what she receives in the hospital.

“I’ve been seeing their advert on the tele[vision] and I think when I go there maybe I will get a solution to my problem... They have been giving me their concoction... but... nothing”:
ESI’S STORY

Esi is a 51-year-old middle-school leaver. She is the wife of a contractor and a mother of 3. In 2019, she started experiencing pain in her waist and back. She went to a clinic in her neighborhood where she was given painkillers, and the pain ceased; however, after 2 weeks, the pain returned. She also started feeling pain in her hip and experienced difficulty walking, so she went to a larger private hospital and was asked to do an X-ray. The doctor said the X-ray was normal, but the pain persisted, and out of desperation in search of a solution to her problem, she went to a private trauma and orthopedic health facility because she felt her problem was a spinal issue. She was, however, not told what the problem was, so she was referred to a national referral hospital to consult a neurologist.

The neurologist asked her to do some tests, including an MRI. *“The MRI... I spent 30 million [US\$ 225]... It’s a headache... not for me but [for] the one who is sponsor[ing] me... My husband... has been supporting me for all these years.”* At a point, her husband tried to take her for herbal treatment, hoping to get a remedy for her condition and ease the financial burden on himself. While still undergoing tests at the national referral center, she visited a herbal clinic after seeing advertisements on television. She was asked to pay GH¢6,000 [US\$ 450]. She paid half of the amount and started treatment. *“I don’t know what they [were] treating.”* She wasn’t diagnosed with any condition at the herbal clinic but she was given in her words *“a concoction”* to take. After a month of taking the concoction with no results, she left and went back to the national referral center where further tests, including a lumbar puncture, were conducted. In 2022, Esi was diagnosed with MS, a condition that she had never heard of.

After the diagnosis, Esi started receiving treatment and was placed on newer MS treatment. She is, however, unable to pay for the treatment upfront so she has been given a payment plan. She pays GH¢3,000 [US\$ 225] monthly and receives an infusion every 6 months. In addition to caring for their three children alone, Esi’s husband pays for her treatment. *“I am a seamstress... but because of [my] health, I had to stop the sewing and come and stay in the house... I think my treatment has been weighing my husband. He say[s] he cannot do anything for himself... I am very sad.”*

According to Esi, people have attached spiritual connotations to her condition but she does not believe in that. *“People... say... won’t you go here, won’t you go there. I don’t have that faith so when I go, I won’t get my healing... My God is only one, the Catholic... God.”* Esi currently uses a cane to aid her in walking, and will soon begin physiotherapy.

***“[The] Prophet... I want to go to him and see what will happen... I believe in miracles”*: FIIFI’S STORY**

Fiifi is 29 years old and on a government of Ghana scholarship to study for a PhD in South Africa. He began experiencing MS symptoms in 2021. *“My right limbs, they... stopped working.”* Fiifi is a music student who plays six different musical instruments. In 2021, he could no longer play any instrument because his right hand suddenly stopped working. Walking also became difficult because he could barely move his right leg and could walk only short distances. He visited a general practitioner (GP) who, after listening to his complaints, told him that he was overthinking, which is why he was experiencing what he was going through. The GP told him to stop thinking too much. Apart from his studies, Fiifi stopped thinking about everything else. This seemed to work because he regained the use of his right hand and could play musical instruments once again, but his walking worsened. *“If I walk, it looks like I’m drunk... but it was a norm in South Africa because people drink almost always so they thought I was like that.”* Fiifi also experienced double vision but that stopped after a while.

On the advice of his supervisor, Fiifi visited a neurologist who ran some tests and told him that his PhD program was stressing him out and told him what the GP had told him. The neurologist referred him to a counselor for stress management. His difficulties persisted even after stress management sessions with the counselor. Fiifi's PhD proposal was approved only around this time, and he had to return to Ghana to collect the data for his study. He also decided to seek help for his condition in Ghana: *"I was just thinking maybe [when] I come to Ghana... then I [can] take traditional herbs."* Fiifi returned to Ghana in a wheelchair because he could not walk. After telling his brother what he had been going through, his brother sent him to the Neurology Clinic of a national referral center in Accra. After an MRI scan of his brain and a lumbar puncture, he was diagnosed with MS in 2022. Fiifi started treatment, and by 2023, he was put on one of the newer MS treatments. The cost of the treatment is US\$ 1,350 every six months. He is now out of the wheelchair, can walk longer distances, and can use his right hand better than before.

Fiifi also receives physiotherapy at the hospital. Additionally, he bathes with some herbs his mother gives him. Fiifi does not know where or how he got this condition, and before his diagnosis, he had never heard of MS. *"People have suggested that it could be spiritual based on... how it started... I don't care whether it is or not and I don't care where it comes from. I know I will be healed."* Fiifi believes he will be healed because of an

experience he had as a child when he had asthma and received healing at a crusade he attended. *"God has done it in my life before."* Fiifi plans to see a prophet his girlfriend has recommended to him.

Fiifi's parents are on pension and he lives with his brother. His brother finances his treatment and it appears that it is not a burden on him. *"He doesn't complain actually."* Fiifi's brother is the special assistant to a minister of state in Ghana.

"I don't believe in that... I'm a Roman Catholic... I'm also part Jewish": EFE'S STORY

Efe is a 56-year-old divorcée. She is British and has lived in Ghana for the past five years. Efe holds a Master's degree and is currently unemployed. She does not have any children. In 2003, Efe was jogging when she lost sensation in her right foot and fell. She used to be an illustrator and started feeling the pins and needles in her hands, which affected her ability to draw. Therefore, she had to stop drawing. She also felt pins and needles in her legs.

Efe suspected MS because a friend of hers had died from the condition, and her symptoms were similar to what her friend went through. Additionally, she had seen media messages from the National Health Service (NHS) in the UK about MS and its symptoms. *"I went to see several private specialists in London... most of which told me there was absolutely nothing wrong with me."* MRI scans showed no evidence of immune system activity in the brain; hence, the doctors could not diagnose her with MS. However, Efe continued

searching for a doctor who could tell her exactly what was wrong with her. She visited a doctor at a private hospital who in 2006 diagnosed her with MS.

Efe was placed on one of the newer MS treatments not available in Ghana. This medication is administered via injection three times a week to reduce the frequency of relapse. Efe stated that she knew the treatment was very expensive, but she did not pay for it. The payment was covered by the NHS in the UK. She moved to Ghana because her husband was a diplomat who posted to Ghana. In Ghana, she receives treatment at the Neurology Clinic of a national referral hospital in the capital. Because the medication she was on in the UK is not available in Ghana, she was put on the same treatment Araba, Esi and Fiifi are on. The treatment costs US\$ 1,350 every 6 months, and her family pays for it. According to Efe, even though she was not on this medication in the UK, she is familiar with it and it is significantly cheaper in Ghana. Efe has never tried receiving treatment outside the hospital for MS, and has never considered faith healing. *“There is no way in the world I would believe in... that.”*

Efe fell a while back and broke her hip. She is currently using a wheelchair and is supported by a caregiver at home. She plans to return to the UK when her hip improves.

Discussion

Knowledge about Multiple Sclerosis

Before being diagnosed with MS, except for Efe, none of the patients was

aware of the condition and its symptoms. Efe knew about MS because a friend of hers had the condition, and she had also seen media messages about MS in the UK. The other four participants did not know anyone who had MS nor had they heard or seen any information about it. After their diagnosis, they received information about their condition.

In assessing MS awareness and knowledge in Saudi Arabia, Faran et al. (2021) found that aside from MS patients who have received basic information about their condition from their doctors, public knowledge of the condition was below average. Similar findings were reported by Khader et al. (2022) in Palestine. Public knowledge of MS is important because it promotes early detection and appropriate management of the condition (Dehghani, 2021; Faran et al., 2021).

Determinants of Health-Seeking Decisions

At the time of the interviews, all participants had received treatment at a national referral hospital in the capital. However, Adwoa and Esi had stopped receiving care in this hospital to pursue faith healing and herbal treatment, respectively. For Adwoa, her father was prompted by family members to seek healing in a church because care in the hospital appeared ineffective. On the part of Esi, as a result of the cost of care in the hospital, her husband suggested herbal medicine hoping for an absolute cure for her. In both instances, their desire for absolute healing drove them to seek

care elsewhere. According to Aziato and Antwi (2016), a belief in the effectiveness of herbal treatment informs its preference for allopathic care, especially in the treatment of chronic health conditions (Stanifer et al., 2015). Participants in a study by Okyerefo and Fiaveh (2017), such as Adwoa's relatives, believed that only God could heal.

Araba resorted to non-adherence to her treatment when she returned from the USA out of frustration with the process. According to Jimmy and Jose (2011), the long-term nature of taking these medications is a barrier to medication adherence. Fiifi looked forward to his return to Ghana so that he could use herbal treatment because he was not getting a solution to his problem while pursuing allopathic care in South Africa. However, after receiving a diagnosis in Ghana and while receiving orthodox medicine, he plans to seek divine healing. Similarly, despite receiving allopathic care, participants in the study by Okyerefo and Fiaveh (2017) also pursued faith healing because they believed that even though doctors can treat some conditions, only God can heal. Efe has only been on biomedical treatment since her diagnosis.

Believers in faith or divine healing tend to be Pentecostals and members of Charismatic and Pentecostal-like churches (Anderson 2002). "...healing and miracles has been prominent in Pentecostal praxis... Pentecostals see the role of healing as good news for the poor and afflicted" (Anderson, 2002, p. 363). The popularity of faith healing in Pentecostal and Charismatic churches

might explain why Adwoa's father and Fiifi, who are members of Pentecostal churches, are open to it and not Araba, Esi, and Efe, who are members of the Roman Catholic Church. Adwoa's father has, however, given up on seeking divine healing for his daughter from church because he was taken aback when he was asked to pay for prayers for his daughter. He felt that it was just a business for the man of God. "Christianity in Ghana today appears to have taken on a business-like outlook. It is generally characterized by the sale... of religious items and services" (Anderson, 2019, p. 172).

The ability to afford treatment was also a determinant of health-seeking behavior. Esi at a point abandoned allopathic care because of the cost and although she now receives care in the hospital, she is unable to pay for the treatment upfront. She pays in installments. Adwoa gets care in the hospital but her father complained bitterly about the cost and is at his wits end as to how he will raise money for her next infusion. Araba was able to seek a second opinion in the USA when she was not satisfied with the treatment in Ghana, and Fiifi's brother, who finances his treatment, is not affected by the cost. As a foreign national living in Ghana, Efe's experiences are markedly different from the other participants. She receives foreign exchange from her family in the UK to pay for her treatment and even finds the cost of treatment in Ghana cheaper than in the UK. Accounting for the differences among the participants, Aikins (2005) notes that the high cost of biomedical care determines cure-seeking

behaviors, with the wealthy having more options than the less privileged.

Multiple Sclerosis Knowledge and Health-Seeking Behaviour

Of the five participants, only Efe knew about MS before she was diagnosed. This could account for her use of biomedical care since she was diagnosed. Lack of previous knowledge about MS could also explain why other participants engaged in what Benyon (2014) identified as risky behavior when it comes to the management of chronic health conditions. Adwoa was removed from the hospital where she was receiving treatment and sent to the church for divine healing; Esi left the hospital to receive herbal treatment for her condition; and Araba stopped taking her medication out of frustration with the treatment process. Fiifi is the exception. Although he has plans to see a prophet for divine healing, he does not plan on abandoning the treatment he is currently receiving until he is healed.

Conclusion and Recommendations

This study highlights a lack of awareness of MS and how it affects the health-seeking behavior of patients. Desperation for an absolute cure to end suffering and the unending drain on their finances led patients to seek other modes of care. The cost of biomedical care has proven to be a barrier to patients' ability to receive allopathic care, which is the only proven method for managing MS (Humphries, 2012).

To effectively counter this, there is a need for public awareness of the

condition. This can be done using various media channels throughout the year and escalated during the MS awareness month of March. The Ghana Health Service can lead this campaign. Additionally, the diagnosis and treatment of MS, which is currently not covered by the NHIS, should be added to the conditions covered by the NHIS to ease the financial burden on patients.

This study aimed to understand the health-seeking behavior of patients with MS in Ghana. Still, the participants also touched on some challenges they experienced living with the condition. Future studies could examine the challenges MS patients experience due to living with the condition.

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