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CONTAINING SICKLE CELL ANAEMIA DISEASE AND INFANT MORTALITY THROUGH LITERARY TEXTS WITH HEALTH MOTIFS

Iwabi Abraham Modahunsi, (PhD)

Institute of Health Humanities and Entrepreneur,

University of Medical Sciences,

Ondo, Ondo State, Nigeria

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Abstract: **Nigeria occupies the highest position in the global epidemiology of sickle cell anaemia. This raises concern among some Nigerian writers and prompts them to make anaemic crisis the motif of their texts in order to create awareness that will reduce the number of anaemic patients. This study is delineated within the medical humanities to conscientise people to the portraiture of genotypic compatibility in literary texts. It aims at exploring literary dimension to curtailing the menace of sickle cell anaemia. The research elucidates the interface between literature and medicine, in multidisciplinary studies, to reduce infant mortality through literary studies. Qualitative research methodology is employed in the study. It enhances the hermeneutics of two Nigerian literary texts thematising the causes of anaemic crisis. The literature review deconstructs mythical proposition about sickle cell anaemia. The study reveals that sickle cell anaemia is topmost among the causes of infant mortality in Nigeria. The finding also shows that anaemic children and their parents live unhappy life often characterised by crisis management and infirmary journeys. Their parents are always dejected and take responsibility for the pains of the anaemic children. In spite of the pains, both texts beacon hope, explaining bone marrow transplant as veritable treatment that cures sickle cell anaemia. However, the texts recommend genotypic compatibility as the best way to avoid giving birth to an anaemic child. Nigerian scholars in the humanities, sciences, and the social sciences, with background in health education, have to sensitise the populace about genotypic test before marriage is contracted.**

Keywords: **Anaemic patients, genotypic compatibility, literature and medicine, Nigeria.**

1. INTRODUCTION

The musings culminating in this study arose from a caption in the *Guardian* newspaper of September 15, 2023, authored by Paul Adunwake. The headline was: "Lawmaker, others advocate genotype screening for couples" [sic]. In the piece, Desmond Elliot, the lawmaker representing Surulare Constituency I at the Lagos State House of Assembly, called for "genetic counselling and genotype screening among intending couples towards preventing sickle cell disorder". The write-up stemmed a sense of déjà vu − a recollection of the interface of literature and medicine, a non-pharmaceutical and non-drug administration procedure, in the control of infirmities, especially the creation of awareness about sickle cell anaemia. It spurred the explication of Samira Sanusi and Jude Idada's advocacy of genotypic diagnosis as a premarital requirement for prospective couple in their debut novels. Sanusi's novel, an autobiography, is titled *S is for Survivor, Sickle Cell Anemia: My story* (2014); and Idada's fictional text is *Boom Boom* (2019). On this premise, this study

foregrounds the imperative of scholastic nexus among literary field of study and the medical profession to earn a healthy life through reduction of sickle cell anaemia cases. It is a research geared towards the humanisation of the medical profession, through multidisciplinary clinical approaches, to contain sickle cell anaemia and its debilitating infant mortality. stem

Statement of the Problem

In spite of what previous researchers have done on the measures to curtail sickle cell anaemia in Nigeria, available studies, up to February, 2023, lament its devastating effects on infants (Nnodu, Oron, Sopekan, Akaba, Piel and Chao, 2021; Ogbonna, Uwa and Okechukwu 2022; Isa, et al., 2023). A model-estimated and population-level analysis of data from Nigeria's 2018 Demographic and Health Survey (DHS) conducted by Nnodu, Oron, Sopekan, Akaba and Chao (2021) revealed that "the burden of child mortality from sickle cell disease in Nigeria continues to be disproportionately higher than the burden of mortality of children without sickle cell disease". In like manner, Arwa et al. (2019) are unapologetic as they declare unequivocally that "Nigeria leads the world in the number of cases of sickle cell disease (SCD)". This discovery was substantiated by Isa et al. (2023). Isa and his co-researchers observe that sickle cell anaemia is highly prevalent in Nigeria and, among other measures to contain it, suggest health education and genetic counselling. Such health education should involve multidisciplinary episteme, including literary studies − the thrust of this article.

If the number of sickle cell anaemia sufferers must be reduced, all scholars in the humanities, sciences, and the social sciences, with background in health education, have to strive to create genotypic awareness across all the federating states of Nigeria. Most of the infant mortalities can be prevented if there is adequate awareness about genotypic compatibility before marriage is contracted, as well as useful information about bone marrow transplant and cell editing. This explains why this study examines awareness of genotypic compatibility in selected literary texts from Southern and Northern Nigeria.

2. RESEARCH METHODOLOGY/THEORETICAL FRAMEWORK

Qualitative research methodology is deployed in this study. The methodology entails, among others, collection and analysis of non-numerical data from the selected literary texts for the study. It is an interpretative and text-based research delimited to medical humanities, which is also dubbed narrative medicine. It hinges on deconstructionist literary theory and magical realism. Deconstruction literary theory evolved from the writings of Jacques Derrida that logical structures, or binary oppositions, are the bone of society and language. Hence, a binary has two ideas and/or concepts that are presented in opposition to one another, such as life/death, feminine/masculine, mind/body, etc. On the other hand, magical realism is a literary genre that depicts the real world fantastically, by connecting it to the spirit realm, which gives it some gothic imagery. In the context of this study, medical reality versus myth, as well as sickle anaemia versus suppositions *Abiku* are presented antithetical on the basis of literary hermeneutics, within the ambits of deconstructionist theory and magical realism. Deploying the two literary approaches in this study helps to unearth the disparity between sickle cell anaemia and Abiku.

Deconstruction, on a literal sense, involves dismantling of an old element or a structure and erection of a new one in its place. In a deconstructionist analysis, a text is subjected to a new perspective of analysis that reveals hidden layers of meaning. It pays attention to the intent of an author, as well as how the concepts, language, and images of the text have been previously examined.

Deconstruction of Myth about Sickle Cell Anaemia

Research paradigm has shifted from monodisciplinary to multidisciplinary approach. This enables scholars to pull research ideation from different disciplines in a bid to proffer solutions to problems. Multidisciplinary study in Literature and Medicine focuses on the complementary roles and the affinity between the disciplines in dealing with health challenges. It broadens one's knowledge on how lives can be saved through literary studies the same way the medical profession saves lives. Medical advancements have demystified a number of unfounded postulations about some diseases and health conditions in Nigeria. Some of the medical discoveries/innovations are thematised in science fiction. Sickle cell anaemia is one of such diseases. Sickle cell anaemia (also called sickle cell disease or drepanocytosis) is a preventable genetic disease; but it is rampant in Nigeria. It is one of the infirmities Nigerian creative writers depict in

their works. Sickle cell anaemia is a non-communicable disease. It is an inborn red blood cell disorder emerging as a result of genotypic incompatibility.

The myth about infant mortality, which offered a spiritistic explanation to the phenomenon, is one of such unscientific ground medical education has decentred and unravelled. The genotypic cause and traumatogenic effects of infant mortality are analysed in this study, through the analysis of one selected (science) fictional text and an autobiography. The study demystifies the mystery of the age-long myth about infant mortality, commonly referred to as *Danwabi* among the Hausas in Northern Nigeria; *Abiku*, among the Yorubas in the South-Western Nigeria; *Ogbanje* among the Igbos in South-Eastern Nigeria. Hence, it deconstructs the Danwabi/Abiku/Ogbanje myth or superstition. Doing this, the pragmatic value of literature to educate, enlighten and disentangle the underlying factor behind a particular phenomenon is given credence premised on reliable medical proofs.

Belief in reincarnation holds sway among the ethnic groups in Nigeria. Onyekwere, Uche and Chioma (2013) argue that "*Ogbanje*, *Abiku*, *Eka-Abasi*, *Fon* and *Danwabi*" among the Igbo, Yoruba, Efik and Hausa respectively refer to those children who are born but die shortly after or later in their youthful age. It belongs to the variety of undomesticated spirits who do not have shrines or temples". Such child is born and (s)he dies shortly after birth, months or few years after birth and the belief exerts a very powerful influence on the cultural worldview of the people. More often than not, the death-prone child dies during infancy. It is believed that those children have extraordinary power to follow a cycle of rebirth as often as possible. Even among the pioneer Nigerian writers, the phenomenon has been textualised. Wole Soyinka and John Pepper Clark-Bekederemo espouse the belief in their poems titled "Abiku" (Nwoga, 1967).

Before the advent of Western education in Nigeria, some women experienced stillbirth in succession and such occurrence was puzzling. The myth on which the occurrence hinges is that such children have supernatural power kept usually in trees, operating at the spirit realm, which enables them to enter into the womb of a pregnant woman, displace the foetus spiritually, take its position and be born. They die after birth and continue the cycle. The widely held belief is that a "Danwabi/Abiku/Ogbanje" defies all efforts (both physical and magical) to make him/her live.

Attempts have been made to deconstruct the "Danwabi/Abiku/Ogbanje" myth and tag it as sickle cell anaemia. Many studies have been conducted to uphold or reject the idea since its popularity in literary study by Soyinka and J.P Clark. Asakitikpi's research (2008) conducted on the phenomenon in the South-South and South-East Nigeria, and its implication on childhood mortality in Southern Nigeria, ended with caution about hasty disregard of the belief. According to the research, many people in the traditional setting attest that children are born with serrated marks, a replica of the one given to a dead child. Providing a scientific base for this may be difficult. Asakitikpi (2008) avers, from the medical perspective, that Ogbanje or Abiku children may not have the powers conferred on them by people; such children may not even exist but may be real only in the imagination of traditional people. The children so labelled may actually be sickle cell patients or victims of other childhood diseases that were, and are still, prevalent in most parts of southern Nigeria. But then, he notes that:

> The questions that arise from the belief in Ogbanje are varied and complex and they are by no means restricted to medical explanations. Indeed, majority of them border on the realm of enquiry that makes scientific explanation both irrational and antithetical. For example, how do we explicate the power behind the dead child to "assemble" a mutilated body to be reborn if we hold that after interment the body disintegrates? Or how do we rationalize the idea that a child could 'relocate' the womb that first gave birth to him? How can science explain the serrated marks given to a dead child and yet those same scars would be visible on the succulent body of another baby that has just been born as has been experienced by some mothers? An attempt to explain this phenomenon using, for example, Mendel's laws of inheritance, falls like a pack of cards. It suffices, therefore, to say that this belief and other similar beliefs must not be disregarded as phantom ideas arising from simple minds. It is about time scholars in this part of the world started probing into the interface of religion and science and between traditional belief systems and Western rationality. It is only by so doing that we will begin to reconstruct traditional people's ideas and ultimately to understand the underlying reasons why they behave the way they do….local beliefs and traditional cosmology must be properly analyzed, using the appropriate tools, to uncover the deep meaning they contain. (p. 4-5).

It is reasonable, scientifically, that not all deaths attributed to "Danwabi/Abiku/Ogbanje" are true. Some infant mortality may be caused by other diseases, which are not properly treated during pregnancy or at birth, but to disregard the Abiku phenomenon when there is myriad evidence from affected parents, with serrated scars, is erroneous. It is not all dead children at infancy that are called Danwabi/Abiku/Ogbanje in Nigeria cosmology. The Abiku type is identifiable; such child is not just christened arbitrarily. Marks would be inscribed on the body of a child suspected to be an Abiku in the first or second coming. In the subsequent birth, a child born with such scar would be labelled an Abiku. The identifying features are well articulated in Soyinka and Clark's poems.

Onyemelukwe (2015) unambiguously calls the Abiku/Ogbanje phenomenon a superstition and berates Africans for accepting its existence. She bears her thought thus:

> Africans are really steeped in superstition. While the developing countries of the world are busy exploring the moon and other planets other than the earth, coming up with scientific discoveries and inventions, our people and other Africans are talking of mystery of *Ogba nje* rather than recurrent death caused by sickle cell disease in an offspring whose genotype is SS; a situation triggered off by marriage between partners who are both carrier of S, for example, AS+AS or AS+SS or SS+SS. We have a long way to go".

It should be noted that Soyinka and Clark do not designate all dead infants as Abiku in their poems. They do not keep their readers in the dark concerning how an Abiku (child) is different from other children and would have been marked out before being labelled as one. Line 17-20 of Clark's version clear the doubt about the identity of an Abiku. Clark states that:

…We know the knife scars
Serrating down your back and front.
Like beak of the sword-fish,
And both your ears, notched
As a bondsman to this house,
Are all relics of your first comings.

In a similar vein, stanzas two and three of Soyinka's version emphatically states how an Abiku is identified from other children and how it is different from Sickle cell anaemia:

So when the snail is burnt in his shell
Whet the heated fragment, brand me
Deeply on the breast. You must know him
When Abiku calls again.
I am the squirrel teeth, cracked
The riddle of the palm. Remember
This, and dig me deeper still into
The god's swollen foot.

Once and the repeated time, ageless
Though I puke. And when you pour
Libations, each finger points me near
The way I came....

Adetuyi (2017) avers that the belief in reincarnation and the transmigration of souls, by which a human soul, at death, passes into another body and returns again, into the world, is a major theme in Nigerian literature. In his words, "within the Nigerian context, the relationship between the worlds of the living, the dead and the unborn is a cyclical one, involving a lot of mutual interaction.

Because sickle cell anaemia is a common life-threatening genetic disorder among the people of African descent (Nnodu, Oron, Sopekan, Akaba, Piel and Chao, 2021), it is often called African disease. A numbers of scholars have asserted that Nigeria is the epicentre of sickle cell disease (Idada, 2019; Ogbonna, Uwa & Okechukwu, 2022). In the postscript of *Boom Boom* (2019), Idada states that:

> According to the World Health Organisation, there are currently approximately 250 million people worldwide who carry the gene responsible for sickle cell disease and other haemoglobin diseases. Each year about 300, 000 infants are born with the disease worldwide.
>
> Sickle cell anaemia is particularly common among people whose ancestors come from sub-Sahara Arica, India, Saudi Arabia and Mediterranean countries. In some parts of sub-Sahara Africa, about 2% of all children are born with the disease. Nigeria is by far the country with the highest amount of people with sickle cell anaemia. Up to 24% of the population are carriers of the mutant genes and the prevalence of sickle cell anaemia is about 20 per 1000 births. Which means that in Nigeria alone, about 150,000 children are born annually with sickle cell anaemia. This means that half of all children born with sickle cell anaemia yearly, in the world, are born in Nigeria (sic).

Three years after Idada's publication, Ogbonna, Uwa and Okechukwu (2022) contend that about fifty million people are living with sickle cell anaemia globally out of which four to six million people are Nigerians. These scholars and medical practitioners aver that, annually, about 300,000 newly diagnosed sickle cell disease children are born worldwide. Sub-Saharan Africa contributes nearly seventy-five percent (75%) of the number while Nigeria accounts for 100,000-150,000 newborns living with the sickle cell disease annually. This figure implies that Nigeria accounts for thirty-three percent (33%) of the global problem of sickle cell anaemia. Hence, Nigeria takes an unfortunate strategic position in the epidemiology of sickle cell anaemia. While sickle cell anaemia poses enormous challenge to global wellbeing by contributing significantly to the morbidity and mortality of paediatric and adult population, Nigeria is where the disease is mostly prevalent. Ogbonna, Uwa and Okechukwu (2022) stated that 1 in 4 Nigerians has the sickle cell anaemia trait.

Nnodu, Oron, Sopekan, Akaba, Piel and Chao (2021) contend that, in sub-Saharan African where the number of children with sickle cell anaemia is the highest, progress has been far lower than in high-income and middle-income countries. These scholars opine that Nigeria, African's most populous country with estimated population of 206 million, probably has the world's largest population of people living with sickle cell anaemia. This is blamed on lack of genotypic awareness, inadequate health-care access and high cost of healthcare services borne by individuals.

Portraiture of Gene, Genotype and Sickle Cell Anaemia in Nigerian Literary Texts

Nigerian literary texts reflect multifaceted areas of life. Those reflecting medical themes often dwell on wellness and healthy living. For instance, Jude Idada's *Boom Boom* (2019) borders on sickle cell anaemia. It is a humorous, educative and cautionary text detailing the importance of genotypic compatibility before marriage is contracted. *Boom Boom* (2019) exposes the health implication of genotypic incompatibility on expectant child(ren), individual already born with the disease and its attending financial burden on parents. It is a narrative evolving around an eight-year old Osaik, the protagonist, whose mother and younger sister are anaemic. As much as Idada warns would-be couple against genotypic incompatibility, he goes further to enlighten his audience on available medical treatment that can guarantee an anaemic patient a good life free from incessant anaemic crises.

Told in first person narrative technique, *Boom Boom* (2019) espouses that sickle cell anaemia crisis can be tiresome. It makes life uncomfortable for the sufferers, their relations and, more especially, the caregiver. A sickle cell anaemia patient hardly enjoys life. His/her life is often characterised by sudden crises which "…lasted a couple of hours sometimes and other times a couple of day…" The narrator explains that sickle cell anaemia is an illness one is born with from birth, from which one always falls sick. It is a disease affecting people whose red blood cells are defective. The red blood cells carry oxygen around the body. By so doing, they help to enhance the respiratory system. They are round in shape and flexible, making them to move easily around the body through the blood vessels. According to Idada (2019), "for people …who have sickle cell anaemia, the red blood cells are not flexible but rigid, and they are shaped like sickle or the crescent moon…" (p. 24). Such curved sickle-like cells block the blood vessels, thereby preventing the free-flow of oxygen. This obstruction causes severe pains, especially in the body joints and bones. Osaik's mother laments that "it is

horrible kind of pain that spreads all over your body, particularly your joints, your spleen and even your entire bones and makes you scream out in anguish. That is what I mean when I say I am in crisis…A crisis is the period in which the sickle cell anaemia flares up, the pain rises, and you scream" (p. 25). In the text, Idada explains that:

> A gene is what determines a characteristic you have. It is like a recipe that makes food come out a certain way. …You get your genes from your parents, and it controls how you look, speak and behave". On the other hand, "a genotype is the totality of the genes that is given to you by your parents when you are born. There are seven major types of genotypes. They are AA, AS, SC, CC, S Beta Thalassaemic and SS. The last one, SS, is the genotype that causes sickle cell anaemia" (sic).

There is a consensus between Idada's *Boom Boom* (2019) and Snusis's *S is for Survivor, Sickle Cell Anemia: My story* (2014) establishing that genotypic incompatibility is the cause of sickle cell anaemia. *S is for Survivor, Sickle Cell Anemia: My story* is Sanusi's autobiography recounting her experiences as an anaemic patient. The texts presents her travails, labyrinth of medical procedures and tribulation — including condemnation to death and the attending psychological trauma she has during seven-year infirmary transfers across four countries, and her triumphs. It is a clinical autobiography presenting clinical challenges and conquest bordering on sickle cell anaemia. Dejected but spirited, and assisted by consanguineous love, empathy from medical personnel, therapies and self-built courage, the narrator survives twenty-eight surgeries and Bone Marrow Transplant.

Born on 6th May, 1988 in Funtua, Jos, Plateau State in Northern Nigeria into the family of Haroun and Zainab Sanusi of Islamic faith, Samira Haruna Sanusi was ambitious to school up to the university level but acute Sickle Cell Anaemia truncated her dream abruptly at a very tender age. In the narrative, the persona introduces her readers to the root cause of sickle cell anaemia, pointing out that it is congenital and arises from the genetic composition of parents. If the genetic make-up of either parent (widely known as genotype) has trait of the disease, any of their children could be a potential carrier of sickle cell anaemia. In Samira's case, her parents did not do genotype test to determine their genetic compatibility before they went into marriage.

More often than not, a potential sickle cell anaemia child may look healthy after birth for some months or few years before the symptoms begin to manifest. In the words of Idada (2019), sickle cell anaemia "...is not the kind of illness you can see just by looking at the person. Most time they are okay. But when they have a crisis, you will know how sick they are" (sic). Signs and Symptoms of Sickle Cell Anaemia are legion. They include, as depicted in *S is for Survivor, Sickle Cell Anemia: My story* (2014), episodes of pain, frequent infections, stunted growth and yellow tint to the skin or whites of the eyes. Episodes of pain, also called crises, are common symptoms of sickle cell anaemia. As Samira (2014) explains, pain occurs when sickle-shaped red blood cells block blood flow through tiny blood vessels to the chest, abdomen, bones and joints. Frequent infections as a result of damaged organs usually occur. In this case, sickle cells damage organs that fight infections, making the patient vulnerable to infections. This results to life threatening infections, such as pneumonia. It is evident in blur vision in which the tiny blood vessels that supply blood to the eyes may be blocked by sickle cells. If blocked, it damages the retina – a part of the eye that projects visual images and thus results in vision problem. Stunted growth is common among sufferers. Red blood cell does not only provide the body with oxygen; it circulates nutrients round the body for proper growth. A shortage of healthy red blood cells impedes growth from infancy, retards general body development and affects puberty. In Sanusi's words:

> Some sickle cell patients are small and slim because the disease stunts growth. From childhood, I felt insecure about myself. I was smaller than all my friends, even the ones who were younger by a year or two. In high school, when my friends reached puberty, I felt left behind. Anytime I hung out with friends in school or outdoors, I looked like a young sibling tagging along…. (81)

Months or few years after birth, if the symptoms and the accompanying crises are not well managed, the child could experience physical body deformation and possibly drop dead.

Bone Marrow Transplant as Sickle Cell Anaemia Cure

A number of science fiction texts have explicated the various procedures of treating anaemic patients, emphasising permanent cure through bone marrow transplant. Sanusi (2014) and Idada (2019) explain bone marrow procedures. Both authors explain that the first thing to do following the diagnosis of sickle cell anaemia is to locate the hospital where bone

marrow transplant is done. Having ascertained that, a donor (someone who does not have the SS gene) will be sought. The hospital will take the blood samples of the donor and the would-be recipient for test to see if their blood matches. The donor donates cells from their bone marrow to the patient. The bone marrow cells will be harvested and transplanted into the recipient's bone marrow, after the sickle-like bone marrow cells of the receiver have been drained. The transplanted cells have to be accepted by the receiver's body for the transplant to be successful. The donor can be a close relation of the recipient. But, when there is no one in the family whose bone marrow cells match the recipient's, a donor can be sought outside the family. However, the donor has to be someone whose bone marrow cells are as young as the patient's. Idada (2019) explains that, "the younger the volunteer, the better the match for the transplant itself…the transplant is better and safer for young patients".

Idada's educative novel, *Boom Boom* (2019), explains the imperative of Human Leukocyte Antigens (HLAs) of the donor and the recipient in the course of bone marrow transplant. He states that:

> HLAs are the molecules found on every cell of our bodies. They define us. This is why if a foreign cell...for example from an unmatched transplant, or bacteria or a virus or any of those germs we cannot see with our eyes is introduced into our body, the fighter cells, …the white blood cells, …will attack the foreign cell or cells in order to protect the body. This attack or reaction can be so intense that even normal body cells may be destroyed….That is why you have to ensure that your HLAs are very close to that of the person who will receive the transplant from you.

Sanusi survives sickle cell anaemic through the transplanting of some bone marrow cells from her half-brother into her own body.

3. CONCLUSION

The narrators of the two texts analysed in this study reveal that people who allow love to becloud their sensitivity to genotypic compatibility always regret their action when they give birth to anaemic child(ren). In a moment of sober reflection – a belated realisation and teary flashback − into courtship, Osaik's father states, concerning his wife, that:

> She told me not to marry her, but I didn't listen. She warned me. She begged me. But I loved her too much to let her go. I thought we would be lucky. I begged God not to allow any of you have the diseases. When you were born and didn't have it, I was happy. I believed God had heard my prayers. We decided not to have any more children. Just you. But then one day, we found out that your mom was pregnant with your sister. We prayed and fasted. We were afraid. And our fear came true…..I should have done what was right when I had the chance to, by not going ahead with the marriage to your mum when I found out she had the SS genotype; and even after I did, I should have stopped us from having children and adopted instead (p.95-97).

In Samira's situation, it is during a medical check she is diagnosed with sickle cell anaemia. She explains that:

…eight months after that beautiful Friday in May 1988 when Haroun and Zainab first held me in their arms, the mood changed to bleakness. After making many trips to the Emergency Room (ER) for high fever and non-stop crying, my sister and I underwent a comprehensive medical checkup and we were both diagnosed with Sickle Cell Anaemia. The revelation was a blow to my parents, especially because it was only then that they learned about the genetic make-up of parents… (3).

Results of the diagnosis do not only shatter the children's lives but they also bring guilt, sadness and disappointment to their parents. The parents express guilt because they are responsible for bringing the children to life. That way, they feel they are the cause of the children's suffering. From a patient-writer's point of view, Sanusi states that sickle cell patients often have crises that cause severe pains in the body joints, chest, shortness of breath and lack of mobility and such crises could last for days or weeks. During an episode, the sufferer may require the use of oxygen mask to aid breath and painkiller to palliate the excruciating crisis.

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