

# **UNDERSTANDING OF SICKLE CELL DISEASE FROM A SOCIAL AND CULTURAL PERSPECTIVE**

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# What is Culture?

**Culture** is that complex whole which includes knowledge beliefs, art, morals, laws, customs and capabilities or habits acquired by a person as a member of society.

Overall cultural background has an important influence on many aspects of people's lives, including their beliefs, behaviour, perceptions, emotions, language, religion, rituals, family structure, diet, dress, body image, concepts of space and time, and attitudes to illness, pain, and other forms of misfortune all of which may have important implications for health and health care.

# The Epidemiological Context of Illness, Disease and Sickness

## **Illness**

**Illness** refers to the subjective experience of feeling sick or assuming that you are sick. This includes experiences of symptoms, suffering, side effects of treatment, explanations of causes, diagnosis, prognosis, as well as personal consequences in the family life and occupation. **Illness** therefore relates to a way of being for the individual concerned or it signifies what people feel when they go to the doctor. Therefore indeed locally shared illness idioms create a common ground for the patient and the practitioner to understand each other in their initial encounter. For the practitioner, has also been socialized into a particular collective experience of illness.

# Disease

**Disease** refers to the diagnosis of the doctor or folk healer. It is the clinician's definition of the patient's problem, taken from the paradigm of the **disease** in which the clinician was trained. For example, a disease-centered psychiatrist is trained to diagnose brain diseases, a psycho-analyst is trained to diagnose psychodynamic problems, and a traditional healer might be trained to diagnose spirit possession or sorcery.

In each case the clinician's diagnosis is the **disease**. So in epidemiological terms **disease** is a condition that **physicians diagnose and treat**. It is the pathological changes in the body. Because clinicians are trained to treat **diseases** that are defined by their own cultural reality or professional paradigm, the prescribed treatments must match the **diseases** thus extracting **disease** from the **illness**, and this makes a great difference for control and treatment.

# Sickness

**Sickness** is a social identity. It is the poor health or health problem (s) of an individual defined by others with reference to the social activity of that individual. It happens that the society and/or its institutions decide who is entitled to treatment and economic rights and who is to be exempted from social duties. In this sense **sickness is a social phenomenon constituting a new set of rights and duties**. Therefore sickness can be conceived as an event located in society--- defined by participation in the social system.

# Contrast between Illness and Disease

The experience of pain may not entail a person seeing himself/herself or being seen by others as being ill. **Illness** is only one possible perspective that might be adopted by a person who has been jarred out of his or her normal stance toward the world by marked shift in mood and behaviour that is associated with an irrevocable loss. It is important to note however that much **experienced pain** never leads to the adaptation of a **disease perspective**. In many societies, **illness** and **suffering** are not clearly distinguished as perspectives. Therefore one's **un wellness** may not be interpreted as a **disease** that requires treatment by a medical specialist.

# Cultural Meaning of Illness

When anthropologists say that **illnesses/diseases** are culturally constructed, they are not denying the existence of **disease** or the **pathological** changes in the body as such but their concern is with meanings and interpretations that a society has for a particular **disease or illness**.

In the Western World, biomedicine is usually considered to be the only legitimate explanation of **disease** and in these societies it is assumed that people have rid themselves of the tendency to let meaning from other domains of life affect their view of the bodily functions.

However, from an **anthropological perspective and also a clinical one, illness experiences and events** usually conceal more than one **meaning**. Some meanings remain more potential than actual. Others become effective only over the long course of a **chronic disorder**. Yet others change as changes occur in situations and relations.

So when people do not accord with a scientific line of reasoning they are not necessarily acting irrationally. Rather, they may be acting in accordance with another explanation based on different assumptions.

It has been argued that whenever science fails to come up with an effective cure, psychological and social explanations invest **diseases** with meanings the ramifications of which go far beyond the field of medicine.

Therefore in the studies of illness representations, medical anthropologists have usually asked:

- How does cultural consensus emerge?
- How do illness representations and the realities they organize, and constitute come to being?
- How are the new representations related to the existing structures?
- How does the suffering of particular human beings contribute to the collective understandings of illness/disease, and how much of individual experience is not captured in cultural meaning.

# What are the Social and Cultural Perspectives of Sickle cell Disease?

Sickle cell is an **illness, disease** and **sickness** and there are four ways in which it has social and cultural me

## 1. Symptoms

**A symptom is an indicator of illness.** A particular experience, a sensation, thought, emotion, or behaviour becomes a symptom (an indication of illness) only when it is cognized as such. But cognizing something as a symptom is interpretation. The interpretation or cognitive construction of the event takes place within a **cultural meaning of system**. A particular event is experienced as a **symptom** because the **cultural meaning system** defines it as an indicator of illness.

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But since symptoms vary significantly across cultures, the difficult of establishing the **cross-cultural validity** of what a **symptom signifies** must be faced. This means that the manner in which the **symptoms** are put together, and given a cultural meaning or symbolization is intrinsic to their nature as **illness/disease**. In this case **sickle cell disease symptoms** e.g having **yellow eyes etc** are among the cultural entities that are interpreted differently in various cultures.

## 2. Cultural Significance

Cultural significance refers to the meanings projected onto the ill person by the surrounding society which then structures the person's experience of suffering. These meanings include:

- What the society thinks about the ill person
- About his/her particular illness/disease
- About sickle cell disease in general

These meanings and their consequences become part of the lived illness experiences of the individual. This is especially true in societies where **sickle cell related disease** are seen as particularly stigmatizing.

The individual is forced to live with the meanings imposed by the culture.

### **3. Personal and Social meanings**

This refers to the interpersonal relations and social life of the ill person. Interpersonal relationships particularly family relations possess meanings that can add to or shape the suffering associated with sickle cell disease. Defining who is sick or healthy is arrived at through social interaction with family, friends and acquaintances, as well as with those who have special knowledge or training in health matters. Part of this negotiation is likely to involve comparisons with other people's conditions and with past and future states or stages in one's own life. The formation and retention of beliefs, schemata and representations about pain and illness enables people to make these comparisons.

## 4. Explanatory Model

This model refers to the way a set of cultural systems explain the causes of sickle cell disease , the effects of the illness, what course the illness will take, and what treatments are appropriate. These meanings dramatically affect the lived experiences of people with **sickle cell disease** in many ways structuring the subjective illness experiences.

**Therefore it is through understanding the processes and contexts given to the meaning of illness from the perspective of the people who are involved that effective sickle cell programs can be designed and also that people can seek and/or adhere to any kind of treatment.**

## CONCLUSION

In the context of chronic disorder, sickle cell disease becomes embodied in a patient's life trajectory. Acting like a **sponge**, **sickle cell disease** and the **cultural meaning of illness** that is attributed to it **soaks up personal and social significance** from the life of the patient and transfers it to the **illness experiences**.