STIGMATIZATION OF LEPROSY AND EPILEPSY: IMPLICATION FOR SUFFERERS

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Summary
Supportive interaction is what the persons with illness seek from spouse, relatives, friends and other members of society. Contrarily, leprosy and epilepsy are socially defined as disreputable ailments whose sufferers possess discreditable attributes. On the basis of this social construction of illness, the experience of sufferers becomes increasingly traumatic, not due to pain, impairment and disfigurement only, but the social devaluation and rejection which find expressions in an unbridgeable social gap between sufferers and previously intimate persons, role restrictions, loss of self respect, feelings of helplessness and despondency. The paper addresses the whole issue of stigmatization and its implications on symptom management and social functioning of the victim and proffers micro and macro options for coping with and ameliorating the stigma and its debilitating effects.
INTRODUCTION
A large and growing body of literature presents detailed discussions of aetiology, symptomatology, treatment and diseases. This outpouring of information however generally ignores a basic aspect of illness especially those defined as chronic. The ignored aspect borders on how to deal with such ailments like leprosy and epilepsy in social terms.

Leprosy and epilepsy are major health problems that are mostly experienced in developing countries. Leprosy is a chronic disease caused by Mycobacterium leprae, an acid and alcohol fast bacillus. Its most common first symptom is a small but persistent area of impaired sensation or numbness. The bacterium affects the peripheral nerves, the skin and in rare cases, the mucous membrane of the respiratory tract. Infected persons have their nerves damaged causing obvious deformity and disability (Ewhrudjakpor 2004).

Modern medical conceptualization of epilepsy sees it as a seizure produced by intermittent electron and chemical impulses to the brain (Govan et al, 1981). The causes of epilepsy are mainly idiopathic as medical investigation of patients with epilepsy reveals no cause in many cases (Cull and Will, 1995). Its classical signs are generalized convulsion and a loss of consciousness (Laidlaw et al, 1993), and according to Temkin (1971) and Pelman (1977), these convulsions, even though appear threatening, are not usual. Common factors that precipitate seizures are sleep deprivation, emotional stress, physical and mental exhaustion, loud noise, flickering light, etc. Trimble (1989) identifies a life threatening variant of epilepsy known as status epilepticus. It exists when seizure occurs without the patient regaining consciousness between attacks.

Though leprosy and epilepsy manifest symptom variation, they have certain elements in common. Both of them are diseases of ancient origin with causal linkage with disreputability, demonic possession, pernicious acts and necromantic attacks. Patients with both diseases are vulnerable to discreditable responses from family and other members of society. The reason for this form of response is the social definition of the ailment.

What constitutes an issue of societal attention is not the disfigurement, pains, loss of body mobility and the death trajectory associated with the diseases, but rather, from the alteration of the sufferers’ social relationships and the implications of the alteration on symptom management and identity crisis.

SICK ROLE, SOCIAL REPROACH AND STIGMATIZATION
Illness generally has a potentially disruptive consequence on group or society. Parsons (1951) argues that in order to prevent this disruptive effect, there exists a set of shared cultural norms known as sick role. The essence of the sick role is to
legitimize the deviation caused by the illness. Parsons (1960) identifies four components of the sick role in the society.

i) The sick person is exempted from normal social responsibilities, at least to the extent it is necessary to get well. For instance, people with illness are not expected to go to school or work.

ii) The individual is not held responsible for his or her condition and cannot be expected to recover as an act of will. It is assumed that being sick is not a deliberate and knowing choice of the sick person.

iii) The person must recognize that being ill is undesirable and must want to recover as quickly as possible.

iv) The sick person is obligated to seek and cooperate with expert advice, generally that of a physician. Sick people are not blamed for their illness but must work towards recovery.

Illness experience reveals the inapplicability of the sick role to patients of leprosy and epilepsy in the Nigerian society. Instead of adhering to blame-free component of the sick role, certain negative impressions and evaluations are used on the lepers and epileptics. Consequently, people proceed to relate with them on the basis of expectations derived from these impressions and evaluations (Chalden, 2006). This interaction mode signifies social reproach, a deviation from the normative principles of the sick role. Goffman (1970), sees this response pattern of individuals in society as the root of, and pathway to stigmatization.

Stigmatization is a fundamental variant of symbolic interactionism. It is an act of negatively evaluating with attributes that differ from other members of society (Byerne 1997). The attributes (leprosy and epilepsy) per se are not the stigma; rather, it is the definition of the situation or the social perception of the attributes. Becker (1963), sees stigma as the way the significant others perceive and define the attributes. Thus upon diagnosis, the non sufferer perceives the afflicted persons as having scores to settle with preternatural (witches and wizards) and supernatural (ancestral, deity and God) forces, a perception that is deeply rooted in the belief system. (Hall, Brockington, Levings & Murphy 1993).

Goffman’s (1970) interest is not on the origin of the stigma but in the impact of the stigma on the social interaction of the stigmatized person. He maintains that whenever there is a significant difference between a person’s virtual identity (what a normal person is like) and their actual identity then negative consequences are bound to follow.
He made a distinction between a discrediting stigma and a discreditable stigma. The former is when it result from a response on a clearly visible disfigurement or disability while the latter is when the disfigurement is not too obvious and the sufferer has the possibility of concealing.

Scrambler and Hopkins (1986) adopted Goffman’s concept of stigma to study people with epilepsy and came out with a further distinction of stigma. They distinguished between enacted stigma and felt stigma.

Enacted stigma refers to instances of discrimination against people with epilepsy on the ground of their perceived unacceptability or inferiority. Felt stigma refers principally to the fear of the enacted stigma but also encompasses a feeling of shame associated with being epileptic (Scrambler & Hopkin 1986).

Individuals’ negative response to those with epilepsy (enacted stigma) and so the sufferers have to find a way of managing it (felt stigma). There are basically four ways of responding to felt stigma namely selective concealment, covering up, medicalising behaviour and condemning the condemner (Scambler 2002). This perception and definition of the attributes significantly impair social relationship and interactions. It is in the light of this, that Goffman refers to stigma as a language of relationship. Stigma interferes with what otherwise might have been a normal social relationship because of their undesired differences from what has been attributes.

The diagnosis and apparent manifestation of symptoms induce stigmatization from family and other members of society. At the initial stage of illness, family members and close friends try as much as possible to conceal it from public glare. As soon as the illness gets out of hands and symptoms become conspicuous, interaction becomes characterized by discreditable comments and avoidance.

**STIGMATIZATION AND COPING WITH CRISIS**

Certain chronic diseases are fraught with a constant threat of grave medical crisis. Diabetics for instance can fall into insulin coma and die. Epileptics may go into convulsion and be killed in fire, pool of water, or traffic accident. The death arising from the crisis of epilepsy lies not in the convulsion but in the scene of the convulsion. These crises need to be controlled so as to minimize their impacts on the patients. The onus lies with members of the family and friends to be organized around the sufferer. They must be prepared to read and understand the warning signals or signs that portend the crisis. It is fundamentally the first step in helping the sufferer to cope with the crisis.

Relevant to the issue of crisis is how far they can go before dying, how fast the crisis appears, the clarity of the advance warning signals, the probability of
recurrence, the complexity of the saving operations and the completeness of recovery from them. Granted that these critical issues are favourably disposed of the sufferer still has a traumatic moment coping with the crisis.

Instead of getting the needed assistance from family members and friends, the epileptic is abandoned to manage or cope with the crisis alone. During convulsions, non sufferers stay far away from the victim or even ignore him or her. Apart from this unnecessary abandonment, people are also warned, out of ignorance, against touching the victim until he regains consciousness. This behaviour is derived from the cultural heritage which forbids touching the epileptic during crises or the leper for fear of contacting the disease.

Ordinarily, epileptics need not suffer physical deformities but for the crisis environment which makes the patients prone to fatal consequences resulting from convulsions. Epileptics are seen with wounds resulting from burns, cuts from sharp objects and water and traffic accidents due to lack of attention during convulsions. The negative social aspect of it is the embarrassment that may emanate from the crisis. Most epileptics regain consciousness only to discover their nudity in a crowd. This reason account for why epileptics opt for the back stage in life. In some cases, due to their inability to put up with life in the back stage or solitary life, epileptics contemplate suicide which they feel is an eternal panacea to the mortifying moments in their lives.

THE BURDEN OF SYMPTOM MANAGEMENT
The control of symptom, otherwise known as symptom management, extends beyond the frontiers of medical management and adherence to regimens. Most times, due to lack of proximity to medical facilities, the patient, his/her family members and friends rely upon their own ingenuity in the management of symptoms.

Central to the issue of symptom management is that the patient will be concerned primarily with whether the illness has any impairment on his functioning capacities or is evidencing disfigurement. Major symptoms may affect habits and subsequently call for the redesigning or reshaping of important aspects of the sufferer’s life style. Reshaping activities could be made possible through the efforts of persons around him. A severely deformed and disabled leprosy patient may decide to carefully arrange every object he needs within arms reach. In the same vein, the epileptic, through the assistance of members of his family, has errands run for him, spends very little time in the kitchen to avoid fire accidents and is often in bed to cushion the effects of a fall.
The interference of the sufferers’ lives with social relationships depends largely on a number of factors. The withdrawal of relatives and friends from sufferers may be due to the excessive demands by the patient in relation to symptom management and reshaping of activities. Also, whether the illness is terminal, publicly visible, unpredictable, degree of pain and the nature of regimen for the management of symptoms, are put into consideration. More importantly, the status or the social worth of the person before and during the illness determines how long relatives, spouse and friends get on with him. The moment the sufferer is not favourably disposed to these critical factors or conditions, the basic target of the patient is defeated. The fundamental aim of leprosy or epilepsy patient is not just to stay alive or to keep the symptoms of the disease under control, but to live as normally as possible in the face of the symptoms.

**THE BORDER LIMITS OF STIGMATIZATION AND THE SUFFERERS’ RESPONSE**

The collective definitional process in which the leprosy and epileptic patients are described as possessing discreditable attributes does not leave the sufferer in a passive shape. Rather, the stigmatized actively learn the meaning of their attributes or performance through direct exposure to rejection and disapproval from non-sufferers in society.

The perception of stigma or what the putatively stigmatized think of others in relation to reaction inform their series of response to the reproach. The first response to the collective definition is the evaluation of the self or personal identity. The self concept is the totality of our beliefs and feelings about ourselves. Geca (1982) simply sees the self concept as our perception about who we are and this can only be established in our social encounter with others.

The social construction of self identity is derived from what Cooly (1998) refers to as the looking glass self - the way in which a person’s sense of self is derived from the perception of others. The looking glass self of the sufferers is not who they actually are but rather their perception of how non sufferers see them. It is a three step process.

i) The sufferer’s imagination of how their personalities and appearances will be judged by non sufferers or other members of society.

ii) The perception of how the sufferers think they are being judged. They are judged as possessing discreditable attributes.

iii) Based on the perceived judgment, the sufferers experience what Kendall (2001) refers to as social devaluation - the possession of less social value than others in a group or society. Social devaluation becomes acute as
sufferers begin to exit roles that are central to their social identity. As a result of this unfavourable evaluation, the self concept begins to diminish.

In the face of social devaluation and diminishing self identity, the sufferers are left with no option but to eventually recreate their social lives on a daily basis in relation to the situation on ground. Central to the recreation of social life is tactical withdrawal from other members of society or social environment as a strategic measure of impression management. In the process of this situational withdrawal, an unbridgeable social distance between the sufferers and non sufferers is established (Goffman 1959, 1968).

In furtherance of the situational withdrawal, sufferers go in search of persons with similar health problems. The rationale behind this action is for the sufferer to have the desired understanding and support that is lacking in the larger society. However, this experience is prevalent among leprosy patients who can afford to form leper colonies due to their numerical strength. It is in this colony that they adopt the beggarly life style as a survival strategy (Ewhrudjakpor 2004). Being alluded to severe loss of social contact, and by extension, great social isolation, sufferers of disreputable illness opt for speedy death. This is very common because they see an endless time ahead depending on people who are not readily available, increasing social isolation and a purposeless life. In other words, sufferers prefer suicide to staying alive in acute hopelessness.

Granted that leprosy and epilepsy are analytically similar to deviance because both represent threat to effective role performance, reaction from ‘normal’s’ ought to be different towards illness due to intentionality or willfulness that is attributable to deviance and not illness. There is no doubt that the social functioning of the leprosy and epileptic patients is severely jeopardized. The basic components of social functioning - satisfaction with roles in life, feeling of self worth and positive relationships with others, have been impaired due to stigmatization for faults that are unintentional. Considering the extent of stigma and its attendant impact on the sufferers or patients of leprosy and epilepsy, there are two options at their disposal. The first option is to enable the sufferers manage the stigma and the second option is aimed at amelioration or eradication of stigma in society.

Summary
Leprosy and epilepsy through manifest symptom variation, they both share certain characteristics in common. Both have causal linkage with demonic attack, pernicious behaviour and necromantic attack. Secondly, sufferers of both diseases are vulnerable to discreditable responses from family member, friends and other members of society based on the cultural definition of the diseases. It is this sufferer’s social relationship with members of society and its implication that attract
the attention of the sociologist. This explained why the paper occupied itself not with the disfigurement, pains and death trajectory associated with the ailments but with sufferer’s social relationship.

Rather than enjoy sympathy and care from relatives, friends and other members of society, sufferers of leprosy and epilepsy are stigmatized. This social devaluation is of course a negation of Talcott Parsons’ sick role component. Stigmatization no doubt, has grave implications for sufferer. As a way to manage the social devaluation, the sufferers withdraw from other members of society. The social distance created by the sufferers further aggravate their predicaments.

CONCLUSION

The desire for lepers and epileptics to be normal and live conventional lives is hardly or never achieved even when the leprosy patient is already cured. This is due to the cultural context in which they find themselves. This social experience is as traumatic as the agony of pain, deformities and disabilities associated with leprosy and epilepsy (Hunt 1996 & Charton 1998).

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People should understand that leprosy and epilepsy are like any other form of ill health that is independent of the sufferer’s intention. Singling the lepers and epileptics out for blame and reproach is not a positive measure; rather, it is a conscience-soothing strategy of doing nothing about the problem of lepers and epileptics.

Recommendations

Based on the above discourse, the following recommendations are put forward:

i) Sufferers should identify with those who posses similar attributes. These people will not use derogatory labels on them.

ii) The sufferers should embark on concealment or cloaking of symptoms by artfully striving to play extra role to demonstrate their fitness.
iii) The value system of society need overhauling on the need to empathize with sufferers of leprosy and epilepsy.
iv) The state should make provision for their adequate care of sufferers through provision of drugs, food and other social welfare packages.

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