Details of Module and its Structure

| Module Detail | | | |
|-------------------|---|--|--|
| Subject Name | Sociology | | |
| Paper Name | Sociology of Health and Illness | | |
| Module Name/Title | Health and Disease: Illness and sickness | | |
| Pre-requisites | Concept of health, disease, illness and medicine | | |
| Objectives | To analyze the basic concepts of medical sociology | | |
| Keywords | Health, disease, illness, sickness, medical sociology | | |

| Structure of Module / Syllabus of a module (Define Topic / Sub-topic of module) | | | |
|---|---|--|--|
| Illness and Sickness | Introduction, Medical Sociology, Conceptualising Illness and Sickness Illness Behaviour, Acute and Chronic illness, Illness Narrative, Illness as Deviance, Social Construction of Illness, Body and Illness, Conclusion. | | |

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ILLNESS AND SICKNESS

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1. **Introduction**

Issues of health and illness were exclusive for the medical field for long time where scientific knowledge on it was produced by trained professionals, physicians, biologist etc. Convergence of medicine and sociology is a 19th century phenomenon due to many developments both in the medical field and society in general. Medical sociology is thus a sub discipline in Sociology which deals with the nature and impact of relationship between medicine and other social elements.

"Medical Sociology is the study of health care as it is institutionalised in a society and of health, or illness, and its relationship to social factor". (Ruderman, 1981: 927)

Emergence of welfare state was a landmark in the development of medical sociology. It got evolved when the Western state initiated to address the social and health challenges after World War Second. State policies were formulated to control and maintain the health of the population. Scientific expansion in the medical field, increasing medical inventions and technical developments made medicine a crucial part of social life which in turn triggered the institutionalisation of medical sociology as a discipline. Gradually the concept of social medicine emerged which implies the state efforts to improve the public health.

Medicine and health was not area of focus for classical sociologist. Later with the development of medical sociology, re-reading of theorist like Marx, Durkheim and Weber explored the macro dimension of the distribution and functioning of medical systems in a society. Parson's book *The Social System* (1951) was a landmark intervention in the study of health and medicine with his concept of sick role. This functionalist approach was later challenged by symbolic interactionist school of thought; for example Irwin Goffman's study of life in mental hospital in his book *Asylum* (1961). Later tremendous works came under the discipline of medical sociology which varies from social inequalities in the health care distribution, women's health, de-professionalisation, lay conception of health and illness etc. Now medical sociology as a discipline has a huge literature on both theoretical contributions on the link between medicine and society and also practical interventions at policy level for the distribution of health care.

Unlike the biomedical definition of health, medical sociology is concerned with different dimensions of the social aspect of health like; relationship between social environment and health, nature and effect of health policies, examines health and illness behaviour in a particular community, analyse the power dynamics in the interaction between health practitioners and patients, study on different medical care systems in a social setting, critically engage with the impact of globalisation and liberalisation in the medical field etc.

Sociology of medicine and sociology in medicine is different at both its conceptual engagement, methodological approach and the field of study. Robert Strauss (1957) coined these terms to make a theoretical distinction on the purpose of the discipline. Sociology in medicine is incorporation of social science views within the institutionalised medical settings. Social impact of medical inventions, effectiveness of medical interventions, effectiveness of both private and public policies for the expansion of medical care, etc. were the major concern under this approach. Here, sociological lens is used under larger medical framework. But sociology of medicine is a sociological study of medicine as a social phenomenon. It analyse the social impact of medical systems. Public health, distribution of medical care, nature of social inequalities in medical field, people's perceptions of health, role of state and market etc. are some of the area of study within this discipline. Mechanic (1990) points out that sociology in medicine is an applied approach in which the medical sociologist addresses the issues of interest to those outside of sociology and sociology of medicine involves the study of medicine within sociological contexts.

2. Conceptualising Illness and Sickness

According to what constitute health, medical sociology differentiate the concepts of disease, illness and sickness. What is meant to be healthy is a difficult question to address. Defining the concept of health is complicated because it is influenced by different factors. The dominant biomedical model defines health as absence of disease with specific symptoms and particular causes. Psychological approach expands on this scientific model and incorporates the subjective assessment of the state of health. Socio-cultural approach on the other hands deals with the social factors influencing the health of the people. Different positions on health produced multiple positions on what is not health. Disease, illness and sickness are thus three aspects of being non-healthy.

Differentiate disease, illness and sickness

"Disease is something an organ has; illness is something a man has" (Helman 1981: 544).

In medical sociology, disease is the professional definition of what constitute not healthy. It is a biological abnormality caused by specific physical dysfunctions. Medicine is used to diagnose the causal factors and treat the disease to maintain healthy state. Here, disease is uniform across community and culture. Production of scientific medical knowledge and its distribution is part of this biomedical process. Patient and professional relationship is always hierarchical and body of the patient is treated as an excluded physical entity.

On the other hand patient's view of disease is defined as illness. The subjective experience of illness may not be similar to the biomedical definition of disease. Layman's perception of what constitute health and illness is cultural specific. It is influenced by the local beliefs about disease, social and familial status of the patient, age and gender factors, state level policy interventions, nature of medical care systems etc. influence the subjective experience of illness. Previous experience of illness, physical capacity of patient etc. are also important factors. Thus subjective experience of illness is context specific and thus its expressions also vary.

Sickness is defined as social perception of disease. It is influenced by nature of social roles and hierarchy of disease and social distribution of disease. It is complimented with biomedical definition of disease and individual perception of illness.

"Sickness exists when people are defined by others as having a problem that requires a therapeutic response" (Twaddle and Hessler, 1987: 101)

In his study on personal narratives of illness, Robinson (1990) distinguish illness, sickness and disease based on the trajectory of their focus.

Table 1: A taxonomy of accounts of changing health status

| Source of | Designation of | Description of | Focus of | Imputed |
|-------------------|----------------|-----------------|------------|---------------|
| attribution | health status | trajectory | account | negative |
| | | | | change in |
| | | | | health status |
| Self perception | Illness | Individual | Personal | Loss |
| | | narrative | life goals | (bereavement) |
| Social perception | Sickness | Social career | Social | Handicap |
| | | | status | (stigma) |
| Biomedical | Disease | Physical course | Medical | Deficit |
| perception | | | diagnosis, | (impairment) |
| | | | prognosis, | |
| | | | therapy | 1500 |

The relationship between illness, sickness and disease is complex. Biomedical explanations of disease, personal illness narratives and social legitimation of disease are not exclusive aspects of non healthy but are inter related in multiple ways. In illness narration the focus is personal goal of better life, and social status is the concern of the social perception of sickness and biomedical model is engaged with medical diagnosis and treatment to maintain the physical impairment.

Illness as deviance

Illness is generally considered as deviance from the social system. This understanding of illness is influenced by the functionalist approach to health and medicine. Analogy of society and body is the basic of this approach where like any dysfunction of a single organ effect the entire functioning of the body as a whole, illness is a social deviance form the normal functioning of the society. Parson (1951) explains disease as a deviance from the normal social role. He explains sick role as a temporary role of the patient during illness period who is formally exempted from the everyday social roles. Influenced by this understanding of disease, later studies consider illness also as a social deviance. Freidson (1971) regard illness as a form of physical and social deviance from the normalcy. He says that physical

consequences of illness may not change but the social dimensions of it is cultural specific; depends on the norms and values of the society.

Illness behaviour

- ✓ Why some people are consult doctor for minor symptoms and not others?
- ✓ What cause people to interpret symptoms in different ways?
- ✓ How will you know that you are ill and should medicate?
- ✓ Why is that variations in the utilisation of medical services?
- ✓ How do people come to feel ill?

These are some of the questions which arise when dealing with individual perception of illness. Cultural variations in the subjective experience of illness make it complex and context specific. Illness behaviour is a means to understand these complexities.

"Illness behaviour refers to the ways in which symptoms are perceived, evaluated, and acted upon by a person who recognises some pain, discomfort or other signs of organic malfunction". (Mechanic and Volkart, 1961:52)

Individuals are active and critical with their own complex idea about what constitute health and modes of treatment for illness. Meaning of actions for individuals is important factor to be studied than just observing the actions. Thus an interpretative approach should be developed to the layman's conception of illness. This lay perspective may contradict professional definitions or compliment but it has unique role in the decision making of the patients and influence largely on the subjective experience of illness. Individual accept some symptoms as serious according to their idea of normalcy in everyday life. This decision making is influenced by many factors like age, gender, financial position, family structure, occupation etc.

For example for a coolie, back pain to certain intensity may not be an illness but for a teacher the initial stage of its occurrence itself must be a state of illness. Here we can see how occupational variation influences the illness behaviour of individuals. In other situation, children's health is a priority which requires urgent treatment but the old age health issues are approached as a normal condition. Here, the age factor is crucial in decision making

regarding medical treatment. Gender also plays an important role in the nature of illness behaviour. For example, a girl grown up in a family with open space for woman equal to men might consider the menstrual pain as a biological state and depending on the severity of pain will go for medication. But a girl with a background of sexist childhood socialisation might perceive the same pain as a burden and may be reluctant to share with others and won't go for medical consultation. This clearly shows how familial status and social circumstances influence the individual illness behaviour in defining what constitute health and where the illness state starts and how to proceed with it further.

This is a long process which starts with occurrence of physical discomfort followed by individual acceptance of illness. Individual decision making for further treatment of illness is influenced by many social and cultural factors. Suchman (1965) in his study on illness narratives explains different stages of illness experience which reflects on relationship Debetween social structure and medical orientation.

Table 2: Stages of illness experience

| 4000 | C | A | M. P1 | D14 | D |
|------------|--------------|---------------|---------------|--------------|----------------|
| | Symptom | Assumption | Medical care | Dependent- | Recovery |
| ا برند | experience | of the sick | contact | Patient role | and |
| 3111113 | | role | 000 | | rehabilitation |
| Decision | Something is | Relinquish | Seek | Accept | Relinquish |
| | wrong | normal roles | professional | professional | sick role |
| | EWON |) | advice | treatment | |
| Behaviours | Self | Provisional | Authoritative | Undergo | Resume |
| D | medication | validation of | validation | treatment | normal roles |
| , | | sick role and | for sick role | procedure | |
| | | continue | and negotiate | and follow | |
| | | remedies | treatment | regimen | |
| | | | procedure | | |
| Outcomes | Denial | Denial | Denial | Rejection | Refusal |
| | Delay | Acceptance | Shopping | Secondary | Malingerer |
| | Acceptance | | Confirmation | gain | Acceptance |
| | | | | Acceptance | |

- 1. Symptom experience: It is the stage where physical discomfort is experienced. Then individual recognise and emotionally response to it and proceed for some measures to maintain the balance of the body. Observing the entire process is the major feature of this stage.
- Assumption of the sick role: If the individual accept the existence of illness then they
 transform in to the stage of sick role where individual relinquish some social roles.
 Here, illness is perceived as a social deviance. Transforming in to sick role exempt
 individual from some of the normal social roles.

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- 3. Medical care contact: This is the point in which individual seek medical care. This involves self medical care to rational choice of biomedicine, practicing alternative medical practices like folk medicines, ayurveda etc. In this stage authenticity of the physical illness from the professionals is crucial.
- 4. Dependent-Patient role: In this stage individual perform the dependent patient role by accepting the professional treatment measures. Nature of this role is influenced by the nature of the illness, individual's ability to cope up with the situation, nature of familial support, social approach towards the particular disease etc. Accordingly patient approach for further treatment by experimenting complimentary medical practices.
- 5. Recovery and rehabilitation: This stage depends on the type of illness whether it is acute or chronic. For the patients who is recovered from the illness go back to their normal social role and those continue with the disease tries to resume the normal role to a certain extend along with the sick role.

Acute Illness and Chronic Illness

Any illness constitutes a disruption and a discontinuance of an ongoing life (Bury 1982). Severity of illness influence illness behaviour. According to the duration of the illness, it is

divided into two: acute and chronic illness. In general, illness which sustains for less than three months and is cured is considered as acute illness which includes cold, various kinds of fever etc. Acute illness is a transitory period after which the normalcy of daily life can be attained. Chronic illness are the prolonged and mostly uncured diseases; for example, cardiovascular diseases like hyper tension, stroke etc., respiratory problems like asthma, diseases like AIDS, cancer etc.

Experiencing chronic illness

Chronic illness is not just a severe physical problem which requires long term medical treatment. It creates ethical dilemmas, identity crisis, isolation and many other psychological issues. Restricted social interaction and isolation from daily life activities is a consistent issue faced by chronic ill patients. Chronic ill patient will be in a vulnerable stage which will make the life so normal that everyday life is arranged only in a way to reduce the growth of illness. The experience of chronic illness is influence by may factors like; nature of the disease, for example social stigma related to disease like AIDS will effect patient's perception of self and influence social interaction. Age is a crucial factor because if a young man who is the bread winner of the family fall ill then the familial approach to him will be so different compared to a man with an age of 60 above. Thus the experience of chronic illness is a complex phenomenon.

Kathy Charmaz (1991) explains three major stages of chronic illness in his study on the relationship between identity and self formation among chronic ill patients.

- 1. As an interruption in life: This is the initial stage where illness is considered as in interruption in life. Patient keep hope of recovery and do anything for it. Here, the disease is perceived as something external and maintains the self as before.
- 2. As an intrusive illness: In this stage illness is accepted as permanent part of life and efforts are taken to maintain a balance in health condition by preventing further development of the illness. Here, the patient loses some control over the life but measures are taken to maintain self esteem.

3. As an immersion in illness: This is a critical situation where the disease starts to dominate the daily life of the patient. Loss of control over the physical body makes them depend on others and the social life is also restricted. This is a stage where new self is created and the identity changes with the shift in the nature of social interaction.

Illness narratives

"The narrative is one of several cultural forms available to us for conveying, expressing or formulating our experience of illness and suffering. (Hyden 1997:64)

Study of narratives has become part of social science in general and medical sociology in particular due to the philosophical shift from grand structural narratives to the subjective experiences of life. Illness narratives help to understand how patients perceive, experience and express illness in a particular cultural context and time. The study of illness narrative is not jut about the content of the narration, but the form of narration which enquires how patients narrates the experience like the language, metaphors, gestures etc. used for narration. Thus the object of study is not just about what they narrate but narration itself becomes the focus.

The study of illness narratives has evolved from differentiating illness from disease to explaining illness behaviour, role of language and culture in determining illness narration, and now it is integrated with the story of suffering. Illness narratives are a means to understanding of both individual and social sufferings. For example, Klienman's study on various aspects of suffering in his book *Illness Narratives* (1988) explains illness narratives as a form in which patients shape and gives voice to their suffering. Different versions of illness narratives denote the cultural variations in the experience of illness.

"The illness narrative is a story the patient tells and significant others retell, to give coherence to the distinctive events and long term course of suffering" (Klienman 1988: 49)

Thus study of illness narrative is important in understanding the experience of illness. (Hyden 1997) points out some of the major uses of illness narratives in the study of illness.

- 1. To transform illness events and construct a world of illness
- 2. To reconstruct one's life history in the events of a chronic illness
- 3. To explain and understand the illness
- 4. As a form of strategic interaction in order to assert or project one's identity
- 5. To transform illness from an individual into collective phenomenon

Illness narrative involves three elements, narrator (patient), narration and the listener. For narrator, illness narrative helps to express the experience of illness and create a new world of illness. For the listener, illness narrative is a means to understand illness, its intensity and the nature of suffering. Narration of illness involves complex factors like the language and metaphors used for expression, form and structure of the narration etc. Based on the relationship between illness, narrator and narrative Lars-Christer Hyden (1997) has divided illness narrative in to three:

1. Illness as narrative:

Here, illness, narrator and narrative are combined in a single form. The narrator narrates the subjective experience of illness and thus illness itself is a narrative.

2. Illness about narrative:

This illness narration gives knowledge and idea about illness which helps the medical treatment of the patient. Here, illness is described to know about the status of illness, forms of its appearances etc. through which physicians get a clear medical picture of the patient for further treatment.

3. Narrative as illness:

This is a case in which patient has insufficient means to narrate the experience of illness or the cases in which inappropriate or excess narration itself creates illness. For example the patients with head injury might suffer from memory lose and thus they face difficulties in narrating the experience by connecting with the past life.

Body and Illness

In recent years, approaches to study the body have increased significantly. These approaches can be grouped in to two broad categories- Foundationalist and anti foundationalist (Turner 1996). In foundationalist perspective, body is seen as a lived phenomenon while anti foundationalist perspective views body as a product of discourse. The perspectives of anti-constructionism and social constructionism on body are related to these theoretical positions. In social constructionist theory, the construction of body through discursive practices is the focus while in anti constructionist theory body exist independent of any form of discourse.

Social constructionist theory questions the dominant medical/biological understanding of body. This theories range from radical positions which claims that there is no body beyond the social discourse to the positions which discuss categories which influence body but not necessarily dominate it. While difference on social production involved in the construction of body exist in terms of the degree of emphasis within social constructionist approach, these theories tend to agree that body is significantly shaped and produced by society. The work of Foucault represents an important contribution to the social constructionist understanding of the body. According to Foucault (1973) the body is totally constituted by discourse and subsequently a concrete site for the operation of knowledge/power in modern societies.

Post modernism as an intellectual tradition is also closely associated with social constructionist approach, but focuses on deconstructing the existing discourses of body. Post modernism raises many questions regarding the authenticity of clinical medicine and clinical construction of the body and validity of sociological theories on medicine thereof, the importance of layman's understanding of medicine and the cultural basic of alternative medicines and thus asserting that there is no single truth regarding the experience of health and illness. Also feminist critique of patriarchy by looking at different dimensions of biology, sexuality and gender contributed to the development of different studies on body.

Embodied Illness

Existing narratives on body like foundationalism, anti-foundationalism, phenomenology, social constructionism etc. have not fundamentally challenged the Cartesian legacy which distorts the understanding of reality. An interaction between these positions is required for the construction of sociology of embodiment. Embodiment can be used as a methodological tool to understand the lived experience of body. As against positions on body either as physical

entity or as a social product, embodiment perspective is seen to the complexity of the body and its experiences.

Body is the primary basis of being in the world. Importance of body in social and individual life is crucial. Formation of self, nature of social interaction, way of life style, construction of social identity, expression of health status etc. are mediated through body. It is thus an important and changing element in daily life. Biological reductionism of modern medicine's approach is been critiqued on different account like focusing cultural variations in illness experience, impact of public health policies, coexistence of different medical practices, complexities of subjective experiences of illness etc. These accounts against biological reductionism was never neglected the role of physical aspect of health and disease experience. Body was never part of sociological enquiries in the initial disciplinary stage where agency and structure was the primary focus. Body has become a discourse in medical sociology due to its complex existence. Physical reality of illness was addressed broadly in two ways:

- As a physical reality which was primarily the subject of medicine. This is the biomedical understanding of body.
- As a social reality where body is a discursive product of social structure. This is a social constructionist approach towards body.

In both the cases; former as a physical entity and later as a social product misses the subjective experience of body. Thus medical sociology started to look at different dimensions of lived body. Bringing body in to the picture of study of illness helps to understand how body as a tool is used in different stages of experience of illness and at the same time on how body itself influence the subjective perception of illness. Thus, medical definitions of body, social conception of physical body and individual perception of subjective body influence the experience of illness. These three dimensions of body compliments or sometimes contradict the experience of illness; for example, social moral codes on body and the individual experience of body may not be same and thus the stigmatised approach to diseases like AIDS and the subjective experience of illness by the patients are also different. Thus knowing the complexities of body is about understanding the different dimensions of experience of illness.

Role of body in the chronic illness reveals how is biology and social facts interlinks. Body is directly linked to the construction and reconstruction of self and identity based on the intensity of the illness, social response to the disease and individual perception of self. Language is also a prominent factor in this embodied experience of chronic illness.

Conclusion

Illness and sickness are two different perceptions on the experience of disease. These two concepts move beyond the biomedical descriptions of disease as a biological abnormality. Illness and sickness explain the social dimensions of health and disease. They are two inter related concepts where individual perception of illness influence the social definition of sickness and vice versa. Studying illness and sickness opens a wider area of the relationship between medicine and health. This has become a multidisciplinary by engaging with anthropological studies on the cultural variations of illness, feminists works on the subjective experience of body, sociological analysis of the social constructions of illness etc.