Chapter 1
Introduction
Every victorious scientific discipline in due course develops an historical story of how it all started. For medical sociologists, the genesis of the social study of medicine originates in Talcott Parsons’ (1951) theoretical account of the doctor-patient relationship. In his work The Social System, Parsons conceptualised illness as a form of deviant behaviour with the physician as societal gatekeeper to restore patients to normal societal functioning. Parsons noted that both patient and physician performed specific role expectations to triumph over disease. The actual genesis of medical sociology occurred early in Chapter X when Parsons justified the study of medicine for social scientists. Parsons first argued that health was functional for individuals and society.

Parsons then noted that health would already be of interest to social scientists if it was ‘purely a “natural phenomenon,”’ without involving the motivational aspects of social action because it would be then interesting to know how people react to uncontrollable events. Health and illness, however, are sociologically interesting because social factors play a role at various stages of sickness and cure: ‘In a variety of ways motivational factors accessible to analysis in action terms are involved in the etiology of many illnesses, and conversely, though without exact correspondence, many conditions are open to therapeutic influence through motivational channels’ (Parsons 1951: 430). Here, Parsons rejects a narrow view of medicine which is concerned with pathophysiology.
At one point of time most medical opinion tended to the ‘reduction’ of all illness to a physiological and biological level in both the sense that etiology was always to be found on that level, and that only through such channels was effective therapy possible. This is certainly not the predominant medical view today (Parsons 1951). If it ever becomes possible to remove the hyphen from the term ‘psychosomatic’ and subsume all of ‘medical science’ under a single conceptual scheme, it can be regarded as certain that it will not be the conceptual scheme of the biological science of the early nineteenth and twentieth centuries. It is also certain that this conceptual scheme will prove applicable to a great deal of the range of social action in areas which extend well beyond what has conventionally been defined as the sphere of medical interests (Timmermans S & Haas S 2008: 660).

In contrast to the exaggerated view that medicine is only about biology, Parsons distinguished a clear social or psychosocial dimension that every aspect of health maintenance and is open for social analysis. He anticipated that these social factors would play a crucial role in medicine of the future, although hedging on their specific importance (Parsons). In fact, observers noted that while Parsons led the fight against psychological and biological reductionism in the 1930s (Camic 1989: 423), he saw a place for translating biological pathology into ‘psychogenic’ processes (Gerhardt 1986, 1990: 345).

Combining the functional aspects of health services and the social aspects of the illness experience together, Parsons articulated the social study of medicine in the following terms:
Summing up, we may say that illness is a state of disturbance in the ‘normal’ functioning of the total human individual, including both the state of the organism as a biological system and of his personal and social adjustments. It is thus partly biologically and partly socially defined. Participation in the social system is always potentially relevant to the state of illness, to its etiology and to the conditions of successful therapy, as well as to other things (1951: 431).

Parsons foresaw a division of labour where social scientists would work along with biological scientists to deal with health problems. Annemarie Mole (2002: 10) work has criticized Parson as a outdated functionalist. Parson’s book on Social System was famous in 1951. It is also evident to note that there is a lot more has changed in medical sociology since Parson’s time. The notion of disease has also undergone a massive change from sinful and sick to diseased caused by work stress or social isolation. Still people are holding Parson because he is the person who invented medical sociology, the manner in which he relates biology and sociology in his work ‘social system’ is a vital contribution to the field. Although Parsons was more open to biology than many of his descendants, in effect, he articulated the sociological study of illness in contrast to biological disease. Consequently, social scientists have mainly become interested in the experience, culture, and social structuring of illnesses while bracketing the biological foundation of disease. Parsons’ contribution as a founding figure of medical sociology consisted of parcelling out a social sphere of medicine while leaving biology, physiology, and pathology for others. Medical sociology, like all sociology, is concerned with social relationships and social processes, and its theoretical base must of necessity be that of general sociology.
Transformation from Medical Sociology to Sociology of Health and Illness

Through a gradual process, medical sociology was transformed into the sociology of health and illness. Social scientists considered medicine too restrictive as an indicator of the sociological interest in the health realm (Cockerham 2009). ‘Medical sociology’ implied a discipline focused on the medical profession, hospitals, and the broader health service industry. In particular, it may have implied a discipline that uncritically worked within the value parameters and priorities set by clinicians. To rename medical sociology as the sociology of health and illness thus manifested a recognition that illness experiences spilt over into family, work, school, and other areas of life. In addition, social scientists were interested not only in how people’s health improved but also in how they prevented health problems in the first place. Health care became one aspect of the social study of health and illness. Sociologists also became cognizant of the role of nurses and other allied health professionals in maintaining health.

The origin of any discipline is often based on the healthy discussion it generates in finding out the crux of what is actually dealt with but once the queries are cleared, it goes into regular stream. Similarly Medical Sociology also was accepted and the assumption that qualifies it is taken for granted. It gives a prime importance to Social study of health and illness excluding biology and disease as research foci. This area of research aims to develop the research in sociology of health and illness and this helps in understanding how social processes affect the severity or course of diseases and how, in turn, specific stages of disease affect social relationships, work, neighbourhood, or family life. For example, Sociology of
disease, as Timmerman (2008) explains like to know whether the extensive literature on medicalisation or biographical disruption matters for patients’ health; how exactly neighbourhoods may affect asthma morbidity; or whether the biology of methamphetamine addiction affects treatment modalities.

Under the influence of Talcott Parsons, the social study of health began as medical sociology and then morphed into sociology of health and illness, focusing largely on the social aspects of health-related topics. Social scientists have been reluctant to tackle disease in its physiological and biological manifestations. The result is an impoverishment of sociological analysis on at least three levels: social scientists have rarely made diseases central to their inquiries; they have been reluctant to include clinical endpoints in their analysis; and they have largely bracketed the normative purpose of health interventions. Consequently, social scientists tend to ignore what often matters most to patients and health care providers, and the social processes social scientists describe remain clinically unanchored. This study in general explores the dialectic between social life and disease; aiming to examine whether and how social life matters for causes of disease and vice versa.

**An added view of history of Medical Sociology**

Medical sociology was not established until after World War II when the American government provided extensive funding through the National Institutes of Health for joint sociological and medical research projects. The same situation prevailed in Western Europe, where, unlike in the United States, few medical
sociologists were affiliated with university sociology faculties and connections to the general discipline of sociology were especially weak (Cockerham 2006). It was primarily through the motivation of the availability of government funding that sociologists and health professionals embraced medical sociology as a new sub-discipline. Funding agencies were not interested in theoretical work, but sponsored research that had some practical utility in post-war society as Western governments had come to realize that social factors were important for health.

By the end of the twentieth century, however, this situation had changed significantly. Most research in medical sociology remains oriented toward practical problem solving, but the use of sociological theory in this venture is now widespread (Cockerham 2006). There has been a general evolution of work in medical sociology that combines both applied and theoretical perspectives, with the utilization of theory becoming increasingly common as a framework for explaining or predicting health-related social behaviour. At the same time, medical sociology moved away from a state of dependence upon medicine for defining and guiding research agendas to a position of relative independence. Although the relationship between medical sociology and medicine has been important, it has not always been harmonious. Medical sociology tended to side with patients and call attention to instances of poor treatment, while some physicians have been contemptuous of medical sociologists in clinical settings. Yet medicine nurtured, funded, and sponsored medical sociology early in its development and continues to do so today. In fact, one could arguably state that medicine has supported medical sociology with funding and job positions to a much greater extent than sociology. This is true because one of the prime sector in which sociologist seek employment is medical
field. It can also be claimed that the increased use of theory in medical sociology represents more of an effort on the part of medical sociologists to establish and reinforce links to the parent discipline than vice versa. In many ways, medicine has been a better ally of medical sociology than sociology. But relationship has also been critiqued (ed Vincente Navarro, N. Mol, etc.) by numerous scholars. It would be good to note this fact because the relationship is not unproblematic.

While medical sociology is moving closer to sociology, it has generally removed itself from a subordinate position to medicine. There are four reasons for this development. First, the shift from acute to chronic diseases as the primary causes of death in contemporary societies has made medical sociology increasingly important to medicine. This is because of the key roles of social behaviour and living conditions in the prevention, onset, and course of chronic disorders. Medical sociologists bring more expertise to the analysis of health-related social conditions than physicians, who typically receive little or no training in this area. Second, medical sociology has moved into a greater partnership with medicine as it has matured and fostered a significant body of research literature, much of it relevant to clinical medicine and health policy. Third, success in research has promoted the professional status of medical sociologists, in relation to both medicine and sociology. And fourth, medical sociology has generally set its own research agenda, which includes medical practice and policy as an object of study. In the case of malpractice, failure to police incompetent practitioners, limited access to quality care for the poor, and placing professional interest ahead of the public’s interest, medical sociologists have been significant critics of medicine. In doing so, they have established themselves as objective professionals. (Cockerham 2009).
The movement of medical sociology toward greater connections with general sociology reflects the desire of a mature sub-discipline to expand its analytic capabilities and reinforce its potential. Changing social conditions associated with the transition in society from the post industrial to the current late modern period requires all of sociology to account for altered circumstances and formulate new concepts. This situation suggests that not only is medical sociology connecting with general sociology, but that sociology is moving toward a closer affiliation with it – given the considerations of health increasingly evident in the everyday social lives of people and medical sociology’s capacity for explaining it. Under the current conditions of social change, medical sociologists are making greater use of sociological theory because theory promotes the explanatory power of their empirical findings.

This development has led some to suggest that medical sociology may indeed prove to be the “leading edge” in some areas of the development of contemporary theory (Turner 1992). The extent to which this assertion will be fully realized is not yet certain, but it is clear that a considerable amount of theoretical work is taking place in medical sociology (Cockerham 2007a). The rest of this chapter will provide an overview of the field with respect to theory and the development of the sociological study of chronic illness which is later addressed as chronic disease.
Structural Functionalism

From 1946 to 1951, the new field of medical sociology was almost completely an applied area of research. Medical sociologists worked with psychiatrists and other physicians on government-funded projects to largely address medical problems; few were employed in university departments of sociology in the United States and they were generally absent from sociology faculties in Europe and Asia. However, a crucial event occurred in 1951 that oriented medical sociology toward theoretical concerns and initiated the establishment of its academic credentials. This was the publication of Talcott Parsons’ long anticipated book, *The Social System*, which established the author at the time as the dominant figure in American sociology (Ritzer 2008). Anything Parsons published attracted great attention because he was thought to be charting a course for all of sociology. This book, providing a structural-functionalist model of society, contained Parsons’ concept of the sick role and was the first time a major sociological theorist included an analysis of the function of medicine in his view of society. Parsons was interested in the differing roles of professionals in capitalist and socialist societies and decided to include physicians and their relationship to their clients in his analysis because this topic was an area of long-standing interest and one in which he felt he had familiarity. Parsons himself had undergone training in psychoanalysis in the 1950s at the Boston Psychoanalytic Institute when he was on the faculty at Harvard University (Smelser 1998: 246).

This experience had grounded him in the theories of Sigmund Freud which became an important influence on his own work, along with the ideas of the classic sociological theorists Emile Durkheim and Max Weber. Parsons had completed his
doctoral studies at Heidelberg University in Germany in the mid-1920s where he participated in the “Weber Circle” that continued to meet regularly to discuss sociology after Weber’s death at the home of his widow, Marianne Weber. Parsons subsequently translated Weber’s book *The Protestant Ethic and the Spirit of Capitalism* (1958) into English, and reintroduced the work of both Weber and Durkheim to European sociologists after the disruption of their work during World War II. Freud’s concepts of transference and counter-transference can be seen in the way Parsons drew analogies between the roles of parent–child and physician–patient important in his notion of the sick role. Freud’s structure of the personality and theory of the unconscious are also apparent in his ideas on the motivation of sick persons to either recover or desire the “secondary gain” of privileges and exemption from normal social roles that accompany sick-role legitimation. Parsons likewise incorporates Durkheim’s ideas on moral authority and Weber’s analysis of religion into his discussion of the normative requirement to visit physicians when sick and the dominant position of the physician in the doctor–patient role relationship.

Parsons’ concept of the sick role is a clear and straightforward statement of four basic propositions outlining the normative pattern of physician utilization by the sick and their respective social roles. Parsons not only constructed the first theoretical concept directly applicable to medical sociology, but by utilizing the work of Durkheim and Weber, he did so within the parameters of classical sociological theory. His formulation was recognized as “a penetrating and apt analysis of sickness from a distinctly sociological point of view” (Freidson 1970a: 228), which indeed it was. Parsons also influenced the study of professions by using
the medical profession as the model for professions based on proficiency and a service orientation. Although extensive criticism was to subsequently lessen the acceptance of the Parsonian approach to theory, this outcome does not negate the significant influence Parsons initially had on promoting debate and research in medical sociology. Parsons, more so than any other sociologist of his time, made medical sociology academically respectable by providing it with its inaugural theoretical orientation.

However, structural functionalism, with its emphasis on value consensus, social order, stability, and functional processes at the macro-level of society, had a short-lived period as the leading theoretical paradigm in medical sociology. Robert Merton and his colleagues extended the structural-functionalist mode of analysis to the socialization of medical students in their book The Student Physician (1957), but other major works in medical sociology were not forthcoming. Structural functionalism itself was under assault by critics in the 1960s and early 1970s and lost considerable influence.

Durkheim, who was generally responsible for the theory in sociology, emphasized the importance of macro-level social processes, structures, norms, and values external to individuals that integrated them into the larger society and shaped their behaviour. People were portrayed as constrained in exercising free will by the social order. Durkheim’s only work that had a direct application to medical sociology was his theory of suicide in which the act of taking one’s life was determined by the individual’s ties to his or her community or society. This is seen in his typology of three major types of suicide: (1) egoistic (social detachment), (2)
anomic (state of normlessness), and (3) altruistic (a normative demand for suicide). The merit of his concept is that it shows the capability of the larger society to create stressful situations where people are forced to respond to conditions not of their own choosing. Thus, Durkheim helps us not only to understand the social facets of suicide, but also to recognize that macro-level social events (like economic recessions) can affect health in a variety of ways through stress and that the effects of stress can be mitigated through social support (Cockerham 2010). Indirectly, Durkheim also influenced the study of health professions in noting the transition from mechanical to organic social solidarity, with its emphasis upon specialization, in the modern division of labour.

However, symbolic interactionists objected to the relegation of individuals to relatively passive roles in large social systems, while conflict theorists found structural functionalism inadequate in explaining the process of social change and the social functions of conflict. The theory’s emphasis on equilibrium and consensus also seemed to favour maintenance of the status quo and support for dominant elites (Ritzer 2008), at a time (the 1960s) of widespread social protest against authority in the West. Structural functionalism in general and Parsons in particular suffered a serious fall in popularity, although Parsons’ work enjoyed a mild resurgence in the 1990s (Callinicos 2007). Parsons’ concept of the sick role, however, has remained a central theoretical proposition in medical sociology, despite challenges. It is still utilized as a basic (“ideal-type”) explanation for physician – patient encounters in which the model of interaction is primarily that of guidance on the part of the physician and cooperation by the patient in clinics or patient care office settings.
Symbolic Interactionism

The first major theoretical perspective to challenge Parsons and structural–functionalist theory in medical sociology was symbolic interactionism, based largely on the work of George Herbert Mead (1934) and Herbert Blumer (1969). Symbolic interactionism maintained that social reality is constructed on a micro-level by individuals interacting with one another on the basis of shared symbolic meanings. Human beings were seen to possess the capacity to think, define situations, and construct their behaviour on the basis of their definitions and interpretations. “It is the position of symbolic interaction,” states Blumer (1969:55), “that the social action of the actor is constructed by him [or her]; it is not a mere release of activity brought about by the play of initiating factors on his [or her] organization.”

Social life was therefore produced by interacting agents choosing their own behaviour and acting accordingly, not by large-scale social processes and structures channelling behaviour down optionless pathways. Symbolic interactionism had not only its particular (micro-level) orientation toward theory construction, but also its own qualitative research methodologies of participant observation that focused on small group interaction in natural social settings. A related approach was ethnomethodology, which featured description of taken-for-granted meanings in natural settings, rather than analysis.

The major figures in early medical sociology working in the symbolic interactionist tradition were Anselm Strauss and Erving Goffman. Strauss joined
with Howard Becker and others in their now classic study of medical school socialization, *Boys in White* (Becker et al. 1961). Strauss made his own contributions to theory and methods in a number of areas, including seminal work on the social process of death and dying (Glaser and Strauss 1965, 1968); observation of the “negotiated order” of hospital routine featuring a minimum of “hard and fast” regulations and a maximum of “innovation and improvisation” in patient care, especially in emergency treatment (Strauss et al. 1963); and formulation of grounded theory methodology featuring the development of hypotheses from data after their collection, rather than before (Glaser and Strauss 1967).

Goffman, who became a major theorist in sociology and later with more of a health emphasis, began his research career in medical sociology by using participant observation to study the life of mental hospital patients. His classic work in this area, *Asylums* (1961), presented the concept of “total institutions” that emerged as an important sociological statement on the social situation of people confined by institutions. His observations also led to the development of his notions of impression management and the dramaturgical perspective in sociology that views “life as a theatre” and “people as actors on a stage,” as well as his concept of stigma (Goffman 1959, 1967).

With the introduction of symbolic interactionist research into an area previously dominated by structural functionalism, medical sociology became an arena of debate between two of sociology’s major theoretical schools. By the mid of 1960s, symbolic interaction came to dominate a significant portion of the literature
in the field. One feature of this domination was the numerous studies conducted in reference to labeling theory, a variant of symbolic interaction, and the controversy it provoked. Labeling theory held that deviant behaviour is not a quality of the act a person commits but rather is a consequence of the definition applied to that act by others (Becker 1973). That is, whether or not an act is considered deviant depends upon how other people react to it. Although labeling theory pertained to deviance generally, the primary core of argument was focused on the mental patient experience, with Thomas Scheff (1999) the principal proponent of the labeling approach. Labeling theory was also employed in studies of the medical profession as seen in Eliot Freidson’s (1970 b) alternative concept of the sick role.

By the 1980s, however, symbolic interaction entered a period of decline in medical sociology. Many of its adherents had been “rebels” intentionally challenging the dominant paradigm of structural functionalism and giving voices to women and marginal social groups like mental patients, the physically handicapped, and the aged and their caretakers by entering their social world and observing it. Yet, as Norman Denzin points out, between 1981 and 1990, the canonical texts in the field had shifted from Mead to Blumer and Blumer himself was under attack on several methodological and substantive issues – but most importantly for not advancing the field to meet his own early criticisms; moreover, practitioners of the perspective were getting older (“the graying of interactionism”), the number of students advocating interactionism was decreasing, and the old enemy (structural functionalism) had been largely vanquished. Elsewhere, in Great Britain, where interactionism had been the dominant theoretical perspective in medical sociology as seen in the majority of published studies (Annandale 1998), a related theoretical
perspective–social constructionism – is now the leading theory (Nettleton and Sarah 1995).

Unfortunately, symbolic interaction had taken on the image of a “fixed doctrine” and, except for Mead’s concept of the “generalized other,” was unable to satisfactorily link small group processes with social phenomena reflecting the behavioural influences of the larger society. It was particularly unable to account for interaction between institutions or societal-level processes that affect each other, not just individuals or groups. In addition, labeling theory, despite its merits in accounting for the powerful behavioural effects of “labels” placed on people, had not been able to explain the causes of deviance (other than the reaction of the social audience), nor whether deviants themselves share common characteristics like poverty, stress, family, or class background.

But it would be a mistake to relegate symbolic interaction to history, as participant observation remains the primary form of qualitative research in medical sociology. Participant observation and ethnomethodology are still the best methods for recording social behaviour from the personal standpoint of those being studied and the settings within which they lead their usual lives. Moreover, the observed patterns of behaviour and first-person accounts of social situations bring a sense of “real life” to studies that quantitative research is unable to capture. While symbolic interaction theory has not moved far beyond the original concepts of Mead and Blumer, it persists as an important theoretical approach to the study and explanation of social behaviour among small groups of people interacting in ways that are relevant for health.
One area of research in medical sociology helping to revive symbolic interaction is the sociology of emotions, a topic neglected in the past. Research in this field seeks to understand the link between social factors and emotions, since emotions are expressed either in response to social relationships or situations or both. Symbolic interactionism fills in the analytic gap between organic or biological approaches to the study of emotions and sociological approaches like social constructionism that ignores biological processes and focuses more or less exclusively on the social and cultural components of emotions (Williams and Bendelow 1996). Interaction between people plays perhaps the major role in the activation and expression of emotions and analyzing interpersonal relations is strength of symbolic interaction. Emotions, as Simon Williams(1998) points out, are existentially embodied states that also connect “personal troubles” to social structures in ways that affect health and shape patterns of disease. Williams finds, for example, that feelings of stress, helplessness, depression, sense of coherence, insecurity, and lack of control have consistently been shown to be associated with increased levels of mortality and morbidity. There are other sociological theories conflict theories, critical theories, and theories of twenty first centuries such as Poststructuralism, Social constructionism, Feminist Theory, Postmodern Theory, and Critical Realism. These theories also play a vital role in understanding social factors influencing health disorders.

The notion that medical sociology is atheoretical is wrong. This chapter has provided a brief account of the history and variety of viewpoints in sociological theory that have been utilized within the field and provided influential statements on the relationship between society and health. Beginning with Parsons and
structural functionalism, medical sociology in reality has a rich theoretical tradition spanning almost 60 years and incorporating the work of both classical and contemporary theorists. Debates in general sociology, such as those involving the opposition of symbolic interactionists and conflict theorists to structural functionalism and the current agency versus structure dispute, became points of theoretical contention in medical sociology as well. During the latter part of the twentieth century, structural theories like structural functionalism were largely abandoned in favour of agency-oriented theories like symbolic interaction, labelling theory, and the agency side of social constructionism. However, improved statistical techniques to measure the effects of structure—such as hierarchical linear modelling—forecast a paradigm shift back to greater considerations of structure and structural approaches to theory (William Cockerham). Although it is too early to determine the ultimate direction of theory in medical sociology this century with exact precision, these improved statistical procedures should provide a more comprehensive approach to research with theory guiding and adjusting to this capability. Already the theoretical basis for work in the field is extensive and its potential explanatory power is likely to increase. Medical sociology has become a theoretical subdiscipline.

**Chronic disease**

Throughout the history of medical sociology, social scientific study of chronic conditions has taken two major directions: epidemiological studies of specific populations in relation to disease and analyses of the experience of illness, the primary focus of this study. In the sociological literature, disease and illness are neither interchangeable nor equivalent. Disease is the undesirable biological process
or state affecting the individual, and illness is the person’s experience of the
disease, including its social and psychological impacts (William C. Cockerham, 2009). Just as disease may be unrecognized and unfelt, deeply disturbing symptoms
may arise without being diagnosed as a disease, even in the absence of perceivable
organic causes. To study illness, then, is to study human experience without
reference to organic causes, although it may include lay understandings of these
causes and the experience of diagnosing them. This study also leaves aside the
equally interesting sociological question of the social causes of the unequal
distribution of chronic organic conditions, instead, it emphasizes the history and
contributions of studies of the lived experience of chronic illness.

Studies of the illness experience began with analyzing the realities of the
lives of people with chronic conditions and focused on how they defined and
managed their illnesses. The implications of this research ranged from practical
possibilities to social relations and, finally, to self-image, identity, social relations,
and imagined futures. Although the temporary incapacitation of acute illnesses
inspired early medical sociologists (specifically, Parsons 1951) to consider the
impact of illness on social structure, the long-term nature of chronic illness grounds
sociological interest in how sufferers manage the personal experience of their
disease’s duration and uncertainty. The disease is not the focus; the illness is.
Correspondingly, the emphasis in sociological studies of chronic illness is less on
the actor’s physical symptoms and more on the following:

(1) the meanings that actors impute to these symptoms;

(2) the consequences that these meanings have for daily living as they filter
through such social concerns as stigma, social norms, expectations, and
relations with self and other; and
(3) how actors manage the impact of long-term, sometimes intermittent and unpredictable, physical incapacity on their respective selves and social worlds.

This section of the thesis sketches the rise of sociological research into chronic illness and reviews its core substantive foci and contributions. These studies illustrate the implications of chronic illness for self, identity, and social relations. Because these studies showed how people accomplished routine daily actions in the face of physical challenges to them, they drew on a wide range of sociological theories and approaches, primarily social constructionism, symbolic interactionism, and the sociology of the body. But their general focus on chronic illness in micro social contexts (self and intimate others) has produced a literature that, while robust in its treatment of this arena, remains thin in its consideration of more meso and macro contexts and processes that shape chronic illness such as health care systems, community relations, medicalization, and the pharmaceutical industry. Although such studies exist, they tend to be seen as about these contexts and processes rather than about chronic illness itself. After reviewing the findings and contributions of sociological studies of chronic illness, we then discuss some works that take a more distal view of chronic illness and consider their possible linkages.

**A Brief History of Chronic Illness Research**

Chronic illness as an area of intellectual investigation was inspired by both an epidemiological shift and ethnographic challenges to the dominant sociological conception of illness. The epidemiological shift marked the emergence of chronic disease as the major cause of death, supplanting the acute illnesses that had prevailed in the era of infectious disease. This epidemiological transition (Omran) occurred in tandem with three other key changes in the developed West:
(1) the increase in life expectancy,

(2) the drop in overall mortality and in infant and maternal mortality in particular, and

(3) the surpassing of women’s life expectancy over men’s.

The last century, then, produced a vastly different picture of Western health than had previous centuries. These changes spawned major concerns in medical sociology and the sociology of health about the relative distribution of health and illness (MacIntyre 1997) and the respective reasons for these distributions (Wilkinson 1996 and Marmot 2006). Most relevant to this discussion, is the rise of chronic disease (specifically, cardiovascular disease, stroke, and cancer) as the most common cause of death led sociologists to recognize that Talcott Parsons’ (1951) work on the “sick role,” the seminal functionalist piece of work in medical sociology, was not only inapplicable to the chronic illness experience, but also problematic in its own right. This issue grounded a sociological concern with the experience and management of health and illness.

**From sick role to biographical disruption**

Parsons regarded illness as a form of deviance that the social system had to contain through institutionalized practices of social control over patients by medical agents and organizations. He began his analysis by looking at how the institution of medicine contributes to a functioning social system. For Parsons, illness was a safety valve that released pressures from the social system in general and the family system in particular, because being in the sick role temporarily removed a person
from ordinary role obligations. Acute illness, in Parsons’ view, necessitated that patients be temporarily exempted from their adult responsibilities but obligated them to seek help, to follow their physician’s orders, and to concentrate on getting well. The sick role controlled and regulated the illness experience and held the ill person accountable to the larger social system.

Parsons uncovered the deeply social nature of illness by pointing to how illness could be problematic for the social system. Yet his theory suffered from major limitations. First, because it assumed acute illness, it posited a relatively straightforward curative pathway and an objective, authoritarian doctor – passive patient role relationship operating within a smoothly functioning institutionalized system. Yet these characteristics of the sick role do not fit people’s experience of chronic illness or of disability. Rather than taking time out for illness, many people with chronic illnesses must learn to live with their conditions while keeping their jobs and maintaining their family obligations – managing a continuing and, often, deteriorating condition takes priority, and recovery cannot be assumed. Now, neither can physicians’ authority, as national health services, insurance plans, and medical consumerism reshape their relations with patients (Bury and Taylor). Moreover, because routine treatment and illness management occur at home rather than at the clinic, patients and families become active participants in treatment and care rather than the passive recipients of unilateral directives. Indeed, physicians must rely on patients and families to inform treatment planning and consult with them about treatment outcomes. Thus, the patient – physician role relationship shifts toward a partnership that relies on mutual efforts to manage the illness.
Second, Parsons’ theoretical model remained limited because it adopted an outsider’s rather than an insider’s view. The concept of the sick role acknowledged physicians’ expertise but not patients’ experience, an important area of inquiry in its own right and an increasingly important feature of the doctor – patient interactional landscape. Within a decade of Parsons’ publication of the sick role, medical sociologists recognized that understanding the actual experience of chronic illness, its consequences, and its management, as well as its definition and regulation, required an entirely new conceptual apparatus for investigating the social nature of chronic illness (Gallagher 1976; Koos 1954; Levine and Kozloff 1978; Raynor 1981; Zola 1973).

The makings of an alternative conceptual model arose as ethnographers began to study patients’ experience of illness and disability, which were linked in the early studies. For example, the studies conducted by researcher Erving Goffman (1968), Elliott Freidson, Fred Davis (1964), Anselm Strauss (1975), Janine Pierret, Brooks and Matson, Susan Gregory challenged Parsons’ view of medical authority and patient compliance.

In 1982, the focus on the experience of chronic illness was formalized in a special issue of *Social Science and Medicine* entitled “Social Factors in the Etiology of Chronic Disease” and rejuvenated by Michael Bury’s (1982) influential article “Chronic Illness as Biographical Disruption” in Sociology of Health and Illness. Bury argued that chronic illness challenged how people understood the world and their position in it, disrupting both “the structures of everyday life and the forms of knowledge which underpin them.” (p.169, 1982) Sufferers were thus forced into a
more reflexive, and uncertain, relationship with taken-for-granted forms of knowledge than they had enjoyed while physically well. His argument hinged on the following facts. First, chronic illness introduces a heightened and alien state of bodily awareness: determining the nature of initial symptoms requires “attention to bodily states not usually brought into consciousness and decisions about seeking help.” (p.169, 1982)

Second, it challenges forms of knowledge, causing “a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others,” and disrupting “explanatory systems normally used by people, such that a fundamental re-thinking of the parson’s biography and self-concept is involved”. Third, it has social repercussions, “bring[ing] individuals, their families, and wider social networks face to face with the character of their relationships in starker form, disrupting normal rules of reciprocity and mutual support”, and calls for a responsive mobilization of resources. Finally, it forces the ill person to re-examine her “expectations and plans … for the future”. Strengthened by the recognition of the increasing prevalence of chronic illness, Bury’s framework spawned a wave of studies on the biographically disruptive nature of chronic illness, and, more recently, critiques of his implicit argument that chronic illnesses are universally and uniformly disruptive regardless of age and life-course location, life history, and socioeconomic context.

Bury’s concept of biographical disruption focus on adults and hence omits the complex relation that those who have come of age with a chronic illness might have with it (Williams S. 2000).
Thus, while a chronic illness is undoubtedly disruptive in many ways, it does not always remain disruptive, or equally disruptive, over time, as actors bring biographical and narrative resources to bear. More recent work has uncovered other, perhaps more complex criticisms of Bury’s biographical disruption (Williams, 2000). Critiques signify the coming of age of much research into the chronic illness experience, as it takes stock of the need to expand the literature beyond the realm of managing illness to consider deep connections between self, biographical reconstruction, and bodily experience. This brings us to two other dimensions of chronic illness that remain under investigated: the body’s corporeal facticity and emotions.

**The Impact of Uncertain Chronic Disease on the Self**

Recent research remains strong about the impact of chronic illness on everyday life, from the self and identity to relations in public centering on the management of stigmatized bodies and bodily behaviors caused by chronic disease. The research has also moved to address the implications of having an uncertain chronic condition on self and identity. Uncertainty pervades the course of illness – it undermines our “sense of constancy of the embodied self and the ability to plan and predict future actions” (Kelly and Field 1996:244) – and thus imposes a central problem for people with intrusive chronic illnesses and for their families (Pitt 2006), although often in gender-specific ways.

Men tend to have life-threatening chronic diseases in which uncertainty and risk of death appear large, whereas women tend to have more disabling
conditions such as rheumatoid arthritis, multiple sclerosis, and fibromyalgia that may worsen suddenly but typically have a lengthy trajectory (Courtenay 2003) (Verbrugge 1990). Uncertainty becomes infused with “shoulds” and “oughts” because people view it as something to manage so as to reduce risk of further episodes or death. Meanings of uncertainty and risk figure in people’s accounts of their health and illnesses. Consistent with Radley and Billig (1996), these accounts are ideological, showing that meanings of uncertainty elicit a moral discourse around legitimacy and credibility.

For example, some chronic conditions such as epilepsy, heart disease, and AIDS bring uncertainty and risk into the foreground, but whether and how people attend to them elicit statements of moral evaluation and self and social scrutiny. Other chronic conditions such as chronic fatigue syndrome, environmental illness, and fibromyalgia are fraught with a more fundamental type of uncertainty: their legitimacy as real diseases. These conditions give rise to what Stockl calls “existential uncertainty” as sufferers struggle not only with symptoms but also with establishing the veracity of these symptoms and their own credibility as competent adults (Shriver and Waskul 2006; Travers and Lawler 2008; Ware 1992; Werner and Malterud 2003). Adamson (1997) and Broom and Woodward (1996), however, noted that “clinical uncertainty can provide grounds for hope, alleviating feelings of existential uncertainty associated with the contemplation of worst – case scenarios” (Adamson 1997).

Crises underscore an uncertain course of illness. A life-threatening crisis or debilitating episode of illness suggests an uncertain future ahead – at least for a
while. Strauss and his colleagues (1984), however, observe that the further away people are from experiencing a crisis, the less vigilant they become. Their attention to regimens and restrictions falters. In addition, ill people, their families, and health professionals may invoke conflicting definitions of uncertainty and risk that, in turn, affect what the person should do and who he or she can become. Speedling found that wives of men who had heart attacks often viewed their husbands’ health as uncertain and tried to restrict their activities while the men chafed to resume their earlier pursuits. Several of these men then focused on the tussle for control rather than on monitoring symptoms and following their regimens while their wives attempted to enlist physicians’ concurrence of their definitions of uncertainty and what needed to be done about it (1982).

People with chronic illnesses develop ways of handling uncertainty. They may give considerable efforts to reducing its potential deleterious effects. Certainly, people aim to reduce uncertainty by engaging in symptom control and following a regimen. Yet they may also try to protect themselves from uncertainties by testing the continuous applicability of a disease regimen to their own condition by, for example, withholding or manipulating their own medication use (Schneider and Conrad 1985) and by reconceptualising its meaning. Individuals may bracket uncertainty and treat it as though limited to crises (Charmaz 1999). They may also invoke idiosyncratic beliefs that they have already met a taken-for-granted measure of suffering and therefore should be exempt both from crises that make their lives uncertain and the day-to-day uncertainties of being able to live on their own terms. Under these conditions, they may be stunned by new concrete reminders that they still face uncertainty. In total, meanings of uncertainty are imbedded in moral
discourses about self, suffering, and action although, at first glance, uncertainty may seem like a characteristic of a disease process (Werner et al. 2004).

Shame and Stigma

Shame and stigma are interwoven in people’s experience of chronic illness. Being stigmatized means that, however silently it occurs, other people mark the person as different and less than his or her peers. Those who stigmatize ill people separate and marginalize them, while simultaneously conferring and confirming their unrecognized identities. In turn, “identity spread” (Strauss et al. 1984) occurs as the stigmatized identity spreads over all other identities and redefines individuals in terms of the stigmatized attribute. Thus, a young mother with multiple sclerosis who uses a walker becomes a “disabled mother.” Robert F. Murphy (1987), who used a wheelchair, states that the stigmatized identity leads to shame, guilt, and mortification, although the person realizes that he or she is undeserving of blame for the stigmatized disability. Quite possibly, such stigma increases when, like Murphy, people once applied the same stigmatizing definitions and marginalizing actions to others that they later experience themselves.

Whether stigmatizing definitions come from self in addition to others, the process of being stigmatized arises through interaction and relies on language and shared meanings. Stigma potential increases when the person: (1) has a condition such as AIDS and epilepsy that invoke other people’s fear and dread, (2) has suffered disfigurement such as results from scleroderma, (3) behaves erratically or loses composure, (4) loses control of bodily functions, and (5) is viewed by other people as being culpable or morally suspect for having the condition. A difference
that might have once invoked sympathy and caring becomes the source of separation and marginalization. People who have unexplained illnesses often find themselves blamed not only for their claims of being ill, but also for receiving stigmatized responses to these claims.

**Chronic Illness in socio-structural context: Medicalized Environments, Medicalized Identities, and Chronic Illness**

Understanding the social impacts and experience of chronic illness requires considering how chronic illness plays out in wider social contexts and, indeed, social institutions, many of which have emerged specifically to handle chronic illnesses. Although it is not possible to explore these wider contexts in full, a socio-historical approach to medicine that has deep implications for the experience of chronic illness, and can briefly identify areas of research that merit more explicit inclusion in the quest to understand that experience.

Sociological analyses of what Klawiter (2004) termed disease regimes reside in two distinct approaches to the role of medicine in regulating social life: the Foucauldian approach, grounded in Foucault’s Birth of the Clinic (Armstrong, Lupton (1995), and the medicalization thesis. A strong example of the first is Arney and Bergen’s (1983) article tracing the emergence of the chronic patient not as a neutral reaction to epidemiological shifts but as a discursive and political construction emerging from changes in medical formulations. The authors note the shift from the nineteenth-century and earlier medical concern with making hidden bodily processes visible, which entails erasing the patient’s personality and
circumstances from the medical gaze and ceding compassionate responses to the patient’s social needs to socio-moral agents, to a medicine that was, by the mid-twentieth century, equally concerned with the patient’s organic and “socio-emotional developments.” Arney and Bergen (1983) cite medicine’s post-war construction of alcoholism as a symptom of maladaptive responses to life that required “compassion within medicine.” Thus “the search for non – maladaptive means of living a life became an explicit medical responsibility.”

They argue that medicine’s conscious adoption of new scientific reasoning practices sparked this construction and, by the 1940s, was replacing a Victorian mechanistic view (with the patient the victim of an internal breakage) with a dynamic understanding of the natural world in which the sick man is “an energy-system in which the balance of forces has been disturbed” Disease as a state of disequilibrium required a more totalizing program of disease management, hence new forms of health care delivery such as support teams and new connections between the clinic and the community were “deployed over a wide social space” (Arney and Bergen, 1983). The 1940s saw a massive growth in government-sponsored agencies in the United States designed to define, monitor, and manage chronic illness, framing these illnesses as economic as well as personal problems and seeking to find a productive place for the chronically ill. This trend fostered a more holistic medicine and medical regime that: (1) included prevention as well as management, (2) acknowledged the personal as well as the social, and (3) increasingly became organized around health promotion and prevention deployed through health care teams in a widening circle of contexts outside the clinic.
In the critical approach this article represents, proactive medical responses to chronic illness, while much sought after by patients and patient groups, can take on a less than positive or even benign form. Here, the management of chronic illness, and even more its prevention and screening, then becomes an insidious form of social control (to those adopting the medicalization thesis) or regulation in which patients themselves collude (to those holding to a Foucauldian approach). The medicalization thesis, initially offered by Illich and Zola (1990) and most widely known through Conrad’s (1975) extensive work, tends to trace the medical framing of previously unproblematized (or problematized through religious or criminalizing frames) qualities and/or behaviors. Often using a social constructionist approach, medicalization theorizes this process of redefinition as originating in specific institutions’ quest for professional power. While often engaged in the same process of tracing the emergence of medical categories, Foucauldian approaches view medicalization as one expression of more complex and diffuse power relations, and health promotion efforts as deeply enmeshed in the overall process of producing self-regulating actors (Bunton, Nettleton, and Burrows, Lupton, Petersen (1996). Both approaches, however, highlight and deeply problematize the roles of agencies of social control in the construction of chronic illnesses, and call attention to the production of the “worried well” by newly dominant discourses of prevention and life/disease management (Crawford, Fitzpatrick (1980). They also, in their own ways, extend Parsons’ recognition of the deeply social nature of illness, and of the social, political and economic investment in healthy, self-regulating bodies that has increasingly insinuated itself into the fabric of social and moral life (Turner 1996).
We do not depict the chronically ill as passive recipients of power. Just as sociological studies of chronic illness have demonstrated chronically ill persons’ active engagement with their illness and its meanings and consequences, through which they craft a chronically ill self that is integrated into the social - moral order so has sociology recognized and examined the social and political organizing in which the chronically ill have come to engage. This organizing is not, it must be stressed, a simple rejection of medical diagnoses and forms of regulation: on the contrary, it often takes the form of demands for the development of medical diagnostic criteria, therapies, and identities. The chronically ill increasingly agitate for their own medicalization (Conrad 1975), a phenomenon perhaps most visible in the cases of post - traumatic stress disorder (Scott 1995), fibromyalgia (Barker 2002), chronic fatigue syndrome, and Gulf War Syndrome. To Foucauldians, this consumer quest for medicalization exemplifies the rise of new forms of self - governance rather than the beneficial growth of access to medical care. Here, then, the experience of chronic illness is not an exotic, exceptional domain but one deeply tied to the project of self-care, or “technologies of the self” (Foucault 1988), in which all social actors engage.

This discussion has first traced chronic illness research’s exploration of the challenges that chronic disease poses to everyday life, social relations, and self and identity; second, described how people with chronic illnesses manage those challenges; third, noted the relatively new forms of collectivizing of and political organizing around the experience of chronic illness that have emerged over the past two decades; and fourth argued for the expansion of the scholastic project to capture the chronic illness experience beyond the micro - sociological domain. To conclude,
we continue this argument by suggesting other new directions this research might take.

Sociological studies of chronic illness are faced with the task of characterizing its experience in the face of continuous change; indeed, attempting to characterize chronic illness in stable and abiding terms is a virtual impossibility once one recognizes the sheer range of fast-changing factors that shape its experience. These include those shifts in scientific formulation and health care provision noted above, which, to critical sociologists, both ground and reflect tensions between medical and other agencies of social control and actors controlled and implicated by them. But a push of other meso- and macro-level changes and factors impact the chronic illness experience as well. Consider, for example, caregiving, which underwent major transformations given the need to provide long-term care for chronically ill and frail people rather than to provide curative care to the acutely ill and palliative care for the dying (Abel 1991). Here, too, the temporal dimension of chronic illness poses long-term challenges, not only for the recipients of care, but also for those providing it across a range of settings (home, community, and long-term care facilities). An impressive body of research into care giving and the experience of receiving care has emerged over the last 30 years which should, we argue, be recognized as being just as much about chronic illness as is the more local, individualized realm most often associated with the term (Corbin and Strauss 1985).

Similarly, social, political, and financial institutions are also deeply affected by the demands of citizens of all ages suffering from chronic diseases. The political
economy of care provision for the chronically ill merits inclusion in the sociological study of chronic illness because governmental and private insurance structures and policies shape the care and quality of life. Indeed, much of the political organizing by the chronically ill centers on agitating for more and/or different provision by these agencies. Medical care takes an increasingly significant place in discussions about citizenship, the rights of ill people, and the obligation of a nation’s citizenry to remain healthy in the interest of the financial health of the polity. Much of the discourse about adherence to medical directives remains tied to issues of the financial viability of health care systems as well as to health outcomes: Vermeire (2001) and colleagues, for example, characterize non-adherence as “a major public health problem that imposes a considerable financial burden upon modern health care systems”. Adherence became a pressing problem for the medical enterprise only when the long-term management of chronic illness became both possible and the central task of medical care. Finally, the role of the pharmaceutical industry in shaping the experience of chronic illness cannot be underestimated. In addition to strongly shaping medical care and provision, this industry provides medication that can vastly alter the severity, incidence, and even visibility of physical symptoms (though sometimes introducing painful, debilitating, and/or disfiguring side effects that may affect adherence to drug regimens), all of which offer new opportunities and challenges for the presentation of self. As a key claims maker in the medicalization process (Conrad 1975; Conrad and Schneider 1992), this industry also crafts and markets new categories of illness or redefines existing ones that may produce new categories of person or alter the membership of such categories. The effects of such macro-sociological factors on the micro-sociological dimensions
of chronic illness must be explored to more fully appreciate the chronic disease experience.

Nonetheless, those dimensions of the chronic illness experience summarized above also merit further consideration. The situations that people with chronic illness face mirror and magnify less visible problems that others face throughout adult life. Living while under duress, experiencing biographical disruptions, facing uncertainty, constructing selves and identities, being viewed as acceptable, and relating to others all pose problems to many individuals in Western societies. Such topics raise numerous significant sociological questions that have not yet been fully explored. Thus, studying the experience of illness still offers rich opportunities for shaping sociological knowledge.

With this brief introduction about the history of medical sociology and how the development of studying chronic illnesses in sociology, further this chapter will discuss the current scenario of chronic disease. Here for this research purpose chronic illness in literature is addressed as chronic disease.

**Problems of people living with chronic disease**

There is considerable variability among chronic conditions in their severity, symptoms, and the extent to which they impose limitations on their victims. Some are relatively mild "lived-with" conditions that require lifestyle changes and/or compliance with medical regimens, whereas others are severe, life-threatening, and/or degenerative. In either case, the first step in living with chronic illness is
emotional acceptance of the diagnosis and its implications. The diagnosis of chronic disease can generate intense emotional distress in patients and their families. Parents of chronically ill and/or disabled children often experience shame and guilt, and these feelings are exacerbated if they feel responsible for the condition. Their emotional distress is often manifested as feelings of extreme vulnerability, helplessness, and uncertainty over the future (Cohen 1996). As the mother of a fifteen-year old diabetic son said:

"I was completely devastated, I was—just really couldn't believe it, like the rug had been pulled out from under me" (Williams 2000, p.262). In most cases, these feelings wane as individuals accept the diagnosis and begin to cope with its implications. Some research, however, challenges the notion that people move through a series of stages that culminate in emotional acceptance of the illness. Parents may experience chronic sorrow, a "continuous sense of sadness that does not exhibit stages such as shock, anger, and guilt" (Shannon 1996, p. 322). Others deny the diagnosis for an indefinite period of time—often years. For example, a study of families with children who have sickle-cell disease found that mothers denied the diagnosis for a number of reasons—fear that it was racially motivated, the belief that their children were not like others who had the disease, and because they did not want to face the reproductive implications of passing the disease on to future children (Hill 1994). Although denial is typically seen as maladaptive, some research has indicated that denial can have beneficial effects, such as reducing psychological distress and allowing people to continue to participate in important roles and activities (Handron 1993).
Depending on the nature and severity of the condition, living with a chronic disease can prove extremely challenging. Psychologically, people with chronic diseases experience a number of fears, for example, the fear of keeping their body and self-esteem intact, of losing love, relationships, and the approval of others, and of pain and discomfort (Miller 2000). Constant, recurrent, and/or unpredictable episodes of pain often cause feelings of loss of control. This pain can be constant and all-consuming, making symptom management and participation in everyday activities difficult. Peter E. S. Freund and Meredith B. McGuire (1991) have noted that chronic pain can jeopardize social relationships and lead to isolation, as it often invokes invalidating responses from others. The pain experienced by chronically ill persons often has no organic basis and cannot be verified medically, so others may doubt its existence. This can lead to loss of social relationships with others, as the empathy and support of friends and relatives begins to wear thin. Chronically ill people also have to contend with medical treatments and their side-effects, inexplicable remissions and exacerbations of the disease, and changes in lifestyles, activities, roles, and relationships. Some changes are relatively minor; however, others are substantial and are often experienced as a series of losses—of freedom, of hobbies, of employment, of physical appearance and abilities, and even of friendships. Many cause a loss of control over the body, which can lead to stigma and devaluation. In describing living with a chronic respiratory illness, characterized by lack of energy and breathlessness, Clare Williams (1993) sees the illness as causing "dwindling social and recreational lives; social isolation; problems of social interaction, stigma, legitimacy and the tolerance of others towards the condition; the threat or reality of 'dependency' . . . and problems pertaining to family life".
Current Scenario

World Health Organization (WHO) defines chronic diseases as diseases of long duration and generally slow progression. Chronic diseases are the leading cause of mortality in the world, representing 60 percent of all deaths. Out of the 35 million people who had died from chronic disease in 2005, half were under 70 and half were women.

Chronic disease simply means persistent or recurring disease, usually affecting a person for three months or longer. A chronic disease is generally one that is hereditary or one that is the result of factors such as poor diet and living conditions, using tobacco or other harmful substances, or a sedentary lifestyle. Such a disease is not typically contracted from another person by contagion, because most chronic illnesses are not caused by infection. The term chronic disease commonly applies to conditions that can be treated but not necessarily cured.

According to WHO global report Preventing Chronic Diseases A vital investment (2005), Chronic diseases are the major cause of death in almost all the countries. Major Chronic diseases include heart disease, stroke, hypertension, cancer, chronic respiratory diseases and diabetes. It is estimated by WHO that 60 percent of all the deaths are due to chronic diseases and 388 crore people will die in the next 10 years of a chronic disease (2005). It is stated in the report that the poorest countries are the worst affected. Only 20 percent of chronic disease deaths occur in high income countries, while 80 percent occur in low and middle income countries, where most of the world’s population lives. Chronic diseases hinder economic
growth and reduce the development potential of countries, and this is especially true for countries experiencing rapid economic growth, such as China and India. *(The data presented in this overview were estimated by WHO using standard methods to maximize cross-country comparability. They are not necessarily the official statistics of Member States)*

WHO report also insist that there is strong evidence to suggest that the epidemiologic transition is well underway in India and other less industrialized countries. Hence there is a need to review the status of our understanding of the awaiting epidemic of non-communicable diseases (NCD) in India, given their chronic nature and their impact on individuals, families and society.

The Government of India (GOI), Ministry of Health and Family Welfare (MOHFW) in its Annual Report to the people on Health (2010) states that, India is witnessing a rising incidence of non-communicable diseases (NCDs) and diseases characteristic of old age. This rise is occurring in a setting where health expenditures are growing rapidly led by an unregulated private sector and where health insurance and pension coverage are still limited. These financial concerns are further aggravated by the emerging evidence that the India’s poor are at heightened risk of acquiring NCDs owing to high rates of smoking and tobacco use, occupational risks, and living conditions. According to a World Bank report (1996), it is estimated that Indians spent nearly Rs. 84,600 crores out of pocket on health care expenses (year 2004), amounting to 3.3 per cent of India’s GDP for that year. If we consider only those who are working, the annual income loss to households associated with NCDs is estimated to be Rs. 28,000 crores.
Until now GOI had no policy for intervention with regard to non-communicable diseases barring giving some limited financial assistance for purchasing of equipment or undertaking pilot projects or studies. Recently, a National Programme for the Control of Cancer, Vascular Diseases and Diabetes, Health Care of Elderly (Geriatrics Care) and Mental Health have been approved to be taken up in 100 districts in India during the next two years (2010-11 and 2011-12). Major NCD programmes under approval for the remaining two years of the XIth Five-Year Plan are:

- National Cancer Control Program with an outlay of Rs. 731.52 crores.
- National Programme for Prevention and Control of Diabetes, Cardiovascular Diseases and Strokes with an outlay of Rs. 499.38 crores.
- National Mental Health Programme (district component) with an outlay of Rs. 600 crores.
- National Programme for Health Care of the Elderly with an outlay of Rs. 288 crores.

Under this key initiative, dedicated staff will be positioned in community health care centres and district hospitals and training given to frontline health workers as well as medical and paramedical staff at different health facilities for diagnosis and early referral at appropriate health care facilities. It is also believed that decentralisation of such a comprehensive package of services (including
prevention, diagnosis and early treatment) would reduce patient flow to city hospitals, reduce out-of-pocket expenses among the affected families and save lives due to timely treatment. Effort has been made to integrate and synergise all these programs at various levels.

There is an acute shortage of specialists in the fields of diabetology, nephrology, cardiology, etc required to cope with the NLDS (National Level Deficiency Syndrome) in periphery institutions. The health ministry is currently engaged in formulating short-term courses for in-service MBBS doctors working in periphery services to gain technical proficiency in these areas. A one-year course on dialysis for physicians would be started by IGNOU for which an amount of Rs. 28.60 lakhs has been provided.

The Ministry of Health has also launched a pilot project to evaluate the efficacy and reliability of stand-alone dialysis units that can be set up outside a hospital environment without the availability of a nephrologist. The PPP (Public Private Partnership) pilot on stand-alone dialysis unit is being established in CGHS (Central Government Health Scheme), Delhi, in partnership with a leading hospital chain. After the experience gained, this model may be replicated at more centres.

“The lives of far too many people in the world are being blighted and cut short by chronic diseases such as heart disease, stroke, cancer, chronic respiratory diseases, and diabetes” World Health Organization (2005).
WHO report predicts that globally, of the 58 million deaths in 2005, approx. 35 million were as a result of chronic diseases. It is projected to increase further by 17% in the next 10 years. At the same time, child overweight and obesity are increasing worldwide, and incidence of type II diabetes is growing. In India, the means of preventing and controlling most chronic diseases are already well established. Investment in development of drugs for prevention, control, and treatment of chronic diseases is a real opportunity to make significant progress and improve the lives of populations across the globe.

According to the official statistics, in India, deaths due to chronic disease were 3.78 million in 1990 (40.4% of all deaths) and are expected to reach 7.63 million in 2020 (66.7% of all deaths). India is the second largest producer and consumer of tobacco in the world, consequently huge rates of cancer, particularly oral cancer in the world. This cost India, for the individuals affected (treatment costs for tobacco related diseases) about US $7.2 billion just for the year 2002-2003. In diabetes, we had an estimated 19.3 million in 1995. The projected number is 57.2 million by 2025. An integrated national programme for the prevention and control of cardiovascular diseases and diabetes is under development.

<table>
<thead>
<tr>
<th>Projected Global Deaths by Cause.</th>
<th>All Ages: 2005 – 35 million</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cardio Vascular Diseases</td>
<td>17.528 million</td>
</tr>
<tr>
<td>2. Cancer</td>
<td>7.586 million</td>
</tr>
<tr>
<td>3. Chronic Respiratory Diseases</td>
<td>4.057 million</td>
</tr>
<tr>
<td>4. HIV-AIDS</td>
<td>2.830 million</td>
</tr>
<tr>
<td>5. Tuberculosis</td>
<td>1.607 million</td>
</tr>
<tr>
<td>6. Diabetes</td>
<td>1.125 million</td>
</tr>
<tr>
<td>7. Malaria</td>
<td>0.883 million</td>
</tr>
</tbody>
</table>
Only 20% of chronic diseases deaths occur in high income countries. While 80% occur in low and middle income countries where most of the world’s population lives. Of the projected 64 million people who will die in 2015, 41 million will die of a chronic disease – unless urgent action is taken. About 100 crore people are overweight in the world. It is estimated that out of these, 38.8 crores will die in the next 10 years.

In a country like India which is embracing neo-liberalism, chronic diseases will hinder economic growth and reduce the development potential. This is a theological argument….in fact it has been clearly shown that neo-liberal industrial development cause disease and illness. Each of us has a choice: whether to continue with the status quo, or to take up the challenge and invest now in chronic disease prevention. It is entrusted on every one to take up the challenge of preventing and controlling chronic diseases in India for a healthier future generation in India.

There is a general misconception that chronic diseases mainly affect rich people but the actual truth is that poor people are more affected and cause significant financial burden, and can push individuals and households into poverty. Another misunderstanding is that chronic diseases affect old people at large extent but in reality young people are also affected by chronic diseases. In low and middle income countries, middle-aged adults are especially vulnerable to chronic disease. One more misunderstanding is that chronic diseases affect primarily men. Certain chronic diseases, especially heart disease, are often viewed as primarily affecting
men. The truth is that chronic diseases, including heart disease, affect women and men almost equally (WHO 2005).

Chronic diseases are the result of unhealthy “LIFESTYLES”. Many people believe that if individuals develop chronic disease as a result of unhealthy “lifestyles”, they have no one to blame but themselves. The truth is that individual responsibility can have its full effect only where individuals have equitable access to a healthy life, and are supported to make healthy choices. Governments have a crucial role to play in improving the health and well-being of populations, and in providing special protection for vulnerable groups. This is especially true for children, who cannot choose the environment in which they live, their diet and their passive exposure to tobacco smoke and other kind of pollution due to industry and automobiles.

An additional misunderstanding by the people is that chronic diseases can’t be prevented. In reality, the major causes of chronic diseases are known, and if these risk factors were eliminated, at least 80 percent of all heart disease, stroke and type 2 diabetes would be prevented; over 40 percent of cancer would be prevented. Now the cost of treatment for treating chronic diseases has gone down unlike previous days. In reality, a full range of chronic disease interventions are very cost effective for all regions of the world, including sub Saharan Africa where the development is very low. Many of these solutions are also inexpensive to implement.
Poor people also have limited choices about the food they eat, their living conditions, and access to education and health care. Supporting healthy choices, especially for those who could not otherwise afford them, reduces risks and social inequalities. It is important to note that it has been emphasized by a number of important scholars such as Vincente Navarro and some of the likeminded scholars also have studied about the chronic diseases in the context.

Health care in Puducherry

In the Health Care Delivery Services, the Union Territory of Puducherry has been adjudged as the best in the country by the Indian government. The population of Puducherry has an accessible medical care within an average distance of 1.18 kms through a network of Primary Health Centres, Sub Centres, Disease specific clinics besides 8 Hospitals. The per capita expenditure on Health Care Services is Rs.1337/-. Annually over 53 lakhs out-patients and 1.5 lakhs in-patients are treated at the various Government medical institutions of Union Territory of Puducherry. (Health Department, Government of Pondicherry)
Table 1.1: Health Indicators of Puducherry

<table>
<thead>
<tr>
<th>Sl. No.</th>
<th>Item</th>
<th>Unit</th>
<th>Indicators as on 31.03.2007</th>
<th>Indicators as on 31-3-2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Birth Rate (2007)*</td>
<td>Per 1000 population</td>
<td>15.1</td>
<td>15.1</td>
</tr>
<tr>
<td>2</td>
<td>Death Rate (2007)*</td>
<td>Per 1000 population</td>
<td>7.7</td>
<td>7.7</td>
</tr>
<tr>
<td>3</td>
<td>Infant Mortality Rate (2007)*</td>
<td>Per 1000 live births</td>
<td>25.0</td>
<td>25.0</td>
</tr>
<tr>
<td>4</td>
<td>Bed - Population Ratio</td>
<td>Ratio</td>
<td>1:425</td>
<td>1:433</td>
</tr>
<tr>
<td>5</td>
<td>Doctor - Population Ratio</td>
<td>Ratio</td>
<td>1:1913</td>
<td>1:1950</td>
</tr>
<tr>
<td>6</td>
<td>Nurse – Population Ratio</td>
<td>Ratio</td>
<td>1:850</td>
<td>1:866</td>
</tr>
<tr>
<td>7</td>
<td>Eligible Couples</td>
<td>Nos.</td>
<td>160500</td>
<td>167500</td>
</tr>
<tr>
<td>8</td>
<td>Per-Capita Health Expenditure</td>
<td>In Rs.</td>
<td>1071</td>
<td>1337</td>
</tr>
<tr>
<td>9</td>
<td>Family Welfare Programme:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>i) Sterilisation</td>
<td>Nos.</td>
<td>10483</td>
<td>10303</td>
</tr>
<tr>
<td></td>
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<td>iii) Conventional Contraceptive users</td>
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<td>iv) Oral Pill users</td>
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<td>Health Institutions:</td>
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<td>i) Primary Health Centres</td>
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<td>ii) Sub-Centres</td>
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<td>iii) Community Health Centres</td>
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<td>iv) Hospitals</td>
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<td>v) Physical Medicine &amp; Rehabilitation Centre</td>
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<td>v) ESI Dispensaries</td>
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<td>Immunization Coverage Status in %</td>
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<td>Tetanus Taxied for Preg. Women</td>
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<td>T.T. (10 Years)</td>
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<td>18329</td>
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<td>T.T. (16 Years)</td>
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<td>14649</td>
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<td>BCG</td>
<td>Nos.</td>
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<td>14</td>
<td>Leprosy Prevalence Rate (PR%)</td>
<td>%</td>
<td>0.36</td>
<td>0.23</td>
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<td>15</td>
<td>Cataract Surgery Rate</td>
<td>Per lakh population</td>
<td>1162</td>
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* Source SRS Oct. 2008

The overall health indicators in Puducherry have been very encouraging compared to the national indicators. The U.T. of Puducherry has been able to
achieve the Infant Mortality rate of 28 against national goal of 45 during the tenth plan period. Since more than 99% deliveries are conducted in the health institutions, it has been able to achieve the lowest Maternal Mortality Rate of 36 against the national target of less than 100 / 1 lakh live births. Total Fertility Ratio of 1.6 is the lowest in India against national goal of 2.2. Due to the strict implementation of the The Pre-Natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act, 1994 (PNDT) in the UT and close monitoring of the sex ratio of children, it is possible to achieve SEX RATIO (0-5 years) of 977 (female to male children / 1000) which sufficed the goal set by the Government of India.

To improve the overall health of adolescent girls in the Union Territory of Puducherry, special school health programmes were initiated comprising of general health check-up, haemoglobin estimation and treatment of anemia, de-worming, nutrition, immunization, health promotion, raising awareness about sexual and reproductive health. The Union Territory of Puducherry has not only provided training to the teacher in health promotion but has also integrated the leprosy, blindness control & prevention programme activities in the School Health Programme. It is a comprehensive programme with long term future vision of promotion of positive health. The Union Territory of Puducherry is declared as Leprosy Free State. 100% Pulse Polio Immunization successfully achieved throughout the state. Medical assistance is extended for treatment of life threatening diseases to patients below poverty line category by the Puducherry Medical Relief Society for the past ten years.
In the treatment of tuberculosis, conversion rate more than 90% and a cure rate above 90% is achieved. To control the incidence of Filarial and Malarial diseases, Anti larval activities and surveillance activities are carried out. An ambitious project for providing health cards to all citizens in the UT of Puducherry has been launched in 2005 and more than 70% population has already been issued with cards.

Kidney transplantation is performed free of cost to the Below Poverty Line category patients. The Hospital has been equipped with latest medical equipments like CT Scan, MRI Scan, Cardiac Monitors, etc. A separate geriatric ward for senior citizens is available. Hospital Information System has been established through computerization and transmission of various investigation results to the wards. Post graduate courses (DNB) in 7 disciplines are offered. C.T Scan facilities have been established at Govt. General Hospital, Mahe. Telemedicine Centre for establishing contact with premier health institutions of the country and abroad is functioning. 25 numbers of Ambulances have been purchased and provided to all the PHCs for transportation of critical patients from rural areas. Monetary incentives are provided to the patients for promotion of Institutional Deliveries under JSY (Janani Suraksha Yojana). The pregnant women living below poverty line are assisted with Rs.700 in rural areas and Rs.600 in urban areas in case they deliver in a health institution. Separate 700 bedded hospital for Women & Children with specialized services provide health care to people in and around Puducherry. Government Medical College has been started to impart health education and provide health care for the public. A Health Insurance Scheme has
been commissioned in outlying regions of Mahe and Yanam, when by compensation, cash free Secondary and Territory care is made available.

**Concept of Chronic disease**

Chronic disease simply means persistent or recurring disease, usually affecting a person for three months or longer. A chronic disease is generally one that is hereditary or one that is the result of factors such as poor diet and living conditions, using tobacco or other harmful substances, or a sedentary lifestyle. Such a disease is not typically contracted from another person by contagion, because most chronic illnesses are not caused by infection. The term chronic disease commonly applies to conditions that can be treated but not necessarily cured.

**List of chronic diseases:**

**Different types of chronic diseases are there and the list is given below:**

Addison's disease, Asthma, Bipolar mood disorder, Bronchiectasis, Cardiac failure, Cardiomyopathy, Chronic obstructive pulmonary disorder, Chronic renal disease, Coronary artery disease, Crohn's disease, Diabetes mellitus types 1 & 2, Diabetes insipidus, Dysrhythmias, Epilepsy, Glaucoma, Haemophilia, Hyperlipidaemia, Hypertension, Hypothyroidism, Multiple sclerosis, Parkinson's disease, Rheumatoid arthritis, Schizophrenia, Systemic lupus erythematosus, Ulcerative colitis
Out of the above list, the highly prevalent chronic disease in the study area was identified and accordingly only people living with hypertension and diabetes mellitus were selected for the study because the number of people living with this condition is highly prevalent in the study area.

**Chronic Diseases can be Prevented and Controlled**

Every country, regardless of the level of its resources, has the potential to make significant improvements in chronic disease prevention and control, and to take steps towards achieving the global goal. Resources are necessary, but a large amount can be achieved for little cost, and the benefits far outweigh the costs. Leadership is essential, and will have far more impact than simply adding capital to already overloaded health systems.

Chronic diseases can be prevented and controlled says the WHO report. The rapid changes that threaten global health require a rapid response that must above all be forward-looking. The great epidemics of tomorrow are unlikely to resemble those that have previously swept the world, thanks to progress in infectious disease control but there has been a re-surgence of infectious disease see Daar and Singer et al 2002, 2007, etc... While the risk of outbreaks, such as a new influenza pandemic, will require constant vigilance, it is the “invisible” epidemics of heart disease, stroke, diabetes, cancer and other chronic diseases that for the foreseeable future will take the greatest toll in deaths and disability.
After carefully considering all the available evidence, WHO (2005) offers the health community a new global goal: to reduce death rates from all chronic diseases by 2% per year over and above existing trends during the next 10 years. This bold goal is thus in addition to the declines in age-specific death rates already projected for many chronic diseases, and would result in the prevention of 36 million chronic disease deaths by 2015, most of these being in low and middle income countries. Achievement of the global goal would also result in appreciable economic dividends for countries.

There is important work to be done in countries at all stages of development. In the poorest countries, many of which are experiencing upsurges in chronic disease risks, it is vital that supportive policies are in place to reduce risks and curb the epidemics before they take hold. In countries with established chronic disease problems, additional measures will be required, not only to prevent disease, but also to manage illness and disability.

*Chronic diseases are the major cause of death and disability worldwide.*

In India, chronic diseases account for 53 percent of all deaths. WHO projects that in the next 10 years in India, over 60 million people will die from a chronic disease. Cause of deaths out of infectious diseases, maternal and perinatal conditions, and nutritional deficiencies together will decrease by 15 percent. There will be increase by 18 percent of deaths out of chronic diseases, most distinctly; deaths from diabetes will increase by 35 percent. There will be a huge adverse
economic impact due to chronic diseases. India will lose 237 billion dollars over the next 10 years from premature deaths due to heart disease, stroke and diabetes.

By proper care, guidance and support we can bring down this number. At least 80 percent of premature heart disease, stroke, hypertension and type 2 diabetes, and 40 percent of cancer could be prevented through healthy diet, regular physical activity and avoidance of tobacco products. Cost effective interventions and awareness building among the people are most successful strategies to combat this problem. WHO estimates that an additional 2 percent annual reduction in national-level chronic disease death rates in India over the next 10 years would result in an economic gain of 15 billion dollars for the country (WHO 2005).

In view of the global and national situation and increasing number of deaths due to chronic diseases there is a need to conduct a detailed study from different aspects about the problems of people living with chronic diseases. In general, in our society there is common understanding that people don’t care for their health unless a critical situation arise. Even though, they have been diagnosed for chronic disease, majority doesn’t care much for their health and also do not follow the doctors advice. They feel comfortable with their regular diet and activities. There differences between urban and rural contexts, age, class or gender variables in the above claim.

The researcher intends to study the health behaviour of people living with chronic disease and the problems they face from sociological outlook. Although
there are various studies on chronic diseases conducted around the globe and this study is distinctive by concentrating only on problems of people living with diabetes and hypertension in Puducherry state with particular focus on Puducherry region from sociological perspective.

In this chapter the researcher has discussed about the background and development of the research, and introduction of context, which has had significant influence on implementation and objectives of his research. This introduced chronic disease as a vital area of contemporary research. It has also brought into picture the origin and development of medical sociology and its transformation as sociology of health and illness and then the development occurred in the study of chronic disease. The following chapter deals with the various studies pertaining to chronic diseases, and also tries to bring out current perspectives and debates on the Sociological Theory and Chronic Illness. The third chapter deals with the Research Methodology adopted in the study such as scope, objectives, hypothesis, research design, sampling techniques used, limitations of the study and difficulties encountered in the data collection.

The fourth chapter deals with the demographic and social life of chronic patients and with particular focus on socio-economic characteristics and the prevalence of the chronic disease in the study area. It also discusses in detail the economic status of the study population and its implication on the disease. The Fifth chapter deals with problems due to chronic diseases of the study population and elaborates upon the duration of the disease coping up with the disease and control over the disease. Later on, it examines the difficulties faced by the diseased. The
sixth chapter deals with patterns of treatment for chronic diseases, diet and exercise, quality of treatment, and overall satisfaction towards health. It also exposes the hypothesis testing and in details discusses about the case studies. The seventh chapter deals with the findings, summary of the thesis, the researcher’s conclusions and suggestions.