# Neuroepidemiology:
# Difficulties and Future Perspectives

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Master Degree in Neuropsychiatry

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# *Introduction*

Epidemiology is the study of distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems. It has evolved rapidly during the past three decades and entered an important phase in its evolution by identifying the risk factors of chronic diseases and evaluating treatment modalities and health services. It has provided new opportunities for prevention, treatment, planning and improving the effectiveness and efficiency of health services *(Torner and Wallace, ١٩٩٣; Park, ٢٠٠٠).*

Although the general field of epidemiology has advanced alot, the progress in neuro-epidemiology has been slow in the past ٣٠ years because of several methodological problems such as complex sampling techniques, nosological difficulties, problems in case identification and developing an acceptable case assessment instrument for large scale studies. In addition one of the most important difficulties met in epidemiological studies in neurological diseases is that epidemiologists are not familiar with neurological diseases

and neurologists are not familiar with epidemiological approaches *(Hernan and Logroscino, ٢٠٠٤).*

Some neurological disorders will be discussed from its neuroepidemiological aspect like MS, Dementia, motor neuron disease.

Multiple sclerosis (MS) is an inflammatory demyelinating disease in the nervous system and clinically it is characterized by multiplicity in time (relapse and remission) and space (multiple lesions in CNS). The prevalence of MS varies widely in different geographic locations from less than ١/١٠٠,٠٠٠ to more than ١٠٠/١٠٠,٠٠٠. Epidemiological studies of MS have been used to generate etiological hypotheses, to asses local needs for the provision of services and the allocation of resources, and to define the natural history of the disease. Epidemiological studies of MS face many difficulties such as being a chronic condition continuing over many decades which is variable, unpredictable, and subject to spontaneous improvement during the first ١٥ years in many patients. At the same time a number of diagnostic and descriptive scales for MS have been used by many clinicians that depends on subjective assessments of physical examination, does not assess handicap, provides no information on how the present state has risen, or what

is to be expected (*Compston, ٢٠٠١; Dhib-Jalbut, ٢٠٠٢; Dobkin, ٢٠٠٤).*

Dementia is a heterogeneous clinical syndrome characterized by a decline in memory and other cognitive functions. In addition to the decline in cognitive abilities, there are clear decrements in every day functioning such as activities of daily living and social activities. Epidemiological studies of dementia face many difficulties such as the absence of universal agreement on criteria for the dementia syndrome. Surveys of dementia are sometimes hampered by several factors including frequent supervening of substantial clinical illness and refusal or inability of demented patients to participate in surveys (*Rossor, ٢٠٠١; Jorm, ٢٠٠٥).*

Motor neuron disease (MND) is a progressive neurodegenerative disease resulting in progressive weakness of voluntary muscles throughout the body. It is a rare neurological condition with worldwide distribution; its incidence is ١،٨ per ١٠٠,٠٠٠. Motor neuron disease is very difficult to diagnose, to date there is no one test or procedure to ultimately establish the diagnosis of MND especially amyotrophic lateral sclerosis (which is the most common type of MND) *(Sorenson and Stalker, ٢٠٠٢).*

It is important for the caring professionals to assess the problems of their patients and clients in a systematic and up to date way. Otherwise, we would not be able to convince ourselves or our clients that changes have taken place and we may therefore continue to apply ineffective and wasteful treatments from this aspect arises the importance of epidemiology and facing its difficultie*s* *(Peck and Shapiro, ١٩٩٠).*

# *Aim of the Work*

١. Reviewing the methodology and basic principles of the epidemiology in neurological diseases.

٢. Highlighting the difficulties that meet us to study the epidemiology of neurological diseases.

٣. Reviewing the epidemiology and its difficulties of multiple sclerosis, dementia, and motor neuron diseases as examples of epidemiology of neurological diseases.

# *History of Epidemiology*

Neuroepidemiology is the branch of epidemiology that deals with disorders affecting the nervous system *(Nelson and McGuire, ٢٠٠٤)*.

Many definitions of epidemiology were prescribed starting with *Parkin in ١٨٧٣* who said that epidemiology is a branch of medical science which treats epidemics. *Frost in ١٩٢٧* said it the science of the mass phenomena of infectious diseases. *Greenwood in ١٩٣٤* said that epidemiology is the study of disease, any disease, as a mass phenomenon. *McMahon in ١٩٦٠* said that epidemiology is the study of distribution and determinants of disease frequency in man and finally *last in ١٩٨٨* said that epidemiology is the study of the distribution and determinants of health-related status or events in specified population, and the application of this study to the control of health problems *(Park, ٢٠٠٠)*.

The current interest of medical science in epidemiology has given rise to newer branches such as infectious disease epidemiology, chronic disease epidemiology, clinical epidemiology, serological

epidemiology, cancer epidemiology, occupational epidemiology, neuroepidemiology, genetic epidemiology, and so on *(Tanner and Ross, ٢٠٠٤)*.

Although the field of neuroepidemiology is young compared to other epidemiologic specialties such as cancer epidemiology and cardiovascular epidemiology, the number and quality of neuroepidemiological studies have rapidly increased in the last two decades *(Nelson and McGuire, ٢٠٠٤)*.

Many scientists plays important role in development and progression of neuroepidemiology like " the Father of Neuroepidemiology" *Dr. Kurland* (١٩٥٠-١٩٩٥) who believed that a rigorous evaluation of the occurrence of diseases, including where and how often they occur, among what populations and seasons, might yield more insight into the cause of the disease than examination of individual patients. He was actually the first person to be interested in the epidemiological aspects of neurological diseases. His studies on the epidemiological aspects of multiple sclerosis in the United State of America and Canada in the early ١٩٥٠'s are legendary *(Radharkrishnan, ٢٠٠٢)*.

# *Principles of Neuroepidemiology*

Neurological disorders are major contributors to death and disability. One in every nine individuals dies of a disorder of nervous system disorders that begins in early or midlife, such as seizure disorders, brain injury, repetitive trauma disorders, and multiple sclerosis. In addition these disorders are responsible for a considerable lifetime burden of chronic disability and lost productivity *(Tanner and Ross, ٢٠٠٤)*.

In addition, the disorders of nervous system causing highest rate of death and disability are preventable and treatable so, these push the health care planners and the neurological community to set appropriate priorities in the neuroepidemiological research aiming for prevention and management of these condition *(Silberberg and Bergen, ٢٠٠٢)*.

## Goals of neuroepidemiology

The most important goal of neuroepidemiology is to provide the basic information necessary for planning and implementing public health research in diseases of nervous system. In addition, neuroepidemiology is concerned with

various goals, as; (a) detection of natural history of diseases which is the course of disease and its outcome unaffected by treatment, (b) monitoring of the time trend of disease occurrence, (c) description of the health status of population, (d) evaluation of the effectiveness of intervention, standardization and quality control of investigation methods and (f) prevention of disease occurrence. *Primary prevention* that involves halting any occurrence of a disease or a disorder before it happens, *Secondary prevention,* aimed at health screening and detection activities used to discover pathogenic states in individuals within a population **and** *Tertiary prevention*, that aims to retard or block the progression of a disability, condition, or disorder in order to keep it from becoming advanced and in need of excessive care and rehabilitation, *(Timmer, ٢٠٠٢).*

## Steps of epidemiological research

Many epidemiological and clinical studies in neurology are of poor methodological quality because of lack of background knowledge in clinical methods of neuroepidemiology and study designs. Many steps should be followed to obtain trustable results. First, develop research question to address etiology, diagnosis, prognosis, or treatment. Second, choose optimal study design to

address the research question. Third, define source population in which to conduct study. Fourth, decide on sample method for selecting subjects for source population. Fifth, statistical work as regard collects data regarding health predictors or risk factors for neurological condition, data presentation and data analysis. Finally, determine outcome measures *(Feigin et al., ٢٠٠٤).*

## The research questions

The first step in any research study is to clearly articulate the research question. A clear statement of the study aims and the specific hypotheses to be addressed will guide selection of the study design, the outcome measures, the population, and the analysis plan *(Hustey, ٢٠٠٥)*.

There are Common epidemiologic questions like, (a) how many cases of the disease are there in a population, (b) what are the demographic features of the disease, (c) what is the natural history of the disease, (d) what factors determine a good or poor prognosis of the disease, (e) what are the determinants of the disease both genetic and environmental, (f) what are the economic characteristics of the disease, (g) what are the best treatments for the disease and (h) how can the disease be prevented. These broad

questions typically are addressed by answering a logical series of more focused questions, ideally refined through a dialogue of clinicians, epidemiologists and basic scientists. The research question may address a novel hypothesis, provide better quality data to address an existing hypothesis, or reformulate an existing hypothesis to gain a better understanding of the underlying mechanism. Often, iteration of the question among epidemiologists, clinicians, and basic researchers results in heightened understanding of the disease and a more focused direction of the inquiry *(Tanner and Ross, ٢٠٠٤)*.

## The study design

The design of a study is dictated by the research question(s) posed by the investigator(s). The goal is to design a study that will provide a valid answer to each of the research questions, and this often begins with deciding what the optimal study would be, disregarding cost, feasibility, and ethical concerns. Choosing the type of study depends on what are the research question or objectives, time available for study, resources for the study, is it common or rare disease, and quality of data from various sources. Often there are multiple approaches which will all work together for choosing well established design *(Feigin et al., ٢٠٠٤)*.