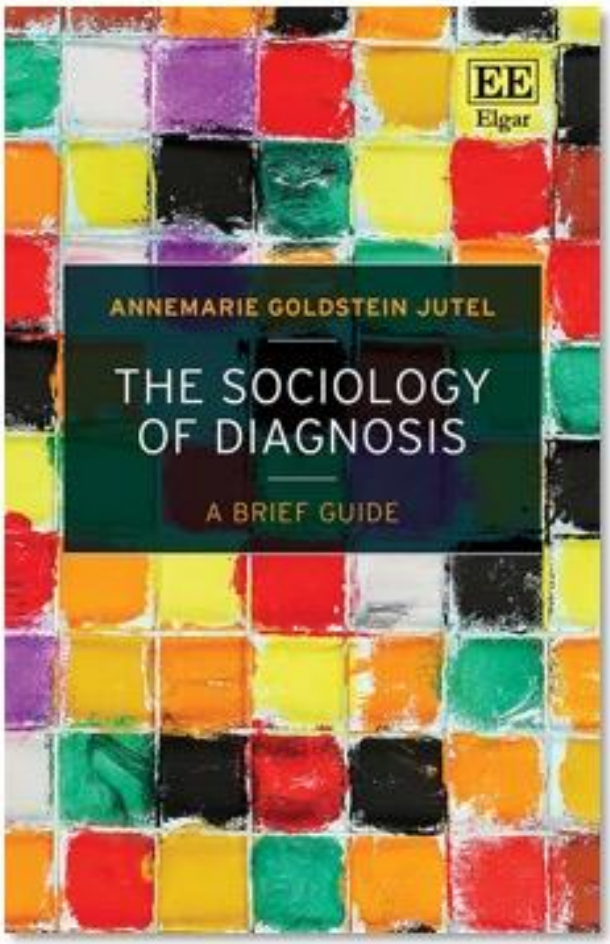
dear residents

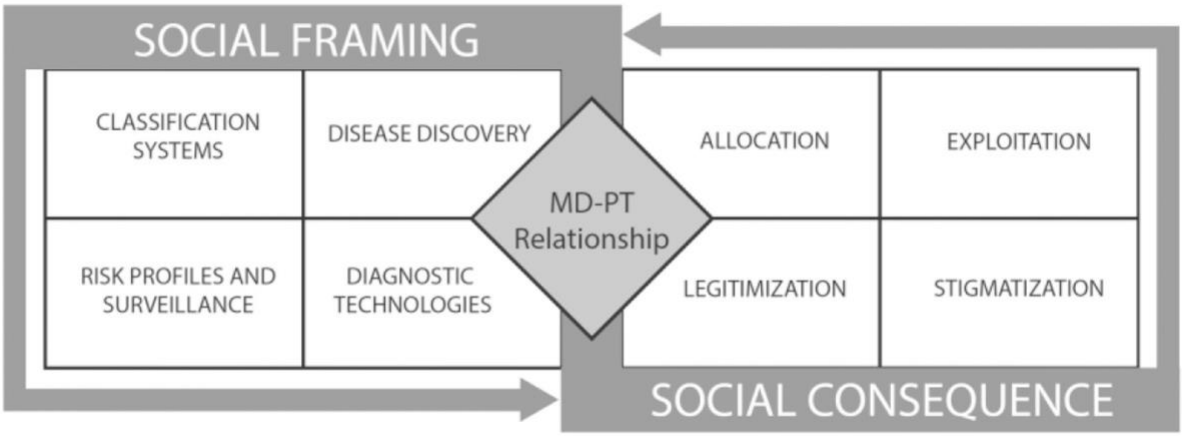
The Sociology of Diagnosis **September 15, 2024**

Dear Residents,

I recently read a book about **The Sociology of Diagnosis** by Annemarie Jutel. She illuminates diagnosis as both a category and a process and explains that “illness is a fact of nature, but the categories within which illnesses are placed are human creations, and are themselves the product of consensus, power, inequity and prejudice.”



She proposes a social model of diagnosis as illustrated below:



For physicians, the diagnostic process lies at the heart of medicine, and we expend much of our training in developing the skill of diagnostic reasoning. This should not surprise anyone because diagnosis is what "determines treatment and prognosis, allocates resources, differentiates lay from professional, and provides a hierarchy of authority within the professions." Diagnosis carefully guards what counts as disease. Diagnosis is more than a clinical entity because it pervades the social culture.

I want to take you back to 1987 when I was a house officer in Medical Unit II in Civil Hospital Karachi. Our 50-bed ward was typically filled with admissions from the ED (we called it "casualty" because most ED visits were related to accidents), but once a week we walked across the street to the OPD (outpatient department), where we faced a sea of people seeking care for all sorts of ailments. In retrospect, I don't think we were doing much ambulatory care – a salve here and an antibiotic there – we were mostly engaged in "admission hunting." We were looking for patients that needed an admission for diagnostic work up. Often these were individuals with weight loss, jaundice, rheumatic heart disease, protracted fevers, etc. As we screened scores of patients, we also treated scabies, asthma, UTI's, UTRI's and other everyday ailments along the way. I recall a very memorable patient. He described his illness as follows: "a gas ball starts in my knee as I walk to work, by lunch time, the gas ball migrates to my stomach, and by bedtime it's in my head." With animated gestures he traced the path of this "gas ball" as it travelled from his knee to his head by way of his abdomen. My version of his illness was osteoarthritis of the knee, dyspepsia, and tension headache. I prescribed him Carminex (Pakistan's version of Maalox) and Paracetamol (acetaminophen). For those of you who know Urdu or Hindi – the phrase he used was "gas ka gola."

When a patient tells us their story (the history of the present illness), and as we gather additional information, we develop our version of their story (the assessment). The patient then goes through "narrative surrender" giving away their story and accepting our narrative. Foucalt refers to this as "silencing the patient." I dismissed the "gas ball" theory and replaced it with my own explanation.

As physicians, we have extensive social agency, because we alone guard diagnostic labels, and in doing so enable access to the "sick role" as described by Talcott Parsons. "Diagnosis differentiates between sick and malingering, between badness and sickness." When we confer a diagnosis, we add credibility to suffering, absolve those who are sick of their many responsibilities, and pave the way for hope through treatment. Our authority is such that we can "swap sadness for depression, distractibility for ADD, and shyness for social anxiety disorder."

When I chose rheumatology as a specialty, I was fully aware that it involved a range of diseases where there was diagnostic ambiguity. I also recognized the historical misnaming of systemic autoimmune conditions like lupus and myositis as "connective tissue diseases." Rheumatology is also sprinkled with diseases that are primarily "soft tissue" in

nature like tendinitis and bursitis. Because many rheumatic diseases present with or can involve the joints, I also became a bone and joint doctor. There is considerable diagnostic uncertainty in rheumatology. Both patient and physician narratives are often superseded by tests and imaging – some help but some don't. When diagnostic uncertainty cannot be solved with testing or imaging, we use terms like "medically unexplained symptoms." Jutel writes that "what makes this a sociologically interesting proposal is that by calling the absence of diagnosis 'uncertainty' it is discursively placing the non-diagnosis into a cognitive space." She goes on to clarify that "uncertainty is the lack of confidence in available knowledge – it is not the same as not having a diagnosis."

Our power to make/withhold diagnoses is not unchecked - because diagnostic related groups (DRGs) are connected to quality metrics and reimbursement, we find ourselves constantly grading malnutrition, immune status, obesity, and types of heart failure. We need to decide if bed sores were present on admission or developed subsequently, we adjudicate VAP, CAUTI and CLABSI. This is where diagnosis intersects with the business of medicine. Jutel also brings attention to "pre diagnosis" or what she refers to as the "surveillance culture" which forms the basis of screening, creating "pre-patients." Sometimes diagnoses and "pre-diagnoses" are promoted by pharma through disease awareness seminars for physicians and by direct-to-consumer marketing. Novo Nordisk (the Danish company that makes and sells Ozempic and Wegovy) has a net worth greater than the GDP of Denmark. Jutel ends with a case study of Alzheimer's disease, explaining the encircling of senile dementia within the original concept of Alzheimer's disease which was restricted to a diagnosis of presenile dementia. This has had profound social implications.

Ours is still a noble profession – we entered it for altruistic reasons and accepted the sacrifice of many years of training. It is an exciting and constantly evolving profession. Our focus should not be limited to just the science of medicine, because we wield considerable influence over society. The authority to make a diagnosis separates us from other health professionals (with some exceptions) and it is the basis of the doctor-patient relationship. Understanding our power and place in society and the influence we have on patients and society needs to be managed with care and humility.

Wishing you an amazing week,

Dino Kazi