THE SICK ROLE
Sociology of Illness and Disease

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The defining characteristics and behaviors of how an individual is expected to act during periods of sickness has changed over the years. Initially the role was passive, expected little from the patient in terms of participation in managing and deciding on treatment, and suggested a rigid set of obligations and rights. Later, the characteristics and behaviors expanded to include rights and obligations that better reflected the changing cultural and societal norms. Both definitions contributed to the academic and societal understanding of what it means to act the sick role, while simultaneously exposing the limitations associated with each definition.

The concept of the ‘sick role’ was first introduced in 1951 by Talcott Parsons. In Parsons’ definition, the sick person had two rights and two duties to fulfill. The first duty was to recognize that sickness creates dysfunction in the life of the affected. This lead to the second duty of seeking technically competent assistance to cope with their sickness, whereby it was assumed the advice would be followed. The fulfillment of these two obligations guaranteed the sick person the rights of being exempt from normal obligations and from normal blame (Rier, February 2014). This definition captured the culturally and socially accepted patient behavior during the 1950s. Despite the obligations and rights’ seemingly innocent implications, the definition presents a number of limitations.

To begin, this definition applies almost exclusively to the role of patients suffering from acute diseases. As a result, one of the limitations is that the rights and obligations do not apply to patients with chronic illnesses, such as diabetes, heart disease, epilepsy and others. While patients with chronic illnesses are expected to seek medical help and to comply with recommendations, they are also encouraged to learn how to continue with their activities of daily life independently. This is a rejection and deviation of the first obligation of accepting the dysfunction caused by their illness. Furthermore, if a patient with chronic illness exercises the rights prescribed to them under
the Parsonian sick role for an extended period of time, then the individual contributes less to the functionality of both their personal life and society at large. This concept is the antithesis of Parsons’ perception of structural functionalism, which states that society has an interest in defining deviant behavior and the role of sickness (Rier, February 2014). For similar reasons, this model is limited because it doesn’t fit the role of patients suffering from mental illness. Other limitations include the inherent conflict between the patient’s sick role and stigmatized diseases. In cases of adult onset diabetes, HIV/AIDS, cirrhosis of the liver caused by chronic alcohol consumption, and others, the healthy population may place blame on the patient for their disease on personal behavior. Consequently, this attitude would delegitimize the rights they are offered under the Parsonian definition and undermine or undervalue the individuals acting the sick role because of stigmatized diseases.

Additionally, the Parsonian definition of the sick role assumes that people living with ailments accept their status as being sick or their willingness to act the prescribed role. However, that is not always the case. For example, deafness is considered by many to be a physical limitation. However, as described in The Disabilities Studies Reader (1995), those in the deaf community often ascribe to be considered members of a linguistic minority rather than members of a disabled group (Lane, 1995). They argue that deafness is a culture with its own historical figures, customs, and cultural relevancies, and not the ailment society constructs it to be. Consequently, they do not consider themselves living with a dysfunctional attribute, and refuse to participate in the Parsonian sick role. Additionally, the Parsonian sick role is limited because it offers a substitute status for people currently occupying undesirable roles in society. For example, during the late 1960s and early 1970s in the New York metropolitan area, a sample population of single mothers on welfare was interviewed. It was found that that women who had given up hope that they would ever cease
to be on welfare were significantly more likely to identify as perceiving themselves as sick compared to women who still retained hope they would eventually get off welfare (Cole, 1972). This finding suggests that in an effort to justify personal failure, the individual who has lost hope projects the blame for their circumstance onto a perceived illness, thereby allowing them to exercise the rights of being exempt from normal obligations and blame.

The problem of acting the sick role according to Parsons is further limited when considering the current phenomenon of medicalization of conditions that historically have not been considered diseases. For example, obesity in the United States and much of the developed world has been termed an ‘epidemic’ (Oliver, 2006). The semantic use of this term indicates that society has medicalized the condition because it suggests that those deemed obese require normalization or cure to the socially acceptable standard (Conrad, 2004). Consequently, if all people currently living with medicalized conditions, like obesity, start acting the Parsonian sick role, then the condition could be used as an excuse for not fulfilling the roles they are expected and capable of fulfilling.

When Parsons first described the sick role in the 1950s, American medical culture was conservative and the paternalistic nature of the patient-physician relationship was accepted as dogma. However, the cultural revolution of the 1960s and 1970s ushered in a sentiment of empowerment, anti-establishment, and anti-paternalism. Therefore, the combination of these factors and the greater understanding of modern diseases led to a situation where his role was no longer valid and a new sick role was needed. However, the great contribution of Talcott Parsons was that he started a dialogue in academia and in a social context about the role sick people should act in society.
As American culture changed and patients became more empowered, the participatory nature of the patient in the sick role changed. Norman Cousins, one of the first to write about the patient’s ability to take charge of his or her own health, published a book exploring the effects of humor, placebo effects, and the chemistry of the ‘will to live’ on the outcome of the patient (Rier, February 2014). This book described the changing phenomenon that was occurring in the context of America’s view on what it meant to be sick and how the anti-establishment movements of the 1960s regarding other socio-political issues trickled into the collective thought of the patients contributed to this transformation. As a result, the post-Parsonian sick role emphasizes patient autonomy, the right to information, patient participation in the clinical decision making process, and taking control of one’s health beyond the realm of the medical establishment. Furthermore, it integrates the availability of information in today’s society into the role of the patient, which creates the idea of an ‘expert patient.’ The combination of these attributes constitute a sick role that rejects the paternalism associated with the Parsonian model and emphasizes a more liberal idea of autonomy and disclosure (Rier, March 2014).

The post-Parsonian sick role yielded a number of benefits to people acting the sick role. As noted by Norman Cousins, personal perception and participation in treatment, one of the underlying concepts of the post-Parsonian sick role, can improve patient outcome. However, there is an inherent limitation with this notion because not all populations have equal self-confidence. Contrast, for example, those who have experienced the privileges of the middle and upper classes, such as access to education, capital, power, and social status, versus those who have not. The population that has not experienced minor successes in their daily lives will be less likely to have the self-confidence to achieve health successes (Rier, March 2014).
One component of the post-Parsonian sick role is for the patient to become educated about his or her disease. With vast amounts of information freely available on the web, it is easy for an individual to become an “expert patient.” However, this phenomenon also represents a limitation of the post-Parsonian sick role. When a patient consumes too much information without having the qualifications of knowing how to apply the information, it creates tension and confusion for the patient. An example of this was published in a study of five breast cancer patients choosing between treatment options in an Ontario hospital. The study found that the perception of the physician-patient relationship varied among the women from conservative to liberal, but all were capable and willing to become knowledgeable and engage with the physician when discussing treatment options. However, as Sinding (2010) discussed, this led to a situation where patients would accept, deflect, reframe or negotiate the terms of treatment with their physician. A concern of this finding is that the scenario allows for patients to decide on a treatment that does not align with evidence-based-medicine. This study represents a distinctly post-Parsonian sick role dilemma as it rejects the paternalistic approach to deciding on treatment options. Furthermore, the study also indicated that within the framework of a patient acting the post-Parsonian sick role, they could choose to regress to the Parsonian sick role. For example, one study participant indicated that her goals dictated the way she discussed treatment options. In a scenario where she wants to be cured, she would heed the physician’s recommendations, whereas in a palliative care scenario, she would base treatment options on her personal experiences and wishes (Sinding, 2010).

The expanded knowledge and self-efficacy of the patient when he or she is acting the post-Parsonian sick role introduces another potential limitation. The ideal post-Parsonian sick role patient will possess a belief that, according to Rotter’s Locus of Control spectrum, control of their health is internal (Rier, March 2014). However, some patients will believe that control of their
health and behavior comes from external loci, which could lead to a projection of blame and responsibility onto other entities. This follows along the debate trajectory of those who claim health is a byproduct of life choices versus those who claim that health is a byproduct of life chances (Pietilä, 2008). If a patient lacks the self-efficacy required by the post-Parsonian role, then they can start to blame SES, education, or other external factors (life chances) for their ills.

Beyond the role the patient acts in the context of the traditional patient-physician relationship, the post-Parsonian sick role encourages patients to participate in embodied health movements (EHMs). Participation in EHMs by patients demonstrates that they not ‘sick’ all the time, and are capable of contributing valuable firsthand knowledge about the disease to the public dialogue (Brown, 2004). This participation allows them to become policy partners in shaping the public discussion of health concerns, and further expands their role beyond what was expected in Parsons’ era.

In summary, the major difference between the Parsonian and post-Parsonian sick roles is the level of passivity or activity the patient exhibits during the process of his or her sickness. The passivity of the Parsonian role is limited by the inherent paternalism. Furthermore, the role is not generalizable to modern diseases, such as chronic diseases and mental illness. On the other hand, the post-Parsonian role is more active on the part of the patient because it encourages the patient to acquire knowledge about their disease, participate in treatment discourse, and internalize their control of personal health and treatment. This role is limited by the fact that some patients do not yet possess the efficacy expected. However, as the years go on, and more patients gain the efficacy required to fulfill the post-Parsonian sick role, patients will become a bigger partner in all aspects of the patient-physician dialogue. As a result, this role implies that society will have a better informed patient population willing to contribute to defining the social construct of being sick.
References