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TRANSLATIONAL SOCIAL SCIENCE:

The importance of stigma theory for clinical decisions related to diabetic foot amputations

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ABSTRACT The authors examine the unconsidered impact of social stigma theory on the shared clinical decision-making process for a patient with foot osteomyelitis and MRSA bacteremia facing the prospect of an amputation.

Keywords: *social stigma, amputation, diabetes, diabetics, foot ulcers*

Clinical-Social Context

Tom Williams (pseudonym) is a 57 year old male with a past medical history significant for end stage renal disease on hemodialysis, type 2 diabetes mellitus, and history of diabetic foot ulcer status post amputation of multiple toes who presented to the emergency department for a right foot injury. Upon presentation, there is a 4 cm puncture wound draining a serosanguinous fluid with surrounding erythema on the plantar surface of the right foot. Following a thorough workup, Mr. Williams is found to have right foot osteomyelitis and MRSA bacteremia. Of note, he was recently seen and treated in the hospital for a similar episode. Two attending physicians discussed the case and both understood that amputation was the inevitable and only long term clinical management that was appropriate.¹

Over the next three days, every visit to the bedside resulted in a negotiation about discharge so the patient could attend his son's graduation. This involved multiple rescheduling attempts of the dialysis, frustration and difficulties arranging outpatient antibiotics, and many other discussions that all resulted in avoiding discussion of definitive treatment of amputation. This may have been a result of the patient's own words, "I would rather live one year on antibiotics with my foot than three more years without it." Notably, Mr. Williams chose this same antibiotic treatment option during his last hospital stay earlier in the month. Even more significantly, this patient has since been re-admitted an additional two times for sepsis and cellulitis, foregoing lifesaving treatment, choosing antibiotic management each time.

This same pattern of social interaction has been noted previously in *Clinical Research in Practice: The Journal of Team Hippocrates*. David Adams [pseudonym] hid his diabetic foot ulcer from his only remaining relative—his father—for two years.² He "believed that he would constantly receive strange 'looks' wherever he goes. He feared that others will believe he is not capable of completing simple tasks. And soon that fear consumed him." In terms

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of stigma theory, this is called information management. When you can hide the stigmatizing attribute, patients spend time and energy to prevent disclosure, fearing the reaction of others. For Mr. Williams, these fears also provoked a long inpatient negotiation related to limb salvage with long term antibiotic therapy.²

Christopher Hopper also reported a clinical decision based on a patient desperate to avoid amputation with long term antibiotics.³ Because of the limitations of study design and potential publication bias, amputation may only be delayed instead of prevented. Careful critical appraisal—the lack of ability to randomize amputation—should be considered when appraising clinical research design.⁴ Additionally, stigma should be quantified with validated scale measures when appropriate.⁵

Upon further discussion, we realized that this situation occurs every month on the inpatient medicine service, which made us ask ourselves if there might be some underlying social process that repeatedly prompts these types of treatment decision negotiations that can be frustrating and terrifying. Although the discussions of the best management of Mr. Williams’s osteomyelitis seem endless, our attending physician mused that these discussions might be merely rationalizations and an underlying social process may be affecting our clinical decision making. Although we subscribe to the ideal of shared decision making, being unaware of social processes would prevent us from achieving this ideal with this patient.

Statement of Social Science Concept Illustrated in the Clinical Social Context

How does social stigma affect clinical decisions related to diabetic foot amputation?

Illustration of Translational Social Science Concept

Unfortunately, the word *stigma* has a common English definition, but in this article, we attempt to discuss stigma as a social theory that impacts relationships between individuals. The doctor-patient relationship is also affected by this universal social process. The classic definition of social stigma is attributed to Erving Goffman⁶ and the shorthand definition is *spoiled identity*. Attributes, behaviors, or reputations which are socially discrediting cause an individual to be mentally classified by others in an undesirable way that falls short of the cultural ideal. Goffman categorizes stigma associated with three domains:

1. “Abominations of the body—the various physical deformities” [amputation, facial disfigurement, etc.] (p. 4)⁶
2. “Character perceived as weak will...” [mental illness, addiction, imprisonment, etc.] (p. 4)⁶
3. “Tribal” [race, religion, etc.] (p. 4)⁶

Others have elaborated on this concept.⁷

Goffman gives the following example, quoted from Katharine Butler Hathaway’s memoir *The Little Locksmith*. Hathaway, following a long childhood treatment for spinal tuberculosis, finds that she has failed to avoid developing a hunchback:

“When I got up at last...and had learned to walk again, one day I... went to a long mirror to look at myself, and I went alone. I didn’t want anyone... to know how I felt when I saw myself for the first time. But there was no noise, no outcry; I didn’t scream with rage when I saw myself. I just felt numb. That person in the mirror *couldn’t* be me. I felt inside like a healthy, ordinary, lucky person—oh, not like the one in the mirror! ...when I did not cry or make any sound, it became impossible that I should speak of it to anyone, and the confusion and the panic of my discovery were locked inside me then and there, to be faced alone, for a very long time to come.” (p. 8)⁶

As our team reflected on Mr. Williams’s comments about forgoing two years of life, we wondered if he imagined or was experiencing a similar unspoken, unacknowledged fear. Our decision making was about biomedical outcomes, but the unacknowledged trauma was the social devaluation associated with limb loss. Using Erving Goffman’s theory of stigma, we were forced to ask ourselves: what is Mr. Williams’s identity? How does amputation of a body part spoil that identity? How would his

family members at the graduation party treat him differently knowing a limb amputation was imminent? Is Mr. Williams's fear of losing his current identity hindering him from realizing what his new identity could be? Stigma is real, but not often consciously acknowledged when making clinical decisions. Until our patient is afflicted with a visible disability, he can avoid dealing with these perplexing social interactions (a form of information management, mentioned above.). How we imagine others to perceive us and how we see ourselves plays a huge role in our decision making. Having a limb removed can cause a crisis of identity, so the question remains: how can we help patients better cope and adapt to a new identity, post amputation?

In a comparative study by Senra et al., different experiences of limb amputations were explored.⁸ They postulated that the changes in self-identity experienced by these patients occurred in 3 phases: self-awareness, changes beyond body image, and embodiment of a new self. Some patients mourned the loss of their independence and were afraid of becoming a hindrance. This paper, however, offers a perspective of social interactions *after* the amputation. This is a good example of being wise as described by Goffman.

New Knowledge Related to Clinical Decision Science

Goffman guides us when doctors interact with otherwise stigmatized patients. He notes that non-stigmatized persons can become wise:

“One type of wise person is he whose wiseness comes from working in an establishment which caters either to the wants of those with a particular stigma or to actions that society takes in regard to these persons. For example, nurses and physical therapists can be wise; they can come to know more about a given type of prosthetic equipment than the patient who must learn to use it so as to minimize his disfigurement.” (p. 29)⁶

Social stigma surrounding amputations is real. It changes the quality of interactions not only between the patient and their physician but also within a team of physicians taking care of the patient. The decision to proceed with limb amputation in the face of life-threatening infection is both complex and complicated. In addition to the clinical research on biomedical outcomes, doctors need to recognize there are also other social processes that make these decisions even more complex.

The elephant in the room when making clinical decisions about amputations is the implicit bias related to physical deformities that is created. Implicit bias is synonymous with culture as conceptualized by social scientists: the beliefs, values, and behaviors of a social group.

As a self-reflective exercise, we scored ourselves on the Implicit Association Test (IAT) for disability.⁹ As expected, three of the four members of our group showed a moderate to strong preference for able-bodied compared to disabled when assessing implicit bias. “Implicit” means that we are *not* consciously aware of how these cognitive preferences become manifest in behaviors and decisions. Knowing this truth about ourselves, what can we learn about our patients who are faced with making this self-altering decision? How do we better help our patients grieve the loss of a prior identity and how can we be there with them to better the transition to a newly chosen identity?

Doctors who demonstrate acceptance of the impact of the trauma of amputation, understand the bereavement of a lost identity and are knowledgeable about creating a valued new and acceptable identity for patients facing the possibility of amputation are more likely to be able to facilitate optimal clinical decision making.

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Conflict Of Interest Statement

The author declares no conflicts of interest.

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