Published in final edited form as:

Med Humanit. 2018 June ; 44(2): 137–139. doi:10.1136/medhum-2017-011364.

At the intersection of self and not-self: finding the locus of ‘self’ in autoimmunity

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Abstract

Individuals with chronic autoimmune disease experience a sense of vulnerability. In part, this relates to the struggle for finding the meaning of the illness. The consequent existential distress may manifest in an unseated sense of personhood. Insight into the mechanism of this state of powerlessness and of perceived loss of agency is central to establishing a supportive clinician–patient relationship. This present exposition underscores the concept of autoimmunity as one that represents a demarcation in the psyche: one that is not just a threat to our sense of self-hood but also to our humanity. Autoimmunity exposes the challenge imposed on the relating of the self to one’s own self and hence is an ontological challenge. The breach of the boundary between self and *not-self* that is caused by the autoimmune process culminates in feelings of alienation.

Autoimmune diseases (sometimes called connective tissue diseases) refer to a collection of chronic illnesses wherein normal tissues are misidentified by the endogenous immune system as ‘foreign’. In these conditions, organ damage may occur as a consequence of the body ‘attacking itself’. Famous examples of autoimmune diseases include rheumatoid arthritis, systemic lupus erythematosus and type I diabetes mellitus. Because there is no cure for these types of diseases, chronic pain and debility may ensue. Independent functioning may be threatened. This essay analyses an underappreciated aspect to the psychological despair that may accompany the lived experience of autoimmunity. It is not a prescription for practice but rather an exploration of the tension that arises when healthcare providers struggle to define and validate the internal experience of disease.

Individuals with chronic autoimmune disease experience a sense of vulnerability. In part, this relates to the struggle for finding the meaning of the illness. The consequent existential distress may manifest in an unseated sense of personhood. Insight into the mechanism of this state of powerlessness and loss of agency, also termed ‘psychic dethronement’, is central to establishing a supportive clinician–patient relationship.

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Contributors JDK is the sole contributor.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

An article in a recent issue of a primary rheumatology journal elegantly illuminates the scientific understanding of auto-immunity.¹ Tracing the germination of the idea back thousands of years, the author endorses an intuitive, almost ancestral, knowledge that the dangers of the world exist both ‘without’ and ‘within’. Tellingly, the article is titled ‘Autoimmunity: The History of an Idea’ to highlight the advent of the concept as opposed to the illumination of the biochemistry. As pointed out by Dr Plotz, the scientific challenge is that ‘It is not an obvious idea at all. There were no readily observable natural phenomena that would suggest it’.

Dr Plotz has pointed the way to an important but obscure dialectic. The physician–patient encounter is a moment of drama. This is because it is an encounter with human suffering and therefore necessarily imbued with passion. The patient brings hope and the physician brings caring. Unfortunately, what is notable about medicalised caring is how frequently it is characterised by dispassion. Without the defences of distancing and denial, the interaction may be overwhelming for the healthcare provider and unsatisfying for the patient. Without a shared language of ‘dis-ease’, the experience is devoid of empathy. Dr Plotz’ exploration of the concept of autoimmunity is transformative towards rectifying this deficiency. His exposition highlights the fact that the concept of autoimmunity represents a demarcation in the psyche of humanity. ‘Horror autotoxicus’ transitions human psychology from an era of privilege (wherein one perceives the self not only as unique and self-contained but uncontaminated), to a modern ungrounded sense of self that acknowledges that we may be victims of our own undoing—toxic to ourselves.

Physicians confront this tension daily. For example, the now-common occurrence of organ transplantation is a challenge to an individual’s sense of wholeness. Depression and anxiety are common psychological responses to organ transplantation. The new organ may be perceived to harbour the identity of the donor causing the recipient to feel both psychologically and physically like a chimaera. Hence, the equally potent feelings of psychological distress resulting from transformation into a ‘hybrid being’, one that is composed of two entities inhabiting the same body may be overlooked. This is a situation of intrusion that undermines the notion of self and questions what it means to be a distinct and separate human. These questions concern the nature of the ‘self’ and how symptoms are interpreted in light of beliefs. In essence, they are questions about hopes and worries and about how disease changes one’s perspective. Put succinctly, the patient with autoimmunity faces an ontological challenge.² Factor into the equation the added stress of the life and death dilemma of potential organ rejection, and it is readily appreciated that the patient must make peace with such alienated feelings to accept the ‘stranger within’. Specifically, the patient must reconcile the ‘hostage status’ of one beholden to the survival of the transplanted organ.³ This tension escalates with the phenomenon of autoimmunity. In other words, ‘What happens when one’s very self *is* the ‘transplanted organ’? Simply put, what happens when autoimmunity alienates the self?’

Autoimmunity encompasses the challenge that the relating of the self to one’s own self imposes. In philosophical terms, the relating of ‘self to itself’ exposes a ‘subjectification’ of the self.⁴ In other words, exposing subjectification asks how society (culture) and history (learnt behaviour) impact self-consciousness. Exploring this relationship also has

implications for our sense of agency and power in the world. Finally, analysing the subjectification of the self provides insight into psychological defence mechanisms such as displacing fear onto pain or even the process of substituting pain for dread. Consider the case of a patient with a gradually disfiguring disease such as scleroderma who declares, 'If I look in the mirror, I don't see me. I am not me!' Here the fear of non-recognition is a metaphor for social isolation that in turn hides a subtext, namely, the loss of 'groundedness' in the world. A physician might respond, 'You have an autoimmune disease and that means your immune system is out of balance. It is as if your own immune system perceives that your tissues are themselves foreign invaders—akin to germs'. While this response is scientifically reductionistic in nature, it also introduces the term 'out of balance'. Consequently, it opens the door to discussing frightened feelings of alienation. In this manner, rheumatologists daily find themselves at the front lines wherein patients struggle with threats to self-identity.⁵

The meaning that a patient attributes to a disease state may cause somatic complications. Anticipatory anxiety and symptom amplification are examples of what oncology researchers term 'embodied suffering'.⁶ And although the patient's distress may derive from fear secondary to a sense of loss of control, this type of ontological suffering exceeds embodied suffering. The reason for this derives from the fact that the boundary between self and *not-self* is breached by the autoimmune process. In the non-autoimmune state, a normally functioning immune system is a reference point for positioning the self within the universe.⁷ For the individual with connective tissue disease, the dilemma posed by autoimmunity is a new ontological challenge. It represents the transformation of the individual self while the organism is still alive. A Jungian psychologist would say that the locus of agency has been ungrounded.⁸ This transformation is a metaphorical death of the individual self.

When a part of an individual (such as a kidney) dies, it is only natural to feel unwhole. The ensuing emotional jumble is often described in terms of frustration and anger. The perception is that of being victimised. This emerges as the over-riding emotion when the temporary restorative reserve once provided by nature is rudely reclaimed. When the body is damaged, wounds repair, cells regenerate and new blood vessels grow. If a fracture can re-knit, why cannot the alienated self rekindle? Escalated to a systemic process, the patient with autoimmune disease struggles to grasp why nature has the power to redeem with completion that which is unwhole, but still cannot integrate the alienated self.

To a psychoanalyst, the fear of being unwhole is a greater motivator than anxiety over personal death. Unwholeness is the antithesis of growth and expansion. It is symbolic of both existential aloneness and deterioration. Kierkegaard addressed this point. He emphasised the process of self-conscious relating of the physical self to the symbolic self.⁹ Specifically, the symbolic self resides at the penetralia of the physical self. It is the internal voice that encompasses agency and self-judgment while residing in existential isolation. In other words, Kierkegaard asserts that we anthropomorphise the self (here termed the symbolic self) and attribute to it the singular capabilities of thinking, emotional response, reasoning and choice. Moreover, we attribute to this entity the capability to reflect on all of these mental activities, that is, to self-reflect.

Since the symbolic self has no substance, this is the closest we come to non-decay. Perhaps we cherish this symbolic self because it encompasses the delusion of immortality. Autoimmunity is a powerful example of our impotence against entropy. It represents an intrusion into our private repression. Put another way, Kierkegaard's definition of self as that which relates to itself is in truth an identification of the process of self-consciousness. In short, self-reflecting is self-revealing.

Although it seems cliché for the patient to ask the doctor, 'Who am I?', it is nonetheless evident that the patient with autoimmunity can no longer rely on a privileged sense of the self as being unique and separate from a hostile world. In other words, autoimmunity dismantles a lifetime of maturing individuation and asserts in no uncertain terms that '*you* do not *belong*'. This may have profound implications for the suffering patient in terms of love, self worth and inclusion in society. It is not uncommon for the individual with chronic disease to struggle with psychological factors such as mental defeat, catastrophising, hopelessness, a perceived sense of burdensomeness and, ultimately, thwarted belongingness. Indeed, thwarted belongingness is a risk factor for suicidal ideation.¹⁰ Given that empathy is the only available pathway forward in this aspect of the therapeutic interaction, the question at hand is now reframed thus: How can a physician initiate a healing relationship with a patient who no longer identifies with the person of the patient?

To answer this, it is necessary to struggle with semantics. We have seen that the meaning of the word 'self', itself, vacillates between the psychic and the physical. The term denotes both personhood and process. For example, a transplant patient may mourn the loss of a rejected kidney.¹¹ In this case, grief and loss can be attributed to an event (organ failure) rather than a process (individuation failure). But when it comes to mourning the rejected self, how should the health-care provider respond? What should be said to assuage the patient with systemic lupus erythematosus? 'You are you, but you are not you'. Will a disembodied perspective be appeasing? 'You may look in the mirror and see a stranger but your soul is unaltered'. Perhaps it is best to help the patient embrace a new self, one that is strange, uncomfortable and threatening.¹² In the final analysis, this dilemma does not appear to be a philosophically existential problem where choice and personal responsibility predominate. Instead, it is a crisis derived from a lack of wholeness in which the individual is metamorphosed into an alien.¹³ Put succinctly, medicine lacks the language for the 'first person' of *autoimmune* illness.¹⁴ Of course, finding this language is important because, as Milstein writes, 'Addressing the human experience may help restore a sense of control and meaning.'¹⁵ Ultimately, this despair is fuelled by the desire to discover a new 'ontological literacy'.¹⁶¹⁷

The *Lingua Medica* is the hybrid language of medicine that encompasses more than just biopsychosocial terminology. It is both a bid for alignment of thinking among healthcare providers and a bid for the alignment of shared objectives between the healthcare provider and the patient. At its semantic core is the task of relating science to emotion. Relating the science of immune system aberration to the lived experience of disease is not unlike the arena of palliative care medicine where physicians are expected to relieve suffering while aiding the patient in the journey towards achieving 'existential maturity'.¹⁸¹⁹ It involves the process of getting to know the person of the patient. In short, it is contextualised medicine

(so-called ‘medicine of the person’). This necessitates attention by the health care provider to feelings of fear and ambivalence towards the state of chronic disease. The contrast to this type of empathy is scientific medicine (so-called ‘medicine of the disease’). This may be defined as medicine that is absent the therapeutic component of healing through relationship.

Medicine of the person recognises that illness may be perceived as a threat. It is a threat that may undermine hope and that may force confrontation with mortal fears. For example, the oft repeated statement by patients with arthritis: ‘Now I know what it feels like to get old’, reflects more than fear and ambivalence. It reflects anxiety due to distrust (‘my body has let me down’), anger (‘I am not what I used to be’) and sadness (‘I have lost hope’). Succinctly put, admitting to basic human frailty unseats the psychological myth of personal heroism. In other words, confronting dread is at the interface between ‘medicine of the person’ and ‘medicine of the disease’.²⁰²¹ Specifically, dread is the consequence of the transformation from self to alien that accompanies autoimmunity. In this context, it is not a natural developmental stage of personhood. Moreover, it exposes the linguistic weakness that derives from the fact that what we define as self is neither static nor universal.²² In the current state of *lingua medica*, perhaps it is time to move beyond the language of ‘existential maturity’ to a language wherein scientific alienation of the self may be better reconciled with a disrupted psychological locus of the self.

Models of the healing relationship emphasise trust and clinical knowledge as key to a successful clinician–patient encounter. To achieve peace of mind in the setting of autoimmunity is to confront painful feelings of alienation.²³²⁴ In short, whereas medicine embraces the tension born of existence (suffering), rheumatology must embrace the tension born of essence (loss of self). What we need, therefore, is a new language of the medically disembodied self; a new poststructuralist framework that reveals by virtue of the non-conceptual interplay between presence and absence.²⁵ The autoimmune patient vacillates between a sense of self and not-self. The symptom (loss of self) becomes a metaphor (unwholeness). And the metaphor is displaced onto a sense of dread (deterioration).

Since the meaning of the word ‘self’, itself, vacillates between the psychic and the physical, this implies that the unstable self is based on an unstable language. This reflects the poststructuralist assertion that language is innately subject to metaphorical reinterpretation. Uncovering meaning in the setting of metaphorical reinterpretation is what enables us to face uncertainty and move through dread. Hopefully, finding personal meaning that is structured on the idea of the unstable self will, as Dr Plotz points out, have the power to ‘profoundly alter our exceptionalist, even narcissistic, isolation as a species’.

Acknowledgments

Acknowledgements The author thanks Dr Paul Plotz and Dr Adam Schiffenbauer for helpful comments on the manuscript.

Funding This study was supported in part by the Intramural Research Program of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institutes of Health.

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