REFLECTIONS

Autoimmunity: An in-sight narrative

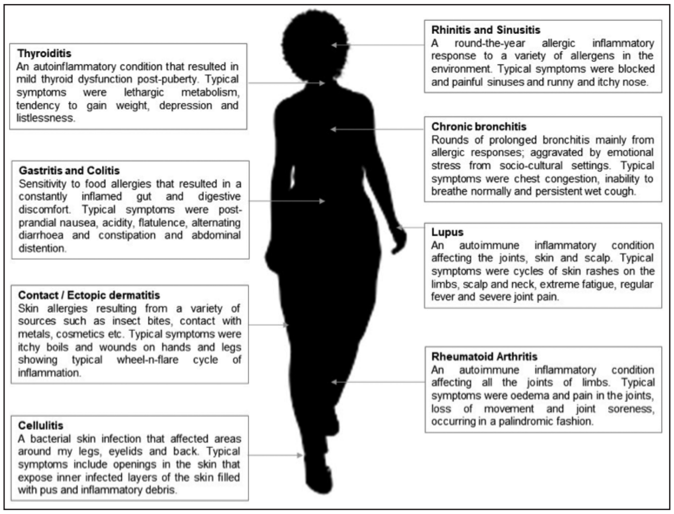
GIRIJA VENKATESH

Abstract

Autoimmune conditions can mirror dis-ease at many levels, each of which blurs the boundary between self and non-self. While medicine captures the inflammatory angle involving the immune system, this article presents perspectives on other players in this dis-ease—lifestyle, mental and emotional states and sociocultural settings—gathered from the author's own journey with autoimmunity.

The *itis* spectrum

Let us begin with my medical history. The first inflammatory symptoms appeared when I was a toddler. By the end of my teens, the entire spectrum was out in the open, recorded in big, fat case-files, hospital-wise and specialist-wise. To keep it simple, I have used an illustration to summarise my case files. (Figure 1)



Thyroiditis
An autoinflammatory condition that resulted in mild thyroid dysfunction post-puberty. Typical symptoms were lethargic metabolism, tendency to gain weight, depression and listlessness.

Gastritis and Colitis
Sensitivity to food allergies that resulted in a constantly inflamed gut and digestive discomfort. Typical symptoms were post-prandial nausea, acidity, flatulence, alternating diarrhoea and constipation and abdominal distention.

Contact / Ectopic dermatitis
Skin allergies resulting from a variety of sources such as insect bites, contact with metals, cosmetics etc. Typical symptoms were itchy boils and wounds on hands and legs showing typical wheel-n-flare cycle of inflammation.

Cellulitis
A bacterial skin infection that affected areas around my legs, eyelids and back. Typical symptoms include openings in the skin that expose inner infected layers of the skin filled with pus and inflammatory debris.

Rhinitis and Sinusitis
A round-the-year allergic inflammatory response to a variety of allergens in the environment. Typical symptoms were blocked and painful sinuses and runny and itchy nose.

Chronic bronchitis
Rounds of prolonged bronchitis mainly from allergic responses; aggravated by emotional stress from socio-cultural settings. Typical symptoms were chest congestion, inability to breathe normally and persistent wet cough.

Lupus
An autoimmune inflammatory condition affecting the joints, skin and scalp. Typical symptoms were cycles of skin rashes on the limbs, scalp and neck, extreme fatigue, regular fever and severe joint pain.

Rheumatoid Arthritis
An autoimmune inflammatory condition affecting all the joints of limbs. Typical symptoms were oedema and pain in the joints, loss of movement and joint soreness, occurring in a palindromic fashion.

Figure 1: The itis spectrum. (Image source: https://encrypted-tbn0.gstatic.com/images? q=tbn:ANd9GcQuvx8JTVtub8-S-rAYTglAeE8clev_Rz2K8K4C_RHHVR01pOd0w)

"Itis" is the suffix used in medical language to indicate an inflammatory condition. I choose to call my medical history the *itis* spectrum due to its inflammatory nature.

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Other diagnoses include vasovagal syncope, an acute *Helicobacter pylori* infection, Gilbert's syndrome and polycystic ovarian syndrome. Some conditions were visitors, others stayed, but all of them left their mark on my being. As I grew up into a teenager, my definition of freedom was a day spent without burning, itching and pain. That simple!

Dis-eased lifestyle

Even before I learnt to speak, I was battling irresistible urges to scratch the omnipresent boils and rashes on my skin. If I scratched, they bled. Being a child, I would watch the outcome; not sure why it was happening, but curious to know if it would happen every time, the itchy urge adding to my scientific experimentation! This initially annoyed and then, began to worry people around me. After much deliberation came the solution to this *behavioural* problem! Reprimanding and name-calling – the strategy of shaming. It worked. The name-calling stopped the digging (as onlookers perceived it: a little one ploughing her wounds needlessly). Only in public though. I quickly learnt to subdue the itch and burn as part of acceptable social behaviour and moved to doing it in private. The ensuing pain conditioned me to fear everything, escape all activities, avoid social gatherings and coil up within. Arthritis kept me away from games, exercises and outings with friends, and I was too ashamed to confess my pain. To compensate for the lack of acceptance I felt, I took to binging on sugar-laden processed food items like biscuits, sweets, Bournvita, etc. Fruits and vegetables were not palatable (as with any other kid). When reprimanded, I either threw a tantrum or increased this emotional binging. This was my way of getting back at "them", not realising then that I was feeding myself the raw materials for inflammatory mayhem.

Till I believed that the food I eat has no relation to the pain I suffer, I was under the grip of inflammations. When I began to carefully watch my plate is when I began to heal.

I do not recall any instance of medical counsel on processed food and inflammation during my prolonged search for anti-inflammatory solutions inside urban multi-specialty hospitals. The wisdom came from a gynaecologist, who was not in a hurry to prescribe tests or pills for my hormonal maladies, after the damage was done. To know about the strong correlation between diet, gut lining and inflammation was empowering. As I set out to experiment with diets came the next question – What is the correct diet for a person with chronic malnourishment and a genetic predisposition to allergies and inflammation? Ayurvedic texts gave insights. That system of medicine provides a compositional classification of living things, including sources of the food. Choosing a source of food that aligns with your own body composition gives you the right nutrition without the danger of inflammation, was my lesson. I now realise that eating wholesome healthy food is more expensive - than binging on processed, pro-inflammatory food. With the growth of packaged / fast-food / street-food culture in urban spaces, inflammatory diseases are here to stay. Unless, we are ready to take nutritional awareness to another level—nutritional therapy over drug therapy.

Dis-eased personality

At first, I and the diagnoses were separate. I had the condition. Every time I visited a specialist with a new condition, I started off by describing how I felt but soon moved to the what and how of the case. That is what doctors wanted to know. New pills and syrups got added to the existing bucket of medicines. As the disease list grew, and doctors became increasingly clueless on how to treat me, I became the condition. *She is arthritic; she is a case of chronic dermatitis; she is ____ condition*. The transition was seamless, both for me and my healthcare provider. As a teenager struggling to cope with daily routine, I accepted this identity because it aligned with the only way of living I had ever known.

Till I believed the conditions to be my only identity, I was under the grip of inflammations. When I began to look for an identity beyond the conditions is when I began to heal**.**

Two common approaches are used by specialists when talking to patients with chronic genetic diseases: (i) nothing can be done to cure it, but it can be managed with drugs (which are quite expensive actually) and (ii) there are advanced and expensive treatments, but without the assurance of a sure cure. Hearing this repeatedly from healthcare providers can take the will to live out of a patient with such diseases. The patient goes from the state of denial to determined compliance to desperate search for better symptom management to, finally, a quiet submission to morbidities of the disease. It is essential to delineate, right from the start of the treatment, the patient's identity from the disease manifestations. The patient may not always be able to do this independently, given the pain, confusion and despondency that the patient faces. Family and friends also may not be equipped or knowledgeable enough to meet this need. Hence, it is important for specialists to work closely with mental health counselors or patient support groups when treating patients with chronic genetic diseases. The body and mind work in a synergistic way to help us live a healthy and meaningful life; one out of this pair cannot be ignored when looking to cure (or manage) a disease affecting the other.

Dis-eased socio-cultural settings

I was born the third girl child to a conservative Tamil brahmin family. The pressure to perform existed even before I was conceived; this child *should* be a boy. The parents were under immense pressure to gift themselves and the extended family a boy. And, despite all the prayers and astrological predictions, out I came, a baby girl! (I was informed later that disappointment and denial loomed) Taunts followed. My parents gracefully accepted the responsibility of parenting three girl children. But I was the last hope and so, the first to be blamed by the extended family. I responded. With a firm resolve, I started believing that even if I am not born a son, I can be a son to my parents. I observed and moved around with boys of my age to understand how they think, act and be a son to their parents. I picked up clues on being a son from the social environment around me and made active attempts to incorporate those aspects into my daily living. Somewhere down the line, unknown to me, I was overpowered by the urge to suppress everything that was feminine in me. When adolescence hit, I was a confused person; not happy to be a female and not designed to be a male.

Till I believed that being a son to my parents was important to retain my relevance in their lives, I was under the grip of inflammations. When I began to resolve my family role and gender identity, welcoming the feminine in me, I began to heal.

The relation between emotional stress and inflammation is now well established. And yet, this important factor is not considered when taking patient history for chronic inflammatory diseases. More often than not, the person with a chronic disease also has a story of social discrimination, abuse or identity crisis faced in loneliness, away from the gaze of family and loved ones. These patterns of mental stress (and the resulting imagined or wrongful social isolation) can often feed and accelerate inflammatory processes over time. The relation between the source of stress and pattern of inflammation cannot be undermined. My own healing started only when I clearly identified the mental (emotional) 'trigger/feed' patterns that preceded massive inflammatory cycles and took firm steps to arrest as well as reverse them.

Dis-ease to ease

For the first 16 years of my life, I went through the phases of denial, anger, frustration, resistance and submission to the diseases I had. The only upside—I never quit asking questions—to myself and my healthcare providers. At age 17, I decided to pursue biochemistry so that I could understand and participate in finding a cure for some, if not all, of the diseases. Finding information in this digital age is not very difficult. Fighting your own biases and those imposed by family and society is. That has been my biggest roadblock. I find myself constantly battling biases related to modern medical practices, conventional social practices, traditional systems of medicine, spirituality, yoga and pranayama, lifestyle choices, career choices (where I am not a superwoman!) etc. I keep asking myself - *Are you making a well-informed and empowered choice or just complying with a borrowed belief?* This one question has prevented me from falling into the I-am-helpless-because-I-have-a-genetic-disease trap. It has helped me find ways to healthy living by digging through the knowledge repositories offered by medical science, traditional medicine, psychology and spirituality and most importantly, by listening carefully to the language of my own body.

In all honesty, I have just begun to put the pieces of the puzzle together from the answers I found to questions like — What is a genetic disease? How do epigenetic factors influence disease progress? What is the role of nutrition, mental health, spiritual pursuits and societal factors in modulating disease onset / progression / regression? What is my role in my own healing? — in a way that is meaningful and beneficial to me. Up ahead, lies the task of leading a healthy life, sustainably and joyfully, and sharing my learnings in a responsible way. I have my hands full, so no complaints!

I am asked how I feel being a survivor of debilitating inflammatory diseases or how I fought them. I confess my approach is that of a learner. My medical journey taught me many a lesson, some of which I have shared here. This does not imply that I am a sage girl fighting the assaults on my immune system, on my being, with quiet calm and resilience; that is far from the truth. But the fact remains that I choose to give the student in me the upper hand always, which helps me cut through biases coming in the way of my healing. I dared to question and learn amidst pain and inner chaos, and continue to do so.

Acknowledgments

While the health solutions came from personal choices, making these choices needed support. And I did get plenty of support. My parents – mother, who never let me accept defeat even when the body was crumbling under the inflammatory burden, and father, who shouldered the financial burden of a very expensive medical journey. My husband – who loves me for what I am and gracefully accepts the scars from diseases I had before we met. My doctors – who empower me by being honest with their answers. My friends – who fuel my intellectual pursuits and inspire me to learn more. My students – who refine my questioning skills by asking their questions fearlessly. And above all, my spiritual guide and guru – who lives as the voice of conscience inside me, prompting me to always be loving and compassionate in my ways, towards self and others.

Here are some empowering resources that broadened my understanding of things.

Resources

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The ethics of teaching in medicine: A personal view

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Abstract

While there is considerable literature on the teaching of medical ethics, much less has been written about the ethics of medical teaching. This article is a personal reflection on the latter. The devaluation of medical teaching, in part, but not only because of the difficulties of objectively assessing it, has serious ethical implications. Teaching, including medical teaching is a moral enterprise. The most serious consequence of inadequate medical teaching/learning is the graduation of incompetent and unethical