

What Lies Beneath: Making Rheumatoid Arthritis Visible for the Seronegative Patient through Precision Medicine

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Background & Purpose

Getting a diagnosis of inflammatory arthritis, like rheumatoid arthritis (RA), brings a combination of relief and disbelief. Relief because all my symptoms finally made sense and were validated with a diagnosis. Denial because a seronegative diagnosis meant blood work did not show autoantibodies nor positive Rheumatoid Factor (RF). My denial posed a challenge in starting treatment with disease modifying anti-rheumatic drugs (DMARDs) and glucocorticoids to curb inflammation because the disease remained “invisible,” even in my blood work.

Intervention

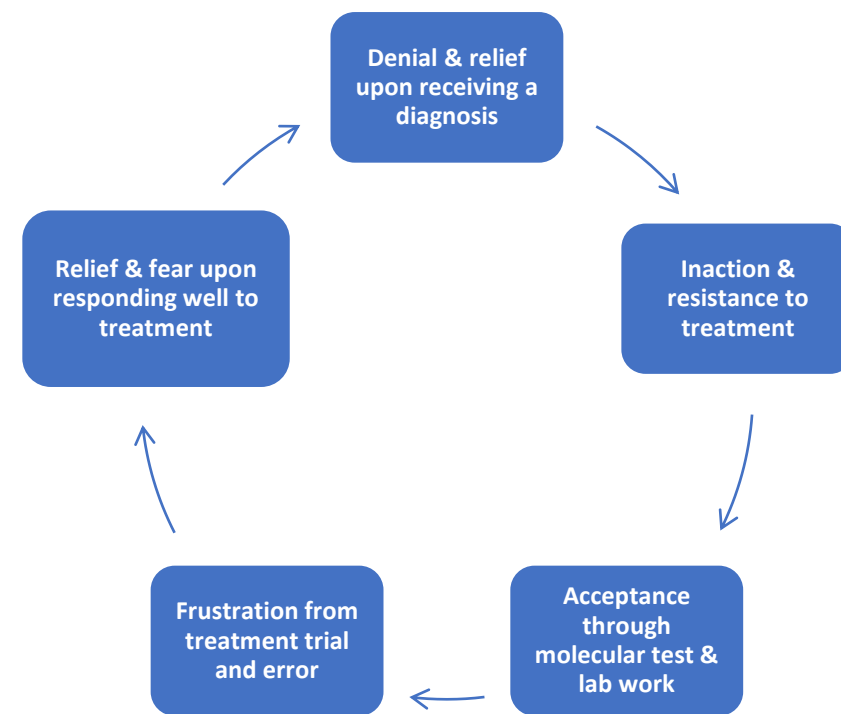
Getting biomarker tests for my disease activity was pivotal for me in confirming my diagnosis and making it “visible”. By providing me with a sense of how bad my inflammation was, and what the likely prognosis indicated, these tests highlighted the urgency of starting treatment (DMARDs + biologics). Because the journey with RA medications tends to be one of trial and error, it can be frustrating. The experience of diagnosis is an ongoing process of working from denial to acceptance. This is something I go through every time I need to reassessment my disease and change treatment.

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Diagnosis to Acceptance to Reevaluation: The Non-Linear Disease Journey of Seronegative RA

EVENT	INTERNAL RESPONSE	ACTION I TOOK
Rheumatologist diagnosis of RA (Year 1)	Denial: “I don’t have a chronic condition. I think this is temporary so let me wait it out.” Relief: “It makes sense. This explains the joint stiffness, pain, fatigue, bony inflammation, recurring tendinitis, GI issues.”	Scheduled follow-up visits to review labs per my doctors’ advice
Seronegative rheumatoid factor (Year 1)	Inaction: “I probably don’t have a chronic condition. There is an error in my diagnosis. I’m not going to start treatment until I’m sure I have RA.” “My labs don’t show a positive RF factor, this could be a mistaken diagnosis.”	Resisted treatment, thus losing my ‘window of opportunity’ to achieve early remission
Follow-up visit	Fear: “Why should I take medications that can have side effects that may be short-term and long-term?”	Questioned whether treatment was good for me holistically
Multifactorial biomarker test of inflammation / disease activity (Year 3)	Acceptance: “I can see that I have a chronic disease and that my inflammation is bad. Maybe I do need treatment. This is all making sense now.”	Escalated to biologic DMARD treatment
Trial & error with treatment (Year 4)	Frustration /Fear: “Why isn’t any medication working?”; “Why can my care team not know what will work for me?”; “What if nothing works for me”	Explored options
Responding well to treatment (Year 5)	Relief/Confidence/Fear: “I do have RA because this medication is working-what a world of difference.” “What happens when this medication stops working?” How will I know what to try next?”	Changed treatment when my disease has not been well-controlled on current treatment



Quality of Life

Molecular tests that provide visual representation of my disease helped me move from denial to taking action to understand and treat my disease. This included initiating and staying on treatment and adding non-pharmacological approaches to disease management. Molecular tests and blood tests do more than just help the physician to understand the pathophysiology of a disease. It helps those of us living with a disease to “see” it and believe it. In turn, this helps with treatment decision making.