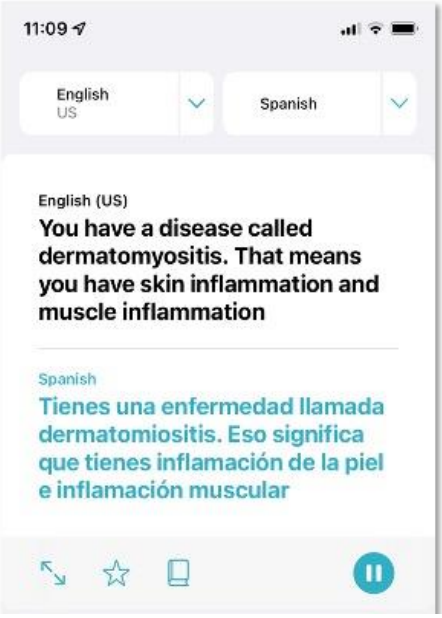
dear residents

Bittersweet **April 24, 2022**

Dear Residents,

I am coming off a 2-week rotation on the rheumatology consult service. It can be hectic because one covers two hospitals and consults pop-up unpredictably - sometimes a few, sometimes very many. There were patients with established disease presenting with flares and others in whom their rheumatic disease was newly diagnosed. The young lupus patient always evokes the regret that the lupus happened in the first place. It is so life-altering. Like you, I enjoy the diagnostic puzzles and the challenge of making effective and judicious therapeutic choices, but I most relish getting to know the patients as people. One new diagnosis we made (actually it was quite obvious because of the characteristic rash and accompanying proximal weakness) was dermatomyositis in a woman who had been quite healthy until now. We had trouble with Language Line Solutions over the weekend and I resorted to Google Translate to begin to explain the diagnosis to her. This was just the first step, and I knew that much more needed to be clarified.

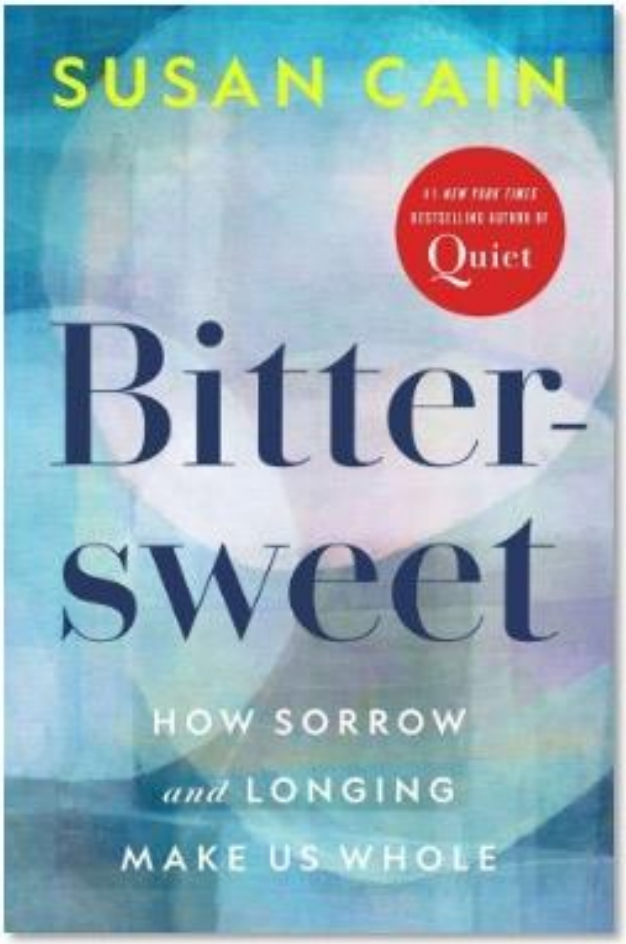


She was quiet and did not say much, other than a confused but polite thank you but did inquire if we could allow her to eat and drink because she was hungry and thirsty. Over the next few visits, our conversations were longer (with the help of Language Line Solutions) and we went over the treatment, the need to screen for cancer and to assess her swallowing. Each day I would ask her if she was better – I

thought she was – the skin seemed less violaceous, and her legs seemed stronger. She did not feel that she was much better. Over time, it because apparent that she was in a state of deep grief about her illness. She explained that she had lived a very clean life, eating right and exercising and this malady was very undeserved. She showed us a photo of hers from a year ago – she was quite radiant in this photo – a bright smiling face. And look at me now, she said and lowered her head as tears streamed down her face. The next day she was standing. Peering over her glasses she gave us a small concession that perhaps she was better because she was now standing. I watched her rise from her chair. She had to lean forward, rock twice and then, with the assistance of her hands, she stood upright. She remained very concerned about the weakness in her arms – my hands are useless she exclaimed. She wanted to know if she would ever be back to her old self. I'm afraid not, I said. You will improve – the rash should fade, and the muscles would improve but not quite back to fully normal. We can't always move on from our losses, but we can move forward with them. I didn't quite get to explain that to her. It's just a thought I had. She did begin to work with PT and OT and, as I left the service, I had my fingers crossed that PM&R would accept her for inpatient rehab.

Other patients we saw had established disease and some were quite accepting of their condition. One such patient was a resilient young woman with industrial-strength lupus - replete with transverse myelitis, lupus nephritis and terribly scarring widespread discoid lupus (especially prominent on her face). After failing standard first-line therapy, she seemed to have found some benefit from belimumab. But there was trouble keeping her appointments and "they stopped sending my medication to me." I asked her about her work, her family, her loved ones. She lives with her 11-year-old son and has a boyfriend who seems kind and attentive. "He wouldn't be my boyfriend, otherwise," she quipped. The father of her child, on the other hand, "owes me child support" and is not in the picture. She rolled her eyes. She herself has worked, until recently, in customer service, a job she really enjoyed. I remarked to her that she had a friendly voice – she smiled. We talked about how she has handled the scarring on her face. She joked that she gets some strange looks, and she laughs when children ask her if her face had been burned. We then explored why she has trouble keeping her clinic appointments. Childcare, she said. I excitedly mentioned Annie's Place to her. She said that she had inquired but that her son was above the age limit. Why not bring him to your appointment, I asked. She reported that this has been expressly prohibited. I promised her that I would inquire if this was a COVID-specific proscription.

While I am trained to care for rheumatic diseases, and while I derive pleasure from having the skills to diagnose and treat these patients, the often severe nature of the illness and the accompanying loss of vitality saddens me. It is bittersweet. I have been reading Susan Cain's book with the same name – Bittersweet. In her own words, "This book is about the melancholic direction, which I call the "bittersweet": a tendency to states of longing, poignancy, and sorrow; an acute awareness of passing time; and a curiously piercing joy at the beauty of the world. The bittersweet is also about the recognition that light and dark, birth and death – bitter and sweet – are forever paired… The tragedy of life is linked inescapably with its splendor; you could tear civilization down and rebuild it from scratch, and the same dualities would rise again. Yet to fully inhabit these dualities – the dark as well as the light – is, paradoxically, the only way to transcend them."



Perhaps you might enjoy reading this book on a rainy day. Our profession is particularly awash with bittersweet moments – triumph, despair, helping people get better, and assisting them manage the end of their lives, when that time comes.

I hope you are enjoying Spring – nature is glorious.

Dino Kazi