

THE COVID-19 PANDEMIC: ONE PERSON, VARIOUS PERSPECTIVES

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At 62 years-old I am experiencing the COVID-19 pandemic from various perspectives: as a wife, mother, grandmother, family doctor, teacher, manager, and patient. I was diagnosed with rheumatoid arthritis (RA) five years ago. Initially, control of the disease was complicated but eventually it was achieved through a combination of medications (hydroxychloroquine, methotrexate injection, and tofacitinib, all at maximum doses). This renders me immunosuppressed but works quite well especially since I am adherent to the treatment regimen. However, I am more susceptible to infections. If I stop taking the medications, symptoms and synovitis would recur. I have been a family physician since 1983, but three years ago stopped working in the clinic due to my susceptibility to infections that circulate there. I truly enjoyed interactions with patients, so this was one of many losses due to RA. Now I concentrate my professional energies towards management, teaching and research full time at the Faculty of Medicine. My spouse is a rheumatologist and we have been working together on research projects since 2007, prior to my diagnosis. Moreover, I am the mother of three grown daughters as well as the grandmother of 6 adorable grandchildren aged one to six years old. What a joy! Yet, being immunosuppressed has impacted my role as a grandmother because children in daycare are often sick and I sometimes am forced to cancel planned activities with them - such as outings or babysitting.

In February 2020 we spent a few days at Disney with one of our daughters, her husband and their two children. This had been planned for a year prior to any indication of COVID-19 in America. After our vacation, we took the plane to Victoria, British Columbia, to attend a Canadian rheumatology congress where we both presented. This too had been planned for several months. We passed through Seattle without any knowledge of COVID-19 in those areas. The congress went well with participants from across

Canada mingling during breaks, presenting and sharing, as is common during such events. On Thursday evening, we learned about the first case of COVID-19 in Quebec; it was a traveller returning from Iran. This news was like a quiet alarm bell that rang as we set out to go home. I was anxious about returning while at the same time, I could not wait. We had to transit through Vancouver, so I took care to wash my hands often and distance myself as far as possible from the others while we waited and boarded the large cross-continent airline. I was especially vigilant during the 6-hour flight from Vancouver to Montreal (in the washrooms, during meals and when people coughed around me).

Once back in Sherbrooke, a small university town in Quebec, I learned that there had been several cases in Seattle and Vancouver. I decided not to hold face-to-face meetings at the faculty, favouring virtual meetings, and cancelled a concert scheduled before the official announcement of province-wide confinement. The next day, the government announced several closures: schools, universities, rallies, ski resorts and imposed a lockdown. Like everyone else, I followed to the news regularly on television and on the Internet. I received instructions right away from my department regarding the impact on residents' internships. As Program Director, I received daily updates and resident placement instructions as things changed quickly and frequently. As a member of a crisis cell, we had regular virtual meetings, received daily emails and reorganization notices. The spirit of collaboration and support in the team has helped me considerably. Nonetheless, I spent many hours per day online and experienced fatigue, accordingly.

The recommendations of the Ministry of Health were/are clear: immunosuppressed patients must remain at home and take extra precautions to stay safe. My family, colleagues and friends worry about me and encourage me to follow the recommendations. Because my spouse must go to the hospital to treat patients, there is added stress for us. Is he able to prevent contamination at home? The Faculty of Medicine and the University Hospital Centre quickly organized virtual platforms for telehealth and teleconsultations from home. My spouse has become the shopper for groceries and medication since I must stay home. Like many patients, I feel like I am losing my autonomy and I wonder for how long... not knowing is difficult for me. In addition, the government has announced a shortage of hydroxychloroquine in Quebec. I hope I do not have too many problems. Because I am a family doctor, I receive numerous questions from my family about COVID-19 as they seek advice for themselves and their children. I respond as best I can but so much remains unknown. Nonetheless, I forward interesting articles and offer recommendations.

As a patient-partner, I am asked to be involved in fund-raising requests for urgent research projects "COVID-19 and inflammatory diseases." I find it satisfying to be in the action and able to collaborate in my own way. However, I feel guilty that I cannot help my clinical colleagues on the frontline. Being a doctor and not being able to help because I am also a vulnerable patient is a hard pill to swallow. My three daughters (an internist in Montreal, a neurologist, and physiotherapist in a geriatric unit in Sherbrooke) all work in the health care system in essential services; they are on call, remain exposed and I worry about them. I also feel culpable because I am less available than the other grandparents. I cannot assist my children with their

children as I must avoid associated risks. I deeply miss social contact with them all. We meet via facetime regularly, and once allowed, began to visit outside two meters apart, but hugs are forbidden.

A chronic illness for five years with losses, bereavements, reorganizations at work and in life, limitations, constraints, adjustments after relapses and infections, has been manageable. I have been able to accept all of this because I am resilient. But, when COVID-19 and confinement were added to the equation, I lost my bearings and regressed into the familiar processes of loss and grief experienced when first diagnosed. My morale took a hit, sometimes showing up as discouragement, other times resulted in tears. Despite relatively good arthritis control, I feel sicker and more fragile than before. I harbour many questions; I even considered stopping the biological medications. Yes, I would be less immunosuppressed and more "normal" yet I know that this is not a solution. My partner and my rheumatologist concur.

How can I cope and adapt to all this? I continue to walk outside every day, bike, engage in telehealth, eat well and practice mindfulness meditation. Yet, my sleep has worsened with me waking up earlier and more often. I have limited my exposure to the news, especially in the evening. I talk with my loved ones (family, friends, and colleagues) and express my worries when I feel down. I also find it helpful to chat with other patients. Since 2018, I have been part of a group of patient-partners in Quebec (PIRA: Patients Interested in Arthritis Research). We meet virtually four times a year. The May 2020 meeting was appreciated by all, both to share our experiences of confinement and progressive deconfinement. We published a collective article that appeared in a journal, the *Arthritis Research Canada*.

Despite my efforts, in the midst of messages conveyed in the media about vulnerable and immunosuppressed patients, certain contradictions and questions about the severity of the disease versus a certain protection against severe inflammatory respiratory syndrome, long-term confinement and restrictions, I have become ambivalent. Is it better to contract COVID-19, which may not be that bad, or wait for future treatments and vaccines? I mull over questions about serologies, responses to the upcoming vaccine, and long-term immunity. It is reassuring to know that other patients have similar vexing issues. I must stand firm and remind myself that there are people for whom all this is much worse. I remain hopeful while gradually engaging in permitted activities. I wear a face mask and wash my hands often. I continue to be involved in work, collaborate on COVID-19 research projects, and I enjoy my family from two meters distance! My various roles are in balance, at least for now. ■