

Idiopathic Pulmonary Fibrosis patients' COVID-19 quarantine; not just a routine

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Key words:

- Idiopathic pulmonary fibrosis
- Interstitial lung disease
- COVID-19, quarantine

Abbreviations:

IPF: Idiopathic pulmonary fibrosis
COVID-19: Corona Virus Disease 19
QoL: quality of life

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Amidst the Corona Virus Disease 19 [COVID-19] pandemic we have been receiving an increasing amount of open-hearted concerns from Idiopathic Pulmonary Fibrosis (IPF) patients regarding the unraveling global tragedy through phone call appointments, which have replaced outpatient visits during the national lockdown¹. Upon reflecting on their sincere thoughts one can sympathize with the predicament IPF patients are currently encountering, which is highly unrecognized because of global turmoil and the fact that this population is in many aspects (research, public awareness, media coverage...) underrepresented. Therefore, we decided to provide insights into the COVID-19 calamity from an IPF patient point of view, drawing inspiration from our patient's confessions.

IPF remains a rapidly progressive disease with poor prognosis. It wasn't until recently that disease modifying drugs, pirfenidone and nintedanib, were approved heralding a new era in the treatment of IPF. Prior to this benchmark event, patients had no choice but to come to terms with the fact that there is no treatment proven effective in slowing pulmonary function deterioration². Currently, they find themselves placed within a population susceptible to a novel disease that yet again lacks evidence-based therapeutic interventions.

Nowadays more than ever, IPF patients experience diminished quality of life, not only because of physical symptoms but also due to the associated anxiety and depression that are precipitated by the aftermath of the COVID-19 pandemic³. In our small patient cohort, self-reported levels of quality of life (QoL) have been markedly reduced as strict measures are issued to combat viral transmission. It is well established that dyspnea, reduced mobility and cough underlie the diminished patient-reported QoL and are important inducers of anxiety and depression⁴. Symptom-related discomfort can perturb involvement in daily activities (household maintenance, socializing, exercise...) and many aspects of the treatment plan (such as pulmonary rehabilitation and group therapy sessions), a sequence which culminates in additional negative emotion. Given that most patients are older adults and are therefore likely to have their own family, it is expected that the impact of IPF extends to their family members as well. IPF applies additional emotional pressure through concerns regarding: i) the disclosure of the diagnosis to close relatives (spouse, children, siblings...) ii) treatment-

related expenses that may strain the household budget; iii) the inability to take part in family activities; and iv) sexual dysfunction, that is increasingly recognized as an important issue⁴.

As if the life of an IPF patient wasn't challenging enough, COVID-19 introduces another level of complexity. Implementation of home confinement, high predisposition to severe COVID-19 and increased hospital workload are likely to hamper access to healthcare facilities for routine physical examination, emotional support and prescription of medication. In cases of emergency, such as an IPF exacerbation, it is expected that IPF patients may be driven to delay their visit to the hospital on fear of contracting the virus in the process. Alternatively, some may misinterpret the signs of an acute flare as development of COVID-19 symptomatology precipitating domestic discomfort. Therefore, IPF patients may opt to spend most of the time away from the family amid transmission concerns, considering that their partners have to occasionally break the quarantine for household necessities. Most importantly however, it remains unknown when the global pandemic will be resolved. With the expectancy of IPF averaging 3 years, even a few months under such conditions amounts to a significant portion of the predicted lifetime. It is highly unfortunate that even prior progress in terms of symptom-relief could be wiped due to psychological unrest and abstinence from pulmonary rehabilitation, whose benefits fade following cessation⁴. One can only imagine how devastating that is for the morale of an IPF patient.

There is an ongoing effort to modernize IPF treatment as per the principles of personalized medicine. Comprehensive treatment plans are advocated that incorporate extension of survival in tandem with interventions aimed at enhancing QoL. The shifting paradigm of IPF management suggests that anxiety and depression are starting to be duly recognized by the scientific community as important variables in maintaining QoL. The pillars of the approach consist of individual assessment of patient needs and values, patient education, symptom and comorbidities relief, disease modification and timely discussion of end-of-life decisions⁴. To a sufficient degree, it is possible to allow patients under domestic confinement to follow aspects of the treatment plan. During the pandemic home based web-solutions have been increasingly employed for a variety of tasks (work, shopping, communication etc) and it would be

prudent to continue this trend into the post COVID-19 era. Telemedicine services have successfully entered the market and promise to revolutionize the patient-doctor dynamic in the forthcoming years. Telemedicine providers are urged to utilize novel digital means to: i) become a vehicle of reliable information; ii) enable teleconference appointments with IPF specialists; iii) promote online group therapy sessions; iv) provide at-home pulmonary rehabilitation tutorials, or even v) host cognitive behavioral therapy sessions⁵. Apart from internet-based means, the combined effort of family members and specialized caregiver services are indispensable in ensuring comfort care. Delivery and administration of essential medicines, measurement of vital signs, meal preparation and psychological support are only some of the basic needs that can be effectively satisfied particularly from immobile patients.

Sooner or later COVID-19 will become a lesson from the past. In anticipation of the next epidemic/pandemic, authorities and healthcare systems are going to draw from this experience⁶ and be better prepared in terms of detection, containment and if required, development of a treatment. Special emphasis should be placed in establishing emergency protocols to assist people suffering from chronic, debilitating and rare conditions to maintain their physical and emotional well-being. By no means can such solutions replace personal contact between the patient and his partners, namely, family, physicians, nurses, caregivers and social circle. However, they do allow the patient to retain his progress and remain confident in his ability to overcome the hardships of his condition. Besides, for IPF patients, adopting Jo Nesbo's words, losing their life is not the worst thing that can happen; the worst thing is to lose their reason for living.

CONFLICT OF INTEREST

None

AUTHORS' CONTRIBUTIONS

All authors contributed equally in the production of the manuscript.

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