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Letter to the Editor

How can we support COVID-19 survivors? Five lessons from long-term cancer survival

Although more than 41 million individuals are considered to have recovered from SARS-CoV-2 infection, emerging evidence indicates that many (including young, formerly healthy people) suffer from protracted symptoms¹ and may even live with lasting impairments.

With the large number of affected individuals and the virus still spreading in many countries, the well-being of this growing survivor population presents an urgent public health issue.

To address this new challenge, the medical community can harness knowledge from decades of previous research in a different, but also heterogeneous, survivor population.

Initially, cancer survivors' needs were an afterthought despite great medical advances in cancer diagnosis and treatment. Mullan,² a physician and cancer survivor himself, noted that "It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can."

COVID-19 survivors should not be left stranded either. Rather, insights from (psycho-)oncology could inform approaches to COVID-19 care and research – not only because of parallels but also because of relevant differences between the diseases:

1. The notion that 'cure is not enough':³ With respect to, e.g. pediatric cancer survival, registries and other organizations conducted long-term studies in large cohorts. The aims were to assess late effects and to understand predictors of differential outcomes. This research was instrumental in improving monitoring and intervention in cancer survivors and found expression in risk-stratified follow-up care guidelines.⁴ With the many unknowns shaping COVID-19 survivorship, long-term surveillance is a requirement for evidence-based care for this population too. It is necessary to ascertain the proportion of COVID-19 survivors who suffer from severe late sequelae and who are in need of ongoing care. It will also be important to identify risk factors to adequately support the most vulnerable patients.⁵
2. A life-threatening illness and its treatment are potentially traumatic events. By definition, traumatic events are experiences that confront us with our own mortality or our loved ones' mortality and elicit feelings of fear and horror.⁶ Depending on individual differences and other factors such as social support, they can lead to post-traumatic stress disorder (PTSD).⁷ Like in cancer survivors, studies found elevated rates of PTSD among COVID-19 survivors,⁸ indicating not only physical but also psychological/psychiatric sequelae. One of the symptoms of PTSD is that individuals re-experience the traumatic event. Cues that

resemble aspects of the experience can therefore cause great emotional distress. The constant media coverage of COVID-19 thus likely constitutes an additional stressor for survivors who suffer from PTSD. Survivors could benefit from PTSD screening and offers of trauma-focused psychotherapy.

3. No survivor is an island: In cancer research and care, there is a growing involvement of family members. The patient and his/her social environment are often conceptualized as a system whose members' well-being is interrelated⁹ as the next of kin provides meaningful social support, which influences the patient's long-term mental health.^{10,11} In case of a viral disease, however, the risk of infection suspends or alters these social connections. As a consequence, patients with COVID-19 experience social isolation, a health risk in its own right.¹² For family and friends, not being able to be close to the patient might instill feelings of helplessness.¹³
4. (Former) 'patients should be involved' in the research in line with the Patients Included charter initiative (patientsincluded.org/) as they are experts in living with their condition. Regarding cancer survival, multidisciplinary consortia that include survivors have produced significant research and policy advice, e.g. PanCare (pancare.eu). Lived experience is especially relevant as COVID-19 survivors' care needs are largely unknown. They might also shift over time as survivors' symptoms change and new challenges emerge.
5. There is a 'need to counteract stigma.' Stigma diminished well-being of patients with cancer.¹⁴ COVID-19 survivors also reported shame and guilt.¹⁵ What is more, the pandemic provoked stigma and discrimination on a large scale. There were attacks on healthcare providers,¹⁶ increases in anti-Asian racism,¹⁷ and discrimination against people in precarious housing (e.g. refugees).¹⁸ Hence, stigma is hurtful to society as a whole: It exacerbates societal disadvantages of vulnerable populations. It might also lead people to hide their symptoms, thereby subverting efforts to control the spread of COVID-19 in the community.

In summary, COVID-19 survivors might need medical and psychosocial attention. The nature of an infectious disease outbreak diminishes sources of support and amplifies risk factors.

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4 December 2020

Available online 16 January 2021