RESEARCH IN NURSING & HEALTH WILEY

How an effective response to post-acute sequelae of SARS-CoV-2 infection (PASC) relies on nursing research

To the Editor,

We write in response to your editorial, "How effective response to COVID-19 relies on nursing research," published in June 2020 (Lake, 2020). We applaud your leadership in pointing out how nursing science already has an evidence base that can be leveraged to meet the challenges of an effective coronavirus disease (COVID) response: (1) restricted access to health care, (2) surging demand for healthcare personnel, and (3) moral distress and/or injury among providers (Lake, 2020). Additionally, we applaud our nurse colleagues—in education, research, and practice—for their quick responses to the pandemic, and all of whom took action to promote the health and safety of patients and communities. Because of their efforts, we are now emerging from the pandemic and seeking some sense of normalcy. However, for some coronavirus disease 2019 (COVID-19) survivors, their life was forever changed when they contracted severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2); they developed persistent symptoms, variously referred to as "long-haul," "long-COVID," or post-acute sequelae of SARS-CoV-2 infection (PASC). PASC manifests as a constellation of symptoms, varying from patient to patient. In Fall 2020, our team identified over 100 patient-reported symptoms of PASC, including debilitating symptoms like fatigue, "brain fog," and alterations in mood that cause profound distress and functional impairment (Lambert & Survivor, 2020; Lambert et al., 2021). Additionally, we identified five symptom clusters associated with long-haul and noted a prevalence rate of 11% in nonhospitalized patients 6 months after a polymerase chain reaction (PCR) confirmed SARS-CoV-2 infection (Huang et al., 2021). And nearly one-third of long-haulers were asymptomatic at the time of receiving a positive PCR test (Huang et al., 2021). PASC affects all demographics, independent of initial symptom severity, and preliminary analysis of patient-reported symptoms suggests variable onset thereof (Lambert et al., 2021). Because PASC has no cure, symptom management is currently the gold standard.

We aim to further the conversation you began in June 2020; we argue that, as nurses, we have a strong track record leading symptom science and self-management research, and are thereby, well-poised to address the needs of PASC survivors. Nurses actively help patients to self-manage their health, and symptom science is a central focus of our research. In fact, the National Institute of Nursing Research (NINR) leads the Symptom Science Center, a transdisciplinary resource for the scientific community, at National Institutes of Health (National Institutes of Health NIH/National Institute of Nursing Research NINR, 2019). Yet nursing is essentially invisible in leading or participating, in national PASC initiatives.

Our nurse-led team, the COVID-19 Research Collaboration (C19RC), is highly multidisciplinary and involves five academic institutions across the United States. In early 2020, our team partnered with Survivor Corps, the largest grassroots COVID survivor advocacy group in the United States, in the conduct of patient-reported outcomes PASC research and to better understand the patient experience. Therefore this is the lens with which we view our next set of challenges, knowing that this is an area in which nursing is optimally equipped to lead.

1 | CHALLENGE 1: RECOGNIZE PASC DISEASE PROCESS, REAL-WORLD SUFFERING, AND LEARN FROM THE PATIENT EXPERIENCE

History has taught us that an effective way to understand new or emerging diseases is to listen to patients. Indeed, this was crucial to early efforts in the HIV epidemic. Regrettably, since 2020, PASC survivors have posted to Survivor Corps their narrative accounts of providers dismissing their complaints when they sought care for unresolved symptoms following COVID-19 (Survivor Corps, 2021). This observation is not unique and has been documented by others internationally (Greenhalgh et al., 2020; Lokugamage et al., 2021; Verduzco-Gutierrez et al., 2021). PASC patients report feeling "traumatized" and betrayed by providers' responses; after this experience, some have sought out "PASC-friendly" providers or others have disengaged entirely from the healthcare system (Survivor Corps, 2021). It is worth noting that medical gaslighting and pathologizing were experienced by nurses, at all levels of education and practice, by their peers (Survivor Corps, 2021). Because nursing has led the scientific charge in symptom science and symptom management, as well as consistently been voted the most trusted profession (Saad, 2020), it is imperative that nurses lead efforts to understand and validate patient experiences with PASC to advance understanding of PASC and restore trust in the healthcare system.

2 | CHALLENGE 2: UNDERSTANDING THE BIOLOGICAL BASIS OF SYMPTOMS

Precision health is predicated on understanding the biological interactions within an individual that contribute to pathology or influence outcomes. Nursing research has begun to utilize precision health tools to identify, characterize, and manipulate the biologic, genetic, and behavioral mechanisms underlying symptoms to improve outcomes across many chronic health conditions. In fact, this is a focus of the NINR. We currently understand PASC as the persistence or non-resolution of symptoms among survivors of COVID-19. It is clear SARS-CoV-2 is the causative agent, but our understanding of the fundamental biological interactions resulting in symptoms is incomplete. PASC has no known cure, and current treatment strategies focus on alleviating symptoms. Therefore, research is needed to identify and characterize PASC symptoms and their biological basis to develop tailored interventions for this emerging health crisis. This challenge is well-aligned with the goals of nursing research and is consistent with the evidence base from previous studies of symptom biology across a variety of chronic diseases, such as mitochondria and fatigue, inflammation and mood, and so forth. In short, nursing is poised to lead in addressing this challenge.

3 | CHALLENGE 3: SELF-MANAGEMENT OF DEBILITATING SYMPTOMS OF NEW ILLNESS

The World Health Organization (WHO) global research roadmap urges the development of PASC management strategies (WHO, 2021). Nursing research has generated considerable breadth and depth of knowledge related to symptom management across populations and disease conditions. Nursing is poised to refine or retool these interventions to address the immediate need for managing symptoms of PASC, a disease without as yet treatment or cure. Data suggest that PASC results in a significant symptom burden that hinders function, and this step of repurposing our existing interventions may be an effective and expeditious approach to address the critical challenge of assisting patients in recovering as fast as possible.

In summary, PASC is an emerging global health problem, or what we call a shadow pandemic, emerging from the pandemic caused by a novel virus; it affects previously healthy children and adults. Moreover, further delays in addressing these challenges include the normal course of securing research funding—often more than nine months from submission to receipt of funding—-can only serve to intensify the need for interventions and responses. Because of the nursing profession's contributions to and leading efforts in patient advocacy, symptom science, and self-management, nursing is poised to lead in addressing the challenges of PASC. NINR should be spearheading initiatives that facilitate nursing representation. In addition, our collective expertise should be visible, present, and vocal in national efforts related to PASC.

Melissa D. Pinto[1]
Charles A. Downs[2]
Natalie Lambert[3]
Candace W. Burton[1]

[1]Sue & Bill Gross School of Nursing, University of California Irvine, Irvine, California, USA
[2]School of Nursing and Health Studies, University of Miami, Coral Gables, Florida, USA
[3]Department of Biostatistics & Health Data Sciences, Indiana University School of Medicine, Indianapolis, Indiana, USA

Correspondence
Melissa D. Pinto, Sue & Bill Gross School of Nursing, University of California Irvine, 100D Berk Hall, Irvine, CA 92697-3959, USA.
Email: mdpinto@uci.edu

ORCID

Melissa D. Pinto https://orcid.org/0000-0002-1003-180X
Charles A. Downs https://orcid.org/0000-0003-4859-7929
Natalie Lambert https://orcid.org/0000-0002-4820-2619
Candace W. Burton https://orcid.org/0000-0002-0557-6020

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