The Elephant in the Waiting Room: An Urgent Call for Papers to Address the Public Health Crisis of Long COVID

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Over the last two and half years, the COVID-19 pandemic has dominated headlines around the globe with Long COVID (also known as Post-Acute Sequelae of Covid-19 [PASC]) emerging as a significant health issue. The World Health Organization (WHO) defines Long-COVID as a post COVID-19 condition that occurs among persons with probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19, that lasts for at least 2 months, and cannot be explained by an alternative diagnosis (2021). Fatigue, shortness of breath, and cognitive dysfunction are among the most common symptoms (WHO, 2021). However, clinical presentations are variable. In fact, more than 100 symptoms have been documented; at least a quarter of affected patients report symptoms, including pain, that impact their activities of daily living (Davis et al., 2021; Lambert et al., in press). Symptoms may be new onset, following recovery from acute COVID-19, or persist from the initial illness. Symptoms can also fluctuate or relapse and remit over time.

As nurse clinicians, scientists, physicians, and health care providers, it is important to address Long COVID in our practice and research, as quickly as possible, and share findings in a manner that promotes universal awareness of Long COVID as a global health crisis. Just as we need to repurpose or innovate novel treatments, there is an impetus for our science to promptly contribute to establishing a Long-COVID evidence base, which is currently sorely lacking (Pinto et al., 2021).

The National Institutes of Health launched the Researching COVID to Enhance Recovery (RECOVER) initiative, with a budget of over $1B to support research on Long COVID-19 (Collins, 2021). While there is great hope for RECOVER to yield important discoveries in the long-term, RECOVER has recently faced staunch criticism for moving at a "glacial pace," especially given the considerable resources dedicated to this effort (Wadman, 2022). Furthermore, Wadman's (2022) recent article in *Science* cites an investigator who wished for more transparency in communicating standard data collection instruments, enrollment, and the rationale for dispersing funds to support research in this area (Wadman,

2022). Additionally, there are a limited number of patients enrolled in RECOVER; as of late September 2022, 8,000 participants were enrolled (Wadman, 2022). This number of enrollees is relatively small given the large body of investigators, the numerous study sites across the United States (U.S.) and time elapsed for enrollment (DePeau-Wilson, 2022).

Despite the slow start for RECOVER, the Biden administration has proactively opened the Office of Long COVID Research and Practice under the U.S. Department of Health and Human Services. This office is a step toward legitimizing the lasting, often debilitating effects of the post-viral illness that has been conspicuously absent from public health messaging on the virus.

In August 2022, the U.S. Department of Health and Human Services also released a National Research Action Plan on Long COVID (2022). Long COVID advocacy groups like Survivor Corps have been sounding the alarm about the debilitating impacts of Long COVID and needs of patients since early in the pandemic (U.S. Department of State, 2020). While patient groups' efforts have won greater awareness of the disease, Long COVID patients are still often on their own in trying to manage symptoms, with little evidence-based guidance from the medical community.

The elephant in the waiting room is Long COVID; it is a real illness, with considerable morbidity and mortality. The fears of many patients are exacerbated by the unknown trajectory of this illness. It is the opinion of several investigators that the rate of scientific discovery has not been rapid enough over the last 3 years to address the considerable public need (Wadman, 2022). At this point, Long COVID patients are the "walking wounded" of the pandemic. As the

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world resumes the new normal, Long COVID survivors may be left behind.

In the July 2022 issue of Clinical Nursing Research, the Editor-In-Chief discussed the importance of not waiting until the "big" study or the "gold-standard" randomized control trial is complete to release findings that could be beneficial to the scientific community. (Pinto, 2022). Instead, we should consider discussing and disseminating science in real time and sharing data in both traditional and nontraditional venues like short communications and briefs published electronically—ahead of print—instead of relying on meetings for this more "preliminary" type of dissemination (Pinto, 2022). One example where scientists worked together in a coordinated manner and shared findings promptly is the Human Genome Project (HGP) (Powell, 2021). While the investigation of Long COVID has different nuances from the HGP, the main point is scientists were able to come together and collaborate toward a common goal, approach the conduct of research in a coordinated fashion, and rapidly disseminate findings (sometimes on a daily basis) (Powell, 2021). This approach is known as The Bermuda Principles; it was developed and adopted by HGP investigators in 1996 and allowed for multiple scholars to constantly contribute to maintain the validity of findings over time (U.S. Department of Energy, 2019). While the HGP was completed several decades ago, this model of quickly sharing preliminary findings supported acceleration in scientific discovery with prompt dissemination to academics, clinicians, public health, and policymakers. Thus, we are calling for greater transparency so studies can be replicated in parallel, and in real-time, with different samples, populations, and settings; not duplicating, but rather extending the work without waiting for final results. Faster dissemination of discoveries must, of course, be tempered against premature application.

There are four actions that can be implemented immediately to accelerate scientific progress in Long COVID research without duplicating large-scale efforts. First, repurposing longitudinal data, when possible, that may have originally been intended for other research questions but could validly be used now to answer questions about Long COVID. Second, repurposing symptom management interventions until there is a cure or way to prevent Long COVID; this step is needed immediately to restore function and ensure quality of life (Pinto et al., 2021). Third, repurposing previously developed medications for symptom relief and potential treatment and/or cure for Long COVID. This is currently not a primary focus of Long COVID research and a frustration for patients and clinicians alike (DePeau-Wilson, 2022). There are several medications already FDA approved for other uses and may be effective, when used under medical supervision, in treating Long COVID (Nurek et al., 2021). It is known that developing novel medications can be resource-intensive and time-consuming. Since safety at certain dosages has already been established, repurposing medications to treat Long COVID should be a

consideration (DePeau-Wilson, 2022). Fourth, while we cannot control the speed of review and how quickly grants are awarded, there appear to have been time-lags with data generation and dissemination with RECOVER. Finally, involvement of the private sector, including donors and philanthropists, may help us get answers faster. In short, alternative methods to support research are needed for Long COVID, and relying on one major study, RECOVER, to provide all the answers is unrealistic.

In 2021, we called for Nursing to be involved in a collective and coordinated response to Long COVID, including repurposing pharmacological and non-pharmacological interventions for symptom management (Pinto et al., 2021). More research into symptom management is an important component of treating Long COVID (Pinto et al., 2022). This requires the key involvement of academic nursing to play a major role in developing clinical management algorithms and protocols at national, state, local, and community levels to optimize patient care.

While Long COVID may be one of the largest global health crises of our lifetime, there have been other public health challenges that we can learn from. The accumulation and dissemination of HIV science is one roadmap for responding to a public health crisis that moved from a fatal diagnosis in the 1980s, to the current day, where most individuals can expect a full life expectancy with good access to adherence to medication. We are optimistic that with coordinated efforts, with multidisciplinary teams, and in authentic partnership with patients, we can make great progress with the goal of prevention and cure of Long COVID. We are therefore announcing a broad call to develop at least one themed-section, if not a special issue, on Long COVID in 2023. We believe that Long COVID is a hidden public health crisis that has upended the lives of individuals worldwide. The urgency is found in the headlines. Every day that we are without effective treatment is another day a person experiences the consequences of Long COVID as noted in news headlines including loss of employment, housing, or even life. We aim to lead a themed section with a multidisciplinary group of Guest Editors, us, Dr. Rana Chakraborty and Dr. Natalie Lambert, and Editor-In-Chief, Dr. Melissa Pinto. However, we expect to expand opportunities to others.

Because of the depth and diversity of our Editorial board and focus for the journal, we encourage articles from nurses, and colleagues in a broad range of disciplines who can address one of the three areas that we have mentioned above or who are conducting primary research in any area related to Long COVID. All papers must have implications for research and/or clinical practice including for nurses. The roles of nurses in clinical practice and conducting research are broad, and therefore, we believe that scientists outside our field can also contribute and work collaboratively. An example of this can be found in this issue in an article by Huang et al. (2022) and a multidisciplinary team, that includes three nurses, and

colleagues from computer science, medicine, communication sciences, and basic science who have worked to begin to characterized Long COVID clinically.

We are interested in manuscripts that adopt a diverse approach to investigating and managing this condition. Some examples include, but are not limited to, clinical and biobehavioral characterization with attention to subgroups, mapping of trajectories, understanding of underlying risks for Long COVID, understanding cumulative exposures (multiple SARS-CoV-2 infections) on Long COVID symptomatology, symptom management interventions, and use of innovative methods for analysis of large datasets including natural language processing and machine learning. We encourage authors to collaborate with patient groups and include open-ended approaches in their data collection to ensure that patients' experiences with Long COVID are represented in both the data and interpretation of results. We will be launching a formal announcement soon. We look forward to reading your contribution.

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