A Fond Farewell

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A Fond Farewell

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Perhaps the most exciting summer of my professional career was 2013. On top of my customary administrative and clinical duties, I was part of a small team working on a tight timeline to publish the inaugural issue of the Journal of Patient-Centered Research and Reviews (JPCRR). Humble beginnings, indeed: journal staff consisted of a contracted managing editor (two, actually, in all-too-short succession), a fresh-out-of-college extern seeking editorial experience, and a single part-time copy editor. No interactive website, no publishing history, no subscriber list … but we did have email, a volunteer editorial board, and lots of enthusiasm. Moreover, we had an idea.

As quoted from the publisher’s first introductory message, scribed by Nick Turkal and Randall Lambrecht, leadership at Aurora Health Care (now Advocate Aurora Health) “recognized an ethical obligation to communicate original research findings [publicly] in the hope of improving quality outcomes” both within and beyond our organizational walls. In addition, they wanted to offer a no-fee journal to authors and readers that could reach a multidisciplinary, multispecialty clinical audience to directly inform their patient care, perhaps even pique interest in topics or new discoveries outside each reader’s area of expertise. Review articles would provide similar benefits and give contributing experts the means to investigate and answer the occasional esoteric question from a patient (or, in this editor’s case, inquisitive family members).

Choosing a journal title was a big decision but, surprisingly, turned out to be one of the easiest. Our mission of disseminating rigorous scientific research that was also geared to and accessible by lay patients already differed from most peer-reviewed journals. Still, I remember being astounded that only a handful of existing medical journals contained the word “patient” in their titles, and even fewer emphasized the contemporary concept of “patient-centered” care. It was so important to the JPCRR founders to foster that patient-caregiver informational relationship.

As professed in my very first editorial, “We should always make the link between our work and the care of the patient.”

To further this goal, JPCRR quickly embraced the use of patient-friendly article recaps. For me, the most gratifying moment during my tenure as editor-in-chief was when the parent of a child with a rare recurrent disorder contacted me about one of our articles. She felt that in its contents she had finally found the answer to their child’s vexing problem and now had hope of treatment. I have always believed, as an author and as an editor, that if a scholarly work aided in the care of just one patient, that it was worth the effort of researching, writing, and publishing.

That Was Then, This Is Now

A lot has changed over the past near-decade. JPCRR has made good on those lofty ambitions, growing exponentially in terms of reach, impact, and diversity of contributors — qualities reflected by its acceptance into PubMed Central and Web of Science, among other prestigious indexes. Its current footprint knows no borders, with readers hailing from Australia to Austria, Jamaica to Japan, Uruguay to Zimbabwe. While such advances are unquestionably for the better, I am most heartened to report that the journal’s core mission remains essentially unchanged.

In fact, I see the 9 articles published within this current issue as a microcosm of JPCRR’s publishing history. For starters, Olden and colleagues share their health system’s flexible patient engagement model, including a process to recruit, orient, and retain a large panel of patient advisors who provide patient-centered input into clinical operations and research. These investigators found that imparting a sense of every voice being important, along with consistent feedback, kept patient advisors engaged. In a similar vein, Fruytier et al describe a framework for monitoring patient engagement on community advisory boards in the context of health product research for Europeans with rare diseases, while Lieberz et al present the feasibility of a physical therapy mobility checkup along

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with patient feedback, solicited using a discrete choice experiment, on this investigative model of care. All three of these studies included patient engagement and span multiple clinical disciplines.

It is important to note that while patient engagement in the research process is appreciated, it is not a prerequisite for a study’s potential to contribute to improving patient-centered care. Five articles in this issue utilized larger patient databases to arrive at their findings. Storey and colleagues mined health care network data to discover that the diagnosis of diabetes in breast cancer survivors is associated with higher likelihood of anemia and infection and higher utilization of outpatient resources. The authors call for more tailored clinical guidelines for managing diabetes in this population. Knutsson et al., using data from the Swedish National Register for Spine Surgery, found greater improvements in pain and a disability index 1 year after spine surgery in those who reported being more satisfied with their surgical care and shared decision-making. Likewise, the research team of international adult Down syndrome expert (and JPCRR editor) Brian Chicoine drilled down into a large health system database to analyze prevalence of specific mental health, infectious disease, and endocrine conditions in individuals with Down syndrome. The general overview paper of this study was published in JPCRR last year. As the parent of an adult child with a trisomy, I am particularly gratified that we can publish such reports to raise awareness of the nuances of specific health issues in persons with trisomies or other lifelong disabilities.

Lastly, my colleagues and I report our own findings of low COVID-19 seroconversion among resident and fellow physicians in the greater Milwaukee area during the early phase of the pandemic. This article suggests that health care staff was well-protected from contagion despite challenging, uncertain circumstances and lies at the intersection of two of JPCRR’s specialized manuscript categories: COVID-19 and Medical Education.

Such Sweet Sorrow
I hope those of you who were “early adopters” of JPCRR — you know who you are — have enjoyed witnessing the journal’s rapid development as much as I have! I would be remiss not to extend my thanks to all who have contributed to the success of JPCRR and apologize that I cannot print the names of all those who have given their time and talent during these past 8 years. On a personal level, I thank my wife, Mary, and our 7 children for their constant support. I am grateful to the health system and journal publisher, Advocate Aurora Health, for making this journal free and convenient to all readers. I thank my superb longtime managing editor, Joe Grundle, without whom JPCRR could not have functioned or succeeded. Thanks to Julie Walters, the journal’s excellent production manager, and the editorial staff, system librarians, editorial board, and associate editors. Special thanks to all of the journal’s many submission reviewers, who are recognized in print annually (as in this issue) but cannot be appreciated enough; JPCRR only functions because of their very capable and innumerable volunteer hours.

Finally, a giant thank you to our readers — clinicians, researchers, and patients alike. As I stated in the inaugural editorial, this journal is, and remains, for you!

References

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