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Narrative Inquiry in Bioethics, Volume 11, Number 1, Spring 2021, pp.
35-37 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2021.0012>

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Reflections on Conducting Pediatric Mental Health Research as a Result of the COVID-19 Pandemic

Patrick W. Romani

The deadly disease caused by the novel coronavirus (SARS-CoV-2), better known as COVID-19, has produced a public health crisis around the world. Public health orders have been issued at various times throughout the pandemic to control community spread of COVID-19. These orders have ranged from highly restrictive stay-at-home orders to slightly less restrictive orders that limited the number of people dining in a restaurant. In response to these orders, many workplaces transitioned to remote work, and schools and daycares temporarily closed, thus requiring students to engage in virtual education. This meant that working families used to working and having their children receive education or care outside of the home suddenly needed to cope with the reality of needing to complete all of these activities together, under the same roof. Feelings of isolation and stress with managing demands of being a parent, educator, and professional have led to the untoward side effect of a mental health crisis pandemic.

At a time when mental health research was perhaps most important, universities placed significant restrictions on research practices. These restrictions included limiting in-person contact between research teams and participants and funding agencies instituting temporary freezes on distribution of research funds. Thus, researchers needed to modify protocols to maintain productivity during

this challenging period when they may also have been asked to be parents and educators for their children. My research protocols involved evaluating medicine-behavior interactions among children diagnosed with autism spectrum disorder (ASD) and delivering in-person trainings to school teams throughout the state of Colorado.

With a young son, now at home full-time and a wife who also worked in the healthcare field, these projects would have been adversely affected if the University had not already shut them down. While highly disappointing and stressful, I used this situation to leverage my experience both conducting research and using technology to deliver mental health services to maintain research productivity.

First, over the years, I had many interactions with the Institutional Review Board. During this time, reviewers became familiar with the types of projects I typically put forward for review and they had given me valuable feedback on how to format applications appropriately. Second, the advice a previous mentor had once given me took on new meaning. He told me that an effective psychologist should participate in 100% clinical activities and 100% research activities. That is, all clinical work should be done in a manner that can undergo a peer-review process and be published. I believe this mindset was important when considering the rest of my experience conducting research during the COVID-19 pandemic.

While I have personally heard the saying, “these are unprecedented times,” in reference to the challenges presented by the pandemic, this awful situation has led to unprecedented creativity and strength. I became connected with a multidisciplinary group of pediatric mental healthcare professionals in a collaborative manner to meet the ever-growing mental health needs of children and adolescents. We were particularly proud of our development and execution of partial hospitalization programs (PHP) via telehealth. These incredible clinical efforts deserved to be rigorously studied to (a) document these creative and innovative services and (b) ensure effective clinical care was being delivered to a population of children that sorely needed it.

An obvious area for investigation was evaluating the clinical outcomes of these programs. To my knowledge, the delivery of PHP services via telehealth had not been completed. Many hospital settings were charged with creating them, though. We worked to adapt our data monitoring procedures to track child progress with virtual PHP services. In one example, we used previously published research to guide procedures to coach parents of children diagnosed with intellectual or developmental disabilities (IDD) while conducting behavioral assessment and treatment procedures. The IDD PHP program delivered therapeutic services for 3.5 hours per day (a half-day PHP program). A behavior technician coached parents remotely to conduct behavioral therapy with their child while supervised by a psychologist and board-certified behavior analyst. Additionally, a social worker and psychiatrist met with the patients multiple times per week to identify after-care services and an effective medication regimen, respectively. The average reduction in child problem behavior from admission to discharge was 87.0% following a virtual PHP program. The previous two years' data from this PHP documented an average reduction in problem behavior of 87.5%. Thus, the virtual services were approximately equivalent to the in-person treatment.

While these results were encouraging, providers and families reported concerns. For example, families reported that their children would refuse to log into the virtual therapy sessions or that they struggled to balance work and be present for their child's therapy to ensure participation. Providers reported similar concerns. Anecdotally, providers expressed concern about their ability to coach patients and families using a virtual platform they had not previously been trained to use. Many healthcare providers (e.g., psychologists, social workers, psychiatrists) were not trained to deliver telehealth services in graduate school. Following approval from the IRB, my research team sent acceptability surveys to all providers in the PHPs delivering care and the children and families receiving this care via e-mail.

We had 44 providers and 19 children/caregivers enroll in the study. Overall, participants

recommended having at least a portion of therapeutic visits occur in person before transitioning to telehealth visits. Additionally, the preferred length of telehealth visits was approximately 1 hour, which was consistent between providers and children/caregivers.

While the aim of much of my research activities changed as a result of the COVID-19 pandemic, they were nonetheless important and fulfilling. Studies using medical providers or children/families experiencing a mental health crisis are vulnerable populations, particularly during a pandemic. Thus, the informed consent process was highly important to us when we could not physically see participants face-to-face. We ultimately received approval to use a post-card consent form. Since our project evaluated child, family, and provider perception of the telehealth services being delivered, the risks were minimal. This allowed our research team to avoid in-person encounters to document consent to participate. In addition to being able to use an electronic consent document, I believe our endeavors were successful because the surveys were accessed by participants remotely. My co-investigators and I could meet, develop the surveys, and execute the project at home, at night, or on weekends, whichever was most convenient. While conducting survey-based research was not any of our typical research procedures, we were able to adapt to our environment and find success. Third, I believe our research endeavors were successful because of the numerous interactions I had with the IRB prior to the pandemic. During the pandemic, IRB committees reported being overburdened by the number of pandemic-related research studies sent for review. This led to a slow-down in reviews. However, because IRB reviewers were familiar with the types of research protocols I usually put forward for review and have given me ample feedback on formatting applications, this application quickly moved through the institutional review process. Rapid reviews were important to my co-investigators and me because of the time-sensitive nature of the projects. Clinical activities truly did change on a daily basis. Thus, to conduct the evaluations described above, we needed to have the IRB applications approved quickly. We made it clear

in the cover letters that this research was to evaluate the effect of the pandemic on pediatric mental healthcare services. This, along with the previously discussed relationships, led to these successes. I would heavily encourage researchers to connect with their IRBs early and often to ensure understanding of preferred formatting characteristics of applications and to communicate idiosyncrasies of applications to ensure rapid review.

The COVID-19 pandemic has produced disruption around the world. Researchers were also affected by sometimes having their protocols abruptly stopped or needing to learn how to balance being a parent, educator, and researcher at the same time. A team of us modified our traditional research studies to continue evaluating important clinical outcomes for a high-need population of children. While this is a once in a lifetime experience (hopefully!), I believe there are activities every investigator can consider to improve their flexibility and skills to interact with the many stakeholders responsible for conducting a successful research study.

Remote Research Hinders Recruitment of a Diverse Sample

Beth Prusaczyk

Funding. This work was funded by the Institute for Public Health, Washington University in St. Louis

When the pandemic began, many researchers sought to capture the historical event from the perspectives of different groups of people. As someone who conducts research related to older adults, I knew the pandemic was a matter of life and death for them. Along with my colleagues, I wanted to understand the pandemic's impact on older adults from a "whole-person" perspective. We wanted to know how older adults' health and mental health were affected and what they saw as the positives to come out of the

pandemic, and how the pandemic fit within the other events in their lives or lifetime. Therefore, we began a study for this purpose and designed it, knowing it would have to be conducted during the pandemic. We did not have to transition a pre-existing study into this new environment and were able to plan for an entirely remote operation. For their part, the IRB reviewed and approved the study quickly, though we purposefully chose not to collect Protected Health Information (PHI) so that our study would not have some of the required restrictions and protocols necessary when collecting PHI. We had conducted studies online or over the phone before, but we were still not prepared for some of the challenges we faced.

From the beginning, we decided to make a concerted effort to recruit older adults who were low-income, Black or African-American, or identified as LGBTQ. We wanted to ensure our sample did not represent only more privileged older adults who were likely to navigate (and literally survive) the pandemic better than these other groups. However, our intentions to recruit a diverse sample were met with significant logistical challenges as we attempted to conduct a fully remote study during the pandemic. First, we knew we would be using an online survey since there was no way we could have in-person study visits at this time. An online survey would be the easiest and most efficient way to reach a large number of older adults. Second, we also wanted to compensate our participants for their time but what would normally be trivial tasks for an academic research shop—the purchasing of gift cards, printing letters, addressing and stamping envelopes, and putting them in the bulk mail—became impossible in the pandemic. Therefore, we decided we would send e-gift cards to the participants' email addresses. However, both the online survey and e-gift cards would require the older adult to have Internet access, have the proficiency to navigate the online survey, and use email; things not every older adult may have, especially those who are low-income. Fully virtual/remote research, whether done out of convenience or necessity, brings with it a significant cost to recruiting and enrolling diverse populations who are often excluded from research to begin with.