Journal of Pediatric Psychology, 45(9), 2020, 977–982
doi: 10.1093/jpepsy/jsaa079
Original Research Article

The Impact of COVID-19 on Pediatric Adherence and Self-Management

Jill M. Plevinsky,[1] PhD, Melissa A. Young,[2] PsyD, Julia K. Carmody,[3] PhD, Lindsay K. Durkin,[4] MS, Kaitlyn L. Gamwell,[1] PhD, Kimberly L. Klages,[1] PhD, Shweta Ghosh,[5] PhD, and Kevin A. Hommel,[1] PhD

[1]Center for Adherence and Self-Management, Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, [2]Department of Psychology, The Hospital for Sick Children, [3]Division of Gastroenterology and Nutrition, Boston Children's Hospital, [4]Department of Clinical Psychology, College of Health Professions, Rosalind Franklin University of Medicine and Science, and [5]Cancer and Blood Disorders Center, Department of Psychiatry and Behavioral Medicine, Seattle Children's Hospital

All correspondence concerning this article should be addressed to Kevin A. Hommel, PhD, Center for Adherence and Self-Management, Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, Cincinnati, OH 45229, USA. E-mail: Kevin.Hommel@cchmc.org

Received 27 June 2020; revisions received 7 August 2020; accepted 7 August 2020

Abstract

The COVID-19 pandemic has presented unique circumstances that have the potential to both positively and negatively affect pediatric adherence and self-management in youth with chronic medical conditions. The following paper discusses how these circumstances (e.g., stay-at-home orders, school closures, changes in pediatric healthcare delivery) impact disease management at the individual, family, community, and healthcare system levels. We also discuss how barriers to pediatric adherence and self-management exacerbated by the pandemic may disproportionately affect underserved and vulnerable populations, potentially resulting in greater health disparities. Given the potential for widespread challenges to pediatric disease management during the pandemic, ongoing monitoring and promotion of adherence and self-management is critical. Technology offers several opportunities for this via telemedicine, electronic monitoring, and mobile apps. Moreover, pediatric psychologists are uniquely equipped to develop and implement adherence-promotion efforts to support youth and their families in achieving and sustaining optimal disease management as the current public health situation continues to evolve. Research efforts addressing the short- and long-term impact of the pandemic on pediatric adherence and self-management are needed to identify both risk and resilience factors affecting disease management and subsequent health outcomes during this unprecedented time.

Key words: adherence; pediatric chronic illness; COVID-19; self-management.

Introduction

Under typical circumstances, approximately 50% of children and 65–90% of adolescents are nonadherent to their treatment regimens (Hommel et al., 2009; Logan et al., 2003; Rapoff, 2010). Nonadherence adversely impacts health outcomes and often leads to unnecessary treatment escalation (Carmody et al., 2019), as well as increased healthcare utilization (McGrady & Hommel, 2013). Given the prevalence and multi-faceted impact of nonadherence on pediatric health outcomes, the primary goal of this article is to identify and address how circumstances

surrounding the COVID-19 pandemic may affect adherence and self-management among youth with chronic medical conditions. This article will (a) provide an overview of the ways in which the COVID-19 pandemic may exacerbate barriers to adherence and self-management; (b) address healthcare disparities including how COVID-19 may result in greater consequences for adherence and self-management among underserved populations; and (c) offer suggestions for adapting and virtually delivering evidence-based interventions for monitoring and promoting pediatric adherence and self-management during COVID-19.

The pediatric self-management model (Modi et al., 2012) conceptualizes pediatric disease management as not only medication-taking but also healthcare maintenance tasks (e.g., blood draws, routine procedures, appointment attendance), adjunct therapies (e.g., physical therapy), and health behaviors (e.g., exercise, nutrition, sleep). The model poses that both modifiable (i.e., psychological symptoms, treatment regimens) and nonmodifiable (i.e., cognitive function, socio-demographics) factors influence adherence to disease management tasks across the following four levels: individual, family, community, and healthcare system. While the long-term impact of COVID-19 on health outcomes remains unknown, the immediate obstacles to self-management and treatment adherence are apparent and ever present across multiple systems, and each of these domains has been strained by the pandemic. Therefore, it is important to identify and address potential factors specific to the COVID-19 pandemic that may exacerbate poor adherence and self-management and highlight how pediatric psychologists can support these behaviors as the pandemic continues.

Medication Adherence and Healthcare Maintenance

Individual Factors

Aspects of physical health, psychological functioning, and cognitive processes that may ordinarily pose challenges for self-management and adherence among youth may be even more detrimental during the pandemic. A reduced focus on symptom monitoring and potential disruptions in routine medical care due to COVID-19 may result in a false sense of physical health or treatment effectiveness, thus leading to a potential lapse in treatment adherence (Hanghoj & Boisen, 2014). Psychological and behavioral problems are also associated with greater interruptions in pediatric adherence and self-management (Modi et al., 2012). While many are adjusting well to the stay-at-home orders, several experts indicate that there has been an increase in internalizing and externalizing symptoms in children and adolescents (Fegert et al., 2020). Deficits in cognitive processes (e.g., executive functioning) as a result of increased difficulties with mood (Robinson et al., 2015; Snyder, 2013) likely interfere with treatment adherence (Duke & Harris, 2014; Stern et al., 2018). Specifically, when youths' self-management responsibilities outweigh their cognitive capacity to successfully manage their treatment regimen, adherence and self-management behaviors suffer (Sonney & Insel, 2019). Additionally, increased variability in daily structure and routine during the pandemic may contribute to increased forgetting and decreased self-monitoring, both of which are very common barriers to adherence reported across almost all pediatric populations (Hanghoj & Boisen, 2014).

While youth and their families may have experienced some declines in functioning affecting adherence during this public health crisis, others may have noticed improvements in overall functioning that may support adherence and self-management. For one, the impact of daily stressors that may impact adherence such as missed school, participation in activities, and concerns about friends (Compas et al., 2012) likely have lessened due to social distancing guidelines. Additionally, at least one study among adults with asthma (e.g., Kaye et al., 2020) observed a positive change in rates of adherence during the COVID-19 pandemic, providing added support for improved adherence and self-management for a subgroup of individuals.

Family, Caregiver, and Community Factors

The impact of variability in daily structure and routine during the pandemic extends to caregivers and the family system. Potential changes within the family system, such as caregivers having to physically go into work or working from home while simultaneously providing childcare and/or filling the role of a classroom teacher, may place greater demands on youth to perform self-care tasks independently. In contrast, increased parental supervision and support in the home may benefit adherence and self-management. This may also be an opportune time to refine strategies to improve self-management in cases where parent support and supervision has increased. However, increased parental involvement may exacerbate difficulties in cases where parental over-involvement constrains the normative development of independent self-management, especially in adolescents and young adults who otherwise would be spending more time outside the home and taking more responsibility for their treatment regimen. Additionally, many children and adolescents receive support and medical care at school or via routine visits with in-home medical personnel to support self-management and adherence, yet in many cases these supports were abruptly withdrawn

due to school closings and other COVID-19-specific precautions.

Healthcare System Factors

During the COVID-19 pandemic, a host of medical procedures and treatments deemed non-critical, including healthcare maintenance appointments (e.g., physicals, routine follow-ups) were canceled (Center for Disease Control and Prevention, 2020). Consequently, youth who were previously receiving adjunct therapies (e.g., physical, occupational, or psychosocial therapies) experienced an abrupt stop and/or prolonged interruption in services. Under typical circumstances, such large gaps in treatment would be considered nonadherence. Moreover, the rapid adjustment to telemedicine was especially complex for pediatric healthcare systems, requiring medical centers to quickly adapt to using new technologies to provide care (Patel et al., 2020). Despite the gradual reopening of healthcare services, COVID-19-related precautions (e.g., limited capacity for face-to-face appointments, additional time to sanitize equipment, extended wait times, postponing of appointments) continue to pose threats to effective adherence and self-management. These rapid deaccelerations in care delivery likely contributed to unprecedented levels of nonadherence caused by healthcare system factors. Additionally, families with youth who are immunocompromised may now be fearful of returning to the hospital for fear of contracting COVID-19 (Headley, 2020). Overall, families' experiences with lapses in insurance coverage, the burden of the cost of these services, limited accessibility to in-home medical personnel, and worry about returning to routine in-person care during the pandemic are likely impacting pediatric disease management as well.

Physical Activity, Nutrition, and Sleep

Self-management behaviors that promote health outcomes such as exercise, nutrition, sleep, social interaction, and reducing sedentary behavior (e.g., screen time) have likely also been altered by the pandemic. For example, many youth received the bulk of their physical activity, nutritious meals, and social interaction with peers at school (Wechsler et al., 2000), which was closed to reduce the spread of COVID-19. Stay-at-home orders are critical for reducing the spread of COVID-19 and, on one hand, may create or exacerbate poor adherence and self-management; but they may also create opportunities for improved adherence and self-management. Some families may be cooking at home more leading to positive changes in diet, and a more flexible schedule may allow for more time for daily physical activity, relaxation for stress management, and hours of sleep per night.

Healthcare Disparities

Notably, the detrimental impacts of the COVID-19 pandemic that can exacerbate nonadherence are disproportionately higher in low-socioeconomic communities, compounding pre-existing health disparities. Over one-third of vulnerable populations have reported job losses and material hardship, which may have ended insurance coverage for many youth (Jenco, 2020; Millett et al., 2020; Van Dorn et al., 2020). Telehealth has offered benefits to vulnerable populations (i.e., removing transportation barriers, not missing work due to a child's medical appointment). Still, the pandemic created additional barriers to healthcare service delivery for underserved youth and their families, including barriers to telemedicine (e.g. inability to acquire appropriate technology, affordability of internet access), changes to medical appointment scheduling, difficulty accessing interpreter services, and visitor restrictions (e.g., only one caregiver being allowed to accompany the child) at the hospital. Quickly having to learn and navigate new technology systems to access healthcare can result in frustration and reduced utilization of care for these families as well (Children's Health Fund, 2020). Additionally, adherence and self-management support via psychology, social work or child life services may be limited given reduced capacity of these services due to limited staff hours, reduction in hospital revenue resulting in temporary discontinuation of services, or time needed to transition to telehealth platforms. Last, pediatric patients from underserved populations likely face reduced community supports (i.e., Boys and Girls Club) and reduced access to supportive health services via their school system (e.g., physical education, school nurse support). Given that the pandemic is differentially affecting underserved populations, they are more vulnerable and therefore at greater risk for poorer adherence and self-management as a result.

Monitoring and Promoting Adherence and Self-Management During COVID-19

It is incumbent on providers to proactively identify and address challenges to adherence and self-management with communication at the forefront of this process. Patient–caregiver–provider communication is critical to identifying adherence and self-management concerns and enacting individual, family, community, and healthcare system-level interventions to identify and develop effective solutions to barriers. For example, prior to the pandemic, a multidisciplinary urban clinic serving youth with HIV developed a robust and effective adherence support program, which relied on frequent clinic appointments, strong patient–provider relationships, and directly observed therapy. In response to the pandemic, the clinic

adapted this model and has been proactively contacting patients to assess medication needs, explain new clinic procedures, and provide relevant COVID-19 education to patients and families via frequent phone check-ins, directly observed therapy via telemedicine, and connecting patients with medication delivery services (Armbruster et al., 2020). While resource and time intensive, this approach may serve to mitigate risk factors and minimize consequences of nonadherence during this time.

For patients with chronic conditions, regular outpatient consultation and disease monitoring via telemedicine are critical to promoting continued adherence and self-management during the pandemic. While providers may have reservations about the effectiveness of telemedicine, pre-COVID-19 studies directly comparing traditional face-to-face versus telemedicine services have not found telemedicine to be inferior (Bahrani et al., 2017; Tates et al., 2017). Virtual communication platforms such as messaging embedded in the electronic medical record and HIPAA-compliant smartphone applications (e.g., Doximity) can also enable communication sharing in the absence of face-to-face visits. Many of these platforms also enable patients to share pictures, videos, and other helpful data so that providers can deliver targeted recommendations and support. Regardless of the platform, it is crucial for providers to recognize how various aspects of the pandemic may be contributing to poorer adherence and self-management as previously discussed. Providers should maintain a non-judgmental stance in order to yield more accurate information while avoiding evasive or defensive reactions (Rapoff, 2010). Many families are having to make compromises regarding how time and resources are spent, and it is critical that providers take the time to understand each family's circumstances in order to align and set the stage for collaborative problem-solving.

Increased assessment and monitoring are also recommended, as a variety of strategies exist to assess adherence, including assays, observation, electronic monitors, pill counts, provider estimates, and patient/caregiver report (McGrady et al., 2018). While access to bioassays may be restricted in the COVID-19 pandemic, others can be modified and implemented in the absence of face-to-face visits. Video observation (i.e., either live or recorded and shared electronically) can offer insight into how well a treatment regimen is performed (e.g., exercises for physical therapy, inhaler use, chest wall oscillation, etc.). Moreover, home observations can reveal contemporaneous variables related to treatment adherence that may be amenable to intervention (Mash & Terdal, 1988). Patient and parent reports including global reports, structured interviews and questionnaires, and daily diaries can be easily adapted to telemedicine with patients or parents recording specific adherence behaviors over time (Plevinsky et al., 2020). This format can be particularly useful for identifying problem areas and problem-solving with families around their daily routine in order to maximize adherence. Daily monitoring can improve adherence (Greaves et al., 2011) and facilitate caregiver monitoring and implementation of behavioral strategies to promote adherence (e.g., token economy).

Adherence apps are one form of intervention freely available to youth and families with access to a smart phone or tablet. These apps can provide scheduled reminders, allow users to track adherence behaviors over time, and allow users to share these reports with their providers (Carmody et al., 2019). App-based medication adherence interventions have been associated with short-term improvements in adherence (Badawy et al., 2017), therefore these solutions can serve to supplement behavioral health interventions via telemedicine, or bridge patients until more intensive adherence interventions (e.g., accessing a psychologist) are available.

Summary and Future Directions

Although the circumstances surrounding the COVID-19 pandemic and its broad impact (both positive and negative) across individual, family, community, and healthcare systems factors impact pediatric adherence and self-management, pediatric psychologists have the expertise to recognize, assess, and address these challenges to promote health outcomes. Future research ought to utilize a mixed-methods approach to examine how the COVID-19 pandemic has affected pediatric adherence and self-management in order to best inform clinical care and healthcare policy development. Research is especially needed to examine the extent to which the pandemic has exacerbated pre-existing pediatric healthcare disparities that affect these outcomes and health outcomes broadly. Digital tools, such as electronic adherence monitors, adherence-promotion mobile apps, and telehealth can be used to facilitate these efforts (Stiles-Shields et al., 2020).

Youth with chronic medical conditions and their families are resilient, and with support from their medical teams and behavioral health providers, can achieve optimal adherence and self-management despite the challenges brought about by the COVID-19 pandemic. However, we must acknowledge the potential enduring adverse effects of the pandemic on pediatric adherence and self-management. Long-standing adverse effects may come as a result of unemployment and associated loss of family healthcare benefits, as well as youth and caregiver mental health sequelae due to prolonged social isolation or other pandemic-induced stressors. Families may also receive reduced

support from illness-specific non-profit foundations due to financial strain. Furthermore, youth with comorbid learning disabilities may receive reduced special education support from schools in developing skills necessary for optimal adherence and self-management (e.g., problem-solving).

As the current public health situation evolves, pediatric providers will need to continue to support these youth and their families in being able to adapt to uncertainties, establish new routines, access healthcare (e.g., medications, medical interventions, healthcare services), and use new technologies (e.g., telemedicine, adherence apps) to promote disease management and reduce poor health outcomes.

Acknowledgments

We are grateful for support from the National Institutes of Health, including the National Institute of Child Health and Human Development (T32 HD068223).
Conflicts of interest: None declared.

References

Armbruster, M., Fields, E. L., Campbell, N., Griffith, D. C., Kouoh, A. M., Knott-Grasso, M. A., & , ... Agwu, A. L. (2020). Addressing health inequities exacerbated by COVID-19 among youth with HIV: expanding our toolkit. *Journal of Adolescent Health*, *67*, 290–295. https://doi.org/10.1016/j.jadohealth.2020.05.021

Badawy, S. M., Thompson, A. A., & Kuhns, L. M. (2017). Medication adherence and technology-based interventions for adolescents with chronic health conditions: a few key considerations. *JMIR mHealth and uHealth*, *5*, e202.

Bahrani, K., Singh, M. B., Bhatia, R., Prasad, K., Vibha, D., Shukla, G., & , ... Patterson, V. (2017). Telephonic review for outpatients with epilepsy—A prospective randomized, parallel group study. *Seizure*, *53*, 55–61. https://doi.org/10.1016/j.seizure.2017.11.003

Carmody, J. K., Plevinsky, J., Peugh, J. L., Denson, L. A., Hyams, J. S., Lobato, D., & , ... Hommel, K. A. (2019). Longitudinal non-adherence predicts treatment escalation in paediatric ulcerative colitis. *Alimentary Pharmacology & Therapeutics*, *50*, 911–918.

Center for Disease Control and Prevention (2020). *Interim CDC guidance on handling non-COVID-19 public health activities that require face-to-face interaction with clients in the clinic and field in the current COVID-19 pandemic*. https://www.cdc.gov/coronavirus/2019-ncov/hcp/non-covid-19-client-interaction.html Retrieved July 23, 2020.

Children's Health Fund (2020). *Telehealth helps with access barriers during COVID-19, but also underlies systemic inequities*. https://www.childrenshealthfund.org/telehealth-helps-with-access-barriers-during-covid-19-but-also-underlines-systemic-inequities/ Retrieved July 23, 2020.

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*, *8*, 455–580.

Duke, D. C., & Harris, M. A. (2014). Executive function, adherence, and glycemic control in adolescents with type 1 diabetes: A literature review. *Current Diabetes Reports*, *14*, 532.

Fegert, J. M., Vitiello, B., Plener, P. L., & Clemens, V. (2020). Challenges and burden of the coronavirus 2019 (COVID-19) pandemic for child and adolescent mental health: A narrative review to highlight clinical and research needs in the acute phase and the long return to normality. *Child and Adolescent Psychiatry and Mental Health*, *14*, 20. https://doi.org/10.1186/s13034-020-00329-3

Greaves, C. J., Sheppard, K. E., Abraham, C., Hardeman, W., Roden, M., Evans, P. H., & Schwarz, P; The IMAGE Study Group (2011). Systematic review of reviews of intervention components associated with increased effectiveness in dietary and physical activity interventions. *BMC Public Health*, *11*, 1–12.

Hanghoj, S., & Boisen, K. A. (2014). Self-reported barriers to medication adherence among chronically ill adolescents: A systematic review. *Journal of Adolescent Health*, *54*, 121–138.

Headley, M. (2020). *Managing medication adherence during COVID-19*. https://www.psqh.com/analysis/managing-medication-adherence-during-covid-19 Retreived July 23, 2020.

Hommel, K. A., Davis, C. M., & Baldassano, R. N. (2009). Objective versus subjective assessment of oral medication adherence in pediatric inflammatory bowel disease. *Inflammatory Bowel Disease*, *15*, 589–593. https://doi.org/10.1002/ibd.20798

Jenco, M. (2020). *Study: COVID-19 pandemic exacerbated hardships for low-income, minority families*. https://www.aappublications.org/news/2020/06/03/covid19hardships060320 Retrieved July 23, 2020.

Kaye, L., Theye, B. T., Smeenk, I., Gondalia, R., Barrett, M. A., & Stempel, D. A. (2020). Changes in medication adherence among patients with asthma and COPD during the COVID-19 pandemic. *The Journal of Allergy Clinical Immunology: In Practice*, *8*, 2384–2385.

Logan, D., Zelikovsky, N., Labay, L., & Spergel, J. (2003). The illness management survey: Identifying adolescents' perceptions of barriers to adherence. *Journal of Pediatric Psychology*, *28*, 383–392.

Mash, E. J., & Terdal, L. G. (1988). *Behavioral assessment of childhood disorders*. The Guilford Press.

McGrady, M. E., Holbein, C. E., Smith, A. W., Morrison, C. F., Hommel, K. A., Modi, A. C., & , ... Ramsey, R. R. (2018). An independent evaluation of the accuracy and usability of electronic adherence monitoring devices. *Annals of Internal Medicine*, *169*, 419–422. https://doi.org/10.7326/m17-3306

McGrady, M. E., & Hommel, K. A. (2013). Medication adherence and health care utilization in pediatric chronic illness: A systematic review. *Pediatrics*, *132*, 730–740.

Millett, G. A., Jones, A. T., Benkeser, D., Baral, S., Mercer, L., Beyrer, C., & , ... Sullivan, P. S. (2020). Assessing differential impacts of COVID-19 on black communities. *Annals of Epidemiology*, *47*, 37–44. https://doi.org/10.1016/j.annepidem.2020.05.003

Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., & , … Drotar, D. (2012). Pediatric self-management: A framework for research, practice, and policy. *Pediatrics*, *129*, e473–e485. https://doi.org/10.1542/peds.2011-1635

Patel, P. D., Cobb, J., Wright, D., Turer, R. W., Jordan, T., Humphrey, A., & , … Rosenbloom, S. T. (2020). Rapid development of telehealth capabilities within pediatric patient portal infrastructure for COVID-19 care: Barriers, solutions, results. *Journal of the American Medical Informatics Association*, *27*, 1116–1120. https://doi.org/10.1093/jamia/ocaa065

Plevinsky, J. M., Gutierrez-Colina, A. M., Carmody, J. K., Hommel, K. A., Crosby, L. E., McGrady, M. E., & , … Modi, A. C. (2020). Patient-reported outcomes for pediatric adherence and self-management: A systematic review. *Journal of Pediatric Psychology*, *45*, 340–357. https://doi.org/10.1093/jpepsy/jsz096

Rapoff, M. A. (2010). *Adherence to pediatric medical regimens* (2nd edn). Springer Science & Business Media.

Robinson, K. E., Pearson, M. M., Cannistraci, C. J., Anderson, A. W., Kuttesch, J. F., Wymer, K., & , … Compas, B. E. (2015). Functional neuroimaging of working memory in survivors of childhood brain tumors and healthy children: Associations with coping and psychosocial outcomes. *Child Neuropsychology*, *21*, 779–802.

Snyder, H. R. (2013). Major depressive disorder is associated with broad impairments on neuropsychological measures of executive function: A meta-analysis and review. *Psychological Bulletin*, *139*, 81–132.

Sonney, J., & Insel, K. C. (2019). Exploring the intersection of executive function and medication adherence in school-age children with asthma. *Journal of Asthma*, *56*, 179–189. https://doi.org/10.1080/02770903.2018.1441870

Stern, A., Driscoll, C. F. B., Ohanian, D., & Holmbeck, G. N. (2018). A longitudinal study of depressive symptoms, neuropsychological functioning, and medical responsibility in youth with spina bifida: Examining direct and mediating pathways. *Journal of Pediatric Psychology*, *43*, 895–905.

Stiles-Shields, C., Plevinsky, J. M., Psihogios, A. M., & Holmbeck, G. N. (2020). Considerations and future directions for conducting clinical research with pediatric populations during the COVID-19 pandemic. *Journal of Pediatric Psychology*, *45*, 720–724. https://doi.org/10.1093/jpepsy/jsaa055

Tates, K., Antheunis, M. L., Kanters, S., Nieboer, T. E., & Gerritse, M. B. (2017). The effect of screen-to-screen versus face-to-face consultation on doctor-patient communication: An experimental study with simulated patients. *Journal of Medical Internet Research*, *19*, e421.

Van Dorn, A., Cooney, R. E., & Sabin, M. L. (2020). COVID-19 exacerbating inequalities in the US. *Lancet (London, England)*, *395*, 1243–1244.

Wechsler, H., Devereaux, R. S., Davis, M., & Collins, J. (2000). Using the school environment to promote physical activity and healthy eating. *Preventative Medicine*, *31*, S121–S137. https://doi.org/10.1006/pmed.2000.0649