Wisconsin's COVID-19 Safer-at-Home Order: Perspectives on Pain, Stress, and Functioning From Pediatric Patients With Chronic Pain

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ABSTRACT

Background: Given that enforced quarantine is associated with psychological distress, our objective was to understand factors that either helped or harmed pediatric chronic pain patients during Wisconsin's 2020 safer-at-home quarantine.

Methods: We reviewed the electronic medical records of 145 pediatric chronic pain patients seen at the Jane B. Pettit Pain and Headache Center, Children's Wisconsin, between April 1 and July 30, 2020.

Results: Stress and poor/disturbed lifestyle factors were primary contributors to increased pain. Over half of the sample (58.7%) reported COVID-related stressors as contributing to increased stress levels. Coping, engagement, and socialization were primary contributors to patient functioning.

Conclusions: Continued access to clinicians who can help with coping and stress management techniques is necessary for the well-being of pediatric chronic pain patients during a quarantine.

BACKGROUND

Chronic pain is typically defined as pain lasting 3 or more months and can be either recurrent or persistent.[1] Pediatric chronic pain affects approximately 1 in 4 children[1] and is associated with anxiety, depression, fatigue, and impaired physical and academic functioning.[2] Known deficits in academic functioning, including school attendance, were of particular importance when COVID-19 disrupted in-person schooling.[3] While the negative psychological effects of quarantine are well established, factors that affect mental health during quarantine are not well understood.[4] Identification of such factors may mitigate the negative effects of a quarantine, especially for vulnerable populations, such as youth with chronic pain.

To slow the spread of COVID-19, governments around the world issued safer-at-home (SAH) orders, with the state of Wisconsin issuing an order on March 25, 2020. Historically, forced quarantine has been associated with a number of problems.[5] For example, during lockdowns for Severe Acute Respiratory Syndrome (SARS), 28.9% of people had symptoms of posttraumatic stress disorder (PTSD), and 31.2% exhibited signs of depression.[6] During COVID-19 quarantines, a study found a 42.5% increase in anxiety, 74.3% increase in depression, and 63.3% increase in suicidal thoughts.[7] While the majority of such studies have been conducted on adults, children are similarly affected. Our objective was to understand factors that positively or negatively affected pediatric chronic pain patients' pain, stress, and functioning during the COVID-19 quarantine period in Wisconsin.

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METHODS

Study Design and Setting

This retrospective chart review included patients seen at the Jane B. Pettit Pain and Headache Center, a multidisciplinary pediatric chronic pain and headache clinic located at Children's Wisconsin. Data from patients with follow-up or therapy appointments from April 1, 2020, through July 30, 2020, were included in the study. The hospital Institutional Review Board approved the study.

Table 1. Patient Demographics and Pain Characteristics, N = 145

Age, years; mean (SD)	13.8 (3.1)
Age group, n (%)	
Children (≤12 years)	46 (31.7)
Adolescents (≥13 years)	99 (68.3)
Sex, n (%)	
Female	107 (73.8)
Male	38 (26.2)
Race, n (%)	
White	121 (83.4)
Black	17 (11.7)
Asian	1 (0.7)
Unknown	4 (2.8)
Mixed	2 (1.4)
Ethnicity, n (%)	
Hispanic	18 (12.4)
Not Hispanic	124 (85.5)
Unknown	3 (2.1)
Primary pain location, n (%)	
Head	106 (73.1)
Limbs (arms/legs)	7 (4.8)
Abdomen	17 (11.7)
Back	4 (2.8)
Other	11 (7.6)
Number of appointments, N	310
Mean	2.6
SD	2.7
Appointment type, n (%)	
Follow-up	260 (83.9)
Therapy	50 (16.1)
Appointment format, n (%)	
Virtual	252 (81.3)
In-person	45 (14.5)
Phone	13 (4.2)

Measures

All data were extracted from each patient's electronic medical record (EMR). Demographic data included patient age, sex, race, and ethnicity. Other data included pain intensity and pain location, appointment date, appointment type (follow-up or therapy), and appointment format (virtual, in-person, or phone).

The primary outcomes included patient responses to questions that were designed specifically to capture factors that were helping or hurting patients' pain, stress, and functioning during the quarantine. Immediately after the SAH order was issued, a panel of experts in pediatric chronic pain at Children's Wisconsin developed a set of questions to capture these factors. Clinicians then posed the questions to patients at follow-up or therapy appointments and recorded patient responses in the EMR. These "COVID-19 questions" included the following:

1. "What are you doing now that is helping your pain?"
2. "What are you doing now that is not helping your pain?"
3. "What are you doing now that is helping your stress?"
4. "What are you doing now that is not helping your stress?"
5. "What are you doing now to help your functioning?"
6. "On a scale of 0 to 10, how stressed are you, with 0 being no stress and 10 being the worst stress possible?"[8]

Data Analysis

Descriptive statistics were used to characterize the sample (including COVID-19 question 6). Patient responses to COVID-19 questions 1 through 5 were analyzed with interpretive phenomenological analysis (IPA).[9] IPA utilizes inductive analytic techniques, which emphasize data interpretation at multiple levels. Three study team members (a medical student, clinical psychologist, and research psychologist) contributed to the thematic analysis. The first step required coders to read and reread patient responses to gain familiarity with responses and response types. Second, coders generated initial codes intended to be short, exploratory comments that were descriptive, linguistic, or conceptual in nature.[9] Next, coders collaboratively identified themes based on initial codes, moving toward the development of broader, emergent themes. In a collaborative group process, coders discussed the emergent themes to ensure that they accurately reflected participant data. Emergent themes were grouped to create superordinate themes through abstraction and subsumption.

RESULTS

A total of 145 patients gave responses to the COVID-19 questions at a minimum of 1 appointment (range 1–17 appointments). The most common pain location was the head (73.1%) followed by abdominal pain (11.7%), and pain onset ranged from 4 months to 7 years. For a subset of patients (n = 54; 37.2% of sample), data were available on current pain intensity. Mean rating was 1.94 (SD 2.5), with responses ranging from 0 to 8. For a subset of patients (n = 100; 69.0% of sample), data were available on stress ratings at the time of the appointment. Mean rating was 3.3 (SD 2.8), with responses ranging from 0 to 10. Data are shown in Table 1.

Qualitative Results

Superordinate and emergent themes based on patient responses to each COVID-19 question are shown in Table 2. Each superordinate theme (in bold below, for each question) characterized the majority of the sample.

What are you doing now that is helping your pain?

Superordinate themes: **(1) lifestyle factors, (2) medical interventions, (3) psychosocial/stress management, and (4) other.** Lifestyle factors was the most common response (52.3%). Common emergent themes were drinking water and increasing physical activity. About half the sample (50.5%) reported medical interventions, and almost a third (27.1%) reported psychosocial/stress management factors, including practicing stress management skills and engaging in pleasurable activities. Approximately 23.4% reported other factors (eg, using a heat pack).

What are you doing now that is not helping your pain?

Superordinate themes: **(1) stress, (2) poor/disturbed lifestyle factors, (3) other, and (4) treatment plan not working.** Stress, including school stress, emotional factors, and pain triggers, was reported by 50.8% of patients, and 46.3% reported poor/disturbed lifestyle factors, such as disturbed sleep patterns. Other factors (eg, environmental triggers such as sounds and odors) were reported by 15.9%. Some patients (13.0%) reported that an aspect of their treatment plan was not working (primarily medications).

What are you doing now that is helping your stress?

Superordinate themes: **(1) pleasurable activities, (2) stress management/coping skills, (3) school, (4) pets, and (5) other.** Most patients (56.7%) reported that pleasurable activity helped their stress, including music, electronics, and time with friends/family. Almost half (48.9%) reported a specific coping skill as beneficial (eg, working with their pain psychologist), 13.3% reported school-related factors (eg, keeping a structured school schedule), 11.1% reported pets, and 7.8% reported some other factor (eg, taking prescribed medication).

What are you doing now that is not helping your stress?

Superordinate themes: **(1) COVID-19-related stressors, (2) anxiety/general and family stressors, and (3) other.** Over half of patients (58.7%) reported COVID-19-related stressors, including stress stemming from quarantine, worry about the safety of family and friends, and stress from adjusting to virtual school. Anxiety/general and family stressors were reported by 39.7%, and 28.6% reported other reasons for worsening stress (too much screen time or increased pain).

What are you doing now to help your functioning?

Superordinate themes: **(1) coping, engagement, and socialization; (2) lifestyle factors; (3) pets; and (4) other.** Most (57.0%) reported some type of coping, engagement, or socialization factor as helping them function. Examples included engaging in pleasurable activities and socializing with friends/family. One patient reported engaging in socially distanced gatherings that included friends meeting but staying in their own cars. Adjusting lifestyle factors also was reported (42.0%). Examples included better sleep hygiene and eating healthier foods. Time with pets was reported as helping patients' function (6.9%). Finally, 5.8% reported other factors, such as taking prescribed medications.

Table 2. Superordinate and Emergent Themes for Key COVID-19 Questions

Superordinate Theme	Emergent Themes
What are you doing now that is helping your pain?	
Lifestyle factors (52.3%)	Drinking water, being more physically active, getting more sleep or rest, eating healthier and having regular meals
Medical interventions (50.5%)	Engaging in physical or occupational therapy, taking prescribed medications
Psychosocial/stress management (27.1%)	Practicing stress management skills, engaging in pleasurable activities, structuring activities throughout the day
Other (23.4%)	Getting new eye glasses, other
What are you doing now that is not helping your pain?	
Stress (50.8%)	Increased school stressors, increased family or social stressors
Poor/disturbed lifestyle factors (46.3%)	Disturbed sleep patterns, eating unhealthy food or skipping meals, not drinking enough water, not getting enough physical activity, increased screen time
Other (15.9%)	Environmental triggers such as light, sound, or odors; other
Treatment plan not working (13.0%)	Prescription medications not helping or increasing pain, not taking prescription medications
What are you doing now that is helping your stress?	
Pleasurable activities (56.7%)	Pleasurable activities (eg, music, self-care, social media, relaxation), socializing with friends and family, getting physical activity
Stress management/ coping skills (48.9%)	Practicing stress management and coping skills
School (13.3%)	Prioritizing and taking charge of school work
Pets (11.1%)	Spending time with pets
Other (7.8%)	Taking prescribed medications, pain is improving, better sleep hygiene, other
What are you doing now that is not helping your stress?	
COVID-related stressors (58.7%)	School stress induced by online adjustment, social isolation and missing friends, worries about getting COVID or quarantining
Anxiety/general and family stress (39.7%)	Worrying about family conflict
Other (28.6%)	Too much screen time, pain or illness, poor sleep hygiene, eating unhealthy or infrequently
What are you doing now to help your functioning?	
Coping, engagement, socializing (57.0%)	Engaging in pleasurable activities, socializing with friends and family, keeping up with school work
Lifestyle Factors (42.0%)	Getting physical activity, drinking more water, better sleep hygiene, eating healthier and more frequent meals
Pets (6.9%)	Taking care of and playing with pets
Other (5.8%)	Taking prescribed medication, complementary medicine (eg, yoga), other

For each question, patients' responses could be categorized multiple times across the superordinate themes but only once within a superordinate theme.

DISCUSSION

This study evaluated factors that affected pain, stress, and functioning for pediatric chronic pain patients during the COVID-19

SAH order period. Contrary to expectations, patients reported relatively low pain and stress levels during this timeframe. Key findings included the following: (1) lifestyle factors were as important as medical management to pain reduction; (2) stress and poor/disturbed lifestyle factors were the most common reasons for increased pain; (3) stress was increased by worries about COVID-19 and other general stressors but was deceased by engaging in pleasurable activities and stress management/coping skills; and (4) coping and lifestyle factors were the most frequently reported as helpful to patients' functioning.

This study also highlighted the ups and downs that are common in chronic pain. For example, flexibility with online schooling helped patients adapt to quarantine, but the increased screen time exacerbated pain for some. Those who used the increased leisure time afforded by remote schooling to get/play outside reported lower pain and stress, while others found themselves more sedentary. Spending more time than usual with friends/family also had either positive or negative effects.

Strengths and Limitations

Almost nothing is known about the impact of quarantine on pediatric chronic pain patients. This study highlights factors that both helped and hurt patients' pain, stress, and functioning during the Wisconsin SAH order period in 2020. The subjective nature of qualitative data and lack of standardized questionnaires limit the study's replicability. Data were missing, in part, due to staff shortages during the quarantine and, in part, due to the retrospective design. Nonetheless, the data shed light on important facets of patient well-being during the pandemic.

CONCLUSIONS

Continued access to clinicians who can help with coping and stress management techniques is necessary for the well-being of pediatric chronic pain patients during a quarantine.

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REFERENCES

1. King S, Chambers CT, Huguet A, et al. The epidemiology of chronic pain in children and adolescents revisited: a systematic review. *Pain*. 2011;152(12):2729-2738. doi:10.1016/j.pain.2011.07.016

2. Harrison L, Wilson S, Munafò MR. Exploring the associations between sleep problems and chronic musculoskeletal pain in adolescents: a prospective cohort study. *Pain Res Manag.* 2014;19(5):e139-e145. doi:10.1155/2014/615203

3. Gorodzinsky AY, Hainsworth KR, Weisman SJ. School functioning and chronic pain: a review of methods and measures. *J Pediatr Psychol*. 2011;36(9):991-1002. doi:10.1093/jpepsy/jsr038

4. Almomani EY, Qablan AM, Almomany AM, Atrooz FY. The coping strategies followed by university students to mitigate the COVID-19 quarantine psychological impact. *Curr Psychol.* 2021;40(11):5772-5781. doi:10.1007/s12144-021-01833-1

5. Gensini GF, Yacoub MH, Conti AA. The concept of quarantine in history: from plague to SARS. *J Infect.* 2004;49(4):257-261. doi:10.1016/j.jinf.2004.03.002

6. Hawryluck L, Gold WL, Robinson S, Pogorski S, Galea S, Styra R. SARS control and psychological effects of quarantine, Toronto, Canada. *Emerg Infect Dis.* 2004;10(7):1206-1212. doi:10.3201/eid1007.030703

7. Kaparounaki CK, Patsali ME, Mousa DV, Papadopoulou EVK, Papadopoulou KKK, Fountoulakis KN. University students' mental health amidst the COVID-19 quarantine in Greece. *Psychiatry Res.* 2020;290:113111. doi:10.1016/j.psychres.2020.113111

8. Karvounides D, Simpson PM, Davies WH, Khan K, Weisman K, Hainsworth K. Three studies supporting the initial validation of the Stress Numerical Rating Scale-11 (Stress NRS-11): a single item measure of momentary stress for adolescents and adults. *Pediatr Dimens*. 2016;1(4):105-109. doi:10.15761/PD.1000124

9. Smith JA, Flowers P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method and Research. *SAGE*; 2009.

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