REGULAR ARTICLE

Perspectives on Mental Health Evaluation in Pediatric Pulmonary Hypertension: A Call to Action

Claire Parker, RN, MSN, CPNP-AC
University of California San Francisco
Benioff Children's Hospital
Pediatric Critical Care
San Francisco, CA

Elise Whalen, MSN, APRN, FNP-C, CPN
Baylor College of Medicine
Texas Children's Hospital
Pediatric Pulmonology
Houston, TX

Julia McSweeney, RN, MSN, CPNP
Boston Children's Hospital
Department of Nursing/Patient Services
Boston, MA

Anna Brown, DNP, APRN, RN, CPNP-BC
Vanderbilt University Medical Center
Monroe Carell Jr. Children's Hospital
Pediatric Pulmonary Medicine
Nashville, TN

J. Usha Raj, MD, MHA
Department of Pediatrics
University of Illinois at Chicago
Chicago, IL

Mary P. Mullen, MD, PhD
Boston Children's Hospital
Harvard Medical School
Boston, MA

Background: The already high rates of anxiety and depression among healthy children have increased further since the COVID-19 pandemic began in early 2020. Prepandemic data suggest children with chronic disease were already experiencing increased rates of anxiety and depression as compared to their healthy peers. There is currently a paucity of literature on the prevalence of anxiety and depression in patients with pediatric pulmonary hypertension. In addition, there are no practice recommendations regarding mental health screening in this population.

Implications for Providers: We evaluated provider perception of mental health screening at 14 pediatric pulmonary hypertension care centers across the United States and Canada using a cross-sectional survey. Thirty-seven providers from 14 pediatric pulmonary hypertension centers in North America completed the survey.

Conclusion: Health care providers caring for pediatric pulmonary hypertension patients perceive their patient cohort to frequently experience anxiety and depression. In addition, these providers believe that their patients would benefit from formalized, and routine, assessment of anxiety and depression with referral to mental health services as appropriate. This highlights the need to better understand the prevalence of anxiety and depression in pediatric pulmonary hypertension patients and to establish formal mental health screening practices within pediatric pulmonary hypertension care centers.

PERSPECTIVES ON MENTAL HEALTH EVALUATION IN PEDIATRIC PULMONARY HYPERTENSION

Current studies on rates of anxiety and depression suggest an increased prevalence in pediatrics, with 25% of youth worldwide experiencing symptoms of depression and 20% of youth worldwide facing symptoms of anxiety.[1] This rate has increased from before COVID-19 pandemic times, highlighting the mental health toll of worldwide illness and isolation. There are few data on the pandemic's effect on the rates of anxiety and depression in children with chronic disease. Prepandemic data suggest children with chronic illness were already experiencing increased rates of anxiety and depression as compared to their healthy peers. In a meta-analysis, Pinquart and Shen evaluated 350 studies and 450 subsamples with the conclusion that children and adolescents with chronic illness have higher rates of depression than their healthy peers, which in turn can negatively influence the child's chronic medical condition.[2]

Pulmonary hypertension (PH) is a chronic disease characterized by a marked elevation of pressures within the pulmonary vasculature, associated with many diverse cardiac, pulmonary, and other systemic disorders.[3] It has

Key Words—mental health, anxiety, depression, pulmonary hypertension, pediatric
Correspondence: Claire.parker@ucsf.edu
Disclosure: The authors have no relevant personal financial relationships to disclose.

significant morbidity and mortality with poor overall patient outcomes despite new therapies.[4] Studies have reported that pediatric PH patients have a significantly lower quality of life than other chronic disease cohorts as well as healthy norms, suggesting a need to assess and treat this patient cohort holistically rather than with a disease-specific approach.[5,6] One important aspect of quality of life is mental health. Currently, there are limited data on the prevalence of anxiety and depression among pediatric PH patients. In addition, there are no practice guidelines or recommendations regarding anxiety and depression screening practices in PH clinics. This paper examines current provider and care team perspectives on anxiety and depression in their pediatric PH patient cohorts.

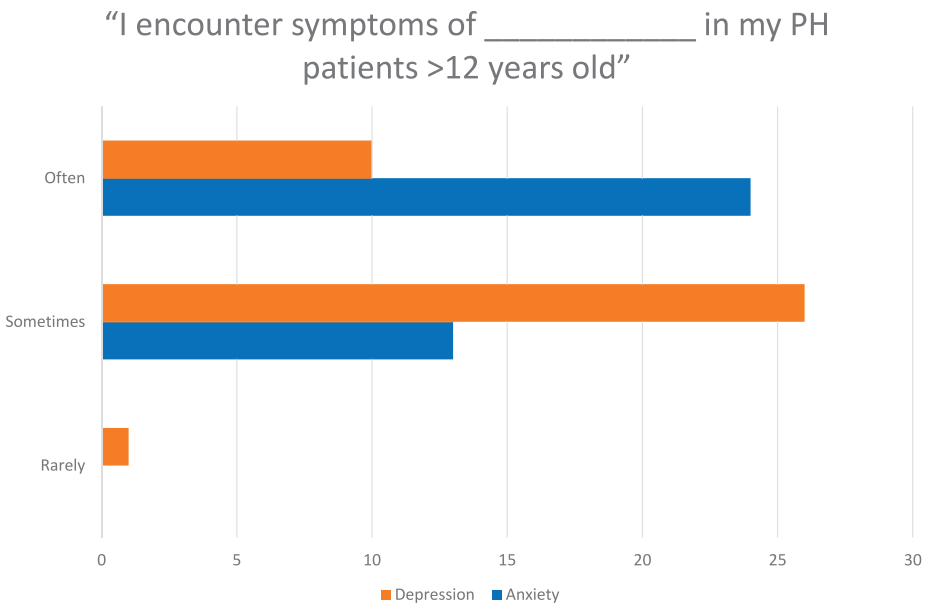

Figure 1: Providers encounter symptoms of depression and anxiety in pediatric pulmonary hypertension patients >12 years old.

METHODS

With increasing recognition of anxiety and depression among pediatric PH patients and growing concern, a mental health subcommittee was formed within the Advanced Healthcare Provider Committee of the Pediatric Pulmonary Hypertension Network (PPHNet). We developed a formal survey (REDCap) to characterize health care provider practices and perspectives of anxiety and depression in pediatric PH patients (Supplemental Material). The REDCap survey was distributed via email to staff at all 14 PPHNet sites. Participants were invited to respond to the survey individually, and as such there was the potential for more than 1 survey from each center.

Aside from basic provider demographics including the name of the institution and participant's profession, the survey consisted of 18 questions. Four questions asked participants to place a mark on a sliding scale, from *disagree* to *agree*, regarding the perceived benefit of formalized depression and anxiety assessment as well as resources available should a referral be required. The remaining questions were polar questions about perceived frequency of depression and anxiety, mental health screening practices, and resources available to the center. Several open-ended questions allowed participants to specify tools used to screen for depression and anxiety, describe barriers associated with the assessment of mental health and referral for services, and comment on existing mental health resources available to the practice and any additional relevant comments about pediatric PH patients and depression and anxiety. The results were analyzed descriptively with categorical data reported as percentages.

FINDINGS

The survey was returned by 37 respondents from 14 pediatric PH centers in North America. Respondents included 13 MDs, 13 NPs, 6 RNs, 3 social workers, 1 psychologist, and 1 child life specialist. Many of the institutions had respondents from more than 1 profession. Most programs did not have representation from every profession.

When asked if they encountered symptoms of anxiety in PH patients >12 years old, 24 of the respondents replied *Often*, while 13 replied *Sometimes*. None of the respondents replied *Rarely*. When asked if they encountered symptoms of depression in their patients, 10 replied *Often*, 26 replied *Sometimes*, and 1 replied *Rarely*. (Figure 1) Respondents were then asked to rate several statements from 0 to 100, with 0 representing *disagree* and 100 representing *agree*. When asked to rate the statement "My PH patients >12 years old would benefit from a formalized, and routine, assessment for anxiety with referral to mental health services," respondents had a mean score of 94.24 (range 60-100). When asked to rate the same statement in relation to depression, the mean response was 91.82 (range 59-100). For the statement "If a PH patient screens positive for anxiety, there are appropriate mental health resources for referral," the mean score was 65.97 (range 10-100). The response for the same statement for depression had a mean score of 69.05 (range 10-100).

Only 3 of the 37 respondents implemented screening tools for anxiety in their clinical practice. One psychologist and 1 social worker used the GAD7 to screen for anxiety with clinical concern. A child life therapist screened for anxiety with each visit, the method of which is unclear. Only 2 respondents implemented screening tools for depression in their clinical practice. One psychologist uses the PHQ9 with clinical concern. One child life specialist implemented screening for depression with clinical concern but does not list the tool that is used. Of the 14 pediatric PH programs, 13 have access to a social worker, and 6 have access to a psychologist. Five of the programs had respondents from different professions, some answering *yes* and others answering *no* when

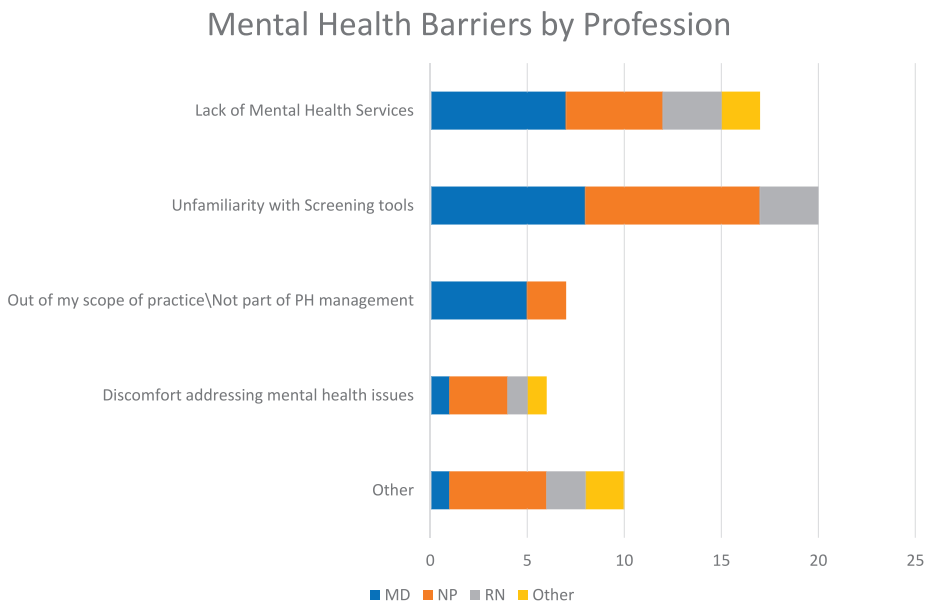

Figure 2: Barriers to accessing mental health services by profession.

asked about access to a psychologist. Two programs did not have access to a psychologist.

When asked about barriers to mental health services, respondents could check all that apply. Unfamiliarity with screening tools was the most frequently cited barrier (57%), followed by lack of mental health services (48%), out of my scope of practice/not part of PH management (20%), and discomfort addressing mental health issues (17%). Ten respondents identified other barriers with free text. Other barriers fit into 4 categories including clinic time, patient location, patient family buy-in, and immediate availability of services. (Figure 2)

Respondents were asked to comment via free text about the mental health services that are available to their practice. Seven respondents indicated that appropriate mental health services were available and accessible to their practice. Sixteen comments mentioned that services were available, however, there were access issues including long wait lists, limited referrals in the community, insurance issues, social work and psychology over-extension, and lack of direct mental health access within the PH clinic. Three comments directly pointed to a lack of available services, specifically citing paucity of services in the community, where it could be convenient for families and used for long-term follow up.

DISCUSSION

The pediatric PH care team members surveyed describe recognizing symptoms of anxiety and depression in their patients >12 years old. This is not surprising given the national rates of anxiety and depression among healthy adolescents and the knowledge that children with chronic illness have higher rates of anxiety and depression than their healthy peers.[1,2] More than half of the respondents recognize symptoms of anxiety in their patients *often* and symptoms of depression *sometimes*. While these providers agree that adolescent PH patients would benefit from regular assessment of anxiety and depression, there is lower confidence that there are appropriate mental health services to refer their patients to if they screen positive.

Despite provider perception of anxiety and depression in PH patients >12 years old, none of the MDs, NPs, or RNs surveyed screen for anxiety and depression with a validated tool with any regularity. It is possible that inclusion of more social workers or psychologists trained to care for PH patients as respondents in this survey would have resulted in increased reporting of screening practices. In a comparable chronic pediatric disease, the Cystic Fibrosis Foundation and the European Cystic Fibrosis Society have published guidelines to make screening for anxiety and depression part of general care for cystic fibrosis patients.[7] Liu et al published a QI project at Seattle Children's Hospital implementing the suggested guidelines into their cystic fibrosis practice. They found a prevalence of anxiety and depression in their population similar to other chronic disease states. Most importantly, they were able to leverage their findings to improve mental health services at their center.[8]

Of those surveyed, all but 1 of the programs have direct access to a social worker in their clinical practice. At least 1 of these social workers screens for anxiety in patients where there is clinical concern. The survey did not elicit more detailed information regarding the social worker's role in mental health screening within the PH practice. While a social worker seems to be a consistent member of a PH program, the presence of a psychologist to the multidisciplinary PH team varies among centers. More interestingly, different members from the same program at 5 of the 14 institutions gave conflicting answers as to access to a psychologist within their practice. At least 2 free-text comments alluded to having a psychologist within their division, however, the psychologist did not provide care for PH patients. This may speak to the fact that mechanisms of accessing mental health services at many institutions is unclear, leaving room for improvement.

All PH care team members surveyed recognized multiple barriers to providing mental health access to their PH patients >12 years old. Some of these barriers may be overcome by PH practice changes, while others are larger systems issues. Eight MDs, 9 NPs, and 3 RNs were not familiar with screening tools for anxiety and depression. Five MDs and 2 NPs noted mental health screening to be out of their scope of practice/not part of PH care. Six providers stated that they were uncomfortable addressing mental health issues. If PH providers followed the lead from their cystic fibrosis colleagues and integrated mental health screening into routine PH care, it would potentially increase provider familiarity with screening tools and their willingness to address anxiety and depression as part of routine clinical

practice. Additionally, routine screening will quantify prevalence of anxiety and depression and highlight the need for improved timely access to mental health services. While integrating routine mental health screening may not alleviate all of the barriers noted by providers, it may highlight faults within the system and serve as a call to action for hospital and governmental leadership to improve access to pediatric mental health care.

LIMITATIONS

One main limitation of this survey is the timing of distribution of the survey during the COVID-19 pandemic. It is not possible to determine how these answers may have been prior to the pandemic. In addition, the primary respondents were physicians, nurse practitioners, and nurses. There were only a few responses from social workers and psychologists, who may be more involved in the mental health screening process in PH clinics. Lastly, there was some variability between respondents at the same center (eg, 1 respondent indicated psychology resources were available while the other indicated they were not). It is unclear as to why some of these questions were answered with variability.

CONCLUSION

This cross-sectional survey highlights the need for improved mental health screening practices within the pediatric PH population. While the current prevalence of disease in this population remains unknown, providers perceive anxiety and depression to be very real issues for their patients. The COVID-19 pandemic has increased rates of anxiety and depression in healthy children, but the presence of an interval increase in pediatric PH patients is not known due to lack of formalized screening practices. As medical care of PH in children continues to improve, management strategies that focus on holistically treating the patient and improving quality-of-life efforts, including mental health evaluation, are important for the long-term health and wellbeing of this unique patient population and their families and caregivers.

References

1. Racine N, McArthur B, Cooke JE, Eirich R, Zhu J, Madigan S. Global prevalence of depressive and anxiety symptoms in children and adolescents during covid-19: a meta-analysis. *JAMA Pediatr*. 2021;175(11):1142-1150. doi:10.1001/jamapediatrics.2021.2482.
2. Pinquart M, Shen Y. Behavior problems in children and adolescents with chronic physical illness: a meta-analysis. *J Pediatr Psychol*. 2011;36(9):1003-1016.
3. Abman SH, Hansmann G, Archer SL, et al. Pediatric pulmonary hypertension. *Circulation*. 2015;132(21):2037-2099. doi:10.1161/cir.0000000000000329.
4. Abman SH, Mullen MP, Sleeper LA, et al. Characterization of pediatric pulmonary hypertensive vascular disease from the PPHNet Registry [published online ahead of print Jun 17, 2021]. *Eur Respir J*. 2021;59(1):2003337. doi:10.1183/13993003.03337-2020. PubMed PMID: 34140292.
5. Mullen MP, Andrus J, Labella MH, et al. Quality of life and parental adjustment in pediatric pulmonary hypertension. *Chest*. 2014;145(2):237-244. doi:10.1378/chest.13-0636.
6. Handler SS, Hallis BJ, Tillman KA, et al. Assessment of quality of life in pediatric patients with pulmonary hypertension. *Pulm Circ*. 2019;9(3):204589401882298. doi:10.1177/2045894018822985.
7. Quittner AL, Abbott J, Georgiopoulos AM, et al. International committee on mental health in cystic fibrosis: cystic fibrosis foundation and European cystic fibrosis society consensus statements for screening and treating depression and anxiety. *Thorax*. 2016;71(1):26-34.
8. Liu FF, Lew A, Andes E, et al. Implementation strategies for depression and anxiety screening in a pediatric cystic fibrosis center: a quality improvement project. *Pediatr Pulmonol*. 2020;55(12):3328-3336. doi:10.1002/ppul.24951.