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Sudden cardiac death in the young: An update for NPs

Abstract: NPs can identify risk for sudden cardiac death in children during physical exams to prevent tragedy. The updated American Academy of Pediatrics 2021 policy statement on this issue provides guidance on using a combination of elements to determine and manage risk, including the organization's own 4-question screening tool, the American Heart Association 14-Element Preparticipation Cardiovascular Screening of Young Competitive Athletes, personal history, family history, physical exam, ECG, and cardiology referral as indicated.

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NPs conduct periodic, comprehensive history and physical exams to promote wellness and identify disease risk. Although the incidence of sudden cardiac arrest (SCA) in the young is low, this condition is most often fatal; identifying risk is therefore the key to prevention of a tragedy. With identification of cardiac conditions that put patients at risk for sudden cardiac death (SCD) in the young (SCDY), the NP can provide anticipatory guidance and education to individual families and the community to reduce risk.

SCA is defined as "the abrupt and unexpected loss of heart function."[1] In the past, the identification of risk of SCA was focused on athletes due to the publicized and

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tragic sudden deaths of teens participating in sports. In 2021, the American Academy of Pediatrics (AAP) updated their policy statement on the topic of SCDY to provide guidance for primary care providers (PCPs) related to preventing, screening for, and managing any cardiac risk factors.[2] The updated statement emphasizes identifying risk of SCA for all children regardless of athletic participation and in particular recommends that screening begin as children enter middle school. It also acknowledges that not all conditions associated with increased risk will be detected via screening to achieve primary prevention and that secondary prevention measures, such as CPR and automated external defibrillator (AED) training in the community, should therefore constitute an important additional focus.[2] Additionally, the role of genetic testing for surviving family members to determine their risk level is discussed.

Owing to COVID-19, the public is now more aware of heart conditions such as myocarditis that contribute to SCDY risk: as described in news reports, some pediatric patients infected with COVID-19 ultimately developed myocarditis, which in turn led to concerns over SCA. Therefore, now is an excellent time for NPs to discuss heart health with every pediatric patient and family and to identify those at risk for SCDY.

Purpose

The purpose of this article is to update NPs on the new 2021 AAP policy statement on the identification of risk factors for SCDY. The article also provides guidance for assessing SCDY risk in the primary care setting as well as recommendations for testing and referral of those identified as at risk. Finally, it offers information regarding secondary prevention of SCDY through community education, which can be undertaken at the NP level.

Epidemiology and risk factors

The true incidence of SCDY is difficult to discern due to methods of reporting and variations in populations studied (such as athletes only), although overall incidence seems to be decreasing over time.[3] The healthcare system in the US currently does not maintain a registry of "near-miss" SCDY events or actual SCDY incidents, making population-level study difficult. A systematic review across countries suggested that there are approximately 1.7 SCDs per 100,000 person-years in people ages 12-39 globally.[4]

Demographic risk factors for SCDY include infancy and adolescence, Black race, and male biological sex.[5-10] Further research into these risk factors could result in future interventions—economic, environmental, and educational—to address them.[7] Additional individual risk factors include athletic participation and physiologic risks. A prospective study of people ages 5 to 34 years in Oregon between 2002 and 2015 who experienced SCA found that athletic participation was reported as the cause in 39% of individuals ages 10 to 18 years.[11] Furthermore, the top risk factors for SCA in the study population were identified as arrhythmias (31%), coronary artery disease (22%), and hypertrophic cardiomyopathy (14%).[11] The study found that, prior to SCA, 58% had at least one identifiable risk factor, including smoking, obesity, diabetes, hypertension, and/or hyperlipidemia.[11] With innovations in wearable devices in the pipeline, cardiac monitoring and individualized care could contribute to risk identification and intervention to reduce morbidity and mortality.

Etiology of SCA/SCDY

NPs should be aware of common cardiac conditions that increase the risk of SCDY. A history of congenital heart disease (CHD) increases risk of SCA and death.[9] In fact, the most common cause of SCDY is congenital or inherited cardiac abnormalities.[2] In addition, a previous history of SCA is a red flag that indicates an increased risk of SCDY.[9] According to the updated policy statement by the AAP, the following categories of heart conditions are correlated with an increased risk of SCDY:[2]

1. cardiomyopathies: heart muscle problems such as dilated cardiomyopathy (which can be sequela from COVID-19-related myocarditis); hypertrophic cardiomyopathy, which is the most common cause of SCDY in athletes; restrictive cardiomyopathy; arrhythmogenic cardiomyopathy; noncompaction of the left ventricle; and myocarditis.
2. channelopathies: diseases marked by abnormalities in the ion channels in cardiac cells but otherwise normal anatomy and heart function. Abnormal ECG results, such as long QT syndrome, short QT syndrome, Brugada syndrome, catecholaminergic polymorphic ventricular tachycardia, and idiopathic ventricular fibrillation, are often present.
3. other cardiac causes, such as CHD, Wolff-Parkinson-White syndrome, Marfan syndrome, aortic stenosis (and rupture), mitral valve prolapse, commotio cordis, aortic dissection, coronary artery disease, and coronary artery anomalies.

The new AAP policy statement includes more detailed information on cardiomyopathies and channelopathies.

Potential prodromal warning signs

There are many symptoms that warrant further investigation for possible underlying cardiac conditions that put a patient at risk for SCA. Syncope, chest pain, shortness of breath, lightheadedness, irregular heartbeat or palpitations, extreme fatigue, and seizures should be taken seriously when a patient voices these prodromal symptoms. One-fourth to one-half of children who die from SCA may have symptoms such as syncope or seizures prior to death.[9] Some children with a congenital or inherited cardiac abnormality may have signs or symptoms such as an arrhythmia in infancy; however, the condition may not be detectable until adolescence in other children, hence the need for assessment over time and periodically.[12]

Syncope can be benign, as in the case of vasovagal syncope; however, this symptom should be investigated thoroughly prior to diagnosis of hypotension, as syncope can be a sign of a cardiac disorder, thereby potentially signifying increased risk of SCDY, or of a neurologic disorder.[13] If a child or teen has a history of syncope, the NP should find out if the child was exercising or experiencing palpitations or chest pain during the time surrounding the syncope, as that could potentially signify a serious concern.[9,13] Referral to cardiology would be recommended in such cases.

Shortness of breath and/or chest pain can also be a sign of cardiac disease; however, these symptoms are often treated as pulmonary in nature. If a patient with asthma who complains of shortness of breath or chest pain does not improve with asthma treatment such as use of a bronchodilator, then the possibility of cardiac cause should be pursued.[14]

Evaluation to identify individual risk factors: History and physical exam

The best approach constitutes a combination of elements and screeners to determine SCA and SCD risk. The primary care NP should obtain a comprehensive personal and family history and should perform thorough physical exams during routine visits for all children and adolescents, regardless of whether the patients plan to participate in sports. The AAP recommends that SCA screening be done for all children, at a minimum, every 3 years or on entry into middle and high school, with more frequent screening as appropriate.[2] In some situations, yearly preparticipation physical evaluation (PPE) exams should take place. However, many child and teen athletes do not have a PCP, and documentation of the PPE may be inconsistent.

The updated AAP policy statement recommends that individuals ages 6 to 21 who are participating in sports be evaluated each year via the PPE, which should include the 14-point American Heart Association (AHA) screening (see *AHA's 14-Point PPE*).[2] In addition, use of the modified 4-question AAP screening tool is recommended for all children at least every 3 years or when entering middle school and high school to detect risk (see *Modified 4-question AAP screening*).[2]

Parents or legal guardians sign the history section of the PPE form for any child under 18 years of age to provide consent for the exam. State laws vary regarding whether NPs or collaborating physicians are allowed to sign PPE forms for school and athletic participation clearance. Pediatric practitioners should discuss transition of teens with known cardiac risk to practitioners for adults to monitor the condition and risk as these patients age.

Of note, interestingly, athletes may have what is described as "athlete's heart," a normal physiologic adaptation of the heart to athletic training that can include muscle hypertrophy, chamber dilation, increased vagal tone, bradycardia, augmented stroke volume, and increased diastolic function but that may appear as an abnormality on the ECG such as sinus bradycardia, sinus arrythmia, AV block, repolarization changes, and isolated voltage criteria of left ventricular hypertrophy.[15]

Diagnostic testing

Primary care NPs should consider an ECG as a component of the PPE, especially if any risk is detected during the history or physical exam. Some cardiac conditions that may put youth at risk for SCDY will be detected via ECG. The AAP recommends an individualized approach to ordering diagnostic tests such as the ECG; consensus on routine use for all pediatric patients undergoing the PPE has not yet been reached.[2] Although primary care NPs read ECGs in many settings and refer when abnormal, interpretation by a pediatric cardiologist is recommended for ECGs when they are done as part of the PPE due to concern for SCA risk.[2] Providers should not use the computer interpretation

AHA's 14-Point PPE
Personal history
1. Chest pain, discomfort, tightness, or pressure related to exertion
2. Unexplained syncope or near-syncope not felt to be vasovagal or neurocardiogenic in origin
3. Excessive and unexplained dyspnea or fatigue or palpitations associated with exercise
4. Previous recognition of a heart murmur
5. Elevated systemic blood pressure
6. Previous restriction from participation in sports
7. Previous testing for the heart, ordered by a physician
8. Family history of premature death (sudden and unexpected or otherwise) before 50 y of age attributable to heart disease in ≥1 relative
9. Disability from heart disease in close relative <50 y of age
10. Hypertrophic or dilated cardiomyopathy, LQTS, or other ion channelopathies, Marfan syndrome, or clinically significant arrhythmias; specific knowledge of genetic cardiac conditions in family members
Physical Examination
11. Heart murmur, not felt to be innocent
12. Femoral pulses to exclude aortic coarctation
13. Physical stigmata of Marfan syndrome
14. Brachial artery blood pressure (sitting position), preferably taken in both arms

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Source: Erickson CC, Salerno JC, Berger S, et al. Sudden death in the young: information for the primary care provider. *Pediatrics*. 2021;148:e2021052044.

Previously adapted from Maron BJ, Friedman RA, Kligfield P, et al. Assessment of the 12-lead electrocardiogram as a screening test for detection of cardiovascular disease in healthy general populations of young people (12-25 years of age): a scientific statement from the American Heart Association and the American College of Cardiology. *J Am Coll Cardiol*. 2014;64(14):1479-1514.

Abbreviation: LQTS, long QT syndrome.

of the ECG because athletes can have physiologic changes that the computer system inaccurately interprets as abnormal.[15] Current normal ECG guidelines are based on studies outside the US; therefore, there is a call to collect data in the US to determine normal pediatric testing values.[16] Studies show that cardiac issues can be detected more accurately using all modalities (history, physical exam, and ECG) together; however, there has been some controversy over false-positive ECG tests.[12] The echocardiogram and genetic testing are additional diagnostic tests that may assist in providing information about cardiac conditions.[17]

Referral to cardiology

When a child visits the primary care NP, the provider must determine if the child has an identifiable or suspicious risk factor (either demographic or individual) or no risk factors for SCA/SCD. If significant risk factors are present, including a positive response to any of the AHA 14-point PPE questions or the four AAP questions, then the AAP recommends referral to a pediatric cardiologist.[2] According to the AAP, best practices include interpretation of the ECG by a pediatric cardiologist or healthcare practitioner trained in recognizing electrical heart disease and referral to cardiology if abnormal.[2] Although there may be resistance, the child who is undergoing further workup for a positive response should not participate in athletics until the evaluation is complete and a cardiologist has given approval.

Secondary prevention in the community

Although SCA in the young is a low-frequency event, it is highly impactful and traumatic due to its dramatic presentation in well-appearing youth. Years of research and practice by the AHA and AAP support efforts to improve pediatric outside-the-hospital survival via early symptom recognition, early deployment of the emergency medical services system, and effective bystander CPR and use of AEDs in the community. CPR and AED training is required in 39 out of 50 states and

the District of Columbia as a high school graduation requirement.[18] NPs can engage in collaboration with high school nurses to implement CPR and AED training for the next generation of youth and encourage use of these skills as needed in the community.

Coaches, trainers, parents/legal guardians, and other personnel must be educated to be ready to respond when a child has symptoms that require further examination (or warning signs), as well as in the event of an actual SCA during a sporting event. Components of CPR (especially chest compression and early defibrillation) are linked to increased survival.[9] Knowledge of proper methods for chest compression and defibrillation, along with basic airway management, are key in improving the chain of survival.[9] Community engagement is important, and Ackerman et al. rightly point out that rural communities and those with a high proportion of Black and Hispanic residents, who may be at increased risk, may be difficult to reach and engage in CPR training due to cost and other challenges.[6,8,9]

Finally, from a public health perspective, a National Institutes of Health/National Heart, Lung, and Blood Institute Working Group offered several recommendations.[17] They include:

1. develop an SCDY registry and perform case-control studies to identify risk factors;
2. develop pilot ECG screening studies to test screening characteristics in target populations and, for comparison purposes, determine the value of various screening methods;
3. manage asymptomatic heart disease that has been detected via ECG screening and develop novel study designs and recruitment strategies for low-prevalence diseases;
4. evaluate screening program impact, including its cost, resource utilization, and effects on quality of life.[17]

Support for families

Support is necessary for children and families at many different points along the continuum. Initially, if a screening exam indicates a risk factor that necessitates ordering an ECG or referral to a cardiologist, the family will need reassurance and support as the workup continues. Since the child is instructed not to participate in athletics until the evaluation is complete and approval is granted, disappointment and frustration may ensue. The NP can be instrumental in providing this support and being proactive in arranging referral in a timely manner.[9]

Patients found to be at risk could benefit from interventions to prevent SCD. For example, in the case of hypertrophic cardiomyopathy, use of implantable cardioverter defibrillators (ICDs) or, for long QT syndrome, medications such as beta-blockers may be indicated.[19] Although an intervention such as placement of an ICD is potentially lifesaving, it may be unexpected and shocking for the child to transition from a healthy young person to a different reality. Therefore, support from an NP and/or mental health professional may be necessary.

Additionally, if a child is found to be at risk after having undergone appropriate screening as outlined above, screening should be expanded to include first-degree relatives, and genetic testing and evaluation may be indicated. Currently, the scope of cardiac evaluations among first-degree relatives is not standardized and lies with the response of the involved cardiologists. Genetic testing is a valuable tool for further investigation but may not be covered or reimbursed by the family's insurance, potentially limiting its utility for all populations. Genetic testing should be carefully interpreted by specialists in cardiology.

If an SCD occurs, surviving first-degree relatives should undergo cardiac testing, at a minimum including a 12-lead ECG, 24-hour ambulatory ECG monitoring, treadmill stress test, and echocardiogram.[2] Implantable devices may be recommended for other family members following screening. Beyond testing,

Modified 4-question AAP screening

1. Have you ever fainted, passed out, or had an unexplained seizure suddenly and without warning, especially during exercise or in response to sudden loud noises, such as doorbells, alarm clocks, and ringing telephones?
2. Have you ever had exercise-related chest pain or shortness of breath?
3. Has anyone in your immediate family (parents, grandparents, siblings) or other, more distant relatives (aunts, uncles, cousins) died of heart problems or had an unexpected sudden death before age 50? This would include unexpected drownings, unexplained auto crashes in which the relative was driving, or SIDS.
4. Are you related to anyone with HCM or hypertrophic obstructive cardiomyopathy, Marfan syndrome, ACM, LQTS, short QT syndrome, BrS, or CPVT or anyone younger than 50 years with a pacemaker or implantable defibrillator?

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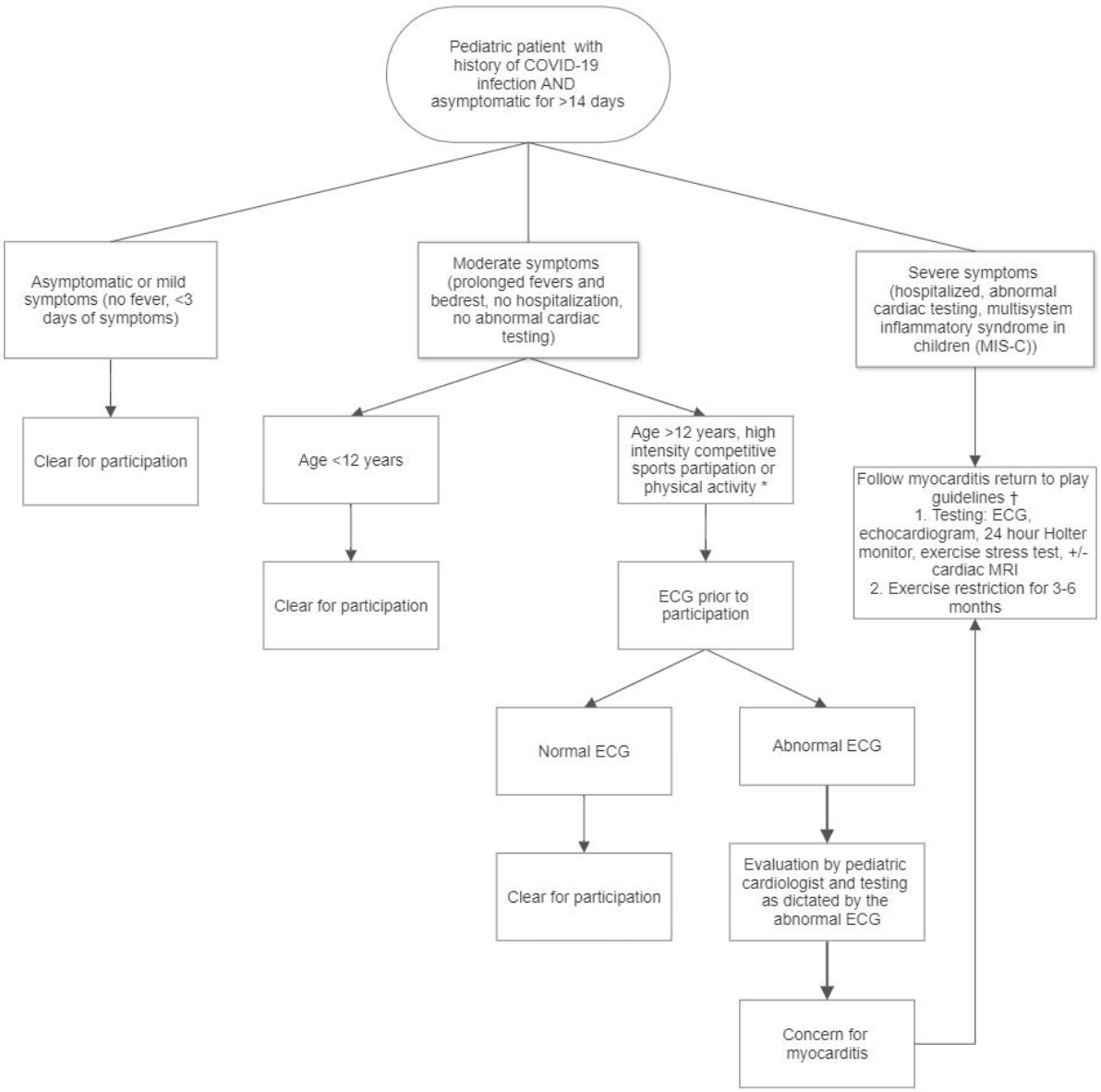
Source: Erickson CC, Salerno JC, Berger S, et al. Sudden death in the young: information for the primary care provider. Pediatrics. 2021;148(1):e2021052044.

Abbreviations: AAP, American Academy of Pediatrics; ACM, arrhythmogenic right ventricular cardiomyopathy; BrS, Brugada syndrome; CPVT, catecholaminergic polymorphic ventricular tachycardia; HCM, hypertrophic cardiomyopathy; LQTS, long QT syndrome; SIDS, sudden infant death syndrome.

Return to Play After COVID-19 Infection in Pediatric Patients



*Depending on the patient and situation, it would also be reasonable to follow the recent adult recommendations for return-to-play in this population.[a-c]

†Maron BJ, Udelson JE, Bonow RO, et al. Eligibility and disqualification recommendations for competitive athletes with cardiovascular abnormalities: task force 3: hypertrophic cardiomyopathy, arrhythmogenic right ventricular cardiomyopathy and other cardiomyopathies, and myocarditis. *J Am Coll Cardiol* 2015;66:2362–71.

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Source: Dean PN, Jackson LB, Paridon SM. Returning to play after coronavirus infection: Pediatric cardiologists' perspective. July 14, 2020. Accessed May 5, 2022. https://www.acc.org/latest-in-cardiology/articles/2020/07/13/13/37/returning-to-play-after-coronavirus-infection

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surviving family members will likely need support for psychological distress due to the sudden death of a seemingly healthy relative. If the arrest was witnessed by parents or guardians, posttraumatic stress disorder symptoms may need to be addressed.

COVID-19 considerations

Recently, with the onset of COVID-19, children have presented to providers with various cardiac issues resulting from SARS-CoV-2 infection and resultant multisystem inflammatory syndrome in children (MIS-C). Venkatesha et al. postulate that MIS-C can emanate from SARS-CoV-2 and is likely to be a multiorgan, hyperinflammatory syndrome involving a cytokine storm.[20] Venkatesha et al. describes a case report of a 12 year old who developed SCA and died following COVID-19 seropositivity and associated symptoms, which included fever, vomiting, rashes, elevated cardiac enzymes, and, ultimately, cardiogenic shock.[20] Acute COVID-19 severity does not necessarily predict subsequent or ongoing signs or symptoms. All children who test positive for COVID-19 should be assessed by a PCP by phone, telehealth, or in-person. It is strongly recommended by the AAP that pediatric patients who had "moderate disease (>4 days of fever >100.4°F; >1 week of myalgia, chills, or lethargy; non-ICU hospital stay) or severe disease (ICU stay and/or intubation)" have an in-person follow-up visit as they are at higher risk of developing cardiovascular disease.[21] Children younger than 12 years of age who have had COVID-19 may progress back to sports/physical activity as tolerated after their isolation period has elapsed and clearance has been given by their PCP.[22] Individuals who are 12 years of age and older should progress in a systematic manner after isolation is complete and clearance has been obtained, if indicated. Children should continue to wear a face mask during all physical activities until 10 days after their last positive test or symptom onset.[22] The American College of Cardiology (ACC) also provides recommendations for return to physical activities after COVID-19 infection in children (see *Return to Play After COVID-19 Infection in Pediatric Patients*).[23]

NPs caring for this population must be aware that an immediate or prolonged immune response to COVID-19 can cause inflammation, myocarditis, and/or MIS-C. When returning to exercise, children, coaches, and parents or guardians must be educated to monitor for signs that any cardiac involvement may not be resolved such as chest pain, shortness of breath that is increased over baseline, heart palpitations in an athlete who has not previously experienced this symptom, or syncope.[22] If these symptoms occur, exercise must be stopped immediately, the child should be seen for an in-person assessment, and the primary care NP must strongly consider a cardiology consult.[22]

Finally, the ACC expert analysis recommends that children refrain from physical activity and sports while actively sick or febrile and gradually return to activities as they feel able after 2 weeks with no symptoms.[23] The ACC further recommends, based on care of athletes with myocarditis, that the patient who had severe disease remain out of sports play for 3 to 6 months and only return to play when/if cardiac testing (ECG, echocardiogram, 24-hour ambulatory ECG monitoring, exercise stress test, and possibly cardiac MRI) shows normal results.[23] The ACC indicates that it is impossible to rule out all etiologies for cardiac involvement, and therefore, high school and youth sports should ensure that emergency plans are in place to attend to cardiac events appropriately with CPR, defibrillation, and emergency response.[23]

Because SARS-CoV-2 is a novel virus and the pandemic is ongoing, the literature in this area is incomplete and long-term data are not yet available. Providers must continually check for updates regarding cardiac screening of children and teens who have had COVID-19.

Summary of recommendations and conclusion

In summary, all children and adolescents must be evaluated for high-risk cardiac conditions that put them at risk for SCDY. Screening via a comprehensive history and physical exam to determine risk may occur in many settings including a primary care clinic or a school "mass screening." The NP is in an opportune position to provide anticipatory guidance and education to individual families and the community to reduce risk of morbidity and mortality from SCA in the young. The NP must be familiar with evaluation of risk factors; use of the PPE, including the AAP's modified 4-question screening tool and the AHA's 14-point survey; diagnostic tests, including the ECG; and when to refer to a cardiologist for further evaluation. Providing preventive care for the at-risk population is key to avoid catastrophic events in the lives of children and their families. NP

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