

**Children's Hospital of Orange County**  
***Best Evidence and Recommendations (BEaR)***

***Pediatric Cardiac Arrest Survivorship***

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**Abstract**

There are approximately 20,000 children that experience cardiac arrest in the United States annually. Efforts in the past decade to improve cardiac arrest systems of care have increased the number of children and adults surviving cardiac arrest. Survivors of cardiac arrest and their families experience a spectrum of physical, neurological, cognitive, emotional, and social issues after the arrest event. Previously, the clinician-defined patient outcomes of return of spontaneous circulation, survival, and minimal neurological sequelae were acceptable survivorship outcomes. However, more recently, a need for clinician and patient/caregiver/family-defined outcomes is emerging. These outcomes bring the focus to patient and family-centered care and recognize the family or caregiver as a crucial part of the multidisciplinary team and recovery journey. Initial work has been completed by the International Liaison Committee in defining a core outcome set. These outcomes have highlighted the current gaps in follow-up care provided. The purpose of this evidence review was to determine how the healthcare system can best support pediatric survivors of cardiac arrest and their families in their recovery process. A synthesis of the current literature from the search reveals a pressing need for clearly defined and adopted core outcomes for pediatric cardiac arrest survivors to drive standardized follow-up care from a multidisciplinary perspective.

**Keywords**

Pediatric, post-cardiac arrest, sudden cardiac arrest, survivor, survivorship, and recovery

**PICO(T)**

What are the best practices to address sudden pediatric cardiac arrest survivorship?

**Background and Significance**

There are approximately 20,000 children that experience cardiac arrest in the United States annually (Hamzah et al., 2021; Topjian et al., 2021). Increased understanding of pediatric cardiac arrest has led to the ongoing development of survivorship outcomes over the past two decades. Prior to 2008, prevention of cardiac arrest shaped the American Heart Association's



(AHA) pediatric advanced life support guidelines. After 2008, the outcomes shifted to focus on the return of spontaneous circulation, survival until discharge, and minimal neurological sequelae (Topjian et al., 2019). As a result of these efforts, cardiac arrest systems of care have improved, and the number of adults and children surviving cardiac arrest continues to increase (Hunfeld et al., 2020; Sawyer et al., 2020). The estimated survival rates for in-hospital cardiac arrest are trending upward with reports ranging from 14-39% in 2009 and up to 48% in 2021 in the United States (Topjian et al., 2021). Similarly, out-of-hospital cardiac arrest is trending upward from 8.3% to 11.1% (Topjian et al., 2021). However, with this increase, knowledge of the physical, neurological, cognitive, emotional, and social issues that accompany surviving cardiac arrest have also emerged (Presciutti et al., 2022; Sawyer et al., 2020; Topjian et al., 2021). An increase in the investigations and reports related to the needs of cardiac arrest survivors and their families has unveiled a need for the previous clinician-defined outcomes to be reevaluated with a patient and caregiver perspective (Dainty et al., 2020; Topjian et al., 2021). Qualitative interviews and survey studies have revealed a lack of standardized assessment or screening tools, a lack of resources available or systems of care to support pediatric cardiac arrest survivorship, and a lack of standardized management and follow-up care (Presciutti et al., 2022). For the pediatric population, a lack of standardized follow-up care leaves this vulnerable population even more at risk for impediments or delays throughout their development.

For the purposes of this review, “*pediatric*” refers to the age of 0 hours to 18 years. *Sudden cardiac* is an abrupt loss of heart function from absent (asystole) or ineffective cardiac mechanical activity (shockable rhythm). The AHA Scientific Statement on sudden cardiac arrest survivorship defines *survivorship* as, “the health and well-being of an individual after treatment until the end of his or her life” (Sawyer et al., 2019). It refers to the “lived experience of long-term survivors of cardiac arrest, which is characterized by many challenges” (Presciutti et al., 2022; Sawyer et al., 2020).

## Framework

This EBP project utilizes the “Translating Evidence into Practice: CHOC’s Approach to EBP” model, adapted from the EBPI Model © 2007 Brown & Ecoff (Ecoff, Stichler & Davidson, 2020).

## Search for the Evidence

Databases searched for this review included CINAHL, Ovid, Medline in EBSCO and Pub Med. Key search words: pediatric, post-cardiac arrest, sudden cardiac arrest, survivor, survivorship, and recovery. This search yielded 26 articles. Websites reviewed included the Sudden Cardiac Arrest Foundation and American Heart Association. A survey was sent to clinicians and care providers from key children’s hospitals worldwide regarding this topic. This survey yielded five responses. Best practices and policies from Children’s Hospital of Philadelphia and Erasmus MC Sophia Children’s Hospital were examined.



## Critical Appraisal and Synthesis of the Evidence

### Risk Without Treatment

- An important difference in post-cardiac arrest care between children and adults is the potential to affect ongoing development in children (Sawyer et al., 2020). Without specialized care and attention, this post-intensive care and post-cardiac arrest population is already at risk for:

**Table 1 – At Risk Body Systems**

At Risk Body System:	Potential Side Effects:
Musculoskeletal	<ul style="list-style-type: none"> <li>Muscle weakness</li> <li>Impairments in fine motor skills</li> <li>Physical fatigue</li> <li>Vision abnormalities</li> <li>Procedural pain</li> <li>Speech disorders</li> <li>Swallowing dysfunction</li> </ul>
Neurological	<ul style="list-style-type: none"> <li>Seizures</li> <li>Stroke</li> <li>Movement disorders</li> <li>Spasticity</li> <li>Ataxia</li> <li>Disorders of consciousness</li> </ul>
Cognitive	<ul style="list-style-type: none"> <li>Impairments in attention, memory, executive function, intellect, language, and perception</li> </ul>
Cardiopulmonary	<ul style="list-style-type: none"> <li>Recurrence of cardiac arrest</li> <li>Ischemia</li> <li>Cardiac muscle weakening</li> <li>Reduced ejection fraction</li> <li>Arrhythmias</li> <li>Dysfunction</li> <li>Chest pain</li> <li>Reduced exercise tolerance</li> </ul>
Psychosocial Well-Being	<ul style="list-style-type: none"> <li>Anxiety</li> <li>Depression</li> <li>Post-traumatic stress disorder</li> <li>Difficulty with attention/concentration</li> <li>Decreased quality of life</li> <li>Spiritual concern</li> <li>Personal relationship stress</li> <li>Difficulty with reintegration into daily life, work, intimacy</li> </ul>

*Note:* Adapted from “Sudden cardiac arrest survivorship: A scientific statement from the American Heart Association,” by Sawyer, K.N., Camp-Rogers, T.R., Kotini-Shah, P., Del Rios, M., Gossip, M.R., Moitra, V.K.,



Haywood, K.L., Dougherty, C.M., Lubitz, S.A., Rabinstein, A.A., Rittenberger, J.C., Callaway, C.W., Abella, B.S., Geocadin, R.G., & Kurz, M.C., 2020, *Circulation*, 141(12), p. 645-685.  
<https://www.ahajournals.org/doi/full/10.1161/CIR.0000000000000747>

- Psychosocial well-being also applies to families of cardiac arrest survivors who may have performed CPR, witnessed the event, or lived through the trauma associated with their child having a cardiac arrest (Mion et al., 2010; Sawyer et al., 2020; Sawyer, 2022). Most pediatric survivors of cardiac arrest will return home to be cared for by their families, and these families are at high risk within the first year of discharge for substantial family burden (Meert et al., 2016).

### Identified Gaps in Care

- AHA Scientific Statement on Pediatric Post-Cardiac Arrest Care and Survivorship recently added 'Recovery' to the 'Chain of Survival,' highlighting its significance and the lack of standardized pathways for delivering rehabilitation services for cardiac arrest (Topjian et al., 2019).
- Qualitative studies focused on survivor, family, and caregiver report experiences. Most of these articles/studies involve the adult population, highlighting a need for pediatric-specific research (Elmer et al., 2016; Mion et al., 2021; Sawyer et al., 2020; Sawyer, 2022).
- **A lack of standardized assessment and screening tools.**
  - Early identification and treatment of cognitive defects is important to help prevent growth into deficit, but little is known about long-term neuropsychological functioning in pediatric survivors of cardiac arrest (Albrecht et al., 2021; Hunfeld et al., 2021; van Zelle, Buysse, et al., 2015; van Zelle, Utens, et al., 2015). Neuropsychological assessment of older children showed impairments in executive functioning, fine motor skills, visuomotor skills, and visual memory. Early screening and identification can help provide cognitive rehabilitation and implementation of appropriate education services (Boyce et al., 2019; Moulaert et al., 2015; Slomine et al., 2016; Slomine et al., 2018; Topjian et al., 2021).
  - Risk for cognitive impairment is poorly understood; in part due to a lack of standardized measurement tools and timing (Haywood et al., 2021; Mion et al., 2021; Ng et al., 2022; Sawyer et al., 2020; Topjian et al., 2021; van Zelle et al., 2016).
  - Long-term evaluation of neuropsychological outcomes in pediatric survivors of cardiac arrest one year or greater after the event demonstrated lower intelligence scores as compared to the normative (Hunfeld et al., 2021; Ng et al., 2022; van Zelle et al., 2015).
  - Further investigation is needed of the best screening tools to identify and predict the cognitive and neuropsychological risks for pediatric survivors of cardiac arrest (Boyce et al., 2019; Sawyer, 2022).
  - There is no standard agreement on which instruments to use for screening and follow-up care when to implement them, and the optimal timing of follow-up evaluations (Haywood et al., 2021; Sawyer, 2022; Topjian et al., 2019).
- **A lack of standardized resources or systems of care to support pediatric cardiac arrest survivorship** (Wagner et al., 2021).



- Survivors reported a lack of support in transitioning from inpatient to daily life, lacking appropriate education, expectations, and resources for recovery (Sawyer, 2022).
  - A disrupted sense of normality, fatigue, guilt, and being left alone without coping strategies (Dainty et al., 2020; Sawyer, 2022).
  - Resources and referrals for multidisciplinary care after hospitalization are needed (Haywood et al., 2021; Mion et al., 2021; Sawyer, 2022).
- Because studies use inconsistent outcomes for pediatric cardiac arrest patients, the International Liaison Committee on Resuscitation with the Pediatric COSCA initiative developed these core outcomes: survival, physical function, brain function, cognitive function, and activities of daily living (Dainty et al., 2020; Topjian et al., 2021).
  - Survival and brain function recommended assessment is at discharge or 30 days after the event and between 6-12 months (Topjian et al., 2021).
  - Physical function, cognitive function, and activities of daily life recommended assessment is between 6-12 months after cardiac arrest (Topjian et al., 2021).
- Following acute cardiac events, patients and families have unmet education needs, and provision of education may assist in managing negative emotions and coping (Boyce et al., 2019).
- There is a need for a post-arrest pathway for rehabilitation and peer support (Sawyer, 2022).
- **A lack of standardized management and follow-up care**
  - There is currently no system for coordinated post-arrest management and care during and after hospitalization from a multidisciplinary care approach (Sawyer et al., 2020; Seelhammer & Wittwer, 2021; Wagner et al., 2021).
  - After a cardiac arrest, routine comprehensive patient and family evaluations are not commonly performed (Boyce, et al., 2019; Haywood et al., 2021; Topjian et al., 2019).
  - No standardized evaluation of the effectiveness of rehabilitation services, the timing of interventions, and the type of intervention provided to pediatric cardiac arrest survivors currently exist (Sawyer et al., 2020; Topjian et al., 2019).
  - Neuropsychological evaluation is recommended after discharge (Haywood et al., 2021; Mion et al., 2020; Sawyer et al., 2020; van Zelle, Buyse, et al., 2015). Follow-up appointments are needed with multiple disciplines, especially in the cognitive and (neuro)psychosocial domains regarding reintegration (van Zelle et al., 2016; Sawyer et al., 2020; Sawyer, 2022).
  - For pediatric cardiac arrest survivors, very long-term follow-up is recommended due to growth and neuro-cognitive development changes (Albrecht et al., 2021; Topjian et al., 2019; Sawyer, 2022). In adolescents, at least 1 year after the event is recommended, and in preschool-aged children, at least 5 to 10 years of follow-up is recommended (Hunfeld et al., 2020).
  - A standardized referral process or follow-up program may provide survivors and families with access to the services needed and, indirectly, produce appropriate expectations for a recovery in each domain through interactions with specialty care providers (Haywood et al., 2021; Presciutti et al., 2022).
  - Improvement in the transition and coordination of care to the outpatient setting is needed.

### Recommendations for Improvement

- In the adult setting, survivors of cardiac arrest repeatedly needed information of the diagnosis and recovery process provided to them while in-hospital and increasingly after discharge, reinforcing the need for consistent follow-up care (Klint et al., 2019).
- Other medical diagnoses of stroke, myocardial infarction, cancer, and transplantation have structured discharge planning protocols and follow-up care guidelines for rehabilitation after discharge. However, rehabilitation services and guidelines after cardiac arrest remains underdeveloped (Sawyer et al., 2020; Sawyer, 2022).
  - Adult survivors of cardiac arrest showed improved outcomes when cared for at centers with implemented comprehensive post-arrest care bundles and a multi-discipline approach to care (Elmer et al., 2016).
- The European Resuscitation Council recommends screening for cognitive and emotional impairments in cardiac arrest survivors. Outpatient care is also recommended for multiple disciplines, emphasizing cardiac rehabilitation, neurologic rehabilitation, psychological support, and family reintegration (Haywood et al., 2021; Moulart et al., 2015; Sawyer et al., 2020; Seelhammer & Wittwer, 2021; Wagner et al., 2021).
- The development of a cardiac arrest-specific core outcome set and scales/tools will allow for more accurate measurement, assessment, and reassessment of outcomes (Ng et al., 2022; Sawyer et al., 2020; Topjian et al., 2021).

### Practices and Policies of Other Institutions and Organizations

- Children's Hospital of Philadelphia (N. Pinto, personal interview, August 1, 2022)
  - Neurology and PMR see patients while in-patient and make recommendations for follow-up care as needed. Their charting system will automatically send a notification if a cardiac arrest patient has a discharge order placed to then approach for education on cardiac clinic follow-up care.
  - One week after discharge, their team will call for a telephone follow-up and see if parents are interested in the cardiac clinic.
  - Three weeks after discharge and before the initial clinic intake visit, a telephone screening assessment with Peds QL or basic surveys is completed to identify needs.
  - Initial intake evaluation includes neurology, neuropsychology, PT/OT as needed.
- Erasmus MC Sophia Children's Hospital (C. Buyse, personal interview, August 8, 2022)
  - While inpatient, several disciplines see the patient, including the rehabilitation team, physical therapy, and neurology. The timing of the consult and assessment depends on the stability and status of the patient. However, a pediatric neurologist always sees the patient on the day of admission.
  - Accounting for the difference in the established national healthcare system as well as the disparity in population in the Netherlands, Erasmus MC Sophia Children's Hospital has an established program that was initiated in 1999 for severe congenital anomalies and expanded to include children with neurological impairments in 2012, which included post-cardiac arrest patients.
  - Patients and families return to the hospital for follow-up care. They are invited to come at:
    - 3-6 months: extensive neurological examination



- 12 months
- 24 months: extensive neurological examination
- 5, 8, 12, and 17 years
- There are no screening tools used after follow-up. The initial evaluation is with a core team of a pediatric neuropsychologist, an intensivist, and the neurology team. Based on their assessment, they generate an extensive packet with results and recommendations for care. These items are not reviewed in person with the families, and the families are expected to follow up on these recommendations independently.

### Practice Recommendations

To prevent the reoccurrence of cardiac arrest and improve the health-related quality of life for each patient, the following actions are recommended:

- Immediate Actions
  - CHOC to adopt/develop and define a core outcome set for pediatric cardiac arrest survivor patients.
  - Implement early integration/consultation of physical therapy, occupational therapy, and speech-language pathology after extubation with an automatic order set.
  - Place a referral while in-patient to the Cardiac Neurodevelopmental Clinic for neuropsychological evaluation and introduce the topic to patients/parents before discharge with additional resources available (van Zelle et al., 2016).
  - Establish a “Roadmap to Recovery” to help appropriately set patient and family expectations before discharge.
- Future Actions
  - Primarily, the need identified is an area for research in creating, testing, and validating appropriate screening tools for the post-cardiac arrest patient and family population that provides more specificity.
  - Develop a program for a consistent workflow for follow-up care specific to the cardiac arrest population. For adults, some research has been done to assess how the structure of a cardiac arrest rehabilitation program or cardiac arrest clinic assists with emotional burdens, support strategies, and transition back into normal life (Elmer et al., 2016; Wagner et al., 2021).

### Outcome Measures

- Development of CHOC Core Outcomes based upon the recommendations from the International Liaison Committee on Resuscitation with the Pediatric COSCA initiative to drive action measures (Topjian et al., 2021).
- Development of a “Roadmap to Recovery” as a reference resource for patients, caregivers, and family to help set appropriate expectations for recovery and follow-up care, reflective of the model presented by the American Heart Association (Topjian et al., 2019).



- Early consultation of and assessment from other disciplines from the in-patient care team, as appropriate, based on the patient's condition. Audit the time to multidisciplinary intervention.
  - For neurology, the recommendation for consultation is upon admission.
  - For SLP, PT, OT, the recommendation for consultation is after extubation.
  - For neuropsychology, the recommendation is to follow up within 3-6 months after discharge with appointments at key times throughout development up to 18 years.
- For long-term post-discharge outcomes, measure the percentage of completed screening phone calls after discharge and the percentage of referrals generated.
  - Measurement of the number of visits compared to the number of referrals generated to the recommended outpatient clinics/rehabilitation services.

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