

AHA SCIENTIFIC STATEMENT

Sudden Cardiac Arrest Survivorship

A Scientific Statement From the American Heart Association

ABSTRACT: Cardiac arrest systems of care are successfully coordinating community, emergency medical services, and hospital efforts to improve the process of care for patients who have had a cardiac arrest. As a result, the number of people surviving sudden cardiac arrest is increasing. However, physical, cognitive, and emotional effects of surviving cardiac arrest may linger for months or years. Systematic recommendations stop short of addressing partnerships needed to care for patients and caregivers after medical stabilization. This document expands the cardiac arrest resuscitation system of care to include patients, caregivers, and rehabilitative healthcare partnerships, which are central to cardiac arrest survivorship.

The number of people surviving sudden cardiac arrest (SCA) is increasing. This includes both adults and children, and it results from successful cardiac arrest systems of care. However, survival often results in lingering effects across a spectrum of physical, neurological, cognitive, emotional, and social issues. Some of these effects may not be apparent until after discharge from the hospital.

A lack of uniform patient-centered assessment and reliable provision of resources for SCA survivors after initial medical stabilization perpetuates a fragmented approach to hospital discharge planning. Resources for physical, cognitive, emotional, and social needs are not standardized. The absence of a coordinated plan during hospitalization to assess (short-term) and reassess (long-term) survivorship before and after discharge hampers improvements in systems to optimize patient-centered care. Without expectation or direction, families and caregivers are poorly equipped to support recovery, to assist in providing rehabilitation care, or to anticipate the patient's psychosocial needs when transitioning from acute care to home or another care facility. Family members, caregivers, and healthcare providers may also need psychosocial support alongside that of the patient.

SCA survivors represent a heterogeneous group of patients, often with unique and complex needs that are inadequately addressed by current treatment recommendations. The few recommendations that do exist for follow-up after SCA are generally borrowed from other specialties for secondary prevention of cardiac events (eg, placement of an implantable cardioverter defibrillator [ICD], need for percutaneous coronary intervention or coronary artery bypass grafting) but do not address other domains affected by SCA (eg, cognitive, psychological, emotional, social). In the absence of structured care plans or support groups, informal communities of survivors have coalesced to discuss shared experiences and to assist with navigating survivorship.

Kelly N. Sawyer, MD, MS,
Chair
Teresa R. Camp-Rogers, MD,
MS
Pavitra Kotini-Shah, MD
Marina Del Rios, MD, MS
Michelle R. Gossip, RN,
CCRN, MSN
Vivek K. Moitra, MD, MHA
Kirstie L. Haywood, DPhil,
MCSP
Cynthia M. Dougherty, ARNP,
PhD, FAHA
Steven A. Lubitz, MD, MPH,
FAHA
Alejandro A. Rabinstein, MD,
FAHA
Jon C. Rittenberger, MD, MS
Clifton W. Callaway, MD,
PhD, FAHA
Benjamin S. Abella, MD,
MPhil, FAHA
Romergryko G. Geocadin, MD
Michael C. Kurz, MD, MS-
HES, FAHA
On behalf of the American
Heart Association
Emergency Cardiovascular
Care Committee; Council
on Cardiovascular and
Stroke Nursing; Council on
Genomic and Precision
Medicine; Council on
Quality of Care and
Outcomes Research; and
Stroke Council

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The current situation for SCA survivorship stands in stark contrast to other disease states (eg, myocardial infarction, stroke)¹ that have comprehensive recommendations for risk factor modification, surveillance, and rehabilitation. Cancer² and solid organ transplantation³ survivorship guidelines are also excellent models that integrate the patient and support systems into the short- and long-term care plans. Finally, there is a growing movement in the critical care community to address the gaps in patient-centered care after critical illness, including providing specialty follow-up clinics.⁴ However, SCA survivors represent a small subset of all critically ill patients with unique needs.

Although the primary focus for this statement is adult cardiac arrest survivorship, much of the content may be applicable to pediatric SCA survivors and their families. Some guidance may be borrowed from the congenital heart disease literature.⁵ Unique issues for the pediatric population may include developmental delays as a result of critical illness, falling behind or feeling socially isolated as a result of missing school, and concerns about body image because of procedural scars or implanted devices. Long-term outcome assessment, rehabilitation consideration, and quality of life after critical illness are covered briefly elsewhere.^{5a}

The purpose of this statement is to summarize the available science that describes the experience of patients and their families and caregivers after cardiac arrest and to organize a template survivorship plan that may be used to communicate across hospital systems and specialties. After reviewing the current post-cardiac arrest literature, the authors concluded that a need existed to expand the cardiac arrest system of care to include and focus on the individual patient (Figure 1). Thus, in this statement, we systematically approach the current gaps in care for cardiac arrest survivors by examining the healthcare system holistically. This statement draws attention to the far-reaching effects that a single cardiac arrest event has on individuals, their care providers, and their community. In addition, the Layperson Summary of Cardiac Arrest Survivorship section seeks to empower patients and caregivers to address their current and future needs with providers across the healthcare system.

SCOPE

Survivorship after critical illness focuses on the health and well-being of an individual after treatment until the end of his or her life. This includes fostering survivors' will to return home and to their families. It also includes, when possible, fostering survivors' ability to return to hobbies and previous work. Survivorship acknowledges the complex emotional, physical, social, and economic challenges associated with life during and after critical illness. It recognizes the importance of

caregivers and support networks, who may also need guidance throughout the long recovery period.

Survivorship has been described as the defining challenge of critical care in the 21st century.⁶ Research into the function, disability, and health of survivors has increased, revealing significant opportunities for improving long-term quality of life, even during the first days in an intensive care unit (ICU).⁷ Although critical care often takes place within closed hospital units, many clinicians, researchers, and patient-partners have called for it to be a priority, necessitating coordination of multidisciplinary teams to assist with ICU therapies, discharge planning, and outpatient follow-up. Interventions and treatments for critical illness have led to increased survival. However, the critical care community recognizes that after surviving invasive and painful procedures, delirium, and loss of independence and function, patients and their loved ones need coordinated guidance beyond the ICU and hospital walls.

Epidemiology of SCA and Its Survivors

Over the past decade, survival after resuscitation from cardiac arrest has increased.^{1,8} The estimated annual incidence in the United States for out-of-hospital cardiac arrest (OHCA) treated by emergency medical services (EMS) is 184 383 encounters, and the incidence of OHCA has increased over time.⁹ Survival to hospital discharge after EMS-treated OHCA is estimated at 10.8% (\approx 19 913 individuals per year)¹⁰ to 11.4% (\approx 21 019 individuals per year).⁹ The annual incidence of in-hospital cardiac arrest (IHCA) is estimated at 209 000 individuals. Survival to hospital discharge after IHCA is 25.8% (\approx 53 922 individuals per year). These survival rates have increased over time, partly from standardized post-cardiac arrest care and avoidance of early withdrawal of life-sustaining therapies.^{11,12} Thus, >70 000 individuals are potentially discharged from the hospital after cardiac arrest in the United States each year without any formal rehabilitation plan, and this number is expected to increase.

Estimates of the functional status of patients who are discharged from the hospital after cardiac arrest vary widely. In large registries, 18% of survivors of OHCA and 40% of adult survivors of IHCA have moderate to severe functional impairments at hospital discharge, preventing return to work and normal daily activities. These registries define good outcomes broadly, using subjective scales that distinguish completely dependent patients from partially or fully independent patients (eg, Cerebral Performance Category [CPC] or modified Rankin Scale). However, the majority of patients report some impairment that alters their function or quality of life compared with their premonitory state on more objective scales or more granular instruments.¹³

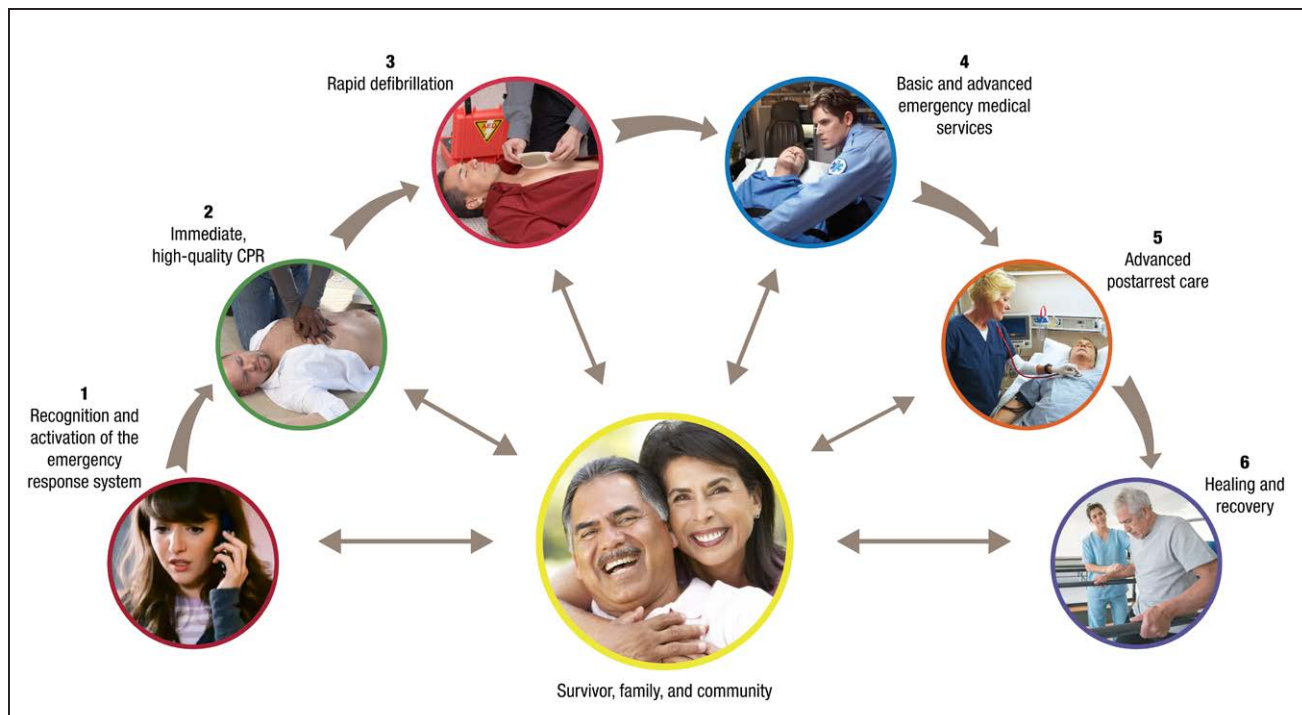


Figure 1. Centralized system of care.
CPR indicates cardiopulmonary resuscitation.

Current Variation in Postarrest Care and Survivorship

Comprehensively understanding the survivorship needs of cardiac arrest survivors requires acknowledging the heterogeneity in clinical post-cardiac arrest care and its association with outcome. One potential reason for this heterogeneity is that different institutions often have unique entry criteria for postresuscitation care protocols. Some facilities have stringent requirements, whereby only patients with witnessed arrest and a shockable rhythm are treated with the protocol. Other facilities have broad inclusion criteria, applying their protocols to a diverse group of patients.¹⁴ Furthermore, once the protocol is engaged, multiple specialists care for these patients with variable coordination between service lines, which contributes to the patients' fragmented postarrest care. Communication across healthcare facilities and care transitions may be hindered by space, time, and medical record incompatibility. This variation in "who" and "how" has implications not only for individual patients but also for measuring outcomes across systems.

Current recommendations for postarrest care include targeted temperature management, aggressive coronary revascularization, normalization of P_{aO_2} and P_{aCO_2} , and a multimodal workup to determine neurological prognosis.¹⁵ High-volume facilities with a standardized postarrest care bundle or a plan for patients resuscitated from cardiac arrest have demonstrated superior outcomes.¹² This has led to a recommendation

for designated cardiac arrest centers.^{11,16,17} The survival effect from treatment at high-volume centers continues for several years and is evident within regions of care.¹²

Components of postarrest care such as targeted temperature management have been studied in isolation, but little attention has been paid to the need for or timing of rehabilitation interventions in SCA survivors. Prior work has demonstrated that a significant proportion of patients are discharged with functional deficits (eg, difficulty walking, writing, or paying bills) but often do not receive rehabilitation after hospital discharge. Individual patients may be identified as needing rehabilitation in one domain or another, but the authors are not aware of existing protocols for systematically assessing SCA survivor rehabilitation needs. A survey study in Sweden revealed that although local guidelines for follow-up exist at some hospitals, they are not uniformly applied or explicit.¹⁸ To date, there has been 1 randomized trial focused on a home intervention in this population, as well as small feasibility trials of interventions delivered by phone.¹⁹ Thus, significant opportunities exist to optimize the physical, emotional, and cognitive aspects of survivorship to further improve outcomes.

CENTERING ON THE SURVIVOR: VULNERABILITY OF THE PATIENT

The *system of care* for a disease refers to the healthcare delivery framework that supports the relevant stakeholders and their associated needs.²⁰ The purpose of



examining a disease and healthcare delivery through this model is to optimize delivery of healthcare resources to the patient. Thus far, the system-of-care approach has been beneficial for cardiac arrest in that it has helped stakeholders grow beyond functioning as independent silos within the house of medicine. It has encouraged the development of multidisciplinary teams that drive optimal care for patients after cardiac arrest. The systems-of-care approach to cardiac arrest has optimized EMS systems and promoted examination of IHCA and OHCA outcomes. However, the current system of care falls short by failing to organize discharge planning and long-term rehabilitation care resources, which, for many patients and their families, may be paramount to improving quality of life after cardiac arrest.

Outcomes and Quality of Life

Clinician-reported outcomes (return of spontaneous circulation [ROSC], survival at discharge, CPC score, modified Rankin Scale score) have been the standard for cardiac arrest studies and for defining good or acceptable outcomes. However, these results are insufficient because they originate from the (healthcare) provider perspective. Moreover, the concept of acceptable is not survivor defined, and assessment is frequently conducted at hospital discharge, thus failing to consider challenges encountered when survivors return home.

Quality of life is a broad term describing a person's overall well-being, determined by satisfaction or dissatisfaction with various aspects of life. It is difficult to define beyond an individual level; therefore, it is difficult to measure. *Health-related quality of life* (HRQOL) is an individual's perception of the impact of illness (and the treatment of illness) on discrete domains of daily life and functioning. It is temporal, should be assessed over time, and is defined only at the individual level. *Patient-reported health status* encompasses HRQOL and the symptoms resulting from a disease, such that disease-specific instruments assessing multiple domains are ideal if available. Although cardiovascular disease-specific health status surveys exist, they are inconsistently used in practice.²¹

Generic measures such as the 36-Item Short-Form Survey or the 12-Item Health Survey^{22,23} have captured reports of lower levels of physical or mental health in survivors of cardiac arrest compared with age- and sex-matched population values at 12 months,^{24,25} 3 years,^{26,27} and 5 years.²⁸ However, these findings are very much influenced by the choice of generic measures, with some studies reporting no difference in generic quality of life between survivors and the general population.^{29,30} Although they support health comparisons across population groups, generic measures lack specificity and may fail to account for variation in patient or system factors such as protocol inclusion

criteria, provider biases, or cultural/religious differences. When used in isolation, generic measures provide a suboptimal assessment of outcome from the survivor's perspective.^{29,31}

For many survivors, their HRQOL may continue to change,²⁴ and a longer-term assessment of HRQOL is recommended.^{29,32} Patient-reported outcome measures seek to assess either specific aspects of or the overarching concept of patient-reported health status.^{13,33,34} Alternatively, the lived experience may be explored with patients and their families by following more qualitative approaches such as interviews or focus groups.^{29,35,36} Although numerous domain-specific measures are available and have been widely used in this population (eg, assessing cognitive impairment²⁷ or emotional well-being),³⁷ a patient-reported outcome measure that is specific to the experience of cardiac arrest survivors is not currently available.²⁹

Quality of life and patient-reported outcome measures are now included as supplementary outcomes in the updated international Utstein statement and reporting framework.³⁸ Existing research has highlighted the lack of assessment guidance after cardiac arrest and the resulting heterogeneity in outcome reporting across many essential elements of survivorship, including HRQOL,^{29,39-41} cognitive function,⁴² and emotional well-being.³⁷ This heterogeneity in reporting adds to the methodological variation reported in studies, thus limiting evidence synthesis of the impact of cardiac arrest and associated health care.

A recent statement from the International Liaison Committee on Resuscitation identified a core outcome set for cardiac arrest effectiveness studies that should include survival, neurological function, and HRQOL.⁴³ As cardiac arrest-specific scales and core outcome sets are developed, both researchers and clinicians will have better tools to measure, assess, and reassess outcomes after cardiac arrest. These tools will also allow treatments and rehabilitation interventions to be in line with patients' values and goals of care.

Addressing Arrest Causes and Preventing Recurrence

The causes of cardiac arrest vary substantially by individual characteristics and age.⁴⁴⁻⁵⁰ Data are lacking that systematically compare the different risks of recurrent arrest across causes among survivors.⁵¹ Given the differing natural histories of each cardiac arrest cause, long-term risks are expected to vary substantially.

The initial workup of patients with a cardiac arrest is focused on identifying reversible or treatable precipitants.⁴ Such precipitants include myocardial ischemia or infarction, cardiac arrhythmias, electrolyte abnormalities, or drug toxicity, among others. Beyond the early stages of the cardiac arrest, identifying the underlying

cause of the arrest may have implications for the intermediate- and long-term management of patients. In CASPER (Cardiac Arrest Survivors With Preserved Ejection Fraction Registry), among patients with a cardiac arrest of unknown cause without overt heart disease, a cause was identified in ≈56% by use of a systematic workup approach comprising electrocardiography and cardiac rhythm assessment, cardiac imaging, provocative exercise and drug challenges, and selective electrophysiology testing.⁵²

Because the ability to predict and prevent recurrent arrests in survivors is imperfect, prevention of recurrent cardiac arrest is focused on both minimizing the conditions that contribute to the arrest and maximizing the probability of survival should a recurrent arrest occur. On the basis of randomized trials,^{53–55} with few exceptions, guideline recommendations highlight the value of ICDs for secondary prevention after a cardiac arrest.^{56,57} Typically, ICDs are not indicated if the cause of the arrest is felt to be reversible and adequately treated.^{56,57}

Beyond ICDs, management that minimizes the probability of recurrent arrest is generally condition specific, for example, optimizing neurohormonal blockade in patients with nonischemic cardiomyopathy, performing revascularization for patients with coronary artery disease, administering β -blockers, avoiding QT-prolonging medications in patients with long-QT syndrome, and abstaining from participation in competitive athletics in patients with arrhythmogenic right ventricular cardiomyopathy. Previous consensus statements can be helpful for the management of patients and prevention of recurrent cardiac arrest, particularly when the cause of the cardiac arrest has been identified.^{58–61}

Efforts to maximize the probability of survival should an arrest occur include educating family and caregivers about what a cardiac arrest may look like and when to call for help. Some hospitals offer cardiopulmonary resuscitation (CPR) training to heart patients and their families before discharge so that if an arrest occurs in the home, family members may feel prepared to provide CPR until EMS providers or other first responders arrive. Few studies have examined the feasibility and outcomes related to such programs.⁶²

Patients with inherited arrhythmia syndromes, which span both channelopathies and cardiomyopathies, may benefit from formal genetic counseling, testing, and familial evaluations.^{63–65} In such patients, the yield of genetic evaluation varies substantially by condition^{66,67} but can facilitate screening and direct carrier testing of relatives at risk for the condition. Genomic analysis with commercial genetic testing has increased dramatically as sequencing technology has become highly efficient, making test selection and variant interpretation more complex. Moreover, discussion of legal, economic, and ethical implications of testing is warranted when counseling patients. Testing in conjunction with

an experienced genetic counselor is highly encouraged. Guidelines relating to the indications for genetic testing in such conditions have been outlined in contemporary consensus statements.^{63,64}

The management of athletes who have experienced a cardiac arrest can be challenging, particularly when the underlying condition represents an absolute contraindication to long-term participation in competitive athletics. For example, because of risks of disease progression and arrhythmia, patients with arrhythmogenic cardiomyopathy should be counseled against participation in competitive athletics.^{59,68} Specific recommendations about participation in athletic activity are summarized elsewhere.^{5,68–75}

Post-Critical Illness Syndrome Susceptibility

Survivors of cardiac arrest are at risk for post-critical illness syndrome, the potential psychological, cognitive, and physical impairments that result from surviving and being treated for critical illness. Whereas no previous guidelines addressing cardiac arrest survivorship exist, standards to discuss the effects of the disease process and treatment, to provide ideals for coordination of care, to address psychosocial care and fatigue, and to provide guidance for screening have been developed for other complex and potentially debilitating disease states (including cancer, stroke, and myocardial infarction).^{76–85} Specifically, guidelines for stroke rehabilitation aim to decrease the morbidity of immobility, depression, loss of autonomy, and loss of functional independence, complications that cardiac arrest survivors also face.⁸⁵

Unanticipated critical illness and its treatments may have long-term consequences. This view has been increasingly recognized among patients requiring extracorporeal membrane oxygenation or ICU admission for sepsis or acute respiratory distress syndrome. The post-intensive care syndrome (PICS) is a collection of psychological, cognitive, and physical impairments that are common among survivors of critical illness.⁸⁶ Few studies to date test interventions for improving PICS, and many studies focus only on the psychological aspects of recovery.⁸⁷ Individual patients also report symptoms for years that are related to specific sequelae of intensive care such as tracheal stenosis, heterotopic ossification in joints, reduced joint mobility, and cosmetic concerns from procedural scars.⁸⁸ Early interventions are increasingly being studied to reduce delirium and to enhance mobility in the ICU setting.^{89,90}

A series of conferences attended by critical care stakeholders from rehabilitation, palliative care, occupational therapy, intensive care, and the National Heart, Lung, and Blood Institute has sought to inform the long-term consequences of critical illness. This group described PICS as a term that could be applied to a patient, a

family member, or both.⁸⁶ Furthermore, the group identified several research areas in which further evidence to understand PICS was required: risk factors (genetic, family characteristics, comorbidities, severity of illness, length of exposure), prevention (speech and swallowing, physical and occupational therapy, nutrition, sleep, psychiatric evaluations, sedation, oxygenation, glucose control), and transitions of care (medication reconciliation, transfer to other healthcare facilities, and end-of-life discussions).⁹¹

Although it is unclear whether the impairments and pathological processes of survivorship after post-cardiac arrest syndrome (PCAS) represent a phenotype distinct from the larger PICS,⁹² PCAS is known to result in a unique cascade of inflammatory processes in the immediate postresuscitation period.⁹³ Unlike the families of other critically ill patients, the families of cardiac arrest survivors may have witnessed the arrest or performed CPR on their loved ones, creating unique psychosocial needs after survival. With PICS as a framework, additional attention is needed for the subset of post-cardiac arrest survivors and their loved ones.

CENTERING ON THE SURVIVORS: AT-RISK BODY SYSTEMS AND THEIR IMPAIRMENTS

The following body and psychosocial systems are presented methodically; however, there is significant overlap among domains. For example, vision impairment may impede a patient's ability to read (physical function) or recognize objects (cognitive function) because of neurological injury, but it is presented in both the physical and cognitive impairment sections. Furthermore, some assessment tools are listed as examples but may not represent the comprehensive measures available to rehabilitation specialists and may not have been validated for use in cardiac arrest survivors. What follows represents just one scheme to discuss issues of survivorship, to provide guidance for measuring impairments, and to highlight the gaps for further investigation.

Musculoskeletal Considerations

Musculoskeletal impairment after critical illness includes muscle weakness, likely through a combination of a stress-induced catabolic state, inflammation, and immobilization. For example, the cross-sectional area of the quadriceps decreases 12.5% by day 7 and 17.7% by day 10 of ICU admission.⁹⁴ Other studies report similar muscle wasting in the ICU.⁹⁵ Survivors of acute respiratory distress syndrome have perceived weakness and limited ability to perform vigorous exercise for up to 5 years after their critical illness.⁸⁸ Longitudinal

studies find improvement in muscle wasting and weakness over 2 years after intensive care.⁹⁶ Furthermore, objective post-ICU muscle weakness and wasting are associated with impairment of function and reduction in quality-of-life measures.

Post-cardiac arrest patients frequently complain of fatigue that limits activity and participation after hospitalization.^{97,98} Symptomatic fatigue is reported by more than half of survivors. To what extent postarrest fatigue is related to post-intensive care muscle weakness is not known. Cognitive and problem-solving strategies can improve participation in post-cardiac arrest patients with fatigue.^{19,99}

CPR can also cause specific physical injuries to the chest. Case series report a prevalence of rib fractures of 9% to 85%. Larger series have identified a prevalence clustering at ≈60% by using more sensitive techniques such as computed tomography scan.^{100–114} Case series report sternal fractures in 4% to 66% of cases, with an overall prevalence of about one-half that of rib fractures (≈30% of cases).^{100,101,103–108,110,113,114} Abdominal visceral injuries occurred in 8% of 39 survivors in a case series.¹⁰³ Chest injuries are reported more often in OHCA than in IHCA,¹¹² more often after mechanical CPR than after manual CPR,^{109,113} and more often in women than in men.¹¹⁰

The duration and severity of pain from CPR-related chest injuries have not been studied. Although it is reasonable to speculate that interventions to treat CPR-related pain and to improve pulmonary hygiene may be beneficial, we identified no studies on this topic.

In addition to chest injuries, many post-cardiac arrest patients report impairment of vision and ambulation.^{97,115} It is unclear how specific these symptoms are to cardiac arrest. There have not been formal investigations of these specific symptoms.

Few specific therapies are established to improve physical functioning in critically ill patients. In a cohort, physical mobility was severely impaired in the hospital and for 3 months after a critical illness, but patients continued to recover for 12 months.¹¹⁶ More intensive physical therapy and occupational therapy interventions in the hospital focusing on improving mobility and strength did not alter objective mobility measures at 3 months, but this therapy did improve patient satisfaction with recovery. This observation suggests that educating patients about expected limitations and expected recovery can improve their adaptation to physical impairments. Table 1 summarizes physical impairments after critical illness and cardiac arrest.

A Cochrane review of post-ICU exercise-based therapy identified no regimen that resulted in a consistent improvement in patients' exercise tolerance.⁹⁵ One exception was a small trial in which 8 weeks of supervised aerobic training after hospitalization (cycle ergometer) increased the anaerobic threshold in 13

Table 1. Musculoskeletal Impairments

Musculoskeletal Impairment	Example	Measure	Interventions/Treatment	Research Opportunity/ Gap in Knowledge
Muscle weakness/wasting, myopathy	Walking, rising from chair, climbing stairs	Modified Barthel Index, Timed Up and Go Test, range of motion and strength evaluations, electromyography	PT, orthotics, protein supplementation	Early intervention in ICU, goals-of-care discussion
Fine motor	Writing, grasping, tying shoelaces, texting, typing	Functional Reach Test, Arm Motor Ability Test, Wolf Motor Function Test	OT, orthotics	Early intervention in ICU, goals-of-care discussion
Physical fatigue	Physical fatigue during prolonged activity	6-Minute Walk Test, Multidimensional Assessment of Fatigue, Modified Fatigue Impact Scale	Adaptations, orthotics, compensatory training	Role of exercise or cognitive behavioral therapy, individualized strategies
Pain from chest wall trauma or procedure site	Rib fracture from CPR, ICD implantation	Visual Analog Scale, Pain Scale	Cough pillow, incentive spirometry, topical or systemic pharmacotherapy, tincture of time	CBT intervention, local vs systemic pharmacotherapy
Vision	Difficulty reading, field cuts, blindness, hemispatial inattention	Visual acuity, brain imaging	Ophthalmology or neurology referral	Early intervention, opportunity for recovery
Speech disorder	Tracheostomy, articulation disorder such as dysarthria (eg, resulting from tongue weakness, cranial neuropathy), vocal cord trauma or paralysis, impaired pulmonary function (eg, short phrase length, hypophonia)	SLP oral mechanism, cranial nerve examination, direct visualization (eg, otolaryngologist flex examination), speech sound assessment, comprehensibility/intelligibility assessment, bedside pulmonary function test	Communication board, speaking valve, speech therapy/training with SLP, family engagement/counseling	Early intervention in ICU, goals-of-care discussion
Swallow dysfunction	Muscle weakness, neurological dysfunction, impaired pulmonary function (eg, swallow-respiratory incoordination caused by tachypnea or reduced tidal volume), iatrogenic (eg, medication effect), altered sensorium (eg, taste)	SLP oral mechanism examination, clinical swallowing examination, fiberoptic endoscopic evaluation of swallowing, videofluoroscopic swallowing study (modified barium swallow)	Swallow training (eg, smaller bites/sips, postural maneuvers), progressive resistive exercise, diet modification, PEG tube, reassessments for removal of compensatory interventions	Early intervention in ICU, goals-of-care discussion

CBT indicates cognitive-behavioral therapy; CPR, cardiopulmonary resuscitation; ICD, implantable cardioverter-defibrillator; ICU, intensive care unit; OT, occupational therapy; PEG, percutaneous endoscopic gastrostomy; PT, physical therapy; and SLP, speech-language pathologist.

subjects compared with 17 subjects with usual care.¹¹⁷ No studies have explored exercise therapy specifically for cardiac arrest.

Neurological Impairment

Neurological injury that occurs while blood flow to the brain is interrupted (no-flow time) or is inadequate (low-flow time during CPR) accounts for much of the morbidity experienced by patients resuscitated from cardiac arrest. The resulting injury cascade (including excitotoxicity, disrupted calcium homeostasis, free radical formation, and pathological protease pathways) ultimately results in cell death. The larger pattern of brain injury is driven by neuron subpopulations selectively vulnerable to hypoxic-ischemic injury and has been well documented in both preclinical and clinical trials. The distribution includes selective neuronal death and cell necrosis in the hippocampus, as well as in the neocortex, the central nuclei, and the brainstem.^{118,119} Common clinical manifestations of this characteristic brain injury after cardiac arrest are summarized in Table 2 and are discussed in the next sections.

Seizures and Status Epilepticus

The susceptibility of the cerebral cortex to hypoperfusion during and immediately after cardiac arrest results in a high incidence of seizures in the early phase of recovery. The reported incidence of seizures after CPR ranges from 24% to 44%.^{120,121} The presence of seizures and status epilepticus has been suggested to herald an unfavorable outcome. However, seizure and status epilepticus may respond to aggressive antiseizure therapy in the acute period.¹²² Survivors who develop chronic epilepsy should be treated with a maintenance antiepileptic regimen.

Post-Cardiac Arrest Myoclonus

Myoclonus after cardiac arrest can occur acutely or may persist chronically, although both forms may coexist. Although early-phase myoclonus was initially deemed to portend a poor outcome,¹²³ favorable phenotypes have been described that are responsive to treatment.¹²⁴ The chronic type of post-hypoxic myoclonus, or Lance-Adams syndrome, includes positive myoclonic jerks from rapid, active muscle contractions triggered by action or attempts to move, particularly movements requiring coordination or dexterity.¹²⁵ As a chronic condition,

Table 2. Neurological Impairments

Neurological Impairment	Example	Measure	Intervention/Treatment	Research Opportunity/Gap in Knowledge
Seizures	Epilepsy	EEG	Antiepileptic	Cause, role and duration of antiepileptic treatment
Myoclonus	Acute, chronic (Lance-Adams syndrome)	EEG	Antiepileptic, PT/OT	Cause, role and duration of antiepileptic treatment
Stroke	Aphasia, locked-in syndrome, cognitive communication disorders, anosognosia	Imaging, SLP aphasia/cognitive-communication assessment	Acute tPA or thrombectomy, rehabilitation with SLP	Risk factor modification
Movement disorders	Chorea, tremor, akathisia	Abnormal Involuntary Movement Scale, Barnes Akathisia Scale	Multisensory feedback, PT/OT	Role for pharmacological treatments
Spasticity	Contracture	Modified Ashworth Scale	Splinting, PT/OT	Role for pharmacological treatments
Ataxia, dysmetria	Gait/balance disturbance, dysarthria	Berg Balance Scale, Scale for Assessment, and Rating of Ataxia	Multisensory feedback, PT/gait training	Rehabilitation opportunity
DOCs	Coma, vegetative state, minimally conscious	GCS, evoked potentials, EEG	Treat underlying medical, assess evoked potentials	Role for neurostimulants, rehabilitation opportunity
Brain death	Anoxic injury	Brain death testing	Treat underlying medical, assess organ donation	Timing of prognostication and WLST

DOC indicates disorders of consciousness; EEG, electroencephalogram; GCS, Glasgow Coma Scale; OT, occupational therapy; PT, physical therapy; SLP, speech-language pathologist; tPA, tissue plasminogen activator; and WLST, withdrawal of life-sustaining therapies.

these symptoms can be mitigated and quality of life optimized. Some of the agents with favorable effects include clonazepam, valproic acid, and levetiracetam.¹²⁶ For cardiac arrest survivors, diagnosis and management of seizures are important for improving outcome.^{127,128}

Stroke and Stroke Syndromes

As the cerebral perfusion drops to ischemic levels, susceptible vascular territories may be infarcted. These injuries typically occur at watershed areas of the major cerebral blood vessels such as the distal areas of the middle cerebral artery and the anterior cerebral artery. This injury results in “man-in-the-barrel syndrome,” a clinical picture of brachial diplegia with intact lower extremity function.

Cardiac risk factors (eg, arrhythmia, heart failure, diabetes mellitus, dyslipidemia) leading to the arrest may also be risk factors for acute ischemic stroke. Stroke that occurs with or around cardiac arrest is approached similarly to a typical stroke, with neuroimaging to confirm diagnosis and options for either intravenous thrombolysis or thrombectomy, as the case may necessitate.

Movement Disorders and Motor Impairment

The areas that control the motor system are similarly vulnerable in cardiac arrest. These areas include portions of the basal ganglia, thalamus, cerebellum, and motor cortex. The clinical manifestation may be confused with seizures, especially during the early period. The electroencephalogram is key to differentiate these conditions from seizures. The nonepileptic movements may include parkinsonism, dystonia, chorea, tics, tremor, athetosis, and myoclonic syndromes.¹²⁹ Patients may

also have difficulty with balance and gait in the form of ataxia and dysmetria. The short- and long-term management of these movement disorders is largely supportive, and long-term care by a neurologist is essential for optimal outcome.¹²⁹

Disorders of Consciousness

The cerebral cortex and other areas responsible for consciousness are among the most sensitive to global ischemia from cardiac arrest. Disorders of consciousness (DOCs) represent a spectrum of disease, distinct from delirium, ranging from the comatose state (extensive injury to areas responsible for arousal and awareness) to the minimally conscious state (inconsistent but clear evidence of consciousness) to the vegetative state (unresponsiveness with preserved arousal and sleep-wake cycles but with persistent lack of awareness of self and environment).^{93,130} DOCs are a major limiting factor in recovery and limit the chances of improvement with rehabilitation.

During the initial phase of recovery, the clinical approach to DOCs includes managing conditions that impair cortical and subcortical areas. Structural brain-related processes (eg, brain edema, seizures) should be treated along with systemic factors (eg, hypoxia, hypoperfusion, metabolic derangements). Some investigators have examined the role of neurostimulants to enhance recovery from DOCs during the immediate phase (5–13 days). Although case series on drugs such as amantadine,¹³¹ methylphenidate,¹³¹ and zolpidem^{132,133} suggest areas for further study, caution is advised because the sympathetic effects of these drugs may have unintended adverse effects, specifically related to cardiac function.

During the subacute phase (14–30 days), clinical decisions should be made about interventions that facilitate long-term care. Some of these include tracheostomy, resources for mechanical ventilator support, gastrostomy for enteric feeding, long-term vascular access, and strategies for the prevention of deep vein thrombosis and skin breakdown. Depending on the degree of the DOC, patients may be candidates for short-term rehabilitation with coma stimulation programs. However, for those who remain unable to participate in their own care (coma, persistent vegetative state, or severe cognitive impairment), long-term full-time nursing facilities may be required.

Withdrawal of Life-Sustaining Therapies and Brain Death

Up to two-thirds of patients with PCAS who are successfully resuscitated die during the hospitalization. The primary cause of death after cardiac arrest is believed to be neurological in nature, regardless of the primary cardiac arrest arrhythmia.¹³⁴ However, some studies show that the most common cause of death in those who initially survive SCA is influenced by withdrawal of life-sustaining therapies. Withdrawal of life-sustaining therapies ranges from 59% to 82% in the literature.^{135–137}

Brain death is relatively uncommon because patients who remain comatose usually retain some signs of neurological function. The diagnosis of brain death needs to satisfy specific clinical parameters such as irreversible absence of cerebral cortex and brainstem functions.¹²³ Although the majority of cardiac arrest literature implicates neurological injury as the cause of death in most patients with PCAS, some studies suggest that a minority ($\leq 10\%$) satisfy the brain death criteria.^{138,139}

Cardiopulmonary Considerations

Cardiopulmonary dysfunction after cardiac arrest may be transient or long term. Ischemia and PCAS may result in cardiac muscle weakening, reduced ejection fraction, and valvular dysfunction that manifest as ongoing or intermittent symptoms of chest pain, shortness of breath, peripheral edema, or reduced exercise tolerance.^{93,140} Patients may be started on new medications, such as for blood pressure or heart rate control, which may carry side effects such as fatigue or depression.

Patients may need assistance with medication adherence because of cognitive impairment after cardiac arrest. Medication dose changes or weaning may be necessary because of side effects after discharge. Cardiac rehabilitation may serve not only to improve cardiopulmonary function but also as an opportunity to screen for and improve affective and cognitive impairments.^{141,142} Rehabilitation programs may also be an opportunity for patients to find a community and to connect with others who have had similar experiences.

Cognitive Dysfunction

Cognitive impairment is one of the most common residual problems among cardiac arrest survivors. Cognitive impairments include difficulty with memory, attention, and executive functioning (eg, planning, organization). Both language and communication may be affected, primarily (eg, as a result of difficulty with comprehension or word retrieval) or as a consequence of cognitive impairment (eg, resulting from difficulty attending to conversation amidst distraction). Patients are exposed to few cognitive demands in the initial hospital setting, making recognition of impairment difficult without specific assessment. Patients and family members may lack awareness of cognitive deficits until the patient is discharged home, after which caregivers may be the first to recognize new cognitive challenges. Table 3 summarizes the cognitive impairments common after global brain injury such as after cardiac arrest.

Most studies evaluating outcomes after cardiac arrest rely on a functional scale (typically the CPC) as the main end point, and these functional scales are insensitive to detect cognitive impairment.¹⁴³ Although the number of studies specifically assessing cognitive outcomes after cardiac arrest has grown in recent years, the quality of evidence in this field remains suboptimal.^{42,144}

Rates of cognitive impairment after cardiac arrest vary across studies. Factors explaining the discrepant findings include differences in the cohorts examined, sensitivity of the cognitive assessment tool, length of and loss to follow-up, and overall methodological quality. Prospective studies have found cognitive impairment in between one-quarter and one-half of cardiac arrest survivors assessed 3 to 6 months after resuscitation with a battery of neuropsychological tests. Contemporary study results show lower rates of cognitive dysfunction than older ones.^{145,146} However, the apparent longitudinal improvement in cognitive outcome after cardiac resuscitation has not been sufficiently studied.

There are limited data on predictors of cognitive outcome after cardiac resuscitation. Time to ROSC has not been consistently associated with cognitive results.^{143,147} Similarly, duration of coma was related to worse cognitive outcomes in some studies but not in others.^{92,148} Age does not appear to be a major determinant of cognitive outcomes^{143,149}; older survivors can recover good cognition, and children and adolescents can remain cognitively impaired.^{150,151} Targeted temperature management may have a beneficial influence,^{152,153} and benefit has been observed with temperature targets of 33°C and 36°C.¹⁵⁴

Among patients with residual cognitive dysfunction, the degree of cognitive impairment is usually mild; dementia caused by global anoxic-ischemia resulting from cardiac arrest is uncommon.¹⁵⁵ Memory (especially short-term memory), attention, executive function,

Table 3. Cognitive Impairments

Cognitive Impairment	Example	Measure	Intervention/Treatment	Research Opportunity/Gap in Knowledge
Attention	Sustained focus, ability to attend to X while ignoring Y	Test of Variables of Attention, Stroop-Effect test	Recognize and manage internal and external distractors	Role for pharmacotherapy, exercise, and rehabilitation
Memory	Short-term (immediate and delayed recall), working (eg, manipulate lists of numbers), long-term, prospective ("remembering to remember," eg, taking medications, making appointments)	Object recall, serial 7s, alphabetizing list of random objects, ordering list of random numbers	Same as above (because of overlap), external memory aids (eg, smartphone calendar, lists, visual cues), chunking strategy (working memory), practice routines (eg, overtraining of procedural memory), enlist caregivers	Role for pharmacotherapy, exercise, and rehabilitation; ability to increase capacity
Executive function	Planning/organization, cognitive flexibility, self-regulation	Tower of London test, Wisconsin Card Sorting Test, verbal fluency test, FAVRES (higher-level functional)	Same as above (because of overlap), break into small tasks, metacognitive training, enlist caregivers	Role for pharmacotherapy, exercise, and rehabilitation
Intellect	Ability to learn or acquire and apply knowledge	Verbal Comprehension Scale, Wechsler Adult Intelligence Scale, Stanford-Binet Intelligence Scales	Same as above (because of overlap), metacognitive training, enlist caregivers	Role for pharmacotherapy, exercise, and rehabilitation
Language	Expressive aphasia, receptive aphasia, apraxia	SLP evaluation	Individualized SLP therapy	Role for exercise and rehabilitation
Perception, visuospatial	Difficulty recognizing or interpreting stimuli (eg, visual agnosia, inattention, tactile agnosia)	Individual sensory tests	Same as above (because of overlap), referral to SLP and neurology, enlist caregivers	Role for pharmacotherapy, exercise, and rehabilitation

FAVRES indicates Functional Assessment of Verbal Reasoning and Executive Strategies; and SLP, speech-language pathologist.

and psychomotor function are generally most affected. These cognitive deficits are dynamic and can improve over time; however, most of the improvement happens over the first 3 months after the arrest,^{24,98} and the dysfunction is persistent after that time.^{156,157}

Survivors with cognitive dysfunction generally have worse quality of life, worse social functioning, and more psychological symptoms such as depression, anxiety, and posttraumatic stress syndrome, along with decreased exercise tolerance. While subjective cognitive complaints and objective cognitive dysfunction may not correlate,¹⁵⁸ both are associated with worse quality of life.¹⁵⁹ Cognitive recovery also influences the likelihood of returning to work.²⁴

Available evidence solidly demonstrates that cognitive impairment is a common complication, even among patients with otherwise good functional recovery (eg, CPC 1). Therefore, studies investigating outcomes after cardiac arrest should include cognitive function evaluated by a validated tool as one of the end points. Currently, no specific tool is preferred. More research is also necessary to clarify the determinants of cognitive outcome and to identify interventions that may both prevent cognitive impairment and facilitate cognitive recovery after the arrest.

Chronic Critical Illness

Advancements in technology and postarrest care have created a new type of patient who challenges models of care, prognosis, and healthcare use. Patients who initially survive cardiac arrest may need prolonged intensive care and may become dependent on critical care

therapies such as mechanical ventilation, mechanical circulatory devices, or hemodialysis.¹⁶⁰ Some of these patients may have never been sick before, whereas some incur added chronic illness. These patients, described as chronically critically ill, require prolonged organ support and develop nosocomial infections and neuroendocrine, metabolic, neuromuscular, and immunological disturbances.¹⁶⁰ Although definitions of chronic critical illness vary, prolonged ventilator dependence (eg, tracheostomy) and increased ICU length of stay characterize this syndrome.

The reported outcomes for this unique patient population are understandably poor. One-year mortality for the chronically critically ill ranges from 48% to 68%.^{161–165} Survivors to discharge experience significant cognitive and physical impairments that require subsequent institutionalization (ie, long-term acute care facilities, rehabilitation) and use a disproportionate proportion of healthcare resources.^{160,166,167}

As cardiac arrest care evolves, support via mechanical circulatory devices (ventricular assist devices, total artificial heart, and extracorporeal membrane oxygenation configurations) is becoming more common as a bridge to recovery, destination therapy, and transplantation. For those patients who survive to discharge, the sequelae of chronic critical illness may persist. Complications from long-term mechanical support such as chronic thrombosis, infection, stroke, gastrointestinal bleeding, and mechanical failure are not uncommon.^{168–183} Device management includes long-term anticoagulation, management of hypertension, and treatment of right ventricular failure.¹⁸³ The return to (new) normalcy for survivors with mechanical circulatory support includes

Table 4. Psychosocial Well-Being

Psychosocial Well-Being	Assessment	Treatment/Intervention	Research Opportunity/Gap in Knowledge
Anxiety	HADS	CBT, pharmacotherapy	Improved assessment, duration, amelioration, role for support group
Depression	HADS, IPAT, Beck Inventory II	CBT, pharmacotherapy	Improved assessment, duration, amelioration, role for support group
PTSD	PTSD Checklist, SPAN, SPRINT	CBT, pharmacotherapy	Improved assessment, duration, amelioration, role for support group
Quality of life	SF-36, SF-12, HUI3, EuroQoL EQ-5D-5L, focus group, direct patient or family interview	Individual strategies	Improved assessment, role for support group
Spirituality/existential concern	WHOQOL instrument, self-reporting, interview	Individual strategies	Improved assessment, role for support group
Return to work	WIS, WALs, WLQ-25	Adaptations, CBT	Improved assessment, barriers to return to work
Personal relationships, reintegration, return to intimacy	Self-reporting, direct patient or family interview	Individual therapy, CBT	Improved assessment, role for support group

CBT indicates cognitive-behavioral therapy; EQ-5D-5L, 5-level EQ-5D; HADS, Hospital Anxiety and Depression Scale; HUI3, Health Utilities Index Mark 3; IPAT, Intensive Care Psychological Assessment Tool; PTSD, posttraumatic stress disorder; SF-12, 12-Item Short Form; SF-36, 36-Item Short Form; SPAN, Startle, Physiological Arousal, Anxiety, and Numbness; SPRINT, Short Posttraumatic Stress Disorder Rating Interview; WALs, Workplace Activity Limitations Scale; WHOQOL, World Health Organization Quality of Life; WIS, Work Instability Scale; and WLQ-25, Work Limitations Questionnaire.

management of fatigue, decreased strength, reduced energy levels, and increased stress and anxiety from adapting to the challenges of a new lifestyle.^{184–186}

Affective Well-Being

The prevalence of affective sequelae after SCA has been an important area of investigation. High levels of anxiety and depression have been identified in SCA survivors after hospitalization.^{37,187} Studies have reported clinically significant depression in 8% to 45%, anxiety in 13% to 42%, and posttraumatic stress disorder (PTSD) in 19% to 27% of survivors.^{188–190} However, several different instruments have been used clinically with no definitive cutoffs for determining a diagnosis, which makes it difficult to know the true depth of anxiety and depression.

Anoxic brain injury after cardiac arrest increases the risk for depression, anxiety, and PTSD but for an uncertain duration of time.¹⁹¹ Over the first year after resuscitation, anxiety, depression, anger, and stress tend to be elevated in SCA survivors who receive an ICD shock compared with those who did not.¹⁹² Spouses of SCA survivors also tend to have higher anxiety and depression if their partner had experienced an ICD shock. In the longest follow-up reported in SCA survivors (up to 8 years),¹⁹³ PTSD was noted in 27% of the survivors, with these individuals also reporting lower quality of life, more limited self-care, and more pain and depressed mood. In a comparison of SCA survivors who received therapeutic hypothermia with those with ST-segment-elevation myocardial infarction after 6 months,¹⁹⁰ SCA survivors had more frequent anxiety (24% versus 13%) and more depression (19% versus 8%). High anxiety and depression levels were more common in women and those who were younger. Although there may be overlap among domains of impairment after cardiac

arrest, patients experiencing significant affective sequelae may have otherwise good neurocognitive function.¹⁹⁴

Table 4 summarizes common tools for assessing affective and psychosocial well-being. No large studies have evaluated the roles for pharmacotherapy, cognitive behavioral therapy, support groups, or exercise in cardiac arrest survivors specifically. Few practitioners discuss the risk of emotional lability with patients.¹⁹⁵

Existential Well-Being

An array of emotions ranging from fear, vulnerability, and loneliness have been described in cardiac arrest survivors. These are often contrasted in the same individuals with feelings of joy, elation, and gratitude for being alive.¹⁹⁶ Feelings of anxiety, irritability, and disappointment have been linked to the challenges of adapting to life after cardiac arrest: difficulty in undertaking activities and roles that were previously taken for granted, a fear of the unknown, and fear of a recurrent arrest.¹⁹⁷ Increased dependency on others may bring new challenges, both physical and emotional, with many (often men) finding it difficult to ask for help. Feelings of loneliness and abandonment may increase after hospital discharge, specifically when a change in care leads to feelings of neglect and unimportance.^{198,199}

Survivors have described being fearful of their new reality, experiencing an existential vulnerability in which the finiteness of life and their own mortality has been exposed.^{36,200} The loss of memory surrounding their event may heighten the struggle to make sense of what happened. This causes many to redefine their attitudes toward life: to find healthier lifestyles, to not take things or people for granted, and to refine priorities with an increased focus on their personal relationships. At the same time, survivors may experience

ongoing difficulties in accepting how their body had failed them and how their life has changed. This may result in an increased dependency on others and feelings of vulnerability, insecurity, and anxiety. Survivors may require long-term support from health professionals, spiritual counselors, and loved ones to accept and adapt to functional and existential changes.

Participation and Social Support

Reintegration and Return to Work

Survivors of SCA may experience a maladaptive pattern of intrusive thoughts, avoidance behaviors, and excessive cardiac symptom monitoring known to exacerbate cardiovascular-related distress and to worsen medical outcomes.^{193,201} Fear avoidance, such as fear of repeat arrest during activity or fear of defibrillator firing, after cardiac arrest may be a more important obstacle to community reintegration than physical impairment.^{26,202,203} Fear of another event may lead to somatic complaints, lack of confidence, and narrowing of social activities,²⁰⁴ as well as poor adherence to medications or follow up and increased mortality.²⁰⁵ However, patients rarely receive information on options for support for themselves and their relatives.²⁰⁶

Cardiac arrest significantly changes the lives of survivors, even among those with favorable adaptation.²⁰⁴ A central goal for patients surviving cardiac arrest is community reintegration, defined as the opportunity for individuals to live in their community with the already present condition (after a state of ill health such as a cardiac arrest) and to be valued for their uniqueness and abilities. We have a limited understanding of how specific barriers to community reintegration unfold for patients and their families after experiencing a cardiac arrest. Thus, we do not know whether certain resources might remove these barriers. Long-term reassessment is vital for societal reintegration of the SCA survivor after discharge from the hospital and rehabilitation.²⁰⁷

Work instability is defined as a state in which a mismatch between an individual's functional or cognitive abilities and the demands of his or her job can threaten employment²⁰⁸ and is an important concern for SCA survivors and their caregivers. The large variation in return-to-work rates (13% and 76%) can be attributed to the variability across studies in severity of cognitive impairment, cognitive fatigue, and psychological distress after cardiac arrest.^{26,159,202,209,210} A recent study reported that 47% of cardiac arrest survivors had not returned to their full-time work or activities 6 months after their arrest.²¹¹ The effects of cognitive and physical impairment during long-term follow-up¹⁵⁹ may be most significant among younger patients (<65 years of age). Younger survivors are more likely to return to their previous occupation where subclinical memory deficits are more easily uncovered and viewed as more serious

compared with survivors who have retired. A greater focus on return to work as part of cardiac arrest rehabilitation may be of value for patients of working age.

Other potential contributing barriers to re-employment can be extrapolated from the literature in other cardiac and neurological pathogenesises. Among patients after ICD placement (many of whom are cardiac arrest survivors), level of education and marital status are important predictors of reemployment status.²¹² In patients with traumatic brain injuries, work-related difficulties are associated with multiple factors, including functional independence, cognitive disturbances, length of stay in rehabilitation settings, and educational level.²¹³

Using energy-conservation strategies such as planning ahead, slowing the pace, delegating to others, and simplifying the task may allow survivors to return to daily activities.¹⁹ However, it is unclear whether these strategies have a positive effect on work reintegration. Most studies measure return to work as one of many other measures of societal participation but provide little insight into how post-SCA functional abilities affect work performance. Productivity measures developed to measure work instability in patients with musculoskeletal and neurological disorders may help quantify the benefits of rehabilitative interventions on SCA survivors. No specific post-cardiac arrest measures have been reported.

Social Support and Relationships

Survivors cite a need to seek a new normal in their relationships. They may have concerns about role changes in relationships and family, difficulty in being alone, and worries about resuming intimacy and sex.²¹⁴ For survivors of cardiac arrest, supportive social relationships affect health outcomes and are important for adjustment to illness.²¹⁵

The literature on social support networks for patients, families, and caregivers of cardiac arrest is deficient. The ideal structure, process, and timing for support groups for survivors of critical illness are not known.²¹⁶ Groups led by a healthcare professional may offer an environment that supports sharing stories and helps participants gain a positive outlook.²¹⁷ Family-centered follow-up programs may provide a dual role in recovery by allowing survivors to gain independence and reduce caregiver burden.²¹⁸ Support groups for family or spouses can provide a resource for camaraderie with others who have shared similar experiences and may be beneficial early in the recovery process.^{197,219}

Support networks such as support groups also have limitations that should be considered. Peer support groups may not appeal to everyone, and clinicians must take several factors into account, including illness presentation, age, sex, personality traits, and previous experiences, when recommending such groups.²²⁰ Virtual support forums have been created spontaneously by cardiac arrest survivors with a need

to connect to others. These may best suit the needs of patients or family members who have limited mobility or restricted availability or who prefer anonymity. Virtual support networks may allow increased access to a support group when local or physical meetings are not available.^{221,222} Conversely, many virtual peer groups are not monitored by an administrative team with clinical expertise and could disseminate inaccurate medical information among members. Caution is advised that virtual forums do not replace communication with and support from close family members and friends during and after the initial recovery period.

There is a paucity of data addressing how sex, race, and other socioeconomic indicators affect societal reintegration for cardiac arrest survivors. Female sex may be associated with impaired physical functioning compared with male sex.¹⁴⁷ Although male patients have been reported to have higher quality of life and cognitive functioning, female patients have higher levels of participation in society and instrumental daily activities, all of which are key elements of societal reintegration.²⁶

Studies on the effect of social class after prolonged illness suggest that patients from manual labor classes have a higher risk of unemployment and adverse social consequences.^{223,224} Much like socioeconomic class, other contributors to chronic burden (eg, ongoing financial strain, multiple comorbidities) may affect self-rated health after cardiac arrest among minority groups.²²⁵ Future research studies on cardiac arrest survivors should include purposeful sampling for enrollment to measure the effects of social determinants of health on the reintegration of cardiac arrest survivors.

EFFECT OF TREATING THE PATIENT: NEEDS OF THE CARE TEAM

The care team refers to the healthcare providers, caregivers, and family members who implement the delivered care for the postarrest patient. The team serves as a clinical microsystem, the purpose of which is to “standardize care where possible, based on best current evidence; to stratify patients based on medical need, and provide the best evidence-based care within each stratum; and to customize care to meet individual needs for patients with complex health problems.”²²⁶

Lay Rescuers and EMS Providers

Much of the chain of survival for OHCA is delivered before arrival to the hospital by prehospital providers and, ideally, the lay public. Witnesses to an unresponsive person should summon EMS and then be instructed by telecommunicators to initiate telephone-assisted CPR and to retrieve portable automated

external defibrillators when available. The arrival of professional rescuers allows the chain to advance to advanced cardiovascular life support and rapid transport to a receiving center.

It is increasingly recognized that lay rescuers who respond to an unconscious patient and provide early interventions may have unique emotional or psychological needs to be addressed.²²⁷ Lay rescuers may experience anxiety or PTSD about providing or not providing basic life support. Similar to EMS providers, they often have no feedback about their performance or the outcome of the patient. Some systems attempt to connect rescuers with follow-up and support, but many initial rescuers remain anonymous. These lay rescuers may represent an untapped resource for improving community engagement and survivorship.

With a focus on the chain of survival in the early 2000s, EMS agencies were among the first to witness improvements in outcomes (eg, more patients delivered to the hospital with ROSC) and took ownership of effecting change for the cardiac arrest care team. Those therapies started by EMS created momentum and were often continued throughout the hospital stay (eg, targeted temperature management). In large municipalities (eg, New York), standardization of EMS care provided momentum to encourage hospitals to adopt in-hospital care pathways or risk diversion of patients with OHCA. The recognition of destination decisions based on in-hospital services gave rise to the concept of regional cardiac arrest centers, discussed later, and solidified the importance of EMS providers as critical to a successful OHCA care team.

Hospital Providers Who Treat Patients With Cardiac Arrest

The current international recommendations on post-cardiac arrest care highlight the complexity of treating PCAS and suggest a multifaceted approach to mitigating the resulting sequelae.^{15,228} Despite research examining the effectiveness of multidisciplinary teams to improve delivery of care to the postarrest patient, no work has evaluated the value of multidisciplinary teams for improving rehabilitative care or improving long-term outcomes or quality of life.

Hospital-based care providers may also experience emotional or psychological effects of caring for a patient with cardiac arrest.²²⁹ Team debriefings may be beneficial after resuscitation efforts have been handed off to new providers. Debriefings allow a review of team performance (education, quality improvement), as well as recognition of the natural stressors associated with caring for a patient near death, especially when the patient is young and the cardiac arrest is unexpected.²³⁰

Caregivers and Family of Survivors

Survival after cardiac arrest is a dynamic experience that extends far beyond the individual patient. It is vital to acknowledge that survivors' and family members'/caregivers' points of reference about the cardiac arrest and subsequent recovery vary on the basis of memory limitations that exist from an undefined period of time before arrest.²³¹ In addition, previous experience with acute illness, whether the arrest was witnessed by family or caregivers, whether family provided initial CPR, and in-hospital treatments (eg, targeted temperature management) influence an individual's ability to cope with recovery from critical illness such as cardiac arrest.²³²

Survivors are focused primarily on returning to their prearrest life, whereas family members and caregivers are left processing the fear, pain, and anxiety of the actual arrest and subsequent hospitalization.^{233–235} A high percentage of relatives experience posttraumatic stress syndrome during the early phase of their loved one's illness, which increases their risk of experiencing PTSD later. The CPR experience has been reported by family in retrospective analyses as frightening, difficult, chaotic, and producing feelings of guilt about whether CPR was performed correctly; support should be focused on removing that guilt.^{232,236}

The demands on friends, family, and caregivers at hospital discharge for survivors of cardiac arrest are substantial and extend beyond physical care.^{234,235,237} In-depth interviews of partners of patients who survived cardiac arrest without serious brain injury identified social network support as both a support and a burden.²³² Immediately after the arrest, partners reported calls and visits by family and friends as supportive. However, as the hospitalization continued, these same supportive measures were perceived as detracting attention from the patient's needs.²³² When participants were able to delegate responsibilities such as providing updates and information to family and friends, the social network burden was reduced.²³² Results from these interviews support the need for patients' relatives to have private time and space to process their feelings.²³⁸

Hospital discharge and homecoming have been identified as stressors in the recovery from cardiac arrest for family and caregivers.²³² Relatives reported a lack of support from healthcare members after transfer from the ICU and again at discharge, creating an increased level of anxiety during recovery.^{238,239} One framework for hospital discharge planning and ongoing follow-up education for patients who have received an ICD after arrest includes (1) education on ICD function, (2) expected progression of emotional and physical recovery, (3) education on safety and maintenance of ICD, (4) discussion of activities of daily living after ICD, (5) strategies to assist with survivors' care, and (6) strategies to assist with partner self-care. Program content should

include psychological and physiological aspects of recovery, as well as education on neurocognitive deficits and family coping.^{240,241} CPR training for families may also reduce fear and anxiety.²⁴² Medical professionals have an important role in providing adequate information about support groups for patients and families during hospitalization and at discharge.²²⁰

Published literature indicates that inpatient hospitalization is not the best time to provide comprehensive education or support programs because patients and their families and caregivers are experiencing high levels of anxiety, depression, anger, stress, confusion, and memory deficit. Therefore, community or outpatient settings should be considered for comprehensive education.^{240,241} Survivors and caregivers are at the highest risk of emotional changes in the first year after cardiac arrest, with the greatest improvement in the first 3 months.²⁴³ Ongoing strategies must be developed, including comprehensive intervention programs, and should be extended to the community or outpatient setting for up to 1 year after cardiac arrest.

Family of Nonsurvivors

Regardless of whether the patient survives, the family is considered an integral part of the system of care. The American Heart Association reports that almost 90% of the 326 000 people with OHCA die annually. That is ≈293 000 families of nonsurvivors from SCA each year who are faced with a devastating event. The disruptive change brought about by SCA is unwanted and unplanned, and as a result, recovery and adjustment take days, months, or years.

Family members are at increased risk of prolonged, complicated grief and bereavement. In a survey analysis of family members of young patients with SCA in Australia, prolonged grief was reported by 20.6%, and posttraumatic stress symptoms were reported by 44% of first-degree family members.²⁴⁴ Participants also reported higher levels of depression, anxiety, and stress compared with the general population.²⁴⁴ Currently, there is no framework to provide support for surviving family members or a systematic approach to engage them in meaningful advocacy. In contrast, breast cancer support networks provide support for families of survivors and nonsurvivors, and they collectively work on advocacy.

Interaction with healthcare providers and surviving family members will affect the grieving process and is a window of opportunity to provide support and lessen the negative psychological impact. However, previous studies have reported that many healthcare professionals are not equipped with the skills to support family members at the time of death.^{245,246} Therefore, healthcare professionals and multidisciplinary team providers need knowledge of the



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grieving stages and bereavement process and how to provide time-sensitive, ongoing support to the family unit. Lessons can be learned from the American Trauma Society, which has developed a program called the 2nd Trauma Program. This program provides lectures and workshops to help staff engage in empathic death disclosure and consulting services to help emergency caregivers cope with the acute and chronic stresses of trauma. Such an interdisciplinary quality improvement program should be considered and replicated to help hospital professionals and teams provide support to the healthcare providers and families of cardiac arrest nonsurvivors.

The narrative analysis by Mayer and colleagues²⁴⁷ of families who experienced an SCA suggests that unanswered questions about the cause of death were especially difficult for surviving family members. Providers must recognize that information may need to be repeated and communicated in lay terms. A common recurring priority for the participants in the Mayer et al study was the importance of sharing the story of their loved one's SCA. Participants were thankful for the opportunity to share their stories. Even people who have endured the worst suffering want to talk about it. Many bereaved survivors also expressed a strong desire to help others.

Family members who are grieving after the loss of a loved one from SCA may suffer from significant psychological morbidity. This may impact their own physical health; hence, additional psychological support should be provided.²⁴⁸ Rehabilitation, which has recently been touted as the missing link in the chain of survival, should include families of nonsurvivors. The best support comes from those who have suffered similar losses; thus, survivor networks are an option for engaging bereaved family members as a means for psychological support and an opportunity for reintegration back into society. General bereavement resources may also be useful.

FEATURES OF THE ORGANIZATION TO IMPROVE SURVIVORSHIP

The first and second levels of the healthcare delivery system for cardiac arrest are the patient and the care team, respectively. The third level of the healthcare delivery system of care is the organization, which "supports the development and work of care teams by providing infrastructure and complementary resources."²⁰ Large strides have been made at this level to effect change.²⁴⁹

Acute Care Hospital Features

Integral to a cardiac arrest center is the post-cardiac arrest service team,²⁵⁰ which can serve to sustain and standardize care between the multiple service lines.²⁵¹ Three studies demonstrate the overall positive effect of

treatment at a cardiac arrest center on outcomes from OHCA.^{12,17,252} Sulzgruber et al²⁵² examined the outcomes at a single high-volume cardiac arrest center over the past 2 decades. Over time, improvements in each link of the chain of survival were observed. Statistically significant improvements in ROSC and 6-month survival were also observed. Schober et al¹⁷ examined a prospective multicenter registry and found that treatment at a high-volume cardiac arrest center was associated with statistically significant improvement in survival. Finally, Elmer et al¹² determined that treatment at an institution classified as a high-volume cardiac arrest center was associated with improved survival. Despite this reassuring research, no study has investigated the effect of a rehabilitation-focused or discharge care protocol or process on improving long-term outcomes or quality of life after cardiac arrest.

Rehabilitation Resources and Outpatient Care

The most recent European Resuscitation Council guidelines incorporate recommendations for a multidisciplinary approach to rehabilitation for post-cardiac arrest patients.²²⁸ They recommend the systematic organization of follow-up care, including screening for cognitive and emotional impairments.

One published article delineates the common elements of the multidisciplinary outpatient treatment services provided at a collection of cardiac arrest centers.²⁵³ Four themes central to postdischarge planning included cardiac rehabilitation, neurological rehabilitation, psychological support, and family member reintegration. Additional rehabilitation services were not standardized in these high-volume centers.

One early intervention service for patients discharged from the hospital after SCA has been described in the literature.²⁵⁴ The early intervention service targeted survivors and their caregivers. The team was composed of specialized nurses with experience in cardiology, neurology, and rehabilitation medicine. The protocol included between 1 and 6 outpatient consultations, initiated immediately after discharge from the hospital. At these visits, survivors were screened for cognitive challenges, emotional changes, principles of self-management, posttraumatic stress, and caregiver strain. Specific tools for measurement are evidence based and provided in this statement.²⁵⁴

Only 1 study has examined the effect of an intervention on post-cardiac arrest patients.²⁵⁵ The intervention comprised 11 individual psychosocial therapy sessions given optimally twice a week after hospital discharge. The primary outcome was mortality. There was a statistically significant difference in mortality between the control and intervention groups (7 versus 1; $P=0.03$).

Outside this literature, little is known about the effect of or the degree of coordination of rehabilitation resources for postarrest patients. Disparities in access

to care are unknown, although family support and socioeconomic status may play a role in how often one can access resources and how likely one is to access resources. Geography may determine how far one might need to travel to obtain resources.

Organizational Feedback: Ongoing Quality Improvement

Local quality improvement data collection is often useful across an individual system to measure outcomes, to assess performance, and to improve quality of care. Several national databases invite data contribution for regional and national reporting, both out-of-hospital and in-hospital arrests, but typically capture survival as an outcome measure at hospital discharge. Attempts to link separate EMS and in-hospital databases have had variable results because of challenges in linking patient records between databases. In contrast to international resources, there is no single national database for cardiac arrest data in the United States. Improving survivorship and quality of life for cardiac arrest survivors necessitates assessing, measuring, and including complex, long-term outcome measures in both quality improvement and research databases.

Organization Feedback: Partners in Celebration

Celebrations of successful resuscitation are complex events with both positive and challenging components. Surviving cardiac arrest makes a sudden, profound alteration in the life of the patient, the caregivers, and the treating teams. Many individuals are affected, including lay rescuers, EMS personnel, dispatchers, hospital staff, patients, friends, family, and caregivers. Stories of survival are impactful and deserve to be shared. "They [survivors] wear their survival stories like badges of honor and relay them to others with revelations of what could have been."²⁵⁶

Survival celebrations are frequently organized as positive feedback for EMS and all those involved in resuscitation. For years, EMS and hospital personnel have provided care with the knowledge that few patients with cardiac arrest will survive. Frequently, survivors and families are seeking an opportunity to give back, to thank those involved. Healthcare personnel are given an opportunity to see that their work includes more than evidence-based, task-driven protocols and in fact has a human factor. Researchers note, "Meeting a patient...is invigorating, motivating, and gratifying....Sometimes, meeting survivors also inspires EMS providers to update local protocols to match the latest evidence, teach bystanders how to perform CPR, or institute new training programs."²⁵⁶

Survivors and their families may find meaning by sharing with rescuers or commemorating a date. Some want to offer thanks; some celebrate their "rebirth-day"; and some need to fill in the missing pieces in their events. Survivors and community stakeholders can leverage survival celebrations to educate their localities on the importance of CPR education, automated external defibrillator use, and prompt activation of emergency response systems. Although the timing and magnitude of a survival celebration should be dictated by the survivor and his or her family, healthcare personnel and support networks can provide structure and connection in bringing such an event together.

FEATURES OF THE ENVIRONMENT FOR IMPROVED SURVIVORSHIP

The environmental level of a system of care refers to "the conditions under which organizations, care teams, individual patients, and individual care providers operate."²⁰ It includes the financial, social, economic, and political aspects of care. The environmental layer of a system of care includes identifying issues such as disparities and coverage. For cardiac arrest, the most relevant issues are as follows.

Economic Costs to the System of Caring for Patients With Cardiac Arrest

Understanding the cost and utility of post-cardiac arrest care can help develop the potential case for increased reimbursement and appropriate resource allocation for these patients. Multidisciplinary postarrest services are often not reimbursed in parity with other critical care specialties. Optimal postarrest care should consider the potential for overuse of surveillance and seek to prevent the underuse of beneficial coordination of care.²⁵⁷

Many survivors of cardiac arrest require significant provocative and diagnostic testing to evaluate for arrest cause. Survivors may require an ICD for secondary prevention of arrhythmia or a cardiac stent for treating coronary occlusion. These downstream interventions help offset the initial investment by the healthcare system in resuscitation care (eg, provision for targeted temperature management) that clearly improves outcomes but is often poorly reimbursed.

Although the economic burden of caring for survivors of cardiac arrest is significant, 1 study found that the costs per life-year and per quality-adjusted life-year were comparable to those of survivors of other critical illnesses.²⁸ Several studies demonstrate that cardiac arrest care per quality-adjusted life-year and per disability-adjusted life-year is an acceptable cost, in line with other healthcare interventions.^{28,258-260} The economic burden of survival includes the cost to

society (loss of productivity and contribution to the work force^{42,207,261,262}) and the cost to the survivor (resource-intensive critical care, readmission, long-term nursing care, rehabilitation, and management of complications^{28,258,263–265}). The cost for index hospitalization after cardiac arrest frequently exceeds twice the US median household income.²⁶⁶

Economic Costs to the Patient of Surviving Cardiac Arrest

The economic impact of survivorship after cardiac arrest is substantial, but interpreting the cost of postarrest care is challenging because survival data may not be adjusted for local hospital policies, do-not-attempt-resuscitation orders, and patient risk. One study estimated a cost of approximately \$100 000 (conventional and rehabilitation care) per patient with OHCA with ROSC.²⁵⁸ Another study reported a cost of approximately \$19 000 for the first year of readmissions and care for patients with IHCA who survived to discharge.²⁶³

Readmission and intensive care costs for both IHCA and OHCA survivors are significant. Costs are influenced by patient-specific factors such as age, race, ventilator liberation, and neurological disability and other factors such as discharge destination (eg, rehabilitation center, skilled nursing facility), interventions (eg, therapeutic hypothermia, time to defibrillation), and geography.^{258,264,267–269} The financial burden of healthcare costs for atherosclerotic cardiovascular disease has recently been identified to have a negative impact on HRQOL, psychological distress, and depression risk but has not yet been explored among patients with SCA.²⁷⁰

Despite the breadth of individual survivorship needs after cardiac arrest, standardized rehabilitation protocols and partnerships for identifying those needs do not exist. Early evaluation for rehabilitation needs is necessary for optimal timing and organization of rehabilitation services.²⁷¹ To qualify for inpatient rehabilitation, patients must typically require services in at least 2 domains such as physical and occupational. Patients must also be able to participate in a minimum of several (>3) hours of therapy per day. Alone, cognitive impairment is typically not enough to qualify for inpatient rehabilitation, although it is very common and often interferes with independent living.

Insurance providers often cover a certain number of inpatient rehabilitation days per plan-year. If days are exhausted, patients or families may pay out of pocket for services, or the patient may be transferred to a skilled nursing facility for additional long-term care. If patients become unable to participate in rehabilitation activities and rehabilitation days still exist, they may need to be moved to a skilled nursing facility temporarily until they may resume full participation in therapy.

As an alternative, intensive outpatient rehabilitation programs have their own prerequisites for treatment of multiple therapy needs. Patients who have enough support to go home and do not qualify for inpatient rehabilitation may travel to these programs several times a week. Finally, there are separate outpatient rehabilitation specialty services such as physical therapy, occupational therapy, speech-language pathologists, and cardiac rehabilitation for which insurance providers typically cover a certain number of visits per plan year. Access to, coverage for, and ability to navigate the complex requirements of rehabilitation services may play a large role in patients returning to work and participating in activities of daily life.² Thus, efficiently optimizing these resources and coordinating their delivery to SCA survivors may have a large impact on society.

Joint Society Recommendations: Guidelines

This statement has summarized the complex and multifaceted areas for assessment and potential treatment for the SCA survivor. Several specialists may be involved in the post-cardiac arrest survivorship plan and need to coordinate care to improve rehabilitation consistency for each patient. Therefore, it stands to reason that joint guidelines are needed to improve treatment consistency across all providers and settings. Partnerships exist among healthcare providers for patients with critical illness, stroke, and transplantation, for example, and may expedite knowledge translation and clinical implementation.

Urgent Research Goals

Table 5 summarizes the top research goals and gaps in knowledge for cardiac arrest survivorship, organized according to presentation in this document. Numerous other knowledge gaps are listed throughout this statement. Future research should focus on elucidating common domains, patterns, and severity of dysfunction in patients discharged from the hospital after resuscitation from cardiac arrest. Initially, this will require multiple measures. It is important to remember that recovery and transition to survivorship occur on an individual's own timeline; hence, engagement with the survivor throughout recovery is critical.

Developing a tailored measure that represents the breadth of postarrest dysfunction should be a goal for the resuscitation community. One potential measure is the CPC-Extended tool, which is more granular than the CPC score and tests 10 domains of function.⁹⁷ Because the domains change (improve/worsen) over time, serial evaluations are recommended.²⁷² At a minimum, all patients should have some assessment of cognition, mobility, and ability to perform activities of daily living before discharge. This can be completed by a psychiatrist

Table 5. Top Gaps*

What do survivor-derived outcome measures of the impact of cardiac arrest survival look like? How do they differ from current generic or clinician-derived measures?
Are there in-hospital interventions that can reduce or prevent physical impairment after cardiac arrest?
What is the optimal multimodal neuroprognostication scheme, and when is it most sensitive?
Are seizure and myoclonus after cardiac arrest treatable or preventable?
Which patients develop cognitive impairments after cardiac arrest; are they treatable/preventable/recoverable?
Which patients develop affective/psychological disorders of well-being after cardiac arrest; are they treatable/preventable/recoverable?
What is the role for support networks/groups after cardiac arrest; who benefits and when is it optimal to refer?
Who has difficulty with reintegration or redefining their role in society/culture/religion/relationships after surviving cardiac arrest? Which interventions are useful?
Does hospital-based protocolized discharge planning for cardiac arrest survivors improve access to/referral to rehabilitation services or patient outcomes?
What are the costs to the healthcare system/society of caring for the patient with cardiac arrest?
What are the costs to the patient/family/caregivers of experiencing and surviving cardiac arrest?
What are the barriers to patient and caregiver engagement in the health care/research/advocacy of cardiac arrest survivorship?

*Listed according to presentation in the statement.

(physical medicine and rehabilitation specialist) or a combination of physical, occupational, and speech-language therapy specialists before discharge from the hospital. Reassessment at 3 and 6 months and 1 year after the arrest should be considered.

Rehabilitation interventions in other disease states with patients who have medically complex conditions have been studied. These may include aerobic exercise, resistance training, cognitive training, or strategy training. Behavioral modification to prevent return to sedentary behavior may also be used. Combining several modalities may be required to optimize recovery for the individual patient after arrest. Research should focus not only on using rehabilitation interventions to improve outcomes for the postarrest population as a whole but also on tailoring components of the intervention to specific deficits found on testing. For example, aerobic exercise may improve mood and decrease fatigue, whereas individualized strategies may improve the ability to complete the complex activities of daily living. Determining an optimal rehabilitation strategy, including its timing, for each domain of dysfunction should be a goal for the resuscitation community.

Finally, many family members experience significant stress when caring for their loved one. Future studies should evaluate coping mechanisms for family members. Empowering both patient and family will help ensure a strong environment for recovery. Engagement with families of nonsurvivors of cardiac arrest is also an

area devoid of research. These bereaved family members may provide insight into prevention, promote community CPR trainings, and be fierce advocates for future cardiac arrest policy legislation. More attention, immediate care during bereavement, and research are needed for surviving family members of those with SCA.

Ethical Considerations

The ethics surrounding initiating resuscitation and deciding to withdraw life-sustaining therapy are outside the scope of this document. Ethical considerations within post-cardiac arrest survivorship are not adequately studied. For example, do we know and inform patients and families of the possible harms pertaining to cognitive testing? Who receives test results, and how do results affect a person's future insurability, return to work, or motivation for social reintegration? Should patients and families provide consent for testing, and what if they decline or decline retesting later? What motivates patients and families to adapt to a "new normal," and how do we empower them to do so?

The accuracy of assessment is crucial to understanding the impact on survival; when assessment is inappropriate or lacks granularity, the impact of survival is underestimated. We may underestimate the need for rehabilitation, such that services may not be provided. Poor access to and poor insurance coverage for rehabilitation may make it difficult to identify improvements or declines over time. Experienced providers are aware that fatigue may be a barrier to completing a test rather than poor concentration or attention. Assessment timing often takes place at easy administrative intervals (eg, hospital discharge), not necessarily at times when testing may best reflect the patient's abilities or participation.

Additional ethical concerns that have not been explored include how patients perceive various testing and whether we are evaluating things that matter to them. Future work may take examples from the field of vascular dementia or Alzheimer disease and should include patients and loved ones as partners. It behooves the resuscitation community to ensure that an adequate and representative picture of the experience and the unmet needs of survivors is presented over both the short and long terms.

Advocacy Considerations

Support groups and counseling for survivors of multiple other conditions such as cancer, diabetes mellitus, stroke, and transplantation are well established and provide a space for both sharing with others who may have had similar experiences and increasing societal awareness of the disease. Because survival rates for cardiac arrest are low in any one system or region, survivors, friends, and family members who are looking for

support may not have local groups to connect with and need to be referred to national support organizations.

Many national nonprofit organizations, readily accessible through the internet, provide treatment, support programs for patients and their families, and advocacy for improved cardiac arrest response. Online communities offer people affected personally by cardiac arrest (whether as a survivor, friend, or family member) a space to share experiences and coping strategies. Many of these programs were founded by either a survivor or a family member of a survivor. Advocacy initiatives for most of these organizations revolve around advancing cardiac arrest prevention programs such as heart screening programs for youth and increasing lay rescuer CPR and

automated external defibrillator awareness and training through legislation to increase public-access defibrillators and CPR training in schools and at work. However, there is a paucity of information on these websites about advocacy directed at improving long-term outcomes. United advocacy efforts could be powerful in effecting change in many areas of survivorship.

Patient Engagement in Health Care and Research

Survivors of cardiac arrest and their family members have a unique knowledge derived from their personal experience of the event that renders them both legitimate and

Domain	Examples: What to Assess	Examples: How to Measure	Referral/Resource
<input type="checkbox"/> Physical/functional	<ul style="list-style-type: none"> Weakness Ability to sit, rise from chair, stand, or walk Fatigue, pain Ability to swallow or speak Continence 	<ul style="list-style-type: none"> Speech/swallow evaluation Get Up and Go Test Functional Independence Measure 	<ul style="list-style-type: none"> PT/OT/SLP, PM&R Inpatient/outpatient rehabilitation
<input type="checkbox"/> Cognitive and communication	<ul style="list-style-type: none"> Speaking/writing for communication Attention and memory Executive functions Disinhibition Compromised insight 	<ul style="list-style-type: none"> MoCA Stroop-Effect test Verbal fluency 	<ul style="list-style-type: none"> OT/SLP, PM&R Outpatient rehabilitation
<input type="checkbox"/> Neurological	<ul style="list-style-type: none"> Gait, balance Movement disorders Myoclonus Seizures Vision 	<ul style="list-style-type: none"> EEG PT/OT PM&R 	<ul style="list-style-type: none"> Neurology Ophthalmology PM&R
<input type="checkbox"/> Cardiopulmonary	<ul style="list-style-type: none"> Cardiac function Pulmonary function 	<ul style="list-style-type: none"> Cycle endurance test Six-minute walk test 	<ul style="list-style-type: none"> Cardiology Pulmonology Cardiac rehabilitation Pulmonary rehabilitation
<input type="checkbox"/> Affective	<ul style="list-style-type: none"> Somatic symptoms Tearfulness Withdrawal or avoidance behavior PTSD/nightmares/flashbacks 	<ul style="list-style-type: none"> HADS PTSD checklist SF-36 	Psychiatry or psychology
<input type="checkbox"/> Social*	<ul style="list-style-type: none"> Caregiver/family relationships Social/religious community relationships 	<ul style="list-style-type: none"> Caregiver Burden Scale Caregiver self-assessment 	Social work
<input type="checkbox"/> Social*	<ul style="list-style-type: none"> Transportation Housing Benefits FMLA/short-term disability documentation for patient/caregivers 	<ul style="list-style-type: none"> Caregiver Burden Scale Caregiver self-assessment 	Care management
<input type="checkbox"/> General medical	<ul style="list-style-type: none"> Medication review/reconciliation Device education CPR training 	<ul style="list-style-type: none"> Teach-back method Show-me method 	<ul style="list-style-type: none"> Multidisciplinary team Pharmacy Service representative
<input type="checkbox"/> General participation	<ul style="list-style-type: none"> Activities of daily living Re-engagement with life/family Fatigue (physical/cognitive) Driving, return to work Return to intimacy Long-term recovery expectations 	<ul style="list-style-type: none"> Reintegration to Normal Living Index Community integration questionnaire 	<ul style="list-style-type: none"> Multidisciplinary team Medicine PT/OT/SLP, PM&R

Figure 2. Discharge checklist.

CPR indicates cardiopulmonary resuscitation; EEG, electroencephalography; FMLA, Family and Medical Leave Act; HADS, Hospital Anxiety and Depression Scale; MoCA, Montreal Cognitive Assessment; OT, occupational therapy; PM&R, physical medicine and rehabilitation; PT, physical therapy; PTSD, posttraumatic stress disorder; SF-36, 36-Item Short Form; and SLP, speech-language pathologist. *Needs begin in the intensive care unit.

powerful experience-based experts. The active engagement of survivors and their family members in both health care and research underscores the unique power of this evidence and the contribution to shared learning, constructive dialogue, and the codevelopment of research programs that have greater relevance to the community of survivors. There is growing evidence that the active engagement of key stakeholders, including patients and members of the public, in defining research priorities shifts the focus of research toward socially grounded endeavors. Although the integration of the values and insights from across the range of legitimate stakeholders may increase the complexity of recommendations, such active engagement may bring us closer to recognizing what is best for survivors and their families. It therefore behooves the resuscitation community to consider how it can engage with and incorporate the values and views of all legitimate stakeholders in moving the challenge of postarrest survival and survivorship forward.

CONCLUSIONS

The number of people touched by cardiac arrest is impossible to measure when considering the layers of the cardiac arrest system of care. Promoting attention to quality of life and survivorship acknowledges the complex emotional, physical, social, and economic challenges associated with life during and after cardiac arrest. It also recognizes the importance of caregivers and support networks, who may also need guidance throughout the long recovery period.

This statement outlines the domains central to systematic hospital discharge planning and rehabilitation after cardiac arrest. We have developed a template discharge checklist for use among multidisciplinary providers involved in caring for patients after cardiac arrest (Figure 2). A 1-year road map to recovery (Figure 3) will also help with transitions of care across the healthcare system. We hope these tools will require updates soon.

LAYPERSON SUMMARY OF CARDIAC ARREST SURVIVORSHIP

SCA stops the flow of blood through the heart to the brain and other vital organs of the body. It can happen at any age for several reasons. There might be an electric problem, also known as an arrhythmia. There might be a blocked artery of the heart (eg, a heart attack). A drug overdose may also cause cardiac arrest.

Over the past decade, survival from cardiac arrest has improved. Like surviving stroke or cancer, it often requires medications and treatments after discharge. It may also create new challenges with physical function, memory, speech, or depression. Recovery can take months to years after the event.

This section is a summary of what may happen to the patient or their loved ones after surviving SCA. What is known about the short- and long-term effects of cardiac arrest are described. This information will assist patients or their loved ones to communicate better with the team at the hospital, as well as with healthcare providers after discharge.

Survival Rates Are Low but Improving

SCA is deadly. If it occurs outside of a hospital, only 11% of patients survive to hospital discharge.

The chance of survival improves when someone contacts 9-1-1 right away. Then, anyone may and should start immediate CPR (chest compressions) and use an automated external defibrillator if available.

After transport to the hospital, more tests and interventions may be necessary.

If cardiac arrest occurs during a hospitalization, 26% of people survive to discharge.

With more uniform postarrest care, survival rates have improved. Each year, 70 000 people in the United States leave the hospital after cardiac arrest. We expect this number to increase.



Survivors May Need New Medications or Rehabilitation for Their Heart

Patients may have a weak heart after cardiac arrest. They may need to take new medications every day and follow a new diet.

Patients may need a small device called an ICD inserted in their chest before discharge or shortly after. This device may shock the heart if an abnormal heart rhythm occurs, which can happen without warning and is a life-threatening emergency.

Cardiac arrest survivors may need to attend a special exercise program to help the heart get stronger (cardiac rehabilitation). This may also allow patients to meet others who have similar heart problems.

Survivors Are Vulnerable to Neurological Injuries

Patients with cardiac arrest may receive temporary life support in the ICU. Patients may remain in a coma for an uncertain period. This means waiting and watching for changes in brain waves or physical examination.

In the hospital, patients may develop seizures, muscle contractions, or tremors. They may be unable to control body movements. These disorders may continue after discharge and are often treated with medications.

Patients may also have a stroke after cardiac arrest. This may lead to further difficulty with physical or cognitive functions such as memory and the ability to think or focus.

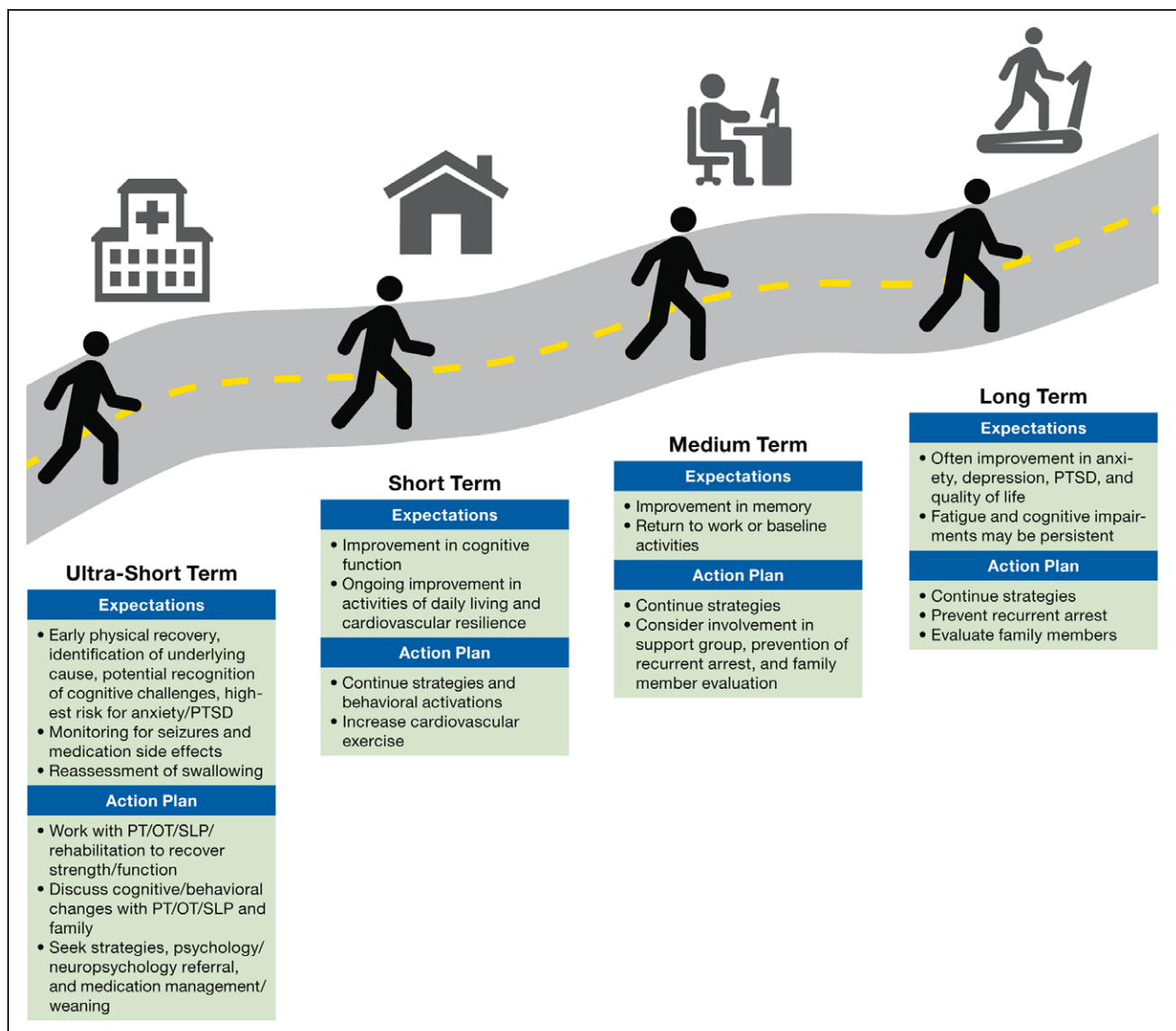


Figure 3. Roadmap to recovery.

OT indicates occupational therapy; PT, physical therapy; PTSD, posttraumatic stress disorder; and SLP, speech-language pathologist.

Survivors Are at Risk for Physical Injuries

Hospitalization causes physical effects from decreased movement or inactivity. This is especially true for patients in the ICU. They may lose muscle tone or become stiff.

Physical injuries may make it hard for patients to feed themselves, write, walk, stand, or even sit. Fatigue, or tiredness, may also limit how long patients can do an activity. Physical and occupational therapists will assess and treat various physical impairments.

Patients who received CPR may have chest pain from bruised or broken ribs. Procedures done in the hospital may leave scars.

Being on a ventilator for a long time can cause voice changes or problems speaking or swallowing. Communication may be difficult and frustrating. Speech-language pathology specialists will assess these

impairments. They can help create temporary tools to help patients communicate in the hospital or at home.

Survivors May Have Trouble With Memory and Thinking Abilities

Patients may have difficulty paying attention. Patients may not be able to have a conversation or complete a task because of an inability to focus. Paying attention is important in many daily activities such as managing medications, cooking, and driving.

Patients may also have difficulty with both short-term and long-term memory. Patients may ask questions over and over. They may not remember a conversation from a few minutes earlier. It is very common for patients not to remember the events of the entire day or days before their cardiac arrest. Difficulty with memory may make

remembering people or names of objects difficult. It may also impair the ability to do simple math or spelling.

Patients may struggle with organizing or planning, self-regulation, and task management. Together, these are called executive functions. For example, patients may be more impulsive than before the cardiac arrest. They may lack the ability to control certain emotions such as anger. They may be tearful often. Patients may be unable to complete a task that has many steps. They may not be able to solve new problems. For these reasons, some patients may not be able to live alone. They may need significant help with shopping or paying bills. They may not be able to drive for months after discharge.

Cognitive fatigue means that someone can think or focus for only short periods of time. This may play a large role in returning to work. Patients may be unable to perform mental tasks at the same level as before. Ways to reduce stress include having a routine and breaking tasks into small pieces.

Specialists such as speech-language pathologists may offer additional therapy and strategies for overcoming some of these impairments.

Survivors May Experience Anxiety or Depression

Cardiac arrest survivors often experience anxiety, depression, and posttraumatic stress. Loved ones or caregivers are also at risk. Loved ones who performed CPR or witnessed CPR may experience posttraumatic stress. Feelings or expectations may strain relationships with friends or family.

Anxiety about the cardiac arrest event itself or whether another event will occur is common. Depression may result from a new medical diagnosis or the new need for daily treatments. Depression may also result from the inability to return to normal.

Financial issues are very common after a prolonged hospitalization. Time away from work for both patients and their family members may also cause a financial burden. Short-term disability and Family and Medical Leave Act paperwork should be filed as soon as possible.

Surviving Cardiac Arrest May Interrupt Daily Life

Surviving cardiac arrest may interrupt daily life for a short or long time. Some patients return to work or hobbies; others struggle. Patients may want to be independent

again, although caregivers worry about them being on their own. Cultural, religious, or personal beliefs may play a role in recovery and healing.

Patients may search for meaning about what happened. Counseling and therapy may be beneficial for patients, their loved ones, and caregivers. Therapy also may be useful for those who have lost a loved one to cardiac arrest. In some cases, support groups may provide a safe place to discuss feelings with others. Advocacy groups can help survivors find community and raise awareness about survivorship.

Conclusions

Surviving cardiac arrest may result in many challenges and is not easy. Both patients and their loved ones may need therapy or counseling for months or years after. With the information presented in this scientific statement, patients and their loved ones will have a better understanding of cardiac arrest and how to be an advocate for their care.

ARTICLE INFORMATION

The American Heart Association makes every effort to avoid any actual or potential conflicts of interest that may arise as a result of an outside relationship or a personal, professional, or business interest of a member of the writing panel. Specifically, all members of the writing group are required to complete and submit a Disclosure Questionnaire showing all such relationships that might be perceived as real or potential conflicts of interest.

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Disclosures**Writing Group Disclosures**

Reviewer	Employment	Research Grant	Other Research Support	Speakers' Bureau/Honoraria	Expert Witness	Ownership Interest	Consultant/Advisory Board	Other
Kelly N. Sawyer	University of Pittsburgh	None	None	None	None	None	None	None
Benjamin S. Abella	University of Pennsylvania	NIH NHLBI (grant to study CPR training)†; Medtronic Foundation (study CPR and cardiac arrest outcomes)†; PCORIT; AHA†	None	CR Bard*; Physio-Control Inc*	None	None	CardioReady*	None
Clifton W. Callaway	University of Pittsburgh	NIH (research grants to study emergency care, including neurological outcomes)†	None	None	None	None	None	None
Teresa R. Camp-Rogers	Central Regional Medical Center	None	None	None	None	None	None	None
Marina Del Rios	University of Illinois at Chicago	AHA (Mentored Population and Clinical Research Award: provides funding for my research "Measuring Disparities in the Chain of Survival Among Latino Communities")†; Medtronic Philanthropy (Coordination Team Member of the Illinois Heart Rescue Program; I receive 7% salary support for research and community engagement activities in this role)†	None	None	None	None	None	None
Cynthia M. Dougherty	University of Washington	None	None	None	None	None	None	None
Romergrzyko G. Geocadin	Johns Hopkins University	None	None	None	None	None	None	None
Michelle R. Gossip	VCU Health System	None	None	None	None	None	None	None
Kirstie L. Haywood	Warwick University (United Kingdom)	None	None	None	None	None	None	None
Pavitra Kotini-Shah	University of Illinois at Chicago	None	None	None	None	None	None	None
Michael C. Kurz	University of Alabama at Birmingham	Zoll Medical Corp (industry-funded research [not cardiac arrest]); ACEP/EMF†; SCCM†	None	Zoll Medical Corp*; Stryker (formerly Physio-Control)*	None	Rapid Oxygen Corp†	None	None
Steven A. Lubitz	Massachusetts General Hospital	Biotronik*; Bristol-Myers Squibb†; Boehringer Ingelheim†; Bayer HealthCare†	None	None	None	None	St. Jude Medical*; Bristol-Myers Squibb*; Quest Diagnostics*	None
Vivek K. Moitra	Columbia University	None	None	None	Malpractice companies*	None	None	None
Alejandro A. Rabinstein	Mayo Clinic Rochester	None	None	None	None	None	None	None
Jon C. Rittenberger	Guthrie Medical Center	AHA (grant evaluating the effect of therapeutic exercise on recovery after cardiac arrest)†	None	None	None	None	None	None

This table represents the relationships of reviewers that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all reviewers are required to complete and submit. A relationship is considered to be "significant" if (a) the person receives \$10 000 or more during any 12-month period, or 5% or more of the person's gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns \$10 000 or more of the fair market value of the entity. A relationship is considered to be "modest" if it is less than "significant" under the preceding definition.

*Modest.

†Significant.

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Reviewer	Employment	Research Grant	Other Research Support	Speakers' Bureau/Honoraria	Expert Witness	Ownership Interest	Consultant/Advisory Board	Other
Steven M. Bradley	Minneapolis Heart Institute	None	None	None	None	None	None	None
Janet E. Bray	Monash University (Australia)	Heart Foundation (grant to study a postarrest cardiac arrest clinic)*	None	None	None	None	None	None
Lorrel Brown	University of Nevada Reno	None	None	None	None	None	None	None
Judith Finn	Curtin University (Australia)	None	None	None	None	None	None	None
Theodore Iwashyna	University of Michigan	None	None	None	None	None	None	None

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*Modest.

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