Follow-Up of Cardiac Arrest Survivors: Why, How, and When? A Practical Approach

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Abstract

Cardiac arrest (CA) survivors may experience cognitive, physical, or emotional problems that can affect their return to everyday activities and quality of life. To improve long-term outcomes, interventions after hospital discharge may be needed. A follow-up plan to identify CA survivors with increased risk of residual cognitive, physical, or emotional problems is important to target interventions and support. Current recommendations suggest that follow-up should include screening of potential problems, sharing information, and relevant referrals when needed. The complexity of the follow-up of CA survivors is due to the fact that several pathways of care may be offered, focusing either on the cardiovascular disease, the postintensive care syndrome, or CA-related brain injury. There is a potential to improve recovery through a more collaborative and holistic approach to follow-up. The aim of this review is to give examples of *why* follow-up after CA should be provided, but also *how and when* follow-up could be performed.

Keywords

- cardiac arrest
- cognition
- depression
- follow-up
- health-related quality of life

Even if the majority (> 90%) of cardiac arrest (CA) survivors have a "good outcome" according to the commonly used Cerebral Performance Category (CPC) Scale, studies with more extensive assessments or subjective reports indicate that a "good outcome" may include mild-to-moderate cognitive impairment and/or emotional distress.[1–6] Cognitive impairment, typically memory problems, can be expected in half of survivors of CA,[1] and emotional problems like anxiety in 25%.[7] Both cognitive impairment and emotional problems may affect patients' ability to return to activities in everyday life[1,3,8] and are important determinants of health-related quality of life (HRQoL).[9–11]

Health-related quality of life in CA-survivors is mostly reported to be good and comparable to normative data, but subgroups of survivors have a worse outcome,[11,12] and more than half (56%) of out-of-hospital cardiac arrest (OHCA) survivors in a large Australian study rated their HRQoL to be lower than prearrest.[12] In more descriptive analyses of HRQoL, some areas like vitality[13] and social participation[10,14] were lower for CA-survivors compared with the general population, and in another trial, 74% of OHCA-survivors reported decreased societal participation 1 to 6 years postarrest.[3]

Follow-Up: Why?

To support recovery to high levels of participation in society and a good HRQoL, interventions after discharge may be needed and should be offered. The patient's ability to participate in activities, however, depends on several factors that may or may not be related to the CA, including age and prearrest comorbidity. In addition, similar impairment may affect individuals differently, depending on the type of activities the patient needs to perform. A younger individual with high demands may experience greater discomfort from mild cognitive impairment compared with an older individual who has an increased ability to adjust his or her time and life to the new situation. This reflects the importance of evaluating outcome after CA individually to provide the best support.

Optimal support includes rehabilitation, a broad concept with many potential interventions ranging from a single follow-up meeting with information and advice, to in-hospital rehabilitation provided for weeks. Today there is no "best practice" of rehabilitation after CA. What the patient will be offered depends on several factors as the etiology of the arrest and local hospital routines, but commonly follows one of

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three pathways: neurologic, cardiac, or that of critically ill patients. Currently, these three pathways of follow-up and rehabilitation are typically separated from each other, and CA survivors may be offered one or the other, or no follow-up at all. A more integrated and collaborative strategy tailored to the specific needs of individual CA survivors would be desirable and probably of great benefit.

The neurologic follow-up and rehabilitation after CA is aimed at decreasing consequences in everyday life due to CA-related brain injury. Cardiac arrest survivors with severe neurologic impairments are often identified early and referred to neurologic/brain injury rehabilitation prior to hospital discharge due to their obvious need for help. Rehabilitation of these survivors is often complicated by severe cognitive impairment, including lack of awareness, decreased motivation, and difficulties in adapting to and memorizing new information. Cardiac arrest survivors with severe neurologic impairments are thus considered by many to have a low rehabilitation potential and may not even be offered this help. Luckily, a few small studies show that rehabilitation of severely impaired OHCA-survivors could be effective in increasing independence and decreasing burden to their families.[15,16] Importantly, rehabilitation for these individuals must be provided over long periods to obtain positive effects,[15] and the goal should be improvements in activities of daily life and not necessarily functional gains.

Although severe neurologic impairment is uncommon among CA survivors ($< 10\%$), half experience mild-to-moderate cognitive impairment and fatigue.[1,3,4] These symptoms may, however, remain unidentified unless actively screened for,[17] and when identified, everyday functioning could be improved by provision of cognitive rehabilitation.[18] This includes the use of compensatory techniques, such as adjustment of activity performance (e.g., more frequent breaks) and/or effective use of memory aids such as smart phones, calendars, to do lists, alarms, etc.

The cardiac pathway is probably the most common follow-up/rehabilitation for CA survivors, focusing on the cardiovascular disease and secondary prevention. Importantly, known cardiovascular risk factors are also associated with an increased risk of cognitive decline.[19–21] In a recent study, cognitive problems were shown to be almost as common in an age- and gender-matched control group of patients with acute myocardial infarction (no CA) as among survivors of OHCA.[4] Therapeutic interventions aimed at reducing cardiovascular risk factors in CA survivors may thus have the potential to decrease cognitive decline as well. These interventions include control of blood pressure and blood glucose, smoking cessation, weight reduction, decreasing stress, and regular physical activity.[22,23] In addition, patients with cognitive impairment irrespective of the cause may need extra support for their secondary prevention because they may be less likely to remember appointments, instructions, and information.[24]

Another follow-up/rehabilitation pathway that CA survivors may be offered is that of critically ill patients, who in general are found to have similar levels of cognitive impairment as CA survivors at follow-up.[25–27] This critical illness-related cognitive impairment is known as the postintensive care syndrome (PICS) that also includes physical and mental impairment.[28] Recommendations for follow-up after critical illness from the United Kingdom National Institute for Health and Clinical Excellence (NICE-guideline number 83)[29] and the Society of Critical Care Medicine[30] argue that screening for cognitive, emotional, and physical problems should be performed at several occasions (in-hospital, at discharge, and 2–3 months after discharge) to identify patients at risk.

Even if most reports of PICS-related cognitive impairment have similar limitations as CA studies (e.g., heterogeneous study samples, lack of baseline data, and lack of controls), some explanatory factors have been suggested including the effects of emotional problems (anxiety, depression, and post-traumatic stress).[26,27] Emotional problems are important to identify among CA survivors, not only for their close association to cognitive problems, but also because patients not feeling well have less ability to implement important lifestyle changes and/or may have delays in seeking help.[31] It is known that depressed patients have a lower adherence to secondary prevention and that depression is a risk factor for adverse medical outcomes after an acute coronary syndrome. The American Heart Association advocates more depression awareness and treatment in cardiac patients.[32] Treatment of depression includes antidepressant medications,[33] psychotherapy, and aerobic exercise.[34]

Physical activity is thus not only important for the patients' secondary cardiovascular prevention, but also a potential therapy for emotional problems.[34] In addition, aerobic exercise could also support improved cognitive performance, especially related to increased mental processing speed.[33] For management of mild cognitive impairment, it is believed that interventions should include regular physical and mental exercise in combination with avoidance of polypharmacy and treatment of common diseases like asthma, obstructive sleep apnea, and heart failure.[22,23,33]

There has been less attention to physical limitations after CA compared with the widespread interest in cognitive and emotional problems. Mobility restrictions are, however, reported by 34% of OHCA-survivors,[12] but it is still unknown if these physical limitations are a result of psychological effects (anxiety, fear), PICS-related symptoms, neurologic impairment, or just decreased physical functioning that comes with age.[12,35] Irrespective of the cause, CA survivors who report physical limitations may be in need of more support to obtain sufficient physical activity for their secondary prevention, everyday activities, and for the potential benefits that physical activity may have on emotional and cognitive performance.

In summary, the need for follow-up and interventions among CA survivors is complex: It is comprised of an assessment of the CA-related brain injury, the effects of the cardiovascular burden, and critical illness-related factors.

Follow-Up: How?

Today there are few studies focusing on follow-up and rehabilitation interventions specifically designed for CA survivors. In one study with an exploratory design, psychosocial therapy for OHCA survivors was found to reduce mortality.[36] Although

the results from that study need to be validated, the potential effects of such an intervention could be addressed during follow-up of CA survivors. In a larger trial with a randomized controlled design, a simple follow-up intervention after CA was found to be effective for both earlier return to work and better HRQoL in some domains.[37] The intervention included screening of cognitive and emotional problems, provision of information and support, promotion of self-management strategies, and referrals when needed. The intervention consisted of only one to six 1-hour sessions starting within the first month after hospital discharge. Another appealing approach has been described by a team from Leiden in the Netherlands, and consists of a combined cardiac and neurologic/cognitive follow-up for OHCA survivors.[11] At their hospital, cognitive screening is provided for all OHCA-survivors referred to the local cardiac rehabilitation unit, and the result from this screening is used to advise patients to follow either the regular cardiac rehabilitation program, or to follow a specially designed cardiac rehabilitation program that includes cognitive rehabilitation. In addition, OHCA survivors with more pronounced cognitive impairment are advised to take part in a more-intense cognitive rehabilitation program.[11] The present guidelines for postresuscitation care from the European Resuscitation Council and the European Society of Intensive Care Medicine have included a novel section about follow-up and rehabilitation after CA, suggesting screening of cognitive impairment, screening of emotional problems, and provision of information.[38]

Screening to identify patients at risk for problems is crucial to be able to provide the best treatment, support, and rehabilitation, but there is currently no gold standard of which assessment to use at follow-up for this patient group. The easy-to-use CPC Scale has been recommended for outcome reports in CA trials and is widely used. But the CPC Scale is a crude outcome measure that almost equals reports of survival, and many symptoms may go unrecognized.[28,39,40] More recent guidelines emphasize the need for more refined assessments to detect clinically relevant differences in neurocognitive outcome and HRQoL.[41,42] If testing is too extensive, however, it may identify very subtle impairments with little influence on most patients' daily lives. If assessments are too crude, on the other hand, patients with mild impairments and/or high demands may remain unidentified. Extensive testing of all CA survivors thus seems impractical, but may be needed for some. The best option is probably to start with a simple screening provided for all, followed by further testing in selected patients with increased risk.

A screening model to identify CA survivors at risk could preferably be designed by using the structure of the International Classification of Functioning, Disability and Health (ICF) that has been recommended for use in resuscitation trials.[41] In addition, this structure could be combined with information of outcome reported from different sources, as suggested by the U.S. Food and Drug Administration (FDA).[43] The ICF structure is presented in ►**Fig. 1**, together with the different sources of outcome reports as described by the FDA.

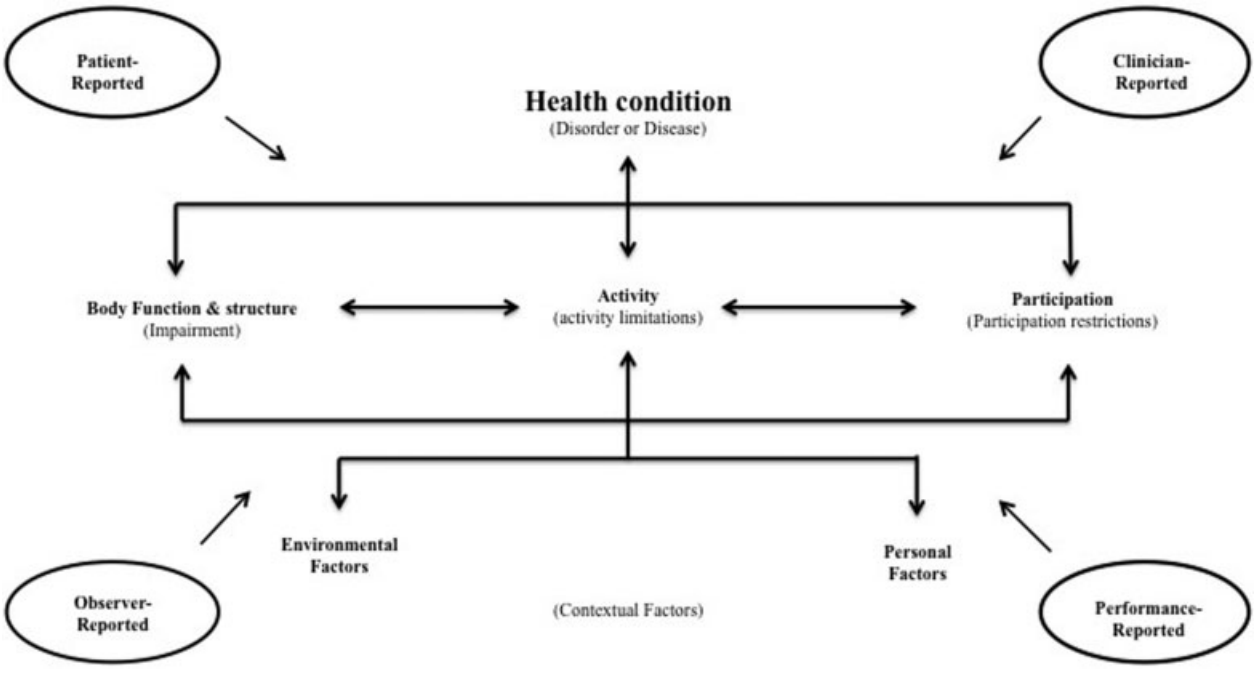

Fig. 1 Overview of health domains (body functions/structures, activities, and participation) described by the International Classification of Functioning, Disability, and Health (ICF). The dynamic interaction includes that the causality is possible in all directions, and all domains have to be evaluated separately to understand outcome. For example, impairment of body functions (as cognitive and physical) may or may not lead to activity limitations or participation restrictions depending on, for example, personal factors, environmental support, use of effective strategies, or the actual level of impairment and activities to perform. Equally, participation restrictions could be an effect of impairment, environmental factors, or other. The ICF components of health are presented together with the four sources for outcome reports as described by the U.S. Food and Drug Administration (FDA) because each source will provide unique information regarding each domain of health. (Reproduced with permission from the World Health Organization).

In the large multicenter Targeted Temperature Management after Cardiac Arrest (TTM) Trial, a follow-up was performed 6 months postarrest.[6] Outcome was reported by the four FDA-recommended sources (patient, observer, performance, and clinician) and included information about impairment, activity restrictions, and participation limitations as suggested by the ICF. The TTM follow-up was based on a model that was already part of the clinical routine in Lund, Sweden. In Lund, all CA survivors initially admitted to the intensive care unit are invited to a follow-up visit with an aftercare nurse at 2 months postarrest (►**Fig. 2**). The follow-up includes discussions about the past (the time in hospital), the present (screening for remaining physical, emotional, and cognitive impairments), and the future (rehabilitation, which may include referrals).[44] To identify cognitive impairment, a short screening is performed by administering the MiniMental Status Examination (MMSE),[45] Two Simple Questions (TSQ),[46] and the Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE).[47] Patients identified as having an increased risk for cognitive impairment are referred to the neurologic department where an occupational therapist (OT), familiar with brain injury-related symptoms and local rehabilitation pathways performs further testing. The OT discusses potential consequences in everyday life, gives information and advice, and evaluates the need for further support and rehabilitation (►**Fig. 2**). This short screening battery was possible to implement in the TTM Trial at multiple sites, in different countries, and by different health care professionals. The high patient inclusion ratio (> 90% of survivors)[6] showed that this screening battery was well accepted among patients and their relatives, but whether it is sensitive enough to identify all patients at risk is not known and needs to be validated.

Our experience is that by simply asking the patient and their informant generates a lot of information about everyday life before and after the arrest. A similar approach as used in the TTM Trial is suggested in the current European guidelines,[38] with minor differences. The more modern Montreal Cognitive Assessment (MoCA)[48] is recommended instead of the MMSE for cognitive screening assessment, and the Hospital Anxiety and Depression Rating Scale (HADS)[49] is recommended for screening of emotional problems. The use of this screening battery would provide a structured and holistic approach to follow-up and could easily be included in patients' ordinary care and without the use of extensive resources. The important part of such follow-up is rather to identify a local structure where patients may obtain further support once problems are identified, and to extend local collaboration to optimize care and provide referrals to appropriate specialists.[29,30]

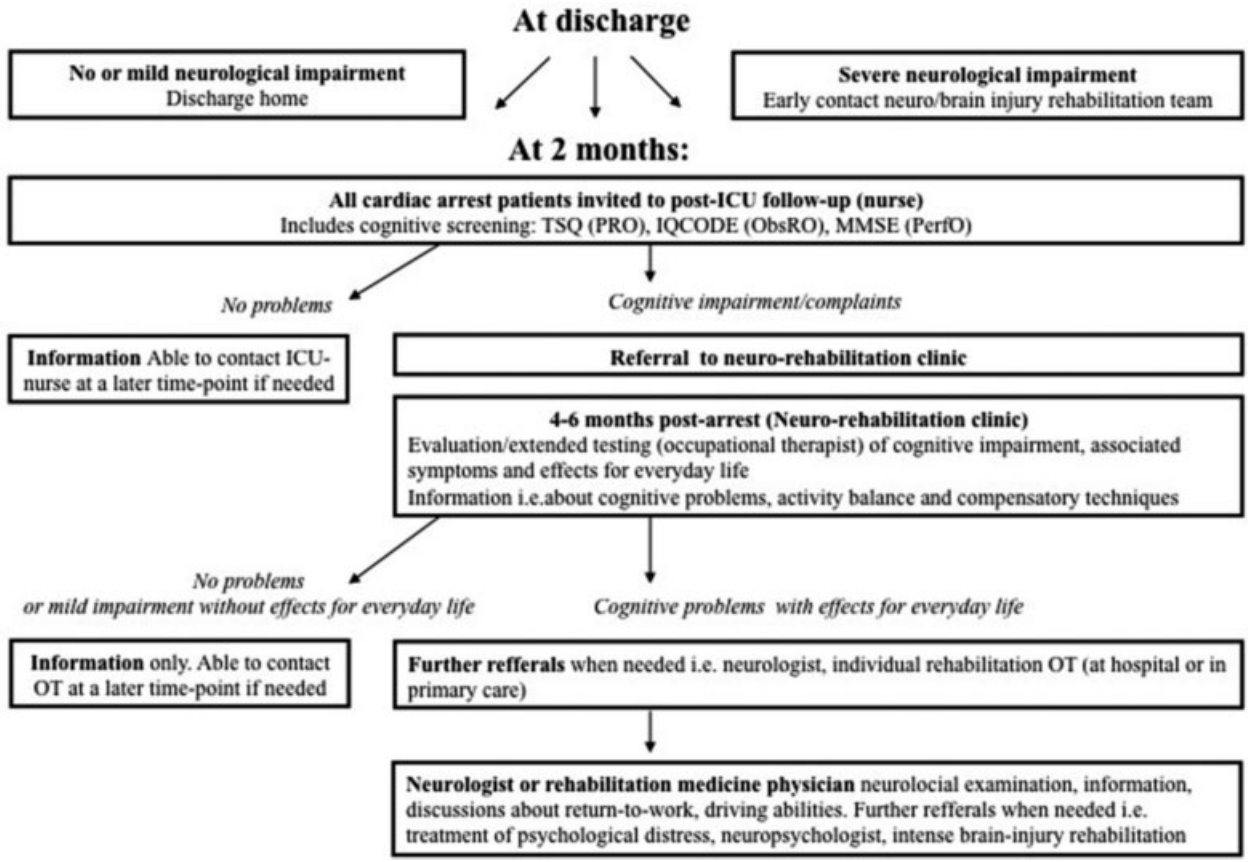

Fig. 2 The follow-up pathway of neurocognitive impairment after cardiac arrest in Lund, Sweden. ICU, intensive care unit; IQCODE, Informant Questionnaire on Cognitive Decline in the Elderly; MMSE, Mini-Mental Status Examination; ObsRO, observer-reported outcome (patient's outcome reported by a relative or close friend that observes the patient in daily life); OT, occupational therapist; PerfO, performance outcome (outcome based on results from objective measures); PRO, patient-reported outcome (subjective reports of outcome by the patients); TSQ, Two Simple Questions.

Follow-Up: When?

We have limited knowledge about the optimal time for follow-up after CA. Whether follow-up at other time points as presented by Moulaert et al[37] have similar or even better effects is unknown. The ideal time for follow-up would optimally be when the need for information and support is greatest, but this time may differ between patients.

An early follow-up after CA may have advantages like establishing an early contact and being less influenced by other factors that may appear with time.[41] It will also provide the opportunity to give patients and relatives' early essential information and support. However, if follow-up is provided too early it may not reflect the long-term outcome of the patient.

According to several studies, the recovery of patients has reached a more stable phase at 90 days postarrest.[8,41,50,51] This is, however, mainly based on the patient's neurologic improvements, and may not reflect the recovery of other important outcomes such as HRQoL, emotional problems, and return to work. For example, the optimal single timepoint for evaluation of return to work is unknown, and wide individual variation has been reflected in a report from the Danish Cardiac Arrest Register, where 77% of OHCA survivors ($n = 796$) who were employed prearrest returned to work at some time, in most cases within 5 months. Twenty-four percent, however, returned to work later than one year postarrest. The full pattern of recovery and need for support both in the early stages and in the long term is of great interest for future trials to understand the true outcome of OHCA survivors and to design the most-effective follow-up programs.

Conclusions

Follow-up and rehabilitation after CA is an emerging field of research that we have just begun to address. Similar to the *chain-of-survival* with its four critical steps for improving survival after CA, a good recovery to everyday life after CA probably constitutes a similar chain, where several factors contribute to an optimal recovery. It may not be the most complicated and costly interventions that will have the best effects for the patient's recovery, but rather small and combined efforts of early and repeated postdischarge interventions. Follow-up of survivors should also include the closest family/caregivers because they may be even more affected by emotional stress than the patients themselves.[3,52]

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