**Care After REsuscitation (CARE):**

**Implementation of the UK’s first dedicated multi-disciplinary follow up programme for survivors of out of hospital cardiac arrest (OHCA)**

Marco Mion PhD1, Firas Al-Janabi1,2, Shahed Islam MD1,2, Neil Magee1, Rajesh Balasubramanian3, Noel Watson1,2, Matthew Potter1, Grigoris V. Karamasis MD 1,2, Jane Harding1, Henry Seligman1, Rajdip Dulai1, Maria Maccarroni1, William Toff4, Veronique Moulaert5, Kees H. Polderman1,2, John R. Davies PhD1,2 , Thomas R. Keeble MD 1,2

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1. The Essex Cardiothoracic Centre, Basildon and Thurrock University Hospitals NHS Foundation Trust, Essex, UK.
2. Anglia Ruskin School of Medicine, Chelmsford, Essex, UK
3. South Essex Partnership Trust, Wickford, Essex, UK
4. Leicester Royal Infirmary, Leicester, Leicestershire, UK
5. CAPHRI School for Public Health and Primary Care, Department of Rehabilitation Medicine, Maastricht University, Maastricht, The Netherlands

**Corresponding author: *Dr Thomas Keeble, BSc MBBS MRCP MD***

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**Abstract**

**Background**

Survival rates after cardiac arrest (CA) are increasing, with more patients and their families living with the psychological consequences of surviving a sudden cardiac arrest. The currently available neuro-psychological assessment tools and therapies were not designed for CA, and may be inadequate.

**Methods**

The Essex Cardiothoracic Centre set up the UK’s first dedicated multi-disciplinary ‘Care After REsuscitation’ (CARE) service, offering cardiac arrest survivors and their caregivers systematic psychological, cognitive and specialized medical support for the first 6 months after CA.

 **Results**

21 patients were recruited into the CARE pilot service evaluation. Patients health at hospital discharge was poor; however, by 6 months all components (except general health) had improved significantly, and were close to that experienced by “healthy” individuals. 5 (26%) required referral to a psychiatrist, with all 5 (26%) subsequently being diagnosed with moderate to severe depression, and 3 (16%) with comorbid post-traumatic stress disorder.

**Conclusion**

Our study demonstrates a large unmet clinical need in general and neuro-psychological assessment, and our results suggest that offering appropriate and prompt specialist diagnosis and therapies lead to an improvement in health at 6 months.

**Key words –** out of hospital cardiac arrest (OHCA), neuro-psychological disability, follow up, multi-disciplinary team (MDT)

**Introduction**

**Rationale for the Care After REsuscitation (CARE) dedicated follow up service**

Out of hospital cardiac arrest (OHCA) is one of the most prevalent causes for mortality and disability worldwide. In England alone, around 30,000 individuals are treated by emergency services for OHCA per year, and in the US, the number of sufferers is 360,000 (Go, 2013; Hawkes, 2017). Survival rates are improving, with better CPR training, early access to defibrillation and expert care in cardiac arrest (CA) centres (Hawkes, 2017; London Ambulance Service, 2012). As a result an increasing number of CA survivors and their families are living with the psychological consequences of surviving an “aborted” sudden cardiac death.

It has become apparent that many patients who survive an ICU admission have considerable physical, psychological and social problems once discharged (Svenningsen, 2017). This has been studied most extensively in survivors of severe septic shock. There is an increasing awareness of, and evidence for, the need to initiate and optimise follow-up interventions to tackle psychological and cognitive morbidity following a critical illness and an intensive care stay (Shankar-Hari, 2016).

In the UK, as in most other countries, there is a lack of specialised support and rehabilitation services for CA survivors, even though a significant proportion experience emotional, cognitive and on-going physical health problems after hospital discharge (Andersson, 2015; Beesems, 2014; Elliot, 2011; Green, 2015; Orbo, 2016; Polanowska, 2014; Steinbusch, 2017; Wilder Schaaf, 2013; Wilson, 2014). Recent evidence also suggests that the combined effects on quality of life and re-integration into society are often far-reaching, with caregivers and close family also experiencing significant physical and psychological symptoms (Zimmerli, 2014).

Although guidelines by the European Resuscitation Council recommend provision of information, screening for cognitive and emotional problems, and prompt referral to a psychiatrist, psychologist or neuro-psychologist when appropriate, there is no national audit on the implementation of this service in the UK (Nolan, 2015). Although similar recommendations have been made by national societies and organisations, for example the OHCA Strategy for Scotland document (Scottish Government, 2015), anectodal evidence suggests only minimal involvement of professionals other than cardiologists, cardiac nurses or physiotherapists in this type of follow-up and support (Israelsson, 2016). Probably the best example of a dedicated psycho-social OHCA follow up service is that developed in the Netherlands by Moulaert and colleagues, but little other high quality data exists in the literature (Cowan, 2001; Dougherty, 2005; Moulaert, 2011).

The reasons for this lack of support for CA survivors is multifactorial. CA patients are cared for by a chain of highly specialised teams, reducing the ability to deliver continuity of care. Patients often present to a local emergency department via ambulance before being transferred to a cardiac centre. In most CA centres the first investigation required is coronary angiography with or without revascularisation. From the catheter lab patients are normally transferred to the intensive care unit (ICU) in an intubated and ventilated state. Only after being transferred from intensive care do patients arrive on the cardiac care ward, having already met potentially four different care giving teams. Different teams may then be involved in their care, ranging from physical therapists, electrophysiologists (for consideration of an implantable cardiac defibrillator), internal medicine (for treatment of frequently present co-morbidities), and general cardiologists. It is therefore not surprising that continuity of care for patients can be a challenge. After discharge from hospital, cardiac rehabilitation is prescribed whenever appropriate and a follow-up is usually offered by a cardiologist and cardiac rehabilitation nurse. This follow-up model however may not be appropriate for OHCA survivors, whose quality of life post-discharge also depends on cognitive outcome, psychological adjustment to the event, and on the impact, when present, of psychological distress of close family members/care-givers (who are at increased risk of developing Post Traumatic Stress Disorder).

The Essex cardiothoracic centre had witnessed this problem first-hand after conducting a study on cerebral hypothermia following CA. Our centre treats in excess of 120 OHCAs a year with a survival rate of 67% (Islam, 2015). During follow up investigators noticed a marked change in cognitive functioning compared to the pre-event status in many patients, despite being discharged with a cerebral performance category (CPC) score of 1-2 implying a good neurological outcome, and highly variable mental and general health of patients and their caregivers. It also became apparent that there was no formal process to identify such issues before discharge from hospital, and that local follow-up provisions for such patients and their families were inadequate. Typically, a 15 minute outpatient appointment was made in a general cardiology clinic at a local hospital several months after discharge. No cognitive or mental health assessment was performed during those visits, and no real support was available for this vulnerable group of patients and their families. The offer of and attendance at cardiac rehabilitation was also hit and miss, with patients suffering CA from cardiomyopathy or non-ischaemic causes not being entitled or commissioned to receive cardiac rehabilitation programmes.

A bespoke approach to the follow up of CA survivors, with an additional focus on the neurological and psychological impact of this event has been advocated (Lilja, 2017; Maciel, 2017), with a pilot service integrating cardiac and neurological follow-up already being offered in the Netherlands (Boyce, 2017). Clinical trials have demonstrated significant benefits in outcomes of CA survivors after early identification and treatment of cognitive and emotional problems (Moulaert, 2014, 2015). Patients undergoing intervention had significant improvements in quality of life, as well as emotional, mental and general health. In addition, significantly more people had returned to work compared to those receiving “standard care”, strongly suggesting that such interventions are not only beneficial to individual patients but would be highly cost-effective from the standpoint of society and insurers.

**Aim of the Care After REsuscitation (CARE) service**

Our institution aimed to create the United Kingdom's first Care After REsuscitation (CARE) service, offering cardiac arrest survivors and their carers early, psychological, cognitive and medical support, supplemented by specialised and tailored follow-up.

**Methods**

**Design of the Service**

*During admission*

A senior ICU nurse and a cardiologist assessed the patient and conducted an extensive physical and psychological assessment prior to hospital discharge. In the absence of validated and psychometrically sound outcome measures designed to assess the quality of life in CA survivors, we used the Short Form Survey 36 items (SF-36) which has shown some acceptable evidence of measurement validity (Haywood, 2018). Of note, only patients with good neurological recovery and a CPC of 1-2 (see Table 1) were invited for follow-up. If any acute adjustment difficulties were identified at this stage, immediate referral to a psychiatrist was made.

Information was given to the patient and caregiver(s) in multiple forms. Firstly, written information was available in leaflet form to answer common questions, including common causes of CA, possible post-CA changes (physical and psychological), and guidance on when to seek help. Secondly, a bespoke video made at our institution using a former patient as a case study to discuss common topics surrounding a CA and its after-effects was provided (www.lifeaftercardiacarrest.com). Lastly, patients were directed towards a social media website founded by CA survivors who had been treated at our institution (www.suddencardiacarrestuk.org)**.** This website provides useful information, but even more importantly opens peer-to-peer communication channels with other CA survivors.

*Post discharge*

At 48 hours, a telephone follow-up was initiated by a senior ICU nurse, where early problems could be identified. Often the transition from a hospital to home environment highlights important changes that were not obvious in the hospital, especially if the patients’ home was the location of the cardiac event. Furthermore, a dedicated 24/7 telephone helpline was started, manned by a senior intensive care nurse via the critical care outreach team.

*First outpatient follow-up*

At 8 weeks, the first specialist outpatient appointment was arranged. This was attended by a senior ICU nurse, a cardiologist and a psychiatrist. Appointments were one hour in duration, and up to two family members/caregivers were invited to attend. Quality of life and emotional health questionnaires were completed by the patient and caregivers as per baseline assessment.

Physical examination, blood pressure measurement, electrocardiogram (ECG) and medication review were done as routine, and outstanding medical issues could be addressed here. Broad psychological questioning was conducted to identify any major issues. These often included depression, anxiety and behavioural difficulties. If psychological issues were identified, patients and caregivers were offered further interventions as appropriate. A summary of the consultation was sent to the patient's general practitioner, with a copy to the patient’s cardiologist.

*Subsequent follow-up*

Two further follow-up appointments were arranged, at 6 and 12 months. Appointments were one hour, as previously. Format and content of the consultation was identical to the initial meeting. Again, a clinical letter was sent to the general practitioner and cardiologist after each consultation.

**Results of the CARE clinic pilot**

**Outcomes and Early Experiences**

The service was initiated one half day per week with 5 one-hour appointments available. Our group collected data on the first 21 consecutive patients who came through this service with a follow-up of up to 6 months. Two patients died before initial 8 week follow-up. Demographics are shown in Table 2.

The SF36 form assesses physical, social, emotional, mental health, bodily pain, vitality and general health. Change in mean scores from baseline to the 6 month follow up is shown in Table 3.

Our cohort was found to have significant emotional and psychosocial problems, resulting in baseline scores on the SF36 that were lower than commonly seen in, for example, patients on dialysis and patients with heart failure (Figure 1) (Juenger, 2002). This indicates severe trauma following the CA event.

Post CA patients scored lower at baseline on all categories except mental health when compared to patients suffering from major depression. These poor baseline quality of life assessments confirmed the huge impact of CA on an individual and their life. The baseline quality of life was compared to well-known chronic medical conditions and is illustrated in Figure 1 (Juenger, 2002).

It was hugely encouraging to see that at 6 months, our cohort of patients were approaching a quality of life experienced by ‘healthy’ individuals. As illustrated in table 3 all SF36 domains improved significantly, apart from general health which was numerically higher but did not reach statistical significance in this small cohort.

Of the 19 patients who could be evaluated at 6 months, 5 (26%) required ongoing appointments with our psychiatrist, with all 5 (26%) subsequently being diagnosed with moderate to severe depression, and 3 (16%) with post-traumatic stress disorder (PTSD). No significant medical issues were identified within 6 months.

**Discussion**

Survivors of CA often have a complex and prolonged hospital stay, cared for by multiple expert teams making patient ownership and continuity of care a challenge. Aborted sudden death brings with it a huge psychological burden to both the survivor and their family, which added with the ‘no flow’ induced brain injury results in a heterogenous group of patients with a far reaching range of physical, neurological and psychological disability. This disability can be difficult to untangle, and requires time and access to expert clinical support.

As discussed, in the UK there is a lack of systematic assessment and provision for the neuro-psychological needs of survivors and families post CA, and currently it is geographically very ‘hit and miss’. We have shown in this small consecutive pilot service evaluation that the general and psychological burden is significant, with preliminary analysis of this cohort proving quality of life assessments at hospital discharge (SF36) being worse than that documented in major depression, heart failure and dialysis. Our educational programme and early psychological assessment enabled us to diagnose moderate to severe depression in over a quarter of all survivors, all requiring and accessing a Psychiatrist (with an expert interest in CA) promptly. Not only that but 1 in 6 survivors suffered with PTSD.

Thankfully, we showed that by 6 months post CA all measures of health outcomes, as measured by the SF36, were significantly improved, apart from general health, allowing the survivors of CA to experience a quality of life much closer to that of their pre-morbid functioning.

Of note, many CA trials have reported significant rates of persistent neurological impairment even in survivors with good outcomes (CPC 1 or 2). For example, the pivotal hypothermia after

cardiac arrest trial reported good outcomes in 55% of patients treated with TH, compared

with 39% in controls; however, around 40% of patients with good outcome had some degree of persistent neurologic disability (Hypothermia after Cardiac Arrest Study Group, 2002). In the pivotal study by Bernard et al., 30% of patients with good outcomes had some persistent neurologic impairment (Bernard, 2002), and similar numbers have been reported in more recent studies, including 50% in the RICH trial as well as the TTM trial where around 36% of patients with a favourable outcome felt they had not made a full mental recovery, with patients working full or part time dropping from 50.8% to 31.6% (Bernard, 2010; Cronberg, 2015; Nielsen, 2013). It is possible, if not plausible, that these numbers could be improved through targeted interventions such as our CARE project. Further studies will be required to address this issue.

Although not described within this manuscript, the psychological burden on the caregiver was also significant. Many loved ones described extreme anxiety and post traumatic symptoms related to the CA resuscitation, in which families have provided basic life support to their loved one in their home prior to the arrival of the paramedic services. This remains relatively unexplored and requires further evaluation and support interventions.

The way in which we measure ‘health outcomes’ within survivors of CA is also important to mention. The SF36 questionnaire has been used previously in other studies, but the development of a cohort specific patient reported outcome measure (PROM) and more sophisticated and bespoke assessment tools are needed. This is the focus of on-going work by our group and others.

**Challenges implementing the CARE Service**

The initial challenges were organisational, and included re-arranging the resources and manpower to deliver, essentially, a new clinical service once a week.

The first issue was gaining time in peoples work schedule to allow five hours of clinic time a week. A senior ICU nurse took the lead in organising patient appointments, and obtaining clinic room space to run the service. A cardiologist was required to give five clinical hours to the service and a selected liaison psychiatrist was approached to accommodate referrals into their general clinic load. During the pilot phase of the project, a clinical psychologist with a specialist interest in neuro-rehabilitation joined the trust, and was seconded into the clinic half a day per week.

Aside from the commitments to the follow-up clinic post discharge, there was a requirement for inpatient identification, assessment and screening of CA survivors before leaving hospital. This was a constant process, which the intensive care, rehabilitation services and cardiac medical and nursing teams had to be mindful of. Designated staff were enrolled to assess patients and identify early problems, which required training and clinical time on the wards.

Importantly there was a hospital-wide need for education on our service and its rationale. The majority of clinical staff were not aware of the far reaching implications and the effect on patients and family post discharge. Understanding was achieved via access to teaching and other presentation sessions.

**Limitations**

The results described are from a single centre with a small number of initial patients. The project will affect a much large number of patients, however detailed neuropsychological assessment was only performed in a small subset of patients during this preliminary analysis. Improvements in SF36 health and functioning at 6 months whilst encouraging must be interpreted with some caution. This was a non-randomised pilot study and it is possible that patients could improve in all aspects of measured health outcomes just with time, acclimatisation and “standard care”. However, the large percentage of patients with persistent neurological symptoms reported at 6 months in many previous studies strongly suggest that these problems don’t completely disappear spontaneously, and that a targeted intervention such as described here could be helpful. A randomised controlled trial (RCT) comparing active CARE-type intervention with a control group receiving standard care will be required to conclusively address this question.

That said we felt that the positive psycho-social benefits demonstrated in the randomised ALASCA trial was evidence enough for us to proceed to a pilot CARE service (Moulaert, 2007, 2014). It is reassuring to note that the improvements seen in the ALASCA trial are remarkably consistent with those reported with our CARE pilot service.

As discussed, the SF36 is not validated in CA survivors, and therefore although objective may not be the correct tool to assess outcomes in this patient category. This and other tools are the subject of ongoing research to help understand what constitutes a ‘good outcome’, which will help identify the patients with a CPC 1-2 but still require intervention.

It is important to note that only patients with relatively spared cognitive function (CPC 1 and 2) were invited to follow-up. CPC scoring was conducted in hospital, meaning some patients may have improved subsequently and were not originally offered the CARE intervention. It may be more prudent to assess patients on an individual basis (including following discharge) and judge whether benefit would be gained from early psycho-social intervention. An arbitrary cut off point may fail some survivors.

It was also possible that some patients were missed by the CARE team when they were inpatients for other reasons including prolonged admission, or repatriation to district general hospitals. With the continued running of our clinic and with increased visibility and on-going education more staff are utilising the clinic, improving access and outcomes.

**Conclusion**

Life after CA poses many psycho-social challenges to both survivors and caregivers. The CARE clinic has demonstrated a large unmet clinical need in general and neuro-psychological assessment and the offering of appropriate and prompt specialist diagnosis and therapies.

The Care After REsuscitation service in Essex now offers every CA survivor and caregiver access to early education about the condition, a support network, a systematic review of neuro-psychological and general health enabling prompt recognition of neuro-psychological disorders, and a framework of therapies through 3 follow-up appointments from within an expert multi-disciplinary team. Although conclusively proving benefits of a CARE-type intervention will require an RCT, the high rate of persistent neurological impairments at 6 months in CA survivors demonstrated in previous studies coupled with the improvements in well-being noted in our study and in the previous ALASCA trial strongly suggest that this approach is feasible and useful.

We believe that a standard offering of care must be agreed for all survivors of cardiac arrest and their families, to improve the systematic neuro-psychological assessment and treatment of this very vulnerable group of patients, helping to remove the current ‘hit and miss’ nature of service provision.

**Author Disclosure Statement**

No competing financial interests exist.

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**Reprint Author:**

Dr Thomas Keeble, BSc MBBS MRCP MD

The Essex Cardiothoracic Centre, Basildon and Thurrock University Hospitals NHS Foundation Trust, Basildon, SS16 5NL, United Kingdom.

E-mail: Thomas.keeble@btuh.nhs.uk

Telephone: +44 1268 524900

Fax number: +44 1268 394802