Cardiopulmonary resuscitation in Sweden – yesterday, today and tomorrow

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“Hi Anneli,

My name is X and I have survived an out-of-hospital cardiac arrest.

One day in January, I suddenly felt confused and shortly thereafter I collapsed. My heart stopped beating. My wife and one of our neighbours started chest compressions and mouth-to-mouth ventilation but before doing this, they called the dispatch centre for further help.

After 20 minutes, the fire brigade and the ambulance arrived and continued the process. I was admitted to hospital and, for the second time, I was treated with percutaneous coronary intervention.

Some days later, I woke up in the intensive care unit and slowly came back to reality.

I am grateful that I have been given a second chance and I wonder what kind of register I am in?”

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ABSTRACT

In Sweden, the reported incidence and outcome of out-of-hospital cardiac arrest (OHCA) vary between counties. In the mid -1980s, a national programme in cardiopulmonary resuscitation (CPR) was developed and rescuers have been educated in CPR. Since 1990, Swedish OHCA data are to be reported to the Swedish Cardiac Arrest Register (SCAR).

The aim of this thesis was to describe and analyse the incidence and outcome of OHCA and the amount of national training in CPR from data reported to the SCAR and to the CPR training register. The data on OHCAs were related to a variety of epidemiological and quality indicators.

Methods: this thesis is based on register data from both the SCAR and the CPR training register. The inclusion criteria were treated OHCAs (I-IV), witnessed treated OHCAs (V) and rescuers educated in CPR (I).The number of participants were:

I: CPR training register, 1983-2007, n=2 million rescuers, and SCAR, 1990-2007, n=45,775, II: SCAR, 2008-2009, n=6,457 registered manually or on the web and n=3,522 registered on the web, III: SCAR, 2008-2010, n=2,398 prospectively registered and n=800 retrospectively registered, IV: SCAR, 1992-2011, n=59,926, V: SCAR, 2008-2010, n=11,005.

Results: since 1983, 5,000 instructor-trainers have trained more than 50,000 instructors who have trained almost two million of Sweden's nine million inhabitants to perform adult CPR. The number of bystander CPR attempts for OHCA in Sweden increased from 31% (1992) to 55% (2007) (I). In 2008-

2009, the number of reported OHCAs varied between 13 and 52 per 100,000 inhabitants and year. Bystander CPR, cardiac aetiology and longer emergency medical service (EMS) response times were more frequent in less populated areas, but survival was not associated with population density (II). A validation process showed that, there was a 25% missing rate between 2008 and 2010 of OHCAs reported to the SCAR. In the non-reported OHCAs, patients were older and had less frequently received bystander CPR, but, despite this, they also had a higher survival rate (III). From 1992 to 2011, the OHCAs reported to the SCAR increased from 27 to 52 per 100,000 inhabitants and year. Survival to one month increased from 4.8% (1992) to 10.7% (2011), particularly among patients found in a shockable rhythm. This increase in survival was associated with signs of improvement in all four links of the chain of survival (IV). Furthermore, estimates indicate that, if the delay from collapse to 1) calling for an ambulance, 2) the start of CPR, and 3) the time to defibrillation is reduced to <2 min, <2min and <8 min respectively, approximately 300-400 additional lives could be saved (V).

Conclusions: there has been an impressive development in the preparedness for and treatment of patients suffering from OHCAs in Sweden during the last 30 years. Improvements in various links in the chain of survival have resulted in a marked increase in survival after OHCA. It suggests that this figure will increase further if the delay to the start of treatment can be reduced still further.

Keywords: cardiac arrest, cardiopulmonary resuscitation, education, register, survival, validity

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SAMMANFATTNING PÅ SVENSKA

I Sveriges samtliga län, varierar förekomsten av hjärtstopp som sker utanför sjukhus och dess utfall. I mitten av 1980 togs ett utbildningsprogram fram med syfte att utbilda livräddare i hjärtlungräddning (HLR). Personer som drabbas av hjärtstopp utanför sjukhus, ska sedan 1990 rapporteras till det svenska kvalitetsregistret för hjärtstopp utanför sjukhus.

Syftet med denna avhandling var att beskriva och analysera förekomsten av hjärtstopp som sker utanför sjukhus där HLR påbörjats och dess utfall vars data rapporterats till det svenska kvalitetsregistret för hjärtstopp utanför sjukhus. Vidare var syftet att beskriva den nationella utbildningen i HLR och dess utfall vars data rapporterats till utbildningsregistret i HLR. Uppgifterna om hjärtstopp utanför sjukhus har blivit relaterat till epidemiologiska aspekter samt olika kvalitetsindikatorer.

Metodologiskt är denna avhandling baserad på registerdata såväl från det svenska kvalitetsregistret för hjärtstopp utanför sjukhus samt utbildningsregistret i HLR. Inklusionskriterier har varit behandlade hjärtstopp som skett utanför sjukhus (I-IV), bevittnat och behandlat hjärtstopp som skett utanför sjukhus (V) och livräddare som utbildats i HLR (I). Antalet deltagare har varit följande:

I: utbildningsregistret i HLR, 1983-2007 (n=två miljoner livräddare) och det svenska kvalitetsregistret för hjärtstopp utanför sjukhus, 1990-2007, (n=45 775), II: det svenska kvalitetsregistret för hjärtstopp utanför sjukhus, 2008-2009 (n=6457 manuellt- eller webregistrerade och n=3522 webregistrerade), III: det svenska kvalitetsregistret för hjärtstopp utanför sjukhus, 2008-2010 (n=2398 prospektivt och n=800 retrospektivt registrerade), IV: det svenska kvalitetsregistret för hjärtstopp utanför sjukhus, 1992-2011 (n=59 926), V: det svenska kvalitetsregistret för hjärtstopp utanför sjukhus, 2008-2010 (n=11 005).

Sedan 1983 har 5000 huvudinstruktörer utbildat mer än 50 000 instruktörer som sedan har utbildat nästan två miljoner av Sveriges nio miljoner invånare för att kunna utföra HLR på vuxna. I Sverige ökade antalet bystander HLR-försök (livräddaringripande före ambulansens ankomst) från 31% (1992) till 55% (2007) (I). 2008 till 2009 varierade antalet rapporterade hjärtstopp utanför sjukhus mellan 13 till 52 per 100 000 invånare och år. Bystander HLR, kardiell etiologi och längre responstid för ambulansen var mer

förekommande i glesbygden än i tätortsbebyggda områden. Dock var överlevanden inte associerat till befolkningstäthet (II).

Efter en valideringsprocess utav det svenska kvalitetsregistret för hjärtstopp utanför sjukhus, påvisades att 25 % av de som drabbats av hjärtstopp utanför sjukhus inte var rapporterade till registret. Av de som inte var rapporterade till det svenska kvalitetsregistret för hjärtstopp utanför sjukhus var patienten äldre, hade mer sällan fått bystander HLR, men trots detta, en högre överlevnad (III).

Mellan 1992 till 2011 ökade rapporteringen till det svenska kvalitetsregistret för hjärtstopp utanför sjukhus från 27 till 52 per 100 000 invånare och år. Överlevnad till en månad ökade från 4,8 % (1992) till 10,7 % (2011), framförallt bland de fall som initialt hade kammarflimmer eller kammartakykardi och som kunde defibrilleras. Denna ökade överlevnad var associerad till en förbättring i samtliga länkar i ”kedjan som räddar liv” (IV).

Vidare så har följande beräkningar indikerat att om fördröjning från hjärtstopp till

- larm av ambulans
- start av HLR och
- tid till defibrillering

minskades med respektive

- < 2 minuter (larm av ambulans)
- < 2 minuter (start av HLR) samt
- < 8 minuter (tid till defibrillering)

skulle 300-400 ytterligare liv kunna räddas (V).

Sammanfattningsvis har det skett en imponerande utveckling i Sverige de senaste 30 åren, gällande förberedandet av att ta hand om och behandla en patient som drabbas av ett hjärtstopp som sker utanför sjukhus. Det är betydelsefullt att rapporteringen ökar till det svenska kvalitetsregistret för hjärtstopp utanför sjukhus. Förbättringar i länkarna i ”kedjan som räddar liv” kan kopplas till en ökad överlevnad av de som drabbats av hjärtstopp utanför

sjukhus och indikationer finns att överlevnaden efter hjärtstopp utanför sjukhus kan ytterligare förbättras om behandling påbörjas i tid.

LIST OF PAPERS

This thesis is based on the following papers, which are referred to in the text by their Roman numerals (I-V).

I. **Strömsöe A**, Andersson B, Ekström L, Herlitz J, Axelsson A, Göransson KE, Svensson L, Holmberg S. Education in cardiopulmonary resuscitation in Sweden and its clinical consequences. Resuscitation.2010 Feb;81:211-6.

II. **Strömsöe A**, Svensson L, Claesson A, Lindkvist J, Lundström A, Herlitz J. Association between population density and reported incidence, characteristics and outcome after out-of-hospital cardiac arrest in Sweden. Resuscitation. 2011 Oct;82:1307-13.

III. **Strömsöe A**, Svensson L, Axelsson AB, Göransson K, Todorova L, Herlitz J. Validity of reported data in the Swedish Cardiac Arrest Register in selected parts in Sweden. Resuscitation. (E-pub 2013 Jan 8).

IV. **Strömsöe A**, Svensson L, Axelsson AB, Claesson A, Göransson K, Nordberg P, Herlitz J. Improved long-term outcome in Sweden after out-of-hospital cardiac arrest due to improvements in the chain of survival with validated data. Submitted.

V. **Strömsöe A**, Afzelius S, Axelsson C, Södersved Källestedt ML, Enlund M, Svensson L, Herlitz J. Improvements in logistics could increase survival after out-of-hospital cardiac arrest in Sweden. J Intern Med. (E-pub 2013 Jan 30).

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ABBREVIATIONS

A - CLS	advanced – cardiac life support
AED	automated external defibrillator
AHA	the American Heart Association
B - CLS	basic – cardiac life support
CARES	the Cardiac Arrest Registry to Enhance Survival
CPC score	Cerebral Performance Category score
CPR	cardiopulmonary resuscitation
EMS	emergency medical service
ERC	the European Resuscitation Council
EuReCa	the European Cardiac Arrest Register
IHD	ischemic heart disease
PAD	Public Access Defibrillator
OHCA	out-of-hospital cardiac arrest
PCI	percutaneous coronary intervention
PEA	pulseless electrical activity
RN	registered nurse
ROC	the Resuscitation Outcomes Consortium
ROSC	return of spontaneous circulation
SAMS	Saving More Lives in Sweden
SCA	sudden cardiac arrest

SCAR	the Swedish Cardiac Arrest Register
SCD	sudden cardiac death
VACAR	Victorian Ambulance Cardiac Arrest Register
VF	ventricular fibrillation
VT	ventricular tachycardia

DEFINITIONS IN SHORT

Bystander	a person who responds to a cardiac arrest without belonging to an organised emergency response system

Swedish definitions

The Federation of Leaders In Swedish Ambulance and Emergency services	Föreningen för Ledningsansvariga Inom Svensk Ambulanssjukvård
The National Board of Health and Welfare	Socialstyrelsen
The National Quality register	Nationella Kvalitetsregister
The Swedish Association of Local Authorities and Regions	Sveriges Kommuner och Landsting
The Swedish Civil Contingencies Agency	Civilförsvarsförbundet
The Swedish Life-Saving Society	Svenska Livräddningssällskapet

Preface

At the beginning of the 1990´-s, I was employed as a registered nurse (RN) at the cardiac intensive care unit at Sahlgrenska Hospital (currently named Sahlgrenska University Hospital) in Gothenburg. This was the first time I was really introduced to the importance of having knowledge of cardiopulmonary resuscitation and what I should actually do if I was confronted by a patient suffering from cardiac arrest. My interest in the subject continued and resulted in my starting to educate people both within the clinical environment and within the teaching environment, regardless of whether the people who were going to learn were medically educated or lay people. With simple tools, such as chest compressions and mouth-to-mouth ventilation and sometimes also having access to an automated external defibrillator, there is no excuse for not learning how to apply this kind of treatment if you have the opportunity to save life regardless of whether it is a newborn, a middle-aged person or an elderly person.

As late as the mid 20th-century, awareness of how to apply research both in the clinic and in society became more central. After making contact with my future supervisor, who also worked as a cardiologist during my employment at Sahlgrenska, he supported me in initiating a research project which has been clinically close to me for several years. This was the beginning and I plan to continue in the same way.

1 INTRODUCTION

The area of interest of this thesis is treated out-of-hospital cardiac arrest (OHCA). The case before the introduction describes the focus of this thesis, the incidence and outcome of OHCA and the use of register-based data.

An OHCA treated by the emergency medical service (EMS) crew or/and a bystander/first responder is defined according to the Utstein style(1, 2) as follows:

"The act of attempting to maintain or restore life by establishing or maintaining airway (or both), breathing, and circulation through cardiopulmonary resuscitation (CPR), defibrillation, and other related emergency care techniques"

1.1 Cardiac arrest

The definition of a cardiac arrest is multifaceted and it is dependent on the context and its occurrence. In general, the definition of a cardiac arrest is when a person is unconscious and there is an absence of respiration and circulation, regardless of whether it is expected or unexpected. Sudden cardiac arrest (SCA) or sudden cardiac death (SCD) is an unexpected lack of consciousness, respiration and circulation, with or without known cardiac aetiology(2-8). In the text in the introduction to this thesis, the term "SCA" will be used.

A variety of mechanisms can explain an SCA. Firstly, they can be divided into two major subgroups, cardiac aetiology or non-cardiac aetiology(9-13). Cardiac aetiology is then divided into topics (Table I). The term "non-cardiac aetiology" includes a number of causes (Table 2). According to previous research from a national perspective, a non-cardiac aetiology represents about 30% of OHCAs (7, 12, 14).

In SCA due to a cardiac aetiology, there is variability in terms of age and distribution of gender (15, 16). The lowest survival rate after OHCA is found among children not older than one year (sudden infant death syndrome) and patients more than 80 years old (10, 17, 18). Furthermore among patients over 18 years of age, there is a negative association between age and survival (18). With increasing age, a higher proportion of women have ventricular fibrillation (VF) as the initial arrhythmia (15, 18, 19). Previous research has

also shown that the proportion of resuscitation attempts decreases with increasing age (15, 18).

One third of all OHCAs take place among women (20, 21). Furthermore women are often older than men and they less frequently receive resuscitation before the arrival of the EMS. Despite this, the proportion of patients admitted to hospital alive after OHCA is higher in women (20).

At the beginning of this thesis, there was no knowledge neither about the age, gender or survival in relation to the population density and furthermore, no knowledge about these characteristics according to whether the OHCA was reported to the Swedish Cardiac Arrest Register (SCAR) by the EMS crew or if the OHCA was forgotten and not reported to the SCAR.

Table 1.

Cardiac aetiology
Ischemic heart disease
Ischemic cardiomyopathy
Dilated cardiomyopathy
Hypertrophic cardiomyopathy
Non-arteriosclerotic disease of coronary arteries
Valvular heart disease
Arrhythmogenic right ventricular cardiomyopathy
Infiltrative and inflammatory myocardial disease
Congenital heart disease
Primary cardiac electrical abnormalities

Table 2.

Non-cardiac aetiology
Bleeding
Pulmonary embolism
Lung disease
Electrolyte abnormalities
Subarachnoid haemorrhage
Drug overdose
Suffocation
Drowning
Sudden infant death syndrome

Death caused by ischemic heart disease (IHD) is the most common cause of SCA and is therefore also the most common cause of OHCA (7, 14, 22-24).

There are vast geographic differences between the Swedish counties in IHD and the highest incidence in IHD will be found in counties as Dalarna and Norrbotten which represent rural areas in middle of and the northern Sweden (25).

In recent times – from a national perspective – there have been fewer autopsies and therefore more uncertain data about the cause of death. In previous research, both national and international, autopsies have shown that a cardiac aetiology was the most common cause of OHCA (8, 13). Furthermore, previous reports have shown that coronary heart disease represents about 90% of all cardiac causes (9, 26).

The reported incidence of OHCA varies both in Europe and in the USA (22, 27-31). The most recent data from Sweden show that the reported incidence of OHCA varies from 37 to 81 per 100,000 inhabitants (7) and year. In Europe the reported incidence of OHCA varies from 17 to 53 per 100,000 inhabitants and year (32). The number of reported OHCAs in Sweden, in 2011 was 4,904, which is the highest number that has ever been documented (7).

There is a variation in survival after OHCA (28, 33-38). A European study has stated that the number of survivors per 100,000 inhabitants and year varies from 5 to 18 (32). Previous studies mention that there is an ongoing increase in survival (21, 39-42).

However, there is a lack of information in Sweden about the incidence of OHCA and survival. Sometimes, it is also problematic to determine the cause of death and, due to a lower autopsy rate, the cause of death is more uncertain (9, 25).

1.2 Shockable rhythm

This is a simplified version of shockable rhythm and its pathophysiology.

Ventricular fibrillation (VF) - is the most common arrhythmia in connection with SCA, especially in combination with myocardial infarction. When the arrhythmia starts, there is still high activity in most of the cardiac muscle cells, electric chaos, which initially results in high amplitudes in the waveforms of the electrocardiogram, but, over time, this amplitude is reduced. The ventricles do not contract, they simply fibrillate. When the supplies of energy in the cells in the electrical system of the heart are

exhausted, the amplitude of the fibrillation waves is reduced to zero and the ventricular fibrillation converts to asystole.

Ventricular tachycardia (VT) – is the same as rapid heart contractions triggered from the ventricles. The problem is that sometimes the rate of the contractions is so rapid that the ventricles are not filled with blood. This leads to a reduced circulation, which can result in an SCA.

In addition, there are two other conditions of cardiac arrest – asystole and pulseless electrical activity (PEA) - which are known as non-shockable rhythm.

1.3 Uniformity of the guidelines and documentation

The history of CPR extends well back in time both outside and inside hospital. Guidelines issued by the European Resuscitation Council (ERC) and American Heart Association (AHA) have led to the implementation of defibrillation in connection with CPR (43-45). In actual fact, the earliest studies, which subsequently led to the implementation of the first automated external defibrillator (AED) in Sweden, initiated the thinking about resuscitation (46, 47). With increasing knowledge about resuscitation around the world, more questions arose about how to document and formulate uniform guidelines for CPR and emergency care (44, 48, 49). In the 1990´-s, the AHA and the ERC reached consensus and this eventually resulted in uniform guidelines – the Utstein style guidelines (1, 2, 43, 50). The uniformity of the guidelines was designed to make it possible - to have similar worldwide documentation of the incidence and treatment of OHCA.

1.4 Education in CPR and its implementation

As previously stated, the thinking about how to resuscitate was initiated many years ago. In a more modern version, the entire education in CPR and its implementation in clinical health care were initiated in Belfast in the 1960´-s, supervised by Pantridge (51). After successful pre-hospital achievements with survivors after OHCA, this knowledge spread to other countries. Cobb, who was the promoter in Seattle,(52) introduced the education in CPR both to the EMS crew and to the fire brigade, which resulted in a two-tier EMS system.

Following influence from the USA and Norway, the Swedish Society of Cardiology, with Holmberg as the leader, initiated a national CPR education programme in 1981 (53). In 1983, there was a complete national CPR education programme. The implementation process was started by inviting a number of physicians to attend the very first CPR course in Marstrand, on the west coast of Sweden. The main purpose of this meeting was to teach all course members to become instructor-trainers. Then, when they returned to their work places, they would act as instructor-trainers train instructors who in turn would train rescuers. Using the so - called "cascade principle" - the ultimate consequence would be a large number of educated rescuers in CPR (Figure 1). The CPR education programme was intended to be used among both medically educated and lay people. The international guidelines for CPR are revised every five years (54-57). These new guidelines are usually implemented in Sweden (7) one year after the new European guidelines have been introduced. The revision aims to adapt to the most recent scientific evidence with regard to various aspects of CPR.

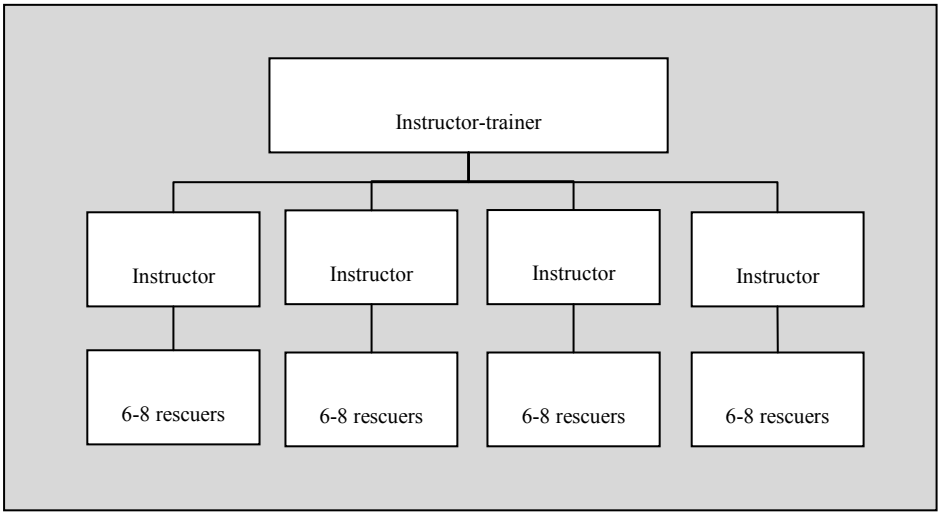

Figure 1. The cascade principle.

1.5 The chain of survival

Survival after an OHCA is dependent on the delay from collapse to treatment. Previous studies have shown the importance of reducing the delay in all four links in the chain of survival (Figure 2) which results in increasing survival (58). Since the model of chain of survival was introduced in 1991, interest

has focused heavily on using the model as a tool in CPR education and its implementation in clinical health care (43). At present, the chain of survival consists of four links. The last link now focuses on post-resuscitation care (55).

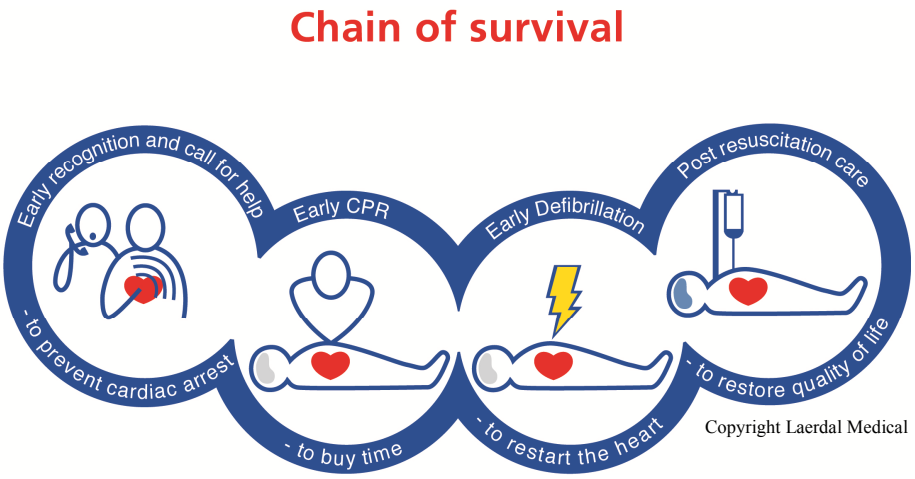

Figure 2. The chain of survival.

The first link - "Early recognition and call for help - to prevent cardiac arrest"
The ideal situation is to recognise early warning signals that could exist before collapse. If the OHCA still occurs, it is important to call the dispatcher as quickly as possible. The dispatcher can then assist in CPR and will send assistance such as an EMS crew, first responder and so on. A previous study has highlighted the association between delay to call and survival after OHCA (59).

The second link – "Early CPR - to buy time"
The next important step is to start treatment with CPR. Treatment such as CPR results in artificial circulation and ventilation, which is essential for the survival of both the brain- and cardiac muscle cells. CPR is necessary if there is a need for defibrillation, since, among other things, it will postpone the conversion of ventricular fibrillation to asystole (60, 61).

The third link – "Early defibrillation - to restart the heart"
Another important treatment is defibrillation. Defibrillation has to be performed as quickly as possible. If the delay increases, there is a risk that the function of the cardiac muscle cells will be impaired and that electrical

activity will decrease, thereby reducing the chance of successful defibrillation (62-65).

The fourth link – "Post resuscitation care - to restore quality of life"
Finally, the last link in the chain of survival involves the situation both prior to and after hospital admission. When there is a return of spontaneous circulation (ROSC), one of the primary aims is to restore good neurological function. Therapeutic hypothermia is one of the treatments in post-resuscitation care (66-69) that is designed to achieve this goal. Moreover, there are other in-hospital interventions, such as percutaneous coronary intervention (PCI), coronary bypass surgery and implantable defibrillators, which might improve the outcome, although there have been arguments about the scientific evidence (32, 70, 71).
There are also other factors that may indirectly affect the chain of survival. Previous research has determined that the place at which the OHCA occurs can be critical for survival and that higher survival was found when the OHCA took place in public areas (64, 72). In Sweden, about 60% of all OHCA occurs at home and this contributes to a lower chance of survival (73). Similar results have been reported by others (74, 75). Furthermore, if the OHCA is witnessed, it is associated with higher survival (34, 76, 77).

1.6 The emergency medical service (EMS) in Sweden

In Sweden, each county is responsible for its EMS system. Most of the EMS systems in counties are controlled by county councils while a few EMS systems counties are controlled by private companies. The most common structure is that the EMS is connected to a hospital located in the same county. Medical treatment guidelines, which were designed to be a tool for Swedish EMS health care, were drawn up by a Swedish association working group. These guidelines are recommendations, but following them is not compulsory (78). Some guidelines such as basic life support (BLS) and advanced life support (ALS) were also formulated by the Swedish Resuscitation Council (7). At present, it is estimated that there are almost 300 EMS stations throughout the country, giving each municipality one EMS station. During the time period of this study, the educational level of the EMS crew varied. At the beginning of the 1990s, the crews were mostly made up of paramedics and, later in the 2000s, there was a successive increase in RNs becoming part of the EMS crew. In some counties, there are also physicians in the EMS system. The medical records used by the EMS differ in the 21 counties and five different medical records are currently available. One of the

records is represented in more than half the counties. Two of the 21 counties use manual paper records, while the others use digital records.

1.7 The Swedish Registers

At the beginning of 1983, the number of educated rescuers, instructors and instructor-trainers in CPR were recorded in a register – the CPR training register. Data from 1983 to 1988 have been merged and as a result, they are not distributed annually. From 1989 and onwards, the data presenting education in CPR have been available on a yearly basis. In addition, information about each instructor´-s profession and work place is also available.

The SCAR was initiated in 1990 and subsequently became a national quality register (79). The primary aim of the SCAR is to find weak links in the chain of survival after OHCA. This is important because it could give the EMS systems an opportunity to find both strengths and weaknesses which could then be corrected. Each EMS system and its crew have the opportunity to obtain feedback through continuous data.

The SCAR is supported financially by the Swedish government and the Swedish Association of Local Authorities and Regions, which makes it possible to operate the SCAR. An annual report shows changes over time in terms of various factors at resuscitation and outcome. This is described both from an overall national perspective and from a regional perspective. Characteristics, such as personal identification, diagnosis, treatment and outcome, are documented by the EMS crew and reported online through a web-based reporting system. The number of OHCAs reported as a result of its coverage has increased over time, but there is variation between the different counties in Sweden. In 2011, reporting to the SCAR was almost complete (80). This completeness is important to enable certain conclusions to be drawn from the data in the SCAR. This is in agreement with a previous study (81). From 1990 to 2008, all OHCAs were reported manually by the EMS systems. In 2008, all the EMS systems reported the OHCAs via web registration.

In addition - at the end of 2012, the name of the SCAR was changed and the register is now known as the Swedish Register of Cardiopulmonary Resuscitation.

At the present time in Sweden, there are about 90 national quality registers. The aim of a national quality register is to contain individualised data on

patient problems, medical interventions and outcomes after treatment, with the final aim of finding weaknesses in the chain of care that can be improved. Moreover, the Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare have underlined the importance of data quality, coverage and reporting completeness to provide the most realistic results in relation to healthcare (25, 79). This means that the organisation of the national quality registers is hoping to achieve higher quality health care documentation and thereby provide feedback to the health care providers. In addition, this will allow for an open comparison of health care between all the counties in Sweden and thereby produce better more equal health care.

When general conclusions are drawn about research results, the validity and reliability have to be taken into account. The validity relates to the measurements and their relevance to the context, whereas reliability refers to the measurements being made in a reliable way (82).

1.8 Utstein data – style and reporting

It has been recommended that OHCA data should be reported according to the Utstein style (1, 2). The reason for this is to obtain data that are uniformly reported from a national and international perspective. This is important to enable data to be compared in a similar way. The event and outcome of a cardiac arrest should be reported as follows (Figure 3):

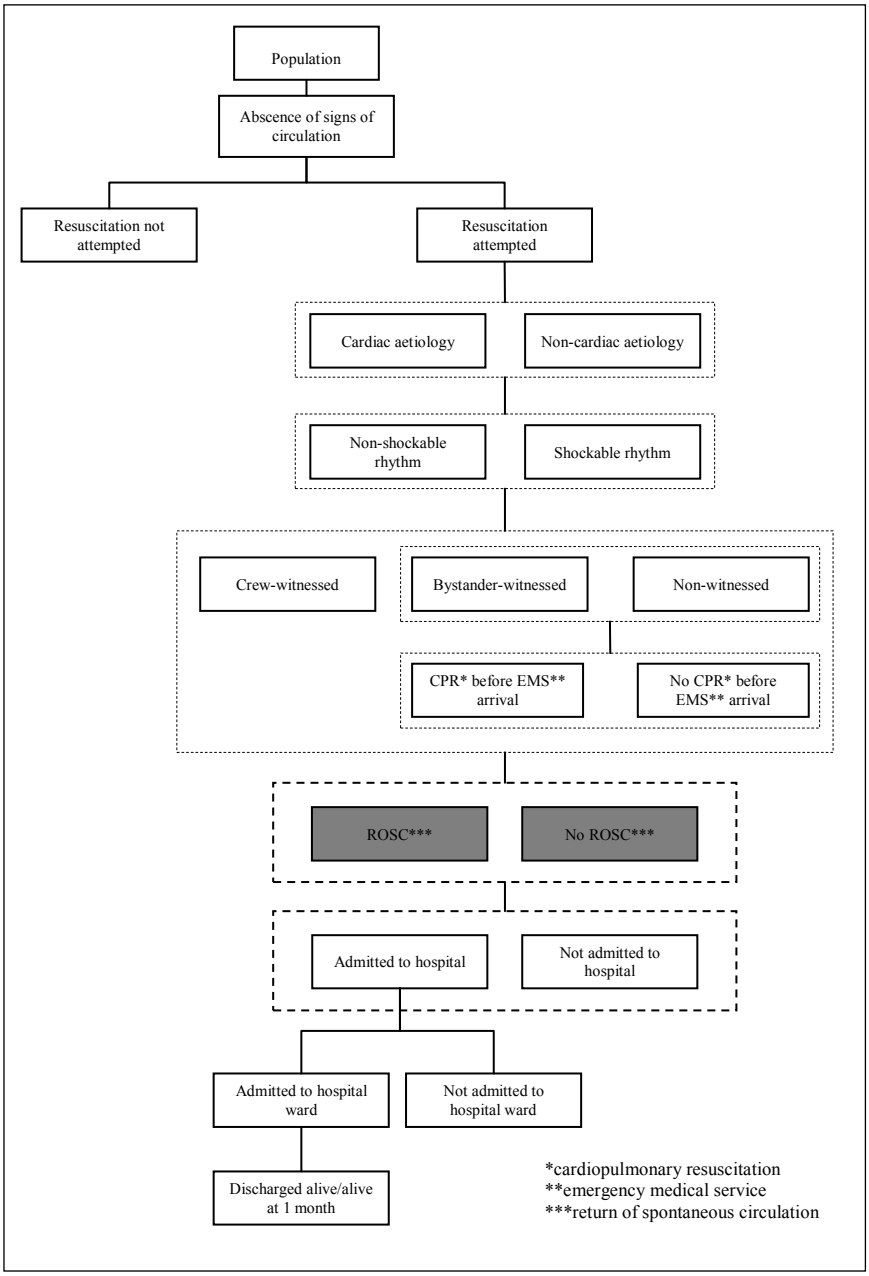

Figure 3. The Utstein style – intended to be used to achieve uniform reporting of OHCAs.

1.9 The international registers of out-of-hospital cardiac arrest

At present, there are different ways to document data on OHCAs. Some existing international registers have been initiated in various time periods with the aim of collecting data on OHCA prospectively. Variables are collected and reported according to the Utstein style (1, 2). These registers include the Resuscitation Outcomes Consortium (ROC), the Cardiac Arrest Registry to Enhance Survival (CARES), the Victorian Ambulance Cardiac Arrest Register (VACAR), the European Cardiac Arrest Register (EuReCa) and the Swedish Cardiac Arrest Register (SCAR) (32, 83-86).

1.10 Previous research from the SCAR

The SCAR has contributed to four theses and in all, generated 36 articles in international peer reviewed journals.

The first thesis, (M. Holmberg, year 2000) was an overall presentation of the register and all five papers dealt with the SCAR (62, 87-90).

The second thesis, (J. Hollenberg, year 2008) included two articles, based on data from the SCAR. The first was a comparison between Stockholm and Gothenburg, in terms of characteristics and outcome after OHCA (91). The second article described changes in outcome after OHCA (92).

The third thesis, (K. Bohm, year 2009) included one article based on data from SCAR dealing with outcome after OHCA in relation to whether bystanders gave chest compression only CPR or standard CPR (93).

The fourth thesis, (C. Holmgren, year 2011) included one paper based on data from the SCAR, describing the number of survivors after OHCA in relation to the first recorded rhythm (94).

Overall one could say, the articles that have been published from the SCAR, have focused on four major topics:1) factors of importance for outcome, 2) changes over time, 3) trying to define patients with bad outcome i.e. those where CPR should not be attempted and 4) specific causes of OHCA, for example drowning.

1.11 Rationale for the thesis

At present, it is more common in Sweden for a victim of an OHCA to die before arrival in hospital rather than having the opportunity to survive the OHCA. During the past decade, from both a national and an international perspective, several studies have been performed to bring about a positive change treatment and outcome and thereby an increase in survival (61, 64, 95-97). Moreover, several studies have presented data on the incidence of OHCA and its variations (22, 27-30).

With previous knowledge in this area – the question is whether it is possible to present fresh analyses that will generate and contribute to new knowledge about the incidence and outcome of OHCAs?

Despite the research results that are currently available, there are still some knowledge gaps in Sweden about the variations in incidence and outcome between counties. In addition, is it possible to use the register data in the SCAR in order to bridge the current knowledge gaps?

To draw robust conclusions about incidence and outcome, reliable data that have been measured in a reliable way must be available and the measurement has to be relevant to the context, i.e. the validity.

2 AIM

The overall aim of this thesis was to describe and analyse the incidence and outcome of OHCA and the amount of national training in CPR from data reported to the SCAR and to the CPR training register.

The specific aim of each paper was:

I. To describe the CPR training programme and the education frequency in various working populations in Sweden and to analyse how it has affected the rate of bystander attempts outside hospital.

II. To describe the reported incidence of OHCA and the characteristics and outcome after OHCA in relation to population density in Sweden.

III. To describe differences and similarities between reported and non-reported data in the SCAR in selected parts in Sweden.

IV. To describe OHCA in Sweden from a long-term perspective in terms of changes in outcome and factors at resuscitation based on validated data.

V. To describe the number of patients who are successfully resuscitated after OHCA in Sweden and the number of lives that could be expected to be saved in the future if delays to the start of treatment could be reduced appropriately.

3 METHODS

The studies in this thesis are designed as observational studies. Papers I-V are based on OHCA data reported to the SCAR and data reported to the CPR training register (Table 3).

Table 3. Overview Papers I-V

	Paper I	**Paper II**	**Paper III**	**Paper IV**	**Paper V**
Aim	To describe the CPR training programme and the education frequency in various working populations in Sweden and to analyse how it has affected the rate of bystander attempts outside hospital.	To describe the reported incidence of OHCA and the characteristics and outcome after OHCA in relation to population density in Sweden.	To describe differences and similarities between reported and non-reported data in the SCAR in selected parts in Sweden.	To describe OHCA in Sweden from a long-term perspective in terms of changes in outcome and factors at resuscitation based on validated data.	To describe the number of patients who are successfully resuscitated after OHCA in Sweden and the number of lives that could be expected to be saved in the future if delays to the start of treatment could be reduced appropriately.
Design	Observational	Observational	Observational	Observational	Observational
Sample	CPR training register, 1983-2007 (n=2 million rescuers) SCAR, 1990-2007 (n=45,775)	SCAR, 2008-2009 Manual/web* (n=6,457) Web** (n=3,522)	SCAR, 2008-2010 Prospectively (n=2,398) Retrospectively (n=800)	SCAR, 1992-2011 (n=59,926)	SCAR, 2008-2010 (n=11,005)
Analyses* **	Non-parametric statistics	Non-parametric statistics	Non-parametric statistics	Non-parametric statistics	

* Based on registered OHCAs from counties.
**Based on registered OHCAs from municipalities
***Statistical tests are described in a separate matrix.

CPR – cardiopulmonary resuscitation
OHCA – out-of-hospital cardiac arrest
SCAR – the Swedish cardiac arrest register

3.1 Definitions

3.1.1 Treated OHCA

A treated OHCA is defined when treatment – CPR and/or defibrillation - is given to an unconscious person with an absence of normal respiration and no sign of circulation. Treatment was given by a bystander and/or EMS crew. These OHCA cases should be reported to the SCAR and conform with the OHCA data in Papers I-V. One exception is when a patient was given CPR by a bystander before the arrival of the EMS and the EMS crew did not continue the treatment due to definite signs of death (such as rigor mortis). These patients should not be reported to the SCAR and were therefore removed from the SCAR and were thereby not included in the data in Papers I-V.

3.1.2 Prospectively versus retrospectively reported OHCA

Reported versus non-reported data are defined as prospectively versus retrospectively reported data. Prospective documentation is when the EMS crew documents a treated OHCA at the time of or soon after collapse. Prospectively reported data are included in Papers I-V. Retrospective documentation is when a specifically trained person performs a search procedure after the occurrence of OHCA and then collects data in medical records of a treated OHCA. Retrospectively reported data can be found in Papers III-V.

3.2 Study population and setting

3.2.1 The EMS (I-V)

During the time when the studies were performed, almost all the EMS systems in Sweden were controlled by county councils apart from a few EMS systems which were controlled by private companies. Furthermore, the medical treatment guidelines designed for the Swedish EMS system, were followed by all the EMS systems in Sweden. The medical records used by the EMS crew differed in the 21 counties during the study periods and are not specified over time from 1992 to 2011.

All the EMS systems took part in Papers I-V with some variation in participation.

3.2.2 The SCAR (I-V)

Treated OHCAs were reported prospectively in Papers I-V and retrospectively in Papers III-V.

In all the studies, the reporting procedure of the EMS mission, both prospectively and retrospectively, was performed in two parts. The first part of the form (Appendix I) was filled in by the EMS crew or specifically trained persons who performed this mission with support from the EMS medical record. The second part (Appendix II) required in-hospital medical records in order to address the required questions. In some cases the national state administrative authority was contacted regarding information about survival when the in-hospital records could not be found (II-IV). The retrospective analysis was undertaken by a specifically trained person who performed a search procedure and then documented the data in the SCAR (III-V).

3.2.3 Documentation of variables in the SCAR (I-V)

In the form for the SCAR there are variables which have to be documented step by step. If there are any errors, it will not be possible to enter the data, warning messages will be given and the variable cannot be documented as part of an OHCA case. When all the data are correctly documented, the form can be submitted by activating a send button.

The documentation in the SCAR started when an OHCA was registered according to the variables on the form for the SCAR (Appendix III).

3.2.4 Documentation in the CPR training register (I)

Educated rescuers in CPR were reported by instructor-trainers and instructors to the CPR training register.

3.3 Data collection (I-V)

The data collection is based on OHCAs reported by the EMS crew and then reported to the SCAR in studies I-V. In Paper I the data collection was primarily based on the CPR training register.

3.3.1 Paper I

The data in Paper I, were based on the CPR training register and the SCAR.

Data from the CPR training register were collected from 1983 to 2007. There were both manually and web-registered rescuers in the CPR training register. The manually registered data were written down manually on a form by instructor-trainers and instructors and then sent to a central office in Gothenburg to be documented in the CPR training register. The web registrations were made on-line and thereby documented in the CPR training register.

Data from the SCAR related to 1990 - 2007. The SCAR documentation was based on manually registered OHCA cases. The manually registered forms were handled in the same way as in the CPR training register.

The inclusion criteria were:

- Educated rescuers according the Swedish CPR education programme
- Treated OHCAs

The following variables were analysed (Figure 4):

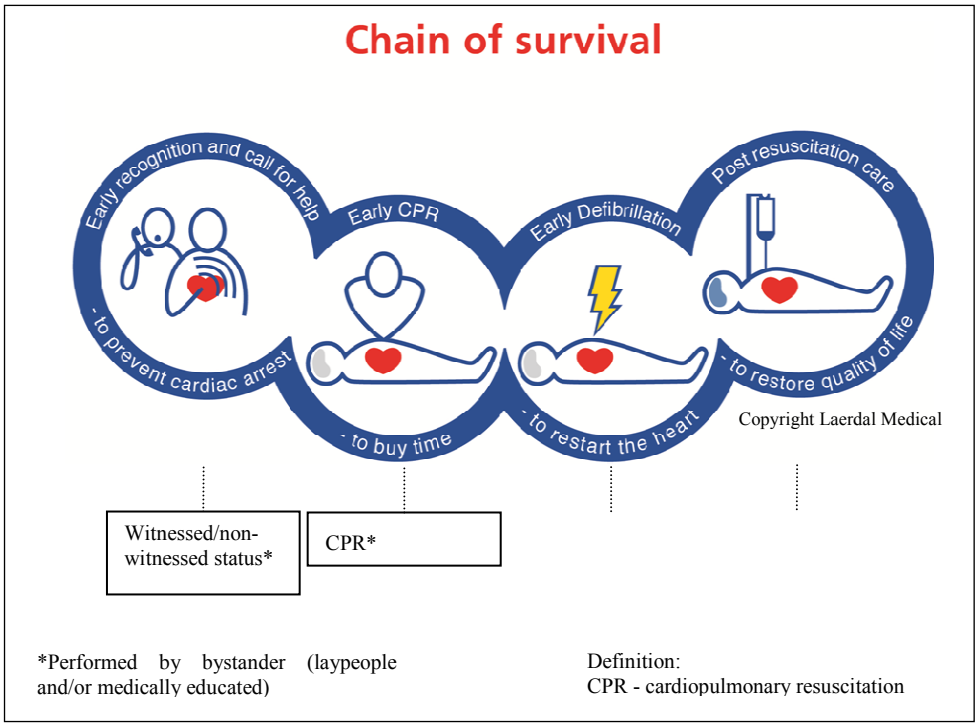

Figure 4. Variables analysed – Paper I based on reported OHCAs.

Other variables, such as social security number, gender, task number, alarm date, location of OHCA, initial rhythm and cause of arrest were also documented (Appendix III).

3.3.2 Paper II

In Paper II, the data were based on the documentation in the SCAR. The data that were retrieved for the study were collected from 2008 to 2009. The reported OHCAs related to both counties and municipalities. The reporting by the EMS crew was performed as both manual and web registrations. The manually registered OHCAs were based on OHCAs from the entire county, while the web registrations were based on OHCAs reported from municipalities. The manual form registrations were handled in the same way as the manual registrations in the CPR training register.

The inclusion criterion was:

- Treated OHCAs

The following variables were analysed (Figure 5):

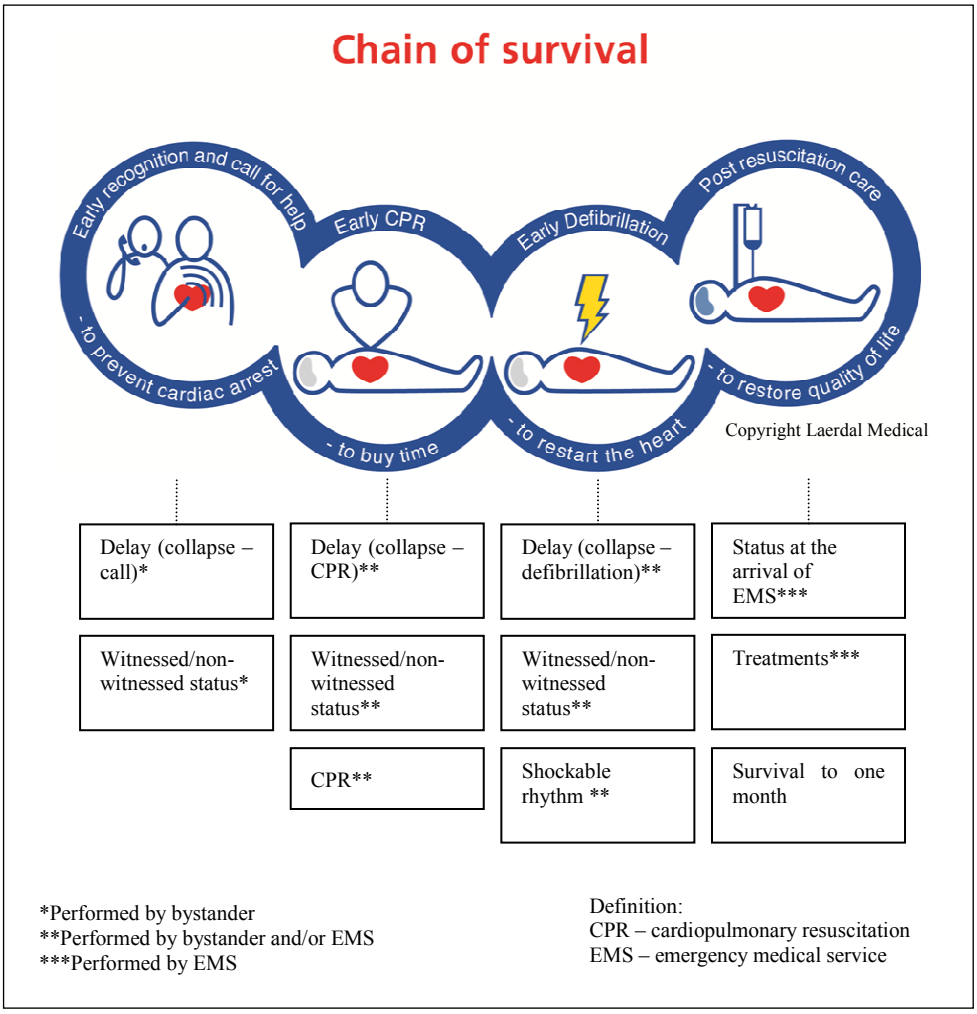

Figure 5. Variables analysed – Paper II registered from both counties and/or municipalities.

Other variables, such as social security number, gender, task number, alarm date, location of OHCA, initial rhythm and cause of arrest, were also documented (Appendix III).

During the time period 1990 to 2007, about 80% of all EMS systems reported to the SCAR. The number of EMS stations which reported to the SCAR was 241.

In addition, in this study, a selected sample of the data reported to the SCAR and the source data – the EMS medical records – were compared. A cross-check with data from Dalarna (279,000 inhabitants), western Sweden (1.5 million inhabitants) and Stockholm (two million inhabitants) was performed.

3.3.3 Paper III

In this study, the OHCAs occurred during the time period 2008 to 2010. The reported data were based on web registrations to the SCAR.

The included OHCAs were reported both prospectively and retrospectively. The number of participating EMS systems reporting OHCAs to the SCAR was 300.

The inclusion criterion was:

- Treated OHCAs

The following variables were analysed (Figure 6):

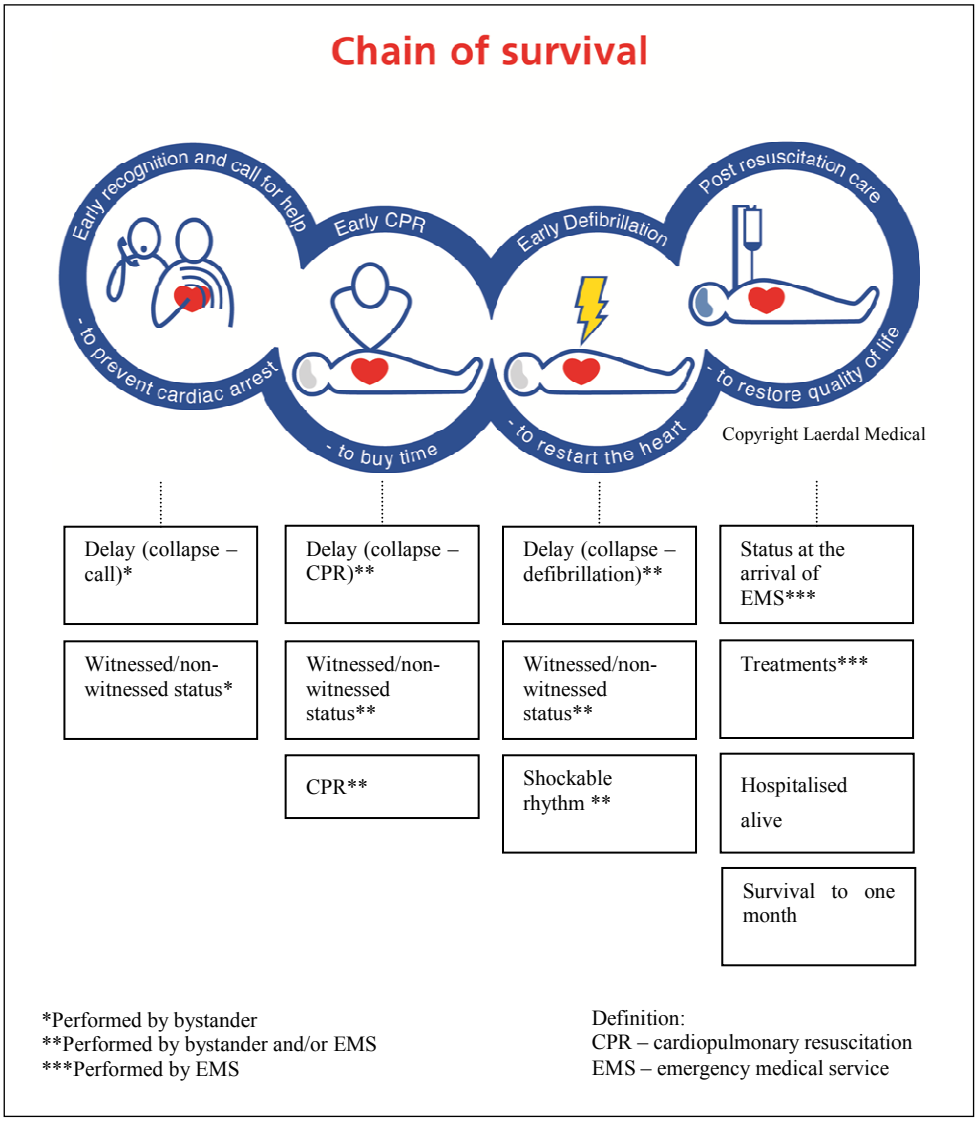

Figure 6. Variables analysed – Paper III based on retrospectively and prospectively reported OHCAs.

Other variables, such as social security number, gender, task number, alarm date, location of OHCA, initial rhythm and cause of arrest, were also documented (Appendix III).

3.3.4 Paper IV

In Paper IV, the OHCA data related to 1992 to 2011 and were based on the SCAR. The reported OHCAs consisted of both manual and web registrations. The definition of manual/web registrations is given in connection with Paper II.

The inclusion criterion was:

- Treated OHCAs

The following variables were analysed (Figure 7):

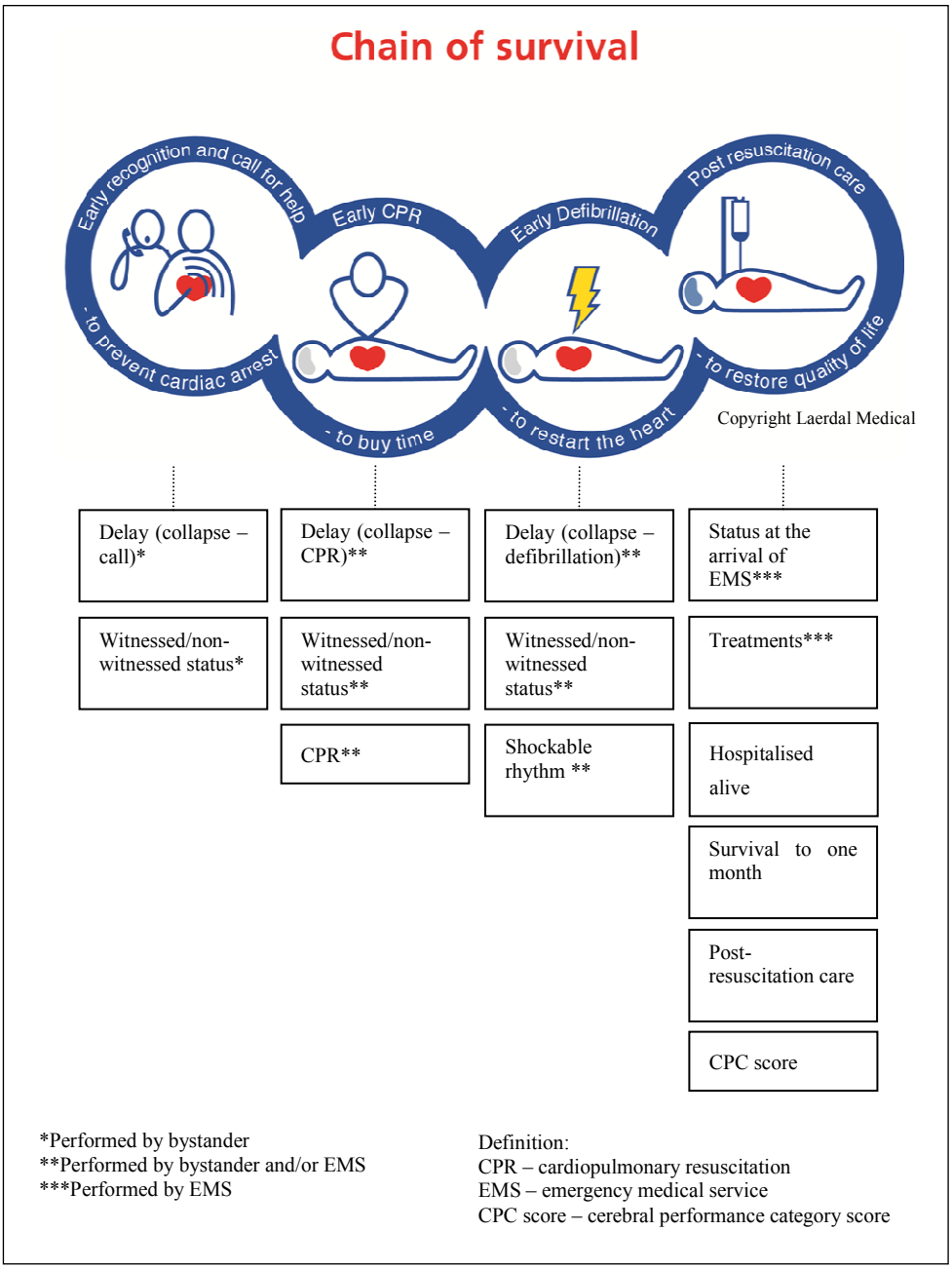

Figure 7. Variables analysed - Paper IV based on reported OHCAs.

Other variables, such as social security number, gender, task number, alarm date, location of OHCA, initial rhythm and cause of arrest, were also documented (Appendix III).

3.3.5 Procedure for the retrospectively reported OHCAs (III–IV)

In Sweden, four different digital EMS medical record systems are in use. In Papers III and IV, one of the digital systems was used in more than half of all 21 Swedish counties and the other three digital systems were distributed in the remaining seven counties. Three counties were using manual EMS medical records in paper form which were documented in an electronic monitoring system. The documentation in the Swedish EMS medical records was performed in different ways. This meant that the searchability was not generalisable in all EMS medical records. To find the non-reported OHCAs in the EMS medical records, a search template, with several keywords that could be used, was followed (Appendix IV). When the search template was constructed, it could be used in counties, providing that the same digital EMS medical record or electronic monitoring system was in use. For each county in Sweden there was one specially trained person who was responsible for constructing the search template and performing the search procedure. When the search procedure was completed, all the retrospective OHCA data were documented by the same person to the SCAR.

3.3.6 Cross-check of the EMS records versus the SCAR (III–IV)

In the next step, all the retrospective OHCA data were compared with the SCAR. In all counties, the responsible specially trained person provided data for his/her own county. The data were delivered to the database manager for the SCAR. The data contained the social security numbers of treated OHCAs and they were compared with the prospectively reported OHCAs in the SCAR. If there were data with the same social security number in the SCAR and in the retrospectively reported OHCAs, the retrospective OHCA was removed, provided that the OHCA occurred on the same day and at the same time. At this stage, when all the variables on the first part of the form in the SCAR were completed, each case became a reported retrospective OHCA. Furthermore, the OHCA was followed up in terms of treatment (PCI, therapeutic hypothermia, drugs) and survival. This information was documented in the second part of the SCAR form. Information about the OHCA treatment in hospital and survival was found in hospital medical records. In some cases where information about survival could not be found,

contact was made with the national state administrative authority. If this occurred, the retrospective OHCA case was removed and only the original data in the SCAR remained. This was done in order to avoid the duplication of documentation.

3.3.7 Validation of reported OHCAs (III-IV)

A validation process was performed, first and foremost in Papers III and IV, with the primary aim of validating the reported incidence of OHCA in each county in Sweden. This was due to the vast variation in reporting frequencies in Sweden. In addition to the validation of reported incidence, it is important to validate the individual variables.

A small investigation designed to compare the documentation of the source data and register data was performed in 2009. A subset of data was randomly collected in western Sweden (n=200) and Dalarna (n=43). The sample was prospectively reported by the EMS crew. When each OHCA case was compared, a self-made template was used to determine whether there was documentation about all the variables both in the EMS medical record and in the SCAR. The variables that were evaluated were initial arrhythmia, place of cardiac arrest, witnessed status, bystander CPR and survival.

In overall terms, the agreement was very high (more than 95%; 100% for survival). These data have not previously been published.

3.3.8 Paper V

In Paper V, the calculations are based on OHCAs reported to the SCAR from 2008 to 2010 and an estimation of OHCAs from 2011 (Tables 4-5).

OHCAs are divided into three different categories

- bystander witnessed
- bystander or EMS witnessed
- bystander/EMS witnessed and found in VF

The number of OHCAs per year in each category is based on estimations from 2011 (Table 4).

The increase in survival rate by reducing the delay to calling, delay to CPR or delay to defibrillation has then been calculated from the estimated number of OHCAs and the distribution (as a function of delay) of survival rate. The distribution is based on OHCAs reported to the SCAR in 2008-2010 (Table 5).

The inclusion criterion was:

- Witnessed treated OHCAs

The following variables were described (Figure 8):

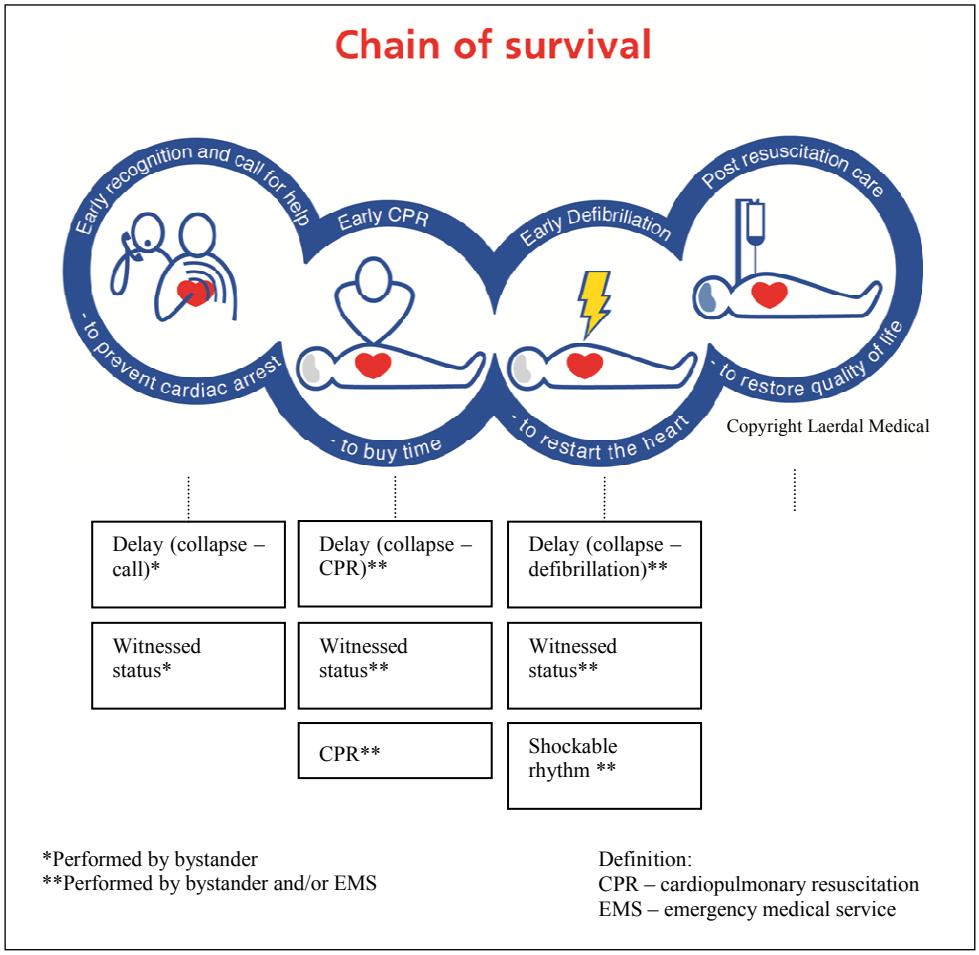

Figure 8. Variables analysed – Paper V based on witnessed reported OHCAs.

Other variables, such as social security number, gender, task number, alarm date, location of OHCA, initial rhythm and cause of arrest, were also documented (Appendix III).

3.4 Data analyses – statistics (I-V)

	Paper I	Paper II	Paper III	Paper IV	Paper V
Descriptive					X
Fisher's exact test			X	X	
Mann-Whitney U test	X	X	X	X	
Spearman's rank correlation		X		X	
Logistic regression		X			

Figure 9. Flow chart for statistical tests used in Papers I-V.

Papers I-V:

Non-parametric statistics were used in Papers I-IV due to the skewed sample. Descriptive statistics such as the mean, median and percentages were used in Papers I-V.

I

Trend tests for associations with the time variable of year of OHCAs were performed using the Mann-Whitney U test. A p-value of less than 0.05 was regarded as significant.

II

Descriptive statistics and correlation analyses were used in this study. The variables were presented as percentages, mean or median. For associations with dichotomous variables the Mann Whitney U test was used and Spearman's rank statistics were used for continuous variables. For calculations of unadjusted and adjusted odds ratios relating to the reported incidence of OHCAs and outcome after OHCAs, logistic regression was used.

When adjusting for initial rhythm, place and aetiology, patients were divided as follows; VF versus no VF (initial rhythm), home versus not at home (place) and cardiac versus non-cardiac (aetiology).

III

The variables were presented as percentages, mean or median. Fisher's exact test was used for comparisons of proportions and the Mann-Whitney U test was used for continuous variables. A p-value of less than 0.05 was regarded as significant. Two-tailed tests were applied.

IV

The data were reported as percentages, mean or median. For tests of trends over time, the Mann-Whitney U test was used for dichotomous variables and Spearman's rank correlation was used for continuous/ordered variables. For comparisons between prospectively and retrospectively reported cases in 2011, Fisher's exact test was used for proportions and the Mann-Whitney U test was used for continuous/ordered variables. The latter test was also used for comparisons of Cerebral Performance Category (CPC) score between patients found in a shockable rhythm and patients found in a non-shockable rhythm.

Table 4. The distribution of the number of OHCAs per year.

	OHCA per year n=5000*		
	Bystander witnessed	Bystander/EMS witnessed	Bystander/EMS witnessed + VF
n(%)	2650(53)	3500(70)	1155(33)

*Estimate based on reported OHCAs from 2011 which are presented in the result text.

Table 5. Calculation from the estimated number of OHCAs and the distribution of survival rate.

	Bystander witnessed			**Bystander/EMS witnessed**			**Bystander/EMS witnessed+VF**		
	Delay to call		Difference	Delay to CPR		Difference	Delay to Defibrillation		Difference
n(%)*	2166(53)	1899(47)		2732(48)	2915(52)		552(31)	1217(69)	
Delay(minutes)	0-2	>2		0-2	>2		5-8	>8	
Survival %*	13	6	13-6=7	18	6	18-6=12	43	18	43-18=25
Calculation* **	0.47* · 2650** · 0.07*=87			0.52* · 3500** · 0.12*=218			0.69* · 1155** · 0.25*=199		

*Based on data reported in 2008-2010 which are presented in Paper V, Figures 3-5.
** Estimate based on reported OHCAs from 2011.
*** Estimated number of additional lives saved per year if delay to call or CPR is reduced to <2minutes (all cases) or delay to defibrillation is reduced to < 8 minutes (all cases).

Definition:
CPR – cardiopulmonary resuscitation
EMS – emergency medical service
OHCA – out-of-hospital cardiac arrest
VF – ventricular fibrillation

3.5 Ethics

The register data in the SCAR is expected to follow the recommendations according the Helsinki declaration (98). The research ethics guidelines including information, informed consent and confidentiality are therefore taken into account and adapted to the documentation of data in the SCAR.

A large number of the patients who are registered in the SCAR are deceased. With respect to information and informed consent, there has been no contact with their relatives or acquaintances after they were reported to the SCAR. Furthermore, there have not been any personal contacts with the survivors who were a part of the sample in the Papers (I-V). All survivors after an OHCA are supposed to receive information about their participation in the SCAR. At present, there is a lack of information about how this works in all the Swedish counties.

Due to confidentiality, all data have been kept locked up when it comes to the EMS medical records. Furthermore all data are analysed on a group level, so, the identity of one single patient can never be revealed.

There has never been any financial compensation to the EMS systems which have reported OHCA data to the SCAR and all the EMS systems were free to terminate the reporting of OHCAs to the SCAR. Ethical approvals for the SCAR have been applied for and were authorised by the regional ethics committee in Gothenburg (S394-00). However, for the papers in this thesis, there were no further ethical questions recognised associated with register issues. These studies have been looked upon as quality work. This has been discussed with one of the most experience members of the regional ethical committee in Gothenburg.

4 RESULTS

4.1 Summary of results (I-V)

From 1983 to 2007, two million people in Sweden were trained in CPR by CPR instructor-trainers. This was associated with an increase in CPR attempts prior to the arrival of the EMS.

The data have been analysed in relation to whether OHCA cases were reported prospectively and retrospectively from 2008 to 2011.These analyses suggest that about 25% of cases are not reported prospectively. There were some differences between prospectively and retrospectively reported OHCAs. When comparing these two groups in 2008 to 2010, the retrospectively reported patients were older, received CPR less frequently prior to the arrival of the EMS but had a higher survival to one month than the reported group. When comparing prospectively and retrospectively reported OHCAs in 2011, it was found that OHCAs occurred more frequently in the time period October to December in the retrospectively reported group and OHCAs were less frequently of cardiac etiology in the retrospectively reported group. Furthermore, the median delay between collapsing and calling for the EMS was shorter in the retrospectively reported group.

Factors at resuscitation and outcome have been related to population density. The main findings were that there was no association between population density and survival after OHCA, regardless of whether it was evaluated from a regional or municipality perspective. Bystander CPR, cardiac etiology and longer EMS response times were more frequent in more sparsely areas.

There was an increase over time in the number of reported OHCAs with an increase in survival rate to one month, particularly among patients found in a shockable rhythm. The total number of lives saved after OHCA today is about 500. The results indicate that the majority of the survivors have a good or relatively good cerebral function.

Regarding survival in relation to the delay to treatment, an estimation showed that, if the delay from collapse to a) calling the dispatchers, b) the start of CPR and c) the time to defibrillation were reduced to: a/ less than two minutes, b/ less than two minutes and c/ less than eight minutes, 300-400 additional lives could be saved.

4.2 Education in CPR in Sweden (I)

From 1983 to 2007, two million rescuers were trained in B-CLS for adults. From 1983 to 1988, the reported educated CPR rescuers were documented as a total number (n=250,000), while, in the following period, from 1989 to 2007, they were reported annually. Fifty thousand instructors and 2,500 instructor-trainers both specializing in B-CLS were educated, thereby enabling the mass training in B-CLS.

In 1998 to 2007, approximately 100,000 rescuers were trained in child CPR. Almost 5,000 instructors and 350 instructor-trainers were educated in same time period.

The numbers of rescuers trained in defibrillation CPR totalled 40,000; 4,000 instructors and 300 instructor-trainers from 1996 to 2007.

Training in A-CLS between 1989 and 2007 resulted in 50,000 rescuers and 2,000 instructors.

The dominant profession that trained rescuers in CPR was nurses during the time period from 1998 to 2007. They were particularly involved in the training of health care providers in the hospital.

4.3 Reported incidence (II–V)

From 1 January, 2008 to 31 December, 2009, 6,457 OHCAs were reported to the SCAR as both manual and web registrations. During the time period 2008 to 2009, 3,522 OHCAs were web registered. Web-registered OHCAs divided between municipalities did not show any association between reported incidence and population density. The incidence of OHCAs was lower in the quartile with the highest population density as compared with the quartile with the lowest population density (II). Furthermore, in Paper II, a cross-check of data reported to the SCAR, in 2009 and source data, in 2009, showed that the proportion of non-reported OHCAs was 23% (western Sweden), 30% (Dalarna) and 15% (Stockholm).

The reported incidence of treated OHCAs in Paper III was 3,198 in 2008 to 2010 (based on three counties, Västra Götaland, Skåne and Dalarna). These cases were divided into prospectively reported OHCAs (n=2,398) and retrospectively reported OHCAs (n=800).

In Paper IV, the overall reported incidence of treated OHCAs was given for each year from 1992 to 2011. The total number of OHCAs was 59,926. The reported incidence varied from 27 per 100,000 inhabitants/year in 1992 to 52 per 100,000 inhabitants/year in 2011.

The overall reported number of treated OHCAs in 2008 to 2010 was 11,005 (V).

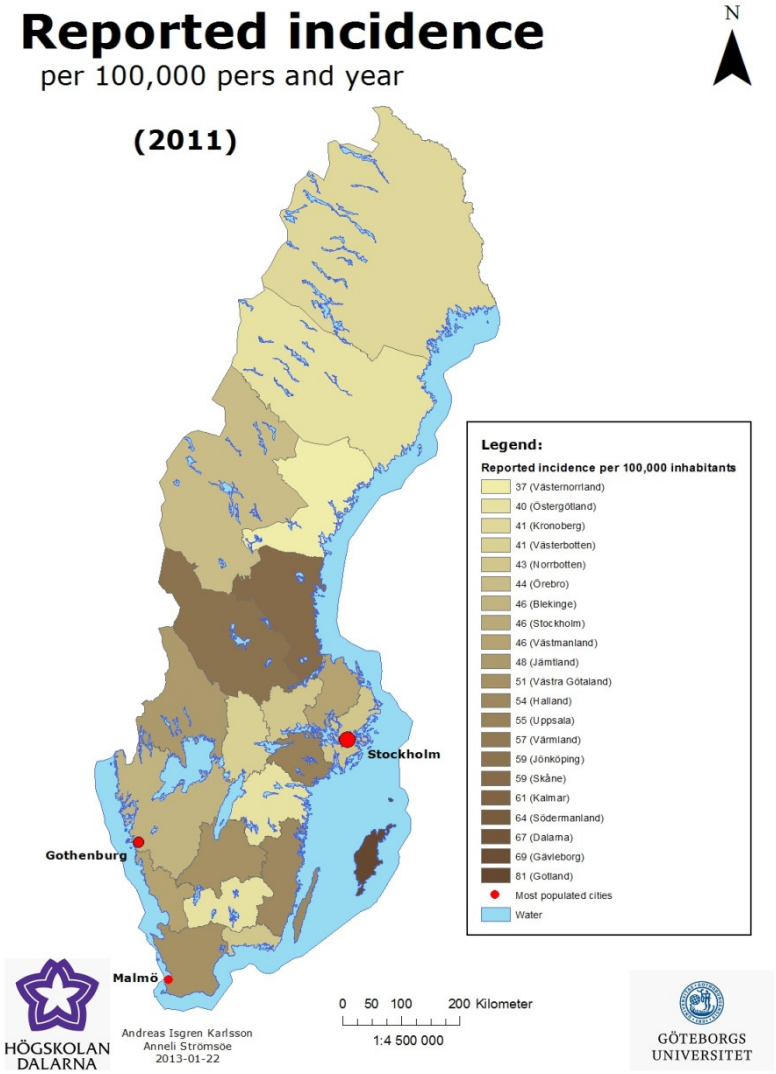

Figure 10. The number of reported OHCAs per 100,000 inhabitants and year, in 2011.

4.4 Prospective and retrospective data (II, III, IV)

When comparing prospectively and retrospectively reported data in the western Sweden (1.5 million inhabitants), Dalarna (279,000 inhabitants) and Stockholm (2 million inhabitants) in 2009 based on EMS medical records

and OHCAs reported to the SCAR, it was found that 23%, 30% and 15% respectively were not prospectively reported (II).

In 2008 to 2010 in Paper III, 3,198 OHCAs were reported to the SCAR, of which 2,398 were reported prospectively and 800 retrospectively. As a result, 25% were not reported prospectively (missing rate) to the SCAR. These analyses were based on the three counties (Västra Götaland, Skåne and Dalarna).

In 2011, 4,904 OCHAs were reported to the SCAR and the reported missing rate was 26% (n=1,279) which were reported retrospectively (IV).

4.5 Gender and age (Papers II–IV)

One third of all OHCA patients were women with the highest reported percentage in Östergötland - 41% (based on counties) (II). There were small changes in the distribution of gender over time (30% in 1992 and 32% in 2011) (2011) (V).

The median age was lower in Stockholm, Gothenburg and Malmö than in the other counties. The median age of an OHCA patient varied from 67 years to 77 years (based on counties, p=0.003 (II). In Paper III, the prospectively reported OHCA patients were younger than the retrospectively reported OHCA patients. The median age did not change over time from 1992 (67 years) to 2011 (67 years) (IV).

4.6 Location of OHCA (II–IV)

The proportion of OHCAs which took place at home varied from 56% to 73% (based on counties) (II). There were no significant differences in prospectively versus retrospectively reported OHCAs (66% vs. 69% took place at home) (III).

4.7 Time of day, day of week and month (III–IV)

There were no significant differences with regard to time of OHCA when prospectively and retrospectively OHCA patients were compared (III). In Paper IV, 35% of OHCAs in the retrospectively reported group took place in October – December, whereas only 24 of the prospectively reported OHCAs took place during these months ($p<0.0001$).

4.8 Etiology (II–IV)

A cardiac etiology, when analysed per county, varied from 43% to 93% and was more common in less densely populated areas (p=0.0015) (II). A cross-check of prospectively and retrospectively reported data for the time period 2011 revealed a lower rate of a cardiac etiology in the retrospectively reported OHCA group (50% versus 67%; p<0.0001) (IV).

4.9 Witnessed/non-witnessed status (II–IV)

The proportion of witnessed cases varied from 63% to 100% (II). There were no differences between prospectively and retrospectively reported OHCAs in terms of witnessed cases (III). From 1992 to 2011, there was a change in witnessed status over time. Crew-witnessed OHCAs increased from 10% to 15% (p<0.0001). Bystander-witnessed OHCAs decreased from 55% to 53% (p<0.0001) and non-witnessed OHCAs decreased from 35% to 32% (p=0.0003) (IV).

4.10 Bystander CPR (I–IV)

Bystander CPR increased from 31% in 1992 to 55% in 2007, p<0.0001 (I). In the same time period, among patients with a witnessed OHCA, the proportion who received bystander CPR increased from 40% to 59% (I). Furthermore, among patients who received bystander CPR, the proportion of lay persons who performed CPR increased from 66% to 77% (p<0.0001) (I). The proportion of patients with a non-witnessed OHCA who received bystander CPR increased from 22% to 51% (I). The proportion of patients with a bystander-witnessed OHCA who received CPR prior to the arrival of the EMS varied between regions from 49% to 79% (II). In sparsely populated areas, more patients received bystander CPR than in highly populated areas (p=0.038) (II). In Paper III, bystander CPR was more common in the prospectively reported group than in the retrospectively reported group (p=0.023). Among patients with a bystander-witnessed OHCA the proportion who received CPR prior to the arrival of the EMS increased from 40% (1992) to 71% (2011) (p<0.0001). Among patients with a non-witnessed OHCA there was a corresponding increase from 22% to 63% (p<0.0001) (IV).

4.11 Delay (II–V)

There were no differences in the delay from collapse to call between the prospectively and retrospectively reported groups (III). However, in Paper IV the median delay between collapsing and calling for the EMS was shorter in the retrospectively reported group (1 minute versus 3 minutes) ($p<0.0001$). Over time from 1992 to 2011, there was a decrease in the median delay from collapse to call from five to two minutes among patients with a bystander-witnessed OHCA ($p<0.0001$).

The median delay between dispatching the EMS to the arrival of the EMS at the patient's side (EMS response time) varied, depending on population density, from six to 11 minutes. The less densely populated areas were, the longer the EMS response time ($p<0.0001$) (Paper II). There were no differences in EMS response time between the prospectively and retrospectively reported groups (III). From 1992 to 2011, the median EMS response time increased from six to nine minutes ($p<0.0001$) (IV).

There were no differences in the time from calling for the EMS to first defibrillation between prospectively versus retrospectively reported OHCAs (III). Among bystander- and crew-witnessed cases, there was a decrease in the median time from collapse to first defibrillation, from 12 to 11 minutes, $p<0.0001$ (IV).

4.12 Shockable rhythm (II–IV)

VF/VT varied from 17% to 60% (II). There was no difference in the proportion of patients found in a shockable rhythm when prospectively and retrospectively reported patients were compared (III). Among all patients, the proportion of patients found in VF/VT decreased from 35% in 1992 to 25% in 2011 (IV).

4.13 Survival (II–IV)

4.13.1 Hospitalised alive (III, IV)

There were no differences in the proportion of patients hospitalised alive between the prospectively reported group (23.6%) and the retrospectively reported group (20.7%) (III). The proportion of patients who were brought alive to a hospital ward increased from 15% in 1992 to 22% in 2011(IV).

4.13.2 Survival to one month (II-V)

Survival to one month differed from 2% to 14% in various counties during the time period 2008 to 2009. There was no significant association between population density and survival (II). Survival to one month was higher in the retrospectively reported group (11.9%) than the prospectively reported group (9.2%; p=0.035) (III). However, in 2011, there was no significant difference in survival to one month between prospectively and retrospectively reported patients (IV). The overall survival to one month increased from 4.8% (1992) to 10.7% (2011) ($p<0.0001$). The most marked increase in survival was found among patients found in a shockable rhythm from 12.7% in 1992 to 31.6% in 2011 ($p<0.0001$) (IV). Among patients who were brought alive to a hospital ward the survival to one month increased from 33% in 1992 to 48% in 2011 ($p<0.0001$) (IV).

The total number of reported survivors was 124 in 1992 and this number increased to 516 in 2011. The number of survivors per 100,000 inhabitants and year increased from 1.4 in 1992 to 5.6 in 2011. In 2011 the number of survivors per 100,000 inhabitants/year varied between counties from 1.2 to 8.9 (IV).

In Paper V the delay was based on speculated time reductions. From collapse to call for EMS estimations showed that, if the time from calling was 0-2 minutes after collapse in all patients, 87 lives could be saved every year. Furthermore, estimations showed that, if CPR was started within two minutes after collapse in all patients, 218 lives would be saved. If the first defibrillation was performed within five to eight minutes after collapse in all patients, 199 lives could be saved.

4.14 Post-resuscitation care (IV)

In 2008 - 2011, among patients who were brought alive to a hospital ward, 41% underwent therapeutic hypothermia and 28% underwent PCI.

4.15 Cerebral function according to the CPC score (V)

In a subset of survivors, the distribution according to estimated cerebral function at discharge from hospital showed that 83% had CPC 1 and 11%

had CPC 2. Survivors found in a shockable rhythm had a better CPC score than survivors found in a non-shockable rhythm.

5 DISCUSSION

This thesis is based on observational studies in all five papers. The most important finding is an improvement in survival after OHCA in Sweden and more aggressive responsive reporting to the SCAR.

Methodologically, the size of the samples has varied, as has the representativeness of the samples. Moreover, the representativeness has become stronger during the time this thesis was written. The variation in the frequency of reported OHCAs might have influenced the results towards bias, but in the end, there is more reliable, valid data from which more robust conclusions can be drawn. However, when significant results are found, it is important to convert them to realistic clinical implications.

5.1 Findings

Is the Swedish system for education in CPR an optimal system?

The Swedish CPR education programme was intended to reach a large population with the aim of educating rescuers in CPR. When the training material was prepared at the beginning of the 1980s, the aim was to educate both lay people and medically educated individuals. Another important goal in the education programme was to implement the cascade principle, which turned out to be unique and necessary for the success of the Swedish CPR education. Using the cascade principle, a large number of rescuers have been educated in CPR. This has become an invaluable resource, thanks both to medically educated rescuers in hospitals and to lay rescuers outside hospital. Furthermore, this education has become more accessible due to the reduced training time. Looking forward, central aspects to take into account are both the quality of the CPR education and the performance in CPR. Now that the quality of CPR education and the performance in CPR is under greater control, it could call the Swedish CPR education programme an optimal system for education in CPR (99-103). A model of this kind might very well become a standard which other countries will attempt to mimic.

Which are the key target groups for CPR in the future?

It is a well-known fact that the early start of CPR increases the chance of survival (88, 104-107). When an OHCA occurs outside hospital and before the arrival of the EMS, someone has to start CPR. Today, in the Swedish counties, first responders such as the fire brigade are often on the scene before the arrival of the EMS. They have a major mission in society. Other target groups which have the potential to start CPR prior to the arrival of the EMS include the OHCA victims' relatives. As most OHCAs occur at home and, if a wife or husband witnesses the collapse, it is essential that they are educated in CPR (75). At present, all the elementary schools in Sweden have an opportunity to obtain knowledge on how to educate their pupils in CPR. Unfortunately, not all schools educate their pupils in CPR. Consequently, a great deal of work remains to be done in order to persuade teachers and the school organisations to make CPR education a matter of routine.

A previous study has shown that, the majority of OHCAs occur at home (73). If the OHCA is not witnessed and occurs at home, it is more or less impossible to obtain a higher survival rate if the victim is found at a later stage. A previous study reported a higher mortality rate for OHCAs witnessed at home and suggested that education for spouses might increase survival among patients who suffer an OHCA at home and have a cardiac aetiology (108). Studies in this thesis, do not have data on whether the non-witnessed OHCA victims were alone at home when the OHCA took place. Unpublished data have shown that, when the home-care staff have found a non-witnessed OHCA at home, an estimate of the time of the collapse was often made and this resulted in unsafe documented data on the OHCA. A recent study indicated the usability of lay people in public areas in combination with a mobile phone positioning system (64). The use of a mobile phone positioning system could be more common in the future with the aim of and as a tool for achieving a rapid response from call to CPR and/or defibrillation.

However, which is actually the target group for CPR education? With knowledge of the two links at the beginning of the chain of survival, everyone could theoretically be trained in CPR in order to produce a rapid call to a dispatch centre and a rapid start of CPR.

Was the vast number of rescuers educated in CPR expected from the start?

Since the CPR education programme was initiated in Sweden, the training of rescuers in CPR has continued on a year-to-year basis. Holmberg, the leader of the Swedish Society of Cardiology during the 1980s, did not forecast the remarkable development in CPR education in Sweden (S. Holmberg, personal communication). The CPR organisation that has built up CPR education in Sweden worked on a voluntary basis from the very start and was therefore not centrally controlled. The lack of a centrally controlled function without central transparency has resulted in both the strengths and weaknesses of the CPR education register. The main strength is the large number of trained rescuers since the first education programme in CPR due to the use of the cascade principle. The main weakness is the general inability and lack of opportunity to follow up the educated rescuers (109).

How were the epidemiological characteristics distributed between the regions in Sweden?

The distribution of gender and age was relatively similar in all the counties but one (II). Previous studies have shown that about a third of all OHCAs involve women in whom CPR is attempted (20, 21). In one county (Östergötland), a higher percentage of female OHCAs were found. This could depend on bias in reporting to the SCAR. According to Statistics Sweden, the distribution of age and gender is fairly similar between the counties in Sweden(110).

This is the first time that OHCA data in Sweden were retrospectively searched in order to ascertain whether the reported incidence reflects the actual incidence (III). When comparing cases which were not prospectively reported with those that were, significant differences were found in some of the reported variables. The retrospectively reported OHCAs were older, had less bystander CPR and higher survival. When it comes to the higher age of the retrospectively reported OHCAs, there is no obvious explanation for this finding. At present, the population in Sweden is getting older. The 65 to 79 age group is one subgroup that is increasing in numbers. According to the National Board of Health and Welfare, about 300,000 people who are 65 or older and are in need of health care and social care (25). To return to the question, the non-prospectively reported OHCAs might involve this subgroup which has been treated by both bystanders and the EMS crew. Ageing and

co-morbidity might be a reason why the EMS crew did not report these cases in the belief that they did not fulfil the inclusion criteria. Perhaps some of the very old patients received CPR from the EMS crew for a very short time and the EMS crew therefore decided not to report the case. This is in accordance with a previous study (111).

A higher proportion of OHCAs with a cardiac aetiology was found in the less populated areas (II). Otherwise the patient characteristics were relatively similar when related to population density. A lower proportion of OHCAs with a cardiac aetiology in more populated areas could perhaps indicate that the OHCAs were more frequently caused by trauma, intoxication or suicide in these areas. A higher proportion of OHCAs with a cardiac aetiology was found in northern Sweden, which also represents the more sparsely populated areas. The higher proportion of cardiovascular disease is in agreement with a previous report by the National Board of Health and Welfare (25).

Was the correct number of patients with OHCAs in Sweden included in whom resuscitation was attempted in 2011?

There might be some questions about the collected sample with regard to the inclusion criteria. A definition of a treated OHCA is: "Treatment was initiated by a bystander or the EMS crew". These cases should be reported to the SCAR. When definite signs of death such as rigor mortis are present, these cases should not be reported to the SCAR, even if CPR was attempted. If the OHCA was reported to the SCAR and the EMS crew did not continue after arrival due to definite signs of death, the OHCA case was removed from the database and was therefore not included in the analyses.

Despite these corrections, there are reasons to assume that there are still some OHCA cases which were not reported to the register. In some counties, such as Västernorrland and Blekinge, the number of reported cases per 100,000 inhabitants and year is so low that it is, most likely, that some cases are not reported.

How well validated are the reported OHCA data in the SCAR?

One important aspect is that the incidence of OHCA is correctly described by gathering knowledge about the representativeness and when conclusions

about research results should be drawn. Previous studies have shown a variation in the reported incidence of OHCA (22, 27, 28, 32). Every year Swedish OHCA reports have shown a variation in OHCA reporting from each county. This has led to a validation process (III-IV) that has been performed to validate the incidence of OHCA in each Swedish county. As a result of the validation process (III-IV), the data on the incidence of OHCA could currently be more reliable.

Furthermore, there is recommendation about the way the OHCAs should be reported in a uniform way from both a national and international perspective (1, 2). This enables the data to be compared in a similar way and the OHCA data are measured in a reliable way. In Paper II, a comparison was made between the documentation of the source data and register data with the aim of investigating the agreement between the documented variables. This was a small sample and, in the future, it is important to continue to validate the individual variables between the source data and register data to determine whether the content of the documentation was equal. This is consistent with previous research (112, 113).

It has to be remembered that the EMS systems in Sweden have different medical records in different counties. A search template was created for use by specifically trained persons when the data were searched retrospectively (III-IV). It is important to take account of the fact that there might be some differences in the search procedure between the various specifically trained individuals. Although clear instructions on how to search for OHCAs were issued, some of these trained individuals may not have followed them.

Why do the EMS crews not report all OHCA cases in which CPR was attempted to the SCAR?

The incidence of OHCA reported to the SCAR has varied and the total missing rate was 25% (III). One theory about the missing OHCAs was that, if the OHCA occurred during the night, there was a greater risk that the EMS crew would forget to report it due to tiredness. Another aspect could be new employees who are not familiar with the routine for reporting to the SCAR. A previous study has found that if the EMS is controlled by a county council or a private company might be of importance for the reporting to a register (114). Moreover, in some OHCA cases when the EMS crew witnessed an OHCA with VF as an initial rhythm, these cases might therefore be assessed as something other than a true cardiac arrest. This is in agreement with a

previous study (115). There are no precise explanations as to why the EMS did not report the OHCAs to the SCAR.

However, based on the findings from two of the studies (III, IV), an overview was made of the reported incidence of both prospectively and retrospectively reported OHCA in 2011 and 2012 (Table 6). This overview indicates that there was an increase in OHCAs reported by the EMS crew (prospectively) to the SCAR from 2011 to 2012. When comparing prospectively reported OHCAs between 2011 and 2012, Stockholm was excluded due to the incompleteness of reporting (Table 7). This comparison has not been analysed statistically and has never previously been published.

Table 6. The reported incidence of prospectively and retrospectively OHCAs in 2011 and 2012 (28/3/2013).

County	Population	Reported incidence 2011				Reported incidence 2012 (2013-03-28)			
		n			per 100 000 inh	n			per 100 000 inh
		Prospective	Retrospective	Total		Prospective	Retrospective	Total	
Stockholms län	2 091 473	471	499	970	46	64	0	64	3
Uppsala län	338 630	150	39	189	56	155	0	155	46
Södermanlands län	272 563	160	15	175	64	178	0	178	65
Östergötlands län	431 075	171	-	171	40	182	0	182	42
Jönköpings län	337 896	165	33	198	59	159	0	159	47
Kronobergs län	184 654	69	6	75	41	73	0	73	40
Kalmar län	233 090	142	0	142	61	170	0	170	73
Gotlands län	57 308	39	7	46	80	28	1	29	51
Blekinge län	152 979	64	6	70	46	84	0	84	55
Skåne län	1 252 933	379	364	743	59	472	29	501	40
Hallands län	301 724	146	18	164	54	147	0	147	49
Västra Götalands län	1 590 604	707	112	819	51	767	2	769	48
Värmlands län	272 736	134	22	156	57	140	0	140	51
Örebro län	281 572	103	20	123	44	106	0	106	38
Västmanlands län	254 257	97	21	118	46	105	0	105	41
Dalarnas län	276 565	126	59	185	67	164	0	164	59
Gävleborgs län	276 130	140	51	191	69	151	0	151	55
Västernorrlands län	242 155	91	-	91	38	78	0	78	32
Jämtlands län	126 299	60	-	60	48	51	0	51	40
Västerbottens län	259 667	99	18	117	45	117	0	117	45
Norrbottens län	248 545	108	3	111	45	118	0	118	47
Total	9 482 855	3 621	1 293	4 914	52	3 509	32	3 541	37
Total (Stockholm excluded)	7 391 382	3 150	794	3 944	53	3 445	32	3 477	47

Table 7. The proportion of reported OHCAs in 2011 and 2012.

County	Prospective reported incidence	
	2011/total 2011 [%]	2012/total 2011 [%]
Stockholms län	49%	7%
Uppsala län	79%	82%
Södermanlands län	91%	102%
Östergötlands län	100%	106%
Jönköpings län	83%	80%
Kronobergs län	92%	97%
Kalmar län	100%	120%
Gotlands län	85%	61%
Blekinge län	91%	120%
Skåne län	51%	64%
Hallands län	89%	90%
Västra Götalands län	86%	94%
Värmlands län	86%	90%
Örebro län	84%	86%
Västmanlands län	82%	89%
Dalarnas län	68%	89%
Gävleborgs län	73%	79%
Västernorrlands län	100%	86%
Jämtlands län	100%	85%
Västerbottens län	85%	100%
Norrbottens län	97%	106%
Total	74%	71%
Total (Stockholm excluded)	80%	87%

During 2011, all EMS systems (n=11) in Dalarna (279,000 inhabitants) were visited, once at a time, at a working place meeting and were given feedback about their efforts in connection with treatments of the OHCAs. Previous research has shown the importance to give the staff oral feedback instead of a written report (116). However, the aim was to investigate if the given feedback about the OHCAs could have an effect on the reporting rate to the SCAR. The compared time periods were 2010 and 2011. The data has not yet been analysed and therefore not been published.

In 2011, the reporting of OHCA per 100,000 inhabitants and year was highest 69 (Gävleborg), 67 (Dalarna) and the lowest 37 (Västernorrland).

Is a golden standard available for finding missing cases in an OHCA register?

When the search process was initiated, to obtain knowledge of the OHCA incidence in Sweden, no previous experience was available to enable it to be performed in a reliable, valid way. Surprisingly, no information was available in the literature. Information was searched which was related to national quality registers other than the SCAR. Information was found in a previous study which provided advice on the process of reporting to a register but no data on how to find missing cases (81). The efforts should be regarded as a pilot study with regard to the search process. Since there are several EMS medical record systems in Sweden, the search template needs to be developed and repeated in future studies.

At present, this search process should probably be regarded as the golden standard, at least in Sweden, for searching for OHCA data which have not been reported to the SCAR.

What are the main differences in term of factors at resuscitation between regions in Sweden?

In one of the studies (II), there was a higher overall frequency of CPR prior to the arrival of the EMS in less populated counties compared with urban areas. This should imply a greater chance of survival. Further, the longer EMS response time in rural areas is another important resuscitation factor. If the EMS response time is longer, survival is lower, due to the delay in

administrating advanced CPR. This means that counties with a low population density should have a poorer chance of survival. There is no knowledge about whether there is an association between the EMS response time and the prevalence of CPR prior to the EMS arriving on the scene. The organisation of the EMS system in Sweden varies between counties. Most of the EMS systems are controlled by county councils, while a few EMS systems are controlled by private companies. All EMS systems have an obligation to follow treatment guidelines drawn up by a Swedish association working group (78). Adherence to guidelines is poorly controlled in Sweden. It is therefore not known whether the treatments are equal in all counties. Based on this knowledge, is the opportunity for equal health care impossible? According to the National Board of Health and Welfare, there is a vision that equitable care should be available to all the inhabitants in Sweden (25). However, with information based on these studies, there is no opportunity to draw conclusions in this area.

If an OHCA occurs near a hospital in Sweden, the EMS crew is more likely to deliver a patient with ongoing CPR to the emergency department staff than it is if the OHCA occurs further a way from hospital. However, there might be some differences between counties when it comes to deciding when the ongoing treatment of OHCA should be withheld. On the other side, previous research has shown that a too early decision to initiate the transport of the OHCA might contribute to a poorer quality in the CPR (117). In principle, it might be more convenient to deliver the patient to the emergency department and hand over the responsibility for continuing or not continuing CPR to a physician.

Finally, the hospitals in Sweden have different post resuscitation care alternatives. For example, some hospitals do not have facilities for coronary angiography. It has been suggested that both therapeutic hypothermia and PCI could be vital actions for obtaining higher survival (69). In some Swedish hospitals it is not possible to obtain this kind of health care.

Why is there a continuous increase in CPR prior to EMS arrival in Sweden?

For the past 20 years, there has been an ongoing increase in CPR prior to EMS arrival in Sweden (60). Since training in CPR in the community was started, the number of citizens educated in CPR has increased. The education programme in CPR has probably become easier to assimilate due to a shorter

training time and it is therefore more practical to implement for both medically educated persons and lay people. Improved reporting to the SCAR might be another contributory factor, but the CPR training register is also a potential contributor. The CPR training register can show the annual number of rescuers educated in both CPR and the more specific parts of CPR, such as advanced CPR, child CPR and so on, and it could therefore act as a kind of feedback system for the people who are educated in CPR.

Another mechanism behind the increase in CPR prior to EMS arrival might have something to do with information to society. Today, it is more common for private companies to offer services such as education in CPR and how to handle an automated external defibrillator (AED), regardless of whether people are medically educated or are lay persons, compared with a few years ago (118).

In some of the regions in Sweden, the fire brigade and sometimes even the police are dispatched simultaneously with the EMS. They often arrive on the scene before the EMS and can then start CPR (61).

In recent years, the organisation of the Swedish Heart-Lung Foundation, has invested in this research area by providing information about OHCA to both the public and health care providers. In collaboration with cardiac arrest research leaders in Sweden, the foundation has initiated several projects with the aim of increasing the activity in the community in terms of an early start of CPR (61).

Another aspect of increasing CPR prior to EMS arrival could be a person's attitude to initiating CPR. In a previous study, young people aged 16-19 were motivated to perform bystander CPR (119). This is in accordance with another study that presents willingness to perform CPR on a wife/husband with heart conditions (120). In another study, bystanders were more willing to perform CPR in rural areas than urban areas (121). Furthermore, there is a recommendation on how to reduce barriers and thereby increasing people's willingness to perform CPR (122, 123).

What should be the ultimate goal for bystander action in bystander-witnessed OHCA?

There is always a race against time in an OHCA situation, where each minute is of the utmost importance. So the optimal situation when a bystander

witnesses an OHCA is to call the dispatch centre, after which CPR is initiated by the witness before the EMS arrival and at best within the first two minutes after collapse (62, 89) (104, 106, 123, 124). In addition to this the presence of an AED is of major importance for further increasing the chance of survival (61-63, 125-127). Today, it is more common to find AEDs or a Public Access Defibrillator (PAD) in public locations and it is easier for everyone to use them while waiting for the EMS (128). Another vital aim is that every potential rescuer in CPR should have a quality indicator device on hand in order to acquire knowledge about the quality of the CPR (100). This has not yet been put into practice.

At present, the Swedish AED registry has been initiated with the aim of providing information about where to find a PAD when an OHCA occurs. The Swedish AED registry is based on voluntary participation, providing PADs in both private and public environments. In the future, the alarm centre in Sweden could be a part of this register, and could co-operate and localise an AED for a caller when a PAD is needed (129).

Which were the main reasons why an association between population density and survival after OHCA not was found?

In general, the interregional variability in terms of various items in the register was minor. It is difficult to find obvious reasons for the lack of association between population density and survival. Perhaps the variables that differed significantly between regions counteracted each other. It has been indicated that the survival in mid-size cities had the best response times and survival rates (130, 131). The distribution of the population varies in Sweden and a more urban population is found in the largest cities and also along the west and east coast of the country. The inland counties are more sparsely populated. One hypothesis was that survival would be lower in the less populated areas due to limited health care resources. This hypothesis was not confirmed.

In one of the studies (II), the distribution of two factors favored survival in less populated areas, since both CPR prior to the arrival of the EMS and a cardiac aetiology were more frequent in these areas. On the other hand, the longer EMS response time in these areas probably acted as a counteracting factor. This has also been determined in an earlier study (132).

It may also be that factors that are not recorded in the SCAR influence the results.

Why was survival higher and bystander CPR lower among patients who were not prospectively reported to the register?

The most striking finding in one of the studies was that there was higher survival among the retrospectively reported OHCAs (III). Due to the data collection and the information flow, it was discovered that the higher survival could be explained by OHCA patients who were defibrillated by the EMS crew. This is in agreement with a previous study (40). It is only possible to speculate about why these patients were not prospectively reported to the SCAR. On many occasions, these cases are uncomplicated and may not be regarded as genuine cardiac arrests by the EMS crew. With this information, it became obvious that no bystander CPR was involved, as these cases were crew witnessed and the EMS crew therefore initiated CPR.

The explanation of why the proportion of bystander CPR was lower despite higher survival could be that the OHCA in these cases was witnessed and treated by the EMS crew and, as a result there was no role for the bystanders.

This is the first time in Sweden that regional population density has been related to survival after OHCA. Since the reporting to the SCAR has varied between counties, it is recommended that some caution should be shown before drawing any firm conclusion. There is a risk of bias and these data need to be confirmed in further studies.

What were the main reasons for the increase in survival over time in Sweden?

The results indicate an improvement in all four links in the chain of survival and this is most probably the most important mechanism behind the increase in survival that was found. This is in agreement with previous reports (58, 133, 134).

Today in Sweden there is a shorter time between collapsing and calling for the EMS than there was 20 years ago. The first link is most probably a major determinant of outcome after OHCA (59). The second link highlights the

early start of CPR. It is of the utmost importance that CPR is initiated as early as possible and, if necessary, this includes defibrillation (60, 61, 77, 135). Without the immediate start of CPR, the chance of surviving falls dramatically (60). Further, the rapid ways of defibrillating by bystanders and/or the EMS crew will help to increase survival (40).

However, one negative experience is the increase in the EMS response time throughout Sweden. At present, it is not know why the EMS response time is increasing. It is only possible to speculate that the contributory factors are an increase in traffic density, regardless of whether urban or rural areas are involved, different ways of organising the use of the EMS vehicles, limited EMS resources, the way the EMS is dispatched and so on. This has been discussed in another study (136). The link which probably affected survival the most is the fourth i.e. post-resuscitation care.

In this study, data on post-resuscitation care have only been available since 2008. Based on previous studies, therapeutic hypothermia and PCI are currently routine in-hospital treatments in defined subsets of patients in hospitals which have the capacity to offer treatments of this kind (68-70, 137, 138). However, from a national perspective there are limitations with regard to the speed with which patients can be offered therapeutic hypothermia and PCI. In many counties, there is only one hospital that is able to offer such treatment. However, in more urban counties like Stockholm, Västra Götaland and Skåne, there is more than one hospital that is able to offer these treatments.

Finally, it is important to highlight the fact that the increase in reporting to the SCAR is still ongoing. From a theoretical point of view this might influence survival to some extent.

Why is it a variation in survival between the counties?

There is variability in survival between the counties. The variability in survival might depend on inadequate reporting to the SCAR resulting in inadequate data on survival.

However, there are other aspects that might contribute to the variability in survival. Whether the OHCA was witnessed or non-witnessed might be a crucial factor for survival, according to previous research (94, 139). In one of

the studies (II), no variation was found in the witnessed status, regardless of whether the witness was a bystander or the EMS crew.

Bystander CPR is important when it comes to increasing survival (135). There was a difference between counties in the proportion of patients who received bystander CPR and this might affect survival. It was found that patients with OHCA in areas with a low population received more bystander CPR than those in urban areas (II). This might result in a higher survival in the sparsely populated counties.

There are two further factors that might affect survival - first, if the delay from collapse to the arrival of the EMS was short and, second, if the initial rhythm was shockable (140, 141). It was found that, with a decreasing population density, there was an increase in the response time taken by the EMS to reach the patient. This might result in delayed post-resuscitation care by the EMS. In these situations, bystanders and possibly a PAD have an important role to play in initiating treatment before EMS arrival (61).

Further, it was found that survivors after OHCA were not reported to the SCAR. Some of these cases had occurred at a health centre. These patients are initially treated by the health-centre staff. When an OHCA occurs at a health-centre, the EMS crew is dispatched with the primary aim of delivering the patient to the nearest hospital for post resuscitation care and, for this reason, the EMS crew is responsible for reporting the OHCA to the SCAR. In some cases, this was forgotten and this might therefore be an additional reason for a variation in survival between counties.

In addition, in the most populated Swedish county, Stockholm, data is available (not yet published) from the time period 2004 and from 2007 to 2009 about the survival regarding the OHCAs in the inner city. The data showed that the survival was 25% versus 15%, in the remaining county (Stockholm). It was also shown that the delay time from collapse to the arrival of the EMS was shorter (three minutes) in the inner city than the remaining county. However, when comparing the survival, the county of Stockholm to the rest of Sweden over time (from 1992 to 2011) the data showed that the survival was similar to each other (Figure 11).

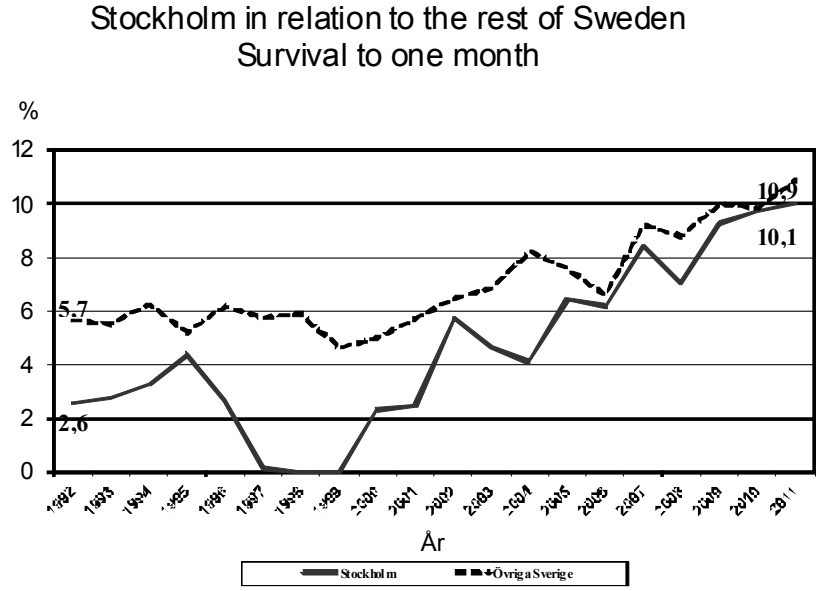

Figure 11. The proportion of survival of reported out-of-hospital cardiac arrest, the county of Stockholm in relation to Sweden from 1992 to 2011.

Is the CPC score an adequate reflection of cerebral function among survivors of OHCA?

Due to the short data collection period, there is a limited opportunity to draw conclusions about whether the CPC score is good enough to determine cerebral function. Based on one previous study and also according to the CPR guidelines there are recommendations that the CPC score should be used to determine cerebral function after a cardiac arrest, regardless of whether the OHCA occurred outside hospital or in hospital (142, 143). The question of whether the CPC score is compatible with activities of daily living or with other expressions of quality-of-life-assessment has been the subject of debate (144, 145). At present, it can only be estimated that about 90% of the survivors appear to have good or relatively good cerebral function. Unfortunately, this does not provide information about whether the

same proportion is able to manage the activities of daily living. However, right now, work is ongoing in Sweden which aims to contact all OHCA survivors and obtain information about various aspects of quality of life three to six months after collapse. A larger amount of data has to be collected and analysed before conclusions can be drawn about the cerebral function and quality of life among survivors of OHCA (103).

Are the goals in terms of delay to treatment after OHCA realistic?

The question of whether or not the goals in terms of delay to treatment can be realised is a difficult one. Firstly, the information on delays is often not very precise. Sometimes, the information on delays is an overestimation and sometimes it is an underestimation. With assistance from the EMS crew, bystanders and Swedish society, these goals should be possible to realise, but there will always be exceptional cases in which the goals cannot be realised. There could be economic limitations and the Swedish counties could have different views on and priorities for health care.

At present in Sweden, there are a large number of alarm operators who are responsible for dispatching the EMS crews. This requires uniform guidelines, on how to dispatch the EMS and make the terms equal for all Swedish counties.

Ongoing research projects have determined the importance of where PADs should be localized (61, 146). Previous studies recommended that PADs should be placed in areas with frequent OHCAs (147) while others have recommended the more general distribution of PADs (148). In order to achieve a reduction in the delay to defibrillation, it is important to consider where a PAD should be placed and/or how the first responder should act in each county in Sweden to provide both CPR and defibrillation within a reasonable time.

How should each of the goals be realised?

A previous study has highlighted the importance of minimising the delay between collapsing and calling for the EMS (59). To implement this reduction in delay, society, including both laypeople and medically educated citizens, needs to obtain information about the importance of rapidly dialling

112 to obtain professional help from the dispatcher as well as the EMS crew, if an OHCA is suspected. Furthermore, it is also important to provide ongoing mass education in CPR to people of all ages. For some time in Sweden, the focus has been on educating school children and making it a natural routine to have a knowledge of CPR (149). Other projects, such as Mobile Lifesaver Service /Mobile Responders and SAMS (Saving More Lives in Sweden) are currently helping to reduce the delay to calling for the EMS, and starting CPR and defibrillation by calling nearby laypersons, the fire brigade and the police to the scene (64). If more actions of this kind were distributed throughout Sweden, it would probably be easier to realise the previously mentioned objectives. These projects are particularly important when it comes to rapid start of CPR and rapid defibrillation.

Which of the three goals will be most problematic to realise?

When an OHCA occurs, it is sometimes difficult to determine whether or not there are signs of breathing. This could make it more difficult for the alarm dispatcher to interpret the caller and decide whether or not an OHCA is involved (150). As soon as possible after the dispatcher perceives that an OHCA has occurred, it is essential to provide telephone CPR (151). This is a critical moment for the dispatcher to determine whether or not CPR should be initiated.

At present, the delay from collapse to defibrillation should be the most critical goal to realise. This is because AEDs are not available everywhere and it is therefore necessary to wait for the EMS. Furthermore the delay can be affected due to the longer EMS response time.

Are there parts of Sweden in which the goals will be particularly difficult to realise?

In one of the studies (V), only witnessed cases were included, but it has previously also been reported that the majority of survivors are found among witnessed OHCAs (94). It therefore depends on where the survivors have been resuscitated. Perhaps some counties are more likely to have a higher survival rate than others and therefore also a more efficient chain of survival. There might be parts of Sweden that are unable to have rapid access to the EMS and the early start of CPR and defibrillation due to inadequate

guidelines within the county. These facilities might differ depending on whether or not the population density is sparse. In one of the studies (II) it has been shown that there is more bystander CPR in sparsely populated areas than urban areas.

Is there an interaction between the three aspects of delay to treatment of OHCA?

In many cases, the estimates of delay to; call, start of CPR and defibrillation could theoretically influence each other. This means that there could be an interaction between these three aspects of delay. In particular, the delay between collapsing and calling for the EMS is often directly related to the delay between collapse and defibrillation, if the patient is defibrillated by the EMS crew. The connection between the delay to the start of CPR and the other two is probably not as strong, as they reflect different things.

5.2 Methodological considerations

When reporting began to the CPR training register in 1983 and to the SCAR in 1990, the reporting frequencies and qualities were relatively poor. The CPR training register started to document data every year from 1989. It is not known how the refresher courses in CPR have been measured and this may therefore have led to the double documentation of some training, but it is also important to remember that there are underestimates of the number of citizens educated in CPR.

There are other organisations, such as the Swedish Civil Contingencies Agency and the Swedish Life-Saving Society, which have educated rescuers in CPR and also reported to the CPR training register. Furthermore, the Swedish Red Cross and other private companies educate rescuers, but these education courses are not reported to the CPR training register and this therefore contributes to the underestimations of the number of rescuers in CPR.

Since the start of reporting to the SCAR, the data quality has become more accurate. This is due to web documentation instead of manual paper documentation in the SCAR. Web registration began in 2008. Before the web-based version became operational, the reporting was done manually from each county and then sent to an evaluation centre in Gothenburg, after which this information was entered into a central database by a single

individual. There was sometimes a delay of up to six months between collapse and reporting the case.

One important weakness that needs to be discussed is the validity of the variables which have been reported. A small sample has been analysed with the aim of comparing whether the variables have been documented in a similar way both in the EMS medical records and in the SCAR. The analyses revealed that the register data were sometimes more complete than the source data (unpublished data).

In Paper III, it was discovered that there was large variability in the reported OHCA incidence between regions in Sweden. This was interpreted as being caused, at least to some extent, by reported cases being missed. The information about the missing reports to the SCAR initiated an information campaign to all Swedish EMS systems, about the importance of reporting to the SCAR and how to do this in the appropriate way.

It is possible to argue about the validity of comparing population density and OHCA incidence. When conclusions were drawn from the data, it became obvious that there are differences in the distribution of the population within a county. Therefore the municipalities were also compared in order to obtain an even more realistic picture of the distribution of the population in relation to characteristics and outcome after OHCA. However, even from a municipality perspective, there is variability in terms of reporting and distribution of the population and therefore a risk of bias in interpretation and conclusions.

Furthermore, in Paper IV, the sample was based on three counties in Sweden and this is probably not representative of the entire country. The retrospective data recordings are mostly limited due to more missing information and inaccuracy in the measurements. The methods for data search differed in the three regions.

As this was the first time this type of method had been used to find OHCAs which were not reported to the register, it is difficult to identify the strengths and weaknesses.

Finally, the calculations in Paper V were only based on witnessed OHCA cases. It should be remembered that there are still a number of OHCA cases which were not included in the analyses.

The weak point in these analyses is that the confounders were not taken into consideration. The strong association that was found between delay to treatment and survival might, for example, be influenced by co-morbidity. There could be several reasons why patients in whom treatment was started at a later stage could have more severe co-morbidity which could partly explain their poorer outcome. It has therefore not been definitely proven that a certain reduction in delay will necessarily increase survival as calculated.

5.3 Ethical considerations

Some patients might raise hesitations to have personal data reported to a register. In the SCAR the social security number and age are documented but never exposed in a result as an individual. One might argue whether it is unethical to report personal information to a register about dead patients without permission by relatives. The relative or other acquaintance has never been contacted to be informed about the documentation in the register.

It is different with the survivors. A project will start all over Sweden within the next few weeks to estimate the quality of life of all survivors in SCAR. Simultaneously, survivors will be informed about the register and that some of their own data are included there.

In principle, patients who are hospitalised in Sweden, receive general information about their inclusion in various quality registers. From an ethical perspective it can be both an advantage and a disadvantage to be informed about ones participation in a quality register. A few patients are not aware of having had a cardiac arrest.

6 CONCLUSION

- Using the cascade principle for CPR education, almost two million rescuers were educated in Sweden from 1983 to 2007. This has resulted in an increase in CPR attempts prior to EMS arrival.

- There was no significant association between population density and survival to one month after OHCA or the incidence of OHCA. However, bystander CPR, cardiac etiology and a longer response time were more frequent in less populated areas.

- Of 3,198 cases of OHCA in three counties in Sweden, 800 (25%) were not reported prospectively by the EMS crews but were reported retrospectively when identified as missing cases. Patients who were reported retrospectively differed from prospectively reported cases by being older, less frequently receiving CPR prior to EMS arrival but having a higher survival rate. Our data suggest that OHCA reports from quality registers which are based on prospectively recorded data may be influenced by selection bias.

- From a long-term perspective, survival after OHCA in Sweden more than doubled. The increase in survival was most marked among patients found in a shockable rhythm and those brought alive to a hospital ward. There were improvements in all four links of the chain of survival, which might explain the improved outcome.

- Based on findings related to the delay to calling for the EMS and the start of CPR and defibrillation, it was speculated that 300-400 additional lives (four per 100,000 inhabitants and year) might be saved after OHCA in Sweden in the future if delays were appropriately reduced.

To summarise, there has been an impressive development in the treatment of patients suffering from OHCAs in Sweden during the last 30 years. Improvements in various links of the chain of survival have resulted in about 500 lives being saved each year in Sweden after OHCA. It suggests that this

figure will increase markedly if delay to the start of treatment can be reduced still further.

7 FUTURE PERSPECTIVES

In this thesis it has been focused on the incidence and outcome of the OHCAs and the usage of register data, the SCAR.

In the future, there will be more research reports about the incidence and outcome of the OHCAs in Sweden. Therefore, a critical factor will be the ongoing reporting of OHCAs to the SCAR. During the time when the thesis was written both EMS crew and specifically trained individuals had reported OHCAs data to the SCAR. In the future, the EMS crew had to increase their ability to report prospectively to the SCAR. To encourage the EMS crew to report, it will be of importance to give feedback about the final outcome and their efforts. This can be accomplished by providing each EMS system with specifically selected data from the SCAR.

Another aspect is to investigate in the validation of register data versus the source data. Are the register data adequately reflecting the source data? In the near future, it will be started, to systematically monitor various EMS systems and evaluate the validity of their register data on OHCAs.

Further on, it is important to shorten the delay – the start of treatment. A better way has to be found, to decrease the delay from the collapse to call – CPR/defibrillation – the arrival of the EMS. At present, there are various projects ongoing in Sweden with its focus to involve the society with the ultimate aim to reduce the delay, in connection with OHCAs. In the future, it is also important to implement positive research results from single counties to all of Sweden with the ambition to achieve equal health care for all patients suffering from OHCAs regardless of where in Sweden you live.

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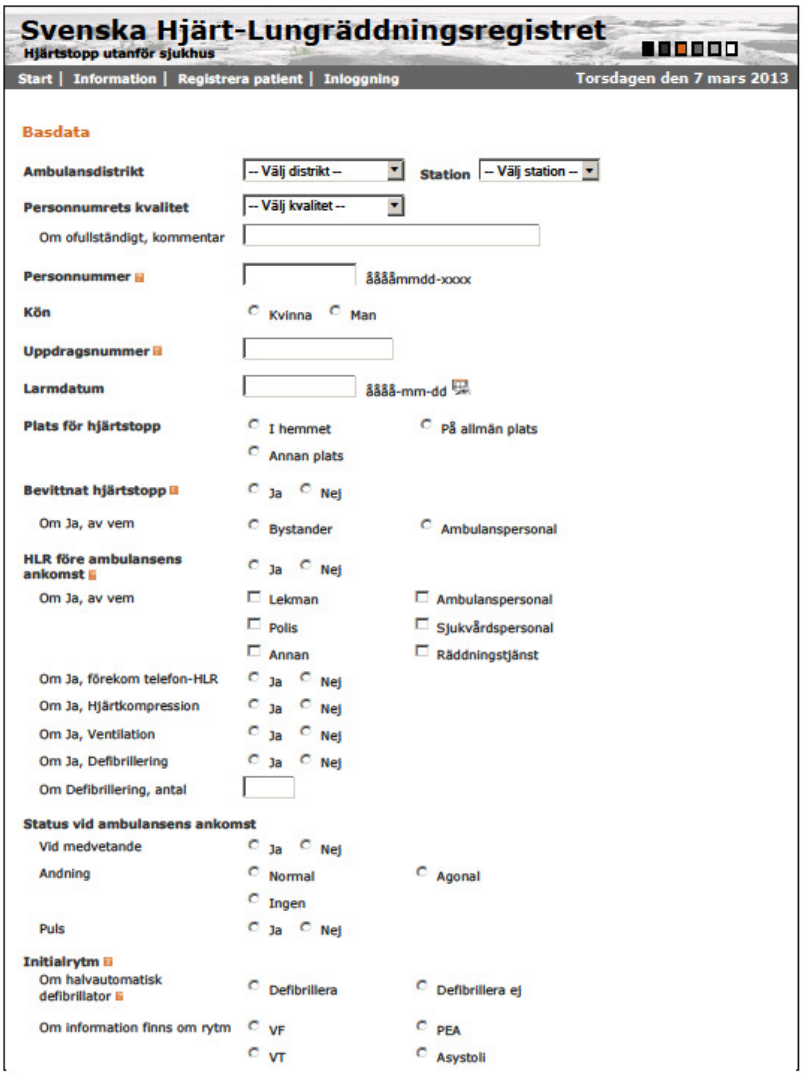
APPENDIX

Appendix I



Svenska Hjärt-Lungräddningsregistret
Hjärtstopp utanför sjukhus

Start | Information | Registrera patient | Inloggning — Torsdagen den 7 mars 2013

Basdata

Ambulansdistrikt -- Välj distrikt -- **Station** -- Välj station --

Personnumrets kvalitet -- Välj kvalitet --

Om ofullständigt, kommentar

Personnummer åååmmdd-xxxx

Kön Kvinna Man

Uppdragsnummer

Larmdatum åååå-mm-dd

Plats för hjärtstopp I hemmet; På allmän plats; Annan plats

Bevittnat hjärtstopp Ja Nej

Om Ja, av vem: Bystander; Ambulanspersonal

HLR före ambulansens ankomst Ja Nej

Om Ja, av vem: Lekman; Ambulanspersonal; Polis; Sjukvårdspersonal; Annan; Räddningstjänst

Om Ja, förekom telefon-HLR Ja Nej

Om Ja, Hjärtkompression Ja Nej

Om Ja, Ventilation Ja Nej

Om Ja, Defibrillering Ja Nej

Om Defibrillering, antal

Status vid ambulansens ankomst

Vid medvetande Ja Nej

Andning: Normal; Agonal; Ingen

Puls Ja Nej

Initialrytm

Om halvautomatisk defibrillator: Defibrillera; Defibrillera ej

Om information finns om rytm: VF; PEA; VT; Asystoli

Troligaste anledningen till hjärtstopp

- ○ Hjärtsjukdom
- ○ Olycksfall
- ○ Kvävning
- ○ Drunkning
- ○ Annat
- ○ Överdos läkemedel
- ○ Lungsjukdom
- ○ Självmord
- ○ Plötslig spädbarnsdöd

Tider

Hjärtstopp	klockslag tt:mm
Larm registrerat	klockslag tt:mm
Larm (utlarmning)	klockslag tt:mm
Start av HLR	klockslag tt:mm
Ambulansens ankomst (bil stoppar klockan)	klockslag tt:mm
Ambulansens ankomst (vid patientens sida)	klockslag tt:mm
Första EKG/rytm	klockslag tt:mm
Första defibrillering	klockslag tt:mm

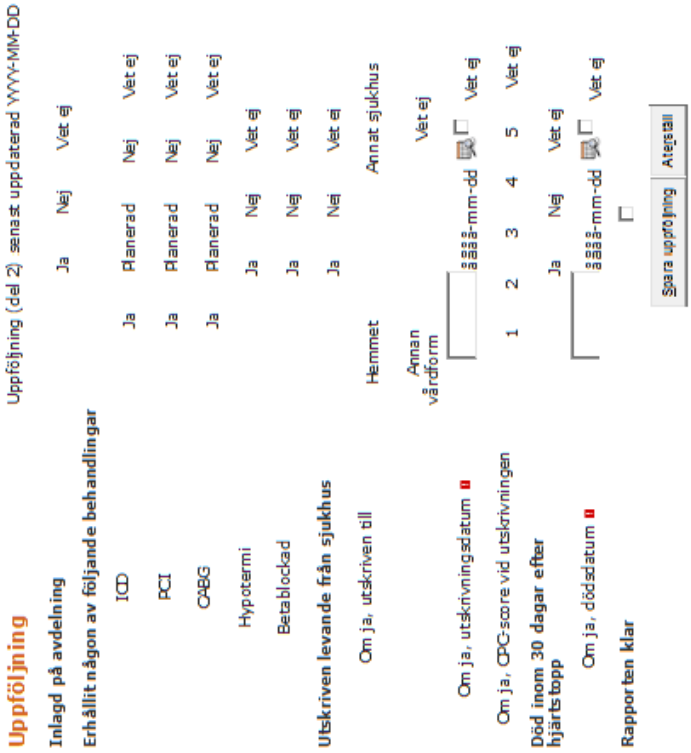
Behandlingar

Hjärtkompression	○ Ja ○ Nej
Mekanisk hjärtkompression	○ Ja ○ Nej
Ventilation	○ Ja ○ Nej
Intubation	○ Ja ○ Nej
Defibrillering	○ Ja ○ Nej
Om Defibrillering, antal	
Adrenalin	○ Ja ○ Nej
Atropin	○ Ja ○ Nej
Cordarone	○ Ja ○ Nej
Hypotermi	○ Ja ○ Nej

Resultat av behandling

Återfått pulsgivande rytm någon gång	○ Ja ○ Nej
Körd till sjukhus/annan vårdenhet	○ Ja ○ Nej
Om Ja, vilket sjukhus/annan vårdenhet	-- Välj sjukhus/annan vårdenhet --
Om Ja, pulsgivande rytm vid ankomst till sjukhus/annan vårdenhet	○ Ja ○ Nej
Om Ja, vid medvetande vid ankomst till sjukhus/annan vårdenhet	○ Ja ○ Nej

Appendix II


Uppföljning
Uppföljning (del 2) senast uppdaterad YYYY-MM-DD
Inlagd på avdelning
Ja
Nej
Vet ej
Erhållit någon av följande behandlingar
ICD
Ja
Planerad
Nej
Vet ej
PCI
Ja
Planerad
Nej
Vet ej
CABG
Ja
Planerad
Nej
Vet ej
Hypotermi
Ja
Nej
Vet ej
Betablockad
Ja
Nej
Vet ej
Utskriven levande från sjukhus
Ja
Nej
Vet ej
Om ja, utskriven till
Hemmet
Annat sjukhus
Annan vårdform
Vet ej
Om ja, utskrivningsdatum
åååå-mm-dd
Vet ej
Om ja, CPC-score vid utskrivningen
1
2
3
4
5
Vet ej
Död inom 30 dagar efter hjärtstopp
Ja
Nej
Vet ej
Om ja, dödsdatum
åååå-mm-dd
Vet ej
Rapporten klar
Spara uppföljning
Återställ

Appendix III

Part I:

The social security number –a complete social security number should be available. When a foreigner suffer from out-of-hospital cardiac arrest (OHCA), the person achieve a reserve number which is possible to track from the emergency medical service (EMS) medical record until the patient's discharge from the hospital.

Gender – documentation if the patient with OHCAs is a female or male

Task number – the EMS missions achieve a task number from the dispatcher at the alarm central. The aim with the task number is to simplify tracking of the mission.

Alarm date – documentation about the date when the OHCAs occurred. The documentation should be according yyyy-mm-dd.

Locations of OHCA – there are three alternatives to fill in where the OHCAs has occurred which could be at home, public place or other. Public place and other are available from a scrolling list.

Witnessed OHCA yes/no – if the OHCA was witnessed. The following objects are possible to choose; lay people, EMS crew, health care personal, police, fire brigade, other.

Cardiopulmonary resuscitation (CPR) before arrival of EMS – if CPR was initiated before arrival of EMS. The OHCA should be reported to the Swedish cardiac arrest register (SCAR) regardless whether the EMS crew continued the treatment with exception for cases being regarded as dead on the arrival of the EMS (for example rigor mortis).

Compression yes/no – documentation if the patient received compression before the arrival of the EMS.

Ventilation yes/no – documentation if the patient received ventilation before the arrival of the EMS.

Defibrillation yes/no – documentation if the patient was defibrillated and how many defibrillations. If the patient was defibrillated, there should be

documentation about who defibrillated and if automated external defibrillator (AED)/public access defibrillator (PAD) was used.

The status at the arrival of the EMS – documentation whether the patient was conscious, was breathing and had a pulse. This is documented yes/no.

Initial rhythm – the first stated rhythm documented regardless if observed by bystanders or the EMS crew.

Cause of arrest – information about the aetiology behind the OHCA.

Time event for the OHCA – the time for the OHCA event and the following point operations should be documented:

- Witnessed OHCAs – at the time of collapse
- Non-witnessed OHCAs – when the victim was found unconscious and without signs of breathing and without a circulation
- Registered alarm – when the dispatcher received the alarm from the caller
- Registered time when the EMS crew was dispatched.
- CPR – when CPR was initiated.
- Defibrillation – when the first defibrillation was performed regardless if it was performed by a bystander, first responder or the EMS crew.
- The arrival of the EMS – when the EMS crew arrived to the place of location of the OHCA.
- The arrival of the EMS – when the EMS crew was at the patient's side.
- The first electrocardiogram registration – the registration could be analysed from an AED or/and confirmed by the EMS crew.

Treatments – documentation of treatments which were given after the arrival of the EMS and during the ongoing OHCAs or/and immediately after return of spontaneous circulation (ROSC). The following treatments should be documented:

- Compression
- Mechanical compression – if a mechanical device was used.
- Ventilation – if the patient was ventilated during the OHCA and how the ventilation was performed (mouth to mouth,

mouth to pocket mask, resuscitator device before and/or after intubation
- Intubation – if the patient was intubated or not.

- Defibrillation – documentation of defibrillations after arrival of the EMS and the number of the defibrillations.
- Adrenaline – if adrenaline was given or not and the volume of dose.
- Atropine – if atropine was given or not and the volume of dose.
- Amiodarone - if amiodarone was given or not and the volume of dose.
- Therapeutic hypothermia – if the patient was treated with therapeutic hypothermia.

Outcome – results of treatments and the patient's status is documented for each OHCA case. The following aspects on outcome are specified as:

- ROSC – documentation if the patient had any ROSC during the OHCA.
- Admitted to hospital – all OHCA cases should be documented if the OHCA was admitted to hospital or not. If OHCA was admitted to hospital, the name of hospital was available from a scrolling list with the possibility to choose one of them.
- ROSC on arrival in the hospital – documentation should be performed if there was ROSC or not on arrival in the hospital.
- Conscious on arrival in the hospital - documentation should be performed if the patient was conscious or not on arrival in the hospital.

When all these variables are documented, the completed form should be sent away by activating the send button.

The data in part II are documented as follows:

Part II:

Admitted to a hospital ward – documentation if the patient was admitted to a hospital ward or not. If the answer was no, the form is completed and saved in the database.

Received following treatments – documentation if treatments as implanted defibrillator, percutaneous coronary intervention, coronary bypass, therapeutic hypothermia or beta blockade are obtained. There is an opportunity to respond do-not-know.

Discharged alive from hospital – documentation if the patient was discharged from hospital or not. The discharge destination should be documented as home, another hospital or other care form and if there was no information about the discharge. The time point for the discharge is documented and also an opportunity to choose do-not-know.

Cerebral performance category (CPC) score – documentation about the CPC score at the discharge from hospital.

Dead within 30 days after the OHCA – the OHCA case is controlled if he/she is alive and documented as yes or no. There is an opportunity to respond do-not-know. The date of death should be documented.

Appendix IV

Search template for OHCA in Sweden

When a patient has been taken care of by the EMS crew, documentation about the mission is produced. The documentation takes place either in a digital medical record or on a paper form which is followed up in an electronic monitoring system. In general, the following facts are documented, regardless of the kind of patient case or EMS medical record:

1. Case number
2. The patient's name and social security number
3. Day and time of the occurrence of the OHCA
4. Observations
5. Assessments
6. Treatments

Observations could involve observing symptoms like respiratory distress, chest pain, cyanosis, stomach pain, unresponsive and so on.

Assessments could involve assessing and then deciding what to do after an observation.

Treatments which have been given after an assessment/s.

In the EMS medical records, the information in items 4-6 is frequently documented as a free text and/or with specific code/s. The specific codes are developed and adapted for each EMS medical record system and connected to a condition with specific symptoms. When an OHCA has occurred and has been documented as an OHCA, pre-symptoms may have existed before the occurrence of the OHCA and they can therefore be picked up in the search procedure, provided that it has been documented as a free text. This is important because a specific code for an OHCA is sometimes not documented and cannot be found in the search.

The following free text examples can be used in the search procedure:

ROSC (return of spontaneous circulation), CPR (cardiopulmonary resuscitation), def (defibrillation), asystole, VF (ventricular fibrillation), PEA (pulseless electrical activity), cardiac arrest and so on.