

A Second Chance at Life

*A Study About People Suffering
Out-Of-Hospital Cardiac Arrest*



Ann-Sofie Forslund

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out-of-hospital cardiac arrest

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“I was at a rehearsal with the choir, and we talked about wings and things like that...and I said:

– I gave my angel wings back [when I got a second chance at life]. I didn’t need them....not now anyway....” (Quotation from a person surviving out-of-hospital cardiac arrest)

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Abstract

Aim

The overall aim of this thesis was to describe people's lives before and after suffering out-of-hospital cardiac arrest with validated myocardial infarction aetiology (OHCA-V). The following specific aims were formulated: describe trends in incidence, outcome and background characteristics among people who suffered OHCA-V (I), describe risk factors and thoughts about lifestyle among survivors (II), elucidate meanings of people's lived experiences of surviving 1 month after the event (III), and elucidate meanings of people's lived experiences of surviving 6 and 12 months after the event (IV).

Methods

Data were collected from the Northern Sweden MONICA myocardial registry and from interviews with people surviving OHCA-V. Quantitative and qualitative methodologies were used for analysis.

Results

The incidence of OHCA-V decreased during the 19 years studied, and people aged 25-64 had an increased survival rate. The proportion of people with a history of ischemic heart disease (IHD) before the event decreased over the years. Among people surviving OHCA-V, 60% had no prior history of IHD, but 20% had three cardiovascular risk factors (i.e., hypertension, diabetes mellitus, hypercholesterolemia and/or lipid lowering medication, current smoker). People

surviving were aware of their risk factors and their descriptions of their lifestyle focused on the importance of having people around, feeling happy and having a positive outlook on life. They made their own choices regarding how to live their lives, which they often referred to as “living a good life.” Meanings of surviving during the first year can be understood as a pendulum’s motion. Participants narrated they thought about the fact that they had been dead and returned to life. They also expressed they wished to know what had happened to them while they were dead, but at the same time they wanted to put the event behind them and look forward. People surviving OHCA-V were striving to get their ordinary life back, but they also wondered if life would be the same. The cardiac arrest affected their body, which felt unfamiliar to them, and they felt they had to learn to feel secure in their body again. People surviving expressed they had been given a second chance at life, and they described the event had affected their outlook on life.

Conclusion

This thesis shows that people suffering OHCA-V are the most likely to die, but the survival rate is increasing. Many people had no known history of IHD before the event, but some had known risk factors for cardiovascular disease. To address these facts it is important for health care to focus both on primary and secondary preventive measures to avoid complications connected to cardiovascular disease. Participants described their thoughts about their lifestyle, which was connected to what they found important in their lives; preventive

measures should be linked to those things to be more successful. People that survived experienced pendulum emotions during their first year, and a movement back and forth in time was expressed. Health care personnel could support people surviving OHCA-V by talking with them about their thoughts connected to the past, present and future.

Keywords

incidence, myocardial infarction, out-of-hospital cardiac arrest, survival, trends, life experiences, qualitative research

List of papers

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

I

Forslund A-S, Söderberg S, Jansson J-H, Lundblad D. Trends in incidence and outcome of out-of-hospital cardiac arrest among people with validated myocardial infarction. *Eur J Prev Cardiol.* 2013;Apr;20(2):260-7. doi: 10.1177/1741826711432032. Epub 2011 Nov 30.

II

Forslund A-S, Lundblad D, Jansson J-H, Zingmark K, Söderberg S. Risk factors among people surviving out-of-hospital cardiac arrest and their thoughts about what lifestyle means to them: A mixed methods study. *BMC Cardiovascular Disorders.* 2013;Aug;27;13 (1):62. doi: 10.1186/1471-2261-13-62.

III

Forslund A-S, Zingmark K, Jansson J-H, Lundblad D, Söderberg S. Meanings of people's lived experiences of surviving an out-of-hospital cardiac arrest, 1 month after the event. *J Cardiovasc Nurs.* 2013;Oct;1. doi:10.1097/JCN.0b013e3182a08aed. Epub ahead of print.

IV

Forslund A-S, Zingmark K, Jansson J-H, Lundblad D, Söderberg S. Meanings of people's lived experiences of surviving an out-of-hospital cardiac arrest, 6 and 12 months after the event. Submitted.

Permission to produce and use contents from the articles above was obtained from the publisher

Abbreviations

BMI – body mass index

CA - cardiac arrest

CAD - coronary artery disease

CPR - cardiopulmonary resuscitation

CHD - coronary heart disease

CVD - cardiovascular disease

DM - diabetes mellitus

ECG - electrocardiogram

ICD - implantable cardioverter defibrillator

IHD - ischemic heart disease

MI - myocardial infarction

MONICA - multinational MONItoring of trends and determinants in

CArdiovascular disease

OHCA - out of hospital cardiac arrest

OHCA-V - out of hospital cardiac arrest with validated myocardial infarction

aetiology

SCD - sudden cardiac death

VIP - the Västerbotten Intervention Programme

WHO - World Health Organization

Definitions

Incidence rate - the number of new cases per population in a given time period.

Case fatality - the proportion of deaths within a designated population of cases (people with a medical condition), over the course of the disease.

Out of hospital cardiac arrest (OHCA). This thesis defines OHCA according to WHO MONICA criteria; if the patient collapsed apparently lifeless or is found dead outside hospital, or if the first medical record on arrival at hospital shows that the patient was in cardiac arrest on arrival. Cardiac arrest does not have to be witnessed or confirmed by electrocardiographic evidence.

The Västerbotten Intervention Programme (VIP) is a community intervention programme intended to reduce morbidity and mortality from cardiovascular disease and diabetes in the county of Västerbotten, Sweden. In this programme, people aged 40, 50, and 60 are invited to participate in individual counselling about healthy lifestyle habits and screening for risk factors.¹

Introduction

Many people are living with cardiovascular disease (CVD) and therefore have to adjust to different preventive measures related to having a lifelong disease. The number of people who die from CVD increases all over the world and is estimated to represent 30% of all global death. Primary and secondary prevention measures are significant for the outcome of coronary heart diseases (CHD). It is also stated that most CVD can be prevented by people addressing risk factors such as tobacco use, unhealthy diet and obesity, physical inactivity, high blood pressure, diabetes mellitus (DM) and raised lipids. Preventive measures, handling risk factors before being struck by the disease, medical care and compliance to medications and lifestyle changes when disease is a fact are associated with a decrease in death and sudden cardiac death (SCD).²

Background

Suffering out-of-hospital cardiac arrest

For people suffering cardiac arrest (CA), this means a sudden and unexpected happening that affects the rest of their lives.³ The majority of people suffering CA outside hospital settings die before resuscitation attempts have been initiated.^{4,5} Studies from the 1970s and forward showed that 66-74% of the deaths from acute CHD occur outside hospital settings.⁶⁻¹¹ The incidence and survival rate of out-of-hospital cardiac arrest (OHCA) varies because of

differences in inclusion/exclusion criteria such as age, aetiology and witnessed not witnessed OHCA, and follow-up time, i.e. discharge from hospital or 28 days after onset of symptoms.¹²⁻¹⁴ Globally, the incidence of people suffering OHCA and treated with cardiopulmonary resuscitation (CPR) varies between 28-55 per 100,000 inhabitants yearly and the overall survival to discharge is low at 2-11%.¹⁴ In Sweden it is reported that 13-52 per 100,000 inhabitants suffer OHCA and survival to 1 month is 2-14%.¹⁵ Additionally people suffering OHCA and dying before resuscitation could be initiated or people found dead are excluded from the research,^{14,16} except in two studies conducted in the 1990s that included witnessed and unwitnessed OHCA events in a whole community.^{10,17}

A few studies describe an increase in survival rates from OHCA.¹⁸⁻²⁰ The increase is thought to be a result of, for example, wider knowledge of CPR in the public population.²¹⁻²⁷ Approximately 60-70% of CA's occur in a person's own home and a majority (63-100%) happens in front of an eyewitness.^{11,15} Therefore the chain of survival that includes early recognition and call for help, early CPR, early defibrillation and post resuscitation care is crucial for survival.²⁸

Risk factors for cardiovascular disease

Since the 1950s, researchers have investigated cardiovascular risk factors. The first causal factors recognized in the Framingham study were hypertension, hypercholesterolemia, and tobacco use; thereafter, other risk factors such as DM, obesity and physical inactivity are included. Risk factors associated with psycho-social surroundings and behaviour also were added.^{29,30} Psycho-social factors are associated with socio-economic status,^{31,32} emotions such as anxiety and depression and work overload.³³ A consensus statement provides a review of the association between psychological stressors and CHD risk, and emphasizes psychological stressors that affect CHD, but further research is required to address clinical significance and prevention. The effects of psychological stressors are far weaker than standard CHD risk factors.³⁴ The World Health Organization (WHO) state behavioural risk factors cause about 80% of CVD in the world. Herein lies a potential for improvements in people's CVD health in addressing unhealthy diets, physical inactivity, obesity, and tobacco use.²

When the WHO Multinational MONItoring of trends and determinants in Cardiovascular disease (MONICA) project in the 1990s compiled the results from 38 participating populations, the results showed that among people who suffered fatal coronary events, a history of CHD was known in 41-98% of the cases.³⁵ Other studies showed that 40-60% of CHD deaths have had no prior

history of CHD before the event.^{10,17,36} Therefore, for some people, a CA might be the first presented symptom of CHD.^{7,17,36-38} Also, it has been reported that not all people with known CHD receive evidence-based treatments, or if they do, they often do not reach the guideline goals³⁹⁻⁴¹ and have a larger risk of complications and premature death.⁴²⁻⁴⁴ Secondary preventive measures are important. These preventive measures include compliance to medications, changes in behavioural risk factors and lifestyle and help prevent complications and promote future health.⁴⁵⁻⁴⁹ Established coronary artery disease (CAD)^{43,44,50} has been shown to be a main risk factor for OHCA as well as hypercholesterolemia,⁵⁰ current smoking, hypertension,^{50,51} obesity,⁵¹ DM,^{52,53} low ejection fraction,⁵⁴ and a family history of sudden death.⁵⁵

Descriptions of lifestyle

The word lifestyle is used often, but a universal definition of its meaning is lacking. The concept was created in 1929 by Alfred Adler, who talked about a “style of life” (lifestyle) that referred to how a person lives his or her life and how he or she handles problems and interpersonal relations. Adler meant that lifestyle was the totality of each person’s values, knowledge, meaningful activities and originality.⁵⁶ Lifestyle is identified in work and leisure patterns and is a combination of motivations and needs. It is influenced by culture, family and social class, for example.⁵⁷

In the 1980s, the WHO offered the following definition: “Lifestyles are patterns of (behavioural) choices from the alternatives that are available to people according to their socio-economic circumstances and the ease with which they are able to choose certain ones over others” (WHO 1986:118). This definition recognises the importance of each individual’s context and says choices may be limited by aspects out of the individual’s control. “It is one of WHO’s responsibilities to ensure that the lifestyle concept is not used as a blanket explanation in which the victim is always blamed” (WHO 1986:118).⁵⁸ The term lifestyle often refers to behaviours that contribute to the development of disease. It has been suggested that some diseases such as CHD, stroke, lung cancer, colon cancer, DM and chronic obstructive pulmonary disease are lifestyle diseases.⁵⁸ Lifestyle changes are difficult to perform and maintain,⁵⁹ and support is important for people trying to make lifestyle changes.^{60,61}

People’s descriptions of lifestyle and what lifestyle means to ordinary people are not elucidated sufficiently. One study described the perceptions of lifestyle among women of retirement age, 61-70 years. The participants in the study described lifestyle as being active within their family and in associations, and being content with choices they made and time spent on different activities. It was also important for the women in the study to be independent and to feel in control and to live life in their own way.⁶²

Experiences of surviving out-of-hospital cardiac arrest

People surviving CA may have had a decreased blood supply to their brain while they were unconscious. The time that passes from CA until resuscitation and defibrillation can affect the brain and lead to a hypoxic brain injury.⁶³ One consequence of hypoxic brain injury is cognitive impairment that can affect people's daily life greatly.⁶⁴ Different questionnaires have been used to explore how people describe their lives after surviving; feelings of anxiety, depression, fatigue and decreased participation in society have been reported.⁶⁵ Many people said they had cognitive impairments, especially memory problems.⁶⁵⁻⁶⁷ Studies show different results regarding changes in cognitive function over time, and improvements have been reported during the first three months, but no further improvements up to six months,^{68,69} while other studies have reported no significant changes during a period of one year.^{70,71} Nevertheless, survivors report a good quality of life⁷² and have been reported to improve during the first six months after cardiac arrest.⁷³

People living with an implantable cardioverter defibrillator (ICD) after CA shared the symptoms above, as well as anxiety and probable depression,⁷⁴ feeling of uncertainty in daily life,⁷⁵ and anxiety connected to receiving a shock.⁷⁶⁻⁷⁸ People living with an ICD experience physical, psychological and social changes. They have to adjust to the device, come to terms with it and get

on with life. Anxiety and fear are connected with receiving a shock and they may affect relationships as well as intimate relations.⁷⁹

There are a few studies that describe peoples' experiences of surviving OHCA and their everyday life afterward. One study described experiences among Spanish people, aged 24-53, surviving SCD. After being discharged from hospital, participants felt lonely and insecure. They described a continued state of fear that affected their lives and tried to handle life through conducting a "go on with life" attitude, but they also prepared for their future death, solving issues and preparing their surroundings. Death became close and personal. They also searched for answers to why they suffered CA, and they felt frustrated when no clear answers could be given.⁸⁰ A study from Iceland included seven men, aged 50-54, that survived OHCA. The men experienced impairments in physical and cognitive functionality and felt anxiety. The study found that security and support were important for participants as they worked to regain their former life.⁸¹

A longitudinal study aimed to explore the experiences of survivors and spouses with aborted SCD. The results showed that survivors and spouses have different reference points when talking about their lives. Survivors focused on their pre-arrest life and wanted to regain activities they found meaningful, while the reference point for spouses that were present during the arrest was the arrest.

Spouses' concerns focused on whether their husband/wife would suffer a recurrence and feelings of guilt that led to protectiveness.⁸²

Patients' experiences with surviving OHCA are described in a Swedish study of nine survivors. They described suffering CA was experienced as a sudden threat to life and reported waking up with a feeling not knowing what had happened and having memory loss. Participants wanted to return to ordinary life and activities they felt meaningful. They searched for an explanation for why this happened and they searched for meaning and coherence in a changed life.³

Rationale

This thesis describes a 19-year period of incidence and outcome from all out-of-hospital cardiac arrests with validated myocardial infarction aetiology (OHCA-V) events in northern Sweden. Both people who were resuscitated outside hospital and those who died before resuscitation were included so the complete spectrum of OHCA-V in a whole community is described. The literature review shows that research usually excludes unwitnessed OHCA events and those who died before resuscitation; therefore knowledge about the whole spectrum of OHCA events can be valuable. Research has not addressed this before over such a long period of time and with validated myocardial infarction (MI) aetiology of all the OHCA events. To the best of my knowledge no studies have been found describing which known risk factors for CHD surviving people had before they suffered OHCA-V or discussing their thoughts about risk factors and what lifestyle means to them. Few studies elucidate meanings of peoples lived experiences in daily life, and results from more recent research points to an increased survival rate after OHCA. Research has focused mainly on spouses' experiences of being present at the event and their situation afterward.⁸³⁻⁸⁵ An increasing number of people survive OHCA, and therefore it is appropriate to search for more knowledge about how this affects people's lives. Increased knowledge improves the opportunities to support people that survived CA and meet their needs in daily life.

Aims

The overall aim of this thesis was to describe people's life before and after suffering an OHCA-V. From the overall aim, the following specific aims were formulated:

- I. to describe trends in incidence, outcome and background characteristics among people who suffered an OHCA-V.
- II. to describe risk factors and thoughts about lifestyle among survivors.
- III. to elucidate meanings of people's lived experiences of surviving, 1 month after the event.
- IV. to elucidate meanings of people's lived experiences of surviving, 6 and 12 months after the event.

Methods

Design

In this thesis, the choice of methods was based on the aim of the studies.

Therefore a combination of methodologies was used because quantitative and qualitative research data elucidate different perspectives. Paper I used a quantitative methodology, Paper II used mixed methods, and Papers III and IV used a qualitative methodology. Figure 1 presents an overview of design, choice of methods and participants.

	Paper I	Paper II	Paper III	Paper IV
Design/Method	Retrospective Quantitative	Mixed methods	Prospective Qualitative	Prospective Longitudinal Qualitative
Participants	n = 2,977	n = 71/13	n = 11	n = 11
Analysis	Descriptive and analytic statistics	Descriptive statistics and qualitative content analysis	Phenomenological- hermeneutical interpretation	Phenomenological- hermeneutical interpretation

Figure 1. Overview of design, participants and analysis, Papers I-IV

MONICA – (Multinational MONItoring of trends and determinants in CARdiovascular disease)

This research was conducted in northern Sweden, where approximately 500,000 people reside and eight hospitals are situated. The basis for this thesis is the

Northern Sweden MONICA myocardial registry and the WHO criteria used in the MONICA project. Since 1985, Norrbotten and Västerbotten County Councils have registered people with MI in the context of the WHO MONICA project. All people who experienced a cardiac event and were cared for in one of the hospitals or health centres in the two counties are eligible for the registry. People who suffered a cardiac event outside hospital or health centre are also eligible for registration. This means people suffering SCD not reached by resuscitation also are included. Hence, all MI events are included in this population-based project.⁸⁶

Registration procedure

The cardiac events are obtained from medical records, death certificates and necropsy reports. Trained nurses, supervised by the register physicians, validated all the events according to WHO diagnostic criteria for definite or possible MI based on a combination of medical history, clinical symptoms, cardiac biomarkers and electrocardiogram (ECG) for fatal and non-fatal events.^{86,87} For fatal events, necropsy findings, if any, and history of ischemic heart disease (IHD) also were used. Based on the original WHO protocol, fatal events are those who die within 27 days after the onset of symptoms. Non-fatal events are those who live 28 days or more after the onset of symptoms. History of IHD, previous MI, DM, coronary interventions (coronary angioplastic and/or coronary bypass procedures) and outcome are also registered for each event. Initially decided within the WHO MONICA project, only men and women

between 25 and 64 years of age were included, but after 2000 the Northern Sweden MONICA myocardial registry decided to include people aged 65 to 74 years. Details about the validation process are presented elsewhere.^{35,86-88}

Paper I

Study population

People with OHCA-V aged 25-64, registered from 1989 to 2007 (n=2,082), and people aged 65-74, registered from 2000-2007 (n=895), in the Northern Sweden MONICA myocardial registry were included (Figure 2). The following inclusion criteria were used: 25-74 years of age, resident of Norrbotten or Västerbotten county, had an OHCA defined as the first CA occurring outside hospital and caused by a definite or possible MI. Both people who were resuscitated outside hospital and those who died before resuscitation were included.

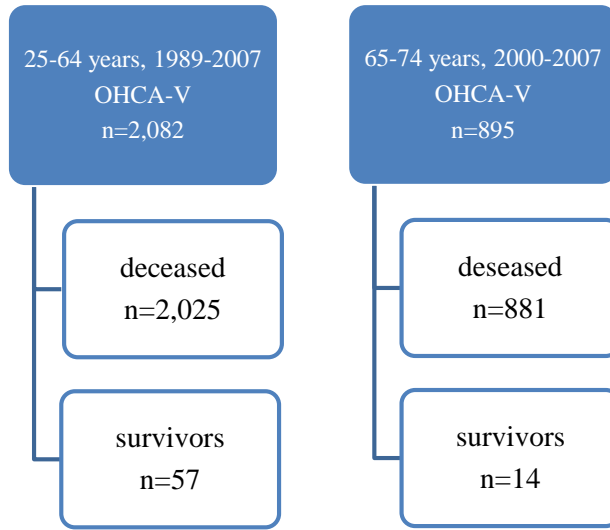


Figure 2. Flow chart of the study population aged 25-64 years, 1989-2007 and aged 65-74 years, 2000-2007

Data collection

Data were extracted from the Northern Sweden MONICA myocardial registry regarding incidence and outcome, history of IHD, previous MI, DM and coronary interventions (coronary angioplastic and/or coronary bypass procedures).

Data analysis

The absolute numbers and proportions of characteristics and survival time were described. Crude incidence rates were calculated for each strata and reported per 100,000 person-years. The p-value for trends was calculated using the Chi-square test and Linear-by-Linear Association. Kaplan-Meier and the log rank test

were used for long-term survival analyses. A p-value < 0.05 was considered significant.

Paper II

Mixed methods design

The aim of this study was to combine a description of risk factors among people surviving OHCA-V with descriptions of their thoughts about lifestyle and risk factors; therefore a mixed methods design was chosen. An explanatory mixed methods design with a participant selection model⁸⁹ was used. This mixed methods design starts with collection and analysis of quantitative data followed by subsequent collection and analysis of qualitative data. The quantitative part was used to guide purposeful sampling for a follow-up in-depth qualitative study. Quantitative data described the risk factors for CHD among people surviving OHCA-V. Thereafter, qualitative data were collected from a purposeful sample of participants that were willing to describe their thoughts about lifestyle linked to their thoughts about risk factors after surviving OHCA-V.

Participants

In the study presented in Paper I, 2,977 people were included, and of those, 71 were alive 28 days after onset of symptoms and are included in this study. The quantitative part of the study included all 71 survivors. On 25 January, 2011, 46 of the original 71 participants were still alive. The author (A-SF) sent them a

letter describing the aim of the study and asking for their participation. People could choose to answer a questionnaire about risk factors with the perspective before and after their OHCA-V (32 people answered the questionnaire) and/or participate in an interview focusing on their thoughts about lifestyle after surviving (13 people participated in an interview) (flowchart in Figure 3). The qualitative part of the study included interviews with 13 people surviving OHCA-V. The interview participants all suffered their OHCA-V 4 to 17 years before the interview (median=8 years) and were 52 to 81 years of age (median=68 years) at the time of the interview. Table 1 presents participants' characteristics.

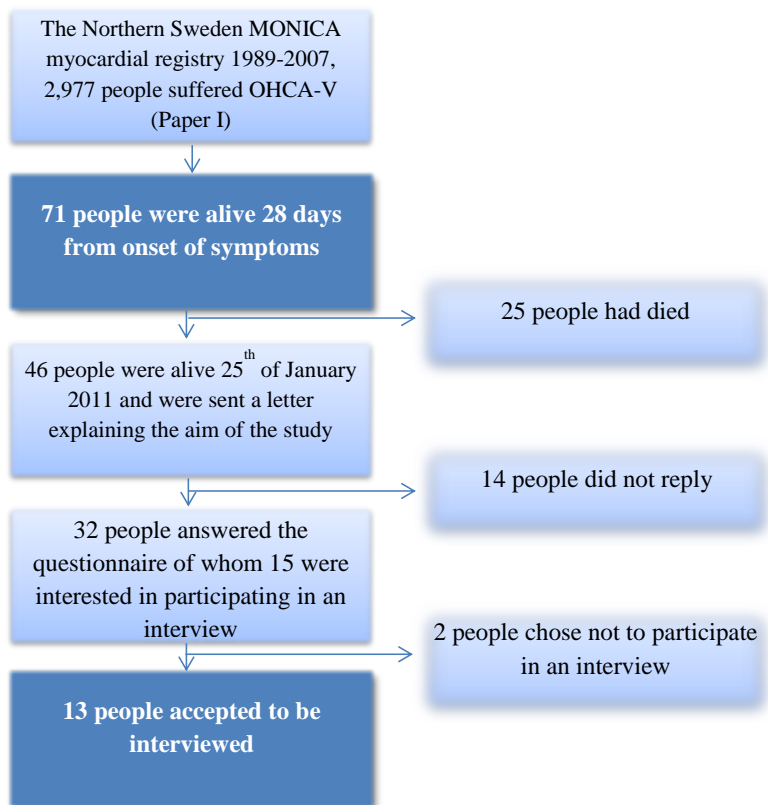


Figure 3. Flow chart-participants included in Paper II, (n=71 in the quantitative part and n=13 in the qualitative part)

Table 1. Characteristics before/at the onset of OHCA-V for people alive 28 days after the OHCA-V (n=71) and for interview participants (n=13)

Variable	n	%	n	%
	People alive 28 days after the OHCA-V		Interview participants*	
	71		13	18.3
Sex, male/female	53/18	74.6/25.4	10/3	76.9/23.1
Age (years, mean \pm SD, min-max)	58.3 (9.1) 35-74		57.5 (9.0) 43-75	
Marital status				
married/cohabitant	58	84.1	11	84.6
Work status				
gainful work	41	61.2	8	61.5

* Interview participants are also included in People alive 28 days after the OHCA-V

Quantitative data collection

Quantitative data regarding which known CHD risk factors people had before suffering CA was selected from the Northern Sweden MONICA myocardial registry and compiled with data about their risk factors prior the OHCA-V from the Västerbotten Intervention Programme (VIP). Data from the questionnaire was added and an additional medical journal review was conducted to make data as complete as possible; however, data about marital and work status, total cholesterol, smoking habits and body mass index (BMI) could not be completed.

Quantitative data analysis

Descriptive statistics were used to analyze quantitative data, and people's characteristics were presented in absolute numbers and proportions.

Qualitative data collection

Qualitative data was collected from interviews with a purposive sample⁹⁰ of people who chose to participate and wanted to share their thoughts about their risk factors and life style after surviving OHCA-V. Interviews were performed as conversations that focused on the following questions: “Please tell me what you think about when I say lifestyle? What does lifestyle mean to you? Has your cardiac arrest influenced your lifestyle? What is important to make you feel good?” A qualitative interview is not just any conversation, but a conversation with a certain purpose and a conversation led by the interviewer that aims to gain descriptions from the interviewee. The interview aims to produce knowledge that is constructed in the meeting and the interaction between the interviewer and the interviewee.⁹¹ All interviews were conducted in the participant’s home according to their wishes. The interviews lasted about an hour, were tape recorded and later transcribed verbatim.

Qualitative data analysis

The interview texts were analyzed with a qualitative manifest content analysis,⁹² because the aim was to describe the content of what the text said. Textual units related to the study aim were identified and extracted. Then the textual units were shortened while preserving the core of the text, which is referred to as condensation. The condensed textual units were sorted into content areas describing a specific, explicit area. In each content area, a category was created to summarize the content. A category refers to a description of the content and

can be seen as an expression of the manifest content of the text. Finally, the categories were divided into subcategories describing different aspects within the category.⁹²

Paper III-IV

Participants

A purposive sample⁹¹ of two women and nine men, aged 49-73 (median=63) participated. The participants were recruited from hospitals in northern Sweden when visiting the cardiac nurse approximately 1 month after their OHCA-V. The cardiac nurse informed about the study's aim and decided if the inclusion criteria for the study were fulfilled—no cognitive impairments assessed by the attending nurse and enough knowledge of the Swedish language to be able to participate and narrate their experience in an interview situation.

Data collection

Narrative interviews were suitable because the aim of these studies was to elucidate meanings of people's lived experiences of surviving CA. Narratives are generally stories with a temporal order that are linked to the past, present and future, and connected in meaning. A narration is the story of a life at a given moment and a re-telling of what a person has experienced.⁹³ Since participants experienced CA, a longitudinal design with repeated interviews was found mostly appropriate although memory loss is common after CA and repeated interviews could benefit the participant's narration. Narrators in a remembering

moment try to achieve a consistent interpretation of what has happened told in the present. Narratives are true stories that are linked to interpretations of what happened and involve a quest to try to understand what something means.⁹³ The interviews were conducted on three occasions about 1, 6 and 12 months after the CA.

All but three participants chose to be interviewed in their home. Those participants chose to meet in a quiet room at the hospital, in their working place or in the author's (A-SF) office. On the first occasion participants were asked to talk freely about what happened the day they became ill, what they remembered and how they lived their life today. Before the second and third interview the previous interview were listened through, by the author (A-SF), by doing so clarify questions about what the participants had narrated during the previous interview could be asked and followed up. The second and third interview started by asking the participant to talk freely about how daily life had been since the last interview. Clarifying questions were asked, such as "Can you tell me more what you mean?" and "Can you give me an example?" The interviews were conducted between February 2011 and April 2013, and all 11 participants completed all three interviews.

Data analysis

Although the aim of these studies was to elucidate meanings of surviving, a phenomenological hermeneutic interpretation inspired by the French

philosopher Ricoeur⁹⁴ and developed by Lindseth and Norberg⁹⁵ for nursing research was used. This methodology combines a phenomenological and hermeneutical attitude. A phenomenological attitude involves describing the life-world or people's daily lives as experienced by that person. Hermeneutics is the attitude of understanding through interpretation, and the hermeneutical circle is vital. This means when interpreting texts, there is a movement between the whole text, to parts of the text, and back again in the process of understanding. Throughout the whole chain or process using this methodology, from planning the study, interviewing, analysing and presenting findings, it is important trying to have an open attitude. Having an open attitude involves having an open mind to the phenomenon being studied, making good choices that promote good narratives and being sensitive to narratives participants share. As a researcher you should have a willingness to listen and understand and let the phenomenon being studied guide the way to meanings. An open attitude is a way of being, showing respect and being sensitive to the phenomenon by making it show itself and its meanings in the most truthful way.⁹⁶

The interviews were transcribed verbatim. The phenomenological hermeneutic interpretation of the interview text involved three phases: naïve understanding, structural analysis, and a comprehensive understanding with reflections.⁹⁵ A movement between understanding and explanation and between parts and the whole is characteristic of the method. A naïve understanding was formulated by

reading the interview text repeatedly; this is a first understanding of what the text talks about or the meanings of the text. The naïve understanding guided the structural analysis. In the structural analysis, the interview text was divided into meaning units that answered the study aim. Meaning units were repeatedly condensed (shortening the text but preserving its essential meaning), and all condensed meaning units were read through and those related to each other were grouped together regarding similarities and differences in meaning. Condensed meaning units were abstracted to form sub-themes, gathered into themes and sometimes even assembled into main themes. Sub-themes and themes were reflected in relation to the naïve understanding, because the purpose was that they should validate each other. In the comprehensive understanding, the research question, context of the study, themes and sub-themes were reflected on, and relevant literature was used to widen and deepen the understanding of the phenomenon under study.

Methodological considerations

During the whole process of conducting this thesis reliability and validity were ensured through verification strategies. ^{97,98} These strategies were included already in the beginning of planning the research studies by formulating aims that are matched to methodology. The samples were appropriate though the included people had knowledge about the research topic to ensure rigour in the results of the studies. While collecting and analysing data verification strategies were used when checking and rechecking the interpretations, within the research group. A movement between parts of the interview texts and the whole interview texts validate the results of the analysis. The sample sizes were judged to be sufficient through the deepness and richness of the data compiled from the interviews.

The major strengths in the study presented in Paper I are the large number of people studied over such a long period of time, that each OHCA event had a validated MI aetiology, and that both people who were resuscitated outside hospital and those who died before resuscitation were included. The strict and uniform use of the MONICA criteria over the whole time period strengthens the validity of our findings. The main limitation in the MONICA myocardial infarction registry is the age limit chosen in the WHO MONICA project. An upper age limit was set at 65 years and 65-74 year olds were included later while

people younger than 25 were not included. Some variables compiled from the MONICA myocardial registry such as smoking habits and history of hypertension included too much insufficient data and therefore they were not used in the analysis.

Although everyone who survived an OHCA-V during a 19-year period was included in Paper II, this population was small. Comparison within the group of 71 people was not meaningful. Risk factors for CHD prior suffering OHCA-V were compiled in a thorough way and insufficient data was small. The number of interviews performed was determined by the number of people who chose to participate. Participants gave rich and deep descriptions of their experiences and the sample size was considered sufficient. The combination of quantitative and qualitative methodology enriched the results when participants gave their words and descriptions about their risk factors and thoughts about lifestyle.

Narratives involve remembering moments and reflecting about happenings in life, and telling a story about the past in the present. Narratives are true stories linked to the narrator's interpretation of what happened, and the meaning of what happened. Sometimes elucidating a certain phenomenon means that time must pass before a story about the happening can be told.⁹³ Special consideration was given to the timing of the first interview in Paper III. At first the intention was to interview participants when they were discharged from hospital, but after

further discussion within the research group it was found more appropriate to wait until their first visit to the cardiac nurse, approximately 1 month after the cardiac arrest. Participants' narratives 1 month after the CA expressed that the first weeks being home from the hospital were intense because they were processing what had happened and talking about it with family and friends. They also described they were tired and needed to rest and sleep. One month after the event participants expressed that life slowly resembled their ordinary life and the timing for the interview was right although they were ready and willing to narrate. Some time had passed and they could reflect upon what happened to them.⁹⁹ The repeated interviews with participants conducted in Papers III-IV resulted in deep and rich narratives about the participants' lives and how their lives were affected after surviving a CA, and the sample size was considered sufficient.

The researcher's pre-understanding is pivotal in qualitative research because the meaning of a phenomenon disappears without pre-understanding.⁹⁵ Some aspects of the researcher's pre-understanding are probably unconscious and therefore difficult to recognize, never the less the need for reflection and awareness of how pre-understanding can affect research and interpretation is necessary.⁹⁶ The interpretation of the findings in this thesis was performed, from my perspective as a human being, my experiences as a nurse working with people in cardiac care and people living with illness, but also with limited

knowledge of peoples lived experiences of surviving OHCA-V. The interpretations of the findings were performed in close collaboration with my supervisors, and discussions were repeated until a consensus was reached. According to Ricoeur⁹⁴ there is not one single meaning in a text, but all interpretations of a text are not equally plausible. The interpretation should be the most probable, the one that elucidates the greatest number of details.⁹⁵

The results from this thesis might be generalized to other contexts than that of people suffering OHCA-V in the northern part of Sweden. It could be assumed that experiences from people suffering life-threatening diseases and living with chronic illness might have similar experiences as those experienced by people surviving OHCA-V. Knowledge from this thesis could fit and be generalized into other contexts if the reader of these results judge it appropriate.⁹⁹

Ethics

The Northern Sweden MONICA myocardial registry has ethical approval from the Regional Ethical Review Board, Umeå, dnr 09-041M. All registered people with non-fatal MIs gave their consent for registration. Approval for this thesis was obtained from the Regional Ethical Review Board, Umeå, dnr 2010-174-31M, and dnr 2011-33-32M.

Since people surviving CA have experienced a dramatic event, special concern was devoted regarding their participation in the study. The participants' wishes regarding time and place for the interview were paramount and if they wanted to have a significant other person present at the interview for their feeling of safety and comfort, this was responded to. It was clarified before the interview that the participants decided what he/she wanted to narrate. The possibility for professional counselling after the interview was considered, although such a need was not expressed by any of the participants. The opportunity for participants to tell their stories and discuss their experiences has been described as having a therapeutic effect⁹¹ and healing power.⁹³ Participants expressed they found the interview sessions meaningful and helpful in their recovery, giving them the opportunity to talk about what had happened to them, how they felt and the ups and downs in their everyday life.

The participants that agreed to participate in interviews signed an informed consent form and were reassured that their participation was voluntary and they could withdraw from the study at any time. The participants were guaranteed an anonymous presentation of the findings.

Main results

Paper I

The results from the study presented in Paper I showed a significantly decreased incidence of OHCA-V among both men and women aged 25-74 years during the 19-year study period (Figures 4A and 4B).

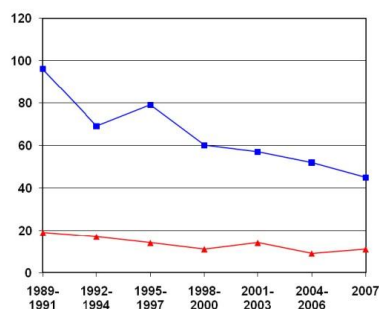


Figure 4A. Incidence rate of OHCA-V per 100,000, 25-64 years, 1989-2007.

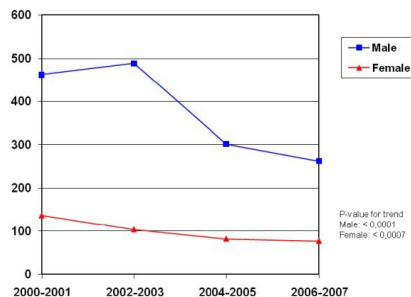


Figure 4B. Incidence rate of OHCA-V per 100,000, 65-74 years, 2000-2007.

The majority (92-97%) of people suffering OHCA-V died within the first 24 hours after the onset of symptoms. Among people aged 25-64 years, survival to 28 days from onset of symptoms significantly increased during the time period studied. Few people survived OHCA-V, but those who did had a fairly good prognosis for long-term survival (28 days and after) compared to survivors after MIs (28 days and after). Long-term survival was significantly better in the younger group, aged 25-64 years, than in the older group, aged 65-74 years (Figure 5). The results showed a significant decrease in the proportion of people having a history of IHD before suffering OHCA-V during the time period.

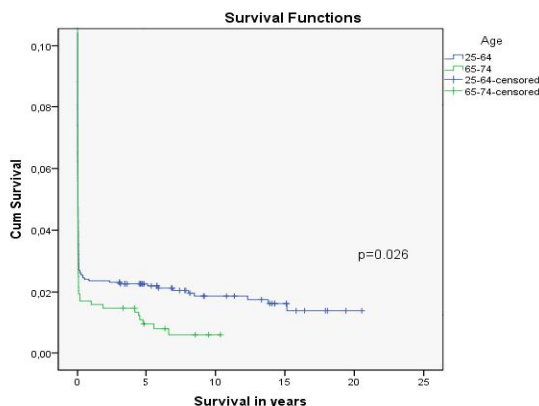


Figure 5. Long-term survival after OHCA-V, 25-64 years vs. 65-74 years.
 25--64 years: 1-year survival 86%, 5-year survival 82%, 10-year survival 73%.
 65--74 years: 1-year survival 93%, 5-year survival 64%, 10-year survival 50%.

Paper II

The results from the study presented in Paper II showed that among people surviving OHCA-V, 60% had no history of IHD before they suffered the OHCA-V event, but one in five had three cardiovascular risk factors (i.e., hypertension, DM, total cholesterol of more or equal 5mmol/l or taking lipid lowering medications, and current smoker). Nearly half was smokers and 63% were overweight/obese. Table 2 presents people's risk factors.

Table 2. Risk factors before/at the onset of OHCA-V for people alive 28 days after the OHCA-V (n=71) and for interview participants (n=13)

Variable	n	%	n	%
	People alive 28 days after the OHCA-V		Interview participants*	
	71		13	18.3
History of coexisting conditions				
IHD	28	39.4	4	30.8
previous MI	18	25.4	4	30.8
hypertension	28	39.4	4	30.8
DM	12	16.9	1	7.7
total cholesterol, mmol/L				
≤ 4.99	14	20.9	1	7.7
≥ 5.0 and/or lipid lowering medication	53	79.1	12	92.3
Smoking habit				
smoker	31	47.7	8	61.5
former smoker	17	26.2	1	7.7
never smoked	17	26.2	4	30.8
BMI, kg/m²				
< 24.99	23	36.5	3	23.1
25-29.99	30	47.6	8	61.5
30-39.99	10	15.9	2	15.4
≥ 3 risk factors**	16	22.5	3	23.1

IHD, ischemic heart disease; MI, myocardial infarction; DM, diabetes mellitus; BMI, body mass index

* Interview participants are also included in People alive 28 days after the OHCA-V

** hypertension, DM, total cholesterol ≥ 5.0 mmol/l and/or lipid lowering medication, smoker

Figure 6 describes the 71 surviving people's lifeline, where each person's line starts on the 28 day from the onset of symptoms and continues until death or a stop at follow-up time of the study. The figure shows no clear link between age and survival time. Indeed, young people and the elderly often live for a long time after their OHCA-V. Moreover, it shows that survival time for the deceased was relatively short in most cases. A greater number of people were included from 2000 on due to the inclusion of people aged 65 to 74 after 2000. Younger people suffering OHCA-V after 2000 showed a better outcome than those suffering OHCA-V before that.

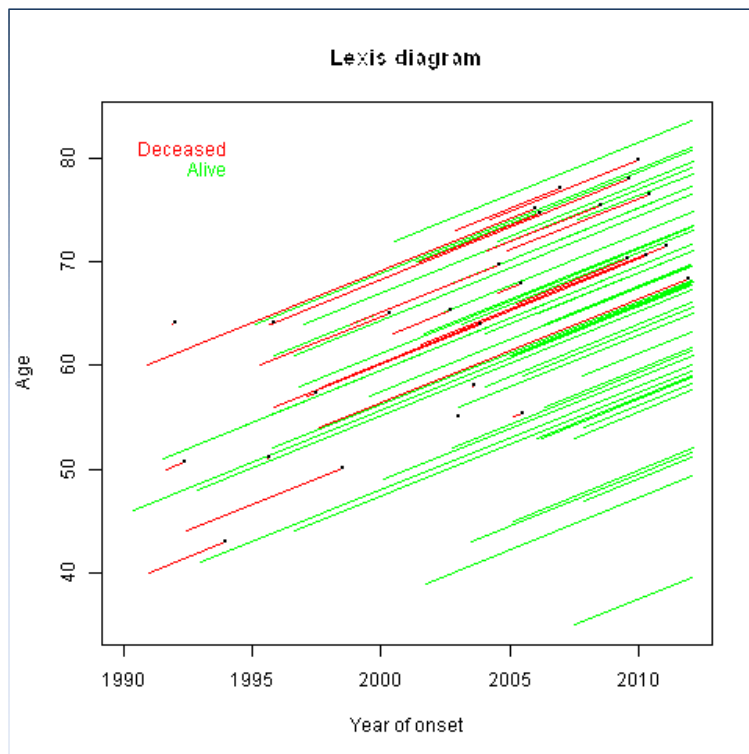


Figure 6: Lexis diagram describing the relation between people's age, year of OHCA-V onset, and survival time through the 17th of February, 2012.

Interviewees described that after the OHCA-V, the significance of lifestyle was having meaningful relationships with family and friends, which also was a foundation of happiness and strength. Social interaction and feeling they were needed and meant something to others was important. Lifestyle was also described as being connected to feeling well, which was not taken for granted. After surviving OHCA-V, participants considered the reason for the MI. Participants believed that one possible reason for the MI could be smoking cigarettes and negative stress at work, and they tried to adopt healthier behaviours. They also mentioned the effects of heritage on CHD. Participants were aware of their risk factors and were informed about the benefits of behavioural changes, but they also described making their own assessment of risk behaviours. They were grateful for a second chance at life, described the importance of doing joyful things, and sometimes prioritized living a “good life” instead of making health promoting choices.

Paper III-IV

Table 3 presents the findings from the studies presented in Papers III-IV.

One month after the OHCA-V (III), participants expressed the event was sudden and unexpected, and was not preceded by obvious symptoms they related to the heart. Surviving meant waking up missing the whole picture. They had fragmentary memories and needed to know what had happened to them, and

they wanted people that had been present when it happened to be the ones that told the story. Participants were grateful that people acted when they became ill and felt they were alive because of those actors. They were also grateful for all the support and kindness from family and friends and believed that health care personnel did everything possible for them. Although they sometimes considered the attention a bit too much when they were tired, needed rest, felt guilty about putting their surroundings in this dramatic situation and wondered what their loved ones had gone through because of them.

Participants described they wondered if life would be the same again because coming home from hospital meant they were tired and lacked energy. They did not have strength to conduct activities they did before, activities they had never considered exhausting. Participants wished to be able to do things they wanted and looked forward to life returning to normal.

Six months after the OHCA-V (IV), participants expressed that suffering illness affected their feeling of security with their body and they wanted to regain a sense of security. This meant a pendulum's motion of testing their body, managing and not managing, and adjusting activities. Participants had experienced chest pain that led to anxiety and insecurity, and they expressed they had wished for better information about chest pain after resuscitation to avoid unnecessary anxiety. They also described they sought explanations to

symptoms they experienced and sometimes blamed medications for symptoms, effects or side effects. Participants expressed the importance of being tested by the doctor, getting test results that were normal and seeing that as a prompt to move on with their ordinary lives. They marvelled that everything had worked out well and the event affected their continued life, but still claimed that being who you are affects how you interpret both the event and the future. Participants expressed that they wanted to know about what happened to them but at the same time they wanted to put the event behind them. They had regained life and described they wanted to focus on the future, but did not plan to much as more living life one day at the time, as life can change quickly, suddenly it is over.

Twelve months after the OHCA-V (IV), participants expressed they had regained a sense of what their bodies could manage after challenging, testing and evaluating how their bodies reacted in different situations. Participants who suffered new disease events during their first year after the CA had to repeatedly strive to regain control of their changed body. They expressed visits to the doctor had not worked out satisfactory--they wanted to be checked, ask questions and receive answers they could understand, possibly getting remedied and being declared healthy. One year after the event they expressed they had embraced changes in their lives. They listened to their own needs and others, and more easily prioritized themselves instead of others. Participants that described cognitive impairments had adapted to a changed everyday life that

sometimes made them feel that they were not the same person anymore and led to shame and isolation. Family and friends were described as extremely important to giving them love and support, although participants expressed it was equally important for them to make their own decisions without other people telling them what to do. Participants wanted to resume their daily life, and certain activities were described as being a significant part of their lives and they wanted to continue those as they were joyful and gave them strength. They looked for the future but did not plan too much, because the event affected them and gave them the awareness necessary to value the time given to them. Meanings of surviving OHCA-V during the first year after the event was interpreted likened to a pendulum's motion. Participants' narratives included pendulum thoughts about their life situation before and after the CA as well as thoughts about the CA event and the future.

Table 3. Overview of main theme, themes and subthemes from Papers II, III and IV.

Interview conducted at	Main theme	Themes	Subthemes
1 month (Paper III)		Returning to life	Waking up and missing the whole picture Realizing it was not time to die
		Revaluing life	Wondering why and seeking explanations Feeling ambiguous in relations Wondering whether life will be the same
6 months (Paper IV)	A pendulum's motion	Aspiration for control	Testing the body Pursuing the ordinary life
		Being the person you are	Marvelling about what have happened Wanting to both know and put it behind
12 months (Paper IV)	A pendulum's motion	Recapitulation	Regaining a sense of security with the body Wanting to be checked and declared healthy Embracing changes Affecting the surrounding
		Foresight	Wanting to resume daily life Being better prepared if it happen again Planning for the future

Discussion of the main results

The overall aim of this thesis was to describe people's lives before and after suffering an OHCA-V. This thesis shows that during the 19-year study period the incidence of OHCA-V decreased. The majority of people died within the first 24 hours after the onset of symptoms, but those who survived had a fairly good prognosis for long-term survival. The proportion of participants with a history of IHD before suffering OHCA-V also decreased during the study period (I).

Participants surviving OHCA-V were aware of risk factors and implemented lifestyle changes but also made their own assessment of risk behaviours and healthier choices. The significance of lifestyle was emphasized by participants to mean having people around them for whom they cared and who cared for them. In referring to 'lifestyle', participants meant feeling well, having fun, and most importantly, living a good life (II).

For participants, surviving OHCA-V meant waking up and realizing that they had experienced CA and had been resuscitated. Participants expressed a need to know what had happened to them while they were dead/unconscious and sought a reason to explain why they had suffered CA (III). Meanings of surviving OHCA-V during the first year after the event was interpreted likened to a

pendulum's motion. Participants' narratives included fluctuating thoughts about their life situations before and after CA, as well as thoughts about the CA event and the future (IV). This pendulum's motion could be seen in the studies presented in Papers III–IV and by examining the results from all three interviews conducted during the participants' first year after the CA event. The pendulum's motion was also visible in the study presented in Paper II as participants oscillated between different time periods in their descriptions of what lifestyle meant to them.

Results show that during the 19-year study period the proportion of people with a history of IHD before the OHCA-V significantly decreased (I). This result points to the difficulty of addressing prevention of OHCA-V, for many people have no previous contact with health care before suffering CA and are not introduced to preventive measures. Herein, primary preventive measures regarding cardiovascular risk factors are significant, and special concern should be devoted toward people at high risk of developing disease by focusing on lifestyle changes in order to reduce risk.¹⁰⁰ To this end, however, difficulty in conducting and implementing lifestyle changes has been repeatedly reported.⁵⁹⁻⁶¹ A generally active daily life has been shown to benefit people, as well as be associated with cardiovascular health and longevity in adults in their 60s regardless of whether they exercise regularly. Both being physically inactive and having an increased waist circumference are associated with CVD, while being

regularly physically active was associated with decreased risk of CHD even if waist circumference was larger than normal. Daily exercise is beneficial and contributes to a reduced risk of CVD and premature death compared to being physically inactive.¹⁰¹ Promoting regular physical activity in general and increased active commuting especially seem to be feasible ways to increase people's daily physical activity and are associated with positive effects and health benefits.¹⁰²

Studies have described prodromal symptoms among people suffering OHCA, in whom the most frequently presented symptoms were chest pain, dizziness, palpitations, nausea, not feeling well, and dyspnoea, as well as pain in the arms, jaws, and shoulders.^{11,17,103} However, many CA events are unwitnessed and occur suddenly without affording any time to call for emergency help. Moreover, many people do not seek medical assistance before suffering CA but only tell their spouses they are not feeling well; if they do seek medical assistance, they present diffuse symptoms that are hard to evaluate.¹⁰⁴ Health care is thus truly confronting major challenges in identifying people at risk of CA.

Results show that, though the majority of people suffering OHCA-V have died, the people who survived after 28 days from the onset of symptoms face a fairly good long-term outcome (I). For people who survived, secondary prevention and

evidence-based treatment are crucial to avoiding further complications. A Swedish study has calculated that approximately half of all eligible patients with CHD receive appropriate treatment and that, if treatments were to be increased to cover 60% of all eligible patients, the result would be 4,100 fewer deaths from CHD during the period of one year.⁴¹ Secondary prevention also includes people's own efforts to choose healthier lifestyle behaviours in order to increase their chances of living a healthy life without further complications. Lifestyle behaviours and behavioural changes are, however, complex by being multifaceted and not only focusing on health.⁵⁸ Behaviours that people choose can be mood enhancing, are often connected with pleasure, and play roles in the development and maintenance of social relationships. All behaviours are to some degree voluntary, though individual control can vary between contexts. Lifestyle behaviours can also be understood to be more chronic than acute behaviours, and regular patterns in a person's life often predict future behaviours. Behaviours connected to a person's lifestyle manifest most of their positive outcomes in the present, while negative outcomes occur more often in the future. Therefore, lifestyle interventions need individuals to be future oriented,⁵⁸ as well as to understand, prioritize, and choose lifestyle behaviours in the light of both positive outcomes in the present and possible negative outcomes in the future.

In the studies presented in Papers II–IV, participants described being motivated to perform lifestyle changes. They searched for a reason to explain why they had suffered CA, and if explanations were found, they tried to conduct lifestyle changes, though doing so sometimes meant choosing less healthy behaviours in favour of living a good life. Results also show that people who shared their thoughts about their lifestyles and their risk factors were aware of their risk factors and had knowledge about healthy behaviours (II). These participants were motivated to perform lifestyle changes and did so, though they occasionally neglected making the good choices in favour of more pleasurable choices. Lifestyle was connected with joyful activities, having fun, and the significance of living a good life. Participants acknowledged that life can change quickly and that from one moment to the next you can be gone (III–IV). The fragility of life was currently apparent in their daily lives in ways different from those before the OHCA-V event. All participants had wondered whether CA would recur and, as a result, found it important to enjoy their lives. Perhaps this partly explains why people surviving OHCA-V want to live their lives to the fullest; in doing so, they get the most out of their lives in the present and do not focus too much on the future, since there is no guarantee that tomorrow will come.

Lifestyle was described by participants to include, most importantly, having social relationships, doing things with other people, and feeling needed (II).

They described the significance of their families' being present during their recoveries and were grateful for all the support that had been given to them (III–IV). Suffering cardiac disease affects both the person and his or her family, and behaviours within the family affect all family members.¹⁰⁵ A review of the natural history of recovery from CA and the implantation of an ICD illustrates the importance of involving both patients and family members in nursing interventions. People surviving CA are often affected both physically, psychologically, and neurologically, and their family play an important role in the recovery process by giving support and being involved in his or /her learning to manage a new life situation.¹⁰⁶

Participants described believing that stress at work, financial concerns, and not being able to find a way out of an unhealthy behaviour could each have explained their suffering CA (II). Psychosocial factors can be divided into two categories: emotional factors and chronic stressors. Emotional factors include depression and anxiety, as well as aggression and hostility. Chronic stressors are connected to low social support, low socioeconomic status, work stress, and marital stress. An imbalance between job demands and the possibility to influence one's work situation is an aspect connected to chronic stress; another is the imbalance between job effort and job reward. There is an overlap between emotional and chronic stressors; for example, stress at work can contribute to general anger and difficulties at home and is associated with higher frequency of

depression. Psychological components, such as presence of energy and enthusiasm, might be central to developing emotional and coping flexibility for handling stress. Emotions like, joy and general interestedness reinforce this coping flexibility and derive from a sense of purpose and self-worth.¹⁰⁷

Participants described having neither the strength nor energy to change their situations, though the dramatic event of CA was nevertheless expressed as a turning point that helped them to make changes in their life situations related to stress at work. They searched for a reason to explain why they suffered the event and even expressed gratitude for the event that had made them set goals for improvement, including changing their job situations (II).

When people suffer an acute illness, existential concerns might arise. In these studies, participants asked questions such as ‘Why did this happen to me?’, ‘How will life become?’, and ‘What is the meaning of this?’ (II–IV). In general, for people to be able to move on, it is necessary to find meaning in what has happened. By setting goals for something better, hope is nurtured; thus hope is a prerequisite for finding meaning. By the same token, without hope there is no meaning.^{108,109} Three elderly women aged greater than 93 years who lived in a nursing home were interviewed about how they create meaning in their daily lives. For these women meaning in their present lives was connected to meaning in their earlier lives and was expressed as ‘still wanting to be needed’, ‘having a sense of physical and cognitive capability’, ‘having a sense of belonging’, and

‘having communication and relationships with others’. They also described that an inner dialogue facilitated meaning creation in both their past and present lives. Inner dialogue can be understood to be the conversation that a person has with him or herself, which is affected who the person is and his or her outlook in life.¹¹⁰ These aspects can be identified in the results at times when participants described the importance of social relationships (II) and the significance of family and friends for support and moving through tough times (III–IV). Participants who expressed having cognitive and physical impairments (III–IV) also expressed more concerns about how life would continue and felt loss when chores they had always performed no longer worked out for them anymore, meaning that other family members had to assume more responsibility for these tasks. Participants also expressed wishing to feel needed and that family and friends were significant to that feeling (II–IV). Human relationships have been found to be important to finding hope and meaning in life,¹⁰⁹ in addition to being closely connected to the feeling of being needed.^{109,110}

The pendulum motion in participants’ narratives was clear when they expressed hope in regaining their ordinary lives by, for example, getting back to work and feeling secure with their bodies again, as well as in their emotional swings between time periods before and after OHCA-V. Participants expressed thoughts of loss upon suddenly being struck by illness and described not knowing their bodily strength and feeling that they had unfamiliar bodies (III–IV). A similar

desire for normality has been described in the pre hospital phase of people suffering MI,¹¹¹ among people with cancer,¹⁰⁹ and people living with serious chronic illness,¹¹² as well as women living with fibromyalgia.^{113,114} The results of these studies^{112,113} are similar to the findings of these studies (III-IV), particularly in that participants longed for the lives they had lead before the illness and tried to understand their changed life situations and seek answers to explain why they had been struck by illness. Another study¹⁰⁹ described this desire as a human force to continue living as usual, since a person's usual life is closely connected with a person's identity. Participants in this study expressed that who you are affects how you interpret and handle what happens to you (IV) and can be understood as the abovementioned inner dialogue that helps to create meaning in both past and present lives.¹¹⁰ Hope has been described as the will to find meaning and is dependent on personal characteristics, personality, and outlook in life.¹⁰⁹

The meaning of hope has been explored in healthy nonreligious Swedish adults,¹⁰⁸ and were interpreted as hope related to being and was linked to experiences of meaning and awareness of the possibilities in one's life. This awareness releases energy and triggers thoughts and feelings that stimulate people to make good and meaningful choices. Hope is a prerequisite for being able to set goals and is related to doing. Setting goals means being active and hoping for a positive outcome. Participants expressed that hope was a positive experience

and a will to be and to live, and from hope, meaning in life is experienced. Setting goals, having something to strive and hope for also means taking risks and requires courage, though there is a risk of disappointment. A person can only hope and believing in something better. Participants expressed that meaningful relationships were connected to experiences of hope. Good relationships meant confirmation of one's value and a sense of being needed; thus wishing nurtured hope. Hope was also connected to well-being when participating in joyful activities.¹⁰⁸ Results show that people surviving OHCA-V (III–IV) sought answers to explain why they had suffered the event and that they sought meaning in their continued lives. They hoped to resume their ordinary lives and challenge themselves with different activities, which were increased with time. This can be understood by their setting both short- and long-term goals.

Conclusion

This doctoral thesis shows a decrease in OHCA-V incidence in northern Sweden and an increase in people survival. Many people suffering OHCA-V had no previous history of IHD and had no previous contact with the health care system, though risk factors for CHD were not unusual. Primary and secondary preventive measures are of utmost importance in addressing the risk of suffering CHD and its complications. The results of this thesis thus suggest that further efforts be made to teach CPR in communities, for the majority of CA events occur outside hospital settings and early CPR performed by bystanders can increase the chances of survival. Results reveal a paradox, that when people surviving OHCA-V were aware of their cardiovascular risk factors and the benefits of risk factor treatment, they occasionally ignored such knowledge and preferred to live good lives. Results also show the significance of lifestyles connected to family and friends and joyful activities. Family-centred cardiac care should perhaps be increased to improve healthy behaviours within the whole family of the person surviving OHCA-V, since behaviours in the family affect the whole family.

Results also show that people surviving OHCA-V described waking up with the realization that they had suffered CA and needed to fill ‘the black box’ with information about what had happened to them while they were

dead/unconscious. Health care personnel play an important role in fulfilling this wish, both during the acute phase and follow-up visits. Participants were grateful to the people who returned them to life and expressed being dead, regaining life, and thus revaluing life. They had become aware of life's fragility and expressed having been given a second chance at life. Meanings of surviving OHCA-V were interpreted as resembling a pendulum's motion since participants' emotions and thoughts oscillated among their past, present, and future lives. The CA event had affected them and was still present in their lives, even though time had passed since the event. Awareness of these aspects expressed by people surviving CA are important to highlight in the meeting between the surviving person and health care personnel in order to support and promote health according to the person's individual needs.

Clinical implications

Knowledge about people's experiences presented in this thesis can be useful in cardiac care, particularly in the meeting with people who have survived OHCA-V. The issues presented regarding lifestyle behaviours and lifestyle changes, existential concerns, setting goals and finding meaning in a new life situation, experiencing an unfamiliar body, and striving for ordinary life to return can be addressed in the dialogue between the person and health care personnel.

Participants expressed needing information about what had happened to them while they were dead/unconscious and wanting people who had attended the CA and cared for them during their hospital stay to (re)tell the story. Furthermore, they wanted more information about the consequences of receiving CPR, as tremendous pain from the chest had caused anxiety for them.

During the interviews, participants expressed wanting to contribute and to improve care for people who would suffer CA after them and wishing that practical matters regarding sick notes, sick leave, and other certificates could be more efficiently attended to, as these matters had caused them agony and troubles. Participants reported wanting information about when future visits to the nurse or doctor had been planned and whether visits were to be attended at the hospital or health care centre. They expressed that attending the cardiac rehabilitation group had been very valuable, for it combined information from

different professionals and physical activities. Participants found it most valuable that their spouses had been invited to attend the group as well, for the spouses could then receive the same information that could facilitate their daily lives.

Swedish summary - Svensk sammanfattning

En andra chans i livet. En studie om personer som överlevt hjärtstopp utanför sjukhus.

Inledning

Att drabbas av hjärtstopp utanför sjukhus innebär en plötslig och oväntad händelse för de drabbade personerna. Den största andelen av personer som drabbas av hjärtstopp utanför sjukhusmiljö avlider innan de får hjälp. Trots detta finns det personer som överlever och de har varit med om en omvälvande upplevelse som påverkar livet efter. I denna avhandling var syftet att studera hur förekomst och överlevnad efter hjärtstopp utanför sjukhus har utvecklats under en 19 års period i norra Sverige. Avhandlingen beskriver även vilka riskfaktorer för hjärt- kärlsjukdom personerna hade innan de drabbades av hjärtstopp, och de överlevande personernas tankar om sin livsstil. Syftet med avhandlingen var även att beskriva innebörden av att överleva ett hjärtstopp eftersom det finns få studier som beskriver hur personer som överlevt hjärtstopp utanför sjukhus upplever livet efter den händelsen.

Bakgrund

I Sverige drabbas årligen ca 10,000 personer av hjärtstopp utanför sjukhus, hälften av personerna nås av hjärt- och lungräddningsinsats och cirka 500 personer överlever. Nationellt register för hjärtstopp utanför sjukhus, inkluderar personer som drabbats av hjärtstopp och där någon form av behandling påbörjats

av ambulanspersonal eller av annan person före ambulanspersonalens ankomst. Personer som inte får någon behandling exkluderas. Flertalet studier som beskriver hjärtstopp utanför sjukhus exkluderar personer som drabbas och avlider innan hjälp hinner fram. Orsaken till hjärtstoppet bedöms ofta av ambulanspersonal som anländer först till personen och den orsaken kontrolleras sällan av ambulansläkare. Hjärtsjukdom anses orsaka cirka 67 procent av hjärtstoppen hos de drabbade personerna. Traditionella riskfaktorer för hjärt-kärlsjukdom som förhöjda blodfetter, rökning, högt blodtryck, ålder, fetma och diabetes mellitus är förknippade med risk för plötslig hjärtdöd. Kontroll av riskfaktorer för hjärt-kärlsjukdom associeras med betydande minskning av död i hjärt-kärlsjukdom och indirekt minskad risk för plötslig hjärtdöd. Många olika faktorer i personers liv påverkar den sammantagna risken att utveckla hjärt-kärlsjukdom och preventiva åtgärder är därför betydelsefulla.

För en del personer är hjärtstopp utanför sjukhus det första symtomet på hjärt-kärlsjukdom och innebär en anpassning till en livslång sjukdom där kontroll av riskfaktorer är viktigt för fortsatt hälsa och överlevnad. Få studier har identifierats där personer som överlevt hjärtstopp utanför sjukhus själva får berätta om hur livet påverkas av den händelsen.

Rational

MONICA-Hjärtinfarktregistret i norra Sverige, är en populationsbaserad totalundersökning, som ger en unik möjlighet att följa incidens, överlevnad och

dödlighet i hjärtstopp utanför sjukhus. Varje hjärthändelse har validerats efter WHO's kriterier och säkerställer för överlevande personer hjärtinfarkt som bakomliggande orsak och för avlidna personer säker eller trolig hjärtinfarkt som bakomliggande orsak. Registret inkluderar även hjärtstopp utanför sjukhus där hjärt- och lungräddande behandling inte påbörjats. Att över en 19-års period, 1989-2007, beskriva trender i incidens, överlevnad och dödlighet i hjärtstopp utanför sjukhus kan generera kunskap som kompletterar befintlig forskning, som exkluderar personer som ej fått behandling. Att beskriva vilka riskfaktorer för hjärt-kärlsjukdom personerna hade innan hjärtstoppet och komplettera med intervjuer med överlevande personer som får berätta om sina tankar kring livsstil efter att ha överlevt kan ge värdefull information och kunskap i det fortsatta preventiva arbetet för att förhindra hjärt-kärlsjukdom och dess komplikationer. Att belysa innebörder i personers levda erfarenheter av att överleva hjärtstopp och deras fortsatta liv ger kunskap i ett område som idag är relativt utforskat. Kunskapen kan användas i den uppföljande vården och omvårdnaden av personer som överlevt hjärtstopp utanför sjukhus för att bättre kunna möta personernas behov i dagligt liv och för att stödja deras välbefinnande.

Övergripande syfte

Avhandlingens övergripande syfte var att beskriva personers liv före och efter det att de drabbats av hjärtstopp utanför sjukhus, orsakat av validerad hjärtinfarkt, följande specifika syften formulerades: *att beskriva trender i incidens, överlevnad/död och bakgrundskaraktäristika hos personer som*

drabbats av hjärtstopp (I), att beskriva riskfaktorer och tankar om livsstil hos personer som överlevt hjärtstopp (II), att belysa innebörder i personers levda erfarenhet av att överleva, 1 månad efter hjärtstoppet (III), belysa innebörder i personers levda erfarenhet av att överleva, 6 och 12 månader efter hjärtstoppet (IV).

Delstudie I

Syftet med delstudien var att under en 19-års period beskriva incidens, överlevnad och dödlighet hos personer som drabbats av hjärtstopp utanför sjukhus orsakat av validerad hjärtinfarkt. Även personernas bakgrundskaraktäristika presenteras i studien. Data inhämtades från norra Sveriges MONICA-Hjärtinfarktregister, 1989-2007, och innebar 2,977 personer i åldern 25-74 år. Både personer som fått hjärt- och lungräddning och de som avlidit innan behandling hunnit påbörjats inkluderades. Personerna delades in i två grupper, 25-64 åringar som studerades mellan 1989-2007, och 65-74 åringar som studerades mellan 2000-2007. Data har analyserats med beskrivande och analytisk statistik.

Resultaten visade att incidensen minskade signifikant i båda åldersgrupperna och likaså andelen personer med tidigare känd ischemisk hjärtsjukdom innan hjärtstoppet. Andelen personer med tidigare känd hjärtinfarkt, diabetes mellitus, kranskärls intervention ökade signifikant och även överlevnad efter hjärtstopp ökade i den yngre gruppen men inte i den äldre gruppen. Andelen personer som

överlevde var liten men i ökande (71 av de 2,977 personerna levde den 28:e dagen efter symtomdebut) och långtidsöverlevnaden var bättre i den yngre gruppen.

Delstudie II

Syftet med delstudien, som har en mixad metoddesign, var att beskriva vilka riskfaktorer för hjärt-kärlsjukdom personer som överlevt hjärtstopp utanför sjukhus hade innan hjärtstoppet och beskriva deras tankar kring livsstil efter hjärtstoppet. Deltagarna identifierades i norra Sveriges MONICA-Hjärtinfarktregister och var de 71 överlevande personerna från Delstudie I. Data kring personernas riskfaktorer för hjärt-kärlsjukdom samlades in via MONICA-Hjärtinfarktregistret och kompletterades med data från Västerbottens hälsoundersökning, (VIP). Till de personer som fortfarande var vid liv 2011-01-25, 46 personer, skickades ett brev med förfrågan om att besvara en enkät kring sina riskfaktorer för hjärt-kärlsjukdom och/eller delta i en intervju gällande deras tankar kring livsstil. Trettiotvå personer besvarade enkäten vars svar kompletterade riskfaktordata. Där datauppgifter fortfarande saknades utfördes journalgranskning i ett försök att få så kompletta data som möjligt. Tretton personer samtyckte till intervju, de hade haft hjärtstoppet för 4-17 år sedan och var 52-81 år vid intervjutillfället. Data analyserades med beskrivande statistik respektive kvalitativ innehållsanalys.

Resultaten visade att innan hjärtstoppet hade 40 procent av personerna tidigare känd ischemisk hjärtsjukdom, 25 procent hade haft en tidigare hjärtinfarkt, 20 procent hade tre riskfaktorer för hjärt-kärlsjukdom (högt blodtryck, diabetes mellitus, total kolesterol ≥ 5.0 mmol/l och/eller blodfettssänkande behandling, nuvarande rökare). Resultaten visade att av de 71 personerna var hälften rökare och drygt 63 procent hade övervikt/fetma när hjärtstoppet inträffade.

Den kvalitativa analysen resulterade i tre kategorier med subkategorier.

Den första kategorin, *Beskrivningar av livsstil*, inkluderade subkategorierna *Att finna glädje och styrka i meningsfulla relationer* och *Att få må bra och välja saker man vill göra*. Personerna beskrev att betydelsen av livsstil var att ha människor omkring sig, att betyda något för någon och att ha någon att bry sig om. Att känna sig behövd var betydelsefullt. De beskrev att livsstil är att få må bra, vilket de inte tog för givet.

Den andra kategorin, *Att anpassa livsstilen till en ny livssituation*, innefattade subkategorierna *Att finna en orsak till varför det hände och göra livsstilsförändringar* och *Att göra en egen värdering av ett risk beteende*.

Personerna beskrev att de funderade över orsaken till att de drabbats av hjärtinfarkt/hjärtstopp. De menade att cigarett rökning och stress på jobbet kunde vara bidragande orsaker och deltagarna försökte göra livsstilsförändringar

utifrån orsakerna de fann. Personerna var medvetna om sina riskfaktorer och var informerade om fördelarna med hälsosamma livsstilsval, men de beskrev även att de gjorde en egen värdering av informationen.

Den tredje kategorin, *En förändrad syn på livet*, omfattade subkategorierna *Att känna tacksamhet för en andra chans i livet*, *Att finna motivation till livsstilsförändring* och *önska påverka familjemedlemmar till livsstilsförändringar* och *Att utmana sin rädsla och ha en positiv livssyn*.

Personerna kände tacksamhet över att de fått en andra chans i livet och beskrev betydelsen av att göra saker de tyckte om och fann glädje i, vilket resulterade i att de ibland prioriterade "att leva ett gott liv" istället för att göra de mesta hälsosamma valen.

Delstudie III

Syftet med delstudien var att belysa innebörder i personers levda erfarenhet av att överleva, 1 månad efter hjärtstoppet. Data samlades in via intervjuer med personer som överlevt hjärtstopp. Personer informerades om studien och dess syfte ca 1 månad efter hjärtstoppet när han/hon hade ett inplanerat besök hos hjärtsköterskan på något av sjukhusen i Västerbotten och Norrbotten. Personer som önskade delta medgav att författaren (A-SF) ringde upp för att boka tid och plats för en första intervju. De medgav att bli intervjuade vid tre tillfällen, ca 1, 6, och 12 månader efter hjärtstoppet (intervjuerna vid 6 och 12 månader presenteras i Delstudie IV). Elva personer, två kvinnor och nio män, 49-73 år

gamla, deltog i studien, och intervjuades februari 2011-maj 2012. Personerna ombads att berätta vad som hade hänt dem den dagen de blev sjuk, och uppmuntrades att berätta fritt om sina upplevelser av sitt dagliga liv efter hjärtstoppet. Intervjutexterna analyserades med en fenomenologisk hermeneutisk tolkningsmetod, vilken syftar till att belysa innebörder i personers levda erfarenheter.

Resultatet av analysen sammanfattades i två teman; *Att återvända till livet* och *Att omvärdera livet*. Personerna berättade att när de drabbades av hjärtstopp innebar det en plötslig och oväntad händelse, utan symptom vilka de kopplade ihop med hjärtat. Att överleva innebar att vakna upp, och inse att de hade haft hjärtstopp och blivit återupplivade. De hade sporadiska minnesbilder och hade behov av att få berättat vad som hänt dem under den tid de varit död/medvetslös, och det var viktigt att det var personer som varit närvarande under händelsen som berättade för dem. Personerna var tacksamma att människor hade agerat när de blev sjuk och beskrev att utan den insatsen hade de inte levt idag. De reflekterade över sitt tidigare liv och sökte en förklaring till varför de drabbats av hjärtstopp. De kände tacksamhet över familj och vänners vänlighet och allt stöd som de hade fått. Personerna funderade över om livet skulle bli som vanligt igen, eftersom de var oerhört trötta och saknade energi när de kom hem från sjukhuset. Vardagliga aktiviteter de tidigare utfört utan att ens fundera var nu

ansträngande. De önskade kunna göra saker de tidigare gjort och såg fram emot att livet skulle bli som vanligt.

Delstudie IV

Syftet med delstudien var att belysa innebörder i personers levda erfarenheter av att överleva, 6 och 12 månader efter hjärtstoppet. Alla 11 personer som intervjuades efter ca 1 månad i Delstudie III intervjuades även efter 6 och 12 månader. Intervjuer genomfördes juni 2011-april 2013. Intervjutexterna analyserade med en fenomenologisk hermeneutisk tolkningsmetod och 6 månaders intervjuer analyserades separat från 12 månaders intervjuer.

Analysen av intervjutexterna vid 6 månader resulterade i 2 teman, *Strävan efter kontroll* och *Att vara den du är*. Temat *Strävan efter kontroll* består av två subteman, *Att testa kroppen* och *Att återgå till vardagen*. Temat *Att vara den du är* består av två subteman, *Förundran över det som hänt* och *Att vilja veta men också lämna det bakom sig*.

Sex månader efter hjärtstoppet beskrev personer att när de drabbades av sjukdom innebar det att deras känsla av trygghet med sin kropp påverkades, de visste inte längre vad kroppen klarade av. De längtade efter att känna sig trygga med sin kropp igen, vilket innebar att testa sin kropp, vad den klarade av och inte klarade av, och att anpassa aktiviteter utifrån kroppens förutsättningar. Personer hade upplevt smärta i bröstet vilket ledde till oro och osäkerhet, och de

uttryckte att de önskat mer information om bröstsmärta efter återupplivning för att då ha undvikit onödig oro förknippad med smärtan. De beskrev att de sökte orsaker till symptom de upplevde och ibland skyllde de på mediciner, dess effekter och biverkningar, som orsak till symptomen. Personer beskrev betydelsen av att bli undersökt och testad av doktorn, få provresultat som var normala ansågs vara ett kvitto på att de kunde gå vidare i sitt vanliga liv. De kände förundran över att allt hade fungerat så bra och händelsen påverkade deras fortsatta liv, men betonade att ”vem du är påverkar hur du tar saker”, förståelsen av händelsen och hur de tog sig an framtiden. Personer uttryckte att de ville veta vad som hänt dem, men samtidigt lägga händelsen bakom sig. De hade fått livet tillbaka och beskrev att de ville fokusera på framtiden, men de planerade inte alltför mycket framåt utan försöka leva mer en dag i taget, eftersom livet plötsligt kan förändras och det tar slut.

Analysen av intervjutexterna vid 12 månader resulterade i 2 teman, *Återblick* och *Framsynthet*. Temat *Återblick* består av fyra subteman, *Att återfå en känsla av trygghet med sin kropp*, *Att vilja bli undersökt och deklarerad frisk*, *Att omfamna förändringar* och *Att påverka omgivningen*. Temat *Framsynthet* består av tre subteman *Att vilja återgå till vardagen*, *Att vara bättre förberedd om det händer igen* och *Att planera för framtiden*.

Tolv månader efter hjärtstoppet beskrev personer att de hade återfunnit en känsla av vad deras kropp klarade av efter att ha utmanat, testat och utvärderat den i olika situationer. Personer som drabbats av förnyade sjukdomshändelser under året hade upprepade gånger varit tvungna att försöka återfinna kontroll över sin kropp. De upplevde att besöken hos läkaren inte hade fungerat optimalt, de hade velat ha besök där de hade haft möjligheten att ställa frågor och få svar som gick att begripa, och bli undersökt och få ett kvitto på att de var okej. Ett år efter händelsen beskrev de att de hade anammat förändringar i sitt liv. De uppmärksammade sina egna och andras behov, men prioriterade sig själv och sina behov lättare än tidigare. Personer som upplevde kognitiva nedsättningar hade anpassat sig till en ny vardagssituation. Detta fick dem att ibland känna att de inte var samma människa, vilket fick dem att känna skam och resulterade i att de isolerade sig.

Familj och vänner beskrevs som oerhört värdefulla genom att de gav kärlek och stöd, men personer uttryckte även att det var viktigt att de fick känna att de fick ta sina egna beslut utan att andra talade om för dem vad de borde göra. Personer ville återuppta sitt vanliga liv och beskrev vissa aktiviteter vara en betydelsefull del i deras liv. Dessa aktiviteter önskade de fortsätta med eftersom de var förknippade med glädje och gav dem positiv energi. De blickade framåt men planerade inte alltför mycket, händelsen hade gjort dem medveten om att värdera tiden som gavs dem. Innebörder i personers levda erfarenhet av att

överleva hjärtstopp kan förstås som en pendelrörelse, där personers beskrivningar av sitt dagliga liv innebar tankar som pendlade mellan livet före och efter hjärtstoppet, likaså tankar om själva händelsen och framtiden.

Slutsats

Denna doktorsavhandling visade att incidensen i hjärtstopp som inträffar utanför sjukhus minskade i norra Sverige under den studerade 19-års perioden, 1989-2007. Många människor som drabbas av hjärtstopp utanför sjukhus har ingen tidigare känd ischemisk hjärtsjukdom och är okända/har ingen kontakt med hälso- och sjukvården sedan tidigare, men att de har riskfaktorer för hjärt-kärlsjukdom är inte ovanligt. Primär och sekundär prevention är av yttersta vikt för att motverka risken att insjukna i hjärt-kärlsjukdom och dess komplikationer. Vidare visar resultaten i denna avhandling på vikten av fortsatt utbildning av hjärt- och lungräddning i samhället eftersom majoriteten av hjärtstopp inträffar utanför sjukhus och tidig hjärt- och lungräddning utförd av lekman kan öka överlevnaden.

Resultaten i denna avhandling avslöjar en paradox eftersom människor som överlevt hjärtstopp utanför sjukhus var medvetna om sina riskfaktorer för hjärt-kärlsjukdom och vinsten med behandling av dessa, men samtidigt valde personer att ibland bortse från den kunskapen och föredrog att leva ett gott liv. Resultaten visar att livsstil för människor som överlevt hjärtstopp var att ha

människor omkring sig, att betyda något och känna sig behövd av familj och vänner, och även att kunna göra saker man tyckte var roliga och fann meningsfulla. Familje-centrerad vård kan vara en möjlighet att förbättra livsstilsvanor hos personer som överlevt hjärtstopp, eftersom vanor inom familjen påverkar den drabbade.

Resultaten i avhandlingen visar att personer som överlevt hjärtstopp utanför sjukhus vaknar upp och inser att de har drabbats av hjärtstopp och återupplivats. De har behov av att få veta vad som hänt dem under den tid de var död/medvetlös och låg på sjukhuset, att fylla den 'svarta lådan' med information. Hälso- och sjukvårdspersonal har en viktig uppgift i att uppfylla denna önskan om information, både i den akuta fasen och på återbesök. Personer kände tacksamhet till de människor som räddat dem tillbaka till livet, de uttryckte att de varit död och återfått livet, denna insikt ledde till omvärdering av livet. De upplevde en medvetenhet om livets skörhet och uttryckte att de fått en andra chans i livet. Innebörder i upplevelser av att överleva hjärtstopp utanför sjukhus kan tolkas som en pendlande rörelse, där personers tankar pendlande mellan dåtida, nutida och framtida liv. Händelsen hade påverkat dem och var fortfarande närvarande i personernas liv trots att tid hade passerat sedan det inträffade. Medvetenheten om dessa aspekter som personer som överlevt uttryckt kan vara betydelsefulla att lyfta fram i mötet mellan personen som

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Paper I

Trends in incidence and outcome of out-of-hospital cardiac arrest among people with validated myocardial infarction

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Trends in incidence and outcome of out-of-hospital cardiac arrest among people with validated myocardial infarction

Ann-Sofie Forslund^{1,2}, Siv Söderberg², Jan-Håkan Jansson^{3,4} and Dan Lundblad^{4,5}

Abstract

Aims: To describe trends in incidence, outcome, and background characteristics among people who suffered an out-of-hospital cardiac arrest with validated myocardial infarction aetiology (OHCA-V).

Methods and results: People from the northern Sweden MONICA myocardial registry (1989–2007) with OHCA-V ($n = 2977$) were divided in two age groups (25–64 and 65–74 years). Both those who were resuscitated outside hospital and those who died before resuscitation was started were included in the study. The younger age group was studied during 1989–2007 and the older group during 2000–2007. The incidence of OHCA-V decreased in both the younger group (men $p < 0.0001$, women $p = 0.04$) and the older group (men $p < 0.0001$, women $p < 0.0007$, respectively). The proportion with a history of ischaemic heart disease prior to the event decreased ($p < 0.0001$). The proportion of previous myocardial infarction decreased ($p < 0.0001$), diabetes mellitus increased ($p = 0.001$), coronary interventions increased ($p < 0.0001$), and survival after OHCA-V increased ($p < 0.0001$) in the younger group but not in the older group. Long-term survival after OHCA-V was better in the younger than in the older group ($p = 0.026$).

Conclusion: The incidence of OHCA-V decreased in both sexes. The proportion surviving after OHCA-V was small but increased, and long-term survival (≥ 28 days) was better in the younger age group. Primary preventive measures may explain most of the improvements. However, the effects of secondary preventive measures cannot be excluded.

Keywords

Incidence, myocardial infarction, out-of-hospital cardiac arrest, prevention, survival, trends

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Introduction

Primary and secondary prevention measures are of utmost importance for the outcome of coronary heart diseases (CHD). Preventive measures are associated with a decrease in death and sudden cardiac death (SCD). The World Health Organization (WHO) estimated that 17.1 million people died from cardiovascular diseases (CVD) in 2004, representing 29% of global deaths. Of these, 7.2 million people died from CHD.¹ Several studies from the 1970s and onwards have shown that 66–74% of the deaths from acute CHD occur outside hospital.^{2–6} A meta-analysis⁷ showed no significant improvement in survival after out-of-hospital cardiac arrest (OHCA) during the last 30 years. Approximately 92% still die before being

discharged from the hospital, but sudden deaths that occurred before resuscitation attempts could be done

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were all excluded from the studies. The WHO MONICA (multinational MONItoring of trends and determinants in CARDiovascular disease) project showed that, among people who suffered fatal coronary events, a history of CHD had been known in 41–98% of the people.⁸ However, other studies have shown that 40–60% of CHD deaths have had no prior history of CHD.^{6,9,10}

Few studies that describe the incidence and outcome of OHCA have included people with OHCA where no resuscitation attempts had been done. Furthermore, the aetiology behind the cardiac arrest is seldom validated. In the present study we describe incidence and outcome from out-of-hospital cardiac arrest with validated myocardial infarction (MI) aetiology (OHCA-V). We included both those who were resuscitated outside hospital and those who died before resuscitation was started; hence, the complete spectrum of OHCA-V in a whole community is described.

The aim of this study was two-fold: (1) to describe trends in incidence and outcome among people who had suffered an OHCA-V; and (2) to describe trends in background characteristics such as age, sex, history of ischaemic heart disease (IHD), previous MI, diabetes mellitus (DM), and coronary interventions.

Methods

Design and setting

Since 1985, Norrbotten and Västerbotten County Councils, in the northern part of Sweden, have registered people with MI in the context of the WHO MONICA project. All people who have experienced a cardiac event and have been cared for in one of the hospitals or health centres in the two counties are eligible for the registry. People who have suffered a cardiac event outside hospital or health centre are also eligible for registration. Hence, all MI events are included in this population-based project.¹¹

Registration procedure

The cardiac events are obtained from medical records, death certificates, and necropsy reports. Trained nurses, who are supervised by the register physicians, have validated all the events according to WHO diagnostic criteria for definite or possible MI based on a combination of medical history, clinical symptoms, cardiac biomarkers, and electrocardiogram in the same way for fatal as for non-fatal events.^{11,12} For fatal events necropsy findings, if any, and history of IHD also are used. Based on the original WHO protocol, fatal events are those who die within 27 days after onset of symptoms. Non-fatal events are those who live 28 or more days

after onset of symptoms. History of IHD, previous MI, DM, coronary interventions (coronary angioplasty and/or coronary bypass procedures), and outcome are also registered for each event. Initially only men and women between 25 and 64 years of age were included, but from the year 2000 those aged 65–74 years were also included. The validation process is described in detail elsewhere.^{8,11–13}

Study population

All people registered from 1989 to 2007 in the northern Sweden MONICA myocardial registry were included based on the following inclusion criteria: 25–74 years of age, resident in Norrbotten or Västerbotten county, had an OHCA defined as the first cardiac arrest occurring outside hospital (not in ambulance or emergency department), and caused by a definite or possible MI. This includes both those who were resuscitated outside hospital and those who died before resuscitation was started. The study population was divided into two groups according to age: 25–64 years and 65–74 years. Long-term survival was followed until 25 January 2010. The proportion of necropsies performed during this study period was higher in the younger age group (60–75% vs. 38–52%) and increased during the study period ($p=0.0001$), but in the older age group there was no significant change over time ($p=0.127$). All people with non-fatal MIs registered in the Sweden MONICA myocardial registry have given their consent for registration. Approval for the study was obtained from the Regional Ethical Board.

Statistical methods

Insufficient data varied due to variable and year and ranged between 0 and 16% (Supplementary material Appendices 1 and 2). Events in the older age group were registered during a shorter time period (2000–2007) and are therefore analysed separately from the younger age group. Absolute numbers and proportions of characteristics and survival time in the OHCA-V population are described. Crude incidence rates were calculated for each strata by dividing new OHCA-V events with the mid-year population of Norrbotten and Västerbotten counties and reported per 100,000 person-years. Age-standardized incidence rates resulted in even more pronounced differences in the younger age group. p -value for trend was calculated with Chi-Square test and Linear-by-Linear Association (Chi Square test for trend). Kaplan-Meier and the log rank test were used for long-term survival analyses. The tests were two-tailed and a p -value <0.05 was considered significant. Analyses were performed with PASW Statistics, version 18.0.

Results

Figure 1A shows that during a period of 19 years, 1989–2007, a total of 9938 events with MI among people aged 25–64 years were registered. This included 2082 people with OHCA-V, and 57 (2.7%) were alive 28 days after the onset of symptoms. Figure 1B shows

that during a period of eight years, 2000–2007, a total of 4278 MI events were registered among people aged 65–74 years. This included 895 people with OHCA-V, and 14 (1.6%) were alive 28 days after onset of symptoms. The proportion which received CPR was 49% in the younger age group and 39% in the older age group, survival to 28 days was 5.3 vs. 4.0%, respectively.

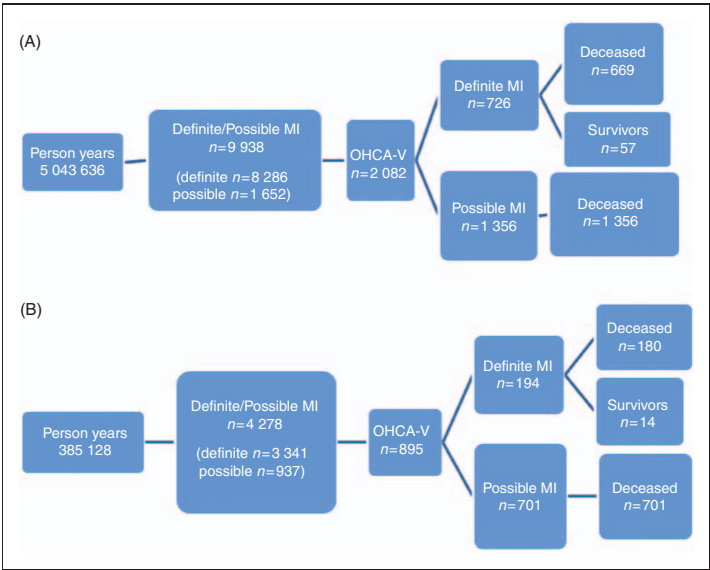


Figure 1. Flowchart of the study population: (A) aged 25–64 years, 1989–2007 and (B) aged 65–74 years, 2000–2007.

Table 1. Incidence of MI and OHCA-V per 100,000 and survival time in the OHCA-V population: 25–64 years, 1989–2007

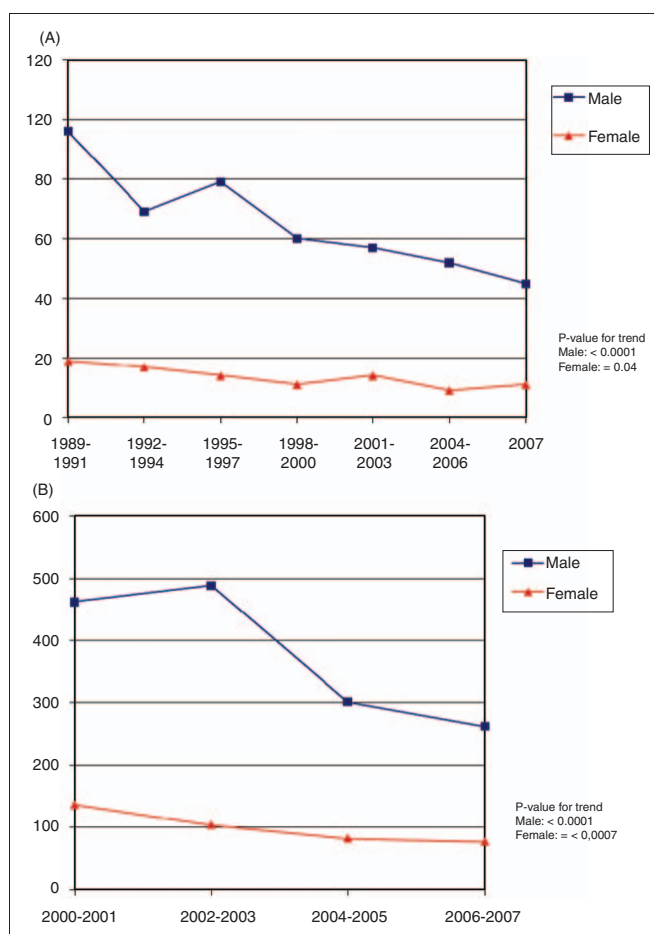
Variable	1989–1991	1992–1994	1995–1997	1998–2000	2001–2003	2004–2006	2007	p-value for trend
Definite/possible MI (n)	239	204	194	188	193	174	169	
OHCA-V (n)	58	44	47	36	36	31	29	
Risk ratio	0.24	0.22	0.24	0.19	0.19	0.18	0.17	<0.0001
Survival time (% , 95% CI)								
<1 h	57.3 (52.7–61.9)	68.6 (63.7–73.5)	65.1 (60.2–70.0)	59.4 (53.6–65.1)	66.4 (60.6–72.2)	66.1 (59.5–72.9)	50.0 (37.8–62.2)	
<24 h	94.5 (92.4–96.6)	93.4 (90.7–96.0)	92.9 (90.3–95.6)	92.2 (89.1–95.4)	92.7 (89.5–95.9)	92.3 (88.5–96.1)	97.1 (93.0–101.2)	0.519
Survival to 28 days (n)	6	4	15	4	9	13	6	
Survival to 28 days (% , 95% CI)	1.3 (0.3–2.4)	1.1 (0.0–2.3)	3.9 (2.0–5.9)	1.4 (0.0–2.7)	3.2 (1.1–5.2)	5.3 (2.5–8.1)	8.0 (1.7–14.3)	<0.0001

CI, confidence interval; MI, myocardial infarction; OHCA-V, out-of-hospital cardiac arrest with validated myocardial infarction aetiology. Survival to 28 days is calculated by dividing survival to 28 days, n (from this Table) with OHCA-V, n (from Table 3).

Table 2. Incidence of MI and OHCA-V per 100,000 and survival time in the OHCA-V population: 65–74 years, 2000–2007

Variable	2000–2001	2002–2003	2004–2005	2006–2007	p-value for trend
Definite/possible MI (n)	1361	1307	1083	879	
OHCA-V (n)	291	288	187	166	
Risk ratio	0.21	0.22	0.17	0.19	0.006
Survival time (%; 95% CI)					
<1 h	62.8 (57.0–68.5)	64.0 (58.3–69.8)	67.4 (59.6–75.1)	56.3 (48.3–64.3)	
<24 h	94.2 (91.4–97.0)	91.8 (88.4–95.1)	93.8 (89.7–97.8)	95.4 (92.0–98.8)	0.595
Survival to 28 days (n)	3	2	6	3	
Survival to 28 days (%; 95% CI)	1.1 (–.1–2.3)	0.7 (–.3–1.7)	3.3 (.7–6.0)	1.8 (–.2–3.9)	0.178

CI, confidence interval; MI, myocardial infarction; OHCA-V, out-of-hospital cardiac arrest with validated myocardial infarction aetiology. Survival to 28 days is calculated by dividing survival to 28 days, *n* (from this Table) with OHCA-V, *n* (from Table 4).

**Figure 2.** Incidence rate of OHCA-V per 100,000 (A) 25–64 years, 1989–2007 and (B) 65–74 years, 2000–2007.

Trends in incidence of myocardial infarction vs. out-of-hospital cardiac arrest with validated MI aetiology

Incidence rates for MI and OHCA-V decreased during the study period in both age groups, but the incidence of OHCA-V decreased more than the incidence of MI ($p < 0.0001$ and $p = 0.006$, respectively) (Tables 1 and 2).

Trends in incidence of out-of-hospital cardiac arrest with validated MI aetiology

The incidence in OHCA-V was initially five times higher for men than women in the younger age group, but the decreases were approximately the same over time for both sexes (Figure 2A). In the older age group a similar difference between the sexes and a similar significant decrease in incidence was seen for both men and women (Figure 2B).

Trends in coexisting conditions and coronary interventions

In the OHCA-V population the mean age and the proportion between men and women were constant during the studied time period in both age groups (Tables 3 and 4). The proportion with a history of IHD prior to the event decreased in both age groups, $p < 0.0001$. The proportion with previous MI decreased in the younger age group $p < 0.0001$, but not in the older group. The proportion with a history of DM prior to the event increased in the younger age group ($p = 0.001$), but not in the older group (Tables 3 and 4). The proportion treated with angioplastic and/or coronary bypass

surgery prior to the event increased in the younger group, $p < 0.0001$ (Table 3). In the older age group the proportion that had undergone these procedures was higher than in the younger group, but there was no change during the 8-year study period (Table 4).

Trends in outcome of out-of-hospital cardiac arrest with validated MI aetiology

Table 1 shows that the proportion surviving 28 days from the onset of symptoms increased from 1.3 to 8% in the younger age group, ($p < 0.0001$). There was no change in the older age group (Table 2). In 92–97% of patients, death from OHCA-V occurred within 24 hours, and most (50–69%) of the deaths occurred within the first hour after onset of symptoms. This trend did not change during the study period (Tables 1 and 2). Long-term survival from OHCA-V showed a difference between the age groups, in favour for the younger group, ($p = 0.026$) (Figure 3). No difference was seen between the sexes (data not shown). For the few surviving an OHCA-V after 28 days the 1-, 5-, and 10-year survival was 86, 82, and 73% in the younger group and 93, 64, and 50% in the older group, respectively.

Discussion

To our knowledge this is the longest population-based study that describes trends in incidence and outcome in OHCA-V and includes all OHCA-V cases in a community with or without resuscitation attempts. Several studies have described that the incidence of, and

Table 3. Characteristics of the OHCA-V population: 25–64 years, 1989–2007

Variable	1989–1991	1992–1994	1995–1997	1998–2000	2001–2003	2004–2006	2007	p-value for trend
OHCA-V (n)	458	351	382	288	283	245	75	
Age (years, mean \pm SD)	57 \pm 7	56 \pm 7	56 \pm 7	56 \pm 6	56 \pm 6	57 \pm 6	57 \pm 6	
Male sex (%)	84.5	81.2	86.1	85.8	81.6	86.1	81.3	0.898
History of coexisting conditions (% , 95% CI)								
IHD	78.2 (74.1–82.3)	70.6 (65.7–75.5)	77.0 (72.6–81.4)	76.0 (70.7–81.2)	69.4 (63.7–75.2)	40.6 (34.1–47.1)	41.9 (30.4–53.4)	<0.0001
Previous MI	54.5 (49.9–59.1)	52.0 (46.7–57.2)	55.8 (50.8–60.8)	46.3 (40.5–52.1)	50.9 (45.0–56.8)	31.6 (25.6–37.6)	32.9 (21.8–43.9)	<0.0001
DM	15.3 (11.9–18.8)	17.5 (13.5–21.5)	20.8 (16.7–24.9)	24.5 (19.5–29.5)	25.0 (19.7–30.3)	21.8 (16.3–27.3)	24.3 (14.3–34.3)	0.001
Coronary interventions (%, 95% CI)	5.1 (3.1–7.1)	7.8 (5.0–10.6)	9.9 (6.9–13.0)	13.2 (9.3–17.2)	12.3 (8.4–16.2)	20.0 (14.7–25.3)	12.5 (4.7–20.3)	<0.0001

CI, confidence interval; DM, diabetes mellitus; IHD, ischaemic heart disease; MI, myocardial infarction; OHCA-V, out-of-hospital cardiac arrest with validated myocardial infarction aetiology.

survival rates after, OHCA vary globally because of differences in patient selection, methodology, resuscitation attempts, and various factors at the time of the cardiac arrest.^{14–16} We found a decreasing incidence of OHCA-V which corroborates a Finish study,¹⁷ while others have found no change.¹⁸ Survival to hospital discharge has been reported to vary between 1.4 and 49%.^{10,14–16} The results of the present study showed that 71 out of 2977 people (2.4%) aged 25–74 survived 28 days after onset of symptoms. Unfortunately, a comparison with previously published results is difficult due to differences in inclusion/exclusion criteria and follow-up times, i.e. discharge from hospital or 28 days after onset of symptoms. The poor survival rate in our study can be explained by the high proportion of medically unattended cardiac arrests and that we included possible MI cases only if fatal. The majority dying from OHCA-V died within 24 hours and more than half within the first hour after onset.

In a previous publication, we analysed long-term survival for MI patients 25–64 years old. When survivors after MIs (28 days and after) were compared to survivors after an OHCA-V (28 days and after) in our study, the 1-, 5-, and 10-year survival rates were 97, 90, and 82% compared to 86, 82, and 73%.¹⁹ Hence, the prognosis for survivors of an OHCA-V is relatively positive.

It has been shown that about half of the decrease in CHD mortality in Sweden could be explained by a reduction in risk factors, which emphasizes the importance of primary preventive measures.²⁰ Our results concerning people with a history of IHD or previous MI indicate that more people suffering from OHCA-V were 'healthy' prior to the event. Effective primary prevention regarding cardiovascular risk factors may explain the decreased incidence rates of OHCA-V in

our study. In the younger age group the proportion with a first MI increased, which may be the result of a decline in the incidence of recurrent MI. Recently we showed significant improvements in cardiovascular risk factors from six population surveys completed over 23 years in northern Sweden. The prevalence of smoking halved, blood pressure and cholesterol decreased, and no change in the prevalence of DM was observed.²¹ Note that those surveys were conducted during the same time period and in the same geographical area as the present study. However, these improvements do not necessarily mirror the actual risk factors for OHCA-V.

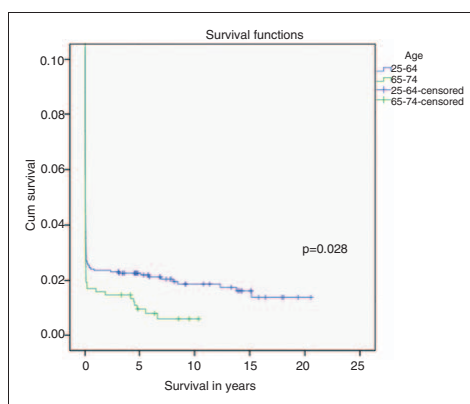


Figure 3. Long-term survival after OHCA-V, 25–64 years vs. 65–74 years. 25–64 years: 1-year survival 86%, 5-year survival 82%, 10-year survival 73%. 65–74 years: 1-year survival 93%, 5-year survival 64%, 10-year survival 50%.

Table 4. Characteristics of the OHCA-V population: 65–74 years, 2000–2007

Variable	2000–2001	2002–2003	2004–2005	2006–2007	p-value for trend
OHCA-V (n)	277	275	180	163	
Age (years, mean \pm SD)	70 \pm 3	70 \pm 3	70 \pm 3	70 \pm 3	
Male sex (%)	75.5	81.1	77.2	76.1	0.990
History of coexisting conditions (% , 95% CI)					
IHD	83.7 (79.2–88.3)	82.2 (77.4–87.1)	65.0 (57.6–72.4)	64.6 (57.0–72.1)	<0.0001
Previous MI	45.5 (39.5–51.4)	50.5 (44.6–56.5)	42.8 (35.2–50.4)	43.3 (35.5–51.1)	0.429
DM	29.4 (24.0–34.9)	27.5 (22.0–33.0)	29.8 (22.7–37.0)	33.3 (25.9–40.7)	0.385
Coronary interventions (% , 95% CI)					
	14.4 (10.3–18.6)	20.4 (15.5–25.2)	18.4 (12.3–24.5)	19.3 (12.8–25.8)	0.230

CI, confidence interval; DM, diabetes mellitus; IHD, ischaemic heart disease; MI, myocardial infarction; OHCA-V, out-of-hospital cardiac arrest with validated myocardial infarction aetiology.

The increased survival rate for the younger age group may be due to more favourable effects of medical treatment and secondary prevention including lifestyle changes in this group. There was also a significant increase in coronary interventions prior to the event among the younger people. Other possible explanations might be a more frequent use of cooling and that more automatic defibrillators have been installed in public places during the years. The survival trend for the older age group may mirror a true unfavourable prognosis due to older age and/or coexisting diseases. In addition, they were observed during a shorter and more recent time period.

Diabetes mellitus is associated with an increased risk of sudden cardiac arrest.²² Therefore primary prevention of DM and CHD and secondary prevention including lifestyle changes are highly recommended to reduce complications.²³ Non-pharmacological secondary prevention programmes for CHD, including exercise and multimodal interventions, have been shown to be safe and effective and to reduce mortality substantially.²⁴ Still, incidence and mortality in MI decreased in non-diabetics but not in diabetics over a 12-year period in northern Sweden.²⁵ The proportion with a history of DM increased in the younger age group (15–24%) in our study in contrast to a history of IHD and/or previous MI. However, this may be the result of a faster decline of OHCA-V in non-diabetics than diabetics.

The major strengths of our study are the large number of people studied over such a long period –19 years – and that each OHCA event had a validated MI aetiology. The validity of our findings is also strengthened by the strict and uniform use of the MONICA criteria over the whole period.

The main limitation and a major drawback of our study and the MONICA myocardial infarction registry is the upper age limit chosen in the WHO MONICA project. When the project was initiated in the early 1980s, the focus was on what then was regarded as premature CVD. Therefore, an upper age limit was set at 65 years for the study and 65–74-year-olds have been registered a considerably shorter period – 8 years – and thus the data concerning trends are less robust. Another limitation is the lack of information for unwitnessed OHCA-V events in people who had not attended the healthcare system prior to the event. The relation between smoking habits, hypertension, and risk of OHCA-V could not be evaluated because this information was missing in up to 50% of the medical records. There is a chance that comorbidity in older people might lead to exclusion due to uncertainty about cause of death, but all death certificates that described anything about ischaemic heart disease were validated.

Conclusion

The incidence of OHCA-V was higher for men and decreased in both men and women. The proportion surviving after an OHCA-V was small but increasing, and long-term survival was better in the younger age group. Primary preventive measures may explain most of the improvements, but effects of secondary preventive measures cannot be excluded. Further research is necessary to gain more knowledge about the total burden of risk factors for CHD before suffering an OHCA-V.

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Conflict of interest

None declared.

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Paper II

RESEARCH ARTICLE

Open Access

Risk factors among people surviving out-of-hospital cardiac arrest and their thoughts about what lifestyle means to them: a mixed methods study

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Abstract

Background: The known risk factors for coronary heart disease among people prior suffering an out-of-hospital cardiac arrest with validated myocardial infarction aetiology and their thoughts about what lifestyle means to them after surviving have rarely been described. Therefore the aim of the study was to describe risk factors and lifestyle among survivors.

Methods: An explanatory mixed methods design was used. All people registered in the Northern Sweden MONICA myocardial registry between the year 1989 to 2007 who survived out-of-hospital cardiac arrest with validated myocardial infarction aetiology and were alive at the 28th day after the onset of symptoms (n = 71) were included in the quantitative analysis. Thirteen of them participated in interviews conducted in 2011 and analysed via a qualitative manifest content analysis.

Results: About 60% of the people had no history of ischemic heart disease before the out-of-hospital cardiac arrest, but 20% had three cardiovascular risk factors (i.e., hypertension, diabetes mellitus, total cholesterol of more or equal 5 mmol/l or taking lipid lowering medication, and current smoker). Three categories (i.e., significance of lifestyle, modifying the lifestyle to the new life situation and a changed view on life) and seven sub-categories emerged from the qualitative analysis.

Conclusions: For many people out-of-hospital cardiac arrest was the first symptom of coronary heart disease. Interview participants were well informed about their cardiovascular risk factors and the benefits of risk factor treatment. In spite of that, some chose to ignore this knowledge to some extent and preferred to live a "good life", where risk factor treatment played a minor part. The importance of the support of family members in terms of feeling happy and having fun was highlighted by the interview participants and expressed as being the meaning of lifestyle. Perhaps the person with illness together with health care workers should focus more on the meaningful and joyful things in life and try to adopt healthy behaviours linked to these things.

Background

Several cardiovascular risk factors have been identified since the 1960s. The first causal factors recognized were hypertension, hypercholesterolemia, and tobacco use; thereafter, other novel risk factors associated with psycho-social surroundings and behaviour have been added [1,2]. Psycho-social risk factors are associated with

for example peoples socio-economic status, emotions like anxiety and depression and work overload [3]. According to the World Health Organization (WHO), behavioural risk factors cause about 80% of cardiovascular disease (CVD) in the world. Such risk factors include an unhealthy diet, physical inactivity, obesity, and tobacco use [4]. Despite this knowledge, not all people with coronary heart disease (CHD) get evidence-based treatments; or if they do, they often do not reach the guideline goals [5-7], thereby leading to risks of complications and premature death [8-10]. For some people, an out-of-hospital cardiac arrest (OHCA) might be the first symptom of CHD [11-15]. The incidence of treated

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OHCA varies between 28–55 per 100 000 inhabitants yearly and the overall survival to discharge is low 2–11% [16].

For people with coronary heart disease (CHD) secondary preventive measures including changes in behavioural risk factors and lifestyle are important to ensure future health and prevent complications [17–21]. However, studies have indicated that lifestyle changes are difficult to maintain [22] and support for people making lifestyle changes is crucial [23,24]. To the best of our knowledge, no studies have described which known risk factors for CHD people had before they suffered out-of-hospital cardiac arrest with validated myocardial infarction aetiology (OHCA-V). Furthermore no studies have described survivors' thoughts about what lifestyle means to them. This knowledge can be used in primary preventive care giving health care personnel information about risk factors among people suffering OHCA-V. It should also provide a deeper understanding of surviving people's own thoughts about risk factors associated with their lifestyle which could be used to identify ways in which to help people in a more supportive and individually suited way in both primary preventive care and in cardiac rehabilitation. With a mixed methods design this study present known risk factors among people before OHCA-V and what lifestyle means to them after surviving.

Methods

Design

An explanatory mixed methods design with a participant selection model was used [25].

Setting

Multinational MONItoring of trends and determinants in Cardiovascular disease (MONICA) is a WHO initiated project intended to monitor trends in cardiovascular disease and is on-going in northern Sweden since 1985. From the beginning people aged 25 to 64 were included but since the year 2000 the inclusion criteria are increased to 74 years of age [26–28].

The Västerbotten intervention programme (VIP) is a community intervention programme intended to reduce morbidity and mortality from CVD and diabetes in the county of Västerbotten, Sweden. In this programme, people aged 40, 50, and 60 have been invited to participate in individual counselling about healthy lifestyle habits and screening for risk factors [29].

Sample/participants

In the first phase quantitative data were selected from the Northern Sweden MONICA project. Included are all people who resided in the area of Norrbotten and Västerbotten who suffered an OHCA-V, were alive at the 28th day after the onset of symptoms, and were

registered in the Northern Sweden MONICA project between 1989–2007 ($n = 71$). In the second phase participants in the quantitative phase were used to guide purposeful sampling for a follow-up in depth qualitative study. All people still alive on the 25th of January in 2011 ($n = 46$) were sent a personal letter that explained the aim of the study and asked for their participation, i.e., completion of a questionnaire focusing on their risk factors for CHD before suffering OHCA-V and to participate in an interview on what lifestyle means to them after surviving. The risk factors registered in the MONICA project and VIP were about the same as in the questionnaire. Thirty-two people answered the questionnaire and of those 15 chose to participate in the interviews. The first author phoned those who had decided to participate and made an appointment for their individual interview. Two of the participants decided not to participate when time for the interview was scheduled. The interview participants all suffered their OHCA-V 4 to 17 years prior to the interview ($md = 8$ years) and were 52 to 81 years of age ($md = 68$ years) at the time of the interview.

Data collection

Participants' ($n = 71$) sex, marital status, work status, and coexisting conditions like ischemic heart disease (IHD), myocardial infarction (MI), hypertension, diabetes mellitus (DM), and smoking habits prior suffering the cardiac arrest, were derived from the Northern Sweden MONICA project, registered at the participants' OHCA-V event. This information was compiled with data prior the OHCA-V from the VIP, which also contributed data on total cholesterol and body mass index (BMI). Answers from the questionnaire were used to add to data about their risk factors. Where data regarding the risk factors was insufficient, an additional medical journal review was conducted to make the data as complete as possible; yet, insufficient data still ranged between 2.8 and 5.6% for marital and work status and 5.6 and 11.3% for total cholesterol, smoking habits, and BMI. Nevertheless, the data for the history of other coexisting conditions was sufficient. Measurements regarding total cholesterol and BMI were from before or in association with the OHCA-V event. Cholesterol measurements were divided into two groups: i.e., ≤ 4.99 mmol/l and ≥ 5.0 mmol/l and/or taking lipid lowering medication. Moreover, BMI values were divided into three groups: i.e., ≤ 24.99 kg/m², 25–29.99 kg/m², and ≥ 30 kg/m² [30].

Interviews

Personal interviews were conducted in 2011 with the participants ($n = 13$). The qualitative interviews were performed as conversations [31] focusing on the following questions: "Please tell me what you think when I say

"lifestyle"? What does lifestyle mean to you? Has your cardiac arrest influenced your lifestyle? What is important to make you feel good?" Clarifying questions were asked, e.g., Can you tell me more? What do you mean? Can you give an example? All participants chose to be interviewed in their homes. Each interview lasted about an hour (md = 55 min), was tape recorded, and later transcribed verbatim.

Ethical considerations

The study was approved by the Regional Ethical Review Board. The participants in the interview study gave their informed consent and were assured confidentiality and an anonymous presentation of the findings.

Data analysis

The characteristics of the participants are presented as absolute numbers and proportions. The text from the interviews was analysed with a qualitative manifest content analysis [32]. The interview text was read several times while considering the aim of the study in order to obtain a sense of the content. In the next step of the analysis, textual units were identified, extracted, and sorted into content areas describing a specific, explicit area. In each content area, a category was created to summarize the content. Finally, the categories were divided into subcategories.

Validity and reliability/Rigour

The quantitative data included are collected through strictly validated procedures (25–27, 29) which also strengthen reliability. Rigour of the qualitative analysis was established through repeated discussions between the first and last author, and finally all authors came to an agreement about the results. The categories are validated with quotations from the interview texts. Findings from this study might be transferred to similar settings, for example people suffering acute illness and thinking about what lifestyle means. The qualitative component in the study adheres to RATS guidelines on qualitative research.

Results

The results are presented in two parts. Part I presents the results of the quantitative analysis, and Part II presents the results of the qualitative analysis.

Part I: Risk factors prior OHCA-V among surviving people

The results (Table 1) show that most people were married or cohabitated and 60% were gainfully employed when they suffered OHCA-V. Sixty percent had no prior history of IHD or hypertension, whereas 25% and 17% had been diagnosed with MI and DM, respectively, prior the OHCA-V. Eighty percent of the people had total cholesterol levels greater than 5.0 mmol/l and/or lipid

lowering medications. Almost half were smokers and 63% were overweight/obese. The characteristics of the interview participants compared to the whole group of participants showed a higher proportion of people that smoked, were overweight, had total cholesterol > 5 mmol/l and/or lipid lowering medication but only one were diagnosed with DM.

Part II: Peoples thoughts about what lifestyle means to them after surviving OHCA-V

The analysis revealed three categories and seven subcategories (Table 2). The quotations is referenced to the participants, male = M and female = F.

Significance of lifestyle

Finding joy and strength in meaningful relationships

The participants described that after the OHCA-V, their lifestyle focused mainly on the importance of having people around. Relationships with their partners, children, grandchildren, siblings, and friends were important and a source of happiness and strength. Social interaction and fellowship included feelings of being needed and meaning something to others. Most of the participants were married or cohabited with others, and they talked about family as their most important relationships. Their partner was described as their companion in life, the one with whom to share things, and the one who cared and looked out for them. Children and grandchildren were given high priority because spending time with them, attending their activities, inviting them to dinner, and being able to help with babysitting were identified as true sources of joy. Participants talked about the importance of having fun and laughing with others.

We get to be there in the mountains with our grandchildren. They are skiing, and I can sit there in the snow, feeling great. Seeing them is so much fun: that you get to be with them, that is life-joy (F2).

Feeling well and doing things of their choice

The participants described that after surviving OHCA-V they did not take feeling well for granted. They described that their lifestyle was connected with feeling well. Participants talked about doing things they had a desire to do and found pleasure in doing. The most important thing identified by all was being able to occupy and engage themselves in something they found meaningful. Overall, the participants' thoughts were imbued by what was good for them.

... do stuff that you feel a desire of doing; don't say 'no'. Take the opportunity and don't think too much, but do it. Indulge yourself in doing these things (M12).

Table 1 Characteristics prior onset of OHCA-V for people alive 28 days after the OHCA-V (n = 71) and for interview participants (n = 13)

	People alive 28 days after the OHCA-V (n = 71)		Interview participants* (n = 13)	
	n	%	n	%
Sex, male/female	53/18	74.6/25.4	10/3	76.9/23.1
Age	58.3 (9.1)		57.5 (9.0)	
(years, mean ± SD, min-max)	35-74		43-75	
Marital status				
married/cohabitant	58	84.1	11	84.6
Work status				
gainful work	41	61.2	8	61.5
History of coexisting conditions				
IHD	28	39.4	4	30.8
previous MI	18	25.4	4	30.8
hypertension	28	39.4	4	30.8
DM	12	16.9	1	7.7
total cholesterol, mmol/L				
≤ 4.99	14	20.9	1	7.7
≥ 5.0 and/or lipid lowering medication	53	79.1	12	92.3
Smoking habit				
smoker	31	47.7	8	61.5
former smoker	17	26.2	1	7.7
never smoked	17	26.2	4	30.8
BMI, kg/m²				
< 24.99	23	36.5	3	23.1
25-29.99	30	47.6	8	61.5
30-39.99	10	15.9	2	15.4
≥ 3 risk factors**	16	22.5	3	23.1

IHD ischemic heart disease, MI myocardial infarction, DM diabetes mellitus, BMI body mass index, * Interview participants are also included in People alive 28 days after the OHCA-V, ** hypertension, DM, total cholesterol ≥ 5.0 and/or lipid lowering medication, smoker.

Several of the participants talked about how exercising made them feel well; they had different abilities to exercise according to their medical status after the OHCA-V. Some participants went to the gym, went skiing, and played tennis, while others were pleased when they were able to go out for a walk, go to the public swimming pool, or attend

senior citizen dances. All tried to find a way to exercise, and for some participants medications helped them to be able to do physical activities. Those who lived in a house had housework that they enjoyed, such as carpentry, mowing the lawn, shovelling snow, even when they had to ask for help with some physically demanding tasks.

Table 2 Overview of categories and sub-categories that emerged from the analysis of the interviews with people who survived OHCA-V (n = 13)

Categories	Sub-categories
Significance of lifestyle	Finding joy and strength in meaningful relationships Feeling well and doing things of their choice
Modifying the lifestyle to the new life situation	Finding a reason why it happened and making lifestyle changes Making your own assessment of a risk behaviour
A changed view on life	Feeling grateful for a second chance at life Finding motivation for lifestyle changes and wishing to influence family members to adopt lifestyle changes Challenging one's fears and adopting a positive outlook on life

It's my health promotion to shovel snow and mow the lawn. I think it is fun. I don't need to shovel like this because that I'm not able to do, but to push like this is ok, and I can stop when I'm out of breath (M3).

Some of the participants felt good when visiting the forest or the archipelago to hunt or fish. Several participants were involved in an association and attended different events, and some enjoyed travelling. Three people still had gainful employment and found joy in working and meeting other people at work. All participants talked about the fact that food had been given more attention after their OHCA-V. They thought about what kind of food was good for them and balanced that with thoughts about how life should be good and they should feel well. That meant they sometimes ate food and snacks that they knew were not the best for them, but they believed that life should be enjoyed. All participants also talked about food in relation to their weight.

Before this event I was eating everything. I didn't care what I ate; I ate everything that was good. Now I think about it (M6).

Modifying the lifestyle to the new life situation ***Finding a reason why it happened and making lifestyle changes***

After surviving an OHCA-V, the participants began to consider the reason for the MI, and according to the reasons identified, they tried to make appropriate lifestyle changes. Smoking cigarettes was one reason discussed. Of the eight people who smoked when they suffered their OHCA-V, five of them stopped at the OHCA-V event. All talked about the effect of heritage on CHD as a reason for their problems, and they indicated that they could do nothing about this. One participant said, "Nobody smoked in my father's family, still they all had an MI" (F8). Three participants continued smoking by choice.

All participants talked about the effects of working and life being filled with negative stress. Several had been in leading positions in their jobs with responsibilities for staff, and some had been self-employed. The stress included long working hours and mental and economic anxiety. Participants expressed that they were not really surprised that the OHCA-V happened because they knew that their life situation prior to the OHCA-V was not sustainable. They talked about physical symptoms related to negative stress, like headaches, migraines, and body pain. However, even if they had understood the connection, they did not have the ability to make a change at the time.

I was working like a fool. I had three jobs at the same time, and there were times when I felt the adrenalin

levels up in the hairline. So afterwards, I was not exactly surprised; I had simply run out of myself. Even if I knew it was wrong, I was not capable to do anything about it (M12).

They needed to survive the OHCA-V in order to clearly see their own working situation and decide what to do in the future. Some expressed gratitude for the event and viewed it as a turning point that was needed for making necessary changes.

The nurse said, I hope you understand that your life will not be the same. I looked at her and smiled and said, Thank God for that. Because what I had I would definitely not want back; I had already decided then to stop with the gasoline station, because it was the reason for the MI. It had dragged me down completely with negative stress for about 15 years (M 10).

Some participants made radical changes in their work life, and for some, the changes were more or less forced on them because of their changed physical capacity after the cardiac arrest. The event led to an awareness of tasks and situations related to stress and a changed approach when deciding what to or what not to do. They made a stand and tried to avoid stress as much as they could, and they expressed that this was a positive change.

What I don't have time to do today, I can do tomorrow. It doesn't matter if it's dust in the corner, I've to live with it, I'll do it when there is time (F13).

Making your own assessment of a risk behaviour

Some participants expressed that they were focused on being fit and maintaining a normal weight, but others seemed to be less focused on that. Participants said that they were aware of the need to exercise more, lose weight to get to a healthy weight, and eat according to all the rules. However, they felt that this was a choice to make and balance with the importance of feeling well and enjoying all things in life.

If I did it by the books – eat right, exercise right – then I probably would feel good but I feel good anyway doing my lifestyle (F13).

As previously mentioned, three people still smoked cigarettes after the OHCA-V, and they had each made an assessment of the risks related to smoking. One participant said he smoked so little that it did not matter. Two people said the cigarettes calmed them down to an extent. One woman said that she sorted through the advice she was given and concluded, "They can say what they want, but I still do as I want,

and I alone take the consequences" (F8). One participant said perhaps 95% of her wanted to quit smoking, but the other 5% considered cigarettes to be a comfort when she was feeling down; the latter attitude actually outweighed the former in terms of her behaviour. Another participant had several relatives and friends that had stopped smoking and still developed lung and brain cancer; therefore, he said, "The physician asked me if I would quit smoking, and I said yes; when I die, I will stop automatically" (M11).

A changed view on life

Feeling grateful for a second chance at life

Most of the participants expressed thankfulness for surviving. Many thought that their survival was a miracle because everything had worked out so well when they suffered their OHCA-V. Indeed, they often described coincidences in their favour, such as the right people being around at exactly the right time. They told stories about the day on which they had their OHCA-V that included ordinary people knowing CPR and people from the fire department and ambulance being around when it happened; all of these circumstances highly contributed to their survival.

But I feel every morning when I wake up, I get one more day..... it's a bit like being lucky or unlucky or coincidences (M12).

Some participants expressed that after their OHCA-V they were more easily moved and cried more often. They felt truly lucky, and several people basically stated, "It was not meant for me to die; it was meant for me to continue living" (M1).

Finding motivation for lifestyle changes and wishing to influence family members to adopt lifestyle changes

Participants expressed that the OHCA-V was a wake-up call, and they stated that they did not want their life to be over. They wanted to continue to be with their partner in life and to see their children and grandchildren grow up. This attitude motivated lifestyle changes in order to increase their chances for a continued life.

I was afraid I wouldn't be allowed to continue living. I've been given a second chance, and I will not aggravate it with cigarettes. If I start smoking again, there is a greater risk that I will get another MI, and to calm down, not stress so I don't get another MI. This I've had to re-learn (F13).

The participants have all told their children of their family history with CHD and told them of the importance of

getting regular healthy checks and informing healthcare personnel that they have a family history of CHD. They also recognized the effects of genetics when their children also developed high levels of cholesterol and high blood pressure and needed medical treatment.

I've preached to my daughters to check your blood pressure and cholesterol (F8).

Two participants that smoked had children that had tried to quit smoking but failed. The participants did not express any distress about this. In fact, one said, "the younger one tried to quit. She said, 'No I cannot do it'. She was so nervous and angry and everything, so I told her to start smoking again" (M11).

Challenging one's fears and adopting a positive outlook on life

Participants said that after their cardiac arrest they were afraid of doing certain things such as solitary activities or physical activities; moreover, they said that they had challenged those fears. They said that they could not walk around being afraid of doing things, having another MI, or dying. They decided that they should not waste time worrying over something that was about to happen because they could do nothing about it if it occurred anyway.

I couldn't go out alone, my life would be ruined if I didn't have my freedom. Finally, I forced myself out into the woods, and there was a lot of agony in that decision, but I thought if I'm about to die, it doesn't matter where I am and how it happens. I turned off my mobile phone, and sat down. Nobody knows where I am, and I feel damn good. After sitting there for a while philosophizing. I kept on walking, and then I experienced in a way that. I had broken the anxiety a bit. After that, I've been out many times by myself (M10).

Participants described trying to be as positive as possible and maintaining a happy attitude about things. Laughing and having fun was described as important, powerful aspects in life. They also described the positive aspects of trying not to worry, but instead first looking at situations as opportunities rather than difficulties and problems.

Discussion

In this study, an explanatory mixed methods design was used to describe which known risk factors for CHD people had before they suffered out-of-hospital cardiac arrest and their thoughts about what lifestyle means to them after surviving. The aetiology of the OHCA in our study was validated MI where 40% had history of IHD

but 60% had not. This means some people suffering OHCA-V are unaware of having an atherosclerosis disease and are not known in health care and available for preventive measures. A study [33] including people who were 25 to 64 years old with a first MI but no OHCA in the same region in northern Sweden found that a lower proportion of their participants had a history of IHD, hypertension, and DM before the event, as compared to those in our study who had suffered OHCA-V. People suffering OHCA-V were not free from risk factors but as many as 20% had three cardiovascular risk factors. This fact points to the importance of both primary and secondary preventive measures in the effort to avoid CVD and possible associated complications, including OHCA-V [34].

In our study most people were married or cohabited, and all interviewed participants talked in a loving manner about their partner when talking about lifestyle. This might have led to a better prognosis since feelings of high social support are health promoting [35]. Supportive social relationships impact health outcomes and are important for adjustment to illness for people with heart failure. Social support is explained as influencing health outcomes by helping the individual to look at stressful happenings in a less stressful way, and social support is implicated with healthy behaviours, like not smoking, adequate food intake, and healthy exercise habits [36]. Meaningful relationships have also been found to be important for women's well-being after an MI. Close relationships provide strength, happiness and joy in life [37].

All participants talked about the negative effects of stress at work and believed that stress at work contributed to their OHCA-V. They had tried to make changes regarding stress at work and stress in general after the OHCA-V, but notably, none of the participants talked about getting help from health care professionals with stress management. Psychosocial factors, like stress at work, can affect people's health. Job strain, low job control, and effort-reward imbalance has been studied and linked to adverse cardiovascular effects [38]. Psychosocial stressors, i.e., stress at work, stress at home, financial stress, and major life events in the past year, were shown to be associated with an increased risk of MI. The effects were found to be similar in both sexes, at various ages, and in different geographic regions of the world [39]. This might indicate that primary prevention should pay more attention to stress levels and that cardiac rehabilitation should involve stress management to a larger extent.

In the present study, the participants emphasized the importance of having people around for whom they cared and who cared for them. They were grateful for still being alive and were determined to keep on living to get to be with significant people in their surroundings. This emotion also gave them motivation to change

behaviours. They focused on trying to do things that were enjoyable, having fun, and balancing these enjoyable activities with things that they knew they should do, like health promoting choices. This can be compared to the results of a study exploring patients' perspectives on making and maintaining lifestyle changes after MI [40]. In that study, patients expressed that they were aware of harmful behaviours and were not really surprised that they were affected by a MI because they knew they had bad habits. They tried to make changes, but making changes was found to be more difficult than they had thought. Survival was a motivator for making lifestyle changes and they felt they had been lucky and expressed gratitude for being alive. Stress also emerged as a contributing factor for MI. A study investigating women's knowledge of cardiovascular risk factors, self-care, and healthy behaviours showed that women's knowledge was not significantly related to heart-healthy behaviours [41]. Indeed, a gap existed between knowing what to do and implementing the recommended behavioural changes. The intention to act and make changes did not translate into action.

This study has limitations. Although this study included all people who had survived an OHCA-V during a 19 year period in northern Sweden, this population was small. The MONICA project's limitation in age inclusion means that people younger than 25 and older than 75 are not included in our study. The number of interviews performed was determined by the number of people who chose to participate.

Conclusions

The results of this study reveal a paradox. The results from the interviews show that the participants seem to be well informed about their cardiovascular risk factors and the benefits of risk factor treatment and behavioural changes. In spite of that, some chose to ignore this knowledge at least to some extent and preferred living a "good life", where risk factor treatment played a minor part. This is important knowledge and either implies that information about risks is still insufficient or simply that they value their life choices and take responsibility for the consequences of their decisions.

Still, the results of this study show the importance of primary prevention making people aware of cardiovascular risk factors and identifying unhealthy behaviours so that necessary lifestyle changes can be initiated before the onset of CHD. The challenge is to make people aware although they feel healthy and do not feel any symptoms of illness. In cardiac rehabilitation, health care personnel should try to get a better understanding of each person's life situation and adjust preventive measures to fit the patient's life situation. However, the following question must be raised: how can people get motivated to change unhealthy behaviours if they believe

that they already have a good life? Perhaps another paradox lies in the preventive work: i.e., health care professionals should support people in their decisions about their chosen lifestyle so that people improve their quality of life as much as possible. The importance of the support of family members in terms of feeling happy and having fun was highlighted by the interview participants and expressed as being the meaning of lifestyle. Perhaps the person with illness together with health care workers should focus more on the meaningful and joyful things in life and try to adopt healthy behaviours and lifestyle changes linked to these things. Perhaps a combination of factors increasing the patient's well-being can be the core to a good life despite illness.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors participated in the design of the study and worked with data analysis. ASF performed data collection, the major part of the data analysis and drafted the manuscript. KZ and SS drafted the manuscript. All authors read and approved the final manuscript.

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Paper III



Meanings of People's Lived Experiences of Surviving an Out-of-Hospital Cardiac Arrest, 1 Month After the Event

Ann-Sofie Forslund, RN, MSc; Karin Zingmark, PhD, RN; Jan-Håkan Jansson, MD, PhD;
Dan Lundblad, MD, PhD; Siv Söderberg, RNT, PhD

Background: The out-of-hospital cardiac arrest (OHCA) survival rate has been poor and stable for a long time, but more recent studies describe its increase. However, there are few studies in which people narrate their experiences from surviving. **Objective:** The aim of this study was to elucidate meanings of people's lived experiences of surviving an OHCA with validated myocardial infarction (MI) etiology, 1 month after the event. **Methods:** A purposive sample of 2 women and 9 men was interviewed between February 2011 and May 2012. A phenomenological hermeneutical method was used for analysis, which involved 3 steps: naive reading and understanding, structural analysis, and comprehensive understanding. **Results:** There were 2 themes, (1) returning to life and (2) revaluing life, and five subthemes, (1a) waking up and missing the whole picture, (1b) realizing it was not time to die, (2a) wondering why and seeking explanations, (2b) feeling ambiguous in relations, and (2c) wondering whether life will be the same. All were constructed from the analysis. **Conclusions:** Surviving an OHCA with validated MI etiology meant waking up and realizing that one had experienced a cardiac arrest and had been resuscitated. These survivors had memory loss and a need to know what had happened during the time they were dead/unconscious. They searched for a reason why they experienced an MI and cardiac arrest and had gone from being "heart-healthy" to having a lifelong illness. They all had the experience of passing from life to death and back to life again. For the participants, these differences led to a revaluation of what is important in life.

KEY WORDS: life experiences, myocardial infarction, out-of hospital cardiac arrest, qualitative research, survival

Background

People who experience out-of-hospital cardiac arrest (OHCA) are unlikely to survive. Studies show that ap-

proximately 92% die before being discharged from the hospital, and this statistic excludes all people who die without any attempt at resuscitation. The OHCA survival rate has been poor and stable for 3 decades,¹ but more recent studies describe an increase in survival rates.^{2–4} Within the multinational monitoring of trends and determinants in cardiovascular disease (MONICA) myocardial registry in northern Sweden, a 19-year trend shows a decreasing incidence of OHCA with validated myocardial infarction (MI) etiology (OHCA-V). People reached by resuscitation and people who died before resuscitation attempts had begun are included in this study, which also shows an increasing survival rate among people aged 25 to 64 years.⁵ The increase in OHCA survival rates is thought to be a result of causes such as wider knowledge of cardiopulmonary resuscitation.^{6–9} This positive trend leads more people to survive both OHCA and OHCA-V.

People who survive OHCA face obstacles in their postarrest lives. Different questionnaires have been used to study how people describe their lives after surviving OHCA. These studies have reported feelings of anxiety, depression, and fatigue; decreased participation in society¹⁰; and cognitive impairments, especially memory problems, among survivors.^{10–12} Nevertheless, many

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survivors report a good quality of life.¹³ People living with an implantable cardioverter defibrillator after an OHCA shared the above mentioned symptoms¹⁴ but also expressed anxiety connected to receiving a shock.¹⁵ There are few studies in which people narrate their own experiences of survival. A study by Doolittle and Sauvé¹⁶ explored the impact of aborted sudden cardiac death on survivors and determined that survivors focus on their prearrest lives and wish to return to the meaningful activities they previously pursued. Another study¹⁷ describes that OHCA survivors find well-being through a search for a sense of coherence and meaning in a changed life.

More people are surviving cardiac arrests, and, consequently, there is a need for greater knowledge about how this event affects their continued lives. Knowledge about surviving a cardiac arrest is necessary to support survivors. People's experiences of surviving a cardiac arrest and their needs afterward should be 1 cornerstone that healthcare personnel focus on in the recovery process. This information can guide healthcare personnel in starting a dialogue about how to best support survivors.

Aim

The aim of this study was to elucidate meanings of people's lived experiences of surviving an OHCA-V, 1 month after the event.

Methods

Setting

This study was conducted in northern Sweden, where approximately 500,000 people reside. The area includes 8 hospitals. The Northern Sweden MONICA myocardial registry is the basis for this study and includes people aged between 25 and 74 years who reside in the area and experienced a cardiac event with MI etiology.

Participants and Procedure

A purposive sample of 2 women and 9 men participated in this study. They were recruited from different hospitals when visiting the cardiac nurse, approximately 1 month after their OHCA-V. The cardiac nurse informed the patients about this study's aim and determined whether they met the specific inclusion criteria for this study: no cognitive impairments assessed by the attending nurse and enough knowledge of the Swedish language to be able to participate and narrate their experience in an interview situation. Those interested in participating got written information about this study and were asked for permission to be contacted by the first author for an interview. The participants' characteristics are presented in Table 1.

TABLE 1 Characteristics of the Participants (N = 11) Who Experienced Out-of-Hospital Cardiac Arrest With Validated Myocardial Infarction Etiology

	n	%
Male sex	9	82
Age, mean (range), y	63 (49–73)	
Cohabitant/living alone	8/3	73/27
Gainfully employed/pensioners	6/5	55/45
Known cardiovascular heredity	10	91
Previously known		
Hypertension	7	64
Hypercholesterolemia	2	18
Ischemic heart disease	2	18
Diabetes mellitus	1	9
No previously known above mentioned risk factors	4	36

Ethical Consideration

The participants signed an informed consent form and were reassured that their participation was voluntary and that they could withdraw from this study at any time. The participants were guaranteed an anonymous presentation of the findings. The possibility for professional counseling after the interview was considered, although such a need was not expressed by any of the participants. This study was approved by the regional ethical review board.

Interviews

The first author conducted recorded narrative interviews.¹⁸ The interviews lasted between 20 and 110 minutes and were later transcribed verbatim. Ten participants were interviewed in their homes, and 1 participant chose to be interviewed in a quiet room at the hospital. All were asked to talk about what happened when they became ill, what they remember about the event, and how they live their life today. Clarifying questions were used—for example, “Can you explain a little bit more what you mean?” and “Can you give me an example?” The interviews were conducted between February 2011 and May 2012.

The Phenomenological Hermeneutic Interpretation

Because our aim was to elucidate meanings of surviving an OHCA-V, we chose a phenomenological hermeneutic interpretation inspired by the French philosopher Ricoeur¹⁹ and developed by Lindseth and Norberg²⁰ for nursing research. The interviews were transcribed verbatim, and the text was compared with the digital recording, and adjustments were made if needed. The interpretation of the text involved 3 phases: naive understanding, structural analysis, and a comprehensive understanding with reflections. A movement between

understanding and explanation and between the parts and the whole is a distinguishing feature of the method. The interpretation was initiated by reading the text several times to get a sense of the text as a whole. A naive understanding was formulated, which guided the structural analysis. In the structural analysis, the text was divided into meaning units. The meaning units were condensed and related to each other and organized into themes and subthemes on the basis of similarities and differences in meaning. The subthemes and themes were reflected on and compared with the naive understanding for validation. In the comprehensive understanding, relevant literature was used to widen and deepen our understanding of the phenomenon under study. The first author conducted the data analysis in collaboration with the last author. The second author checked the analysis. Finally, all authors came to consensus about the interpretation of the text.

Findings

Naive Understanding

Surviving a cardiac arrest meant a sudden unexpected event or an event that was preceded by various symptoms not related to the heart. Surviving also created fragmentary memories and a need to know what had happened. The participants experienced coincidences crucial for survival and gratitude for the possibility to continue living. At the same time, they asked why it happened to them and expressed interest in finding an explanation. Insecurity was salient in the narratives because they wondered how they would be able to recognize the symptoms if it was about to happen again. The participants described that the event affected those surrounding them and that people cared and were genuinely happy that they survived. Energy and strength were lacking; they needed rest and help limiting visits. Questions about whether life would be the same and a wish to be able to do things one enjoyed were expressed. The participants longed to return to normal life.

Structural Analysis

The structural analysis resulted in 2 themes and 5 subthemes. The themes and the subthemes presented below are validated with quotations from the interview texts (Table 2).

Returning to Life

The theme “returning to life” was constructed from the following subthemes: waking up and missing the whole picture and realizing it was not time to die.

Waking Up and Missing the Whole Picture. The participants described that they had fragmentary memories of the time before and after their cardiac arrest. They remembered some sequences, whereas other events were completely inaccessible.

TABLE 2 Overview of Themes and Subthemes Constructed From the Analysis of Interviews With People Who Survived Out-of-Hospital Cardiac Arrest With Validated Myocardial Infarction Etiology (N = 11)

Themes	Subthemes
Returning to life	Waking up and missing the whole picture Realizing it was not time to die
Revaluing life	Wondering why and seeking explanations Feeling ambiguous in relations Wondering whether life will be the same

I changed clothes, and then went out the door, and there my memory stops. I don't remember anything, not the car ride, nothing ... from the intensive care unit (ICU) I've a few memories—my daughter asked me if I recognized her, who she is ... (cries) ... I thought it was a silly question. I got annoyed but I didn't show it but answered who she is and her name ... then I don't remember more from the ICU ... the nurses, I don't remember any of their faces.

The participants experienced various somatic phenomena some time before having their cardiac arrest. They did not recognize them or connect them to their heart, but these made them feel uneasy. Some participants said that they had absolutely no previous symptoms and were totally unaware of having a cardiac arrest. They talked about “suddenly being sucked away” or “being gone and then awake.” One participant said “I was sitting in that armchair over there and just disappeared.”

The participants expressed concern about not remembering or knowing what they had done or said during the times before and after waking up. It was important to fill them in about the time of when they had no memory, and it was crucial for them that those who told the story were the people who had been present during the arrest and the resuscitation. The participants found it offensive when personnel who had not been present during the arrest or the first day at hospital were to tell them what had happened to them. Some people said that they remembered everything before the arrest, “until the lamp was switched off,” and everything since waking up in the ambulance/emergency department. They all had a need to hear what had happened, but it differed with regard to how many details they wanted about the events.

Realizing It Was Not Time to Die. The participants talked about “what if I had not been where I was,” “what if I had been alone in the forest,” “what if my wife had not come,” “then I would have died.” They felt that they had been lucky and felt gratitude to those who were around and came forward and helped with the resuscitation efforts. The participants felt that they had been given a second chance; it was not their turn to die.

"I think about it, I got to stick around for a little while longer, I got to live and was at the right place when it happened."

The cardiac arrest made them aware of their mortality and that life is short. Life should be enjoyed because suddenly it can change; it happens quickly, and then you are gone. Dying was like to faint; it was an easy way to go, and they expressed no anxiety about death. The participants described that returning to life made them think about their eventual death and their close relatives who would be left behind. They described having conversations with their partner about financial matters and forest properties and discussions about selling the house, cleaning up, and throwing away things stored in the basement.

"I think about it this way: it wouldn't have mattered if I had died, it wouldn't have been anything dramatic or difficult or anything like that, but for my relatives ... I wouldn't have known anything."

None of the participants described any scary experiences during the time they were gone, and nobody had experienced near-death experiences, lights, tunnels, or religious revelations.

Revaluing Life

The theme "revaluing life" was constructed from the following 3 subthemes: wondering why and seeking explanations, feeling ambiguous in relations, and wondering whether life will be the same.

Wondering Why and Seeking Explanations. The participants described that they reflected upon their previous life and what could be the reason they had a cardiac arrest. They did not understand why they, of all people, suffered when others who had higher risk factors did not get ill.

"I'm the only one generally that exercises ... (crying) ... and it hit me I'm not jealous, I'm not jealous of them that you must understand, but it's funny, I thought I was the strongest of all ...but I've fooled myself thinking I was so damn healthy, but it's those blood fats that haunt me."

People in the participants' surrounding were also surprised they got ill because they were known as healthy people. The participants said that they wanted to know why they had suffered and wanted to know what they should do to avoid further illness and to stay healthy.

"They said it was unexpected that I got it, you of all people, any one of us but you, you who exercises, you're not overweight like the rest of us, you don't smoke and you eat healthy food ... but what good is it to eat and live healthy I thought then."

This event also made the participants think about previous symptoms and the possibility that they had angina pectoris some time before the cardiac arrest but

they had not understood it. One participant said "in the morning, when the pain was gone, I started to think things through and stated, if I had only thought about it I probably felt it already before Christmas."

Feeling Ambiguous in Relations. The participants felt that the people surrounding them were very happy about their survival. It was considered positive to talk to family and friends about what had happened, and it was described as being a way of processing what had happened. The participants believed that it was important for those who had been present to tell the story as well, to get feedback on how things had turned out for them. They said that it was also hard sometimes to face people. They felt guilty about putting those surrounding them in this dramatic situation and what those people have had to endure because of them.

"I was ashamed to meet my work colleagues. God, it was almost like I didn't want to meet them, it was my fault, letting them be so worried. You feel such guilt, a terrible guilt, what have I put them through?"

It was sometimes considered overly taxing when people telephoned, wanted to come and visit, and asked questions. The participants expressed that family members helped them restrict such contact. One participant also said that knowledge of the incident spread, and it was sometimes hard when unknown people asked what had happened and how the participants were feeling. Those who surrounded the survivor were also affected by the cardiac arrest, and the participants heard that people reflected upon their lifestyles and made changes. The participants were grateful for the healthcare personnel's kindness and believed that everything possible had been done for them. They expressed happiness when people who had performed the resuscitation came to visit and wanted to see how things had turned out.

"He [the ambulance technician] came to visit me in the hospital, he was so happy for me being there, I said how nice to hear you say that. It was close, he said. Yes, I said, I have realized that."

Wondering Whether Life Will Be the Same. The participants said that they were tired and lacked strength when coming home. They needed to take naps during the day, something they were not used to doing. The resuscitation had resulted in fractures, and they were in tremendous pain, which also affected their sleep, but this faded with time. At the beginning, it was enough to walk to the mailbox, but the walks could be extended each day. The participants described that going up and down the stairs was exhausting, and it surprised them because they had never found it exhausting before.

"I don't have the strength now either, not a whole day, I have to rest quite a lot. You have to try to get back to normal, get the strength to get everyday life to work out first."

The participants expressed anxiety, which their husband/wife shared, leading them to do most things

together at the beginning. This fatigue and anxiety subsided with time, and they felt strength and life slowly return and resemble normality more closely. They expressed a wish to be able to do the things they had enjoyed before and looked forward to life returning to normal. The participants talked about having their coronary stenosis corrected. It was somehow felt to offer safety and the hope that in time, perhaps, they would feel even stronger now that they had been fixed.

“... now I have fresh coronary arteries, now I have at least a much better position than many others ... it would be fun if you became alert and came back with lots of energy and everything.”

At the same time, concerns about a new episode and how they should recognize symptoms if it was about to happen again were expressed. Having an MI meant getting used to having a lifelong illness and a need for medications. The medications made the participants tired.

“It was almost the toughest thing when they came with a medical box filled with drugs and said you should take this and these two all your life, it was terrible, me who hadn’t eaten a pill in my whole life except for a painkiller once in a while.”

Comprehensive Understanding and Reflections

In the last phase of the interpretation process, the entire text was viewed as a whole. In this study, we suggest that the participants experienced surviving an OHCA-V as a return to life, and the event led to a revaluation of their life. The participants’ return to life included some degree of memory loss, and they needed to know what had happened. These missing pieces can be compared with the image of a black box in which lost information can be found. It seems like they had a need to fill the black box with narratives from, and conversations with, those who were present to be able to move on with life. They wanted life to get back to normal, but that “normal” life was different.

The participants remembered that they experienced an unknown feeling in the body before they had their cardiac arrest. They described a feeling they neither recognized nor connected to their heart. Similar experiences are also expressed among older men and women upon having their first MI.^{21,22} The participants looked for a reason why and found it strange that they experienced an OHCA-V and not someone else who they thought had a worse lifestyle. Thoughts about being a terrible person who deserved this were expressed. This phenomenon, people’s search for causes as to why they experience an illness, is described by Toombs.²³ Individuals can come to see illness as a punishment for something one has done or something one deserves because of a bad lifestyle or bad morals. The search for a

cause is also a search for the meaning of the illness, and gathering information is a way to learn to live with the illness and gain control. Frankl²⁴ suggests that man’s search for meaning is a fundamental force in life. Every situation in life requires something new from man, and every situation requires different actions. Thus, occasions differ, but each situation is unique. Every person creates his/her own meaning, which must be searched for and fulfilled by that person alone to satisfy the will for meaning.

The participants said that they had become aware of their own body when it did not function as it used to. It was a new experience to not be able to do everyday activities such as going for a walk, doing the dishes, or staying awake during the day, although they felt that they were doing nothing. Toombs²³ explains that when a person experiences an illness, he/she is often forced to become more aware of the body in daily life. When healthy, the body is been taken for granted, but when a person falls ill, the body becomes an obstacle. Some participants in this study had had known ischemic heart disease before the OHCA, whereas for others, the event meant a change from being “heart-healthy” to a life with a chronic illness. Others had never taken medications before, and for them, the event meant a need to take medication for the rest of their lives, which was a tough experience. Some had thought of themselves as healthy individuals and “Superman,” and this event turned that perception on its head.

People who experience personal tragedy try to cognitively adapt. Taylor’s²⁵ theory regarding cognitive adaption to threatening events suggests that the adaption process focuses on 3 areas: searching for the meaning of the event, trying to regain control of life, and trying to increase one’s self-esteem and love oneself despite the personal setback. The search for meaning includes trying to find a cause that explains why one suffered and rebuilding the meaning of one’s life. Personal tragedy can lead people to revalue life and adopt a new approach to life. Things that had been important before the event are experienced as less important. Regaining control over life includes gaining control over the illness and life in general. Searching for information and answers about the cause and trying to make changes regarding things in life that are felt to negatively impact the prognosis create a sense of control. People try to increase their self-respect by finding positive aspects of the event by comparing their situation with that of others who are less fortunate and focusing on aspects of their situation that make them feel that they managed well.

It is reasonable to suggest that the experiences of people who had an OHCA-V and people who had an MI without OHCA differ. The difference is that the participants described waking up and not knowing what had happened and being unaware of having had

a cardiac arrest and being resuscitated. Their life had been in the hands of others. They wanted to put the pieces together and were totally dependent on others to tell them the story. Levinas²⁶ expresses that a person's face is exposed and defenseless, and the face displays a responsibility for the other person. The participants expressed gratitude and amazement that determined people came forward and came to the rescue: if it had not been for those people, their life would have ended. The participants also described the trust they felt for healthcare personnel. They felt safe and had faith that everything that was possible to do for them had been done. According to Lögstrup,²⁷ people usually meet each other with a natural trust; we have a built-in faith in each other. As human beings, in the encounter with others, there is an unspoken demand that says that we should gently guard the life that trust puts in our hands. Lögstrup²⁷ argues that life is given to us as a gift, and therefore, another person, regardless of whether a stranger or a friend, whose life depends on us in different situations will make us do deeds of love. As fellow human beings, but also as healthcare professionals, we have an ethical demand to care for life.

The participants expressed that dying was easy and not frightening, but it made them become explicitly aware that life is not endless. This revelation made them calm and also made them think about and make preparations for their coming death.

According to Andersen et al,²⁸ people with long QT syndrome said that their perspectives on life were somewhat different from those of others without long QT syndrome. They tried to live normal lives and felt that death was nothing to worry about but rather a part of their life. They reported that they wanted death to come quickly. This attitude was also described by people living with life-threatening diseases, who said that dying from an MI was considered a good way to go, like turning off the switch.²⁹

A person's narrative automatically includes the present, the past, and the future. When describing the present, the person relates events to what has been and what is about to come. The awareness of events in life places them on a timeline that offers context before and after a specific event.³⁰ The participants described their present daily life in relation to their previous life situation and wondered whether life would be the same. They compared the present with the past, and this meant that they also thought about the past and things they wanted to do differently, change, and focus on in other ways in the future. Some events can change life dramatically, and afterward, life is not what it had been. The presence of a life-threatening illness can interrupt a person's time flow and make him/her aware that everything has changed. The event can alter people's vision of and approach to life when looking at the present, the past, and the future.³⁰

Methodological Considerations

The researcher's preunderstandings are pivotal in qualitative research. According to Lindseth and Norberg,²⁰ the meaning of a phenomenon disappears without preunderstanding, and therefore, the preunderstanding cannot be put aside in brackets. In this study, we have been aware of our own preunderstanding, and the interpretation has been performed from the perspective of our experiences as nurses and physicians and researchers. The first, third, and fourth authors have experience in cardiac care for people experiencing OHCA-V, and all authors have experiences with people living with illness. In qualitative research, the sample size should be big enough to achieve variation of experiences and to permit a deep analysis of the data.³¹ In this study, the participants were chosen by purposive sampling, that is, the participants were chosen because they had special knowledge about the phenomenon under study, because this is the intent in using qualitative methods. Purposive sampling provides a theoretical richness when seeking to elucidate experiences as richly and accurately as possible.³² The participants shared their lived experiences with an open heart and shared deep and rich descriptions. Thus, we judged that the sample size was sufficient. Three of the participants wanted their wives present during the interview. This might have influenced the narration, but the participants' wishes were prioritized. It is said that there is no single possible meaning in a text, but all interpretations of a text are not equally plausible. We consider our interpretation to be the most probable one, which elucidates the greatest number of details.²⁰ We believe that our findings may transfer to similar situations and people experiencing life-threatening events. Follow-up interviews with the participants are planned 6 months and 1 year after their OHCA-V to elucidate their feelings about surviving in a long-term perspective.

Summary and Clinical Implications

One month after the event, meanings of surviving a cardiac arrest seem to entail a search to fill the black box with information about what happened. The participants in this study woke up and realized that they had had a cardiac arrest and had been resuscitated. They experienced memory loss and needed to communicate with people who had been present during the time they were dead/unconscious. The participants wanted to find a reason for the MI so they would be able to make changes in their life. They had gone from being heart-healthy to having a lifelong illness, and they all had the experience of passing from life to death and back to life again. These experiences led the participants to reevaluate what is important in life.

Research that elucidates the meanings of people's lived experiences of surviving an OHCA-V 1 month

What's New and Important

- Participants expressed needs to fill the black box with information and dialogues with people who were at the event. Healthcare personnel have an important part in fulfilling this wish not only in the acute phase but also in follow-up visits.
- Participants searched for answers to why they experienced the event and were motivated to make changes in life if they only knew which ones. This motivation might be used in the early stage of recovery by healthcare personnel and might be a fertilizer for a healthier future lifestyle.
- Surviving an OHCA-V meant returning to life and revaluing life. Awareness of and support in those aspects might be important knowledge for healthcare personnel to highlight in their dialogue with people surviving a cardiac arrest.

after the event is sparse; therefore, the findings from this study could be used directly in clinical/practical care. Checklists could easily be constructed as a reminder of what to consider in dialogue with the survivor. The participants expressed a need to engage in dialogue, not a one-way conversation, with people who had been present for the cardiac arrest and the resuscitation and who had given care at the hospital. This dialogue is best carried out repeatedly. The participants searched for an explanation for why they had an OHCA-V, and they had a high degree of motivation to make healthier choices in life. This motivation should be encouraged by all professionals surrounding the survivor in the recovery process. The participants in this study all felt that they had been dead and returned to life. Healthcare professionals might invite survivors to talk about the fact that they were dead/unconscious and returned to life. These experiences are not always easy to talk about with family and friends. The participants also mentioned that the event affected them and made them revalue things in life, and that is an important factor that healthcare professionals should highlight in such dialogues.

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Paper IV

Meanings of people's lived experiences of surviving an out-of-hospital cardiac arrest, 6 and 12 months after the event

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Abstract

Background. Little is known about people's experiences about surviving out-of-hospital cardiac arrest and how the experience affects people's daily lives over time.

Objective. This study aimed to follow surviving people for one year after out-of-hospital cardiac arrest in order to elucidate meanings of survival.

Design. A longitudinal qualitative design was used.

Setting. Eleven people surviving out-of-hospital cardiac arrest from northern Sweden agreed to participate and were interviewed at 6 and 12 months after cardiac arrest.

Method. A phenomenological hermeneutic interpretation was used to analyze the interviews. The phenomenological hermeneutic interpretation involves three steps: naïve understanding, structural analysis, and comprehensive understanding. Interviews at 6 months were analyzed separately from those at 12 months.

Findings. At 6 months participants described an "aspiration for control" and expressed that "being the person you are" had influenced how they had reconciled the event. At 12 months participants recollected the year that had passed (recapitulation) as well as looked forward to the future (foresight).

Conclusion. Meanings of surviving out-of-hospital cardiac arrest, the first year after survival can be likened to a pendulum's motion. Participants had pendulum emotions connected to the event, life before and after the cardiac arrest, as well as thought about the future. Participants were striving to regain control over their bodies to feel safe. The event was still present in their lives, though they wanted to look forward and pursue their lives.

Keywords: life experiences, myocardial infarction, out-of-hospital cardiac arrest, qualitative research, survival

Introduction

People who suffer out-of-hospital cardiac arrest (OHCA) face dubious outcomes as most people die before cardiopulmonary resuscitations (CPR) have been attempted.¹⁻⁴

Improvements have occurred in pre-hospital care, as well as in hospital care and rehabilitation⁵ but despite these efforts, the survival trend for OHCA remains poor.⁶ During the last decade efforts to educate the public about why and how to perform CPR have been implemented and automated external defibrillators (AED) deployed in public places to reduce the time from cardiac arrest until defibrillation.^{7,8} Due to such efforts, studies have been able to report an increasing trend in survival rates.^{3,9-11} If this upward trend continues and more people survive, then health care personnel would benefit by expanding their knowledge about peoples' experiences and how cardiac arrest affects their lives after the event. Though studies have described surviving peoples' quality of life¹²⁻¹⁴ and cognitive performance,¹⁵ as well as investigated how partners and relatives present at the event have been affected over time,¹⁶⁻¹⁹ surprisingly few studies describe surviving peoples' own experiences about the event and their everyday life experiences after survival.²⁰⁻²¹ The aim of this longitudinal study was therefore to elucidate meanings of surviving for people during their first year after OHCA.

Methods

Design

A longitudinal qualitative design was used to elucidate meanings of surviving OHCA over the period of one year.

Setting

This study was conducted in northern Sweden, where approximately 500,000 people live and eight hospitals are situated. The Northern Sweden Multinational Monitoring of Trends and

Determinants in Cardiovascular Disease (MONICA) myocardial registry and World Health Organization criteria used by MONICA formed the basis of this study.

Participants and procedure

A purposive sample of two women and nine men participated in this study, all of whose characteristics are presented in Table 1. Participants were aged from 25 to 74 years (median =63), resided in the area, and had experienced an out-of-hospital cardiac event with myocardial infarction aetiology (OHCA-V). They were recruited from different hospitals while visiting the cardiac nurse for follow-up approximately one month after experiencing cardiac arrest. The cardiac nurse informed the patients about the aim of the study and determined whether they met the specific inclusion criteria for this study (i.e., no cognitive impairments assessed by the attending nurse and enough knowledge of the Swedish language to be able to participate and narrate their experience in an interview. Those interested in participating received written information about the study and were asked whether the first author could contact them. Participants consented to be interviewed on three occasions: at 1 month, 6 months, and 12 months after cardiac arrest. Meanings of the participants' lived experiences of surviving OHCA-V 1 month after the event have been presented in a previous study.²² The present study describes results from the interviews conducted at 6 and 12 months.

Insert Table 1 about here

Interviews

Narrative interviews²³ were conducted with the participants by the first author. All participants were asked to talk about their daily lives after surviving cardiac arrest and encouraged to narrate their stories as freely as they liked. When necessary, clarifying questions were asked (i.e., "Can you explain more?" "Can you give an example?" and "How

did you feel then?”). Interviews lasted from 30 to 110 minutes (median= 63) and were recorded and transcribed verbatim. Ten participants were interviewed at their homes, while one participant chose to be interviewed in a quiet room at the hospital. The interviews were conducted from June 2011 to April 2013.

Phenomenological hermeneutic interpretation

To elucidate meanings of surviving cardiac arrest, we chose a phenomenological hermeneutic interpretation inspired by the French philosopher Paul Ricoeur²⁴ and developed for nursing research by Lindseth and Norberg.²⁵ Interview transcriptions were compared to the digital recording and adjustments made if necessary. The interpretation of the text involved three phases: naïve understanding, structural analysis, and a comprehensive understanding with reflections. Since interviews performed at 6 months were analyzed separately from those at 12 months, the results of analysis are also presented separately. A movement between understanding and explanation and between the parts and the whole of the text is a distinguishing feature of the method. Interpretation was initiated by reading the text several times in order to get a sense of it as a whole, upon which a naïve understanding was formulated that guided structural analysis. During structural analysis, the text was divided into meaning units, which were condensed, related to each other, and organized into themes and subthemes based on similarities and differences in meaning. Subthemes and themes were reflected on and compared to results of our naïve understanding for validation. For the comprehensive understanding, relevant literatures were used to widen and deepen our understanding of the phenomenon under study. Data analysis was performed collaboratively by the first and last authors. All authors came to consensus about the interpretations until a consensus was reached of the text.

Ethical considerations

Participants submitted a signed informed consent form and were reassured that their participation was voluntary and that they could withdraw from the study at any time.

Participants were guaranteed anonymity for the presentation of the findings. After interviews the possibility of further professional counseling was considered, though no participants expressed a need for such consultation. The study was approved by the Regional Ethical Review Board.

Findings

Meanings of surviving out-of-hospital cardiac arrest at 6 months after the event

Naïve understanding

Life 6 months after cardiac arrest meant learning to trust the body again. At first participants described not knowing what their bodies could manage and thus testing it. Though participants' symptoms varied, all experienced the insecurity of not knowing where their unique symptoms originated. Medications contributed new symptoms and side effects, some of which were so severe that participants sought care from the emergency room. Participants described feeling safe when their bodies were recognized and when doctors reported that blood samples and tests were within normal ranges.

The event of cardiac arrest was still quite present in the daily lives of participants, and attested to the importance of their personality when handling their continued life. Feelings of amazement and gratitude that everything had worked out well were coupled with a mentality of wanting to put the event behind them. Since no new memories had surfaced, some participants wanted to know more about what had happened and thus searched for answers. An awareness of life's fragility lead to changes in their lives.

Structural analysis

The structural analysis resulted in two themes and four subthemes, as shown in Table 2 and presented below with quotations from the interview texts to validate our interpretations.

Insert Table 2 about here

Theme: Aspiration for control

The theme ‘aspiration for control’ was constructed from the subthemes ‘testing the body’ and ‘pursuing the ordinary life.’

Testing the body

After the cardiac arrest people described feeling bodily limitations that faded with time. Tremendous chest pain was experienced after resuscitation and affected ordinary life both day and night. Participants expressed that chest pain led to insecurity though they did not know if the pain was originated from the heart. They emphasized that they lacked information about the consequences from resuscitation, knowledge that could have avoided unnecessary anxiety regarding their pain.

I wish I had had better information—that it wasn't the pump [the heart] that caused it [the pain] but the treatment [CPR] I had to have in order to survive that had left marks. [Participant 2]

Participants said that they initially compared their symptoms to those felt before cardiac arrest and thereafter tried to explain symptoms logically. They described that if they did not understand the symptoms and deemed them severe, medical assistance was sought. Symptoms were sometimes believed to be effects or side effects of medications, although the participants expressed it was not good to know for sure.

I feel side effects. I get short of breath even though I do nothing...it's like a ribbon across the chest and sometimes I've feel like I've been half-eliminated, sometimes I feel nothing, and sometimes I get them [the symptoms], and I think they're from the medications. [Participant 5]

Adverse effects were even reported to have resulted visits to the doctor as well as changing or discontinuing medications. Participants described being aware of symptoms in addition to challenging and testing to learn how their bodies would react. Upon discovering that activities could be performed without discomfort, participants gradually increased the frequency of these activities.

After a while I started with walking and such. I went to the supermarket, and there is a long path going uphill. You have bags with groceries, and you tested yourself. At first it [walking] was heavy, but now I've got no problems. [Participant 9]

Participants described testing different weather conditions to evaluate how their bodies would react. They had so far avoided certain activities out of anxiety that the activities would not be painless. Participants who experienced setbacks of new disease events described how the process of testing and managing different activities had been ruined and restarted from the beginning. In general, participants expressed striving to control both their everyday lives and their bodies.

Pursuing the ordinary life

Participants described the significance of getting tested and examined by the doctor. Upon learning that test results were in normal range and that their hearts were in good condition, participants took the good news as a prompt to begin moving on with their ordinary lives.

ECG was good, he [the doctor] said, and all of the blood samples. Well, from that you also get slightly stronger, to hear that. [Participant 11]

Participants expressed feeling frustrated when answers from health care services were delayed, they wanted to know when they could begin planning for the future. They described wanting to recommence living the lives they had before cardiac arrest, including the activities they enjoyed. Participants described that being able to perform a physical demanding task was a measure that life had returned to normal. They described that they sometimes chose not to tell their families and friends about every symptom they felt, since they did not want to worry them.

Theme: Being the person you are

The theme of ‘being the person you are’ was constructed from the subthemes ‘marveling about what happened’ and ‘wanting both to know and put it behind’.

Marveling about what happened

Participants were amazed that everything had worked out so well, or as one participant said, “‘imagine I’m sitting here.” Expressions such as, “It was not my turn to die,” “There was no room for me in heaven that day,” and “I’ve got a second chance at life” also contributed to participants’ general amazement. For the first month after the event, participants expressed feeling euphoric about getting their lives back, though after time this feeling stabilized.

Participants expressed gratitude for all of the help they had received. As their lives continued, the event affected the participants in different ways, but in general they claimed that simply being who they were affected how they interpreted both the event and the future. Participants expressed that they were not the worrying kind or usually bury themselves in sorrows, as one participant declared: “I’ve never been melancholy.” They described feeling irritated when people nagged them, told them not to do things, or to be careful. Participants said they liked having things to do, getting things done, and being busy, as well as disliked having nothing to

do. Generally, they also described themselves as people who do not easily seek medical assistance and that conditions had to be quite serious before they telephoned for medical help.

I was half-eliminated....but you know.... you have it in you...you wait to see what will happen. [Participant 5]

Participants experienced side effects from medications, but emphasized that they did not give up easily though tried to make life work with the medications, as well as telling themselves that they would get used to them and that the process would get better with time. Despite these efforts one participant said “I can’t stand anything, it’s still my life.” Participants described experiencing emotional differences after surviving cardiac arrest. To one extreme, one participant declared, “I’m not the same man anymore.” Emotional changes included being easily angered, crying easily, and at times feeling without energy, as evidenced by their postponing activities. At the same time, cognitive impairments prompted participants to mistrust themselves, while their memory impairment resulted in their becoming easily angered, as well as their trying to hide the memory loss and joking about it in front of others. Meanwhile, physical impairments were visible and thus resulted in feelings of not being the same person as before cardiac arrest. These changes resulted in shame and social avoidance.

It [my body] is not quite right; the motor is hacking, the right side limps, and then it’s the arm. I put it [my hand] in my pocket. I don’t know, but it’s a little embarrassing, when I’m out, people are watching, but perhaps I’m imagining.
[Participant 4]

Wanting to both know and put it behind

Participants described having no new memories about cardiac arrest and everything that was gone, was still gone, the cardiac arrest was still a black whole. They expressed that they had a need to know more and to talk to people who had been present during the arrest and at the hospital while they received care. By contrast, participants expressed no need to know

anything about the event: “What has been, has been; there is no need to delve into it.” For participants it was initially difficult to see an ambulance with sirens and blue lights, watch TV programs set in hospitals, and read obituaries in the newspaper, for all of these reminded them of their cardiac arrest. At the same time, since they had not died, participants reported wanting to recommence focusing on their life and their future. In this sense, participants described not planning as much as more often living life one day at the time with the new knowledge that “It’s easy to die from everything.” Those who experienced impairments wondered where the road would lead and what their new goals would be given their changed lives. Participants wished to return to their ordinary lives and to not be limited. The event appeared to affect them still, though expressed having realized that there was no need to do things in a hurry and that they could relax and more often choose what they wanted to do. They were more aware of themselves, others, and everyone’s bodily signals and did not ignore them as easily as before.

I try to think, “I don’t need to do everything at once, straightaway. Just because that pile [of work] is there, it doesn’t matter if it takes all day to finish. [Participant 10]

Good and bad habits, such as exercise and food choices, were also reconsidered, and participants described that they had observed positive lifestyle changes within their families.

Meanings of surviving out-of-hospital cardiac arrest at 12 months after the event

Naïve understanding

Life 12 months after cardiac arrest meant that participants reflected upon their present life situation in comparison with their life situation before the event. Most participants described feeling that their bodies had recovered, and some were in even better shape than before the event. They had regained a sense of what their bodies could manage. Visits to the doctor were

requested mostly to discuss issues and to hear that they were “healthy.” Participants described themselves as being more prepared and that, if they were to feel symptoms similar to those they felt before cardiac arrest, they would not hesitate to seek medical assistance. The year after the event had resulted in changes in their own lives and those of the people around them, especially regarding exercising habits and priorities. Participants described that they had from the beginning aimed to resume their ordinary lives and that they wanted to continue doing activities they liked. As the event became less present, they expressed wanting to plan for the future. These plans usually implied the hope of continued life, though participants did not shy away from expressing their awareness that death is a part of life.

Structural analysis

The structural analysis resulted in two themes and seven subthemes, as shown in Table 2 and presented below with quotations from the interview texts to validate our interpretations.

Theme: Recapitulation

The theme ‘recapitulation’ was constructed from the subthemes ‘regaining a sense of security with the body,’ ‘wanting to be checked and declared healthy,’ ‘embracing changes,’ and ‘affecting the surrounding’.

Regaining a sense of security with the body

During the past year participants described challenging themselves and testing different physically demanding activities to evaluate how their bodies would react. They had learned to be safe with their bodies and its signals again. Some things could be performed as before, while others felt different.

I thought, “Now I’ll test myself by how it feels to go hiking with a backpacker and there were no problems. [Participant 1]

Participants asked for better information about symptoms related to coronary intervention and procedural rib fractures. They emphasized that being better informed would have spared them anxiety, since symptoms were mixed and thought to perhaps relate to the heart. Participants described feeling they were in good shape, some even in better shape than prior to cardiac arrest, as well as that they were lucky for not being as restricted as they had heard others had become. Some participants described that they had suffered new disease events that had repeatedly affected them and led to their constant attempt to regain control of their changed bodies. Medication continued to be disliked, but participants realized that it was something they needed and simply had to accept. They expressed that medication negatively affected their bodies, that side effects were common, and that it had taken some time to learn how their bodies would react to medication.

Wanting to be checked and declared healthy

Participants expressed that visits to the doctor had been unsatisfactory. They wondered whether it was their responsibility to know when it was time to visit the doctor and perhaps something they had to attend to themselves. Medication also justified wanting to visit the doctor, for they did not know when to cease medication or to renew prescriptions.

I believed, and it was stated in the information sheet I got, that I would be called to a doctor's appointment after one year, but it wasn't that simple.

[Participant 3]

Scheduled examinations had taken a long time to be performed, and some participants had become ill while waiting. Participants described wanting to be checked, to ask questions, and to receive answers that they could understand. They wanted to know from health care service agents what their bodies could manage. When participants experienced anxiety over symptoms similar to those before cardiac arrest, they described expressing their anxiety to the

doctor but felt that they were ignored. They wanted to feel secure by getting examined, possibly getting remedied, and being declared healthy.

Embracing changes

Participants expressed that surviving meant listening and paying more attention to their needs and the needs of others. They described more easily prioritizing themselves instead of others. Participants who had regularly exercised prior to or during the first 6 months following the event continued exercising, while those who had not previously exercised had made physical activity a priority.

It was three weeks [between the cardiac arrest and being back at the workout group], then I stood there outside waiting, and they [exercise mates] said, "What are you doing here?" They had thought I would be back in spring at the earliest. [Participant 7]

Participants described that after cardiac arrest they lived less hectic lives and that they did not feel that they had to do something all of the time. They did not avoid doing things but could do things more calmly and even ask for help. Sometimes they wished they would have the strength to do more and that which could be stressful. Participants who were more affected by cardiac arrest and its subsequent complications described a changed and different life situation. Cognitive impairments made them feel that they were no longer the same people. Daily life now required making to-do lists and exact plans for the day in order to make their lives work, for even the smallest distractions would ruin the whole plan. Participants described that these changes meant recovering from bad memories and that physical impairments had led to shame and social isolation. Other participants expressed feeling as if they had won the lottery and that cardiac arrest had urged positive changes in their lives. Participants expressed changes in emotions, such as being more easily moved, happier, angrier, and humbler, along with dreaming more often.

Affecting the surrounding

Participants described that their surroundings had been affected, namely that family and friends were especially worried and cared for them. They initially felt that those around them were watching them and would not let them do things by themselves. This behavior subsided when family and friends saw that things were working out and that life as it was prior to cardiac arrest had more or less resumed. Those around participants reportedly questioned their decisions at time about, for example, wanting to continue working or performing a physically demanding activity. Participants expressed that they wanted to decide for themselves what they should or should not do.

I would be out shoveling snow, and it was working out fine, but then someone would say, "But, should you really shovel snow?" I said that it was going well and that I didn't sense any problems. [Participant 1]

Participants described that physical and cognitive impairments had prompted a changed family situation and that other family members had been forced to take on increased responsibility. Family-bound participants described getting on even more strongly after the event. Participants described that positive changes had occurred in their surroundings. For example, they had started exercising and considering healthy behaviors.

I do my work out, and we [my colleagues and I] have become a group at work that go to the gym regularly. [Participant 8]

Theme: Foresight

The theme 'foresight' was constructed from the subthemes 'wanting to resume daily life,' 'being better prepared if it happen again,' and 'planning for the future.'

Wanting to resume daily life

Participants desired to resume the lives they had led before cardiac arrest, though for some doing so meant getting used to a different life situation due to physical and cognitive impairments. Participants still of working age wanted to get back to work.

I wait and long to get back to work....I'm close to retirement, but want to work a while longer if it works out okay. [Participant 6]

Participants that were retired wanted to resume their ordinary lives of daily activities. Those participants close to retirement looked forward to retiring but wanted to keep on working as long as it felt good. Participants described certain activities as being a significant part of their lives and that they wanted to continue those though they gave much positive energy. They considered doing things and keeping busy to be relaxing.

It's [playing music is] my life in a way Sometimes it gets to be too much, but it's hard to refuse a performance when I find everything to be equally fun.

[Participant 9]

Being better prepared if it happen again

Participants described that they would act sooner and not hesitate to seek medical assistance if they recognized bodily signals similar to those upon suffering cardiac arrest. They described that they would demand a specific examination or go straight to the emergency room.

Now, you know...if it starts to feel heavy like it did last fall ...you should get an exercise test done, not an ordinary ECG, because that doesn't show anything. [Participant 7]

Planning for the future

Cardiac arrest was still quite present in participants' lives, though they did not linger on it but instead reflected on it from time to time. Sentiments such as feeling lucky, getting a second

chance at life, and that, though near, it was not their time to die were expressed. Participants looked to the future, which included plans for retirement, moving closer to their children, and spending more time with their spouses. Still, participants were wary of planning too much and instead took one day at a time, for they expressed, “You never know what will happen.”

For some participants, surviving meant learning to live with new conditions, which complicated planning, though they did not know from day to day or from hour to hour how they would feel. Feelings of burdening their families or that their families would have been better off if they had died were expressed. As one participant said, “Then they [family members] would not have the responsibility for me for the rest of my life. Why did I survive only to suffer repeated setbacks?” Participants expressed that realizing that they should value the time given to them in life, since life is not forever. One participant declared, “I’m not interested in dying. I have too much I still want to do.” Participants were not afraid of death or dying, “it was not a dark place to be afraid of”. They wished to stay healthy and be able to do activities they enjoyed. For some, the anniversary of the event passed without notice; it was a fact, and nothing more. For others, family and friends reminded them of the anniversary. One participant even enjoyed an anniversary dinner with his or her spouse.

The future? [Laughter.] Take one day at a time. Well, I hope to stay healthy; that’s what I wish for the most—that everybody around me stay healthy and that I will be able to do things...just that...I don’t have any advanced plans. I’ll pick berries and fish...things I enjoy. [Participant 1]

Comprehensive understanding and reflections

Meanings of surviving OHCA can be likened to a pendulum’s motion. Participants experienced back-and-forth emotions when comparing their present lives to both their lives

before cardiac arrest and those lives they planned for the future. Comparisons of these lives also invariably included comparisons between their previous, present, and future bodies. In general, participants hoped to resume their ordinary daily lives, despite that the event of cardiac arrest was still quite present for them. Participants wanted to put the event behind them and look forward and hoped for continued lives filled with meaning and joyous activities.

Hope has been described as being of primary significance to making recovery possible, along with finding meaning and purpose in life. To dream and hope for something better and to establish goals in life are helpful in motivating people. Being struck by illness can lead to identity loss, and if people identify themselves with a diagnosis, it can be difficult to find meaning.²⁶ Participants in our study expressed searching for control over their bodies, as they had somewhat had lost their identities upon suffering OHCA. As time passed, however, their physical strength returned, and life increasingly resembled their previous lives and identities.

For people with life-threatening diseases, hope has been observed as three types of dynamic work: to shift perception of mortality from overwhelming horror toward suppression or peaceful acceptance; to foster reconciliation instead of uncertainty when adapting to the new life phase; and to establish go-ahead spirit instead of resigning as their identity. Meanings was sustained despite threats to the person's self-conception, daily life and future.²⁷

Overcoming fear was reported to be a key element to moving on with life after surviving cardiac arrest, in addition to finding meaning in what happened so that moving on was possible.²⁸ Participants in our study expressed neither fear nor horror; furthermore, they neither expressed death-anxiety nor had any fear of frightening memories from having been dead/unconscious or about their future deaths. Death had come quickly, or as one participant

expressed, “The lights were turned off.” As described in other studies, sudden death was even expressed as a preferable way to die.^{27,29}

Participants stated that they were grateful for a second chance at life, had adopted a positive outlook on life, and seemed to have reconciled what had happened to them. People living with an implantable cardioverter defibrillator (ICD)³⁰ also expressed gratitude for continued life and described that, in order to be able to go on with life, it was important to set goals. Hope has been described as being “related to being” and “related to doing,”³¹ and by being linked to a person’s existence, life presumes hope as well as the will to live. By finding hope in simply being, energy is exerted toward finding meaning in life, by which all things can be found and done.³¹ People aged more than 70 years have lower survival rates after CPR than younger people, but no uniform results have shown that older people have reduced functionality or cognitive status.³² Quality of life is reported to be related to cognitive function and difficulties in daily life after surviving OHCA.¹³ In our study participants aged more than 70 years described living a good life and expressed having much more to give and enjoy in life.

One year after the cardiac arrest, participants reflected upon being euphoric during the first month for having had their lives restored. As time passed, however, life was experienced as weightier, while later on daily life became stabilized and increasingly resembled ordinary life and, with that, an increasingly stable mood. During the first year after cardiac arrest, participants reacquainted themselves with their bodies. They did not initially recognize their bodies that were changed by illness. As they recovered, they tested different activities and with time felt security with their bodies again. Toombs³³ explains that being struck by illness can lead to the loss feeling accustomed to one’s body and that learning to live again after

being struck by an illness means accommodating illness and its means into daily life. In our study it seemed important for participants to rediscover themselves and to restore their selves and identities. Participants described cardiac arrest to still be present in their lives and that it had alerted them to life's fragility and impermanence. Life was thus welcomed, and participants looked forward, wished, and hoped for continued good life.

Methodological considerations

As nurses, physicians, and researchers we have experiences of people suffering acute illnesses, though listening to follow-up narratives of people's daily lives after surviving cardiac arrest was a new experience. During interviews the first author benefited from her experiences with nursing people with acute coronary syndrome but was nevertheless aware of that her knowledge of meanings of peoples lived experiences of surviving cardiac arrest was limited. The interpretation and analysis of the interview text was performed collaboratively with the first and last author, which strengthen our findings.

For qualitative research, the sample size should be large enough to achieve a variety of experiences and to permit thorough data analysis.³⁴ Purposive sampling was thus used in this study. All participants had special knowledge about the phenomenon under study, as this is the purpose of using qualitative methods.³⁵ Interviews with each participant were conducted at three times during the year after their cardiac arrest. Interviews conducted one month after the cardiac arrest were presented separately in another study.²² Participants shared deeply rich descriptions about their lived experiences, and the sample size was considered sufficient. Though there is no single possible meaning in a text, all interpretations of a text are not equally plausible.²⁵ We consider our interpretations to be highly probable, which elucidate

the greatest number of details. The study adheres to COREQ criteria for reporting qualitative research.

Conclusion

Meanings of surviving OHCA, during the first year can be likened to a pendulum's motion in light of comparing lives before and after cardiac arrest. Participants generally tested their bodies with different physical activities and strove to regain control over their bodies in order to feel safe. Cardiac arrest was quite present in their lives, though they wanted to put it behind them and look forward to pursue their lives. Participants expressed a need to be supported by health care services when testing their bodies in order to regain control and again feel safe with their bodies. To set goals and feel hope for the future were also underscored as key factors to moving on with life. These aspects should be discussed in dialogue between patients and health care personnel to encourage patients to move on with their lives, as well as to regain a sense of control.

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Table 1: Participants characteristics when suffering out-of-hospital cardiac arrest with validated myocardial infarction aetiology

Participants (n)	11
Male sex (n)	9
Age (years, mean, range)	63, 49-73
Cohabitant/living alone (n)	8/3
Gainfully employed/pensioners (n)	6/5
Known cardiovascular heredity (n)	10
Previously known	
Hypertension (n)	7
Hypercholesterolemia (n)	2
Ischemic heart disease (n)	2
Diabetes mellitus (n)	1
No previously known above risk factors (n)	4

Table 2: Overview of main theme, themes and subthemes constructed from the analysis

Interview conducted at	Main theme	Themes	Subthemes
6 months	A pendulum's motion	Aspiration for control	Testing the body
			Pursuing the ordinary life
		Being the person you are	Marveling about what have happened Wanting to both know and put it behind
12 months	A pendulum's motion	Recapitulation	Regaining a sense of security with the body Wanting to be checked and declared healthy Embracing changes Affecting the surrounding
			Wanting to resume daily life Being better prepared if it happen again Planning for the future
		Foresight	

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