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Surviving out-of-hospital cardiac arrest: The neurological and functional outcome and health-related quality of life one year later

Data from the prospective, nationwide FINNRESUSCI cohort

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Abstract

Background Data on long-term functional outcome and quality of life (QoL) after out-of-hospital cardiac arrest (OHCA) are limited. We assessed long-term functional outcome and health-related QoL of OHCA survivors regardless of arrest aetiology.

Methods All adult unconscious OHCA patients treated in 21 Finnish ICUs between March 2010 and February 2011 were followed. Barthel Index (BI), activities of daily living (ADL), accommodation, help needed and received, working status, car driving and self-experienced cognitive deficits were assessed in 1-year survivors (N=206, 40.9% of the original FINNRESUSCI cohort) with a structured telephone interview. Health-related QoL and more complex ADL-functions were evaluated by EQ-5D and instrumental ADL questionnaires.

Results Good outcome, defined as Cerebral Performance Categories 1 or 2, had been reached by 90.3% of survivors. The median BI score was 100, and 91.3% of survivors were independent in basic ADL-functions. The great majority of survivors were living at home, only 8.7% lived in a sheltered home or needed institutionalized care. Of home-living survivors 71.4% scored high in instrumental ADL assessment. The majority (72.6%) of survivors who were working previously had returned to work. Health-related QoL was similar as in age- and gender-adjusted Finnish population.

Conclusions Long-term functional outcome was good in over 90% of patients surviving OHCA, with health-related quality of life similar to that of an age and gender matched population.

Keywords: cardiac arrest; neurological outcome; functional outcome; quality of life

Introduction

Survival after out-of-hospital cardiac arrest (OHCA) has improved in many countries during the last decade [1-5]. With improved survival, the goal of treatment has shifted to emphasize favourable neurological and functional outcome as well as good quality of life in cardiac arrest patients. Recently patient-reported outcomes and health-related quality of life (HRQoL) were included as supplemental outcomes in the standardized Utstein Resuscitation Registry Templates for OHCA [6]. Data on OHCA survivors' functional outcome one year after the CA are still limited [7-8], partly because of the challenge of such long-term follow-up. The objective of this prospective observational study was to evaluate the functional status and HRQoL of one-year survivors of the FINNRESUSCI cohort [9],

a nationwide cohort of adult unconscious out-of-hospital cardiac arrest patients admitted to Finnish intensive care units during one year, 2010-2011. We specifically aimed to assess the proportion of cardiac arrest survivors living at home one year after the incident, the functional outcome of survivors regarding independency in Instrumental Activities in Daily Living (IADL) functions, activities outside home, return to previous work, car driving, and their self-rated HRQoL.

Methods

This was a prospective observational study. Twenty-one Finnish ICUs treating OHCA-patients participated the study, with referral areas covering approximately 98% of the Finnish adult population (4.3 million www.stat.fi). All participating ICUs belong to the Finnish Intensive Care Consortium. This is a nationwide database including 22 ICUs in Finland which collects data on all ICU treated patients including severity of illness and treatment intensity. Between March 1st, 2010 and February 28th, 2011 adult unconscious OHCA patients were included if they filled the following inclusion criteria: (1) OHCA, (2) successful resuscitation, defined as return of spontaneous circulation and survival to hospital admission, (3) age over 17 years and (4) post-resuscitation care in one of the participating ICUs. No recommendations for treatment of post-resuscitation syndrome and post-resuscitation care were given. Treatment decisions were made by the local treating physicians, in accordance to National Current Care, Scandinavian or the European Resuscitation Councils guidelines for post-resuscitation care. The study protocol was approved by the Ethics Committee of each participating hospital.

Data collection

Data concerning ICU treatment were collected prospectively on internet-based case report form and Finnish Intensive Care Consortium database. Pre-existing diseases were compiled from medical history. Survival data were collected from Statistics Finland. The patients were contacted by

telephone one year after OHCA and their neurologic outcome was evaluated using the Pittsburgh Cerebral Performance Categories (CPC) [10]. Basic activities of daily living, that is activities performed on a daily basis necessary for independent living at home, were assessed using Barthel Index (BI) [11]. The phone call included a semi-structured interview with questions about ADL-functions; accommodation; help received from family members or home care personnel; participation to social activities; occupation and return to work; car driving; and self-experienced cognitive deficits. For institutionalized patients, the assessment included an interview with the nearest relatives, nursing staff or both. Additionally, patients received EuroQol-5D-3L (EQ-5D) and Lawton instrumental activities of daily living (IADL) query forms by mail with return envelope, to evaluate the self-assessed quality of life and performance in more demanding ADL-functions. IADLs are actions that are not necessarily required on a daily basis, but are important to being able to live independently. Both BI and Lawton IADL have been validated, have good test-retest and inter-rater reliability, and are recommended by the national expert network of measuring and evaluating functional ability, maintained by the Finnish National Institute for Health and Welfare. The EQ-5D questionnaire was not sent to survivors living abroad, without permanent address, with limiting neurological condition, or not willing to fill the questionnaire. The outcome calls were made by a specialist in neurology (MT). The interviewer was blinded to incident and management details.

The Barthel Index is a measure to assess an individual's ability to perform activities of daily living related to self-care and mobility. It has ten variables, e.g. feeding, dressing, transfers, stairs, personal care and bathing. On a score ranging from 0 to 100, 95-100 indicates functional independency, 55-90 moderate dependency, and 0-50 full dependency. Blinded assessment by telephone interview is reliable with BI [12]. The Lawton Instrumental Activities of Daily Living Scale is an instrument to assess independent living skills [13]. It complements BI evaluation by providing self-reported information about functional skills necessary to live in the community. There are 8 domains of

function measured with the Lawton IADL scale: using the telephone, shopping, preparing food, house-keeping, doing laundry, using transportation, handling medications, and handling finances. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent). According to the recommendations the query forms were not sent to patients living in long-term facilities, because in these facilities residents perform few IADLs without assistance.

The EuroQol-5D is a generic instrument to measure health outcome [14]. It has 2 parts: EQ-5D and EQ visual analog scale. The EQ-5D-3L records a single digit response to 5 questions/dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with 3 levels: no problems, some problems, and extreme problems (www.euroqol.org). EQ-5D can be converted into a single summary index, where the highest possible index for HRQoL in all domains is 1.00. The EQ visual analog scale is a self-rating of health-related quality of life on a vertical scale, recorded from 0 (worst imaginable state) to 100 (best imaginable health state). The EQ-5D-3L has been validated in Finnish population [15] to measure HRQoL and can be used to calculate quality-adjusted life-years.

Statistical analysis

Continuous data are presented as medians with interquartile ranges (IQR, 25-75%) and categorical data as absolute numbers and percentages. Groups were compared using non-parametric Mann-Whitney U test for continuous data and Fisher's exact test for proportions, when applicable. Interview data were analyzed quantitatively. EQ-5D index- and VAS-values were compared to age- and sex-matched reference values using the Wilcoxon signed matched pair test. P values < 0.05 were considered statistically significant. Statistical data analysis software system® (StatSoft, Tulsa, OK, USA) was used for analyzing the data.

Results

The survival and dichotomized CPC outcome data of the FINNRESUSCI study have been published previously [9]. Of the 504 patients in the FINNRESUSCI cohort, 213 (42.3%) survived to one year. Survival data, or one-year outcome data could not be accessed for two (of four) survivors living abroad. One-year functional outcome data could not be assessed in seven survivors known to be alive; six could not be reached by phone despite numerous attempts and one refused to participate in the follow-up study. Thus, one-year functional outcome data was available for 206 successfully contacted survivors (96.7%). Table 1 presents demographic and clinical data of the studied 206 one-year survivors. Their median age was 61 years (range 18-84 years), 28 (13.6%) were younger than 45 years and 23 (11.2%) older than 75 years. Of the survivors, 167 of 206 (81.1%) had been treated with therapeutic hypothermia.

CPC outcome of the one-year survivors is presented in the Table 2. This data include two survivors living abroad not included in the original Finnresusci study report [9]. Good neurological outcome, defined as CPC 1 or 2, had been reached by 186 of 206 patients (90.3% of studied one-year survivors and 36.9% [186 of 504] of the original cohort). Two survivors were in vegetative state (CPC 4). Of the 18 patients with CPC 3 outcome, five patients had a CPC 3 before the cardiac arrest, and in two patients the pre-arrest CPC was 2.

The great majority of survivors (91.3%) were living at home (Table 3). The majority of them (N=107, 56.9 %) lived in a detached house or townhouse, which usually meant participating in physically straining activities like gardening, and snow clearing. Fourteen (7.4%) home-living survivors received some help from community home-care personnel (N=10) and/or from a family member or a friend (N=5). The help received from home-care personnel was typically not intensive: only two patients had a daily visit of home care, and none required several visits a day. Three survivors were able to live at home with disability, with the help of their spouses who were acting as personal carers.

Of the 18 survivors needing institutionalized care, three had already lived in institution before OHCA. The reason for institutionalized care with onset after CA was related to hypoxic-ischemic encephalopathy in 11 cases, other neurological disease in one case, and old age, cardiac causes and musculoskeletal problems in three cases.

The BI score was available for 205 survivors with a median BI score of 100 (IQR 100-100), ranging from 0 to 100. Median BI scores for institutionalized and home-living survivors were 40 (range 0-100) and 100 (range 30-100), respectively. According to BI, 182 (88.3%) survivors could be classified as independent, 12 (6.3%) moderately dependent, and 11 (5.8%) were fully dependent. In the interview 188 (91.3%) patients considered themselves to be independent in basic ADL-functions; the difference is explained by few home-living survivors regarding themselves not dependent, despite a BI score of 90.

Lawton IADL query forms were sent to 183 patients living at home and 168 filled forms were received back (response rate 91.8%). Reasons for not sending forms were patient refusal (N=3) and patient living abroad (N=2). The median for IADL total score was 8 (IQR 6-8). Altogether, 120 (71.4%) survivors scored 7 or 8 on this scale with a maximum of 8 points, and only 24 (14.3%) scored below 5. In semi-structured interviews, 179 (86.9%) survivors reported going outside home on a regular basis, whereas 23 (11.2%) did not go outside home or had to be accompanied outside home (data missing for 4 survivors [1.9%]). 177 (85.9%) patients were able to run errands and participated in social activities outside home whereas 23 (11.2%) did not. Data were missing for 6 (2.9%) survivors.

Of the 95 (46.1%) survivors that had been employed by the time of CA, 69 (72.6%) had returned to their previous work. Reasons for retirement included medical condition associated with the CA in 23

(24.2%) and reaching the formal age for retirement in 3 (3.1%) cases. Of the 206 one-year survivors, 151 had a driving license and had driven before the CA (data missing for 4 patients). One year after CA, 134 (88.7%) patients had a driving license and continued to drive, whereas 19 had not fulfilled the medical criteria for driving or had voluntarily chosen to abandon driving. Of 151, 39 (25.8%) survivors with driving license did not recall being advised not to drive for at least a period of time after CA.

No subjective long-term cognitive deficits had been experienced by 154 (74.8%), whereas mild and major cognitive deficits had been experienced by 31 (15%) and 13 (6.3%) survivors, respectively. Data were missing for 8 (3.9%) survivors.

The EQ-5D questionnaire was answered by 168 survivors (89.4% of the sent 188 questionnaires). The responses reflect mainly the self-assessed HRQoL of patients living at home. The median EQ-5D index value in the respondents was 1.000 (IQR 0.690-1.000, mean 0.822), which did not differ statistically from the age- and sex-matched Finnish general population, median 0.859 (IQR 0.826-0.882, mean 0.853) ($p=0.18$). The median EQ-VAS value of the respondents was 80 (IQR 70-90, mean 77.8), which is higher than the median reference value of 69.5 (IQR 56.1-87.3, mean 72.1) for Finnish age- and sex-matched general population ($p<0.001$). The distribution of EQ-5D scores for each dimension according to the survivor's age is presented in the Table 4. Figure 1 shows the EQ-5D scores for OHCA survivors at 12 months post arrest.

The studied cohort included 159 survivors with initial shockable and 47 with non-shockable rhythm. In the original cohort of 504 ICU-treated OHCA patients, good neurological outcome was achieved by 148 of the 281 (52.7%) patients with initial shockable rhythm and by 38 of the 223 (16.3%) patients with non-shockable rhythm ($p<0.001$). One year after OHCA, the survivors with initial non-

shockable rhythm were more often in institutionalized care than those with a shockable rhythm, and were less often independent in basic ADL-functions. Home-living patients with non-shockable rhythm scored lower in IADL assessment. This and the EQ-5D HRQoL data according to the initial rhythm is presented in Supplemental Table 1.

Discussion

In our study nine out of ten one-year survivors of ICU-treated OHCA experienced good neurological and functional outcome, living at home and being independent in basic ADL-functions. Less than 10% of the one-year survivors lived in long-term facilities, and only 3% of those OHCA patients who lived at home before the arrest needed long-term facility care one year later. This need was not based solely on the hypoxic-ischemic brain injury.

The high percentage of survivors that were independent in basic ADL-functions is in accordance with previous reports [16-18]. Independency was not limited to basic ADL-functions, as 70% of the home-living survivors scored high in instrumental activities of daily living assessment. This suggests good functional skills also in taking care of the housework and tasks outside home. The remarkably high number of survivors living alone (24%) also indicates good functional outcome. The cohort also included young patients: 14% of survivors were younger than 45 years. Their life-situation appeared different from that of older patients with 8% of survivors living with under-aged children, some of whom as single parents.

In this cohort, three of four survivors had returned to their previous work. The percentage is in concordance with previous reports from USA, Denmark and Australia [18-19,8], and similar to our previous small study [17], but higher than previously reported from Sweden or centers in the USA

[16, 20-21]. However, return to work after critical illness does not only depend on patient's recovery, factors such as profession, employer, economic situation, social security network and personal motivation have a major impact.

One fourth of survivors possessing driving license before CA were not aware of any temporary driving ban, and many of them had started driving early after discharge from hospital, which is alarming. It is possible that some had forgotten receiving the information about driving ban due to their medical condition, but it is unlikely that this would explain all cases. The European recommendations for driving and cardiovascular disease instruct at least a temporary driving ban after CA, with length depending on the underlying disease and the treatment. Regardless of the CA etiology, a temporary driving ban is neurologically justified.

The results of this study support the impression that the quality of life after CA does not differ from that of age- and gender matched population [22]. With current clinical practice, the ICU treatment of cardiac arrest does not appear to result in long-term survival of patients with major functional deficits and poor quality of life. The EQ-5D index score of our responders was comparable to that of age- and sex-adjusted Finnish norm, and their EQ-VAS value was higher than adjusted Finnish norm. Interestingly, the mean EQ-5D index score of Australian CA survivors one year after the incident was 0.82, almost identical to our study [8]. In a recent Finnish study including both in-hospital CA and OHCA survivors, the median EQ-5D index value was 0.89 six months after the CA, slightly lower than in our study [23]. Previously a Swedish study has reported a mean EQ-VAS value of 75 in hypothermia-treated CA survivors six months after resuscitation, comparable to our result [16]. Worse quality of life after CA has been correlated with impaired performance in IADL, severity of fatigue, higher amount of cognitive complaints, anxiety and depression, a high baseline comorbidity burden, and higher degree of post-traumatic stress [24-27]. Cognitive dysfunction may not translate

to worse self-assessed quality of life, especially when mild or moderate [17,28]. In a recent study, 24% of OHCA-survivors reported symptoms of anxiety, and depressive symptoms were reported by 13%, but the numbers were comparable with those of ST-elevation myocardial infarction patients [25]. The long-term consequences of CA are not limited to the survivor: high-level of strain has also been found in 17% of caregivers of CA survivors [7].

EQ-5D has been recommended for evaluations for quality of life assessment in the critical care setting [29]. However, it does not cover all important aspects of HRQoL in critical care population, e.g. cognitive status and the subsequent impact of health status on social interactions and relationships [30]. Additional limitation of EQ-5D-3L in CA survivor population is a ceiling effect [31]. A revised version, the EQ-5D-5L has been developed to better differentiate small changes in health status, but it has yet to be assessed in CA survivors. Currently, a measure of HRQoL specific to OHCA survivors is not available. A need to establish and standardize a relevant and acceptable HRQoL measure for CA survivor population has been recognized [22,32-33].

This study has a number of strengths. It represents data from the FINNRESUSCI study that captured all unconscious OHCA patients treated in ICUs during a one-year period. Patients were unselected, included all CA etiologies and treated in hospitals of different level and case load. There were very few missing patients and the response rate for the IADL- and EQ-5D-questionnaires were high. Therefore, we believe that the results represent the outcome of Finnish ICU-treated OHCA patient.

However, we acknowledge some important limitations. First, given the nationwide study design the outcome evaluations were made by phone and not face-to-face. Nonetheless, this enabled using a single assessor of outcome. Second, we do not have data on pre-arrest ADL-functions and it is possible that some of the noticed deficits existed already before CA. Third, EQ-5D-3L has limitations in capturing some important aspects of HRQoL. Fourth, EQ-5D and IADL data were not available

from every survivor and it is possible that subjects with good self-assessed HRQoL and good functional level were more prone to answer to the IADL and EQ-5D queries, potentially causing some bias.

Conclusion

In this national population based prospective cohort study including ICU-treated unconscious cardiac arrest patients of all etiologies, four of ten patients survived to one year. Nine of ten survivors were independent, lived at home, participated activities outside home, and valued their quality of life to be as good as that of age- and sex-matched general population.

Conflict of interest statement

The authors have no conflicts of interests to declare

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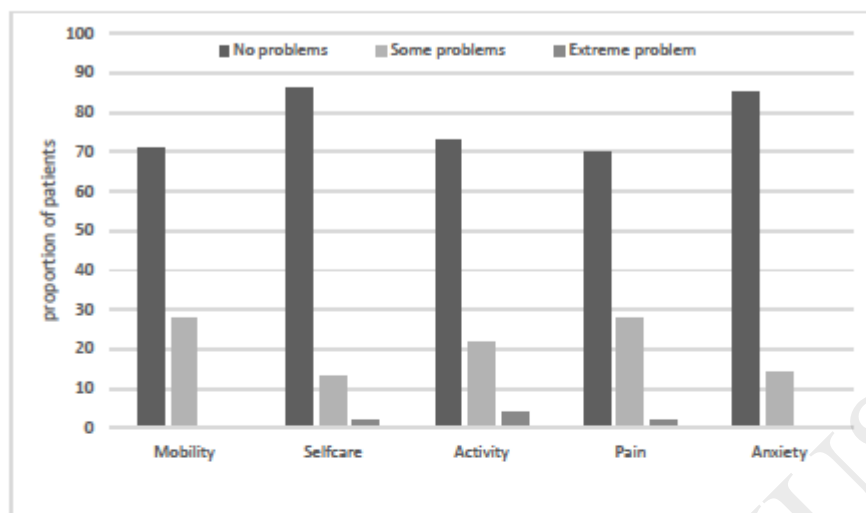
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Legends to figures

Figure 1. EQ-5D-3L scores for OHCA survivors at 12 months postarrest

Figure 1. EQ-5D scores for OHCA survivors at 12 months postarrest



Total N=168 respondents. EQ-5D, EuroQol 5 dimensions; OHCA, out-of-hospital cardiac arrest.

Table 1. Demographic and clinical characteristics of one-year CA survivors

	Number of patients 206
Male/female, N (%)	162/44 (78.6/21.4)
Age, years	61 (53-67)
Shockable rhythm, N (%)	159 (77.2)
Bystander-initiated CPR, N (%)	124 (60.2)
ROSC, minutes	17.0 (12-24)
Therapeutic hypothermia, N (%)	167 (81.1)
ICU length of stay, days	3.3 (2.35-5.66)
Pre-arrest medical history, N (%)	
CAD	48 (23.3)
Hypertension	78 (37.9)
Heart failure	20 (9.7)
Diabetes	34 (16.5)
Kidney failure	2 (1.0)
PCI	14 (6.8)
CABG	15 (7.3)

Data are given as absolute numbers and percentages or as median and interquartile range. CPR, cardiopulmonary resuscitation; ROSC, restoration of spontaneous circulation; CAD, coronary artery disease; PCI, percutaneous coronary intervention; CABG, coronary artery bypass grafting

Table 2. CPC outcome of 206 one-year survivors of OHCA, unconscious at admission to ICU

CPC	Number of patients	Percentage of studied 1-yr survivors	Percentage of ICU-treated OHCA patients
CPC 1	153	74.3	30.4
CPC 2	33	16.0	6.5
CPC 3	18	8.7	3.6
CPC 4	2	1.0	0.4

Table 3. Residential circumstance of one-year CA survivors

	Number of patients
	206
Lives at home	188 (91.3)
alone	49 (23.8)
with spouse	115 (55.8)
with spouse and underage children	13 (6.3)
with other adult family member	7 (3.4)
single-parent with underage children	4 (1.9)
Lives in institutionalized care	18 (8.7)
nursing home	15 (7.2)
sheltered home	2 (1.0)
interval care in nursing home	1 (0.5)

Data are given as absolute numbers and percentages

Table 4. EQ-5D-3L and EQ-VAS at twelve months

		Age 18-44	Age 45-65	Age ≥ 66
		(N=20)	(N=98)	(N=50)
EQ-5D-3L				
Mobility				
	No problems walking	18 (90)	72 (73)	30 (60)
	Some problems walking	2 (10)	25 (26)	20 (40)
	Confined to bed	0	0	0
Self-care				
	No problems with self-care	19 (95)	89 (91)	36 (72)
	Some problems with washing or dressing	1 (5)	8 (8)	12 (24)
	Unable to wash or dress	0	1 (1)	2 (4)
Usual activities				
	No problems with usual activities	18 (90)	71 (72)	34 (68)
	Some problems with usual activities	2 (10)	23 (23)	12 (24)
	Unable to do usual activities	0	4 (4)	2 (4)
Pain or discomfort				
	No pain or discomfort	16 (80)	68 (69)	34 (68)
	Moderate pain or discomfort	3 (15)	29 (30)	15 (30)
	Extreme pain or discomfort	1 (5)	1 (1)	1 (2)
Anxiety or depression				
	Not anxious or depressed	15 (75)	85 (87)	43 (86)

	Moderately anxious or depressed	5 (25)	12 (12)	7 (14)
	Extremely anxious or depressed	0	0	0
EQ-5D-3L utility index	median (IQR)	1.000 (0.309)	1.000 (0.310)	0.766 (0.324)
	mean	0.860	0.832	0.786
EQ-VAS score	median (IQR)	90 (16)	80 (20)	77 (22)
	mean	87	79	72

Data are given as absolute numbers and percentages or median with IQR. EQ-VAS, EuroQol visual analog scale.