Clinical paper

Life after survival: Long-term daily functioning and quality of life after an out-of-hospital cardiac arrest[☆]

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ABSTRACT

Background: Information about long-term consequences of cardiac arrest is sparse. Because the survival rate is expected to increase, better knowledge of long-term functioning and *quality* of survival is essential.

Objectives: To determine the level of functioning of out-of-hospital cardiac arrest survivors 1–6 years later, and to evaluate the predictive value of medical variables on long-term functioning.

Methods: A retrospective cohort study including 63 survivors of an out-of-hospital cardiac arrest, admitted to a Dutch University hospital between 2001 and 2006. Participants received a questionnaire by post. Primary outcome measures were: participation in society (Community Integration Questionnaire) and quality of life (SF-36). Secondary outcome measures were: physical, cognitive and emotional impairment, daily functioning and caregiver strain. Statistical analyses included multiple regression analyses.

Results: On average 3 years post-cardiac arrest, 74% of the patients experienced a low participation level in society compared with the general population. Over 50% reported severe fatigue, 38% feelings of anxiety and/or depression and 24% a decreased quality of life. Caregivers reported stress related responses, feelings of anxiety and lower quality of life. Seventeen percent of the caregivers reported high caregiver strain, which was associated with the patient's level of functioning. Gender, age, percutaneous coronary intervention (PCI) and therapeutic hypothermia contributed to outcome on at least one domain of long-term functioning.

Conclusions: After surviving an out-of-hospital cardiac arrest, many patients and partners encounter extensive impairments in their level of functioning and quality of life. Gender, age, PCI and therapeutic hypothermia are associated with differences in long-term functioning of patients.

1. Introduction

In the Netherlands, the overall incidence of sudden cardiac death is 0.92 per 1000 persons per year.[1] Reported survival after an out-of-hospital cardiac arrest is between 2% and 23% of patients with a bystander-witnessed cardiac arrest surviving to discharge.[2] However, this number is expected to increase with the increasing availability of automated external defibrillators (AEDs).[3]

During a cardiac arrest, the brain suffers hypoxia which may cause diffuse ischemic–hypoxic injury that may result in cognitive deficits.[4] Six months after the cardiac arrest, cognitive deficits are still present in up to half of all survivors.[5] Hypoxic brain injury also has an impact on other important aspects of life. Survivors report symptoms of depression,[6] dependency on others for daily functioning,[6] decreased participation in society with only 13–58% of patients returning to work,[7–9] and a lower quality of life.[6,7]

Research on prognostic factors for surviving a cardiac arrest showed that among predictors of a poor neurological outcome are older age, unwitnessed arrest, lack of bystander cardiopulmonary resuscitation (CPR),[10] a non-VT/VF initial cardiac rhythm

and a long interval between collapse and return of spontaneous circulation.[10,11] However, little is known concerning prognostic factors of long-term functioning and *quality* of life of cardiac arrest survivors. This information could help clinicians to inform their patient and family members about future problems and functioning, and possibly guide intervention in the early stages.

In this study we determined the level of participation in society, quality of life, cognitive, emotional and physical impairment, and daily functioning of out-of-hospital cardiac arrest survivors, and strain on, basic functioning and quality of life of their caregivers several years after the event. The hypothesis was that out-of-hospital cardiac arrest survivors have lower levels of functioning on all domains compared with the general population, and that caregiver strain is augmented. Second, we studied prognostic factors for participation in society, quality of life, cognitive impairment and daily functioning after surviving a cardiac arrest. We hypothesized that the interval between collapse and return of spontaneous circulation,[10,11] application of mild therapeutic hypothermia[12,13] and Implantable Cardioverter Defibrillator (ICD) placement[14,15] would all be associated with level of outcome in one or more of these domains.

2. Methods

2.1. Study population

Out-of-hospital cardiac arrest survivors who had been admitted to the Department of Cardiology of the University Hospital Maastricht, the Netherlands from January 2001 till December 2006 were asked to participate in this retrospective cohort study. The hospital is the primary referral centre for a catchment area of approximately 200,000 inhabitants covered by a single ambulance service. Participants were survivors aged 18 years or older, still alive at the time of the study, and with sufficient knowledge of the Dutch language to complete questionnaires.

2.2. Data collection

Patient data were retrieved from two local databases: a recent study in the University Hospital Maastricht,[16] and the "Maastricht Sudden Circulatory Arrest Registry".[17] Also, the admission registers of the Coronary Care Unit of the University Hospital Maastricht between 2001 and 2006 were hand searched for admission stating "cardiac arrest" or "resuscitation". This combination should identify most of the cardiac arrests, thereby offering a representative sample.

After checking survival status of discharged patients with their general practitioner, potential participants were informed about the study. Both patient and their caregiver were sent a set of questionnaires and were asked for informed consent. One reminder was sent after 2 weeks.

The study protocol was approved by the Medical Ethics Committee of the University Hospital Maastricht.

2.3. Measurement instruments

Socio-demographic variables before the cardiac arrest and current status (as presented in Table 1) were collected by self-report. Main medical variables related to the cardiac arrest (as presented in Table 2) were retrieved from both databases and patient files.

2.4. Outcome measures

The questionnaires for patients encompassed the following domains of the International Classification of Functioning, Disabil-

Table 1
Demographic characteristics of the patients (N = 63).

	At time of cardiac arrest	Current situation
Age		
Mean (S.D.)	57.3 (12.5)	60.2 (12.7)
Range	18–81	20–85
Gender		
Male		54 (86%)
Female		9 (14%)
Marital status		
Married/living with partner	47 (75%)	46 (73%)
Unmarried/divorced/widowed	15 (24%)	15 (24%)
Unknown	1 (2%)	2 (3%)
Living situation		
Home (independent)	54 (86%)	53 (84%)
Home (with help from others)	8 (13%)	8 (13%)
Sheltered housing	1 (2%)	1 (2%)
Nursing home	–	1 (2%)
Education		
Primary school		7 (11%)
Secondary school		12 (19%)
High school		30 (48%)
University		6 (10%)
Other/unknown		8 (13%)
Working situation		
Full-time/self-owned company	30 (48%)	17 (27%)
Part-time	5 (8%)	10 (16%)
Permanently unfit to work	5 (8%)	6 (10%)
Volunteer work	–	1 (2%)
No job	–	1 (2%)
Retired	17 (27%)	22 (35%)
Housewife	6 (10%)	6 (10%)

ity and Health (ICF): basic functioning, activities in daily life and participation in society.[18]

2.4.1. Basic functioning

- The **New York Heart Association Classification (NYHA)**, a functional classification of cardiovascular disability. It ranges from Class I (patients without limitation of physical activity) to Class IV (patients unable to carry on physical activity without discomfort).[19]
- The **Fatigue Severity Scale (FSS)**, a nine-item questionnaire assessing the impact of fatigue on patients' functioning.[20] Scoring is on a seven-point scale. A mean score is calculated (range 1–7) with higher scores reflecting greater fatigue. Construct validity is 0.68 with the visual analogue scale as external criterion,[20] (Cronbach) alpha is 0.89 in stroke patients.[21]
- The **Cognitive Failures Questionnaire (CFQ)**, a 25-item questionnaire that inquires about failures in perception, memory and executive functioning.[22] The total score ranges from 0 to 100, with a higher score indicating more cognitive problems. Construct validity is 0.59 compared with the short inventory of memory experiences.[22] Alpha is 0.88 in a healthy population.[23] The caregivers were also asked to fill out a CFQ for the patient in order to find out whether the scores correlate with one another.
- The **Hospital Anxiety and Depression Scale (HADS)**, a widely used questionnaire designed to assess mood disorders in non-psychiatric hospital outpatients,[24] with 14 items divided in two subscales measuring signs of anxiety and depression. The scale has a concurrent validity of 0.73 compared with the Beck Depression Inventory and alpha is 0.83 (anxiety subscale) and 0.82 (depression subscale).[24]
- The **Impact of Event Scale (IES)**, a 15-item questionnaire that assesses stress reactions after traumatic events, focussing on psychological responses of intrusion and avoidance.[25] The total score ranges from 0 to 75, with a higher score indicating more

Table 2
Medical data regarding the cardiac arrest (CA).

	N	No. (%), mean (S.D.) or median (range)
Age at time of CA	63	57.3 (12.5)
Location of CA	63	
Street/public area		30 (48%)
Home		20 (32%)
In the ambulance		4 (6%)
Other		9 (14%)
Witnessed CA	63	56 (89%)
Bystander CPR	63	
Yes, by lay person		26 (41%)
Yes, by trained person		23 (37%)
No		14 (22%)
Initial cardiac rhythm	62	
VF		55 (89%)
VT/VF		6 (10%)
Other rhythm		1 (2%)
Number of defibrillations	63	2.0 (0–12)
Interval collapse – ROSC (min)	47	10.0 (2–35)
(Sub)acute interventions	63	
PCI		28 (44%)
CABG		13 (21%)
ICD		25 (46%)
Therapeutic hypothermia		17 (27%)
LVEF <1 week after CA	58	47.5 (12.7)
Cardiovascular history	63	
Myocardial infarction		19 (30%)
Cardiac arrest		2 (3%)
Cardiac interventions (PCI, CABG)		8 (13%)
Claudication		4 (6%)
CVA		2 (3%)
Diabetes mellitus		3 (5%)

VF, ventricular fibrillation; VT, ventricular tachycardia; ROSC, return of spontaneous circulation; PCI, percutaneous coronary intervention; CABG, coronary artery bypass graft; ICD, implantable cardioverter defibrillator; LVEF, left ventricular ejection fraction; CVA, cerebrovascular accident.

stress reactions. The scale has a content validity of 0.63, moderate construct validity and alpha is 0.86 (intrusion) and 0.82 (avoidance).[25]

2.4.2. Daily functioning

- The Barthel Index measures basic activities of daily living (ADL)[26] and consists of 10 items, with a total score ranging from 0 (totally ADL dependent) to 20 (independent in basic ADL). Construct validity is 0.92 compared with the Functional Independence Measure, alpha is 0.84 in stroke patients.[26]
- The Frenchay Activities Index (FAI), a 15-item questionnaire for instrumental ADL referring to the patient's ability to perform more complex activities.[27,28] Scoring is on a four-point scale with total score ranging from 0 (low ability) to 45 (high ability). In a stroke population, construct validity is 0.61–0.66 compared with the Barthel Index,[27,28] alpha is 0.87.[28]

2.4.3. Participation in society (primary outcome measure)
- The Community Integration Questionnaire (CIQ), a 15-item questionnaire assessing participation in three domains (home integration, social integration and productive activity).[29] Items are rated from 0 to 2, with 2 representing greater independence and integration. The total score ranges from 0 to 29. In patients with traumatic brain injury, concurrent validity is 0.47–0.60 compared with the Functional Assessment Measure, test–retest reliability is 0.83–0.97.[29]

2.4.4. Quality of life (primary outcome measure)

- The 36-item short form health survey (SF-36), a generic health related quality of life measure containing 36 items, covering eight dimensions of health within a Physical and Mental Component subscale.[30] For each dimension and subscale, scores are transformed to a scale from 0 (worst health) to 100 (best health). Alpha is 0.73–0.96[30] and the scale has good psychometric properties in patients with heart disease.[31]

2.4.5. Caregiver

- The Caregiver Strain Index (CSI), a 13-item questionnaire that measures strain related to provision of care by asking the patient's caregiver to answer yes/no statements.[32] Positive responses to seven or more items indicate a greater level of strain. There is moderate evidence for its construct validity, alpha is 0.86.[32]

The caregivers were also asked to fill in the following questionnaires: Hospital Anxiety and Depression Scale, Impact of Event Scale and the 36-item short form health survey.

2.5. Statistical analysis

Descriptive statistics were used to present demographic and medical characteristics of the participants and their scores on the questionnaires. The percentages of participants with a score below or above the cut-off score of the questionnaire are reported. Cut-off scores were used as presented in the original questionnaires if available, and for the Frenchay Activities Index, Community Integration Questionnaire and the SF-36 a cut-off score was calculated based on mean variable score for the Dutch population (as derived from the literature) ±one standard deviation.[28,33,34]

In cases with ≥15% missing values within a questionnaire, the total score on the questionnaire was not calculated and the data excluded from the analyses. In cases with <15% missing values, the mean score of items per subscale was imputed.

To examine associations between outcome measures and medical variables, Spearman correlation coefficients were calculated. Multiple linear regression analyses with backward elimination were carried out using the variables with the highest bivariate correlation coefficients as independent variables. Dependent variables were cognitive impairment, daily functioning, participation in society and quality of life. Since in previous studies age and gender appeared to be related to the patient's functioning and quality of life, these factors were introduced in the model as potential confounding factors.[9,35] A limit value for elimination in the regression analyses was set at $p < 0.10$ and a p-value of ≤ 0.05 was considered statistically significant. Statistical analyses were performed using the software package SPSS version 12.0 (SPSS Inc., Chicago, IL, USA).

3. Results

As shown in Fig. 1, 220 persons with a possible out-of-hospital cardiac arrest were identified. Due to exclusion, death and loss-to-follow up, 88 persons were eligible for participation in the study. Sixty-three (72%) patients, 54 men and 9 women, with a mean (S.D.) age of 60.2 (±12.7) years, and 42 caregivers participated.

The mean (S.D.) time since cardiac arrest was 36 (±18.8) months. No statistically significant gender- ($t = -0.62$, $p = 0.54$) or age-related (Chi-square = 0.04, $p = 0.84$) differences between responders and non-responders appeared. Demographic characteristics and medical data of the patients are presented in Tables 1 and 2, respectively.

As shown in Table 1, the marital status and living situation did not alter significantly after the cardiac arrest. The
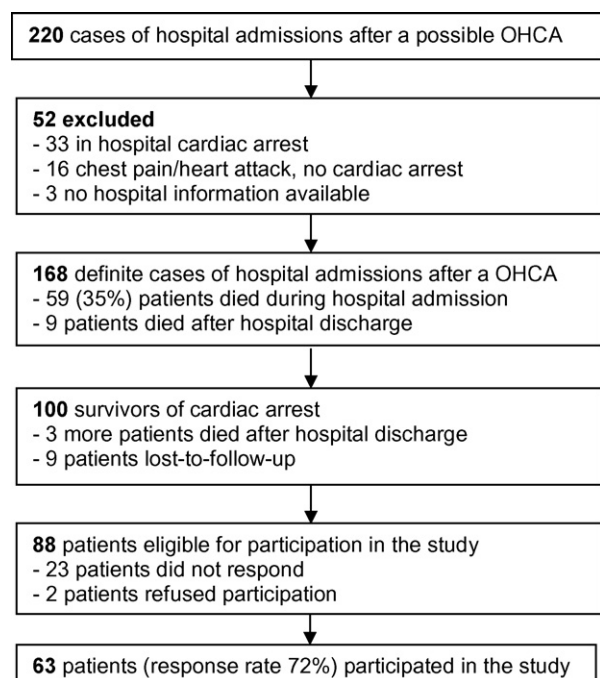
Fig. 1. Flow chart of patient inclusion.

majority of the patients remained independent after the cardiac arrest.

Of the 30 patients working fulltime before the event, 17 people still worked fulltime and eight worked part-time after the cardiac arrest. Of the 5 patients working part-time before the cardiac arrest,

two persons were working less hours and three persons had retired. This means that 17 out of 35 (49%) patients were able to return to their previous job. In addition, 10 (29%) patients were able to return to work, but were working less hours.

3.1. Current level of functioning

The long-term level of functioning of the participants is shown in Table 3. The majority of the patients had a lower participation level in society than the general population and 24% showed a lower quality of life (SF-36). One in five patients experienced cognitive impairments. Caregivers reported better scores on the CFQ focussing on the patients' cognitive functioning as compared to the patients themselves, this difference was not statistically significant ($t = 0.95$, $p = 0.34$).

The situation of caregivers is presented in Table 4. Half of the caregivers scored high on the Impact of Event Scale. These scores were significantly higher than scores of patients ($t = -3.84$, $p < 0.001$). Almost one in five of the caregivers showed a high level of caregiver strain.

3.2. Prognostic variables for current level of functioning

As shown in Table 5, quality of life, participation in society and daily functioning of patients after surviving a cardiac arrest could be significantly predicted by the regression model, mainly due to the contribution of gender and age.

Gender contributed significantly in the explanation of all dependent variables. Male patients appeared to have a higher quality of life and cognitive functioning, but lower levels of participation in society and instrumental daily activities as compared to females. Age contributed significantly in the explanation of the level of

Table 3
Basic functioning, activities in daily living and participation in society of the patients ($N = 63$).

ICF domain	Cut-off score	N	Mean (S.D.) or median (range)	No. (%) impaired
Basic functioning				
New York Heart Association classification (NYHA)	≥3	62	1.0 (1–4)	8 (13%)
Fatigue Severity Scale (FSS)	≥4	61	4.3 (1.6)	34 (56%)
Cognitive Failures Questionnaire (CFQ)	≥44	61	29.8 (18.4)	13 (21%)
Cognitive Failures Questionnaire (CFQ) by caregiver	≥44	42	26.5 (16.2)	6 (14%)
Hospital Anxiety and Depression Scale (HADS)	≥11	63	8.5 (6.4)	22 (35%)
Subscale anxiety	≥9	63	4.4 (3.4)	8 (13%)
Subscale depression	≥9	63	4.2 (3.6)	9 (14%)
Impact of Event Scale (IES)	≥26	63	13.0 (13.7)	13 (21%)
Activities of daily living				
Barthel Index	≤14	63	20.0 (7–20)	2 (3%)
Frenchay Activities Index (FAI)	≤16	61	25.7 (8.7)	12 (20%)
Participation in society				
Community Integration Questionnaire (CIQ)	≤18	61	14.7 (5.5)	45 (74%)
Quality of life				
SF-36 physical component	≤50	58	71.8 (19.6)	10 (17%)
SF-36 mental component	≤55	55	73.0 (20.5)	13 (24%)

Table 4
Basic functioning and quality of life of the caregivers ($N = 42$).

ICF domain	Cut-off score	N	Mean (S.D.) or median (range)	No. (%) impaired
Basic functioning				
Hospital Anxiety and Depression Scale (HADS)	≥11	42	9.1 (7.8)	16 (38%)
Subscale anxiety	≥9	42	5.7 (4.8)	11 (26%)
Subscale depression	≥9	42	3.0 (0–13)	4 (10%)
Impact of Event Scale (IES)	≥26	40	25.2 (16.9)	20 (50%)
Quality of life				
SF-36 physical component	≤50	38	85.0 (21–100)	9 (24%)
SF-36 mental component	≤55	39	74.3 (20.6)	9 (23%)
Caregiver Strain Index (CSI)	≥7	41	3.0 (0–13)	7 (17%)

Table 5
Final step in multiple linear regression analyses with backward elimination.

Dependent variables	Independent variables	R^2	Adjusted R^2	Standardized beta	p-Value
SF-36 physical health		0.16	0.12		0.02
	Gender			−0.26	**0.04**
	Age			−0.32	**0.02**
	Therapeutic hypothermia			−0.23	0.08
SF-36 mental health		0.17	0.14		0.01
	Gender			−0.35	**0.01**
	Therapeutic hypothermia			−0.23	0.08
CIQ		0.33	0.29		0.00
	Gender			0.24	**0.04**
	Age			−0.34	**0.01**
	Catheterization with PCI			0.26	**0.03**
FAI		0.34	0.30		0.00
	Gender			0.23	**0.04**
	Age			−0.31	**0.01**
	Catheterization with PCI			0.31	**0.01**
CFQ		0.34	0.31		0.00
	Gender			0.41	**0.00**
	Catheterization with PCI			−0.32	**0.01**
	Therapeutic hypothermia			0.40	**0.00**

SF, short form 36; CIQ, Community Integration Questionnaire; FAI, Frenchay Activities Index; CFQ, Cognitive Failures Questionnaire. Independent variables: gender, age, number of defibrillations, catheterization with PCI, therapeutic hypothermia, myocardial infarction in cardiovascular history.

quality of life (physical health), participation in society and instrumental daily activities, indicating lower levels of functioning in older patients.

PCI appeared to contribute significantly in the explanation of societal participation, daily functioning and cognitive functioning (β 0.26; p = 0.03, β 0.31; p = 0.01 and β −0.32; p = 0.01, respectively). In addition, mild therapeutic hypothermia appeared to contribute significantly in the explanation of cognitive functioning (β 0.40 and p < 0.01), indicating more cognitive problems in the group treated with hypothermia.

4. Discussion

We found that many patients surviving 6 months to 6 years after an out-of-hospital cardiac arrest experienced severe fatigue, feelings of anxiety and depression, cognitive problems and a decreased quality of life. They also had problems with participation in society. These results can be compared to functioning in the general population, but also to other studies focusing on cardiac arrest survivors or brain-injured patients.

In comparison with the general population, patients in this study seem to have lower levels of participation in society.[33] Their health related quality of life is just below average.[34] The mean score on the SF-36 appeared to be lower than in previous studies in cardiac arrest survivors but higher than in patients with traumatic brain injury,[36,37] whereas the level of participation in society seems comparable with that of patients after traumatic brain injury.[29] However, the mean age of the patients in the current study is higher as compared to the general population, and older age showed to have a negative effect on participation in society. Of the 35 (56%) patients working before the cardiac arrest, 49% were able to fully return to work, which is better than presented in earlier studies.[7–9]

Severe fatigue was present in more than half of the patients. This finding is similar to the rate in patients 1 year post-stroke, where 70% of patients experienced fatigue.[21] The scores found on the HADS, with 14% showing signs of depression, agree with previous studies on cardiac arrest.[6,38] Twenty-two percent of our patients experienced problems with cognitive functioning. In previous studies on cardiac arrest survivors percentages of 11–50% were reported.[5,39] However, we used the CFQ to assess cognitive problems and it reflects the perception of the patients, who may be either less aware or overestimate their cognitive problems. Conclusions on cognitive functioning from this study have to be drawn with caution.

The performance of instrumental daily activities found is comparable with the general population and much better than in stroke patients.[28] Fifty-four (86%) patients in this study functioned independently which seems better than in earlier studies where 23–32% of the patients were unable to live at home independently up to 1 year after the cardiac arrest.[6,8,35]

4.1. Caregivers

Little information is available on the strain put on the partner after a cardiac arrest. Based on the results of this study, many caregivers experience stress reactions and feelings of anxiety after their partner's cardiac arrest, even more so than the patients. Almost one in five caregivers showed a high level of caregiver strain. This is less than the 64% found in a previous study of caregivers to severely brain-injured patients.[40]

4.2. Prognostic factors for long-term functioning

Looking at prognostic factors for long-term daily functioning,[6,7,9] gender and age influenced the patient's quality of life, participation in society and daily functioning. This confirms findings in previous studies.[9,35] Patients treated with PCI after cardiac arrest seemed to have a higher level of cognitive functioning, participation in society and instrumental daily activities than patients without PCI. This may be due to selection bias (only patients with VF, a prognostic favourable initial rhythm, being treated). There were significantly more cognitive problems in patients treated with mild therapeutic hypothermia but this may also reflect selection bias because this treatment is only administered to patients who are comatose upon arrival in the hospital, and coma itself is related to more cognitive impairments.[5,11] Mild therapeutic hypothermia may improve mortality and neurological outcome,[12,13] although a recent study did not show a significant difference in Glasgow Outcome Scale between treated and untreated patients.[16]

Several studies have investigated the influence of having an ICD on the quality of life,[14,15] but we did not find any associations between having an ICD and quality of life.

4.3. Limitations

This study is limited by its retrospective design. Information in the hospital medical files concerning the resuscitation procedures could be prone to bias. In addition, possible associations between resuscitation variables and long-term outcome retrieved from the questionnaires could be influenced by confounders (e.g. level of functioning before the cardiac arrest and changes in the treatment of cardiac arrest) or selection bias through patient participation. This study has a small sample size, but it is larger than many previous studies on this topic.

4.4. Future research

Further research based on prospective studies with larger samples is needed on different domains of long-term functioning of both patients and caregivers, and on prognostic factors for future functioning and quality of survival so that these problems can be discussed more adequately after patients survive a cardiac arrest.

5. Conclusions

Our results indicate that after surviving an out-of-hospital cardiac arrest, both patients and partners can experience important impairments in their lives, similar to those seen in patients with other kinds of brain damage. This might suggest that, in order to improve their quality of life, survivors of cardiac arrest should receive additional therapy similar to patients with other brain injuries rather than regarding them as cardiac patients only. It also shows the need and importance of further research in this field.

Conflict of interest

None declared.

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