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Short paper

A change of perspective? An explorative study on why patients may not subjectively report cognitive impairments after a cardiac arrest



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Abstract

Aim: Cardiac arrest survivors are at risk of long-term cognitive impairment. Patients with cognitive impairments do not always have cognitive complaints and vice versa. Not reporting cognitive complaints could be caused by a lack of awareness. We hypothesized that caregivers report more cognitive failures than patients, indicating patients' lack of insight into cognitive functioning.

Methods: This is a secondary analysis of the Activity and Life After Survival of Cardiac Arrest study on survivors of cardiac arrest and their caregivers. They were assessed at two weeks, three months, and one year after cardiac arrest. At each time point, the patient and the caregiver filled out the cognitive failure questionnaire (CFQ) regarding the patient. We analysed the correlation, intraclass correlation, and self-proxy discrepancy between patients and caregivers on the CFQ over time.

Results: One-hundred-and-nineteen cardiac arrest survivors (mean age = 60, 85 % male) and their caregivers were included. The CFQ scores of the patients and caregivers were equally low. The correlation (T1 $r = 0.31$; T2 $r = 0.40$; T3 $r = 0.55$) and intraclass correlation (T1 $r = 0.48$; T2 $r = 0.56$; T3 $r = 0.71$) between patient and caregiver increased over time.

Conclusion: This study does not support a lack of awareness of cognitive impairments by long-term cardiac arrest survivors. Future research may focus on alternative explanations for why patients have less cognitive complaints than expected based on the frequency of cognitive impairments. Possible explanations include a response shift.

Keywords: Cardiac arrest, Cognitive complaints, Response shift, Awareness

Introduction

The survival rate of out of hospital cardiac arrest (OHCA) increased over the past decades.^{1–4} Therefore, it becomes increasingly important to investigate the long-term outcomes of cardiac arrest. One of these possible long-term outcomes is cognitive impairment resulting from hypoxic-ischemic brain injury.^{5–6} Approximately half of the OHCA survivors have enduring cognitive impairments.^{7–9}

Cognitive impairments refer to objectively identified impairments in cognition with neuropsychological tests. Cognitive complaints refer to subjective reports of experienced difficulty with cognitive functions. Not all patients who report cognitive complaints also have cognitive impairments and vice versa.¹⁰ In contrast with most other types of

brain injury, such as traumatic brain injury, Steinbusch et al. (2017) found that the percentage of patients with subjective cognitive complaints after OHCA is lower than that with objectively measured cognitive impairment.^{11–13}

The reason for these relatively low levels of cognitive complaints in OHCA patients has not been clarified, yet. For possible future interventions, it is important to understand why patients with cognitive impairments do not always report them. One possible explanation is that patients lack awareness of their own cognitive impairments. Awareness deficits are a common consequence of brain injury.¹⁴ A common method to assess lack of awareness is to compare the patients' assessment of their cognitive impairment with that of others (e.g. spouse or clinician), known as proxy measures.^{15–16}

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We aimed to investigate whether the discrepancy between cognitive impairments and cognitive complaints can be explained by a lack of awareness of patients after cardiac arrest. We compared the subjective report of the patient with that of the informal caregiver on cognitive failures of the patient.¹⁷ We hypothesized that the caregiver would report more cognitive failures than the patient. Such 'self-proxy rating discrepancies' would indicate that cardiac arrest survivors lack insight into their own cognitive functioning.

Methods

Study design

This study is part of the Activity and Life After Survival of Cardiac Arrest (ALASCA) project [ISRCTN74835019], carried out between April 2007 and December 2010. This project was a multi-center prospective longitudinal cohort study. Two weeks, three months, and one year after cardiac arrest, patients received an assessment. This study complies with the Declaration of Helsinki and has been approved by the Medical Ethics Committee of Maastricht University Medical Center and the local committees of the participating hospitals.

Participants

Surviving patients were included within ten days after cardiac. Inclusion criteria were: age ≥ 18 years, living within 50 km of the hospital, and having sufficient knowledge of the Dutch language. Patients who had a life expectancy below three months and those who lived in residential or institutional care before the cardiac arrest were excluded. Caregivers could participate in the study if they were closely related to the patient (e.g. partner).

Procedure

Patients admitted to the hospital were asked to participate between three and ten days after the cardiac arrest. The patients and caregivers provided written informed consent or the caregiver was asked for provisional consent for the patient. The measurements were done two weeks (=T1), three months (=T2), and one year (=T3) after cardiac arrest. These were performed by trained research assistants. If the patient at T1 had insufficient awareness, the data was registered as missing.

Assessment

The Cognitive Failures Questionnaire (CFQ) was used to assess subjective cognitive failures.¹⁸ The patients filled out the CFQ to evaluate themselves (i.e. self-assessment). The CFQ was also filled out by the caregiver to evaluate the cognitive failures of the patient (i.e. proxy measure) (CFQ-C). This questionnaire consists of 25 items (e.g. "Forgetting appointments"). Each item can be scored on a scale from zero (never) to four (very often), resulting in a maximum score of 100. A CFQ discrepancy score was calculated by subtracting the CFQ score from the CFQ-C score. A score above zero on the discrepancy CFQ indicates that the caregiver reports more cognitive failures than the patient.

Statistical analyses

Statistical analyses were performed with SPSS version 25.¹⁹ Descriptive analyses were carried out to describe the socio-demographic and injury characteristics of the sample, and the scores on the CFQ. The data were tested for normality with the Shapiro-Wilk

test. Medians and interquartile ranges were reported to give an accurate indication of the central tendency for non-normally distributed data. The CFQ discrepancy scores were tested with paired sample t-tests to take related observations into account. The degree of agreement between patients and caregivers on the CFQ was assessed by Pearson correlations and the intraclass correlation coefficient (ICC). The guidelines for interpretation of Cicchetti²⁰ were used (<0.40 = poor; 0.40 – 0.59 = fair; 0.60 – 0.74 = good; 0.75 – 1.00 = excellent).

Results

Patient characteristics

A total of 238 cardiac arrest patients were originally included in the ALASCA study. Part of the total sample was excluded from this analysis, because of participation in the intervention arm of a nested RCT (n = 97) and because of the absence of a caregiver (n = 22). This resulted in 119 patient-caregiver pairs in the current analysis (Fig. 1). Table 1 shows the socio-demographic characteristics of the sample. The majority of the patients were middle-aged married men. The average age of the caregivers was 55 years, the majority was female (85 %), and the patients' partner (88 %). Cardiac arrest characteristics can be found in Table 2.

Cognitive Failure Questionnaire

CFQ scores of the patients were only significantly higher than those reported by their caregivers at T2 (Table 3). The correlation of the CFQ between patients and caregivers was $r(67) = 0.31$, $p = .01$ at two weeks, $r(76) = 0.40$, $p < .001$ at three months, and $r(70) = 0.55$, $p < .001$ at one year after cardiac arrest. The average measured ICC at two weeks post-arrest was 0.48 with a 95 % CI from 0.16 to 0.68 ($F(68, 68) = 1.92$, $p = .004$). At three months, the average measured ICC was 0.56 with a 95 % CI from 0.32 to 0.72 ($F(77, 77) = 2.34$, $p < .001$). At one year the average measured ICC was 0.71 with a 95 % CI from 0.53 to 0.82 ($F(71, 71) = 3.39$, $p < .001$). As such, ICCs were classified as fair at T1, fair at T2, and good at T3.

Discussion

In this study, we investigated whether caregivers of patients after cardiac arrest report more cognitive failures of the patients than the patients themselves. This would suggest a possible lack of awareness of cognitive impairment by cardiac arrest survivors, which could in turn explain the lower incidence of subjective cognitive complaints compared with objective cognitive impairments as found by Steinbusch et al. (2017)¹¹ However, the results of this study could not confirm this hypothesis. Contrary to our expectations, caregivers and patients reported equally few cognitive failures.

An alternative explanation of the low levels of cognitive complaints could be a response shift in patients after the cardiac arrest.²¹ Response shift refers to a change in one's evaluation of a situation or internal standards after the impact of disease. Over time, patients seem to (psychologically) adapt to their new circumstances. This explains why people with chronic disabilities report a higher quality of life than expected by outsiders, known as the "disability paradox".²² As described in the article of Forslund et al. (2017), patients can experience survival after cardiac arrest as a "second chance at

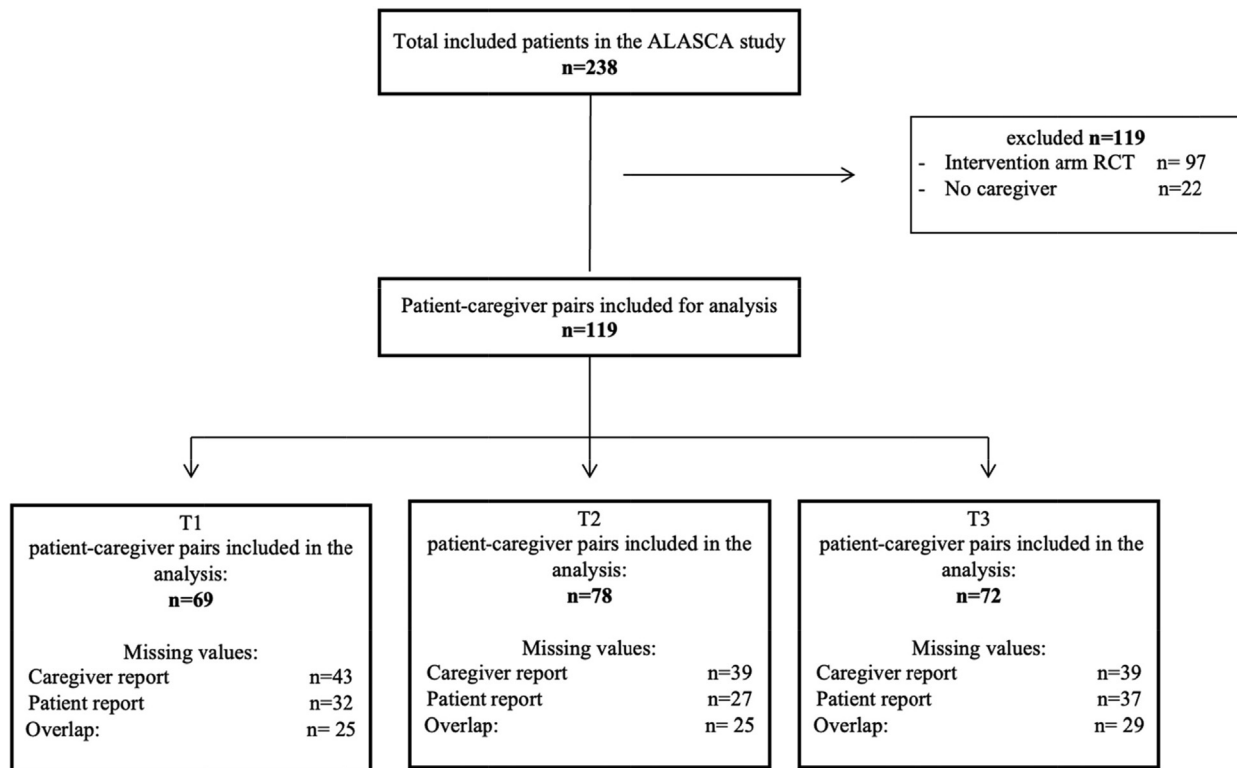


Fig. 1 – Note. T1 = two weeks after cardiac arrest, T2 = three months after cardiac arrest, T3 = one year after cardiac arrest. Flow diagram of participants included in the analysis.

Table 1 – Socio-demographic characteristics of the patient sample before cardiac arrest (n = 119).

Characteristic	n (%) or mean (SD)
Age in years	60 (10)
-Range	37–86
Sex (% male)	101 (85)
Marital status	
-Married/Partner	102 (86)
-Single/Divorced/Widowed	12 (10)
-Missing	5 (4)
Highest level of education	
-None	1 (0)
-Basic education	22 (19)
-Further education	32 (27)
-Higher education	59 (50)
-Missing	5 (4)
Living situation	
-At home	114 (96)
-Rehabilitation center	1 (0)
-Nursing home	2 (2)
-Missing	2 (2)
Employment status	
-Paid job	57 (48)
-Not working	57 (48)
-Missing	5 (4)

Table 2 – Cardiac arrest characteristics (n = 119).

Characteristic	n (%) or mean (SD)
Out-of-hospital	98 (82)
Witnessed	110 (92)
CPR by:	
-Bystander	59 (50)
-Professional	41 (34)
- Missing or not applicable	13 (16)
Duration comatose state in days ^a	2.4 (3)
-Range	0–19
Time till ROSC in minutes ^b	15.2 (13)
-Range	0–52
Glasgow Coma Scale at admission ^c	7 (5)
-Range	3–15

Note. ROSC = return of spontaneous circulation.

CPR = Cardiopulmonary resuscitation.

^a n = 87.

^b n = 53.

^c n = 36.

life”.²³ It seems that the survival of a life-threatening event can cause a change in perspective. The finding that quality of life of cardiac arrest patients does not differ from that of the general population supports this hypothesis.²⁴ Feelings of gratitude may overshadow

residual (cognitive) problems. Response shift can be measured with retrospective ratings.²⁵ Unfortunately, our data did not include such measurements.

The agreement between patient and caregiver on cognitive failures increased over time from fair to good. Probably, over time and with experience, the patient and caregiver both get a better understanding of the level of functioning of the patient and thus increase in agreement.

Table 3 – Medians with interquartile ranges of the CFQ and correlations and ICCs between caregiver and patient on the CFQ, at 2 weeks, 3 months, and 1 year after cardiac arrest.

CFQ	T1 (n = 69)			T2 (n = 78)			T3 (n = 72)		
	Median	IQR	p value	Median	IQR	p value	Median	IQR	p value
CFQ	23	12–32		21	13–29		24	12–35	
CFQ-C	20	7–30		17	10–25		23	10–34	
CFQ discrepancy	–1	–15–11	0.49	–5	–10–8	0.04	0	–8–6	0.86

Correlations/ICC	T1 (n = 69)		T2 (n = 78)		T3 (n = 72)	
	r	p value	r	p value	r	p value
Correlation caregiver and patient CFQ	0.31	0.009	0.40	<0.001	0.55	<0.001
ICC caregiver and patient CFQ	0.48	0.004	0.56	<0.001	0.71	<0.001

Note. T1 = 2 weeks after cardiac arrest; T2 = 3 months after cardiac arrest; T3 = 1 year after cardiac arrest; r = correlation coefficient; ICC = intra-class correlation coefficient; CFQ = Cognitive Failure Questionnaire by patient =; CFQ-C = Cognitive Failure Questionnaire by caregiver; CFQ discrepancy = CFQ-C – CFQ;

Some limitations need to be reported. First, in order to compare the CFQ values between patient-caregiver pairs, data from both parties were required. This resulted in more missing data on T1, T2, and T3, and led to a smaller sample size. Second, the CFQ was developed to measure cognitive failures in elderly people; more studies are needed to guarantee validity in cardiac arrest survivors. Third, although a self-proxy rating discrepancy is a commonly used method to assess awareness deficits, it cannot be guaranteed that proxy reports of caregivers accurately reflect the patients' cognitive failures.¹⁶ One's opinion on cognitive failures of a partner could be subject to change, because of a possible response shift in the caregiver themselves. Lastly, due to missing data the patient-caregiver pairs slightly change per timepoint, which could have affected the correlations.

Conclusions

This study does not support the hypothesis that patients after cardiac arrest lack awareness of tentative cognitive impairments. Future studies could investigate a possible response shift in relation to the relatively low incidence of subjective cognitive complaints in these patients.

CRedit authorship contribution statement

Pauline van Gils: Formal analysis, Writing – original draft, Investigation, Methodology, Data curation. **Caroline van Heugten:** Writing – review & editing, Supervision, Conceptualization, Methodology. **Simone Sep:** Writing – review & editing, Supervision, Conceptualization. **Véronique Moulart:** Writing – review & editing, Resources. **Jeannette Hofmeijer:** Writing – review & editing, Supervision. **Jeanine Verbunt:** Writing – review & editing, Supervision, Conceptualization.

Conflicts of Interest

There are no conflicts of interest.

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