

# The impact of cardiac arrest on the long-term wellbeing and caregiver burden of family caregivers

Citation for published version (APA):

van Wijnen, H. G., Rasquin, S. M., van Heugten, C. M., Verbunt, J. A., & Moulaert, V. R. (2017). The impact of cardiac arrest on the long-term wellbeing and caregiver burden of family caregivers: a prospective cohort study. *Clinical Rehabilitation*, 31(9), 1267-1275. <https://doi.org/10.1177/0269215516686155>

## Document status and date:

Published: 01/09/2017

## DOI:

[10.1177/0269215516686155](https://doi.org/10.1177/0269215516686155)

## Document Version:

Publisher's PDF, also known as Version of record

## Document license:

Taverne

## Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

## General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

[www.umlib.nl/taverne-license](http://www.umlib.nl/taverne-license)

## Take down policy

If you believe that this document breaches copyright please contact us at:

[repository@maastrichtuniversity.nl](mailto:repository@maastrichtuniversity.nl)

providing details and we will investigate your claim.

# The impact of cardiac arrest on the long-term wellbeing and caregiver burden of family caregivers: a prospective cohort study

Clinical Rehabilitation  
2017, Vol. 31 (9) 1267–1275  
© The Author(s) 2017  
Reprints and permissions:  
sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/0269215516686155  
journals.sagepub.com/home/cre  


Helena GFM van Wijnen<sup>1</sup>, Sascha MC Rasquin<sup>1</sup>,  
Caroline M van Heugten<sup>2</sup>, Jeanine A Verbunt<sup>1,3</sup>  
and Véronique RM Moolaert<sup>1,3</sup>

## Abstract

**Objective:** The purpose was to gain insight in the functioning of caregivers of cardiac arrest survivors at 12 months after a cardiac arrest. Secondly, the course of the wellbeing of the caregivers during the first year was studied. Finally, factors that are associated with a higher care burden at 12 months after the cardiac arrest were investigated.

**Subjects:** A total of 195 family caregivers of cardiac arrest survivors were included.

**Main measures:** Quality of life (SF-36, EuroQol-VAS), caregiver strain (CSI) and emotional functioning (HADS, IES) were measured at two weeks, three months and one year after the cardiac arrest. Thereby, the caregiver was asked to fill out the cognitive failure questionnaire (CFQ) to evaluate their view on the cognitive status of the patient.

**Results:** Caregiver strain was high in 16 (15%) of the caregivers at 12 months. Anxiety was present in 33 (25%) caregivers and depression in 18 (14%) caregivers at 12 months. The repeated measures MANOVA showed that during the first year the following variables improved significantly: SF-36 domains social and mental health, role physical, role emotional and vitality, caregiver strain, HADS and IES ( $P < 0.001$ ). At 12 months caregiver strain correlated significantly (explained variance 63%,  $P = 0.03$ ) with caregiver HADS ( $P = 0.01$ ), EuroQol-VAS ( $P = 0.02$ ), and the CFQ ( $P < 0.001$ ), all measured at 12 months after the cardiac arrest.

**Conclusions:** Overall wellbeing of the caregivers improves during the first year up to normal levels, but caregivers with emotional problems or perceived cognitive problems at 12 months are at risk for developing a higher care burden.

<sup>1</sup>Adelante, Centre of Expertise in Rehabilitation and Audiology, Hoensbroek, the Netherlands

<sup>2</sup>School for Mental Health and Neuroscience, Department of Psychiatry and Neuropsychology, Faculty of Health, Medicine and Life Sciences; Department of Neuropsychology and Psychopharmacology, Faculty of Psychology and Neuroscience, Maastricht University, Maastricht, the Netherlands

<sup>3</sup>CAPHRI School for Public Health and Primary Care, Department of Rehabilitation Medicine, Maastricht University, Maastricht, the Netherlands

## Corresponding author:

Helena GFM van Wijnen, Adelante, Centre of Expertise in Rehabilitation and Audiology, Zandbergsweg 111, 6432 CC, Hoensbroek, The Netherlands.  
Email: marjolein1204@hotmail.com

## Keywords

Cardiac arrest, quality of life, caregiver burden, caregiver, spouse

Received: 25 May 2016; accepted: 4 December 2016

## Introduction

It has been established that caring for people with disabilities due to neurological conditions causes stress to caregivers.<sup>1-2</sup> However, this has not been studied in people caring for survivors of cardiac arrest, some of whom will have suffered hypoxic brain damage.

Studies on how the cardiac arrest affects the wellbeing of caregivers of cardiac arrest survivors are scarce. The few studies that focus on caregivers report that they experience stress reactions, feelings of anxiety and high caregiver burden after the cardiac arrest.<sup>3-7</sup> Most studies performed so far have a restricted number of caregivers included, have selected samples and did not investigate the course of the wellbeing of the caregivers during the first year after the cardiac arrest. More information about caregivers of cardiac arrest survivors could help to identify difficulties caregivers may face and which caregivers specifically are at risk for developing high strain. This information could help to improve the current care and possibly even improving the wellbeing of the cardiac arrest survivor.

In contrast to the few studies on caregivers of cardiac arrest patients, many more studies focus on caregivers of stroke patients and show that there are a substantial number of caregivers that experience burden and lower wellbeing.<sup>8-13</sup>

Many studies on stroke caregivers also found that there was a lack of significant change in stroke caregiving outcomes (emotional/social and psychological wellbeing) over time.<sup>14</sup> The significant changes that were found, were not consistent, as wellbeing either increased or decreased over time.<sup>14</sup> Because the wellbeing of stroke caregivers is more often investigated, there is more knowledge and experience in professional care.<sup>15,16</sup>

The aim of this study therefore was to gain insight into the caregiver of cardiac arrest survivors' quality of life, caregiver strain and emotional

functioning at one year after the cardiac arrest. The second goal was to investigate the course of wellbeing during the first year after the cardiac arrest. Finally, it investigates which factors are related with a higher caregiver strain at one year. Caregiver strain is of high clinical relevance and therefore needs to be further investigated.

We expect that the caregivers of cardiac arrest survivors experience problems on quality of life, emotional functioning and caregiver strain at 12 months after the cardiac arrest.<sup>17,18</sup> We hypothesize that the quality of life, caregiver strain and emotional functioning of caregivers improve the most in the first 3 months after the cardiac arrest and will be significantly better one-year post injury in comparison with two weeks after the cardiac arrest.<sup>17,18</sup> We expect that a higher care burden after one year is associated with: higher age, being male, lower education, having a full-time job, and the presence of emotional problems (depression and anxiety).<sup>18</sup> Having a full-time job seems contradictory as returning to work has also been shown to be of positive value, but it appears that having a full-time job during the (sub)acute phase interferes with caring for a partner and can lead to higher strain at a later moment. We also expect that more cognitive problems in the patient is related to a higher burden of the caregiver.<sup>2,9</sup>

## Methods

This is a prospective cohort-study focusing on the caregivers of cardiac arrest survivors which was part of a larger project called "Activity and Life After Survival of a Cardiac Arrest (ALASCA)" [ISRCTN74835019].<sup>19</sup> The project consisted of a multi-center prospective longitudinal cohort study and a nested randomized controlled trial.

The study is a province-based study that consists of caregivers from cardiac arrest survivors who participated in the ALASCA study. All caregivers older than 18 years and with sufficient knowledge of the Dutch language who gave permission to participate were asked to participate, whether or not their patient was included in the randomized controlled trial. If the patient had a partner or spouse, this partner was asked to participate as caregiver in the trial. If the patient did not have a partner or if this partner was not the primary caregiver, they could assign another person who would be the primary caregiver at home.

Inclusion took place between April 2007 and November 2010. The patients were recruited from seven hospitals in the Southern part of the Netherlands.<sup>19</sup> Between three and ten days after the cardiac arrest the patient and caregiver were approached to participate in the study and were then assessed at two weeks, three months and twelve months after the cardiac arrest.<sup>19</sup> The medical ethics committee of the Maastricht University Medical Centre and all participating hospitals approved the study protocol.

At baseline the following patient *socio-demographic variables* were recorded: age, gender, living situation, relationship with patient, work situation and education. The variable education was divided in lower (primary and secondary school) and higher (high school, university) education.

Caregivers were assessed using the following measures:

The *short form health survey (SF-36)*,<sup>20</sup> a questionnaire that consists of 36 items, which measures the quality of life, measured in eight domains of perceived health. For each domain, scores are scaled from 0 (worst health) to 100 (best health).

The *EuroQol-VAS*,<sup>21,22</sup> a visual analogue scale ranging from 0-100; with higher scores indicating a better quality of life.

The *Caregiver Strain Index (CSI)*,<sup>23</sup> a 13-item scale with dichotomous items, which measures strain related to the provision of care. Scores

range from 0-13, with higher scores reflecting a higher caregiver burden. A score of  $\geq 7$  indicates a high-perceived burden.

The *Hospital Anxiety and Depression scale (HADS)*<sup>24</sup> which consists of 14 items and has two sub-scales, namely depression (HADS-D) and anxiety (HADS-A). Scores  $>7$  on a subscale suggest the presence of an anxiety disorder or depression.

The *Impact of Event Scale (IES)*<sup>25</sup> which measures psychological reactions, namely intrusion and avoidance, which can take place after a traumatic event. The scale has 15 items and scores range from 0-75. Scores above 25 suggest a powerful impact event.

The *Cognitive failure questionnaire (CFQ)*,<sup>26</sup> a 25-item questionnaire on self-reported cognitive failure. Total scores range from 0 to 100. Higher scores indicate more cognitive problems. This study only uses the perception of the caregiver on the patients cognitive functioning, because it can be used to see if the caregivers view correlates to a high burden.

The patient was assessed using the following measures:

The *Cognitive Log (Cog-Log)*,<sup>27</sup> a 10-item cognitive screening instrument, measuring higher neurocognitive processes. The Cog-Log scores range from 0 to 30. A score  $\leq 25$  is defined as abnormal.

The *Frenchay Activities Index (FAI)*,<sup>28</sup> a 15-item questionnaire for instrumental Activities of Daily Living (ADL). The items are on a four-point scale, with total scores ranging from 0 (low ability) to 45 (high ability). In this study the situation before the cardiac arrest and the situation on 12 months after the cardiac arrest were compared and the outcome was used as a variable ( $\Delta$ -FAI).

The Hospital Anxiety and Depression scale was also used to measure the anxiety and depression level for the patients.

**Table 1.** Baseline characteristic caregivers (n=195).

Baseline total n = 195	n (%) or mean (SD)
Age (years) (195)	
Mean (SD)	57 (12.0)
Range	19–84
Gender (195)	
Male	30 (15%)
Female	165 (85%)
Relationship with patient (194)	
Spouse	173 (88%)
Child	11 (6%)
Sibling	5 (3%)
Parent	2 (1%)
Other*	3 (2%)
Highest level of education (191)	
Lower education	112 (58%)
Higher education	79 (42%)
Work situation after CA (188)	
Full-time	32 (54%)
Part-time job	69 (37%)
Not working	87 (46%)

CA: cardiac arrest; \*not further specified.

### Statistical analyses

To check for selection bias, differences between caregivers who completed the study and caregivers who dropped out during the study were examined on the following demographic characteristics: age, gender, education and work-situation. Descriptive statistics were used to present demographic characteristics.

To describe the quality of life, emotional functioning and caregiver strain at two weeks, three months and 12 months after the cardiac arrest descriptive statistics were used, presented in mean or median depending on distribution. A repeated measures MANOVA was performed to determine the course of functioning during the first year after the cardiac arrest. Differences in scores on the questionnaires (SF-36, EuroQol-VAS, HADS, IES and CSI) between 2 weeks, 3 months and 12 months were then tested using the Dependent-samples t-test (continuous variables with normal distribution) and the Related-Samples Wilcoxon Signed Rank Test (continuous variables with non-normal distribution).

Finally, multiple linear regression analyses (enter method) were carried out to determine which factors are associated with a high caregiver strain at 12 months after the cardiac arrest. The following caregiver variables were used in the regression analyses: emotional functioning (HADS, IES) caregiver strain (CSI), quality of life (EuroQol-VAS) and perceived cognitive problems (CFQ) at 12 months and the socio-demographic variables. In addition the following patient variables were inserted: Cog-Log, HADS and  $\Delta$ -FAI at 12 months. A limit value for elimination in the regression analyses was set at  $P < 0.10$  and a  $P$ -value of  $\leq 0.05$  was considered statistically significant. Statistical analyses were performed using IBM SPSS Statistics for Windows, version 21.0.

### Results

We assessed all the 195 caregivers of the cohort study at baseline, of which 46 (24%) dropped out and 149 (76%) caregivers were followed up to 12 months after the cardiac arrest. When a patient dropped out, participation of its caregiver also ended. There were no significant differences between caregivers that dropped out during the follow up and the caregivers who completed the study regarding gender ( $P= 0.31$ ), age ( $P= 0.50$ ), education ( $P=0.22$ ) and work situation ( $P=0.32$ ). Table 1 shows the socio-demographic characteristics of the caregivers. The cardiac arrest survivors had a mean age of 60 years and 80% of them were male. Only 1% of the patients had a cardiac arrest before, but 60% had a cardiovascular history. In 4% of the cases the patient was discharged to a nursing home, the other 96% of the patients were directly discharged home.

The quality of life, caregiver strain and emotional functioning at 12 months after the cardiac arrest are shown in Table 2. The quality of life domains Social Functioning, Role Emotional and Role Physical scored the highest. The domains Vitality, General Health and Mental Health scored the lowest.

Looking at the caregiver strain at 12 months, 21 caregivers (15%) had a score above the cut-off point on the CSI. Scores on emotional functioning at 12 months after the cardiac arrest show that 33

**Table 2.** Quality of life, caregiver strain and emotional state of the caregivers.

n=195	2 weeks Mean (SD)/ Median (Range)	3 months Mean (SD)/ Median (Range)	12 months Mean (SD)/ Median (Range)	P-value change over time
<b>Quality of Life</b>				
- SF-36 Physical Functioning	90.0 (5–100)	90.0 (15–100)	90.0 (9–100)	0.53
- SF-36 Social Functioning	62.5 (0–100)	87.5 (0–100)	100.0 (9–100)	<0.001 <sup>a,b,c</sup>
- SF-36 Role physical	75.0 (0–100)	100 (0–100)	100.0 (0–100)	<0.001 <sup>a,b</sup>
- SF-36 Role Emotional	33.3 (0–100)	100 (0–100)	100.0 (0–100)	<0.001 <sup>a,b,c</sup>
- SF-36 Mental Health	60.0 (0–100)	76.0 (8–100)	80.0 (9–100)	<0.001 <sup>a,b,c</sup>
- SF-36 Vitality	55.0 (0–100)	67.5 (0–100)	70.0 (5–100)	<0.001 <sup>a,b,c</sup>
- SF-36 Bodily Pain	90.0 (10–100)	80.0 (20–100)	90.0 (9–100)	0.57
- SF-36 General Health	65.0 (15–100)	70.0 (5–100)	75.0 (5–100)	0.26 <sup>a</sup>
- Euroqol-VAS	77.1 (15.4)	78.7 (15.7)	80.1 (15.5)	0.15 <sup>b</sup>
<b>Caregiver strain</b>				
- Caregiver strain index*	5.0 (3.3)	3.9 (3.2)	3.2 (3.0)	<0.001 <sup>a,b,c</sup>
<b>Emotional functioning</b>				
- HADS Anxiety*	9.0 (0–21)	6.0 (0–21)	5.0 (0–20)	<0.001 <sup>a,b,c</sup>
- HADS depression*	6.0 (0–20)	2.0 (0–20)	2.0 (0–17)	<0.001 <sup>a,b,c</sup>
- Impact of event Scale*	31.7 (15.8)	24.7 (17.3)	22.1 (17.8)	<0.001 <sup>a,b,c</sup>

SF-36: short form health survey; HADS: Hospital Anxiety and Depression scale.

\*Outcome measures on which lower scores indicate better functioning.

a= significant difference between 2 weeks and 3 months.

b=significant difference between 2 weeks and 12 months.

c= significant difference between 3 months and 12 months.

caregivers (25%) had a score above the cut-off on HADS-A and 18 caregivers (14%) on the HADS-D. At 12 months, 59 caregivers (42%) had a score above the cut-off point on the IES.

The course of functioning during the first year, measured by the repeated measures MANOVA, is also shown in table 2. Over time the total group of caregivers improved significantly on the SF-36 domains Vitality, Social Functioning, Mental Health, Role Emotional and Role Physical. The score on the EuroQol-VAS did not improve significantly over time.

In total 60 caregivers (32%) had a score above the cut-off point on the CSI at baseline. The scores on the CSI improved significantly over time.

Scores were above the cut-off score on the HADS-A in 105 caregivers (54%) and in 71 caregivers (37%) on the HADS-D. Looking at the IES one hundred twenty-four caregivers (64%) scored above the cut-off point. Scores on the HADS and IES both improved significantly over time (Table 2).

Multiple linear regression analyses shows that the caregiver strain at 12 months after the cardiac arrest is explained significantly by the emotional functioning (HADS) of the caregiver, the CFQ-score answered by the caregiver but concerning the patient, and the score on the EuroQol-VAS (Table 3). This indicates that caregiver strain is related to emotional problems, the caregiver's perception of the patients cognitive failures and a lower perceived quality of life.

## Discussion

This study shows that in terms of wellbeing, caregivers experience the most problems on the emotional level at one year after the cardiac arrest. It also shows that quality of life, caregiver strain and emotional functioning improves significantly during the first year after the cardiac arrest with the most improvement in the first three months. Caregivers who experienced high caregiver strain

**Table 3.** Multiple linear regression analyse.

Dependent variables	Independent variables	R <sup>2</sup>	Adjusted R <sup>2</sup>	Standardized Beta	P-value
<b>CSI</b>		<b>0.63</b>	<b>0.56</b>		<b>0.03</b>
<b>Patient variables</b>	$\Delta$ -FAI			0.02	0.85
	HADS-total			0.05	0.61
	Cog-Log			-0.16	0.11
<b>Caregiver variables</b>	Gender			0.01	0.92
	Education			0.02	0.87
	Age			-0.12	0.32
	IES-score			0.13	0.22
	Work-situation			-0.14	0.15
	EuroQoI-VAS			-0.24	<b>0.05</b>
	HADS-total			0.35	<b>0.01</b>
	CFQ-score			0.36	<b>0.00</b>

Dependent variable: CSI (caregiver strain index). Independent variables: age, education, gender, work-situation,  $\Delta$ -FAI (Frenchay Activities Index), HADS-score (Hospital Anxiety and Depression scale), IES-score (impact of event scale), EuroQoI-VAS, CFQ-score (cognitive failure questionnaire), Cog-Log (cognitive-log).

at 12 months after the cardiac arrest scored high on the presence of mood disorders, perceived more cognitive problems in the patient and had a lower quality of life at 12 months after the cardiac arrest.

Quality of life improved the most during the first three months and improved even further for social and emotional functioning and mental health up to 12 months after the cardiac arrest. This finding is largely in agreement with the course of the quality of life in stroke caregivers.<sup>15,16</sup> Nevertheless, stroke caregivers experience lower levels of quality of life. The positive recovery of most caregivers in this study may reflect the recovery of the consequences of the cardiac arrest for the patients, thereby influencing the wellbeing of their partner. Another possible explanation may be found in the personal factors of the caregivers themselves; for instance, adaptive coping styles or resilience.

The scores on quality of life of the cardiac arrest caregivers at 12 months after the cardiac arrest, measured on the SF-36, are comparable to the general Dutch population.<sup>29</sup> This is in line with the study of Middleton et al.<sup>30</sup> on caregivers of people with spinal cord injury, but is in contrast with results on stroke caregivers, who experience lower quality of life for several years after the stroke in comparison to controls.<sup>8,10,11</sup>

Looking at the emotional functioning during the first year, feelings of anxiety are more prevalent in the caregivers than depressive feelings. At 12 months after the cardiac arrest feelings of anxiety were present in 25% of the caregivers and depression in 14% of the caregivers. These scores are low in comparison to earlier studies concerning other caregivers of patients with acquired brain injury.<sup>2</sup> Caregiver strain decreased significantly during the first year and at 12 months only 11% of the caregivers experienced a high caregiver strain, which is in line with another study that focused on cardiac arrest caregivers.<sup>8</sup> This is in contrast with caregivers of stroke and severely brain-injured patients, where up to 64% of the caregiver experienced higher levels of strain.<sup>11</sup>

Understanding what caregiver strain means, determining if the strain of a caregiver is high and knowing which factors influence the strain is crucial in the overall medical model of a patient. This is because especially family caregivers play an important role in supporting the patient after recovery from a medical incidence.

As expected, this study did show that having feelings of anxiety or depression is associated with a higher caregiver strain. Studies on stroke patients also showed that having feelings of anxiety or

depression and having emotional distress are related to higher burden.<sup>17,18</sup> A possible explanation could be that the caregiver burden is influenced by the coping mechanisms of the caregiver. A previous study on stroke caregivers showed that caregivers with passive coping styles do not take action when problems occur, which can lead to increasing feelings of anxiety and depression, and therefore leads to a higher strain.<sup>11</sup>

However, coping was not taken into account in this study. Thereby, we found an association between high strain and scoring low on quality of life. Caregivers that score their wellbeing to be low are at risk for developing a higher caregiver strain. In contrast, we did not find an association between a high caregiver strain and the socio-demographical characteristics of the caregivers. However, this finding is in line with studies on stroke caregivers.<sup>17,18</sup>

We did not find an association between caregiver strain and the cognitive functioning of the patient, in contrast with studies on stroke caregivers.<sup>9,17,18</sup> Remarkable is that the cognitive functioning of the patient, measured with a cognitive screening instrument, did not influence the caregiver strain, while the perceived complaints by the caregiver did. A potential explanation is that the perceived cognitive complaints by the caregiver are not determined by the cognitive functioning of the patient, but are associated with other caregiver factors like personality or emotional functioning of the caregiver. Another explanation could be that the measurement instrument for cognitive functioning of the patient (Cog-Log) is limited and did not capture all problems in cognitive functioning.

The present study has several strengths. Firstly, we investigated outcomes on several important aspects of quality of life of cardiac arrest family caregivers. Second, this is the first study to investigate the course of functioning of caregivers of cardiac arrest survivors during the first year after the cardiac arrest. In addition, this study has a large sample size in comparison to other studies on caregivers of cardiac arrest survivors.<sup>10,11</sup>

This study also has some limitations. There may be some selection bias. It could be that patients with major health problems at the time of inclusion did not participate, meaning their caregivers were

not included either. This could influence the outcomes in terms of overestimation of wellbeing. Secondly, the outcome measures are almost all questionnaires, which may cause under- or overestimation caused by self-report. Thereby, the questionnaires that were used are all found to be valid in brain injured populations<sup>23,25</sup> but have not been validated yet in the specific cardiac arrest population. Finally, we did not measure actual hours of care, which could have added an objective measure of caregiving.

Significant improvements were found for the quality of life, caregiver strain and emotional functioning between three and twelve months. Future research should investigate at what point in time final outcome is most commonly reached and what the end-level of functioning is.

In addition, it would be of interest to investigate which early factors are associated with high caregiver strain at 12 months. When these factors are identified, active preventive interventions could be developed at an early stage, which improves overall wellbeing at 12 months after the cardiac arrest. Positive effects of preventive interventions on caregiver wellbeing have been already shown in TBI and stroke caregivers.<sup>15,16</sup>

### Clinical messages

- Caregivers with emotional or mental problems at 12 months after the cardiac arrest are at risk of a higher caregiver strain.

### Acknowledgements

We would like to acknowledge all patients for their participation in this study. All participating hospitals and research assistants are thanked for their cooperation.

### Conflict of interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

### Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

## References

1. Green CR, Botha JA and Tiruvoipati R. Cognitive function, quality of life and mental health in survivors of out-of-hospital cardiac arrest: a review. *Anaesthesia and intensive care*. 2015;43:568–576.
2. Smeets SM, van Heugten CM, Geboers JF, Visser-Meily JM and Schepers VP. Respite care after acquired brain injury: the well-being of caregivers and patients. *Archives of physical medicine and rehabilitation*. 2012; 93: 834–841.
3. Wachelder EM, Moulart VR, van Heugten C, Verbunt JA, Bekkers SC and Wade DT. Life after survival: long-term daily functioning and quality of life after an out-of-hospital cardiac arrest. *Resuscitation*. 2009;80:517–522.
4. Beesems SG, Wittebrood KM, de Haan RJ and Koster RW. Cognitive function and quality of life after successful resuscitation from cardiac arrest. *Resuscitation*. 2014;85:1269–1274.
5. Pusswald G, Fertl E, Faltl M and Auff E. Neurological rehabilitation of severely disabled cardiac arrest survivors. Part II. Life situation of patients and families after treatment. *Resuscitation*. 2000;47(3):241–248.
6. Dougherty CM. Longitudinal recovery following sudden cardiac arrest and internal cardioverter defibrillator implantation: survivors and their families. *Am J Crit Care*. 1994;3(2):145–154.
7. Haley WE, Roth DL, Hovater M and Clay OJ. Long-term impact of stroke on family caregiver well-being: a population-based case-control study. *Neurology*. 2015 31; 84: 1323–1329.
8. van Exel NJ, Koopmanschap MA, van den Berg B, Brouwer WB and van den Bos GA. Burden of informal caregiving for stroke patients. Identification of caregivers at risk of adverse health effects. *Cerebrovascular diseases*. 2005;19:11–17.
9. Rigby H, Gubitz G and Phillips S. A systematic review of caregiver burden following stroke. *International journal of stroke : official journal of the International Stroke Society*. 2009; 4: 285–292.
10. Persson J, Holmegaard L, Karlberg I, Redfors P, Jood K, Jern C, et al. Spouses of Stroke Survivors Report Reduced Health-Related Quality of Life Even in Long-Term Follow-Up: Results From Sahlgrenska Academy Study on Ischemic Stroke. *Stroke; a journal of cerebral circulation*. 2015;46:2584–2590.
11. Visser-Meily A, Post M, Schepers V and Lindeman E. Spouses' quality of life 1 year after stroke: prediction at the start of clinical rehabilitation. *Cerebrovascular diseases*. 2005;20:443–448.
12. Scholte op Reimer WJ, de Haan RJ, Rijnders PT, Limburg M and van den Bos GA. The burden of caregiving in partners of long-term stroke survivors. *Stroke; a journal of cerebral circulation*. 1998; 29: 1605–1611.
13. Bugge C, Alexander H and Hagen S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke; a journal of cerebral circulation*. 1999;30:1517–1523.
14. Gaugler JE. The longitudinal Ramifications of Stroke Caregiving: A systematic Review. *Rehabilitation Psychology*. 2010;55:108–125.
15. Karahan AY, Kucuksen S, Yilmaz H, Salli A, Gungor T and Sahin M. Effects of rehabilitation services on anxiety, depression, care-giving burden and perceived social support of stroke caregivers. *Acta medica (Hradec Kralove)/ Universitas Carolina, Facultas Medica Hradec Kralove*. 2014;57:68–72.
16. Backhaus SL, Ibarra SL, Klyce D, Trexler LE and Malec JF. Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers. *Arch Phys Med Rehabil* 2010;91:840–848
17. McCullagh E, Brigstocke G, Donaldson N and Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke* 2005; 36: 2181–2186
18. Chumbler NR, Rittman M, Van Puymbroeck M, Vogel WB and Qin H. The sense of coherence, burden, and depressive symptoms in informal caregivers during the first month after stroke. *International journal of geriatric psychiatry*. 2004;19:944–953.
19. Moulart VR, van Heugten CM, Winkens B, Bakx WG, de Krom MC, Gorgels TP, et al. Early neurologically-focused follow-up after cardiac arrest improves quality of life at one year: A randomised controlled trial. *International journal of cardiology*. 2015;193: 8–16.
20. Aaronson NK, Muller M, Cohen PD, Essink-Bot ML, Fekkes M, Sanderman R, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *Journal of clinical epidemiology*. 1998;51: 1055–1068.
21. The EuroQol Group. EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199–208.
22. De Smedt D, Clays E, Doyle F, Kotseva K, Prugger C, Pajak A, et al. Validity and reliability of three commonly used quality of life measures in a large European population of coronary heart disease patients. *International journal of cardiology*. 2013;167:2294–2299.
23. Robinson BC. Validation of a Caregiver Strain Index. *Journal of gerontology*. 1983; 38: 344–348.
24. Spinhoven P, Ormel J, Sloekers PP, Kempen GI, Speckens AE and Van Hemert AM. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. *Psychological medicine*. 1997; 27: 363–370.
25. van der Ploeg E, Mooren TT, Kleber RJ, van der Velden PG and Brom D. Construct validation of the Dutch version of the impact of event scale. *Psychological assessment*. 2004; 16: 16–26.
26. Broadbent DE, Cooper PF, FitzGerald P and Parkes KR. The Cognitive Failures Questionnaire (CFQ) and its correlates. *Br J Clin Psychol* 1982; 21:1–16.

27. Alderson AL and Novack TA. Reliable Serial Measurement of Cognitive Processes in Rehabilitation: The Cognitive Log. *Arch Phys Med Rehabil.* 2003; 84: 668–672.
28. Turnbull JC, Kersten P, Habib M, McLellan L, Mullee MA and George S. Validation of the Frenchay Activities Index in a general population aged 16 years and older. *Arch Phys Med Rehabil* 2000; 81:1034–1038.
29. Van der Zee K and Sanderman R. *RAND-36*. Groningen, the Netherlands: Northern Centre for Health Care Research, University of Groningen, 1993.
30. Middleton JW, Simpson GK, De Wolf A, Quirk R, Descallar J and Cameron ID. Psychological Distress, Quality of Life, and Burden in Caregivers During Community Reintegration After Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation.* 2014;95:1312–1319.