



SOPRAVVIVERE: DEFICIT COGNITIVI E ASSISTENZA AI CONGIUNTI

LUCA CABRINI

TERAPIA INTENSIVA GENERALE

OSPEDALE SAN RAFFAELE

NON DI SOLO ROSC:
AI PAZIENTI SOPRAVVIVERE NON BASTA.
E NEMMENO ALLE LORO FAMIGLIE



AMORI CHE SOFFRONO. LA STORIA DI MARIO, AD ESEMPIO



I PRIMI STUDI

Review article

Systematic review of quality of life and other patient-centred outcomes after cardiac arrest survival[☆]

Vanessa J. Elliott^{a,*}, David L. Rodgers^b, Stephen J. Brett^a

Resuscitation 82 (2011) 247–256

- 70 articoli analizzati
- La maggior parte con follow up a sei mesi (ma fino a 15 anni!)
- Grande eterogeneità metodologica
- Conclusioni:

This review provides good evidence that survivors of cardiac arrest have an acceptable or good quality of life, although this is not necessarily the same quality of life that they experienced prior to their cardiac arrest.



MA INTANTO IN OLANDA...

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

E.M. Wachelder^{a,b,*}, V.R.M.P. Moulaert^{b,c}, C. van Heugten^{c,d},
J.A. Verbunt^{b,e}, S.C.A.M. Bekkers^f, D.T. Wade^{a,b,g}

Resuscitation 80 (2009) 517–522

- Studio retrospettivo su 63 pazienti
- Valutazione tramite una batteria di questionari “neuropsicologici”
- Timing: da 6 mesi a 6 anni post cardiac arrest

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,

...E ANCHE IN USA

RECOVERY, LONG-TERM COGNITIVE OUTCOME AND QUALITY OF LIFE FOLLOWING OUT-OF-HOSPITAL CARDIAC ARREST

Chun Lim, MD, PhD¹, Mieke Verfaellie, PhD², David Schnyer, PhD³, Ginette Lafleche, PhD² and Michael P. Alexander, MD^{1,4}

From the ¹Cognitive Neurology Unit, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston

- 25 pazienti
- Test neurocognitivi dopo 1 anno
- Risultati:

J Rehabil Med 2014; 46: 691-697

Conclusions: These survivors of OHCA had persistent long-term cognitive deficits. Quality of life at one year after OHCA was reduced compared to cardiac controls. Coma duration and memory impairment at three months were harbingers of long term reduced quality of life.

PERCHÉ QUESTE DISCREPANZE NEGLI OUTCOME?

- Nell'ultimo decennio c'è stata una maturazione culturale-scientifica:
 - Dagli outcome a breve termine (ROSC, poi dimissione), a quelli a lungo termine
 - Dagli outcome clinici (CPC, ad es.), a quelli patient-centered (qualità di vita, ad es.) e family-centered



CPC: DAVVERO VALUTABILE ALLA DIMISSIONE? DAVVERO COMPLETO? DAVVERO UTILE?



Cerebral Performance Category (CPC)

- 1 - Good cerebral performance: conscious, alert, able to work, might have mild neurologic or psychological deficit;
- 2 - Moderate cerebral disability: conscious, sufficient cerebral function for independent activities of daily life, able to work in sheltered environment;
- 3 - Severe cerebral disability: conscious, dependent on others for daily support because of impaired brain function, ranges from ambulatory state to severe dementia or paralysis;
- 4 - Coma or vegetative state: any degree of coma without the presence of all brain death criteria. Unawareness, even if appears awake (vegetative state) without interaction with environment; may have spontaneous eye opening and sleep/awake cycles, cerebral unresponsiveness;
- 5 - Brain death: apnea, areflexia, EEG silence, etc.

ALTERNATIVE?

- Esistono decine di test neuropsicologici per valutare in modo esaustivo gli aspetti cognitivi

Primary and secondary outcome measures.

Outcome measures	Measurement instrument	Range questionnaire Min (poor)–max (good)
<i>Primary</i>		
Participation in society	Community Integration Questionnaire [23]	0–29
Quality of life	Short-Form-36 (SF-36), 8 subdomains [24]	0–100
	EuroQol VAS [25]	0–100
<i>Secondary</i>		
Cognitive functioning	Cognitive Log [16]	0–30
	Adult Memory and Information Processing Battery [26]	0–~ ^a
	Verbal fluency [27]	0–~ ^a
	Trail Making Test A + B [28]	0–21
	Paragraph recall direct + delayed [29]	100–0
	Cognitive Failures Questionnaire [30]	
Emotional functioning	Hospital Anxiety and Depression Scale (HADS) Total [17]	42–0
	– Subscale Anxiety	21–0
	– Subscale Depression	21–0
	Impact of Event Scale [31]	75–0
Extended daily activities	Frenchay Activity Index [32]	0–45

VALUTAZIONE COGNITIVA SPECIALISTICA VS PERCEZIONE SOGGETTIVA: NON È LO STESSO

Cognitive impairments and subjective cognitive complaints after survival of cardiac arrest: A prospective longitudinal cohort study

Catherine V.M. Steinbusch^a, Caroline M. van Heugten^{b,c,*}, Sascha M.C. Rasquin^a, Jeanine A. Verbunt^{a,d}, Véronique R.M. Moulaert^{a,d}

Resuscitation 120 (2017) 132–137

Results: 141 cardiac arrest survivors participated. Two weeks post cardiac arrest 16% to 29% of survivors were cognitively impaired varying on the different tests, at three months between 9% and 23% and at one year 10%–22% remained impaired with executive functioning being affected most. Significant reduction of cognitive impairments was seen for all tests, with most recovery during the first three months after cardiac arrest. Subjective cognitive complaints were present at two weeks after cardiac arrest in 11%, 12% at three months and 14% at one year. There were no significant associations between cognitive impairments and cognitive complaints at any time point.

COSA SAPPIAMO OGGI SUGLI ESITI COGNITIVI?

Cognitive function and health-related quality of life four years after cardiac arrest[☆]

Eirik Alnes Buanes^{a,b,*}, Arne Gramstad^{c,d}, Karoline Kjellsdotter Søvig^e,
Karl Ove Hufthammer^f, Hans Flaatten^{a,b}, Thomas Husby^{a,b},
Jørund Langørgen^g, Jon-Kenneth Heltne^{a,b}

^a Department of Anaesthesia and Intensive Care, Haukeland University Hospital, Bergen, Norway

Resuscitation 89 (2015) 13–18

- 30 pazienti dimessi con CPC 1 o 2

The main finding in this study is that cognitive impairment persists in 29% (95% CI: 15–47%) of CA survivors with good neurological outcome at hospital discharge four years after arrest.^{10,22} The pattern of impairment indicates dysfunction in medial temporal lobe structures, as seen, for instance, in early Alzheimer's dementia.²³

SAPPIAMO (PROVVISORIAMENTE) CHE:

- I deficit cognitivi riguardano il 20-30% dei sopravvissuti alla dimissione. Principali deficit: memoria e funzioni esecutive
- Solo una valutazione specialistica è in grado di esplorare adeguatamente la funzione cognitiva
- Il miglioramento dei deficit cognitivi sembra raggiungere un plateau già dopo 3-12 mesi; una quota rilevante di pazienti presenta disfunzioni anche dopo molti anni



LA QUALITÀ DELLA VITA È...

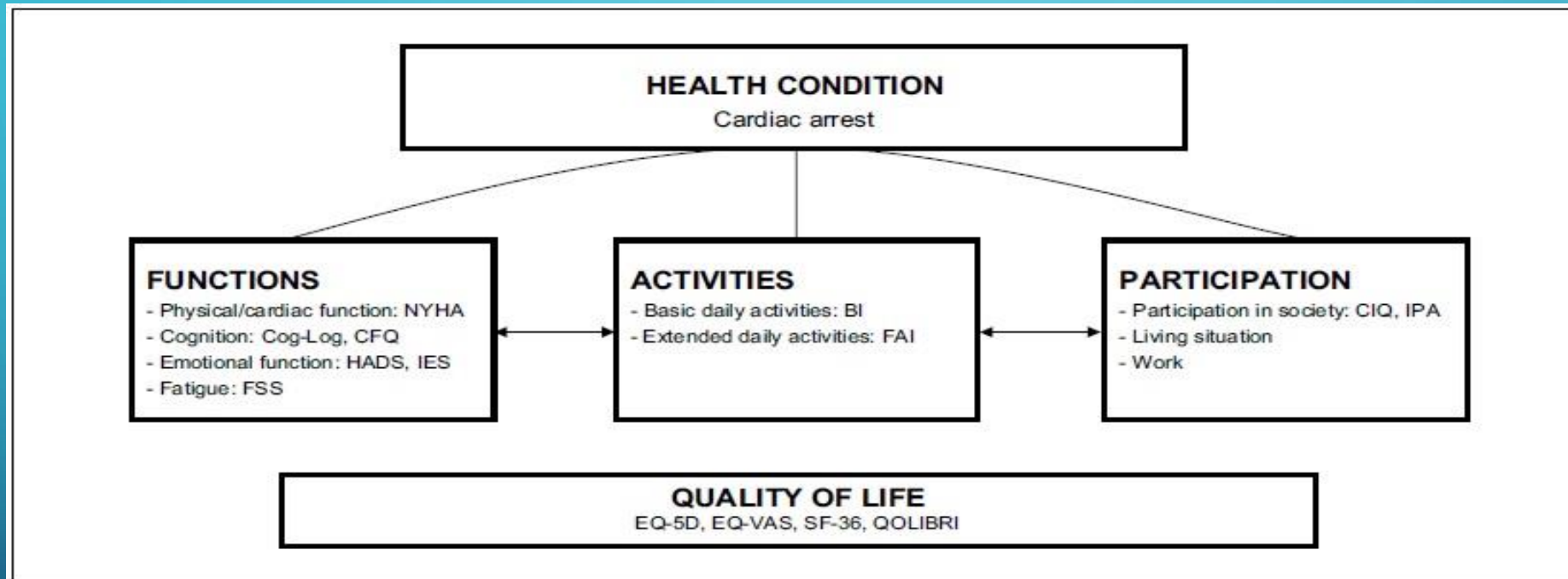


Figure 1. ICF model and measurement instruments used.

Abbreviations: BI, Barthel Index; CFQ, Cognitive Failures Questionnaire; CIQ, Community Integration Questionnaire; FAI, Frenchay Activities Index; FSS, Fatigue Severity Scale; HADS, Hospital Anxiety and Depression Scale; ICF, International Classification of Functioning, Disability and Health; IES, Impact of Event Scale; IPA, Impact on Participation and Autonomy; NYHA, New York Heart Association Classification.

MOULAERT ET AL. LONG-TERM OUTCOME AFTER SURVIVAL OF A CARDIAC ARREST: A PROSPECTIVE LONGITUDINAL COHORT STUDY.
NEUROREHABILITATION AND NEURAL REPAIR. 2017, VOL 31(6) 530-539

QUALITÀ DI VITA



- Circa il 70% dei sopravvissuti la descrive come buona
- Se il pz soffre di ansia o depressione post arresto (presenti in circa un quarto dei sopravvissuti), la qualità di vita è percepita come peggiore
- Anche la funzionalità cognitiva percepita (non quella oggettiva) correla con la qualità di vita

QUALITÀ DI VITA



- La partecipazione sociale è mediamente peggiorata; risente della funzione cognitiva, della presenza di depressione, fatica, e riduzione della mobilità
- Il ritorno al lavoro precedente è possibile solo nel 50-70% dei casi

CAREGIVER: NE SAPPIAMO TROPPO POCO

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

**Helena GFM van Wijnen¹, Sascha MC Rasquin¹,
Caroline M van Heugten², Jeanine A Verbunt^{1,3}
and Véronique RM Moulaert^{1,3}**



Long-term quality of life of caregivers of cardiac arrest survivors and the impact of witnessing a cardiac event of a close relative

Janine van't Wout Hofland^{a,b}, Veronique Moulaert^{c,d}, Caroline van Heugten^{e,f,g},
Jeanine Verbunt^{a,b,*}

Resuscitation 128 (2018) 198–203

CAREGIVER



- La qualità di vita aumenta nel primo anno
- La presenza di ansia o depressione nel caregiver ne riduce la qualità di vita. Idem se il caregiver ritiene che il sopravvissuto abbia deficit cognitivi
- A distanza di due anni dall'evento, un terzo dei caregiver soffre ancora di stress post traumatico (più comune in chi ha testimoniato la rianimazione)

- POSSIAMO MIGLIORARE QUESTI OUTCOME?
- Dobbiamo valutare molto meglio tutti gli anelli della catena della sopravvivenza per capire cosa migliori/peggiori l'esito cognitivo e la qualità della vita
- Dobbiamo studiare e provare. Serve collaborazione per avere numeri sufficienti
- Serve consapevolezza che —come già accaduto per l'ictus o per il trauma cranico- fare meglio si può



DUE ESEMPI

Early neurologically-focused follow-up after cardiac arrest improves quality of life at one year: A randomised controlled trial[☆]

Véronique R.M. Moulaert ^{a,g,*}, Caroline M. van Heugten ^b, Bjorn Winkens ^c, Wilbert G.M. Bakx ^a, Marc C.F.T.M. de Krom ^d, Ton P.M. Gorgels ^e, Derick T. Wade ^f, Jeanine A. Verbunt ^{a,g}

International Journal of Cardiology 193 (2015) 8–16

• Intervento:

Target group Main elements	Survivors of cardiac arrest and their caregivers 1. Screening for cognitive and emotional problems 2. Provision of support and information on cardiac arrest and possible neurological consequences 3. Promotion of self-management strategies 4. Referral to specialised care if indicated
Providers of intervention	Specialised nurses with experience in the field of cardiology, neurology or rehabilitation medicine
Start intervention	Soon after discharge from the hospital, preferably within one month
Frequency	Between one and six face-to-face consultations
Duration of consultations	First session: 1 h Follow-up sessions: 30 min Telephone consultations are optional.
Location	Home visits or out-patient clinic



Early neurologically-focused follow-up after cardiac arrest improves quality of life at one year: A randomised controlled trial[☆]

Véronique R.M. Moulaert^{a,g,*}, Caroline M. van Heugten^b, Bjorn Winkens^c, Wilbert G.M. Bakx^a, Marc C.F.T.M. de Krom^d, Ton P.M. Gorgels^e, Derick T. Wade^f, Jeanine A. Verbunt^{a,g}

Results: After one year, patients in the intervention group had a significantly better quality of life on SF-36 domains Role Emotional (estimated mean differences (EMD) = 16.38, $p = 0.006$), Mental Health (EMD = 6.87, $p = 0.003$) and General Health (EMD = 8.07, $p = 0.010$), but there was no significant difference with regard to societal participation. On the secondary outcome measures, survivors scored significantly better on overall emotional state (HADS total, EMD = -3.25, $p = 0.002$) and anxiety (HADS anxiety, EMD = -1.79, $p = 0.001$) at one year. Furthermore, at three months more people were back at work (50% versus 21%, $p = 0.006$). No significant differences were found for caregiver outcomes.

SECONDO ESEMPIO

Care After REsuscitation: Implementation of the United Kingdom's First Dedicated Multidisciplinary Follow-Up Program for Survivors of Out-of-Hospital Cardiac Arrest

Marco Mion, PhD,¹ Firas Al-Janabi, MD,^{1,2} Shahed Islam, MD,^{1,2} Neil Magee, RN BSc,¹
Rajesh Balasubramanian, DPM, MRCPsych³ Noel Watson, RN, BSc,^{1,2} Matthew Potter, BSc,¹

THERAPEUTIC HYPOTHERMIA AND TEMPERATURE MANAGEMENT
Volume 00, Number 00, 2019

Survival rates after cardiac arrest (CA) are increasing, with more patients and their families living with the psychological consequences of surviving a sudden CA. The currently available neuropsychological assessment tools and therapies were not designed for CA, and may be inadequate. The Essex Cardiothoracic Centre set up the United Kingdom's first dedicated multidisciplinary "Care After REsuscitation" (CARE) service, offering CA survivors and their caregivers systematic psychological, cognitive, and specialized medical support for the first 6 months after CA. Twenty-one patients were recruited into the CARE pilot service evaluation. Patients' health at hospital discharge was poor; however, by 6 months all components (except general health) had improved significantly, and were close to that experienced by "healthy" individuals. Five (26%) required referral to a psychiatrist, with all 5 (26%) subsequently being diagnosed with moderate-to-severe depression, and 3 (16%) with comorbid post-traumatic stress disorder. Our study demonstrates a large unmet clinical need in general and neuropsychological assessment, and our results suggest that offering appropriate and prompt specialist diagnosis and therapies leads to an improvement in health at 6 months.



E PER I CAREGIVER?

- Nulla



E PER SUPPORTARE I CAREGIVER ITALIANI?



○ forse no...



CONCLUSIONI

- Anche i migliori sopravvissuti ad arresto cardiaco hanno spesso sequele cognitive e un peggioramento della qualità di vita
- I caregiver sopportano un peso non indifferente
- Interventi pionieristici per migliorare questi outcome hanno dato buoni risultati, ma devono essere precoci e ben strutturati
- Dobbiamo cercare soluzioni semplici, economiche, accessibili; dobbiamo favorire la creazione di ampie collaborazioni

• PERCHE'...



ROMEO E GIULIETTA: NON DEVE FINIRE COSÌ



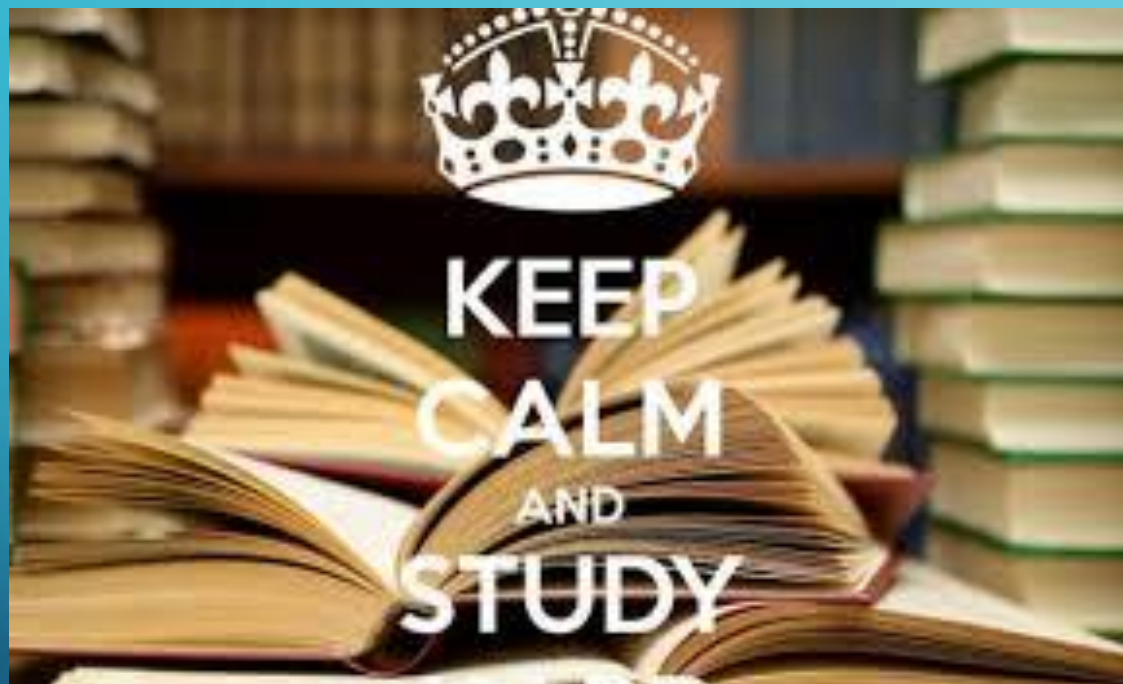
DOBBIAMO LAVORARE PER REGALARE NUOVA VITA



UNA NUOVA VITA LUNGA E BELLA



ED È POSSIBILE.
STUDIAMO. PROVIAMO. INSIEME.



GRAZIE!



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