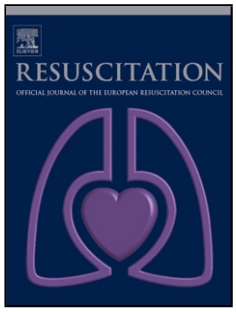

The Second Year of a Second Chance: Long-Term Psychosocial Outcomes of Cardiac Arrest Survivors and their Family

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The Second Year of a Second Chance: Long-Term Psychosocial Outcomes of Cardiac Arrest Survivors and their Family

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Abstract

Aim: Cardiac arrest (CA) survival has diverse psychosocial outcomes for both survivors and their close family, with little known regarding long-term adjustment and recovery experiences. We explored the psychological adjustment and experiential perspectives of survivors and families in the second year after out-of-hospital cardiac arrest (OHCA).

Methods: A prospective, mixed-methods study of adult OHCA survivors in Victoria, Australia was conducted. Eighteen survivors and 12 family members completed semi-structured interviews 14-19 months post-arrest. Survivors' cognition, anxiety, depression and post-traumatic stress symptoms were measured using a battery of psychological assessments. A thematic content analysis approach was applied to qualitative interview data by two independent investigators, with data coded and categorised into themes and sub-themes.

Results: Survivors' cognition, depression, anxiety and post-traumatic stress symptoms were not clinically elevated in the second year post-arrest. Subjective cognitive failures were associated with increased anxiety but not with mental state. Depression was significantly correlated with post-traumatic symptoms. Six primary themes emerged from survivors' recovery stories, focused on: awakening and realisation, barriers to adjustment, psychosocial difficulties, integration, protective factors and unmet needs. Family perspectives revealed four primary themes focused on trauma exposure, survivor adjustment problems, family impact, and areas for service improvement.

Conclusion: Survivors and their family members describe complex recovery journeys characterised by a range of psychosocial adjustment challenges, which are not adequately

captured by common psychological measures. Post-arrest care systems are perceived by survivors and their families as inadequate due to a lack of accurate information regarding post-arrest sequalae, limited follow-up and inconsistent access to allied health care.

Keywords: Cardiac arrest; psychological outcomes; cognition; emotional; adjustment; caregivers

Introduction

Sudden cardiac arrest remains a significant clinical problem, with over 25,000 cases per annum in Australia (1). Increasing awareness of the impact beyond immediate arrest outcomes over the past decade has shifted the focus towards survivorship, with healing and recovery beyond the critical care phase now included in the Chain of Survival (2). Cardiac arrest (CA) survivors experience diverse recovery trajectories, with many eventually achieving good functional outcomes and reporting satisfactory quality of life (3,4). However, there is emerging evidence that a significant proportion report extra-cardiac sequelae including cognitive, affective and emotional symptoms (5–8). Family members of survivors are also at increased risk of psychological disorders, including posttraumatic stress symptoms, depression and anxiety (5,9). However, there is a dearth of psychological assessment tools (i.e. objective or patient-reported measures) validated for use with this population (7,10,11), impacting the reliability and reproducibility of post-arrest outcome data. While there is a growing body of qualitative research emerging in the field of post-arrest outcomes (12–15) there remains a relative paucity of qualitative or mixed-methods studies to explore the long-term recovery experiences of survivors and family.

This study aimed to understand the long-term psychological functioning and service needs of OHCA survivors and their families and is the first qualitative exploration of OHCA outcomes in an Australian population. The primary objectives were to: 1) assess the degree of cognitive and psychological symptoms experienced by survivors 12-18 months post-OHCA; 2) explore

experiential survivor and family perceptions of recovery post-OHCA; and, 3) elicit key concepts that identify relevant domains to inform the development of psychological assessment tools for use with survivors of cardiac arrest.

Methods

Study design

A prospective, mixed-methods study of adults who survived OHCA between January and April 2016 and were alive at one year in the Australian state of Victoria. Ethical approvals were obtained from Monash University Human Research Ethics Committee (MUHREC–0788; MUHREC-22947).

Data sources and materials

The Victorian Ambulance Cardiac Arrest Registry (VACAR) is a population-based register of OHCA events attended by EMS in Victoria, as has been previously described (16). Eligible survivors identified by VACAR were introduced to the study during the VACAR 12-month telephone follow-up (3). Those assenting to further contact were invited to participate in the current study along with a close family member ('family'), sent written study information and invited to attend an interview at a major hospital campus in Melbourne, Victoria. Linkage data for the following variables were obtained from the VACAR registry: patient demographics; arrest features; EMS factors; Glasgow Outcome Scale-Extended (GOS-E)(17) scores; EuroQol (EQ-5D) scores (18). Detailed information regarding the VACAR variables listed here is described elsewhere (3,16).

Interview Schedule. Qualitative data were obtained via semi-structured interview covering a broad range of topics regarding both survivor and family experiences of OHCA recovery (see Supplementary Data – Table 1).

Psychological Outcome Measures

Cognitive Function. The Mini-Mental State Examination (MMSE) screened survivors' broad cognitive function (19). Scores range from 0-30, with scores <27 indicating gross impairment. The Cognitive Failures Questionnaire (CFQ) (20) is a 25-item self-report measure used to assess subjective cognitive errors and mental slips. Scores range from 0-100, with scores >44 indicating cognitive impairment.

Psychological Distress. The Hospital Anxiety and Depression Scale (HADS) (21) is a 14-item self-report measure of distress. The HADS yields two domain scores (depression and anxiety) ranging from 0-21, each with a clinical cut-off of >8. Post-traumatic stress (PTS) was assessed by the 22-item Impact of Events Scale-Revised (IES-R) (22), which generates a total score (range = 0-88, clinical cutoff = >33) and three symptom subscale scores: intrusion, avoidance and hyperarousal.

Analysis

Quantitative data were analysed using SPSS version 27 (23) with *P* values of <0.05 regarded as significant. One-sample T-tests, Wilcoxon Signed Rank and multivariate analysis of variance (MANOVA) assessed group differences, with comparative reference to normative reference data previously published for HADS (24) and IES-R (25). Relationships among key variables were measured using point-biserial and Spearman's rank-order correlation coefficients.

Qualitative interview data were transcribed verbatim and subject to thematic content analysis, independently conducted by two investigators (RC and HP) using a constant comparative method (26). Data were coded and categorised into broad themes concurrently with data collection to monitor emergence and saturation of themes. Codes were then independently refined through re-reading and familiarisation with transcripts, mind-maps and categorical clustering of sub-themes.

Results

Participant Characteristics

Thirty-five survivors were invited to participate (see Figure 1 for recruitment process). The final sample comprised 18 survivors and 12 family members. Five (27.8%) survivors and four (33.3%) family members completed telephone assessments, with the MMSE excluded for survivors assessed remotely. Psychological measures were interview-administered for those completing the assessment via telephone, with all other participants completing these independently at the beginning of the interview. Median time since OHCA was 66 weeks (IQR 60, 74).

Characteristics of responding and non-responding OHCA survivors were all similar (Table 1). Family participants were nine (75.0%) spouses and three (25.0%) adult children of the survivor, predominantly female (66.7%), and aged between 20-70 years (M=49.1; 17.8).

Psychological Outcome Measures

Of the 13 survivors that completed the MMSE, all obtained normal scores (>27) (Median=29, IQR 28-30). Two (11%) had clinically significant CFQ scores (M=26.9; 15.0). Most reported depression, anxiety and PTSD levels within normal ranges (Figure 2), with mean depression and PTSD scores significantly lower than normative reference data (Table 2).

Subjective cognitive failures were significantly correlated with higher anxiety (P=0.013) but not with mental state (P = 0.416). Anxiety levels were significantly correlated with PTSD intrusion (P = 0.014) and hyperarousal symptoms, but not with avoidance (P = 0.174) or total PTSD (P = 0.334). Depression was significantly correlated with PTSD hyperarousal (P = 0.017), total PTSD (P = 0.021), and EQ-5D Index scores. Neither GOSE scores, nor prehospital / arrest variables, were associated with psychological outcome scores.

Qualitative Themes

Thematic content analyses were conducted on 10 patient-only interviews, eight patient-family dyad interviews and four family-only interviews. Interview data were categorised into two distinct sets: (1) Survivor Perspectives, and (2) Family Perspectives.

Survivor Perspectives

Six primary themes emerged from survivors' stories of recovery, comprising multiple subordinate themes: awakening and realisation (euphoria, lack of recall, guilt and concern); barriers to adjustment (physical factors, neurocognitive impairments, fatigue); psychosocial difficulties (loss of independence, fear of recurrence, low mood, irritability); integration (gratitude, anger and ambivalence, making meaning); protective factors (social support, lack of recall, positive experiences of critical care, benefits of cardiac rehabilitation [CR]); unmet needs (need for accurate information, tailored follow-up care, peer-support, arrest-specific rehabilitation) (for detailed quotes see Supplementary Data – Table 2).

Awakening and Realisation

Regaining consciousness following OHCA was described by survivors as a process of awakening and realisation. Almost all (n=17) did not recall the arrest or surrounding events, with some describing retrograde amnesia up to several days prior and anterograde amnesia for day or weeks following awakening. While some described an initially euphoric mood, others were preoccupied with concern regarding the traumatic impact for family and bystander witnesses.

Barriers to Adjustment

Initial post-discharge adjustment was primarily affected by physical factors and neurocognitive symptoms. Physical factors relating to treatment effects or ongoing cardiovascular symptoms (e.g. ventricular arrythmias) were noted by some as trauma cues, triggering feelings of anxiety, frustration and irritability. Two survivors described attacks of nausea, sweating and palpitations that they interpreted as being related to activation of their

pacemaker or implantable cardioverter defibrillator (ICD). Increased anxiety during such episodes compounded distress due to symptom overlap among panic and cardiovascular signs (e.g. breathing difficulty, sweating, dizziness, nausea).

Neurocognitive symptoms were common in the sub-acute (<3 months post-discharge) phase, including short-term verbal memory deficits, aphasia and executive function problems relating to attention, processing and cognitive fatigue. Several survivors reported persistent symptoms beyond the first year, with most noting ongoing problems with fatigue.

Psychosocial Difficulties

Four subthemes emerged from survivor reflections on the psychosocial difficulties faced after hospital discharge. Loss of independence and impaired occupational functioning affected domestic role adjustment, contributing to increased frustration, irritability and conflict with family as survivors struggled with increased dependence. Survivor distress was common following discharge home, with anxiety in particular associated with a fear of a recurrent arrest. Many reported periods of low mood, with most reporting depressive symptoms in the first 3-6 months with resolution by ~12 months post-arrest. Irritability, characterised by low frustration tolerance, was also a common experience in the sub-acute phase; however, unlike depressive symptoms, irritability persisted for some beyond the first year.

Integration

Most survivors reflected on the importance of understanding, accepting and integrating their survival experience as their psychological recovery progressed. While many were grateful for their 'second-chance' at life, several reported ongoing anger and ambivalence regarding their arrest, with one survivor stating he wished he had not been resuscitated given his now reduced quality of life. Existential contemplation was described by most survivors, with several noting considerable reflection on 'meaning' in relation to both their life's purpose and the reason for their survival. The process of understanding and integrating the OHCA

experience was highlighted as important in order to move forward without completely disregarding the significance of one's survivorship.

Protective Factors

Factors associated with adjustment included positive prehospital and inpatient care experiences, social support, lack of trauma recall, and CR participation. Several survivors recognised the protective impact of their lack of recall of the arrest period, noting the absence of intrusive trauma memories and associated posttraumatic symptoms. Attendance at CR was highlighted as invaluable for regaining strength and confidence, supporting improvements in adaptive and occupational functioning.

Unmet Needs

In discussing healthcare service experiences, survivors highlighted potential improvements for post-arrest care systems including early information provision, post-discharge follow-up, OHCA-specific CR programmes, and peer support networks. Many recommended early provision of comprehensive, written information regarding potential extra-cardiac sequelae and potential recovery trajectories. Several noted their lack of knowledge regarding post-arrest psychological impacts perpetuated distress, as emerging and ongoing symptoms were perceived as atypical and reflective of poor recovery.

The need for post-discharge monitoring and psychosocial support was highlighted as a critical aspect of post-arrest care conspicuously absent from most survivors' experience. Several suggested that regular follow-up in the first year would enable ongoing monitoring, early detection of psychological difficulties, and opportunities for specialist allied health referrals. Online information hubs and peer support networks were recommended to promote awareness of diverse survivorship experiences.

Family Perspectives

Four primary themes (containing subthemes) emerged from family perspectives: trauma exposure (witnessing the arrest, critical care trauma); survivor adjustment problems (early emotional challenges, neurocognitive impacts, anxiety and loss of confidence, irritability); family impact (post-traumatic stress and hypervigilance, contrasting experiences and needs); and areas for service improvement (communication and follow-up) (Supplementary Data – Table 3).

Trauma Exposure

Most family reported traumatic exposure to their loved one's OHCA, describing acute feelings of shock, panic and fear. This distress was perpetuated in the critical care setting, as family realised the risk of serious neurological disability or death. Prognostic uncertainty during this period was described as a highly stressful experience that was suddenly disrupted by the survivor's (often unexpected) return of consciousness. Many noted the residual effects of their traumatic exposure.

Survivor Adjustment Problems

Family participants observed that survivors faced multiple psychosocial challenges affecting post-discharge adjustment, including low mood, apathy, irritability and anger, typically attributed to survivors facing new limitations, increased dependence, and role disturbances. While most family agreed with survivor perceptions that mood symptoms resolved over time, some noted ongoing issues with emotion regulation, characterised by reduced frustration tolerance, increased irritability, and verbal outbursts triggered by seemingly minor events that (e.g. the noise of grandchildren playing). Some family observed reduced confidence and increased health anxiety among survivors, typically associated with fear of recurrent OHCA. Most family members reported neurocognitive impacts for survivors, including problems with memory, attention, fatigue, executive functions and speech/language. Fatigue was highlighted as particularly interfering, with some noting that their loved one's energy had

never returned to pre-arrest levels. In several cases, family perceptions of neurocognitive impact differed from those of survivors', with family suggesting reduced insight among some survivors regarding the degree of cognitive impairment evidenced.

Family Impact

The majority of family reported posttraumatic stress (PTS) symptoms, including intrusive memories and distress triggered by environmental cues (e.g. returning to OHCA location), and hypervigilance to risk of recurrence. Many reflected on their PTS symptoms as distinct to their experience as an observer, highlighting the survivor's trauma experience as fundamentally different to that of observers. Survivor unconsciousness and subsequent amnesia was noted by family as a paradoxically protective factor for the patient, defending them from posttraumatic intrusion symptoms. The disjuncture between family and survivor experiences exacerbated adjustment challenges for some, as both survivors and family sometimes struggled to understand and support each other through the survivorship journey.

Areas for Service Improvement

Family highlighted the need for clear, sensitive communication from health providers as important to their own psychosocial functioning. Recommendations included supportive explanations of prehospital and critical care procedures, greater sensitivity in discussions of prognosis, and written information regarding extra-cardiac sequelae. The need for comprehensive post-discharge follow-up care was emphasised; the lack of follow-up support following discharge was experienced in distinct contrast to the intensity of in-hospital care, with some family reporting they felt abandoned when their recovery journey was only just beginning.

Discussion

Our results show the vast majority of survivors are grateful to be alive post-resuscitation, with most evidencing normal levels of cognitive and psychological functioning in the second

year of recovery. However, survivors and families describe diverse symptom trajectories, with many facing challenges in their psychological recovery. Deeper exploration of survivor and family experiences revealed a diverse range of psychosocial challenges and barriers to adjustment following discharge, characteristic of the 'disrupted normality' described by Whitehead and colleagues(8). Survivors and family members highlight critical areas of improvement for CA services, including detailed recovery education, comprehensive follow-up, allied health involvement, tailored CR, and peer support networks. These findings echo those of international studies emphasising survivors' and families' voices in investigations of post-arrest psychosocial needs (8,27–29). Drawing on these, we have developed the Arrest, Awake, Await Adjust infographic to illustrate the distinct experiences of survivors and family as they move through parallel recovery experiences (Figure 3).

The contrast between the qualitative and quantitative findings obtained in this study may reflect a lack of psychometric validity for OHCA in the psychological measures employed. While survivors described a range of significant and sometimes persistent cognitive impairments, corroborated by their family, none obtained scores <27 on the MMSE. This aligns with previous research demonstrating the MMSE's limited sensitivity in the detection of mild cognitive impairment (MCI), contributing to recent shifts towards the use of tools such as the Montreal Cognitive Assessment (MoCA) in its place (30–34). While substitution of the MoCA for the MMSE in the present study may have improved the accuracy of MCI detection, the MoCA's poor specificity and weak correlations with multiple neuropsychological test domain scores should not be overlooked (31,35,36). Similarly, normal CFQ scores reflecting subjective perception of cognitive failures could reflect inadequate scale sensitivity and/or poor construct validity (37,38). Validity issues may also underpin the association between CFQ and HADS-A scores, aligning with previous research suggesting the CFQ more reliably measures trait anxiety (neuroticism) than cognitive

function (39–41). Inclusion of a more sensitive battery of performance-based neuropsychological assessments may have more reliably detected the subtle deficits described by survivors and family.

Depression and anxiety levels among survivors in the second year were not significantly higher than the general community. However, the interview component enabled retrospective exploration of both survivors' and family members' experiences of low mood and increased anxiety. HADS scores aligned with qualitative descriptions of psychological recovery in the first year, with depression and anxiety symptomatology tending to resolve over time. While adjustment is ongoing in the second year of recovery, it should also be considered that psychological constructs of depression and anxiety may not adequately reflect the long-term, affective dimensions of survivorship.

Construct validity is particularly salient in considering the experience of PTSD among survivors. While previous research has identified elevated PTSD rates among survivors (29), most survivors in our sample did not report clinically significant PTSD symptoms. In considering PTSD as a diagnosis following OHCA, it should be noted that a formal diagnosis of PTSD requires the presence of core intrusive symptoms (42). However, 94% of this sample reported no memory of events surrounding the event. It is possible that the distress experienced by survivors post-arrest is not adequately captured by this diagnostic construct. Further research is required to establish the validity of this diagnostic classification following OHCA; in the interim, use of the term 'posttraumatic stress symptoms' is recommended in place of 'posttraumatic stress disorder' or PTSD, unless a formal diagnosis of the latter has been provided by a clinical psychologist or psychiatrist.

Psychological Impacts for Family

While formal screening tools were not administered to family, the qualitative results highlight important psychological needs that warrant greater attention. Family descriptions of

persistent trauma symptoms, including intrusive memories and flashbacks, highlight the risk of psychological disorders such as PTSD among those close to survivors. These findings reflect those of other studies that have identified distress and burden among the family of survivors (5,8), further emphasising the distinct support needs of family.

Strengths and Limitations

This study has several strengths, including the use of a mixed methods design and inclusion of family members. It is the first to conduct a qualitative exploration of OHCA survivorship in an Australian population. Discrepancies between the qualitative and quantitative findings highlight psychometric deficiencies in the use of common psychological measures with OHCA survivors. While the sample size is adequate for qualitative analysis, the reliability of the correlational analysis may have been impacted by low power and thus should be interpreted with caution. Although responders and non-responders evidenced similar baseline characteristics, 12-month GOSE scores were slightly higher among responders, although not to a statistically significant degree. This could reflect a skew towards patients with better functional outcomes, which a larger sample size may help to elucidate.

Conclusions

OHCA survivors and their families emphasise the importance of rapid contact post-discharge, ongoing follow-up from multi-disciplinary teams, better access to specialist assessment and rehabilitation services, and peer support networking opportunities. These priorities notably align with the primary features of recent post-arrest clinic models (28), which have shown encouraging benefits for OHCA survivors following discharge. Future research must focus not only on the development and validation of psychometric tools, but also prioritise the establishment and evaluation of post-discharge care models capable of supporting OHCA survivors and their families across diverse, geo-cultural contexts via both face-to-face and telehealth modalities.

CRediT author statement

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Conflict of Interest Statement

The authors declare no known conflicts of interest.

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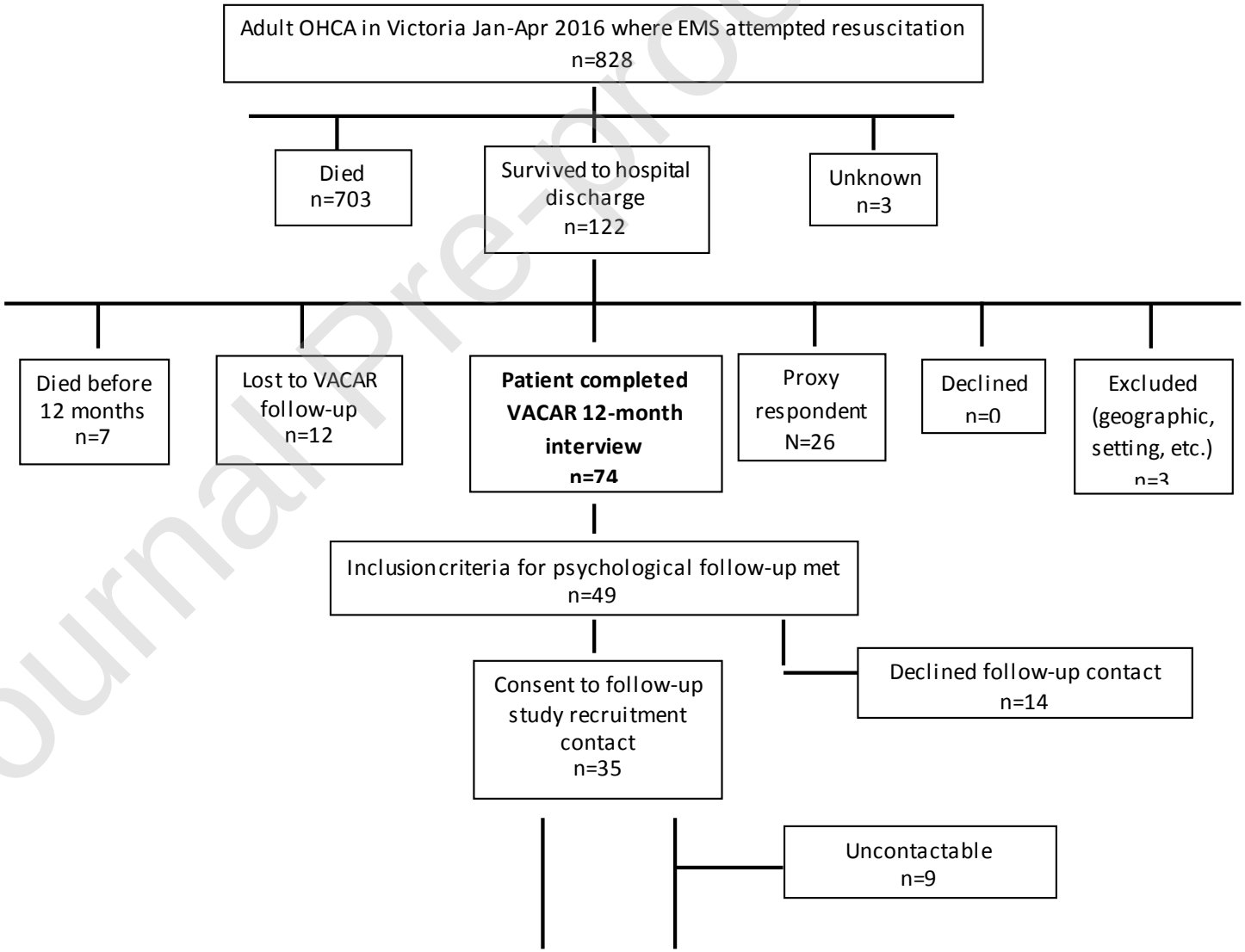
Figure 1. Recruitment Flow Chart



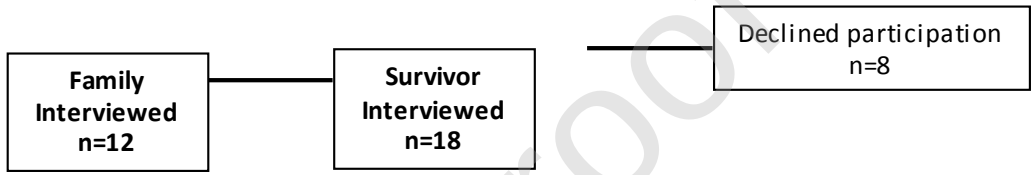


Figure 2. Number of participants obtaining normal vs clinically significant psychological test scores.

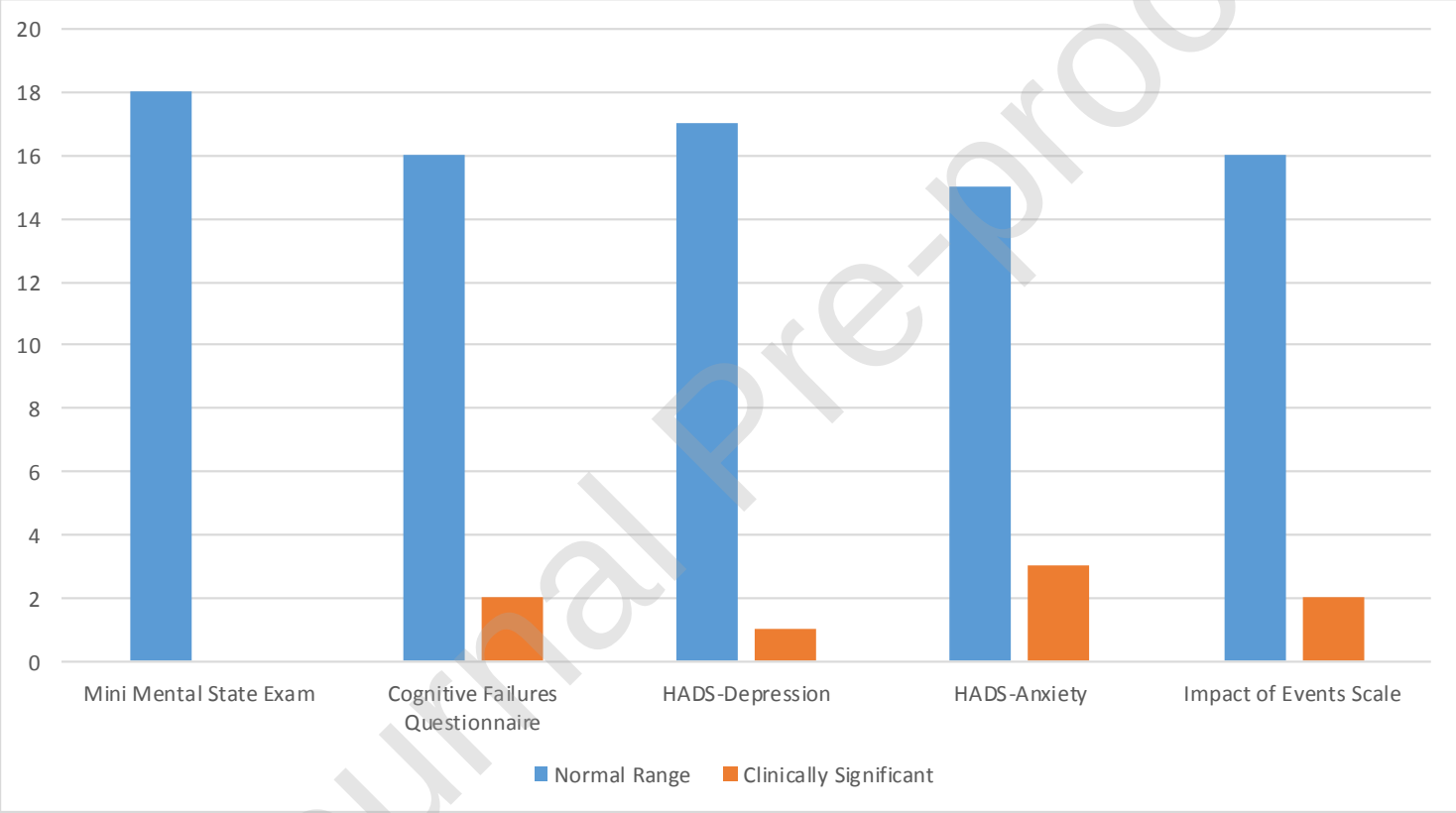


Figure 3. Survivor and Family Perspectives on the Survivorship Process

	ARREST	AWAIT	AWAKE	ADJUST
SURVIVOR			Euphoria Lack of Recall Guilt and Concern	Physical Factors Neurocognitive Impairments Fatigue Loss of Independence Fear of Recurrence Low Mood & Irritability Ambivalence Meaning Making

FAMILY	Trauma Exposure Shock Panic Fear Prognostic Uncertainty	Relief Exhaustion Uncertainty	Post-traumatic Stress Hypervigilance Caregiver Role Adjustment Contrasting Support Needs

TABLE 1.

Characteristics of Responding and Nonresponding OHCA Survivors

	Non-responders (n=17)	Responders (n=18)	*P* Value
Age [mean (SD)]	51.5 (15.9)	57.4 (13.2)	0.239
Male sex, n (%)	13 (76.5)	11 (61.1)	0.328
EMS Response time, median (IQR)	7.2 (4.4)	7.4 (4.4)	0.817
Witnessed to Arrest, n (%)			
By bystander	7 (41.2)	11 (61.1)	0.496
By EMS	6 (35.3)	4 (22.2)	
Bystander CPR, n (%)	11 (64.7)	13 (72.2)	0.632
Arrest location, n (%)			
Private residence	8 (47.1)	8 (44.4)	0.981
Public place	7 (41.2)	8 (44.4)	
Other	2 (11.8)	2 (11.1)	
Arrest rhythm, n (%)			
Ventricular fibrillation/ventricular tachycardia	16 (94.1)	15 (83.3)	0.367
Pulseless electric activity	1 (5.9)	1 (5.6)	
Asystole	0 (0)	2 (11.1)	
Time to first ROSC, median (Q1-Q3)	20.0 (13.0-32.0)	20.5 (14.3-29.0)	0.665
EQ-5D Index – 12 month, median (IQR)	0.89 (0.23)	0.96 (0.17)	0.089
Good Outcome – 12 month GOSE, n (%)	6 (35.3)	10 (55.5)	0.169

OHCA=out-of-hospital cardiac arrest; SD=standard deviation; EMS=emergency medical services; IQR=inter-quartile range; CPR=cardiopulmonary resuscitation; ROSC=return of spontaneous circulation; Q=quartile; EQ-5D=EuroQol-5 Dimension; GOSE=Glasgow Outcome Scale-Extended

TABLE 2. Depression, Anxiety and PTSD Symptoms in OHCA patients compared to normative samples.

	Current Sample Mean (SD)	Normative Reference Mean (SD)[1,2]	*P* Value
HADS-D[i]	2.6 (2.1)	3.9 (3.6)	.013
HADS-A[ii]	4.1 (3.0)	4.9 (3.6)	.312
IES-Int[iii]	5.3 (3.6)	7.4 (7.4)	.028
IES-Hyp[iv]	1.9 (2.9)	4.5 (5.3)	.002
IES-Avd[v]	4.6 (4.4)	8.7 (8.1)	.002
IES-Total[vi]	10.4 (7.8)	20.6 (19.4)	<.001

[i] Hospital Anxiety and Depression Scale: Depression;
[ii] Hospital Anxiety and Depression Scale: Anxiety;
[iii] Impact of Events Scale: PTSD Intrusion;
[iv] Impact of Events Scale: PTSD Hypervigilance;
[v] Impact of Events Scale: PTSD Avoidance;
[vi] Impact of Events Scale: Total PTSD
PTSD=post-traumatic stress disorder; OHCA=out-of-hospital cardiac arrest; SD=standard deviation