

A NATIONAL NEEDS ANALYSIS OF SUDDEN CARDIAC ARREST SURVIVORS

by

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Psychosocial outcomes of sudden cardiac arrest survivors have generally been studied in single center samples. Large, nationally representative patient surveys may offer different perspectives. The aim of the current study is to provide a needs analysis of health outcomes and psychosocial needs for this patient population.

One hundred and eighty nine sudden cardiac arrest survivors (104 men, 84 women, 1 unreported) completed an online survey. A representative sample of time since cardiac arrest was achieved (28.0% within 2 years, 38.6% 2-5 years, 33.3% 5 or more years post-SCA). The self-report survey consisted of retrospective (time of cardiac event to 3 months post-cardiac event) and current ratings of health, which included quality of life, emotional health, and general health. A needs analysis for sudden cardiac arrest survivors addressing acute and long-term concerns was completed to aid in understanding appropriate educational programming for these patients. Approximately 81% of the sample had an implantable cardioverter defibrillator and 45% of patients had experienced at least one shock from their device.

Patient ratings of post-sudden cardiac arrest health outcomes indicated notable change in quality of life (37.7% better, 37.2% same, 25.0% worse). Similar patterns in emotional health (33.8% better, 32.8% same, 33.3% worse) and general health (30.3%

better, 46.3% same, 23.4% worse) were observed. The majority of patients reported desirable (excellent - very good - good) changes in quality of life (88.9%), emotional health (82.0%), and general health (84.1%), while others reported undesirable (fair - poor) current health ratings; quality of life (11.1%), emotional health (18%), and general health (16%). Emotional health emerged as the health functioning area most negatively impacted by sudden cardiac arrest. Needs analysis of top concerns demonstrated that the highest priority concerns were anxiety, depression, and fear of exercise across all time periods. Further analyses indicated that gender and secondary treatment type significantly impacted reported rates of anxiety, depression, and fear of exercise.

To our knowledge, the current study examines patient reports from the largest sudden cardiac arrest sample in the literature. Findings highlight that immediate health outcomes post-sudden cardiac arrest are potentially adverse but many patients later report desirable quality of life, emotional health, and general health. Educational programming initiatives for sudden cardiac arrest patient issues may require shifting focus from broad health concerns to acute and long-term psychosocial needs.

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CHAPTER I: INTRODUCTION

Cardiovascular disease (CVD) is the leading cause of death in the United States (Hoyert & Xu, 2012) and was identified as the leading cause of death worldwide at the turn of the 21st century (Gaziano, 2005). Sudden cardiac arrest (SCA) results in approximately 180,000 to 450,000 deaths in the United States annually (Kong et al., 2011). This broad range is largely due to inconsistent use of appropriate terminology in the literature and adjudication at autopsy as to exact cause of death. Although the exact incidence of SCA is difficult to ascertain, it has been estimated to account for up to half of CVD-related deaths in the United States each year (Kong et al., 2011; Mehra, 2007).

Mortality rates of out-of-hospital cardiac arrest (OHCA) are very high, with only 5-8% of individuals surviving to hospital discharge (Nichol et al., 2008; Stub, Bernard, Duffy & Kaye, 2011). Those who do survive a SCA are faced with a variety of medical and psychological changes and challenges. These may include decisions about medical care (e.g., ICD implantation), family fear, psychosocial distress, and concerns about employment, safety, and longevity (Sears, Todaro, Lewis, Sotile, & Conti, 1999).

The use of an implantable cardioverter defibrillator (ICD) is the treatment of choice for secondary prevention after a SCA (Sears & Conti, 2002). This life-saving intervention is designed to treat future cardiac arrhythmias by producing a direct shock to the heart muscle, preventing SCD by converting it to sinus arrhythmia (Myerburg, Reddy, & Castellanos, 2009). While the technology of an ICD significantly increases survival rates in patients post-SCA, ICD patient adjustment and coping should also be

considered to achieve optimal health outcomes (Sears, Hauf, Kirian, Hazelton, & Conti, 2011).

It can be difficult to study the psychological sequelae of SCA due to the high rate of mortality. However, elevated psychological distress has been recognized in patients following ICD implantation (e.g., Sears & Conti, 2002; Thomas et al., 2009), and ICD shock can have a distinct impact on patient functioning. Poorer quality of life (QOL) outcomes have been reported in patients who have experienced ICD shock versus those who have not been shocked by their device (Sears & Conti, 2003). Patients may also experience anticipatory shock anxiety, or anxiety that is specific to fear of future ICD shocks (Kuhl, Dixit, Walker, Conti, & Sears, 2006). Even partners of SCA survivors may struggle with psychosocial adjustment after the cardiac event, such as difficulty with anxiety or transitioning into a caregiver role (Dougherty & Thompson, 2009). Because the vast majority of SCA survivors are treated with ICDs, research on the psychological impact of ICD implantation in patients with CVD can meaningfully inform hypotheses about the psychosocial needs of patients post-SCA.

The purpose of the current project is to conduct a needs analysis for patients who have experienced SCA, with specific focus on the problematic psychosocial needs identified by SCA survivors across the recovery time period. Providing a comprehensive picture of patient functioning post-SCA could facilitate better care practices and allow future treatment programming to be informed by direct patient feedback.

The current project has several descriptive aims: (1) report patient ratings of current health functioning (i.e., general, emotional, QOL) and ratings of changes in health

functioning post-SCA, (2) report the most commonly identified psychosocial needs of SCA survivors in the acute and long-term recovery periods, and (3) examine the top 3 most problematic psychosocial needs reported in the current time period and describe how these problem areas are related to time since cardiac arrest. Additionally, the current study will examine the impact of secondary treatment type, shock history, and gender on the top 3 most problematic psychosocial needs reported by SCA survivors.

CHAPTER II: LITERATURE REVIEW

Sudden Cardiac Arrest

SCA is an abrupt cessation of heartbeat secondary to cardiac arrhythmia, and will result in sudden cardiac death (SCD) without appropriate medical intervention (Zipes et al., 2006). SCA is commonly secondary to ventricular fibrillation (Deshpande & Akhtar, 1997), which can be caused by a variety of underlying conditions including coronary heart disease (CHD), cardiomyopathies, and ion channel disorders. In some cases, SCA may be the first indication of CVD (Deshpande & Akhtar, 1997; Stub et al., 2011).

Risk profile. Because the etiology of SCA and definitions of this condition are varied (Deshpande & Akhtar, 1997; Kong et al., 2011) defining an exact risk profile is particularly difficult. Coronary artery disease (CAD), which is a complex physical and inflammatory problem that can lead to cardiac arrhythmia, is a significant risk factor for sudden cardiac arrest (Myerburg & Junttila, 2012). CAD has been identified in approximately 70% of cases resulting in SCD (Turakhia & Tseng, 2007). Alternatively, cardiomyopathy (e.g., restrictive/infiltrative, hypertrophic) reduces ventricular plasticity and can lead to disruption of the heart's electrical system (Arnold, 2010). Ion channel disorders (e.g., long QT syndrome) can interrupt proper calcium channel functioning, resulting in failure of normal calcium-ion exchange and subsequent interference with contractile and conduction mechanisms (Ackerman & Clapham, 1997). Left ventricular ejection fraction (LVEF) should be carefully monitored as patients with low LVEF (i.e., less than 35) are at an increased risk for SCA (Mehra, 2007). Conditions resulting in calcium channel and/or electrical conduction abnormalities, loss of muscle contractility,

and/or interruption of regular blood flow are substantial risk factors for SCA. Thus, precursors to relevant types of CVD (e.g., hypertension in the case of CAD) should be considered in describing risk factors for SCA (Deshpande & Akhtar, 1997).

Ventricular arrhythmia. Resting heart rate in adults can range from 60-100 beats per minute (BPM) (Mitchell, 2012). Abnormalities occur when heart rate falls below 60 BPM (bradycardia) or rises above 100 BPM (tachycardia) at rest. Ventricular tachycardia (VT) can lead to ventricular fibrillation (VF). VF occurs when ventricular contractions due to cardiac dysrhythmia disrupt the normal blood flow through the heart, and is present in 65%-85% individuals who experience SCA (Deshpande & Akhtar, 1997).

Acute Response and Secondary Prevention

Regardless of underlying disease state, initial life-saving efforts after SCA focus on re-establishing regular sinus rhythm and application of cardiopulmonary resuscitation (CPR) (Ravindranath & Pelosi, 2012). Patients who are resuscitated or experience return of spontaneous circulation within a five-minute period are more likely to regain premonitory cognitive functioning (Madl & Holzer, 2004). Thus, early resuscitation/defibrillation generally leads to more desirable neurological outcomes and lower mortality rates (Alexander, Lafleche, Schnyer, Lim, & Verfaellie, 2011).

The automated external defibrillator. Acutely, restoring normal sinus rhythm is often accomplished through use of an automatic external defibrillator (AED). AEDs, which can be operated by bystanders or trained responders, work by delivering an electrical shock to the heart to correct cardiac arrhythmia (Marenco, Wang, Link, Homoud, & Estes, 2001; Stub et al., 2011).

The implantable cardioverter defibrillator. Device treatment using an implantable cardioverter defibrillator (ICD) is the most effective form of long-term prevention of repeated SCA, and is the most effective treatment option for preventing mortality (Sears & Conti, 2002). Much like an AED, the ICD responds to cardiac arrhythmia by delivering electrical shocks to the heart muscle until normal heart rhythm is achieved. ICD implantation is indicated in the vast majority of SCA survivors, and can be used in conjunction with antiarrhythmic medication. When the ICD was initially made available in 1980s, implantation was invasive (e.g., thoracotomy) and the device was restricted to delivering high-energy shocks. The modern ICD is transvenous, programmable, smaller, and allows for patient-specific adjustments by medical providers, including antitachycardia pacing and defibrillation (Dougherty, 2001).

The psychologic well-being of ICD patients and, thus, SCA survivors, is becoming increasingly relevant because the technology of the ICD has profoundly influenced patient survival (Sears et al., 2011). However, ICD shock is painful and approximately 15%-25% of shocks are considered inappropriate (Ravindranath & Pelosi, 2012; Tung, Zimethbaum, & Josephson, 2008). The effect of ICD shock, especially when more than five shocks are administered by the device, can negatively impact QOL and increase feelings of distress in ICD patients (Sears et al., 2011).

Antiarrhythmic medications. Other treatment options post-SCA, beyond the ICD, include use of antiarrhythmic medications, such as beta-blockers or calcium channel blockers. Angiotensin-converting enzyme (ACE) inhibitors may be administered immediately post-SCA to promote vasodilation (Nichol & Baker, 2007; Ravindranath & Pelosi, 2012). Significant reduction in mortality has also been reported

with use of ICDs when compared with traditional pharmacological intervention (Bardy et al., 2005; McAnulty et al., 1997; Moss et al., 1996).

Psychological Impact of Sudden Cardiac Arrest

The biopsychosocial model. In contrast to the traditional biomedical model of care, the biopsychosocial model provides a framework in which biological, psychological, and social factors are all important facets of patient health. As Engel (1980) noted, “Each system is at the same time a component of higher systems...in the continuity of natural systems every unit is at the very same time both a whole and a part” (p. 537). A biopsychosocial approach to caring for SCA survivors necessitates consideration of psychologic factors prior to the cardiac event and across time post-SCA (Kirian, Sears, & DeAntonio, 2012).

Accumulating evidence indicates that a substantial minority of survivors experience clinical distress post-SCA (e.g., feelings of anxiety and depression) (e.g., Shaaf et al., 2013). A recent systematic review by Schaaf and colleagues (2013) stated, “on average, one in four patients will experience anxiety, depression, or PTSD following cardiac arrest” (p. 4). Depression, anxiety, and limited social support may also be risk factors for SCA (Ravindranath & Pelosi, 2012). Proposed mechanisms of this significant correlation include abnormal autonomic nervous system functioning (Ravindranath & Pelosi, 2012).

The relationships between emotional state, ventricular arrhythmia, and ICD shock have been examined in vulnerable patient populations. Lampert and colleagues (2000) demonstrated that mental stress could induce more rapid onset of VT, prolong duration of the event, and increase likelihood of ICD shock in patients with preexisting

heart disease. Other emotional states, such as depression and anger, may be important risk factors for ventricular arrhythmia and subsequent ICD shock (Kirian et al., 2012).

Depression and anxiety. Elevated occurrences of anxiety and depression have been identified in patients after SCA and ICD implantation. An estimated 13%-42% of SCA patients report significant anxiety and 8%-45% have depressive symptoms (Shaaf et al., 2013). Comparable rates of anxiety (13%-38%) and depression (18%-33%) have been reported post-ICD implantation (Ford, Cutitta, Woodrow, Kirian, & Sears, 2011) and in larger cardiac populations (Sears & Conti, 2003).

The manifestation of depressive, anxious, and posttraumatic stress symptomology in ICD patients has been well outlined by Ford and colleagues (2011). Depression in this patient population may include themes related to dependence on the device, feeling limited because of the ICD, and concern about the perception of others. Anxiety is often device-specific, and can include anxious anticipation of future defibrillation and related decrease in activity level. Feelings of anxiety and depression may be closely tied to concerns about the cardiac condition and the potential for future adverse events (Ford et al., 2011).

Evidence suggests that there is an inverse relationship between psychological distress and treatment adherence. McGrady and colleagues (2009) found that anxious and/or depressed patients were more likely to drop out of cardiac rehabilitation. Significant gender differences were also noted, with women being less likely to complete the program. Depression has also been shown to interfere with medication adherence in patients with CHD (DiMatteo, Lepper, & Croghan, 2000; Gehi, Haas,

Pipkin, & Whooley, 2005). Severe depressive symptoms have been shown to correlate with increased risk of ICD shock (Ladwig et al., 2008). Thus, psychological distress in SCA survivors may worsen morbidity. Identification of anxious or depressed SCA survivors and the incorporation of psychologic screening services into standard patient care post-SCA may partially address this issue.

Gender differences. Previous research among ICD recipients has related that women are at greater risk for undesirable psychological outcomes (Sears & Conti, 2002). In the ICD literature, statistically significant gender differences have been reported for clinical anxiety and depressive disorders, with women being at much higher risk compared with men (Bostwick & Sola, 2011). To date, gender differences related to fear of physical exertion have not been fully examined, likely due to demographic similarities among participant samples.

Quality of life. Recent data on QOL after SCA is primarily limited to evaluations of neurological outcomes, and has focused on the impact of therapeutic hypothermia (TH) (e.g., Bro-Jeppesen et al., 2009; Middelkamp et al., 2007). QOL in ICD patients has been examined and extensive overlap between the two patient populations suggests that findings may generalize to SCA survivors.

QOL can be negatively impacted in ICD patients who experience more than five ICD shocks and those who demonstrate persistent avoidance of stimuli associated with perceived risk of cardiac events (Kirian et al., 2012). Avoidance of physiological cardiac responses (e.g., increased heart rate) has been documented in ICD patients (Cutitta et al., 2014). Subsequent disengagement in physical activity is a common area of concern, as mild to moderate exercise is recommended in this patient population

(Vanhees et al., 2004). Feelings of anxiety, PTSD symptomology, activity avoidance, and ICD shock can also worsen QOL in ICD patients (Kirian et al., 2012; Sears et al., 2007).

Psychologic Care, Education, Exercise, and Cardiac Rehabilitation

Cardiac rehabilitation services have been shown to be cost-effective and may significantly decrease morbidity and mortality, as well as improve QOL (Ades, 2001; Daly et al., 2002). The most recent update to the Core Components of Cardiac Rehabilitation/Secondary Prevention Programs (Balady et al., 2007) identified the following as essential areas: (1) patient assessment, (2) nutritional counseling, (3) weight management, (4) blood pressure management, (5) lipid management, (6) diabetes management, (7) tobacco cessation, (8) psychosocial management, (9) physical activity counseling, and (10) exercise training. Guidelines on psychosocial management include identification of clinical depression and/or anxiety, social isolation, and marital/family distress, and subsequent patient access to appropriate mental health services. Exercise training guidelines focus on facilitation of physical activity when medically indicated. Thus, examining the psychosocial issues most relevant to SCA survivors, especially those that may contribute to exercise avoidance, would aid in the development of specialized treatment programming for these patients. The current study and its needs analysis will examine the utility of specialized cardiac rehabilitation services for SCA survivors.

Unfortunately, participation and adherence rates for cardiac rehabilitation programs are remarkably low. Only 10-47% of patients who qualify for cardiac rehabilitation services utilize these resources (Ades, 2001). Following MI,

approximately one-third of patients attend cardiac rehabilitation, and approximately two-thirds of those are nonadherent at six months (Daly et al., 2002). Other factors associated with lower use of cardiac rehabilitation services include depression, limited social support, age, gender, and socioeconomic status (Daly et al., 2002; Glazer, Emery, Frid, & Banyasz, 2002; Jackson, Leclers, Erskine, & Linden, 2005). For SCA survivors, anticipatory shock anxiety and the perceived relationship between ICD shock and exercise may also be important barriers. To date, no SCA-specific information is available in regards to cardiovascular rehabilitation.

According to the Office United States Government Site for Medicare, cardiac rehabilitation services are covered for patients with Medicare Part B after recent MI, CABG, heart valve repair/replacement, coronary angioplasty/stent placement, heart or heart-lung transplant, and for those with current, stable angina pectoris (Centers for Medicare & Medicaid Services, 2012). Medicare does not cover cardiac rehabilitation services for SCA survivors, and patients without insurance coverage are less likely to be referred to cardiac rehabilitation (Jackson et al., 2005). This creates an additional barrier to rehabilitative care for SCA survivors, and likely maintains a cycle of exercise avoidance and worsened psychological health for these patients.

Education. Education about a cardiac condition is necessary but not sufficient to impact health outcomes. Dunbar and colleagues (2009) conducted a longitudinal study that examined the effect of a psychoeducational intervention (i.e., education, symptom management training, cognitive coping skills) on psychologic distress in recent ICD recipients ($n = 246$), versus telephone contact and usual care. The intervention group demonstrated significantly decreased anxiety at three months, as well as decreased

likelihood of depressive symptomology at 12 months. Decreased anxiety and depression were observed throughout the study, and the telephone contact group had a lower probability of depression at 12 months when compared with the usual care group.

Exercise. Exercise training, which is a core component of general cardiac rehabilitation programming, is both safe and beneficial for ICD patients when appropriate maximal heart rate is identified (Isakensen, Morken, Munk, & Larsen, 2012; Vanhees et al., 2004). Vanhees and colleagues (2004) found that exercise intervention for ICD patients ($n = 92$) improved aerobic fitness. Although psychological adjustment to ICD implantation was not examined in this study, anxiety related to fear of ICD discharge was noted as an important barrier to exercise in ICD patients.

The Heart Failure and a Controlled Trial Investigating Outcomes of Exercise Training (HF-ACTION) study (O'Connor et al., 2009) demonstrated the safety of exercise training for heart failure (HF) patients ($n = 2,331$) with low ejection fraction. Approximately half of study participants in this large, randomized controlled trial had an ICD or biventricular pacemaker. While no significant differences were found in reduction of mortality or hospitalization, HF patients in the exercise group demonstrated improved aerobic function after three months. More recently, subanalysis showed no difference in number of ICD shocks between the exercise group and the control group at approximately two years, suggesting that exercise for ICD patients is safe (Piccini et al., 2013).

Combined interventions. Fitchet and colleagues (2003) designed a randomized prospective study to assess the impact of a comprehensive cardiac rehabilitation program on ICD patient activity and psychologic health ($n = 16$). The

intervention included exercise training, general ICD and health-specific cognitive-behavioral education, group and individual psychotherapy, and cognitive-behavioral skills training. Findings indicated that the protocol increased exercise capacity for a period of 12 weeks (i.e., exercise time without increase heart rate), as well as decreased anxiety and depressive symptomology as measured by the Hospital Anxiety and Depression Scale (HADS). More than 75% of participants noted that the intervention was beneficial and they felt their confidence in exercise ability had increased.

Similarly, Frizelle and colleagues (2004) examined the impact of an outpatient, cognitive-behavioral cardiac rehabilitation program on ICD patient psychological distress and QOL ($n = 22$). The protocol included exercise training, education sessions, introduction to coping skills (i.e., progressive muscle relaxation, diaphragmatic breathing), and goal setting. Results indicated that this combined treatment approach resulted in improved exercise ability, and decreased clinical anxiety and depression in the ICD patient sample. Collectively, SCA survivors may benefit from cardiac rehabilitation, but barriers to full benefits include dropout, lack of insurance coverage, and dissemination of generic information lacking SCA-specific priorities.

Summary, Aims, and Hypotheses

Research has demonstrated that depression, anxiety, and fear of exercise are areas of significant concern for patients after cardiac arrest and after ICD implantation (e.g., Schaaf et al., 2013; Sears et al., 2011; Vanhees et al., 2004). This type of psychological distress can negatively impact patient functioning (e.g., QOL) and morbidity. The proposed needs analysis targeting perceived health functioning,

identification of psychosocial needs of SCA survivors, and the impact of secondary treatment method, shock history, and gender on patient concerns will aid the development of patient-tailored educational initiatives.

The first study aim is to identify current patient perceptions of health functioning, as well as changes in health functioning resulting from SCA. It is expected that undesirable perceptions of health functioning in both areas will be reported, especially with regard to emotional health and QOL.

The second descriptive aim is to provide descriptive data on psychosocial needs of SCA survivors at acute (three months post-SCA) and long-term (current) time points. It is hypothesized that participants will identify concerns related to anxiety, depression, and exercise as particularly relevant in both the acute and long-term periods.

The third descriptive aim is to examine the top three most problematic psychosocial needs reported in the current time period and describe how these problem areas are related to time since cardiac arrest. It is hypothesized that reported rates will decrease over time.

The final aim of the current study is to examine the impact of secondary treatment type, shock history, and gender on the top 3 most problematic psychosocial needs reported by SCA survivors. It is hypothesized that shock history and gender will impact the most problematic psychosocial concerns.

CHAPTER III: METHOD

Participants

The current project included 189 participants who were recruited from the Sudden Cardiac Arrest Association (SCAA, Washington, DC) database. All were adult survivors of SCA who completed an online survey made available by the SCAA between 10/2012 and 01/2013. Data were collected using software from Survey Monkey, Inc. The study received IRB approval from East Carolina University (ECU) on 8/1/2012. No compensation was provided to study participants.

Measures

Participants completed a 76-item, online questionnaire with an approximate completion time of 20 minutes. Basic demographic information (i.e., gender, date of birth, education level, race/ethnicity, household income) and medical background data about the participant's most recent SCA were collected in the first 9 questions. Items 11 through 16 included self-report ratings of health functioning. Items 20 and 24 were used to identify problematic psychosocial issues in the acute and long-term periods. Additional information about secondary treatment type (i.e., ICD, no ICD) and ICD shock history were collected in items 70 and 72, respectively.

Procedure

The SCAA recruited participants from their database via email, which included a link to complete the survey through the SCAA website. Individuals who had not personally experienced a cardiac event and/or were under the age of 18 were excluded. Informed consent was obtained in question one of the survey. Participants were required to respond by selecting "I agree" on this item before the full questionnaire could

be accessed. As part of the consent process, potential participants were informed that involvement was voluntary and that the study purposes were to (1) conduct a needs assessment to determine appropriate support services in the first few days/weeks and months/years after cardiac arrest, (2) establish the psychological impact of a cardiac event and better understand the experiences of long-term survivors, and (3) obtain patient demographic information. Of the 522 SCA survivors who received email recruitment to complete the study, 189 completed the survey (response rate = 36%).

Analyses

Descriptive analyses were used to report basic demographic information, secondary treatment method, and ICD shock history. Patient-identified ratings of functioning regarding current perceptions of general health, emotional health, and quality of life, as well as self-reported changes in these areas following SCA were included. Additionally, descriptive analyses were employed to identify which psychosocial issues SCA survivors most commonly reported as problematic in the immediate (three months post-SCA) and current time periods. Also examined via frequency reports were current data on the psychosocial need, and change in these reports across time since cardiac arrest.

Patients were classified into three groups based on whether or not they had an ICD and, if they did, whether or not they had received shocks from the ICD. The resulting three groups were (1) No ICD, (2) ICD but no history of shock, and (3) ICD with history of shock. For each of the outcome measures, two contingency table analyses were conducted. The first compared the three groups on the outcome variable and the second compared the genders on the outcome variable. If the first analysis was

statistically significant, two follow-up analyses were conducted, one comparing those with an ICD to those without and ICD and another comparing those with ICD but no history of shock to those with ICD but a history of shock.

CHAPTER IV: RESULTS

Demographic Information

All data were analyzed using SPSS v.20. Mean age was 55.4 years ($SD = 12.1$), and the sample consisted of 104 (55.0%) men and 84 (44.5%) women, with one participant not reporting gender.

Table 1

Participant Gender

<u>Gender</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
Male	104	55.0	55.3
Female	84	44.5	44.7
Unreported	1	0.5	–
Total	189	100.0	100.0

Study participants were primarily Caucasian ($n = 177$; 94.7%), and reported educational background and annual household income were both relatively high. The majority of SCA survivors in this sample reported graduation from college (33.9%) or completion of graduate studies (30.7%), and 82.8% indicated an annual household income of \$50,000 or more.

Table 2

Participant Race/Ethnicity

<u>Race/Ethnicity</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
Caucasian	177	93.7	94.7
Black/African-American/ Caribbean-American	4	2.1	2.1
Hispanic/Latino	1	0.5	0.5
Asian	2	1.1	1.1
Arab	1	0.5	0.5
Other	2	1.1	1.1
Unreported	2	1.1	–
Total	189	100.0	100.0

Table 3

Reported Educational Background

<u>Educational Background</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
Some High School	4	2.1	2.1
Some College	52	27.5	27.5
College Graduate	64	33.9	33.9
Graduate School	58	30.7	30.7
Technical School	11	5.8	5.8
Unreported	–	–	–
Total	189	100.0	100.0

Table 4

Reported Annual Household Income

<u>Household Income</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
\$0 to \$9,999	1	0.5	0.6
\$10,000 to \$19,999	4	2.1	2.3
\$20,000 to \$29,999	3	1.6	1.7
\$30,000 to \$39,999	8	4.2	4.6
\$40,000 to \$49,999	14	7.4	8.0
\$50,000 to \$74,999	33	17.5	18.9
\$75,000 to \$99,999	24	12.7	13.7
\$100,000 to \$149,999	37	19.6	21.1
\$150,000 and Above	51	27.0	29.1
Unreported	14	7.4	–
Total	189	100.0	100.0

Cardiovascular/Medical History

Time since cardiac arrest ranged from within the past year to five or more years ago. The most commonly identified time period reported since SCA was between two to five years since the cardiac event ($n = 73$; 38.6%), followed by five or more years ($n = 63$; 33.3%). Of those who reported secondary treatment type and ICD shock history, 148 (80.9%) individuals had an ICD, and 68 (44.4%) reported experiencing at least one shock from their device.

Table 5

Time Since Most Recent Sudden Cardiac Arrest

<u>Time Since Cardiac Arrest</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
0-2 Years	53	28.0	28.0
2-5 Years	73	38.6	38.6
5+ Years	63	33.3	33.3
Unreported	–	–	–
Total	189	100.0	100.0

Table 6

Secondary Treatment Type

<u>Treatment Type</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
ICD	148	78.3	80.9
Other	35	18.5	19.1
Unreported	6	3.2	–
Total	189	100.0	100.0

Table 7

ICD Shock History

<u>Shock</u>	<u>Frequency</u>	<u>Percent</u>	<u>Valid Percent</u>
Yes	68	36.0	44.4
No	85	45.0	55.6
Unreported	36	19.0	–
Total	189	100.0	100.0

Perceptions of Health Functioning

Regarding self-perceptions of current health functioning (refer to Table 8), the majority of SCA survivors reported desirable (excellent – very good – good) general health (84.1%), emotional health (82.0%), and quality of life (88.9%). However, approximately 11-18% of individuals surveyed reported fair or poor current health in these categories. A greater percentage of patients reported fair or poor emotional health (18.0%) when compared to general health (16.0%) and quality of life (11.1%) ratings.

While many survivors reported desirable (about the same – somewhat better – much better) changes in health functioning following their cardiac event (refer to Table 9), others indicated that their health functioning had deteriorated. The majority of survivors (46.3%) believed that their cardiac event did not affect their general health, while 23.4% felt it was worse. Similar patterns were noted for emotional health (32.8% about the same, 33.3% worse) and quality of life (37.2% about the same, 25% worse). Again, a higher percentage of patients reported that their emotional health was worse after experiencing a SCA when compared with general health and quality of life ratings.

Table 8

Self-Report Ratings of Current Health Functioning Post-SCA

Rating	General Health	Emotional Health	Quality of Life
Excellent	19.7%	27.5%	31.2%
Very Good	36.2%	29.1%	33.9%
Good	28.2%	25.4%	23.8%
Fair	14.9%	14.3%	10.6%
Poor	1.1%	3.7%	0.5%

Table 9

Self-Report Ratings of Changes in Health Functioning Post-SCA

Rating	General Health	Emotional Health	Quality of Life
Much Better	13.3%	18.5%	18.6%
Better	17.0%	15.3%	19.1%
About the Same	46.3%	32.8%	37.2%
Somewhat Worse	22.3%	27.0%	22.9%
Much Worse	1.1%	6.3%	2.1%

Commonly Reported Psychosocial Needs

Immediately following their cardiac event (time of SCA to 3 months post-SCA), over half of SCA survivors (63.0%) stated that feeling anxious was problematic for them. Fear of physical exertion (52.7%), understanding the cardiac event (51.6%), feeling depressed (46.8%), and family emotional reaction (46.8%) were also among the top five

most commonly identified areas of concern during this time point (refer to Table 10 for additional information).

When asked to respond to the same question regarding current needs (refer to Table 10) the highest priority concerns were feeling anxious (32.4%), feeling depressed (24.9%), fear of physical exertion (23.1%), financial impact (21.5%), and concerns about becoming a “burden” (20.3%).

Table 10

Most Commonly Identified Psychosocial Needs

Problematic Psychosocial Need	Immediately Post-SCA		Current	
	Ranking	Percentage	Ranking	Percentage
Feeling Anxious	1	63.0	1	32.4
Fear of Physical Exertion	2	52.7	3	23.1
Understanding the Event	3	51.6	7	17.1
Feeling Depressed	4	46.8	2	24.9
Family Emotional Reaction	5	46.8	8	14.9
Feeling Confused	6	44.8	–	–
Driving/Transportation	7	43.6	–	–
Feeling Like “Damaged Goods”	8	42.7	6	20.2
Becoming a “Burden”	9	37.0	5	20.3
Returning to Work	10	35.2	–	–
Financial Impact	–	–	4	21.5
Sexual Concerns	–	–	9	14.4
Dependence Concerns	–	–	10	14.4

* Items among the top 10 most problematic across both time periods are bolded.

Feeling anxious. Anxiety was the most commonly reported concern for all SCA survivors in the first three months following their cardiac event (63.0% of the total sample) and in the current time period (32.4% of the total sample). Ongoing, problematic anxiety varied across time since cardiac arrest, with the highest rates of anxiety reported by survivors 0-2 years after the event (see Figure 1).

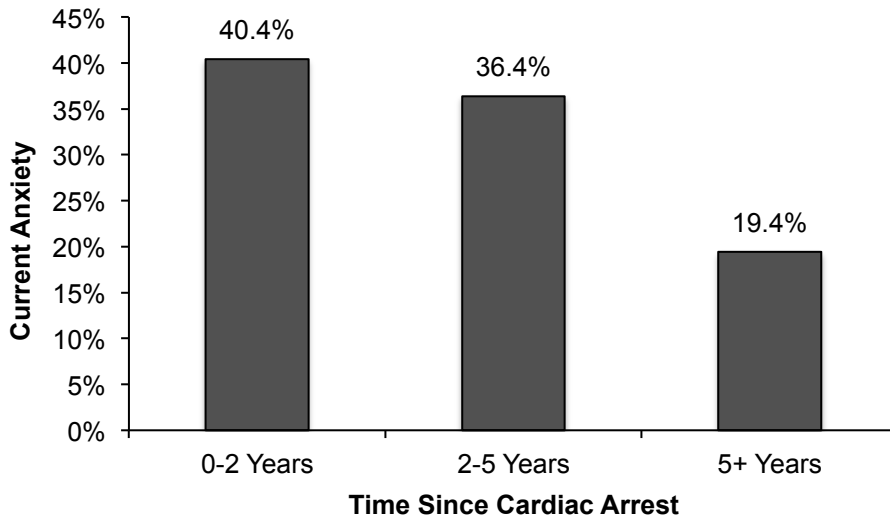


Figure 1. Occurrence of current, problematic anxiety.

Feeling depressed. Depression was the second most commonly reported concern for all SCA survivors in the current time period (24.9% of the total sample). Ongoing, problematic depression varied across time since cardiac arrest, with the highest rates of depression reported by survivors in the first 2 years and 2-5 years after the event (see Figure 2).

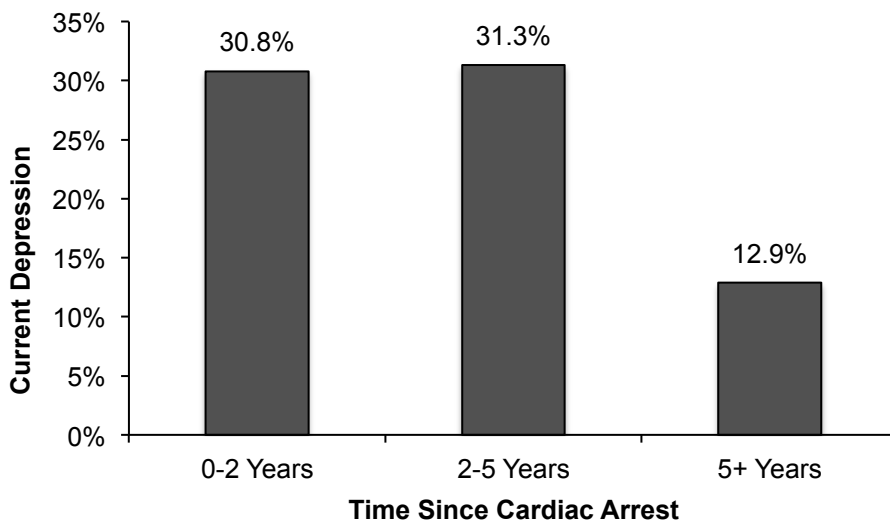


Figure 2. Occurrence of current, problematic depression.

Fear of physical exertion. Fear of physical exertion was the third most commonly reported concern for all SCA survivors in the current time period (23.1% of the total sample). Ongoing, problematic fear of physical exertion varied across time since cardiac arrest, with the highest rates of fear of physical exertion reported by survivors 2-5 years after the event (see Figure 3).

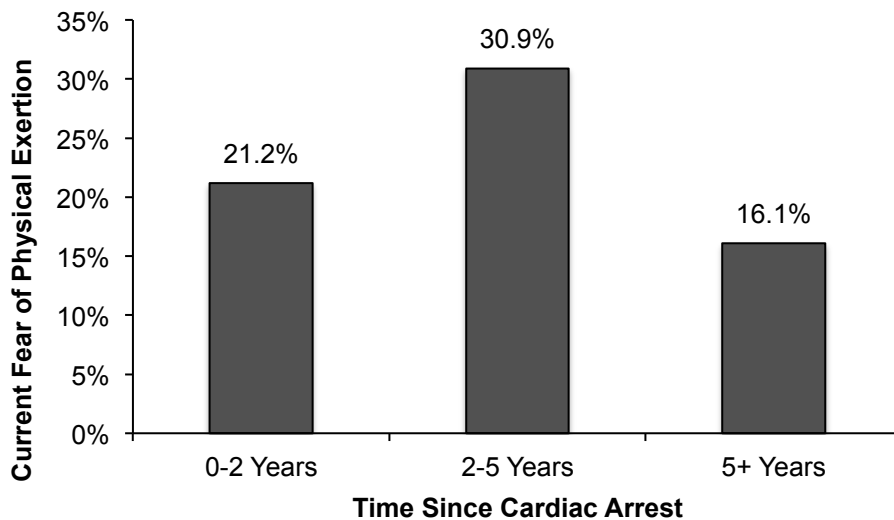


Figure 3. Occurrence of current, problematic fear of physical exertion.

Risk Factors for Psychosocial Problems

Group differences. As shown in Table 11, reported rates of anxiety in the acute time period differed significantly across groups, $\chi^2(2, N = 178) = 6.20, p = 0.045, V = .19$. Anxiety concerns were significantly more frequent among those with an ICD (68.1%) than among those without an ICD (47.1%), $\chi^2(1, N = 178) = 5.27, p = 0.022, OR = 2.39, 95\% CI [1.12, 5.12]$. The odds of reporting problematic anxiety in the first 3 months post-SCA are 2.4 times higher for those with an ICD than for those without an ICD. Among those with an ICD, whether or not they had a history of shocks did not

significantly affect the presence of anxiety concerns, $\chi^2(1, N = 144) = .98, p = 0.32, OR = 1.43, 95\% CI [.70, 2.92]$.

As shown in Table 11, patient report of problematic depression, $\chi^2(2, N = 180) = 2.64, p = 0.27, V = .12$, and concerns related to fear of exercise, $\chi^2(2, N = 182) = 3.12, p = 0.21, V = .13$, did not differ significantly across groups in the acute time period.

Table 11

Acute Group Differences

<u>Problematic Psychosocial Need</u>	<u>No ICD</u>	<u>ICD, No Shock</u>	<u>ICD, Shock</u>
Anxiety	47.1% ^A	64.6% ^B	72.3% ^B
Depression	35.3% ^A	48.1% ^A	52.3% ^A
Fear of Exercise	42.9% ^A	50.6% ^A	60.6% ^A

* If groups have the same superscripts, they do not differ significantly.

As shown in Table 12, both problematic anxiety, $\chi^2(2, N = 176) = 9.60, p = 0.008, V = .23$, and fear of physical exertion, $\chi^2(2, N = 176) = 9.35, p = 0.009, V = .23$, differed significantly across groups in the current time period. Reported concerns related to anxiety were significantly more frequent among those with an ICD (36.8%) than among those without an ICD (12.5%), $\chi^2(1, N = 176) = 7.06, p = 0.008, OR = 4.08, 95\% CI [1.36, 12.26]$. The odds of experiencing anxiety are 4.1 times higher for those with an ICD when compared to those without an ICD.

Reported concerns related to fear of exercise were significantly more frequent among those with an ICD (28.0%) than among those without an ICD (6.1%), $\chi^2(1, N = 176) = 7.09, p = 0.008, OR = 6.02, 95\% CI [1.38, 26.33]$. The odds of experiencing fear of physical exertion were 6.0 times higher for those with an ICD compared to those without an ICD. ICD shock history did not significantly affect the frequency of

problematic anxiety, $\chi^2(1, N = 144) = 2.39, p = 0.12, OR = 1.71, 95\% CI [.86, 3.30]$, or fear of physical exertion, $\chi^2(1, N = 143) = 2.04, p = 0.15, OR = 1.71, 95\% CI [.82, 3.56]$.

As shown in Table 12, reported rates of problematic depression did not differ significantly across groups in the current time period, $\chi^2(2, N = 175) = .68, p = 0.71, V = .06$.

Table 12

Current Group Differences

<u>Problematic Psychosocial Need</u>	<u>No ICD</u>	<u>ICD, No Shock</u>	<u>ICD, Shock</u>
Anxiety	12.5% ^A	31.2% ^B	43.8% ^B
Depression	21.9% ^A	27.5% ^A	22.2% ^A
Fear of Exercise	6.1% ^A	23.1% ^B	33.8% ^B

* If groups have the same superscripts, they do not differ significantly.

Gender differences. As shown in Table 13, reported concerns related to anxiety, depression, and fear of physical exertion were significantly more frequent among women in the first 3 months following SCA than among men. Reported rates of problematic anxiety were significantly more frequent among women (79.5%) than among men (50.0%), $\chi^2(1, N = 183) = 17.03, p = 0.000, OR = 3.88, 95\% CI [2.00, 7.52]$. The odds of having anxiety concerns were, among women, 3.9 times higher than among men.

Concerns about depression were significantly more frequent among women (57.1%) than among men (38.6%), $\chi^2(1, N = 185) = 6.32, p = 0.012, OR = 2.12, 95\% CI [1.18, 3.82]$. The odds of having anxiety concerns were, among women, 2.1 times higher than among men in the acute period following SCA.

Reported concerns related to fear of physical exertion were significantly more frequent among women (63.1%) than among men (44.7%), $\chi^2(1, N = 187) = 6.31, p =$

0.012, $OR = 2.12$, 95% CI [1.18, 3.82]. Thus, the odds of having anxiety concerns were 2.1 times higher among women than among men in the first 3 months post-SCA.

Table 13

Acute Gender Differences

<u>Problematic Psychosocial Need</u>	<u>Men</u>	<u>Women</u>
Anxiety	50.0% ^A	79.5% ^B
Depression	38.6% ^A	57.1% ^B
Fear of Exercise	44.7% ^A	63.1% ^B

* If groups have the same superscripts, they do not differ significantly.

As seen in Table 14, anxiety concerns were significantly more frequent among women (41.5%) than among men (25.3%), $\chi^2(1, N = 181) = 5.37$, $p = 0.021$, $OR = 2.10$, 95% CI [1.11, 3.94], in the current time period. The odds of reporting problematic anxiety were, among women, 2.1 times higher than among men. Neither depressive concerns, $\chi^2(1, N = 180) = .37$, $p = 0.55$, $OR = 1.23$, 95% CI [.63, 1.52], nor fear of physical exertion, $\chi^2(1, N = 181) = 1.11$, $p = 0.29$, $OR = 1.45$, 95% CI [.72, 2.89], were significantly different among women than among men.

Table 14

Current Gender Differences

<u>Problematic Psychosocial Need</u>	<u>Men</u>	<u>Women</u>
Anxiety	25.3% ^A	41.5% ^B
Depression	23.2% ^A	27.2% ^A
Fear of Exercise	20.2% ^A	26.8% ^A

* If groups have the same superscripts, they do not differ significantly.

CHAPTER V: DISCUSSION

Very little is known about the psychosocial outcomes of SCA survivors as most individuals have been studied in single center samples and mortality rates are incredibly high for this patient group. The current study, with access to a large national sample of SCA survivors, described the impact of SCA on patient perspectives of general health, emotional health, and QOL. Emotional health functioning was reported to be the most susceptible to decline post-SCA, and was also the most problematic current health functioning area. Additionally, the project identified the most relevant psychosocial needs of SCA survivors across time since the cardiac event. Concerns related to anxiety, depression, and exercise are relevant in both the acute and long-term periods. This information about health outcomes and psychosocial needs of SCA survivors will aid in clinical care, patient-centered research efforts, and protocol specialization for this patient population.

Health Functioning

The current project demonstrated that most SCA survivors report consistent or desirable changes in health functioning following their cardiac event. However, a significant minority of patients indicated decline in general health (16%), emotional health (18%), and QOL (11.1%). These data suggest that more patients reported that their emotional health worsened after experiencing a SCA when compared with general health and QOL ratings. Increased understanding of SCA survivor psychosocial needs may allow for focused interventions, potentially improving patient emotional health.

Psychosocial Needs

Considering the published literature regarding psychologic outcomes for ICD recipients, it was anticipated that concerns related to anxiety, depression, and exercise-related fear would emerge as problematic areas for SCA survivors in the current study. Consistent with these hypotheses, results indicate that concerns related to anxiety, depression, and fear of physical exertion are immediate and long-term high-priority issues for SCA survivors. Current study findings are consistent with previous research regarding psychological health of ICD recipients and SCA survivors (e.g., Ford et al., 2011; Shaaf et al., 2013) in that study participants reported elevated rates of both anxiety and depression when compared with the general population. In the United States, there is a 12-month prevalence of 18.1% for anxiety disorders and a 12-month prevalence of 9.5% for mood disorders (Kessler, Chiu, Demler, & Walters, 2005). However, the previous study conducted by Shaaf and colleagues (2013) estimated that anxiety was an area of concern for 13%-42% of SCA survivors. Thus, descriptive analyses in the present study indicate that SCA survivors may experience even higher rates of anxiety, specifically in the first three months post-SCA, than have been previously reported.

More than half of the study sample retrospectively self-reported difficulty with feeling anxious (63%), fear of physical exertion (53%), and understanding the cardiac event (52%) in the first several months following SCA. Anxiety was the most frequently reported psychosocial need in this acute period, with over 60% of SCA survivors noting problems in this area. Greater than 42% of SCA survivors recalled problems with feeling depressed, family/emotional reaction, feeling confused, driving/transportation,

and feeling like “damaged goods.” More than a third of the sample stated that becoming a “burden” and returning to work were relevant issues in the acute time period.

Anxiety was a concern for 32.4% of SCA survivors in the current time period, with the highest rates occurring in the first two years after SCA (40.4%). Although problematic anxiety dissipated over time, approximately 20% of study participants related that anxiety continued to be problematic even five or more years after the cardiac event. Concerns related to feeling confused, driving/transportation, and returning to work were not among the most commonly identified current psychosocial needs. However, greater than 20% of SCA survivors reported current problems with feeling depressed, fear of physical exertion, becoming a burden, and feeling like damaged goods. Over 30% of survivors reported feeling depressed in the first five years post-SCA, with approximately 13% of the sample experiencing difficulty in this area after five or more years. Fear of physical exertion was most prominent two to five years post-SCA, with approximately 30% of the sample reporting fear of exercise. After five or more years, 16.1% of study participants related ongoing fear of physical exertion.

Group differences. Contrary to researcher predictions, individuals who had received an ICD were at greater risk for reporting problematic anxiety in the first several months following SCA, as well as in the current time period. ICD recipients were also more likely to report problematic fear of physical exertion in the current time period. Secondary treatment type was not a risk factor for problematic depression at either time point, or for fear of exercise in acute timeframe.

Surprisingly, SCA survivors who had received an ICD after their cardiac event and had been shocked by their device were at no greater risk for reporting anxiety, depression, or fear of physical exertion as problematic in either the acute or current time periods when compared with ICD recipients who had not experienced ICD shock. This may, in part, be explained by the fact that number of ICD shocks were not accounted for in the present analyses.

Gender differences. Consistent with current study hypotheses, significant gender differences were observed across all psychosocial needs examined in the acute time period. Thus, women were at much greater risk for reporting problems with anxiety, depression, and fear of exercise in the first several months following SCA. However, in the current timeframe, significant gender differences were only observed regarding problematic anxiety, with women being at greater risk. No gender differences were observed during this time period for reported rates of depression or fear of physical exertion.

Limitations

A major limitation of the study is that data were gathered via a self-report survey and collected electronically, requiring participants to have both internet and email access. Important to note is that data were collected at one time period; acute psychosocial needs were a product of retrospective patient self-report. Thus, it is difficult to determine accuracy of retrospective self-report data. Due to demographic similarities among SCA survivors included in this project, generalizability is somewhat limited. Participants were mostly Caucasian and reported high levels of education and annual household income. Information was not gathered as to whether SCA survivors

in the study had received psychologic care or participated in cardiac rehabilitation. Interestingly, the demographic information provided by study participants suggests that access to healthcare resources would be relatively high. Yet, a significant proportion of SCA survivors surveyed reported psychosocial difficulties related to mental health functioning. Collectively, these possible selection biases should be considered when interpreting study results.

Future Implications

Current findings indicate that service initiatives for SCA survivors may require shifting focus from broad health concerns to acute and long-term psychosocial needs. With the advent of new technology (i.e., introduction of the ICD in the 1980s and 1990s) recovery from SCA is now akin to coping with chronic illness. The current study had demonstrated that SCA survivors have varied concerns, some of which may be specific to time since SCA. Many SCA survivors could benefit from access to psychological care and physical therapy in the several months following their SCA, as well as in the months and years that follow. Clinically, screening SCA survivors for anxious and depressive symptoms is supported by study findings. The occurrence of anxiety and depression in this population is a point of concern, especially with the knowledge that individuals with concurrent mental health issues tend to have poorer medical outcomes (e.g., Ladwig et al., 2008; McGrady et al., 2009).

It is clear that SCA survivors have specific rehabilitation needs. Thus, specialized programming for this patient group should be a priority in maximizing positive health outcomes. The current study has outlined potentially important psychosocial concerns that could be addressed immediately following SCA, as well as those that persist over

time. Across all time periods, anxiety, depression, and exercise-related fear are the most commonly reported problems for SCA survivors. Additional concerns that persisted from time to SCA to current report included understanding the cardiac event, family emotional reaction, feeling like “damaged goods”, and becoming a “burden.”

It is important to note that in the first several months post-SCA, women are more likely to report concerns about anxiety, depression, and fear of physical exertion. Additionally, ICD recipients are at higher risk for reporting problematic anxiety in the acute period. As well as general concern about anxiety, depression, and fear of exercise across time, SCA survivors have pragmatic concerns related to general confusion, driving and transportation issues, and returning to work in the first several months post-SCA.

In the long-term period, women are at greater risk for experiencing problems with anxiety when compared to men, as are ICD recipients when compared to SCA survivors without an ICD. ICD recipients are also at greater risk for experiencing fear of physical exertion. Across the present sample, SCA survivors also had long-term needs related to financial, sexual, and dependence concerns.

As evidenced by patient-reported difficulty with feelings of anxiety, depression, fear of exercise, understanding of the SCA, and social impact during the first three months post-SCA, further research is warranted regarding combined interventions for this patient group. Problematic anxiety, depression, and fear of physical exertion can be present for many years after SCA, suggesting that interventions may be most successful if time since the most recent cardiac event is considered. Due to reports of ongoing fear of exercise, especially as expressed by ICD recipients (see Table 12),

SCA survivors would likely benefit from education about SCA, ICD implantation, and exercise safety. Additional areas of impact include subsequent exercise training, along with psychological screening with appropriate referral and psychoeducation.

In addition to exploration of appropriate intervention models for SCA survivors, areas of future research should consider the potential relationship between anxiety and exercise-related fear, and how feelings of anxiety or depression may specifically impact patient health functioning, as well as difficulty with other psychosocial factors.

SCA survivors in the present study endorsed psychosocial needs similar to those observed by Ford and colleagues (2011) in research with ICD recipients. According to their research, ICD patients with depressive symptoms reported concerns about device dependence and the perception of others. ICD patients with anxious symptomology indicated concerns about the ICD, anxiety about future defibrillation and subsequent exercise avoidance (Ford et al., 2011). Current findings demonstrate that SCA survivors have concerns about independence, perception of others, being burdensome, feeling damaged, and physical activity. Although many participants in the current study were ICD recipients, approximately 20% had not received this form of treatment. Thus, it is possible that the cardiac event itself has a significant impact on patient functioning and SCA survivors have a similar, but distinct needs profile. Exploration of posttraumatic stress disorder in this patient population, with SCA conceptualized as a traumatic, life-threatening event is an area for further study.

Conclusions

The current study indicated that while many SCA survivors have favorable outcomes, some report decreased health functioning (23.4% - 33.3%) and many

experience psychosocial difficulties during recovery. Current findings indicate that a great number of patients report problematic anxiety (32.4% - 63%), fear of physical exertion (23.1% - 52.7%) and depression (24.9% - 46.8%), demonstrating that these are significant obstacles for many SCA survivors. Current findings may assist providers in identification of comorbid mental health conditions in SCA survivors, understanding that patient needs may change given the passage of time since SCA, and underscore the importance of referral needs in this population.

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APPENDIX A: IRB DOCUMENTATION



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office 252-744-2914 · Fax 252-744-2284 · www.ecu.edu/irb

Notification of Exempt Certification

From: Social/Behavioral IRB
To: [Samuel Sears](#)
CC:
Date: 8/1/2012
Re: [UMCIRB 12-000186](#)
COPE 2012: The Sudden Cardiac Arrest Association Survey of Attitudes and Experiences of a Cardiac Event

I am pleased to inform you that your research submission has been certified as exempt on 8/1/2012. This study is eligible for Exempt Certification under category #2.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

The UMCIRB office will hold your exemption application for a period of five years from the date of this letter. If you wish to continue this protocol beyond this period, you will need to submit an Exemption Certification request at least 30 days before the end of the five year period.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00000781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418 IRB00004971

APPENDIX B: PARTICIPANT SURVEY

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS PURPOSE:

The current survey was constructed to understand the needs of heart patients in terms of education, support, and training related to their heart condition. The goal of this work is to design programs to assist heart patients and their families in being knowledgeable and confident in dealing with their heart disease.

Ultimately, the goal of this work is to provide tools and strategies that effectively target and address survivor needs.

PURPOSE: THE PURPOSE OF THIS SURVEY IS TO GAIN A BETTER UNDERSTANDING OF THE PATIENT EXPERIENCE FOLLOWING SUDDEN CARDIAC ARREST

The survey you are about to take is part of a medical research study on patient experiences after sudden cardiac arrest or a cardiac event. As such, we need your consent to take part in this study.

On the next screen you will see a detailed consent which tells you more about the survey and ensures your total confidentiality.

Please read the consent on the next page and select the "I Agree" at the bottom if you'd like to continue.

CONSENT DOCUMENT

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

***1. Title of Research Study: COPE 2012: The Sudden Cardiac Arrest Association Survey of Attitudes and Experiences of Sudden Cardiac Arrest**

Principal Investigator: Samuel F. Sears, PhD

Institution: East Carolina University

Address: 115 Rawl Building. Greenville, NC 27858-4353

Telephone #: (252) 328-6118

Researchers at East Carolina University (ECU) and the Sudden Cardiac Arrest Association (SCAA) study problems in society, health problems, environmental problems, behavior problems and the human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need the help of volunteers who are willing to take part in research.

Why is this research being done?

The purpose of this research is to assess and gather information in three areas: patient needs assessment to determine what kind of support would have been helpful in the first few days/weeks after a cardiac event vs. current needs months or years after an event; establish the psychological impact caused by a cardiac event and the impact survivors are experiencing currently as a long-term survivor; and, demographics of patients. The decision to take part in this research is yours to make. By doing this research, we hope to learn the needs of cardiac patients in terms of education, support and training related to their condition and to use this knowledge to provide tools and strategies that effectively target and address survivor needs.

Why am I being invited to take part in this research?

You are being invited to take part in this research because you are a member of the SCAA therefore may have experienced a personal cardiac event. If you volunteer to take part in this research, you will be one of about 1,000 people to do so nationally.

Are there reasons I should not take part in this research?

I understand that I should not volunteer if I have not personally experienced a cardiac event or am under the age of 18.

What other choices do I have if I do not take part in this research?

You can choose not to participate.

Where is the research going to take place and how long will it last?

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

The research procedures will be conducted electronically. The total amount of time it will take to complete this survey will be about 20 minutes although some people complete it more quickly while others take longer.

What will I be asked to do?

You are being asked to complete a survey that includes questions about demographics, general health, educational needs, adherence to medication, stress, anxiety, and the experience of a cardiac event. By asking these questions, we hope to learn the needs of cardiac patients in terms of education, support and training related to their condition and to use this knowledge to provide tools and strategies that effectively target and address survivor needs.

What possible harms or discomforts might I experience if I take part in the research?

It has been determined that the risks associated with this research are no more than what you would experience in everyday life. However, it is possible you may experience mild discomfort from answering the questionnaires and discussing potentially difficult topics related to their cardiac event.

What are the possible benefits I may experience from taking part in this research?

We do not know if you will get any benefits by taking part in this study. This research might help us learn more about the needs of cardiac patients in terms of education, support and training related to their condition and to use this knowledge to provide tools and strategies that effectively target and address survivor needs. There may be no personal benefit from your participation but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?

We will not pay you for the time you volunteer while being in this study

What will it cost me to take part in

I Agree

I DO NOT Agree

Before taking this survey, please keep in mind that all answers will be anonymous and will not be traced back to you individually.

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

2. Date survey completed

3. Are You?

- Male
- Female

4. When were you born? Month/Year

5. What is your level of education?

- Grade School
- Some High School
- Some College
- College Graduate
- Graduate School
- Technical School
- Don't Know/Refused

6. For demographic purposes only, can you please tell me your race/ethnicity?

- White
- Black / African-American / Caribbean-American
- Hispanic / Latino
- Asian
- Arab
- Other
- Don't know / refused

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

7. Which category best describes your yearly household income? Include all sources of income, and all people living in your home.

- \$0 to \$9,999
- \$10,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 and above
- Don't know / refused

8. What was the date of your most recent sudden cardiac event?

9. Select the category that best fits with the time point when your most recent cardiac event occurred.

- less than one month ago
- between 1 and 6 months ago
- between 6 months ago and 1 year
- 1 to 2 years ago
- between 2 and 5 years ago
- greater than 5 years ago

10. After your sudden cardiac event, were you visited by, or did you receive information from, Mended Hearts?

- Yes
- No

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

11. Today, how would you describe your general health?

- excellent
- very good
- good
- fair
- poor

12. Overall, how much has the cardiac event affected your general health? Is your general health now...

- much better
- somewhat better
- about the same
- somewhat worse
- much worse

13. Today, how would you describe your quality of life?

- excellent
- very good
- good
- fair
- poor

14. Overall, how much has the cardiac event affected your quality of life? Your quality of life is now...

- much better
- somewhat better
- about the same
- somewhat worse
- much worse

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

15. Today, how would you describe your general emotional health?

- excellent
- very good
- good
- fair
- poor

16. Overall, how much has the cardiac event affected your emotional well-being? Is your emotional well-being now...

- much better
- somewhat better
- about the same
- somewhat worse
- much worse

17. Today, how would you describe your relationship with your family?

- excellent
- very good
- good
- fair
- poor

18. Overall, how much has the cardiac event affected your relationship with your family? Is your relationship now...

- much better
- somewhat better
- about the same
- somewhat worse
- much worse

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

19. How would you rate your sense of security with your overall health on a scale of 1 to 7, where 7 means “very secure” and 1 means “not at all secure”?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7

20. Below we have listed a set of potential topics related to adjustment to your cardiac event IN THE FIRST THREE MONTHS following your cardiac event. Please answer these questions with a focus on what your needs were during the first three months following your event.

If YES to “was this a problem for you” “would you rate this topic...” If NO, proceed to next area of interest

	Was this a problem for you?		How high of a priority is this for education? Very Low		Very High
	Yes	No	Very Low		
Following medical recommendations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Communicating with health care providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Feeling Like “Damaged Goods”- Self image	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Feeling Depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Feeling Anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Feeling Confused	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Understanding your cardiac event	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Returning to Work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Doing Household Activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Filing for Disability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Alcohol/substance Use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Fear of Physical Exertion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Driving/Transportation issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Financial impact	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Sexual Concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Telling Others what happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Family Emotional Reaction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
Communication concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

Dependence concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concerns about becoming a "burden"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frustration of over-protectiveness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling under-supported by family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Following doctor's orders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical decision making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding lifestyle changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. Please describe needs that you had following your cardiac event that you felt were not met that were not mentioned in this survey. This might include ways you wish your experience could have been different, material needs, or assistance/educational needs.

22. Which ways do you prefer to receive education about the above areas of interest?

Choose all that apply.

- Mobile phone application
- Written information
- Pamphlets
- Website
- Workshop
- Primary Care Physician

Other (please specify)

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

24. In this next section, we would like you to think about what your needs are NOW.

If YES to “is this a problem for you” ask “would you rate this topic...” If NO, proceed to next area of interest

	Is this a problem for you?		How high of a priority is this for education? Very Low		Very High
	YES	NO			
Following medical recommendations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communicating with health care providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling Like “Damaged Goods”- Self image	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling Depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling Anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling Confused	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Understanding your cardiac event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Returning to Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing Household Activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Filing for Disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol/substance Use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fear of Physical Exertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Driving/Transportation issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial impact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual Concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telling Others what happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family Emotional Reaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dependence concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns about becoming a “burden”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frustration of over-protectiveness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling under-supported by family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Following doctor’s orders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical decision making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Understanding lifestyle changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Understanding medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SCAA SURVIVORS SURVEY AND NEEDS ANALYSIS

67. If you answered yes, your biological family has a history of heart disease, what type?

- coronary heart disease
- hypertrophic cardiomyopathy
- dilated cardiomyopathy
- long QT syndrome or other channelopathy
- valvular heart disease
- congenital heart disease
- Other

If you answered Congenital or Other (please specify)

68. Do you participate in organized sports activities after your sudden cardiac arrest?

- Yes
- No

If yes (please specify)

69. Was your participation in sports approved by your physician?

- Yes
- No

70. Do you have an ICD

- Yes
- No

71. If you have an ICD, what was the date of your first implant? Month/Day/Year

72. Have you ever been shocked by your ICD?

- Yes
- No

