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# Arrhythmogenic Right Ventricular Cardiomyopathy: From Surviving to Thriving

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# Arrhythmogenic Right Ventricular Cardiomyopathy: From Surviving to Thriving

## **Abstract**

Arrhythmogenic right ventricular cardiomyopathy is a life-threatening, inherited disease, and a leading cause of sudden cardiac death in young, otherwise healthy adolescents and adults. Through the advances of modern technology, those who receive this once-devastating diagnosis, now stand an excellent chance at survival through the use of medication and a life-saving device called an implantable cardioverter defibrillator. However, living under the peril of life-threatening arrhythmias and life-saving shocks can cause considerable psychosocial disturbances, and potentially contribute to diminished medical outcomes. Though living with a chronic, life-threatening illness poses many challenges, it is both possible and imperative that we provide those dealing with such a diagnosis the skills necessary to go beyond surviving to thriving. Borrowing heavily from the research and collaborative efforts from the field of positive psychology, Civilian Resilience Training is an empirically-informed set of interventions designed to protect patients with these diagnoses against psychopathology and promote their ability to be resilient in the face of the significant health crises that inevitably arise as a result of their disease, as well as the lesser day-to-day crises life brings. The program is designed to help diminish the negative effects of diagnosis, reduce disease symptomology, and encourage effective coping with defibrillator intervention, while enhancing psychosocial well-being and flourishing. It is hoped this program will serve as an interventional model to build flourishing among patient populations with other chronic diseases as well.

## **Keywords**

Arrhythmogenic Right Ventricular Cardiomyopathy, ARVD/C, Inherited Arrhythmogenic Disease, Implantable Cardioverter Defibrillator, ICD, Chronic Disease, Resilience, Flourishing, Positive Psychology

Arrhythmogenic Right Ventricular Cardiomyopathy:

From Surviving to Thriving

Jennifer Cory

University of Pennsylvania

A Capstone Project Submitted

In Partial Fulfillment of the Requirement for the Degree of

Master of Applied Positive Psychology

Advisor: Leona Brandwene

August 19, 2015

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From Surviving to Thriving

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Capstone Project

Master of Applied Positive Psychology

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August 19, 2015

## Abstract

Arrhythmogenic right ventricular cardiomyopathy is a life-threatening, inherited disease, and a leading cause of sudden cardiac death in young, otherwise healthy adolescents and adults. Through the advances of modern technology, those who receive this once-devastating diagnosis, now stand an excellent chance at survival through the use of medication and a life-saving device called an implantable cardioverter defibrillator. However, living under the peril of life-threatening arrhythmias and life-saving shocks can cause considerable psychosocial disturbances, and potentially contribute to diminished medical outcomes. Though living with a chronic, life-threatening illness poses many challenges, it is both possible and imperative that we provide those dealing with such a diagnosis the skills necessary to go beyond surviving to thriving. Borrowing heavily from the research and collaborative efforts from the field of positive psychology, Civilian Resilience Training is an empirically-informed set of interventions designed to protect patients with these diagnoses against psychopathology and promote their ability to be resilient in the face of the significant health crises that inevitably arise as a result of their disease, as well as the lesser day-to-day crises life brings. The program is designed to help diminish the negative effects of diagnosis, reduce disease symptomology, and encourage effective coping with defibrillator intervention, while enhancing psychosocial well-being and flourishing. It is hoped this program will serve as an interventional model to build flourishing among patient populations with other chronic diseases as well.

### Acknowledgements

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### **Preface: Sixty Months**

In 2010, while out for a long distance run, I collapsed. My strong and healthy heart had gone into a ventricular tachycardia (VT), recorded at 285 beats per minute. As the gurney I was on was pushed through the bay doors of the nearest hospital, I heard the words “code blue in emergency,” announced over an intercom. I was praying that page wasn’t for me, but in my gut I knew otherwise; I could feel my life slipping away.

One defibrillation, two hospital transfers, 6 days, and a myriad of tests later, I was diagnosed with Arrhythmogenic Right Ventricular Cardiomyopathy (herein referred to as ARVC) and received an implantable cardioverter defibrillator (ICD). I was told by every staff member I encountered in the course of that week (and for months to follow) how lucky I was to have survived. And I was. Grateful and dazed, I left NYU-Langone Medical Center on a beautiful Saturday morning. It was time to go home and resume my previously scheduled life.

Shortly after my diagnosis I would learn that my mother, father, siblings and children would all need to be screened for the same disorder — turns out ARVC is an inheritable disease, with more than 60% of cases traceable to a genetic anomaly. Weeks after my mother’s tests returned positive, while treatment strategies were being explored and decisions about what to do next were being discussed, my mother died from a ventricular fibrillation— the worse case scenario in ARVC, an event I had narrowly escaped six months earlier. It was Christmas day 2010; she died in my arms. Shortly thereafter I would discover that my then teenaged sons were also genetically positive. Life as I knew it was over.

I have spent the years since that time trying to help my now young adult children navigate the implication of this news in their own lives, while living with the reality of ARVC as

both an individual patient and as a family disease. In the sixty months since that fateful day I have said goodbye to my mother, nursed my best friend to the end of her life, buried my father, confronted breast cancer, been shocked by my ICD, pursued a second graduate degree, become a grandmother and empty-nester, and turned 50, all while managing the daily demands of life. Today I know, firsthand, what it means to live with a chronic condition. As a psychotherapist I know, too, what comorbidity and the accumulation of stressors can do to an individual and family already taxed with the uncertainty that chronic or inherited illness can bring, no matter how resilient they may be to the 'ordinary' challenges of life.

There are the heroes walking among us, those facing the difficulties of living with life threatening illness and chronic disease in the midst of the twists and turns of larger life, doing their best to function under the confluence these circumstances create. Such a life requires bravery and determination, resourcefulness and resiliency to get up and face the day ahead when, before your feet hit the ground, you've got the weight, the uncertainty, and the struggle of an illness to contend with. Armed with an insider's perspective, I can report: it's harder than it looks. Despite all of the empathic understanding, professional training, and life skills I came to this experience with, I could not imagine what the ride would feel like from inside the vehicle of chronic illness until I took my seat and strapped in. It is likely that no clinician can, regardless of how many patients they have seen or how deep their compassion runs.

Today I understand better than ever how delicate the balance can be, and how essential the need for strategies are where the potential for accumulating stressors and resulting risks for anxiety, depression, and compromised functioning run high. My decision to study the science of human flourishing, and to make the intersection of illness and comprehensive well-being the



subject of my capstone, are a result of this acquired knowledge and subsequent awareness of how inadequately the psychosocial needs of the chronically ill are presently being addressed. I am passionate about helping individuals and their families living with chronic illness move from enduring to flourishing, from surviving to thriving. I am also committed to helping the helpers, those physicians, nurses, mental health practitioners, genetic specialists and researchers, who care so deeply and are dedicated to seeing their patients function as well as possible in the face of illness, better understand the perils and pitfalls, as well as the opportunities not only in managing the physical symptoms of chronic disease, but in cultivating a meaningful and flourishing life in the process.

Advances in modern medicine have enabled people to survive what would otherwise have been certain death in the case of many diseases. What has been missing is the way to help these survivors thrive. According to Atul Gawande (2014), "We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive" (p. 258).

This capstone is about paving the way for that journey from surviving to thriving. My objective is to help those dealing with chronic illness (and the healthcare professionals who care for them) move beyond the goal of *not dying* to the goal of *optimal living*. By broadening the scope of what it means to 'successfully' adapt, and building a bridge to comprehensive well-being in the midst of living with chronic disease, these imperative twin-goals can and must be realized.

## I. Introduction

I have been interested in the study of human resilience for the entirety of my professional career, particularly regarding how people triumph over adversity. As a psychotherapist, I work with clients facing every kind of hardship imaginable, and understand well the role resilience plays in helping people successfully cope with everything from the unanticipated to the catastrophic. For many the 'crisis' is not a single, aberrant event from which they will eventually emerge, but ongoing trials, often striking the young or those in the prime of life by way of chronic, degenerative diseases. **While there is a long list of chronic illnesses and/or life threatening ailments from which to choose to make a case for applying positive psychology (research and interventions) to the larger field of healthcare, herein I will focus on a single population who stand to benefit from such a collaboration—those dealing with one of the leading causes of sudden cardiac death (SCD): individuals and families diagnosed with Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC).**

ARVC (also referred to as ARVD/C), was initially diagnosed as a dysplasia of the heart and is today recognized as a cardiomyopathic disorder belonging to a class of illnesses known as inherited arrhythmogenic diseases (IAD). In this paper I will refer to ARVC and IAD interchangeably, with some information specifically directed toward ARVC populations (particularly where implantable cardioverter defibrillators are concerned). Given the complex nature of this diagnosis and its accompanying medical interventions, many of the terms herein are abbreviated consistent with medical vernacular in order to improve readability. Please refer to Appendix A for a quick-reference list of these abbreviations.

Diagnosis of the first identified ARVC carrier in a family (the proband) often occurs as the result of the sudden cardiac death (SCD) of a young, otherwise healthy individual, (average age of event is between 18-40) (Anderson, 2006; James et al., 2012; McNally & MacLeod, Dellefave-Castillo, 2005/2014). Once diagnosis of an IAD has been established in a family, all first and second degree relatives of the proband are referred for genetic and cardiac testing to search for evidence of structural and/or molecular anomalies that can lead to fatal arrhythmias (Fowler, Cerrone, Napolitano, & Priori, 2010). Those who meet the criteria for diagnosis are typically placed on beta blockers and/or antiarrhythmic drugs; in the U.S. the majority of ARVC patients will also receive an implantable cardioverter defibrillator (ICD) (Anderson, 2006; McNally et al., 2005/2014).

While implantation of an ICD is the best line of defense against SCD and/or sudden cardiac arrest (SCA), living with a defibrillator and the uncertainty of a progressive and potentially fatal condition can be particularly burdensome to young, otherwise healthy individuals and their families (Day, 2012; James et al., 2012). Diminished quality of life has been reported among inherited cardiomyopathy-ICD recipients, with subsequent anxiety disorders and depression correlated to symptom presentation, changes in life function, and number of shocks experienced (Sears & Conti, 2002). The outcome is particularly grim for younger and female ICD patients, who disproportionately experience shock phobias and clinical levels of posttraumatic stress, the result of a symptom-reaction-anxiety loop (elevating the release of catecholamines thereby increasing the potential for arrhythmias), which increases the potential for shock (van den Broek, Nyklíček & Denollet, 2009). Catastrophic cognitions

consistent with scores found in significant anxiety disorders are not uncommon among young ICD populations (Anderson, 2006; Sears & Conti, 2002).

Health is often erroneously defined as the absence of disease. However, this *deficit theory* is an inadequate measure of either mental or physical health (Keyes, 2007; Seligman, 2011a; Westerhof, & Keyes, 2010). Health cannot be conferred merely by what it is not, but must reflect the presence of something as well (Keyes, 2007; Ryff, 1989; Ryff & Singer, 1996). In 1854, Henry David Thoreau (1854/1971) wrote, “the mass of men live lives of quiet desperation.” Here Thoreau was describing those who were neither suffering (overtly) nor flourishing, but rather trudging through the daily grind - the very definition of ‘languishing’. Research seems to corroborate his poetic and sad depiction, where barely one-fifth of the adult population in the U.S. qualifies as flourishing (Keyes 2002, 2003, 2004, 2007).

Studies using a 2-continua model of mental health and mental illness consistently show that adults and adolescents who present as having less than complete mental health (where mental health is defined as living with generativity, growth mindset, meaning, capacity to function optimally, and without mental illness) demonstrate depressed functioning, diminished psychosocial well-being, ineffective healthcare utilization, and reduced productivity (Keyes, 2002, 2006, 2007; Westerhof & Keyes, 2010). Languishing adults (those who do not meet clinical criteria for mental illness, nor demonstrate moderate or optimal levels of mental health) report higher levels of health limitation in daily living than their mentally ill though flourishing counterparts (Keyes, 2004, 2007). Further, one-third of U.S. adults will deal with mental illness at any given point in life from young adult to senior adulthood (Keyes, 2007), and 46.4% of all U.S. citizens will experience at least one mental disorder over the span of a lifetime (Kessler

2005). Only a small portion of those without diagnosable mental disorders qualify as mentally healthy (considered as flourishing) (Keyes, 2007).

In a mental illness/mental health continua, adults and adolescents who present with incomplete mental health are found to have significantly reduced physical, psychological, and social well-being (Ryff & Keyes, 1995), the results of which manifest in increased health impairment, reduced productivity, and greater burden to self and society. Mental health status, adjusted for sociodemographic variables, provides a strong predictor for chronic physical conditions such as arthritis, high blood pressure, stomach problems, back problems, and hay fever (Keyes, 2007). These are particularly important results to note when dealing with populations with underlying health challenges, who face the likelihood for accumulation of stressors (progression of disease, ICD discharge, health or device complications), in addition to normal life stressors, the results of which may significantly tax patient functioning (Turner & Lloyd, 1995).

With the relationship between physical health and mental health clearly established (Keyes, 2007; Ryff & Keyes, 1995), we can no longer afford to make distinctions nor ignore the impact of mental health on physical, psychological and social well-being. While modern medicine has made great strides in managing and eliminating physical disease, and in classifying and treating mental illness (Seligman, 2011a), too little attention has been paid to the need for human flourishing. When health is weighed in a more comprehensive way, not merely the absence of illness (Westerhof & Keyes, 2010; Keyes, 2007; Ryff & Keyes, 1995), healthcare providers must also consider how to accurately assess both mental illness *and* mental wellness in

order to help patients strive for more complete states of health even while living with chronic disease.

According to David Cutler (2004): “A population that lives long but is in poor health is not (much) better off than one with shorter but healthier life span” (p. 5). As advancements in healthcare and technology have extended life expectancy, so too must we advance comprehensive health across the lifespan. It is time to move beyond the pathogenic to a more holistic model, wherein health is not merely the absence (or management of) disease, but the presence of positive states of human capacity and functioning (Keyes, 2007; Seligman, 2011a; Seligman & Csikszentmihalyi). As long as we continue to make pathology the cutoff for assessing patient adaptation to chronic illness, we will always fall short of the higher goals of ‘health’ care.

We can do better for patients with ARVC. In this paper, I will review inherited arrhythmogenic disease and the preponderance of evidence that mental health status, even when remaining at subclinical levels for ‘diagnosable’ pathology, holds clinical relevance for the medical outcomes and overall well-being among this population. I will discuss how the standard course of treatment for ARVC - the implantable cardioverter defibrillator - brings unique challenges to the psychosocial functioning of these patients even while extending their lives, and will examine the psychological theories and evidence that support this theory. Further, the role of emotional resilience as an essential set of skills that buffer patients against psychological pathology, and their subsequent implications on medical outcomes, will be explored as well. Finally, I will propose a set of interventions, modeled after existing resilience interventions that have been operationalized successfully in other populations, that can be applied to build the

fortitude needed to see patients through a life with chronic illness. This empirically-informed approach, designed to protect the psychosocial well-being of individuals with ARVC while still extending and protecting their physical health, is the final, critical outcome of this paper.

## II. Inherited Cardiomyopathy & ARVC

Cardiomyopathy is a disease of the heart that interrupts the muscle from proper functioning, which may lead to sudden cardiac arrest (SCA) or sudden cardiac death (SCD). In SCA, the electrical system of the heart malfunctions (known as dysrhythmia), interrupting blood flow to major organs. Death can occur within minutes unless the rhythm disturbance is corrected, usually through defibrillation. Cardiomyopathy can be either acquired (through illness or disease), or inherited. Inherited cardiomyopathies are one of the primary causes of heart disease, affecting individuals across all age groups, often diagnosed in adolescence or young adulthood (herein defined as age 50 and younger) (Watkins et al., 2011). Identification of disease genes for inherited cardiomyopathies has profoundly changed the landscape of how this class of diseases is diagnosed and treated, and has led to reduced SCD (Fowler et al., 2010; Watkins et al., 2011). Such advances over the past twenty-five years have led to increased survival rates, longer life spans, and improved cardiac function.

ARVC is one of five types of inherited cardiomyopathy. Together, these arrhythmogenic disorders make up the leading causes of SCD among children and young adults (Fowler et al., 2010). ARVC occurs as the result of a disordered protein complex, causing fibrofatty replacement of the myocardium and interfering with electrical conductivity (McNally et al., 2005/2014). Estimated prevalence of this disorder is between 1:5000 and 1:7000 per 100,000 people. Once a proband is identified (either through autopsy, presentation with ventricular arrhythmia, or survival of a SCA) family members who are positive for ARVC but asymptomatic (known as silent carriers) can then be identified, leading to diagnosis and preventative treatment (Fowler et al., 2010; James et al., 2012).



Patients with ARVC typically present in mid-teens to early 40s, with a mean age of diagnosis of 31 (+/- 13; range 4-64 years) (McNally et al., 2005/2014). Syncope (fainting), premature ventricular contraction and/or ventricular arrhythmias may be among initial presenting symptoms, inspiring further investigation and ultimate diagnosis. However, the SCD of an otherwise healthy young person is often the first sign of the disease in a family (James et al., 2012). Sixty percent of ARVC cases can be traced to genetic mutations in the cardiac desmosome (Fowler et al., 2010; James et al., 2012). Of the 350,000 sudden cardiac deaths in the U.S. every year, the majority are the result of prior myocardial or coronary artery disease; approximately 20 percent of those (or up to 70,000 deaths a year) are caused by IAD, and one-fifth of that number by ARVC specifically (S. Fowler, personal communication, July 10, 2015). Out of hospital survival rates for SCA of all origins are extremely poor. Ventricular fibrillation, the most serious type of arrhythmia-caused SCA, has an out of hospital survival rate of approximately 5% (Sen-Chowdhry & McKenna, 2006).

For many individuals and families, being diagnosed with an IAD will be a pivotal life experience (Day, 2012). For some it will come as a devastating blow negatively impacting all aspects of life, including overall general health (Hamang et al., 2010). For others the initial disruption of diagnosis will eventually recede, to be replaced with a return to homeostasis (Moskowitz, 2010; Bonanno, 2004); though this return may be tentative, depending on the course the illness takes. The degree of adjustment will depend on a multitude of factors, including how diagnosis is made (through autopsy of family member, critical cardiac event, or incidental finding), degree of life disruption, capacity to transition effectively to the 'new normal' and its accumulated risks, and pre-existing personal vulnerabilities (including history of

trauma, genetic predisposition to mental health dysfunction, and reserves of resilience).

Concerns for the safety of probands and potential carriers, limitations on physical activity, and fear of SCD while engaged in ordinary tasks, place a significant burden on those families dealing with IAD. Increased risk for anxiety and depression are not uncommon, as IADs can carry unique challenges (Day, 2012). High school athletes who suddenly lose their identity and dreams of collegiate sports; parents weathering the anxiety of letting ARVC positive children go off to camp or college; a spouse concerned for the partner whose condition has suddenly destabilized (for no apparent cause); an entire family trying to come to terms with the SCD of a loved one - these very real scenarios are the difficult realities with which IAD patients and their families must live. In the limited studies available exploring adjustment to inherited cardiac disorders, anxiety and depression have been identified as consistent issues, presenting at times as significantly distressing (Sowell, Sears, Walker, Kuhl & Conti, 2007). Diminished social and physical functioning has also been identified (Steptoe, Mohabir, Mahon, & McKenna, 2000). Of particular note is that reduced physical capacity is not always consistent with symptoms or severity of underlying disease state (Steptoe et al., 2000), implicating psychosocial adjustment as a partial and perhaps significant factor in diminished capacity and poor outcomes (Sears, Lewis, Kuhl, & Conti, 2005; Sears et al., 2004; Sowell et al., 2007).

Individuals with ARVC represent a unique population in that patients are often asymptomatic even as they are predisposed to unpredictable and life threatening events (McNally et al., 2005/2014). In fact, many of the complaints regarding life with an IAD come not from the disease itself, but from subsequent limitations on lifestyle and side effects of arrhythmia management (Connolly et al., 2006). Significant advancements have been made in identifying

and treating IAD, making the prospects for surviving with an inherited cardiomyopathy greater than they have ever been. But with increased survival comes increased challenges: how individuals and families are surviving and adjusting with a progressive, life threatening condition demands attention. Among the ARVC population, for instance, there is a high risk for arrhythmia (Day, 2012; James et al., 2012; McNally et al., 2005/2014). Patients and families have to adjust to this risk - which is often experienced as the potential for SCD - while not allowing it to damage their (or their children's) capacity to live the fullest life possible (Hamang et al., 2010). This is no small accomplishment.

There are many facets of diagnosis that affect psychological adjustment and quality of life. Genetic risk of arrhythmia, for instance, appears to negatively impact physical and psychological well-being (Ingles et al., 2013, Sowell et al., 2007). Medication management, particularly when used prophylactically (as is often the case in silent carriers), has its own risks with regard to how patients respond (Connolly, 2006), the side effects of which can also result in reduced quality of life (Sola & Bostwick, 2005). ICDs as a primary and secondary line of protection against SCD bring their own share of challenges (James et al., 2012), as will be explored more fully in section IV on this paper. As such, genetic heart diseases, particularly inherited cardiomyopathies and arrhythmogenic disorders affecting the young, present numerous complexities that require specific attention if one is to live 'successfully' with such an illness across the lifespan.

### III. Variables of Chronic Illness

One out of two people in modern Western society will be diagnosed with a chronic illness at some point in their lives (Wu & Green, 2000). While advances in modern medicine have turned conditions with once-poor life expectancy into those with long-term survivorship, the extension of life comes at a cost, and managing life with a chronic, degenerative disease can precipitate or antagonize anxiety, depression, and other mental health issues (Alanzo, 2000; Chapman, Perry, & Strine, 2005; Moskowitz, 2010). The interplay between chronic disease and mental illness is well established: where the effects of chronic disease may exacerbate symptoms of anxiety and depression, ongoing mental health disorders have also been shown to be a risk factor in chronic disease (Chapman et al., 2005; Keyes, 2007).

There is, of course, variability in how people respond to any life crisis (Bonanno, 2004; Meichenbaum, 2007), including diagnosis of a chronic, life-threatening condition (de Ridder, Greenen, Kuijer, & van Middendorp, 2008; Moskowitz, 2010). Factors such as the course an illness will take (from slowly developing to rapidly advancing), type of disease (stable or degenerative), age at time of diagnosis (younger age is correlated with increased psychosocial challenges), support systems (married/divorced/widowed, engaged with family/friends), preexisting stressors (co-morbid illness, financial burdens), predisposition for and/or history of anxiety/depression/trauma, and socioeconomic status, are all influences in outcomes (James et al., 2012; Moskowitz, 2010). Additionally, chronic stress, regardless of the source, is clearly predictive of negative mental health outcomes (Cohn & Fredrickson, 2009; Duckworth, Steen & Seligman, 2005; Turner & Lloyd, 1995).

The Diagnostic and Statistical Manual for Mental Disorders, the classification handbook for mental health professionals, identifies chronic illness as a precipitating feature of posttraumatic stress disorder (PTSD) (American Psychiatric Association, 1994). Those illnesses that create recurrent threat to physical safety and induce feelings of helplessness (due to the unpredictable nature of the illness/symptoms) are likely to pose greater adjustment challenges over the lifetime of the illness than more stable and predictable diseases. When this combination of stressors strikes children, adolescents and young adults, additional challenges emerge, such as the lack of peers to whom patients can look to make sense of their experience (Putter, 2004; Samuels & Samuels, 2004). While the majority of people diagnosed with chronic illnesses tend to be older adults, it is the younger patient who may experience developmentally-related adjustment issues and experience greater challenges over the lifespan of the disease (James et al., 2012; Sears, Burnes, Handberg, Sotile, & Conti, 2001; Sears et al., 2005; Sears, Matchett, & Conti, 2009).

Social comparison theory asserts that individuals measure themselves against those in a similar age/stage of life. Children and young adults who are dealing with inherited arrhythmogenic disease (IAD) and live with an implanted cardioverter defibrillator (ICD), for example, are so small in number that it leaves this population with an absence of peers against whom to measure their own experience (DeMaso et al., 2004; Opić et al., 2012; Sears et al., 2001). The comparisons that these individuals end up making are often to those without similar restrictions or disabilities. Such dissimilar comparisons can negatively impact self esteem and produce feelings of inadequacy (Sears et al., 2001). When, to a young person, it seems that everyone in their age group is playing organized sports or enjoying what appears to be a carefree

life (or at least one free of medical intrusion), it can lead to distorted evaluation and negative self-perception.

Unlike acute illness, chronic diseases should be measured in terms of recurring events and stressors that become stacked over time. According to research, it is the accumulation of stressful events (big and small) that tips the scale in the direction of psychosocial difficulties (Moskowitz, 2010; Turner & Lloyd, 1995). When considering capacity of functioning for patients living with chronic illness, we must take into account those risks that can occur over both the life of the disease and over a normal lifespan (Alonzo, 2000; WHO, 2005).

Psychological symptoms can manifest even after initial periods of adjustment, making some level of ongoing evaluation, particularly following periods of crisis and/or health instability, essential to a comprehensive healthcare protocol.

Symptoms can range in severity from clinical levels of thought intrusion, sleep disturbance, anxiety and/or depression, to milder levels of languishing and degenerative functioning (Keyes, 2007). Events that may cause psychological disruption include sudden onset, lack of preparation, threat to life and/or stability, and repeated adjustments to functioning. This would include those crises that creates sudden, inescapable distress and a loss sense of control (Alonzo, 2000; Sears, Hauf, Kirian, Hazelton, & Conti, 2011). In ARVC for example, the unpredictable yet always present potential for a life threatening event and subsequent shock from an ICD, adds considerable risk from an adjustment and psychosocial perspective. Additionally, while presentation of arrhythmias may be intermittent, management of the disease requires modification of lifestyle and ongoing monitoring that can cause disturbances in daily

living, and serve as a reminder of the underlying seriousness of the disease (Day, 2012; James et al., 2012; Sears et al., 2001).

Progression is another consideration. ARVC is a disease that has four phases: *concealed* (potential risk for sudden cardiac death despite absence of clinical manifestation of disease); *active* (symptoms of disease are present, including ‘hot phases’ in which arrhythmic activity is high and risks for ventricular fibrillation and shocks are also high -- hot phases may be the result of disease progression, secondary illness, stress, or arise without identifiable cause); *right ventricular failure*; and *biventricular pump failure* (heart failure: the result of advanced structural damage). In a small percentage of the ARVC population, the heart failure phase may warrant heart transplantation. While one may never fully progress to heart failure, such outcomes are unpredictable within the disease and within families affected by the disease (McNally et al., 2005/2014). Thus, with ARVC, there exists the potential for progression (without apparent cause) as well as extended periods of stability, (again, without identifiable cause), and always the possibility of advancement adding to both the uncertainty about the where and when a malignant arrhythmia may occur, and to the complexity of living with this illness.

According to Wallander and Thompson (1995) children facing chronic illness deal with distinct stressors that put them at increased risk of maladjustment. Mild mood disturbances may evolve into more significant bouts of anxiety and depression as stress accumulates over time (Turner & Lloyd, 1995). In young inherited arrhythmia patients for whom an ICD may provide protection from SCD, complications from the device and device-related procedures, adjustment issues post implantation (such as body image struggles), along with other psychosocial

implications must be weighed in light of the decades a young patient would have to live with an ICD and its related challenges (James, 2012).

According to Alanzo (2000), pathological manifestation of mental illness such as major depression disorder or PTSD represent the smallest fraction of psychological fallout to significant life stressors, though these states garner the most attention. What lies beneath, including lesser degrees of depression and anxiety that amount to ongoing suffering without clinical diagnosis, must be taken seriously as well. The goal is to create the best possible outcome, not only regarding long-term survival but in paving the way for optimal functioning by moving beyond symptom management and treatment of pathology, to a more integrated state of wellness (Keyes, 2007; Ryff & Keyes, 1995; Ryff & Singer, 1998; Seligman, 2011a). A mind-body approach where the interplay between physical and psychological well-being is factored, is an essential yet often missing element in helping those with chronic illness adjust to and live their lives at optimal levels of functioning.



#### **IV. Implanted Cardioverter Defibrillator (ICD)**

Since the mid-1980's the implanted cardioverter defibrillator (ICD) has become the gold standard treatment for heart rhythm disorders (Dubin, Batsford, Lewis & Rosenfeld, 1995; Eicken et al., 2005), and is both a primary and secondary line of defense against sudden cardiac arrest (SCA) (Kirian, Sears, & DeAntonio, 2012). This small, battery-operated computer, set beneath the skin or in a pocket behind the pectoral muscle, is designed to treat potentially fatal arrhythmias such as ventricular tachycardia (VT) and ventricular fibrillation (VF) (Connolly et al., 2006). While the ICD is not yet capable of preventing a VT from occurring, it can provide anti-tachycardic pacing through a series of electrical impulses delivered to the heart in an initial attempt to try and correct a VT and keep it from becoming a VF (van den Broek et al., 2009). If the pacing is not successful (usually following one or two attempts), a high energy shock is delivered to convert the tachycardia back to sinus rhythm and to keep a fatal VF from occurring (Stutts, Cross, Conti, & Sears, 2007). In the event of a VF, a shock is delivered immediately and repeatedly until the VF is corrected.

In VF the heart chambers quiver (often characterized as a "bag of worms" to describe the ineffective action of the heart muscle during this disturbance), preventing blood flow from being sufficiently circulated to vital organs. Death occurs within minutes if not corrected through defibrillation. Survival rates for a VF outside of settings and/or where defibrillation is readily accessible are very poor; only 5% of those who experience sustained VF without defibrillation survive (American Heart Association, 2007; Kirkian et al., 2007). Consequently, the ICD plays a critical role in the survival of the individual with ARVC.

The ICD is connected to the heart by a single or dual lead. This allows the device to continually monitor the rhythm in the ventricle (and atrium, depending of whether a second lead is necessary, in the event of atrial involvement). Should an arrhythmia be detected, the ICD is programmed to deliver a single or series of shocks until sinus rhythm is restored, the ICD is disabled, or the battery runs out of power. ICD storms (multiple or successive shocks in a 24-hour period) can and do occur, for both appropriate (repeated cardioverting attempts) and inappropriate (device or lead malfunctioning, or misfiring based in false reads) causes. Strong emotional states (anger/anxiety) are correlated to device discharge (Dunbar et al., 1999; Lampert, 2010; Kirkan et al., 2007; Whang et al., 2005), and other variables, such as depression, have been correlated to accelerated time to first shock post-implantation, and to frequency of shocks (Kirkan et al., 2007; Whang et al., 2005).

In ARVC, cardiac dysrhythmias typically occur in a high functioning heart within an otherwise healthy body. While patients have fewer functional and structural issues, the risk for VT/VF and shock are high (Day, 2012; McNally et al., 2005/2015). Patients' perceptions with regard to ICD discharge is an important factor in psychological response and expectation of future shocks. Patient shock reports range from mild to severe, with an average subjective pain rating of 6 on a 1 - 10 scale. ICD discharge sensation has been described as everything from a jolt, to a close fistful punch to the chest, to being kicked by a horse, or being shocked by household current (Kirkan et al., 2007; Pelletier, Gallagher, Mitten-Lewis, McKinley, & Squire, 2002). Some experience shock with very little reaction, others are knocked to the ground, still others pass out. There is typically no warning prior to a VT or VF. This unpredictability has been identified as a further risk factor for negative outcomes. Whether anticipated or not, device

discharge can be both jarring and frightening, adding to anxious anticipation and negative post-discharge reactions (Kirkan et al., 2007; Toise, 2011).

While the ICD has proven itself a game-changer in terms of its lifesaving capacity (where survival rates for ARVC patients are as high as 92%), it is not a preventative for arrhythmia. The job of the ICD is to interrupt rhythm disturbance once detected, and restore the heart to normal function. Arrhythmias will come, and patients must learn to live with and adjust to this reality (van den Broek et al., 2009). Hence, medications (beta blockers and antiarrhythmic drugs) are used supplementally in an attempt to manage rhythm and prevent VT/VF from forming. But these medications can present challenges as well. Side-effects ranging from lightheadedness and low blood pressure, to vertigo and sexual dysfunction, can be particularly troubling in young and otherwise healthy/active individuals (Connolly, 2006).

Research has shown that living with an ICD can lead to or exacerbate anxiety, isolation, hostility, and depression (Eicken et al., 2005; Ingles et al., 2009; Wallace et al., 2002). In patients for whom a high ICD discharge rate is anticipated, the risks for poor psychosocial outcomes are further illustrated (James et al. 2012). Although even a single firing may be a critical experience, research shows that recipients seem capable of tolerating up to five ICD firings before ‘significant’ deficits in quality of life are demonstrated (Ingles et al. 2013; Jacq et al., 2009; Sola & Bostwick, 2005; Passman et al., 2007; Sears, Todaro, Lewis, Sotile, Conti, 1999). Other research disputes this *cumulation of shock theory*, finding instead that it is the loss sense of control and resulting helplessness (a precursor to depression, and compounded with each successive shock) that is responsible for deterioration in quality of life post-shock (Pauli et al. 1999). While these disputes in findings require further exploration, in a patient population for

whom arrhythmia rates run high and ICD is the primary and secondary line of defense, post-implant psychological challenges have been clearly demonstrated (Ezekowitz, Armstrong, & McAlister, 2003) and require focused attention.

Young ICD recipients tend to be higher functioning compared to their more senior ICD patient counterparts (Dunbar et al., 2009; Dubin et al., 1996; James et al., 2012). They also demonstrate considerably higher survival rates (92% compared to 50-60% in older adults with coronary artery disease) due to the absence of structural compromise in earlier phases of the disease. However, younger ICD recipients also demonstrate compromised social functioning and decreased sexual activity post implantation (DeMaso et al., 2004; Dubin et al., 1996). While younger ICD patients may lead more active and productive lives, that does not preclude the challenges of maintaining this higher degree of functioning in the face of the cumulative psychosocial and physical challenges of the disease (Eiken et al., 2006; Sears et al., 2001). Younger ICD recipients demonstrate device adjustment issues ranging from reduced quality of life and heightened anxiety, to clinical anxiety, depression and PTSD. Clinical levels of anxiety and depression ranging between 13-87% have been reported (Carroll & Hamilton, 2005; Matchett, 2009; Sears & Conti, 2002; Sola & Bostwich, 2005). In one of the only studies examining the psychosocial implications of ARVC + ICD, James et al. (2012), found this population to have higher rates of depression and lower quality of life scores than those implanted with an ICD for ischemic or valvular diseases. So while age is on the side of survival in ICD recipients, it appears to simultaneously confer a negative impact on quality of life.

In patients with high potential for malignant arrhythmias, the ICD is a lifesaving device (Ezekowitz et al., 2003), but clearly is not without challenges (James et al. 2012; Sears et al.

2005; Sears et al. 2001). The need for careful consideration regarding implantation has not to do with device success, but the potential, unintended consequences (on top of already increased risk factors) of ICD firings. Where SCD is averted and the disease well-managed, patients with ARVC can be expected to live near normal lifespans. The type of life one may lead, however, remains in question. Individuals with ICDs can and do suffer when interventions (particularly for susceptible populations) do not explicitly address *prevention* for potentially deleterious effects and *promotion* of best possible outcomes on both the physical and psychological front. ICD recipients have rates of clinical anxiety as high as 46% post implantation (Bilge et al., 2006; Burke, Hallas, Clark-Carter, White, & Connelly, 2003; Sears et al., 1999). Subclinical rates for anxiety and depression can be as high as 87% (see Matchett, 2009; Carroll & Hamilton, 2005; Sola & Bostwick, 2005; Sears & Conti, 2002 for further discussion).

There is an opportunity and obligation here to appropriately address this *at risk* population, with its high potential for clinical and subclinical levels of suffering. The natural psychological response to the diagnosis of ARVC and treatment with ICD and medication, are the very responses that increase the risk of psychological harm to these patients. The need to help patients better prepare for life with an arrhythmogenic disorder and ICD, as well as how to face shocks (Ingles et al., 2013; James et al., 2012; Sears et al., 2011; Sola & Bostwick, 2005), is as critical to the prevention of future psychosocial disturbances as the ICD is to management of potentially malignant arrhythmias, where similar levels of risks exist.

## V. Psychosocial Implications

Being diagnosed with an inherited arrhythmogenic disease (IAD) is a major life event (Day, 2012; Ingles et al., 2013). Risk of sudden cardiac death (SCD), heritability of disease, lifestyle restrictions, and high potential for arrhythmias can make adjustment to such illnesses all the more challenging (Jacq et al. 2009). As is well documented, living with an implanted cardioverter defibrillator (ICD), while lifesaving, can exacerbate preexisting psychological symptoms (Day, 2012; Kirkan et al., 2007; Sears et al., 2000), and may cause new-onset symptoms that meet criteria for clinical diagnosis following device implantation or discharge, where no prior pathology existed (Sola & Bostwick, 2005). So while patient history of mental illness certainly deserves attention when evaluating for risks in populations with IAD + ICD, it cannot be the only consideration in screening for psychosocial vulnerabilities.

The benefits of the ICD, while indisputable from a life preserving perspective, may be undermined if anxiety and depression (including subclinical levels) go undetected or unacknowledged, particularly where patients will be living long-term with ICD intervention (Sears et al., 1999; Shiga, Suzuki, & Nishimura, 2013). A positive correlation has been made between shock frequency, anxiety, and depression in ICD patients, with the risk of psychological distress increasing as the number of shocks increases. Those who experience one or more shocks typically fare worse in quality of life and long-term psychosocial outcomes (Connolly et al., 2000; Jacq et al., 2009). Frequent device discharge (which causes higher anxiety and maladjustment outcomes) (Sears et al., 1999; Bostwick & Sola, 2011), predicts further arrhythmias and device firings (James et al., 2012). Moderately-to severely-depressed patients

with coronary artery disease and an ICD have a 3-5 fold increased risk of experiencing ICD shocks (Ladwig et al., 2008), further demonstrating the effects of negative emotional states on arrhythmogenic activity (Lampert, 2010). The cycle of poor psychosocial adjustment to shocks, with its associated negative emotional states, seems to put patients at increased risk of shocks, which may further arouse anxiety and depression.

The majority of cardiac-ICD studies identify gender as a significant risk factor for increased anxiety, PTSD and maladjustment, with female-ICD recipients reporting two times the rate of shock anxiety, increased shock history, and increased mortality rates despite having equal risks for shock and death as their male counterparts (von Känel, Baumert, Kolb, En-Young, & Ladwig, 2011; Vasquez et al., 2008). However, in at least one study that looked specifically at the ARVC-ICD population, this expected gender disparity did not exist (James et al., 2012). Researchers have speculated that this may be due to the fact that both men and women with ARVC score higher than average (cardiac populations) in ICD-related adjustment issues, due in part to factors such as young age, incidence of malignant arrhythmias, and heritability (Vazquez, et al., 2008).

From a physical and psychological perspective, chronic illness represents a marathon, not a sprint. It requires ongoing adjustments in order to manage as the symptoms and effects of the disease ebb and flow (Shiga et al., 2013). In children with IAD + ICD, perceived limitations as well as fears around device discharge increase potential for social withdrawal and phobias (Eicken et al., 2005; Sears et al., 2001). Illness acceptance and perceptions of agency are essential to successful adjustment, making it important, then, to prepare patients for the unique demands that chronic illness can create over time (de Ridder et al., 2008, Krikan et al., 2007).

Common theories regarding psychological response to illness provide a framework for understanding patient reactions both to chronic disease, and to ARVC-ICD patients more specifically. From *classical conditioning*, patients may associate otherwise neutral events that co-occur with device discharge (such as being shocked while showering or out for a walk), creating misplaced associations which may then lead to avoidant behavior, social withdrawal and/or phobic reactions (Sears et al., 2001). In *cognitive appraisal theory (of ICD activity)*, Sears et al. (1999), describe a 'sickness scoreboard,' wherein patients keep a running record of symptoms in a desire to establish a sense of control/predictability, then misattribute these events as signs and symptoms pointing to disease progression, where they may in fact be innocuous. In an illness such as ARVC, where hot periods can manifest without accompanying disease advancement or structural deterioration, this sickness scoreboard can be particularly misleading and cause unnecessary distress (Sears et al., 2001). In the *disability-stress coping theory* (Wallander & Thompson, 1995), the cascade effects of underlying chronic illness effectively 'chip away' at psychosocial coping skills, leaving less with which to face other, typical life stressors. In this case the distress is not merely about the number of shocks, but also about how those shocks will be perceived when someone is already taxed, leaving little functional energy left with which to face the rest of life (Sola & Bostwick, 2005).

One of the most compelling theories with which to explore the psychosocial reaction to ARVC + ICD is the *learned helplessness theory* (see section IX for a more thorough exploration of this theory). According to research (Sears & Conti, 2003; Seligman, 2011a, 1975; Seligman & Maier, 1967), how one experiences an initial aversive event (first shock or illness induced crisis) will lay the foundation for the experiences to follow. Researchers theorize shock interpretation is



the true critical factor in determining quality of life outcomes, making the need for psychological preparation essential to cultivating and sustaining well-being (Pauli et al., 1999; Seligman & Maier, 1967). The absence of this sense of control is the difference between paralyzing, negative emotional states with far reaching consequences, and resilience in the face of high degrees of stress. Hegel et al. (1997), report that even the 'illusion of control' can mediate anxiety over shocks. This is of critical importance when dealing with any condition where (perceived or actual) loss of control and traumatic (or potentially traumatic) events are known to be coupled. In at least one study, those who scored high on ICD concerns (preexisting anxiety about loss of control) demonstrated a 6-fold increase risk of anxiety and 2-fold increase risk of depression independent of shocks (Pedersen et al., 2005). Learned helplessness theory postulates those who experience a loss of control in the face of an aversive event are more likely to extrapolate that helplessness to future circumstances and contexts once a precedent of helplessness has been established (Maier & Seligman, 2015; Seligman, 2011a, 2011b; Seligman, 1975).

It is important to remember that patients are managing the psychological and physical effects of chronic illness in the context of lives that will continue to bring their fair share of stressors, not only from potential comorbidity, but the stress of life itself. Concerns over cumulative stressors must be factored over the course of one's life with both chronic illness and ICD treatment. What will happen after a decade of cardiac events from an arrhythmogenic disorder, after multiple decades? How do we prepare people for both the short- and long-term implications of life with ARVC?

## VI. Learned Helplessness

Control, according to research, is critical to psychological functioning (Kerr et al. 2012). Our ability not only to have explicit control but perceived control impacts psychological and physiological resilience (Barlow, 2002; Maier et al. 2006; Seligman, 1975; Weiss, 1991). Control offers a clear mitigative effect over emotional response to adverse experiences, as well as a shift in physiological reactivity (Kerr et al., 2012). It is lack of control, perceived or otherwise, that intensifies anxiety and powerlessness, and its concomitant cascade of negative emotional effects (Carroll & Hamilton, 2005).

In the late 1960's psychologists conducted a series of experiments involving animals and learned behavior (Seligman & Maier, 1967). Their research included administering shocks to dogs suspended in harnesses while mediating the capacity for control (Seligman, 2011a; Seligman & Maier, 1967). Among the animals who could not employ any effect over the shocks, a passive response was noted that translated into helplessness *in tempore*. When transitioned to new environments with new aversive stimuli, animals who experienced inescapable shock continued to react passively, even when they had the power over which to improve their circumstances. Animals that were able to exercise control to escape the shock in the first part of the study, immediately and repeatedly made efforts to escape this new, noxious event (Seligman & Maier, 1967). An important distinction between the inescapable and escapable shock groups was noted: the inescapable shock group retreated in passivity; the escapable shock group continued on undeterred.

Seligman (2011a) and his colleagues (Maier and Overmier) identified the passive behavior of the inescapable shock group as the animals 'detection' of uncontrollability and resulting 'expectation' of impotency, which the animals then generalized to subsequent aversive circumstances (Maier & Seligman, n.d.). In other words, the perceived failure to be able to navigate distressing events effectively in the first encounter, led to 'giving up' in the face of other stressors even when the context was entirely different. They called this transactional passivity *learned helplessness*, and recognized it as a major feature of depression.

Learned helplessness studies have been replicated in human subjects (Hiroto & Seligman, 1975). Triadic designs involving anagrams, aversive noise, and college students, for instance, demonstrated similar results. In one such study subjects experienced a loud noise and could exercise control (discontinue the noise) by solving anagrams (this would be equivalent to the escapable shock group). The second group experienced the irritating noise but could not make it stop because they had been given unsolvable anagrams (inescapable group). A third group experienced no noise at all but had only to solve the anagrams (control group). At a later time and in a different location, all three groups encountered a noise stressor again. This time they needed only to move their hand, which was placed inside a shuttle-box, above a certain point to stop the aversive event. Those subjects who had been able to escape in the earlier part of the study, as well as the control group, quickly learned to move their hand to stop the irritant. Those from the inescapable group, however, did not make an attempt to stop the offensive noise, but waited for it to stop on its own. The expectation of the inescapable subjects was that 'nothing they did would change the outcome, so why bother,' thus they did not try to escape (Hiroto & Seligman, 1975; Seligman, 2011a). In fact, the human subjects who initially had no control

actually performed worse in the second set of experiments — the earlier absence of control appeared not only to diminish expectation of control but to depress their sense of self efficacy overall (Seligman, 2011a).

Lack of control (perceived or actual) is a primary feature in anxiety, depression and PTSD (Kerr et al., 2012). Initial learning has a powerful impact on future behavior (Sears & Conti, 2003; Seligman, 2011a, Seligman, 2011b; Seligman, 1975; Seligman & Maier, 1967), but perception may be even more important than actual control (Pauli et al., 1999). For instance, subjects who were told they would not be able to solve a puzzle (even if it was solvable) were more likely to give up than those who did not have the expectation of helplessness. Researchers argue that the inescapability of the stimuli could not cause more than momentary helplessness (Abramson, Seligman & Teasdale, 1978); rather the passivity applied to new circumstances was determined to be attributional.

Attribution (also known as explanatory) style was identified as a critical element in the outcome of the learned helplessness studies. Researchers found that those who saw the aversive event as temporary and limited: ‘it’s not that I have *no control*, just that I can’t do anything in the moment,’ demonstrated greater resilience. Those, on the other hand, who used a more pessimistic attribution style - believing their lack of control was pervasive (generalized to other parts of the experience as well), permanent (unlikely to change), and personal (due to their own shortcomings), were more likely to experience the aversive event as evidence that giving up was the only option: ‘I can’t get anything right; this puzzle will never be solved; these tests are always unfair.’ Predictably, the passive-pessimistic subjects were unable to bounce back when placed in new challenging circumstances (Seligman, 2011a, 2011b).

Advances in neuroscience over the past decade have allowed the original research behind learned helplessness to be evaluated under new light, as information about neural mechanics and their impact on helplessness and control have been identified. According to Maier and Seligman (n.d.), research in the medial prefrontal cortex and dorsal raphe nucleus of mice demonstrate that helplessness is not learned at all, but rather is the default response to aversive experiences. Per this new evidence, it appears that it is control that must be learned, not helplessness.

Experiences of mastery (i.e., the perception that one has successfully navigated an adversity) activate regions of the brain that undermine the *default helplessness circuit*. Helplessness, then, can be overcome through mastery experiences. And while it appears that we cannot “undo” the helplessness default, we can create a *hope circuit*, which suppresses the default response by building an expectation of control or mastery. It is this expectation and resulting hope circuit which then becomes a barrier to helplessness. It appears, then, that preventing helplessness requires mastery experiences (those experiences that increase the perception of control) (Seligman & Maier, n.d.).

The very nature of ARVC + ICD, unpredictable inescapable shocks with little control for the patient, affords striking parallels to the helplessness experiments. The recent discovery of the hope circuit points to an opportunity for interrupting the helplessness default and its subsequent negative effects (Seligman & Maier, n.d.). In patients with ARVC + ICD, I hypothesize that the experience of establishing perceived control, particularly at the point of a first ‘inescapable’ shock, is likely to buffer against the experience of helplessness and its subsequent deterioration toward anxiety and depression. Perhaps the first shock represents a critical point in which the seeds of *prevention* (of psychological vulnerability) and *promotion* (of emotional resilience) can

be planted, by providing patients with a perceived sense of control. If the cultivation of control undermines a helpless response, particularly at the point of first shock, this opens up new directions of proactive interventions in the face of significant ‘inescapable’ stressors/trauma.

Of further significance relative to helplessness and its implications are the studies regarding control and physical health. In animal experiments evaluating the effects of a passive response vs mastery/control, rats were injected with tumor cells with a lethality rating of 50%, then divided into three groups: those who experienced mildly painful escapable shocks, those who experienced identical but inescapable shocks, and those who experienced no shock (the control group). Fifty-percent of the control group (those without shock) died from the tumor exposure, as expected. Three-quarters of the rats in the inescapable group died, suggesting the exacerbating effects of helplessness on immunity and physical health. But perhaps the most interesting result of all was that only one-quarter of the escapable shock group (the mastery group) died, which seems to illustrate the buffering effects of control on the body (Visintainer, Volpicelli, & Seligman, 1982).

While more research of this kind is needed, this study appears to further implicate control/mastery as an immunity against the negative effects of helplessness. Research and observation regarding the impact of psychological states on physical function point to the relationship between body and mind. Dunbar (1999) and colleagues note a clear and present dynamic between internal or external prompts, substrate, and sympathetic and parasympathetic activation, in sustained arrhythmia. Better understanding of the relationship between these systems is needed and may provide important future direction in the development of preventative (and promotive) interventions. In the meantime we can begin by acknowledging and acting upon

what current research has already revealed: that we have the capacity to affect change in brain reactivity by training the brain for mastery.

## VII. The Ups and Downs of Emotions

Positive emotions (joy, interest, contentment, love, serenity, hope, pride, inspiration, etc), those brief, personally relevant responses to an antecedent, are a primary factor in resilience and well-being (Diener & Seligman, 2004; Lyubomirsky et al., 2005). Emotions stake claim to every thought, feeling, and action we take, acting as amplifiers between events, experiences and reactions, and coordinating “cognitive, biological and behavioral resources,” often outside our awareness (Algoe & Fredrickson, 2011, p. 35; Seligman, 2011a).

Research confirms that happy people live longer, have better immune function, are more adaptive, and have greater self-regulation (Feder, Nestler, Westphal & Charney, 2010). Those who develop and use positive emotions (born of adaptive cognitions) bounce back from trauma faster, experience greater resilience, and grow stronger in the face of difficulties (Fredrickson, 2009). Positive emotions have been identified as having a favorable effect on the cardiovascular system by ‘undoing’ the effects of stress on autonomic reactivity (Fredrickson, Mancuso, Branigan & Tugade, 2000). How people adjust to and live with chronic illness is determined, in part, on one’s affective make-up (comprised of positive emotions), a precursor to well-being and resilience (Diener & Seligman, 2004; Kahneman, Krueger, Schkade, Schwartz, & Stone, 2004).

Emotions, it seems, serve an important purpose beyond our experiences of sadness and happiness. They trigger a sequence of responses, some of which have the potential to be lifesaving. When we feel threatened, we are physiologically wired to react (fight or flight); it is part of the primal-neural design to ensure survival. Emotions and physiology are inextricably linked (Danner, Snowdon, Friesen, 2001; Feder et al., 2010). The cardiovascular system, adrenal



system, and nervous system work collectively giving us the capacity to evaluate circumstances in the moment and respond quickly and decisively, or slowly and thoughtfully. Negative emotion, quite possibly because of its strong psychologic and physiologic demand for immediate attention, has up to now received the lion's share of scientists' attention (Seligman & Csikszentmihalyi, 2000). It is easy to ignore the need for or take for granted the very experiences, states, and cognitions that make life worth living. Because positive emotions tend to be softer in manifestation and of less urgency than their negative counterparts, because they do not serve to alert us to some immediate need or life threatening danger, it is easy to overlook the critical role they play in wellness and well-being. But without positive emotion we simply cannot flourish (Seligman & Csikszentmihalyi, 2000).

Emotional experiences are happening all of the time, whether acknowledged or not. Emotions, according to Algoe and Fredrickson (2011) are the shapers of our lives. When humans are more attuned to the negative and not as attuned to the positive, negative emotions become the primary influencers over mental and physical health (Algoe & Fredrickson, 2011). When conditions are ideal, emotions are adaptive and help us to navigate the challenges and pleasures of life - in other words, we have equal awareness of both sides of the experience. When dealing with chronic stressors, illness or life threatening events, magnification of the negative can detract from the resilience necessary to cope effectively with such challenging and changing circumstances (Algoe & Fredrickson, 2011; Seligman, 2011a). When optimally functioning, negative emotions (anger, sadness, anxiety) serve an adaptive purpose, whether focusing attention or inciting courage or determination. The physiological changes associated with fear arouse important processes in the body that enable us to respond effectively in times of

stress. The chronic arousal of these processes, however, can have toxic cumulative effects on body and mind (Cohn & Fredrickson, 2009).

While negative emotions may keep us safe in the moment, positive emotions broaden the mind, aid in connectivity, enhance creativity, expand awareness, increase receptivity, and help to build coping skills essential to long-term survival (Fredrickson, 2009). They are foundational to resilience. When we feel awe, for example, we are more apt to savor experiences and connect to a sense of transcendence; interest compels us to explore beyond immediate boundaries; love drives us to connect and invest in others. Positive emotions evoke growth, expanded vision, and improved mental and physical health (Cohn & Fredrickson, 2010). By building optimism, anxiety may be alleviated, depression averted (Seligman, Schulman, DeRubeis, & Hollon, 1999) and hope advanced (Fredrickson, 2009).

Just as negative emotion is geared toward immediate survival, positive emotion contributes to future success. Both are essential. In fact, one way to lose the benefits that positive emotions confer is by using the positive to ignore or deny the negative. A lost sense of perspective is a dangerous thing (as anyone who has ever suffered from an optimistic delusion in a serious circumstance can attest). Rather, positive emotions are seeds in the garden, not intended to supplant but to peacefully coexist with the negative (Ryff & Singer, 1998). This is not about eliminating negativity, but increasing awareness of what positive emotion contributes, particularly in the face of life-threatening illness and/or recurrent stressors. In difficult or extreme circumstances, the addition of positive emotion can provide the equivalent of a psychological breather, boosting coping skills, and reinforcing resources (Ong, Bergman, Bisconti, & Wallace, 2006). Rather than losing all hope when a negative event occurs, negative

and positive emotions that operate concurrently are operating optimally (Fredrickson, 2009). In a study of resilience and loss, resilient widows were those who did not deny the reality of their circumstances, nor were they pulled under by them. Rather, they found a way to hold both the negative (the realities of the loss) and positive (support of family and friends, sweetness of memories) simultaneously. The capacity to continue to find things to be grateful for, even in the midst of loss, works like a reset button on the psychological and physiological impact of stress, sadness, and negative events (Fredrickson et al., 2000). This includes rapid restoration of cardiovascular function to prestress levels (McEwen, 1998).

In a study comparing high-resilient to low-resilient widows, high-resilient widows were more likely to experience the full spectrum of positive (joy, peace, love) and negative (anxious, worried, depressed) emotions throughout the bereavement process (Ong et al., 2006). A key distinguishing feature was their ability to hold both emotional states even while under stress, thereby preserving greater emotional complexity, another important element in resilience. Through the use of positive emotion, the high-resilient widows were able to bounce back from stress more readily (Ong, et al., 2006). For those dealing with an inherently negative experience, the pairing of positive emotion with the negative experience reduces the effects of the negative, and greater psychological well-being is demonstrated even up to a year post loss (Moskowitz et al., 2003).

Positive emotion helps us to become more optimistic, resilient, open, accepting, and purposeful in life (Fredrickson & Joiner, 2002; Fredrickson, Tugade et al., 2003), and is a feature of longevity (Fredrickson, 2009; Seligman, 2011a). Building a positive emotional arsenal over time it is not unlike building muscle: neither can it be done in a week, nor can it be done for a

period of time and then forgotten — with the hope that the protective and promotive benefits will remain. Rather, building positive emotion requires regular practice, and though it should never replace negative emotion, with regular practice building positive emotion tends to outpace the negative, simply because there are more frequent, though often unacknowledged, positive experiences and emotions in the course of the day (Diener, Lucas, & Scollon, 2006).

A number of studies specific to chronic illness and positive emotion have been published in the past 15 years. Results reinforce the idea of positive emotion as a worthwhile consideration for those who are chronically ill: in women with underlying health issues, the beneficial effects of positive emotion on stress hormones, dopamine and opioid levels, and inflammatory markers have been noted (see Ashby, Isen & Turken, 1999; Steptoe et al., 2005; Wager, Scott & Zubieta, 2007 for further discussion). Individuals with a chronic illness who measured high in positive emotion report less pain than those who scored lower in positive emotion (Gil et al., 1997). People high in positive emotion also appear to fight off illness more readily (Cohen & Pressman, 2006; Ong & Allaire, 2005; Seligman, Shulman, & Tryon, 2007).

In a landmark study of positive emotion and anxiety, subjects who had experienced activation of anxiety as measured by physiological stress responses, and were then shown a film that induced mild joy and/or contentment, demonstrated greater cardiovascular recovery compared to control subjects who were equally activated for anxiety but exposed to a neutral film, which had no demonstrable effect (Fredrickson et al., 2000; Fredrickson, Mancuso, Branigan, & Tugade, 2000). Among subjects who demonstrated rapid cardiovascular recovery post anxiety activation, those with the fastest recovery rates also tested highest on a resiliency (as measured prior to inducing stress) (Tugade & Fredrickson, 2004). Research on positive emotion

negating negative effects offer particular promise for IAD patients, where building positive emotion may serve as a buffer over potential negative stressors, and prescribing a positive intervention post-shock may be a beneficial in restoring the body and mind rapidly to prestress levels.

Multiple studies have demonstrated a unique association between positive affect and greater pain management, reduced morbidity and mortality, and increased treatment compliance (Chida & Steptow, 2008; Moskowitz, 2003; Moskowitz, 2010; Moskowitz, Epel, & Acree, 2008; Pressman & Cohen, 2005). For example, in a 12-week study of women with fibromyalgia and/or arthritis, positive emotion was related with diminished experience of pain and reduction in negative affect; these effects were even more pronounced during periods of high stress (Zautra, Johnson, & Davis, 2005). Other research has demonstrated the impact of positive affect on perceptions of pain (Davidson et al., 2003). And in both men with AIDS and people with diabetes, positive affect was a predictor for reduced mortality (Moskowitz, 2003; Moskowitz et al., 2008). Collectively, these studies appear to support theories on the detrimental effects of negative emotion, and the beneficial effects of positive emotion, on the body (Sapolsky, 1999).

Because negative emotions are associated with increased arrhythmias and can impact trajectory of cardiac disease, the implication of positive emotion on the cardiovascular system may prove a most important finding for those with IAD (Lampert, 2010; Sola & Bostwick, 2005). Anxiety and tension involve heightened sympathetic arousal, the continuous experience of which creates imbalances among the sympathetic and parasympathetic systems, which in turn may antagonize arrhythmogenic conditions (Dunbar et al., 1999). Research directly links negative emotion as a cause rather than a consequence of arrhythmic responses (Dunbar et al.,

1999). Additionally, depression has been shown to be risk factor in arrhythmia and SCD (Dunbar et al., 1999). One study shows a high correlation between negative emotion, depression and arrhythmic events, due to stimulation the sympathetic nervous system (among other biological processes) following a negative event/reaction. Given that arrhythmias can be triggered by sympathetic nervous system responses (Lampert et al., 2009), it seems a critical component of ARVC care to help patients understand the importance of emotional regulation and provide empirically based strategies to achieve the same. By promoting positive emotion, the effects of negative emotion, including those on the heart, are clearly mediated (Fredrickson, 1998; 2001).

Even during difficult times, positive emotion can stop the dangerous undertow that unregulated negative emotion can spark. Like negative emotion, positive emotion becomes self-propagating, creating an ‘upward spiral’ which may help people bounce back in challenging times (Fredrickson, 2009). Recognition of the good creates acknowledgement of other positive experiences, each experience becoming a stone in the foundation of psychological resilience. Upward or downward spirals are cultivated one emotion at a time. Understanding and capitalizing on the role of emotions in everyday life can help people navigate the rocky terrain of living with chronic illness, and call upon emotional resilience when it is needed most (Algoe & Fredrickson, 2011).

### **VIII. From Surviving to Thriving— A Primer on Positive Psychology**

Over the span of the past six decades, the primary focus of psychology has been the study and alleviation of psychological suffering. Depression, schizophrenia, anxiety disorders, addiction, trauma, and the like, have been at the epicenter of the field's research and clinical efforts (Seligman, 2011a; 2002; Seligman & Csikszentmihalyi, 2000). This marks a stark departure from the first half century in the history of psychology, during which time researchers were as invested in human functioning and productivity, and identifying exceptional talents in children, as they were in understanding and treating psychopathology. Around the time of World War II, however, government funding for jobs and research in psychology became concentrated in the study and mitigation of mental illness (primarily for soldiers returning from war). As a result, the science and practice of psychology became slanted in the direction of pathology. Since then over 100 mental disorders have been identified and categorized, the Diagnostic and Statistical Manual of Mental Disorders was created, and treatments and cures for many mental disorders discovered— a testament to the field. However, this single-minded approach has come with a cost (Seligman, 2011a; 2002).

Sixty years later psychology has become adept at diagnosing and treating human suffering, but remains underdeveloped in the advancement of human flourishing (Seligman, 1999; Seligman & Csikszentmihalyi, 2000). According to Seligman (2000), despite longer life spans, greater economic stability, unprecedented access to education and healthcare, we find ourselves in the midst of a psychological epidemic in the Western world. Those struggling with mental health issues are diagnosed at ever younger ages, teen suicide has risen threefold, and significant numbers of adults are suffering with anxiety and depression as well as lifestyle and

stress-related conditions (Keyes, 2007; Seligman & Csikszentmihalyi, 2000). Focusing on the mechanics of illness and treatment certainly has had its benefits, but it has not been enough to outweigh the effects of the challenges of life on the masses. Psychology clearly needed to expand its focus to include developing strengths and cultivating resilience. The field needed to increase research and understanding in the areas of hope, wisdom, creativity, courage, spirituality, responsibility and perseverance (Seligman, 1999; Seligman & Csikszentmihalyi, 2000).

The emphasis in positive psychology is on cultivating sustainable well-being, attaining goals, building positive engagement, and establishing a meaningful life (Seligman, 2011a). Turning attention toward the 'positive' is not meant to diminish or disparage research and treatment of mental disorders. Rather, it is an attempt to add a missing voice to what has ended up as one-sided science (Seligman, 2011a; Lopez & Gallagher, 2009). The goal is to go beyond pathology (the disease model of illness) and pleasure (the hedonic view of well-being) to embracing a more eudaimonic view of well-being, one that includes identifying strengths, meaning, and pathways to optimal functioning (Seligman 2002). One need not be suffering from mental illness to benefit from such a science and its application (Lopez & Gallagher, 2009), nor does the presence of mental illness preclude one from its benefits (Rashid, 2009). In positive psychology the goal is not only to relieve suffering but to increase opportunities for flourishing (Seligman, 2011a, 2011b; Csikszentmihalyi, 1990). A proactive model, the interventions in positive psychology are designed to prevent the vulnerabilities that lead to psychopathology, while promoting those characteristics that enhance human thriving (Duckworth et al., 2005).



The evolution of humanistic psychology in the 1950's, (via the work of Maslow, Rogers, May et al.), was established around the pursuit of the positive in human beings (Clay, 2002). In fact, it was Maslow who first coined the term 'positive psychology' in 1954, and Jahoda (1958) who first sought to understand mental health as distinct from the deficit based theories of mental illness. The modern positive psychology movement, however, while building on this rich ancestry, calls for the 'empirical' study of the strengths, characteristics and virtues, attitudes and behaviors that allow human beings to flourish (Duckworth et al., 2005). Since his presidential address to the American Psychological Association in 1998, when Seligman made the case for positive psychology in an effort to rebalance research to include human thriving, social scientists have devoted considerable effort to studying what makes life worth living (Tomasulo & Pawelski, 2012). Seligman had challenged his fellow psychologists to broaden their research, declaring that the field must compliment the melioration of suffering with an equally rigorous exploration of how human beings thrive (Seligman & Csikszentmihalyi, 2000). Many have risen to meet this challenge.

Positive psychology is an integration of science and practice— seeking input from various schools of thought across multiple disciplines (philosophy, business, education, economics, medicine, religion). The goal is to share research, build scholarly integrity, and advance empirically supported protocols (Lopez & Gallagher, 2009). Positive psychology has created a space where those researching human strengths, positive emotion and well-being, from economists to social scientists, can come together to seed the field of human flourishing (Diener, 2009). A foundational premise in positive psychology is that human beings are not merely passive creatures reacting to circumstance, but active participants in the outcome of their

experiences (Seligman, Railton, Baumeister, & Sripada, 2013). The benefits of integrating the study of positive human traits across the sciences is that it allows us to collectively consider how to buffer against mental illness and proactively influence health and well-being, thus expanding not only our understanding but practical application of the research and its reach across disciplines (Seligman & Csikszentmihalyi, 2000).

Positive interventions designed to build positive emotion, cultivate meaning and engagement, enhance positive relationships, and create opportunities for optimal functioning (Duckworth et al., 2005; Sin & Lyubomirsky), are evidenced based, intentional acts aimed at inducing human flourishing (Pawelski, 2014). Where chronic illness is concerned, once imminent threats to life are mediated, it is time to turn the focus to the role of psychological well-being through the use of positive interventions. Positive psychology has much to offer the field of medicine and those caring for the chronically ill, by paving a way to build on what is right even in the presence of daunting circumstances and to prevent deterioration toward pathology, while at the same time promoting resilience and comprehensive well-being.

## IX. Resilience

Life is a series of wonders and hardships. According to the fourth-century Taoist sage, Chuang Tzu, *ten-thousand joys and ten-thousand sorrows* are what make up the human experience (Bernhard, 2013). From the accumulation of daily stressors and disorienting bumps in the road, to major events that call into question everything we thought we knew about life, trials are a part of the journey.

Resilience is the ability to successfully navigate those trials (Reivich & Shatté, 2002). Whether cumulative stressors or major crises, acute events or recurrent episodes, when humans are able to resume their capacity not only survive but to thrive despite significant threats (to safety, stability or life), this successful adaptation is the result of resilience (Masten, 2001). It is the basic strength in a person's emotional and psychological arsenal, allowing them to rise above and beyond potentially debilitating circumstances (Reivich & Shatté, 2002), and resume levels of functioning that are not only devoid of pathology but contain the presence of positive affective states as well (Moskowitz, 2010; Zautra, Hall & Murray, 2010). When we think about the resilient (hero, friend, figure from history or fiction), we are not thinking about those who merely get back on the bike. Conjured in most minds are the images of those who take off in the direction of their dreams, going on to live rich, fulfilling and meaningful lives in spite of (or perhaps because of) the difficulties they have endured.

The ability to exercise resilience is influenced by a number of factors including family and social supports, historical and psychosocial events, and personal vulnerabilities (Luthar & Zelazo, 2003; Masten, 2001; Masten & Obradovic, 2006). The more robust one's capacity for

well-being post trauma, the greater their ability to *bend without breaking* (Cohn & Fredrickson, 2011). Unfortunately, the system as it presently exists, requires that our patients ‘break’ before they are extended the tools that would have helped them to ‘bend’.

As in other aspects of health, resilience is not merely the absence of psychological disorder or paralysis in functioning. It is an active process, arising in the face of circumstance that severely challenges ordinary coping skills, affording protection from the negative and long-term effects of stress (Feder et al., 2010; Masten & Wright, 2010). Resilience does not happen by magical force, but occurs when ordinary people discover their best selves under extraordinary circumstances (Masten, 2001).

According to research, 48% of children who have experienced traumatic or extreme levels of stress (neglect and abuse for example), 70 to 80% percent of soldiers returning from combat, and 70 to 80% of adults following a traumatic event will demonstrate resilience after trauma, defined by the absence of clinical diagnoses or significant dysfunction (Bonanno, 2004; Meichenbaum, 2007; ver der Kolk, 2005). By averaging these statistics it seems most people are capable of recovering following a traumatic event (Bonanno, 2004). We are biologically hardwired for homeostasis, evidenced by the way in which the body organically seeks to rebalance following a traumatic or destabilizing event. Thus, recovery is not a rarity. However, all resilience is not equal, nor is it transferable across all circumstance or time (Masten & Wright, 2010). And the capacity to function is not the same as resuming a fulfilling life (Zatura et al., 2010). Where resilience is considered to be any state shy of a clinical diagnosis, we are missing a large portion of the population for whom functioning has returned yet flourishing remains out

of reach: those who may not be diagnosable yet remain ‘clinically relevant’ from the perspective of need (Keyes, 2007; Meichenbaum, 2007).

A bimodal view which considers two distinct yet related ways of looking at resilience, offers expanded consideration. In IAD-ICD patients, for example, 24 to 87% are found to have anxiety, with 13 to 38% falling into clinical range (Carroll & Hamilton, 2005; Matchett, 2009; Sears & Conti, 2002; Sola & Bostwich, 2005). Symptoms of depression in this population run from 10 to 58%, though less than 20% meet the clinical criteria for diagnosis. What of those who fall just outside of the diagnostic range — those who are functioning (able to perform daily tasks and absent the clinical criteria for mental illness) yet languishing (unable to feel fulfilled, to contribute to life in what feels like a meaningful way, or to pursue their dreams)? People differ in their capacity to handle stress, displaying various levels of coping at different times and according to the challenge(s) being faced (Masten & Wright, 2010; Meichenbaum, 2007). Resilience, if it to contribute to comprehensive well-being, must be viewed through a bimodal lens, where both *recovery* and *sustainability* are sought.

The capacity to regain equilibrium following highly stressful events, often referred to as ‘bouncing back,’ (physiologically and/or psychologically), is reflective of the recovery mode, an elemental level of resilience. Where additional burdens exist, recovery on any level may be more difficult to achieve and/or maintain. Accumulation of traumas, concurrent stressors, minimal social supports, family maladjustment, etc., can limit the reserves that collectively make up resilience (Bonanno, 2004; Bonanno & Mancini, 2012; Masten, 2001; Masten & Wright, 2010; Zautra et al., 2010). The greater the cascade of stressors, the greater the risks to resilience (Bonanno & Mancini, 2012; Masten & Wright, 2010). Chronic disadvantages, low

socioeconomic status, violence, and cumulative health challenges add additional risk factors to diminished functioning. It is not a far stretch, then, to imagine how diagnosis with an IAD along with treatment from an ICD, in addition to ordinary life stressors, could tip the scale toward languishing, or worse.

Resilience that mitigates the potentially negative outcomes while at the same time promotes well-being can be thought of in terms of thriving. Where in resilience, recovery is about returning to pre-adversity states, sustainability is about the capacity to engage in a meaningful life (Zautra et al., 2010). Sustainability has to do with moving forward, regaining momentum, and maximizing opportunities for growth, even in the presence of continuing adversity (Bonanno, 2004; Zautra et al., 2010). This way of thinking about resilience fosters consideration that extends beyond binary distinctions of functioning and nonfunctioning. Rather, it evokes more relevant questions regarding degree of functionality, quality of life, and fulfillment.

Where risks *and* strengths are simultaneously weighed, resilience is not built solely through the elimination of vulnerabilities (many of which are not reducible), but by building on intrinsic and extrinsic strengths (Seligman, 2011a). The recognition that one can be functioning but not flourishing is important, particularly when dealing with chronic disease where resilience should be measured both by capacity to rebound from acute crises *and* successful adaptation to changes in health status in order to regain or achieve optimal functioning (Moskowitz, 2010). In chronic illness, thriving is not a single event but a complex, ongoing process (Bonanno, 2004; Masten & Wright, 2010; Zautra et al., 2010) that develops over time. Helping patients achieve

optimal levels of health and psychological well-being in the presence of continuing challenges must be a primary element in a comprehensive model of well-being.

Positive affect at the time of diagnosis contributes to resilience in coping, and positive disposition correlates with higher levels of resilient responses (Moskowitz, 2010). While some are born with natural positive disposition, the good news is that resilience is not a fixed trait but rather a set of skills that can be learned, developed, and mastered over time (Reivich & Shatté, 2002; Seligman, 2011a). Resilience is made up of, in part: optimistic outlook, cognitive flexibility, active coping, effective problem solving, self efficacy, positive engagement, and strong support systems (Keyes, 2004; Masten & Powell, 2003; Masten, Cutuli, Herbers, & Reed, 2002; Meichenbaum, 2007; Reivich & Shatté, 2002; Seligman & Csikszentmihalyi, 2000; Southwick, Vythilingam, & Charney, 2005). The primary obstacle to resilience is not in the genetic lottery we drew from, but in our thinking and subsequent reactivity (Reivich & Shatté, 2002). Reich (2006) suggests that among the core pillars necessary for recovering from catastrophic events are regaining a sense of control and connectedness. A prescription for cultivating resilience might also include humor and altruism (Meichenbaum, 2007). Still other theories hold that sustainable resilience requires positive relationships and a sense of meaning (Frankl; 1963; Lee, Cohen, Laizner, & Gagon, 2006; Masten & Wright, 2010; Seligman, 2011a). The good news, of course, is that all of these skills can be developed.

Resilience offers protection from the negative effects of stress, depression and anxiety (Reivich & Shatté, 2002). Like building a muscle, it requires active and intentional exercise in the areas of self-evaluation, increased awareness, cognitive reappraisal, and self regulation.

Once individuals master the behaviors and patterns of thinking that drive resilience, this

compendium of skills can be evolved in ways that have a significant and permanent effect on well-being (Seligman, 2011a). One of the most important features in the development of resilience is in recognizing and changing limiting thought patterns. Personal agency is another critical factor in reducing stress and enhancing resilience (Reivich & Shatté, 2002; Seligman, Reivich, & McBride, 2011). Still another important part of the development of resilience is to help people accurately identify what is within their control and exercise control over what they can, rather than expend energy in areas outside of their control. This reestablishes an important sense of self-efficacy, allowing one to better allocate the psychological energy needed for managing stressful situations and problem solving, thereby increasing sense of agency.

To live a fulfilling life, survival alone is not enough. Resilience that does not also re-engage one in life in a meaningful way may be akin to psychological vegetation (Ryff & Singer, 1998). Sustainability, particularly for the chronically ill for whom challenges will be ongoing, is imperative. It offers protection against depression, anxiety, PTSD, all of which negatively impact not only psychological but (critically) physical health. It also builds the capacity for more effective coping, which may positively adjust management of health challenges over time. Given that negative emotional states promote arrhythmias (Lampert, 2010), psychological resilience can be expected to positively impact medical outcomes as well.

Knowing how to operationalize personal strengths, cultivate a sense of purpose and meaning, and promote well-being, creates reserves of resilience that may benefit patients for the challenges to come. The greater the resilience, the greater the capacity to handle changing circumstances and ongoing trials, and to mediate the effects of life and health stress on physical well-being. Considering a bimodal perspective on resilience is not only about resuming



psychological and physiological homeostasis, but about building the skills to flourish (Zautra et al., 2010).

## **X. Army Strong -- Prevention & Promotion Model in Action**

Psychological experiments that began exploring the cause and effect of helplessness on both emotional and physical depression more than forty years ago, and recent neuropsychological research being done in the area of ‘learned optimism’ (Seligman, 2011a; Seligman & Maier, n.d.), have informed our thinking and inspired the development of preventative strategies in the areas of anxiety, depression and PTSD. For many years, successful results in utilizing emotional resilience have been demonstrated with at-risk populations (see discussion on Penn Resilience Program in this section for further details). The U.S. Army decided to test the theory that through applied optimism, mastery, cognitive restructuring, positive emotion, and other tools to develop resilience, psychopathology could be averted and psychological strengths multiplied. They turned to the founding father of positive psychology and pioneer in helplessness research, Martin Seligman, to help develop a comprehensive fitness program for soldiers, the foundation of which would be emotional resilience to both protect against the cumulative effects of daily life stressors, and promote greater reserves of resilience that could be drawn upon in times of crisis and/or traumatic events.

While it may not appear that active duty soldiers and people with ARVC have much in common, the importance of cultivating reserves of resilience to protect against anticipated, recurring stressors, and promote well-being in the face of ongoing challenges, is imperative to the psychological and physical well-being in both populations. Hence, the Army’s decision to cultivate resilience, and efforts toward that aim, seem particularly germane to a discussion of

how to build resilience for those who may face heightened levels of stress over extended periods of time.

## **History**

In 2008, General George Casey, then U.S. Army Chief of Staff, met with Martin Seligman of the University of Pennsylvania with two explicit goals. First, General Casey was determined to address the disturbing levels of suicide, depression, divorce, and PTSD among Army servicemen and women (Casey, 2011; Seligman & Fowler, 2011). Significant resources had been allocated for treatment of the psychological distress soldiers were facing, but no one had yet tackled how to prevent these disorders from occurring in the first place. Second, General Casey described a desire to build psychological fitness in soldiers who were now facing an era of persistent conflict and recurrent deployments, and asked Seligman to help develop a strategy for building resilience in U.S. soldiers going into combat (Seligman, 2011a; Seligman & Fowler, 2011). “The key to psychological fitness is resilience,” argued Casey (Seligman 2011, p.127). Seligman had spent the better part of his career studying *learned helplessness* and its antidote, *learned optimism*. He was fascinated by the forces that determined the difference between retreating and thriving in the face of (and following) highly stressful or traumatic experiences.

Seligman and his team designed an empirically-based program to address and prevent the negative consequences of Army related stress, called Master Resilience Training (MRT). MRT would serve as one component in a larger program to be delivered simultaneously, called Comprehensive Soldier Fitness (CSF). The goal of the Army in investing in these programs was not only to build psychological strength among soldiers (a program that would eventually be

extended to family members and Army civilians as well), but to give them the capacity to flourish even in the midst of ongoing difficulties (Seligman, 2011a). Seligman and his colleagues were confident after decades of research that just as with physical fitness, psychological fitness was something that could, in fact, be developed. And like physical health, this psychological health would require building a solid foundation of resilience followed by ongoing maintenance (Lester, McBride, & Cornum, 2013; Seligman, 2011a).

### **Comprehensive Soldier Fitness**

The Army already knew about (and had invested heavily in) the importance of optimizing physical health. In 2008 they began to turn their attention toward psychological health (to augment the resources already being devoted to after-the-fact treatment of mental illness). They used the World Health Organization's (WHO) Human Health and Fitness Model as their roadmap (1948). According to the WHO, *physical, social, emotional, spiritual, and family health* are the pillars of well-being (Lester et al., 2013). A comprehensive model that promoted thriving across all domains was needed more now than ever, as soldiers were facing multiple deployments in an infinitely connected world, where expectations exist that deployed soldiers will continue to manage their lives, relationships, and home challenges via mobile/internet connection, amidst deployment-related stressors.

With the goal of psychological fitness in mind and the help of Seligman and his team, Comprehensive Soldier Fitness (CSF), a strengths-based program designed to help soldiers better deal with the complexities of modern day service through the use of cognitive restructuring, positive problem solving, and character development, was launched (Seligman, 2011a). With

physical fitness already addressed, CSF would focus on the remaining four components: social, emotional, family and spiritual fitness, through assessment, self-improvement, formal resilience training, and education of on-the-ground master resilience trainers (MRTs), who could then teach and reinforce resilience with soldiers in real-time (Cornum, Matthews, & Seligman, 2011).

CSF is a proactive program designed to meet the needs of soldiers, family members and Army civilians at the point of prevention and promotion, rather than waiting for clinical needs to manifest and then meeting those needs in the clinical intervention phase (Cornum et al., 2011). While CSF was not designed to replace the treatment-based model for dealing with psychological distress, it was designed to build a foundation, allowing soldiers to develop the skills necessary to mitigate the effects of recurrent and compounding stress. The inadequacies of the reactive model - waiting for illness or distress to evolve before intervening - was evident by the present day numbers of soldiers dealing with ongoing psychopathology and suboptimal results, despite extensive treatment availability (Casey, 2011).

The program Seligman (2011a) and his team devised includes development in the areas of positive emotion, positive engagement and positive relationships, through education and strategies designed to increase emotional, social, familial and spiritual resilience. The goal is to build a foundation of well-being and resilience to help individuals move away from pathology and toward human flourishing. The program emphasizes increasing attention to building strengths, rather than focusing primarily on eliminating negatives or avoiding stressors (which in many instances is not possible). Optimism is a well established contributor to growth (Algoe & Fredrickson, 2011; Fredrickson, 2000; Prati & Pietrantonio, 2009), thus the expectation was that by building a foundation of positive mental health and operationalizing strengths, symptoms of

depression, anxiety and PTSD could be prevented from taking hold (Seligman, 2011a). The components of the CSF program are designed to reinforce the concept of the active responder rather than the passive reactor to life's vicissitudes. Participants are taught to identify what can be controlled and to control what they can, rather than expend energy on those things outside the scope of control, the failure of which can induce feelings of helplessness.

Emotional fitness teaches the purpose of emotions, and the deleterious effects of lack of balance between negative and positive emotion. The focus is on education and modulation of reactivity, teaching soldiers how to keep reactions in proportion to events, to conserve emotional energy, and maintain realistic optimism. Individuals learn how to use emotions to their advantage and increase opportunities for the benefits that positive emotion can create (Algoe & Fredrickson, 2011).

Family fitness teaches the foundations of positive relationships and how to cultivate them. Relationship skills are taught to help build and maintain strong family units, another important component in resilience (Seligman, 2011a).

Social skills development help soldiers understand the potentially devastating effects of isolating, particularly when in emotional pain/distress. By understanding the importance of engaging in and maintaining healthy social relationships, participants learn to connect with others more effectively, rather than withdraw during times of stress. Healthy social supports (in good times and in bad) are essential to well-being. Human survival depends on connecting well with others and our resulting collective abilities (Cacioppo & Patrick, 2008).

Spiritual fitness consists of developing self-awareness, a sense of agency, self regulation, self-motivation, and social responsibility. This is the center of a purposeful and meaningful life,

another critical element in resilience (Reivich et al., 2011). People who are able to create a positive narrative about the meaning of their lives, including their traumas (finding the silver lining), as well as have an overarching sense of purpose, fare better emotionally. This module provides soldiers an opportunity to actively reflect on what it means to live with intention and to create a life of meaning (Calhoun & Tedeschi, 1999, 2004; Janoff-Bulman & Franz, 1997; Tedeschi & Calhoun, 1995; Tedeschi & McNally, 2011).

### **Penn Resiliency Program**

The foundation for building mental fitness for soldiers was based, in large part, on the Penn Resiliency Program (PRP). Seligman and his colleagues at the University of Pennsylvania developed PRP to teach the skills of resilience and positive education to adolescents through teachers who attended the program and would then teach these skills to their students in the school setting, through role-modeling, incorporating, and reinforcing the material when opportunities organically present. PRP is made up of the three elements: 1) cognitive skills development, which includes increasing emotional awareness, exploring the link between events, interpretations and actions/reactions; understanding thinking styles and traps (including catastrophic cognitions); and challenging negative beliefs; 2) problem solving skills that include assertiveness, negotiating, decision making, and creative solutions; and 3) enhanced coping strategies, which includes emotional regulation, relaxation techniques, and distraction (Gillham, Reivich, & Jaycox, 2008).

PRP has been shown to reduce anxiety, depression, adjustment disorders and conduct problems through its focus on optimism, problem solving, self-efficacy, self-regulation,

emotional awareness, flexibility, empathy, and the cultivation of strong relationships (Reivich et al., 2011; Seligman, Ernst, Gillham, Reivich, & Linkins, 2009). PRP is among the most well researched anxiety and depression prevention programs of its kind (Brunwasser, Gillham, & Kim, 2009; Gillham, Reivich, & Jaycox, 2008). Seligman and colleagues borrowed much from the PRP curriculum in preparing the emotional resilience components of the CSF program (Seligman, 2011a). For instance, the focus of the emotional resilience in CSF (delivered through the Master Resiliency Training) is on preventing depression and anxiety by cultivating flexible, accurate thinking styles to build psychological resilience-- straight from the pages of the PRP.

### **Master Resiliency Training**

The goal of Master Resiliency Training (MRT) is to cultivate *mental toughness* (the Army's word for resilience in keeping with the military lexicon) as the antidote to helplessness (the antecedent to anxiety, depression, PTSD) by using the skills of learned optimism (Seligman, 2011a). MRT was developed by Seligman and colleagues at the University of Pennsylvania, with the emotional resilience component based, in large part, on their successful PRP (Reivich, Seligman & McBride, 2011). Founded on the research of cognitive restructuring by Aaron Beck (A. T. Beck, 1976; J. S. Beck, 1995; Beck, Rush, Shaw & Emery, 1979) and mindfulness-based cognitive therapy (Segal, Williams, & Teasdale, 2002), treatments initially developed to help those with clinical manifestations of anxiety, depression and PTSD, were later found to be highly effective for non-clinical populations as well, helping people adapt to negative emotional experiences in daily life (Algoe & Fredrickson, 2011). By building on positive traits, states and relationships, health and well-being are cultivated and negative experiences meditated



(Fredrickson & Levenson, 1998). MRT is not a program of denying negative emotion. Rather it teaches the importance of understanding and managing emotions of both positive and negative origin. The idea is not to become pulled into downward spirals that make recovering from adverse events more challenging than they have to be. By developing reserves of positive emotion, protective as well as promotive factors for managing stress are established. Evidence shows that those who are better at self-generating positive emotion have higher levels of resilience and faster rebound rates from adverse events (Tugade & Fredrickson, 2004).

In the first MRT module emotional awareness is developed and the concept of resilience explored, including learning the core competencies: self awareness; self regulation; optimism; mental agility; developing character strengths; and building strong relationships.

In the second module: building mental toughness, recognition of self-limiting and counterproductive patterns of thinking are explored and tools for replacing them with more functional and productive thinking taught. Drawing on the work of Aaron Beck (1976), and Albert Ellis (1962), cognitive-behavioral based strategies include: Adversity-Beliefs-Consequences (ABCs); explanatory styles and thinking traps; identifying icebergs; energy management; problem solving strategies; catastrophic thinking; managing counterproductive thoughts in real time; mental chatter; and cultivating gratitude.

In addition to increasing awareness, exercises such as *best case, worst case, most likely scenario*, are taught to help soldiers mediate catastrophic cognitions and identify and dispute counterproductive thinking (Seligman, 2011a). Additionally, soldiers are taught how to *hunt the good stuff*, a perspective-building exercise, which also helps to increase positive emotion and offset negative thinking (Harms, et al., 2013).

The third MRT module teaches strengths identification and development. Using techniques such as a *trauma narrative* allows soldiers to see traumatic events as a fork in the road, identify the strengths employed, and notice the opportunities that developed as a result of even challenging experiences (Seligman, 2011a). For people facing life-threatening crises, identifying how and where strengths are most present (or can be activated) may facilitate a change in posture from passive receiver to active responder during highly stressful circumstances.

The fourth and final MRT module is building strong relationships. Having the support of others, even perceived support, has been demonstrated to improve well-being and decrease symptoms of depression and anxiety (Gable & Gosnell, 2011). Like all animals, suffering human beings often withdraw, compounding the sense of isolation that exacerbates depression. By increasing social support, learning healthy communication skills, engaging in relationships in a meaningful way, and knowing that it is ok to ask for help, soldiers can increase one of the essential ingredients of well-being— meaningful relationships (Harms, et al., 2013; Haidt, 2006; Seligman, 2011a).

### **From Posttraumatic Stress to Posttraumatic Growth-- Shifting the Bell Curve**

Soldiers trained in emotional resilience demonstrate greater emotional fitness, increased adaptability, reduced catastrophic thinking, increased coping skills, increased professional and social support, and are more optimistic about their lives and futures (Lester et al., 2013). Empirically validated interventions such as: *identifying signature strengths* (Peterson & Seligman, 2004), and *cultivating gratitude* (Emmons, 2007), as well as strengthening

relationships (Gable, Reis, Impet, & Asher, 2004) serve as reinforcers in the development of resilience and in keeping with the WHO's comprehensive model of psychological health (1948).

Concepts like sustainability (meaningful, forward momentum in life despite trauma) (Zautra, Hall & Murray, 2010) and posttraumatic growth, (positive changes that occur as the result of a major life crisis or trauma) (Calhoun & Tedeschi, 1999, 2004) are too often left out of the discussion when considering outcomes to traumatic events. The range of reactions following trauma roughly mirror the Gaussian distribution, from worse case scenarios including posttraumatic stress disorder (estimated between 4-15%) at the far left and clinical levels of anxiety and depression distributed in that direction, to languishing, subclinical levels of anxiety and depression, and moderate functioning making up the largest numbers in the center (estimated at approximately 70%), to flourishing and posttraumatic growth sitting at the far right (estimated between 10-15%) (Keyes, 2007; McNally, 2002; Seligman, personal communication, October 2015).

The goal in creating emotional resilience is not only to diminish the reaches of pathology, but to shift the entire (in this case Army) population toward thriving, moving those soldiers who predictably suffer a clinical diagnosis, as well as those experiencing subclinical levels of distress, into higher levels of functioning (even to thriving). According to Seligman (2011a), transformation following a traumatic event can and does occur. Even severe stress has the potential to reveal hidden talents, strengthen relationships, change priorities, and serve to reawaken meaning in life (Haidt, 2006). This is not about seeking out crises as a means to improving life, but having the tools and skill set to optimize functioning in the face of

unavoidable crises/challenges/traumas. The proverbial fork in the road is in making the decision between hope and despair when faced with significant adversity (Fredrickson 2009).

What ARVC and soldiers have in common are the ongoing stressors relative to ‘repeated deployments’ (aka recurrent crises), and threats to stability and safety that can occur without warning and in the midst of the more ordinary challenges of life. The MRT program provides a template not only for enduring ongoing stress, but offers psychological preparedness to aid dealing with anticipated and unanticipated challenges. It is the proactive and protective elements of this program that make it useful to individuals with life threatening illnesses or chronic degenerative conditions. While those living with ARVC are not going into literal battle, they face a battle of another kind. Medical technology has made surviving this formerly fatal disease possible. Positive psychology, through a civilian version of the CSF program, has the potential of making thriving with ARVC possible as well.

## XI. Civilian Resilience Training

*"Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and freedom." -Viktor Frankl*

Since 2009, Comprehensive Soldier Fitness (CSF) has been delivered to over 1.1 million U.S. Army servicemen and women, their family members, and Army civilians. In that time CSF has demonstrated effectiveness not only in helping the Army population better manage many of the day-to-day stressors they encounter, but in creating protection against future stressors by establishing a reserve of resilience that can be drawn upon in difficult times (Seligman, 2011a; Vergun, 2012).

Following closely in the footsteps of the U.S. Army, the proposed intervention for IAD populations, called *Civilian Resilience Training (CRT)*, incorporates a number of the elements of CSF. Delivery is designed to take place in three parts, combining *in-person* (introduction to the program and distribution of manual), *self-directed* (education and reinforcement exercises delivered through a take-home manual), and *telephone follow-up*. A fourth step, based on the military's *Battlemind Training Program*, an evidenced-based, post-deployment program used to mediate effects of PTSD, is offered as a post-shock intervention-- still preventatively based but an 'after-the-fact' intervention.

Civilian Resilience Training's (CRT) target group are IAD patients, age 18 & up. A second program will eventually be made available to primary caregivers of patients under age 18.

CRT should be introduced at the time of diagnosis or shortly thereafter, as evidence points to this time as a period both high in vulnerability and receptivity (Moskowitz, 2010). While diagnosis does not inevitably lead to aversive or pathological outcomes (Bonanno, 2004), how one processes the experience of a sudden, psychologically jolting event does (Abramson et al., 1978; Pauli, 1999; Maier & Seligman, n.d.; Moskowitz, 2010). As positive affect is a strong predictor of resilience at the ‘critical point’ of diagnosis, and is predictive of psychological and physical health trajectories thereafter (Moskowitz, 2010), it is theorized that by cultivating positive affect as soon after initial diagnosis as possible will confer better outcomes over the lifespan in the chronically ill.

### **Program Introduction Phase**

Patients will meet with their (CRT-trained) electrophysiologist, genetic counselor, nurse/nurse practitioner, or social worker at time of initial diagnosis (or shortly thereafter), who will discuss the normal range of reactions people have upon diagnosis of an unanticipated chronic or life threatening illness. Patients will learn that many people experience an initial (or sometimes delayed) reaction to hearing such news that may involve: shock, anxiety, anger, disorientation, sadness, helplessness. It is equally important to note that in addition to these feelings people also report: increased gratitude, deepened connection to family, renewed sense of commitment to life, enhanced spiritual connection, determination, and hope (Calhoun & Tedeschi, 1999, 2004; Seligman, 2011b; Tedeschi & Calhoun, 1995). Experiencing both positive and negative emotion is not uncommon, and in fact acknowledgement and acceptance of the full emotional spectrum is

an important feature in resilient reactions (Fredrickson, 2009; Fredrickson et al., 2000; Ong et al., 2006).

At this time patients will learn that the content that makes up the CRT program has been demonstrated to be effective in mediating anxiety and depression and improving coping skills in at-risk teens and Army personnel and their families (see section X of this paper for further discussion), and can help individuals better negate the effects of daily stress, as well as crisis-related stress, and reduce the incidence of anxiety and depression (Gillham et al., 2008; Lester et al., 2013). They will also learn that CRT is designed to build coping strategies and elevate positive affect. Further, patients will learn that dealing with day-to-day stressors in life can be challenging enough; dealing with the diagnosis of a chronic illness during childhood, adolescence, or young adulthood has the potential to increase the challenges of living with an IAD, make adjustment to diagnosis more difficult (Day, 2012; James et al., 2012). Finally, patients should be advised that CRT is intended to serve as a long-term navigation system—helping to keep them both on the road to a good life and providing reorientation during turbulent times.

By normalizing potential reactions and teaching patients about the benefits of prevention and promotion in the introduction stage, anxiety may be significantly mediated (Seligman, 2011b; Seligman & Fowler, 2011). Further, normalizing reactions to an aversive event is an important step in laying the foundation for posttraumatic growth (the capacity to flourish because of - rather than in spite of - traumatic events) (Tedeschi & McNally, 2011).

At the point of introduction, patients will be asked to begin the manual within a week of receiving it. This request should be followed by the first of three *follow-up calls*, to evaluate for

progress and/or encourage start of CRT program if that had not yet occurred. This call, which should take place approximately one month after diagnosis (or distribution of CRT) will also provide an opportunity to check on patient adjustment to diagnosis and/or ICD implantation, as well as reiterate the positive effects of resilience building.

With as few as three follow-up calls to review patient care plans, quality of life in ICD recipients has been demonstrated to be significantly increased (Lewin, Coulton, Frizelle, Kaye, & Cox 2009). This program has three follow-up calls from the healthcare provider's office included as part of the overall program. Suggested time frame for the calls are: one-month, three-months, and nine-months post diagnosis.

### **Self-directed Training Phase**

Patients will be asked to begin CRT by taking a short, anonymous quiz to measure pre-intervention levels of positive and negative affect: Positive and Negative Affect Schedule (PANAS). The PANAS is an online test and can be taken as often as they like, but as part of the CRT program, patients will be asked (through instructions within the manual) to take the PANAS at the start of the program and to repeat it semi-annually as a way to keep personal track of their positive and negative affect score (where higher positive to negative ratio is predictive of higher resilience) (Fredrickson, 2000; Fredrickson, 2013; Folkman & Moskowitz, 2000). Scores will remain private; patients will be the only ones with access to their scores.

The CRT manual is an at-home, self-guided program, designed to build emotional resilience, protect against potentially aversive effects of arrhythmogenic diseases and ICD



discharge, as well as enhance management of daily life stressors and promote thriving. Here are the three sections of the program:

**Part 1: Emotional fitness.**

The at-home part of this program starts with understanding (and identifying) emotions, what purpose they serve, why they are worth paying attention to, what control and lack of control over emotions can mean to the larger trajectory of one's life experience (Fredrickson, 2009; Fredrickson, 2013; Reivich & Shatté, 2002). This part of the program will include awareness of moment-to-moment emotions (Lane & Schwartz, 1987), and the relationship between mind, body and health outcomes. The module will cover the importance of honoring the full range of emotional experience (and creating access to the emotional handbrake where and when necessary), and exploring when both positive and negative emotions are adaptive, and when they are not, thus demonstrating that each emotion has its purpose and limitations (Fredrickson, 2009; Kashdan & Biswas-Diener, 2014; Tugade & Fredrickson, 2004).

In this step healthy responsiveness in moment-to-moment experiences, known as *emotional agility* (Algoe & Fredrickson), is developed and the importance of regular training to help emotional fitness to grow is encouraged (Loehr & Schwartz, 2003).

The motto for this first module: *Knowledge equals power.*

The skills developed in this module include: *increasing self-awareness*, including exploration of thoughts, emotions, behaviors, and patterns of thinking, and how they serve and do not serve (Reivich, Seligman, & McBride, 2011); *increasing self-regulation*, which is how to manage thoughts, behaviors and emotional states and cultivate sense of control (Reivich et al.,

2011); *cultivating optimism*: noticing the good in self and others, identifying difference between what can be controlled and what cannot, building positive reserves (Reivich et al., 2011); and *thought-emotion patterns*, ABCs: (Adversity—Belief—Consequence), identifying the relationship between thoughts/feelings and outcomes (Reivich & Shatté, 2002).

### **Part 2: Building mental endurance.**

This module involves recognizing patterns of thinking that are self limiting and counterproductive, such as catastrophizing, and replacing them with more functional and productive thinking. Exercises include *best case*, *worst case*, *most likely scenario*, and *identifying icebergs*, (deep-seated beliefs that drive daily decisions and interactions), inviting patients to notice and challenge thought chains that fuel negative thinking (Seligman, 2011a). Albert Ellis (1962) identified that it is our belief about events, not (only) the events themselves, that drives emotions and behaviors. This theory is reinforced as reorienting strategies are developed.

Antianxiety and antidepressant skills are also taught in this module through visualization, meditation and deep breathing, to help mediate psychological and physiological stress responses and thereby increase sense of control (Harms, 2013). This stage of the training explores how to manage negative emotion, but the real power in it is in cultivating positive emotion. Patients are taught how to *identify the gifts*, in an exercise designed to help build perspective, further increase positive emotion and offset negative thinking (Harms, et al., 2013). The goal is to show patients how regulation of the emotional spectrum contributes to emotional resilience by reinforcing

coping mechanisms ‘before’ significant adversity strikes, and in doing so develop reserves of resilience that can be drawn on in challenges times to come (Algoe & Fredrickson, 2011; Seligman et al., 2013). Evidence based interventions to increase the ratio of positive to negative affect, building the positive and thereby reducing the impact of the negative (Algoe & Fredrickson, 2011) are offered as part of this module.

A final component of this part of the program will be the use of meditation to both develop resilience against anxiety and depression (though skills such as *decentering the mind*, and *cultivating observer’s mind* -- where one learns to notice more but react less) and mediate the effects of subclinical levels of anxiety and depression through the use of mindfulness based meditation practice (Goyal, Singh, & Sibinga, 2014). Loving kindness meditation has further been demonstrated to increase positive emotion and decrease negative thoughts (Fredrickson, Cohn, Coffey, Pek, & Finkel, 2008), improve vagal tone (considered a biomarker for healthy mind-body resiliency) (Kok et al., 2013), and relax the heart (Law, 2013). Both a 20 minute loving kindness meditation, and a 20 minute mindfulness meditation will be available online for patients to use, and they will be encouraged to alternate meditations and to use one each day.

Motto for this module: *Everyday through thought, word, and deed, a stone in the foundation of your life is being laid. What are you building?*

The skills developed in this module include: *exploring explanatory styles*: habitual ways of looking at the world to explain the things that happen, reinforcing either a pessimistic or optimistic outlook (Reivich et al., 2011); *knowing your thinking traps*: patterns of thinking applied to present experiences that can be counterproductive and/or excessively rigid, compromising accuracy in thinking (Reivich et al., 2011; Reivich & Shatté, 2002:); *detecting*

*icebergs*: deeply rooted ideals/belief/values that influence perceptions— for instance “men shouldn’t cry,” reexamined for measure of accuracy and influence on present day life (Reivich & Shatté, 2002); *calming catastrophic thinking*: ruminations (worst-case scenario thinking) are explored and a model for disputing the same (best-case, worst-case, most likely) is practiced (Reivich et al., 2011); *cultivating gratitude*: building a positive portfolio to capitalize on positive events and grow positive emotion; and cultivating inner calm (through meditation exercises).

### **Part 3: Action plan.**

While most people would like to avoid an ICD firing, in arrhythmogenic disorders, where ICD serves as a primary or secondary line of defense from SCD, ICD discharge is a distinct possibility (in ARVC populations, specifically, shocks are highly likely). Having a shock plan with an organized response may help to minimize negative responses (Sears, Shea, & Conti, 2005) by mediating negative thoughts (Godeman et al., 2004) and establishing a sense of control over aversive events, which is critical to better psychosocial outcomes (see section VI for a detailed discussion). Emergency plans that include active pre-planning, direct coping (as opposed to avoidant styles), and flexible problem solving are linked to higher degrees of well-being and increased capacity to handle stress, trauma, and illness outcomes (Southwick et al., 2005). By managing pre- and-post firing cognitions, the meaning associated with ICD discharge may help to reduce fear and helplessness (rather than exacerbate it), and thus mediate potentially negative impact to quality of life (Hegel et al., 1997; Sears et al., 2005; Seligman, 2011b).

The explanatory style one applies to shock is a major contributor to the experience and how that experience impacts subjective well-being and physical health (serving as either a reinforcer or mediator of distress) (Maier & Seligman, n.d.; Seligman, 2011a). One's sense of personal control and the intensity of experienced symptoms have been found to be inversely correlated among patients with post implantation anxiety and depression (Sola & Bostwick, 2005). Even inaccurate explanations that create an 'illusion of control' have been shown to mediate anxiety (Sola & Bostwick, 2005). This section focuses on both preparation for what are likely to be highly stressful events, and how such events can be experienced and interpreted to mitigate potential deleterious effects.

Motto for this module: *Prepared for life.*

In this module the following skills will be developed: creating a personalized shock plan; sharing plan with trusted others; building the patient's familiarity with plan.

### **External Support**

Borrowing from the success of self-help group models (Alcoholics Anonymous for example), wherein more seasoned members self-select to provide guidance or mentorship to newer members, (thereby both giving and receiving benefit) (Gable & Gosnell, 2011), this part of the program will rely on a volunteer army made up of those who have had an IAD + ICD for more than 5 years, have experienced at least one shock, and demonstrate positive adjustment to their circumstances. Volunteers will be trained in CRT, and will be 'paired' with another patient to offer support. This is not therapy; the intention is to reinforce the training as presented in CRT

and have both parties benefit from reinforcement of resilience strategies and the resulting reciprocated support that is developed.

#### **Part 4: Post-shock intervention.**

Following the model of *Battlemind Training*, wherein soldiers who have experienced a traumatic event meet with fellow soldiers and trained leaders (in a group format), not for the purpose of rehashing the details of the trauma but to receive support for and normalization of their reactions, to be supported in regulating hypervigilance, and reinforce resilience training (McNally, 2012), I have devised this post-shock intervention. While arranging for a facilitated, face-to-face group of IAD + ICD patients is not likely (do to the limited number of people in this population), this intervention may still be effective. As part of the post-shock action plan, patients will be encouraged to make a phone call to a trained patient-volunteer (as described above) who will be at the ready to help defuse the emotional reactivity at a particularly vulnerable (and reinforceable) time.

While some research suggests it is shock accumulation (total number of shocks) that determines poor quality of life outcomes in ICD patients, others have found that *interpretation* of shocks causes the negative effects (Maier & Seligman, n.d; Pauli et al., 1999; Seligman & Maier, 1967; Sola & Bostwick, 2005). According to Sears & Conti (2002), patients' response and recovery to first shock has "prognostic implications" for post-shock outcomes. Quality of life in patients who receive shocks is often decreased while anxiety and concerns over health increase, and sadness is pervasive (Sola & Bostwick, 2005). Post-shock is a critical time in terms of

helping patients to (re)establish a sense of control, and mediate feelings of helplessness, a significant factor in poor psychological outcomes (Pauli et al., 1999; Sears & Conti, 2002).

The purpose of this post-shock support call is provide patients the experience of support in identifying, normalizing, and reframing reactions; to reinforce those aspects of CRT responsible for establishing a sense of control, such as catching catastrophic cognitions, identifying thinking traps, and using optimistic explanatory styles to promote upward spirals. It is also intended to re-emphasize the CRT teachings; and to encourage leaning on others for support, thereby discouraging isolation.

Having the support of others, even perceived support, improves well-being and decreases depression and anxiety (Gable & Gosnell, 2011). Like most animals, when human beings are suffering, they often withdraw, compounding the sense of aloneness and exacerbating anxiety and depression. There is a saying in recovery programs when people are experiencing a particularly vulnerable period: *left to your own thinking you are in bad company*. By establishing an immediate (or near immediate) post-shock connection, the patient has the opportunity to mediate some of the known negative effects of shock outcome.

Motto for this module: *Reaching out to regain perspective*.

In this module the following skills will be developed: learning how to ask for support; normalizing and reframing reactions; (re)establishing a sense of control; relying on CRT tools and developed skills when they are needed most.

**Final thoughts**

By providing the CRT program not only to ‘at-risk’ patients but to all patients diagnosed with an IAD, they will be armed with the skills necessary to better adjust to and manage the challenges that living with such illnesses can create. While not a panacea for all of the challenges that IAD patients and their families will encounter, this program lays the foundation to better prepare patients to navigate the road ahead.



## **XII. Conclusion: Where do we go from here?**

### **From Surviving to Thriving**

While those living with inherited arrhythmogenic disease (IAD) and implantable cardioverter defibrillators (ICD) do not face the same challenges as soldiers dealing with the complexities of military life in a time of global unrest, these populations do share parallel experiences in their need to cope with persistent stressors, coupled with a high degree of uncertainty and threats to life over extended periods of time. The necessity for individuals with chronic disease to cultivate and operationalize strategies for dealing with anticipated and recurrent challenges is clearly warranted. Evidence points to compromised resilience as a significant risk factor in experiencing increased stress, depression, anxiety, and negatively impacting interpersonal relationships (Masten & Wright, 2010; Meichenbaum, 2007). In individuals with chronic disease, the accumulation of stressors that accompany the management of their disease (such as ICD shocks and the ever-present risk of sudden cardiac events) as well as the garden-variety stressors of life, can outpace coping ability. The resultant diminished functioning, further reducing the capacity to effectively manage adversity, increases the potential for psychopathology (Bonanno, 2004; Bonanno & Mancini, 2012; Masten, 2001; Zautra et al., 2010).

The ideal, then, is to prevent clinically relevant suffering, rather than treat pathology after-the-fact. Building a diagnosed individual's emotional resilience in anticipation of the stressors to come offers protection against persistent adversity and complex psychosocial outcomes (Lester et al., 2013; McNally, 2012).

Resilience is made up of a number of distinct and empirically validated elements, including: positive emotion, engagement, supportive relationships, meaning, accomplishment, physical fitness, and spiritual health (Meichenbaum, 2007; Rashid, 2015; Ryff & Singer, 1998; Seligman, 2011a, 2011b). While this is not an exhaustive list, these seven areas represent the significant features of human flourishing. In an ideal world, all patients would have access to a full-scale plan to prevent the negative impact of cumulative stress or potentially traumatic events, while promoting resilience and well-being, in each of these domains, (Rashid, 2015; Seligman, 2011). Resources of time and energy, however, necessitated that the scope of this paper focus primarily on emotional resilience. This should not mislead one to believe that these other, independent elements are ‘asides.’ Rather, each deserves specific attention in future writing on the subject of chronic illness and human flourishing, and a prominent place in a more integrated intervention model.

That said, the primary foundation of successful adaptation (a precursor to thriving) is emotional resilience. If emotions are the *shapers of our experience* (Algoe & Fredrickson, 2011), then this is where resilience building must begin. Positive interventions that put the break on downward spirals have been shown to be effective, not only in recovery from aversive events, but in protection of physical health (Algoe & Fredrickson, 2011; Keyes & Eduardo, 2012) and in promoting sustainable well-being (Keyes, 2007; Westerhof & Keyes, 2010). Emotional fitness, developed and maintained overtime, can negate the harmful effects of negative events while improving mental and physical health (Cohen & Fredrickson, 2009).

Through the use of self awareness, cognitive restructuring, and building positive emotion, downward spirals are not only interruptible but reversible (Algoe & Fredrickson, 2011;

Fredrickson, 2009; Reivich et al., 2011; Seligman, 2011a, 2011b). Emotional fitness helps people capitalize on those momentary experiences that cumulatively (and often subtly) create the very tide that impact physical and emotional health over a lifetime (Algoe & Fredrickson, 2011). Emotions turn experiences into embedded memories and protracted events, with interpretations and reinforcing cognitions fueling the fire. This is not to suggest that negative responses to crises or traumas are inappropriate or unwarranted (please see the section VII for further discussion). Quite the contrary— suffering following such events is both expected and appropriate (Calhoun & Tedeschi, 1999, 2004). But persistent, *unregulated*, negative emotion can lead to pervasive feelings and states that contribute to chronic suffering and pathological outcomes (Fredrickson, 2009; Keyes & Eduardo, 2012; Seligman, 2011a).

For patients with arrhythmogenic disorders, the relationship between stress, strong negative emotion, and arrhythmia has been established (Lampert, 2010). Left unchecked, anxiety and depression have the potential to lead not only to downward spirals, but to set off a cycle of distress that can bring about misattribution of symptoms, increased shocks, reduced quality of life, psychopathology, and increased morbidity/mortality (Keyes & Eduardo, 2012; Ryff & Singer, 1998; Sears et al., 2001; van den Broek et al., 2009). Helping patients adjust to new and often challenging circumstances is critical to successful adaptation, particularly in the face of illnesses with known recurrent risks for compromised adjustment and/or functioning (Feder et al., 2010). As previously noted, the range of response to major life crises extends from PTSD and pathology, to depressed functioning and languishing, to flourishing and posttraumatic growth. Unfortunately, mainstream healthcare maintains a reductionistic, binary view, leaving

those not 'sick' enough to qualify for treatment, yet not well enough to thrive, in something of a no-man's land, left to sort out the details on their own.

ARVC is a complex disease from a physical and diagnostic perspective, yet highly survivable thanks to modern medicine, particularly with the advent of the ICD. But, like many chronic illnesses, it is also a disease that poses known risks from a psychosocial and quality of life perspective. This reality deserves to be overtly acknowledged and addressed directly, not as an afterthought. In positive psychology, where the emphasis is on preventing and promoting rather than pathology, one need not wait for clinical symptom development to offer interventions that protect against suffering and promote flourishing. The beauty of the intersection between IAD and positive psychology is that it eliminates the question - for whom is psychological support appropriate or warranted?, and instead makes the case that *all* human beings deserve access to strategies that improve the human condition by cultivating meaning and increasing well-being. Those facing chronic, degenerative illness deserve information and access to such strategies as a *primary* defense against potential consequences from both their diagnosis and treatment. They deserve more than a life of surviving; they deserve a pathway to thriving. Civilian Resilience Training provides such a pathway.

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## Appendix A

### Key to Abbreviations

ARVC:	Arrhythmogenic right ventricular cardiomyopathy
CRT:	Civilian resilience training
CSF:	Comprehensive Soldier Fitness
IAD:	Inherited arrhythmogenic disease
ICD:	Implantable cardioverter defibrillator
PANAS:	Positive and negative affect scale
PRP:	Penn Resiliency Program
PTG:	Post traumatic growth
PTSD:	Post traumatic stress disorder
SCA:	Sudden cardiac arrest
SCD:	Sudden cardiac death
VF:	Ventricular fibrillation
VT:	Ventricular tachycardia