

# Stages of psychological impact after diagnosis with serious or potentially lethal cardiac disease in young competitive athletes: A new model<sup>☆</sup>

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## Abstract

**Importance:** Sudden cardiac death (SCD) in sports is a tragic event. Pre-participation cardiovascular screening is required before participation in high school and college athletic programs and is universally endorsed by major medical societies. The medical impact of a diagnosis may be life-saving; however, the detection of disease should not be the sole endpoint of care. Physicians have an obligation to attend to both the medical and psychological well-being of their patients.

**Objective:** To determine the psychological impact of being diagnosed with cardiac disease in young competitive athletes.

**Design:** Athletes diagnosed with cardiac conditions were recruited to participate in a semi-structured interview, which was analyzed by sport psychology experts using qualitative research. Individuals shared reactions and experiences regarding diagnosis, lifestyle implications, coping strategies, major concerns, and overall impact on psychosocial functioning.

**Setting:** Young competitive athletes from across the United States.

**Participants:** 25 athletes (52% male, 80% Caucasian, median age 17.7) participated. Diagnoses included: 5 hypertrophic cardiomyopathy, 8 Wolff Parkinson White, 4 long QT syndrome, 3 atrial septal defect, 2 supraventricular tachycardia, and 3 other.

**Main outcome measures:** Interviews were analyzed using consensual qualitative research (CQR) to identify domains, categories, and core ideas.

**Results:** Athletes progressed through 4 stages of psychological impact including: 1) immediate reactions and challenge to athlete identity, 2) grief/coping, 3) adaptation, and 4) acceptance. Risk factors for increased psychological morbidity included: higher level of competition, permanent disqualification from sports, persistent reminders (e.g. daily medication, monitoring heart rate during activity), and unanticipated outcomes (e.g. failed procedures). Those undergoing simple corrective procedures came to terms with their diagnosis quickly with little impact on daily life. Few athletes described emotional support mechanisms provided by medical programs. Diagnosis often led to new goals such as mentoring or coaching. All athletes diagnosed through advanced cardiovascular screening stated they would repeat the process.

**Conclusions and relevance:** Athletes diagnosed with cardiac disease represent an emotionally vulnerable population and experience 4 stages of psychological adjustment not previously described. This proposed model of psychological impact should be used to develop improved support mechanisms, awareness, and education to assist athletes diagnosed with serious or potentially lethal cardiac disease. © 2015 Elsevier Inc. All rights reserved.

## Keywords:

ECG; Sudden cardiac death; Prevention; Electrocardiogram; Sport; Athlete; Exercise; Psychology

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## Introduction

Cardiovascular screening is a common practice in sports medicine. A research agenda produced by a working group of the National Heart, Lung, and Blood Institute (NHLBI)

outlined a critical need to understand the psychological impact of cardiovascular screening in athletes [1]. Previously, we examined the psychological implications of cardiovascular screening in athletes, both with and without utilization of an electrocardiogram [2]. A follow-up study with a larger sample size further examined psychological implications in subgroups based on age, race, and gender [3]. Results of these investigations demonstrate that the small number of athletes diagnosed with cardiac disease, regardless of screening modality, appeared most vulnerable to psychological morbidity and highlighted the need for further study in this area [2,3].

The demands of being a young athlete are unique and often different than the general population. The stress of athletics, maintaining academic standards, and challenges associated with adolescence and independence are distinctive. In addition, young athletes are generally healthy, rely heavily on their fitness and athletic success as a measure of self-esteem, and are rarely diagnosed with chronic conditions at their young age. The diagnosis of a cardiac disease and the threat of being restricted from athletic activity could form the basis for profound psychological morbidity. The purpose of this study was to determine the psychological impact of being diagnosed with serious or potentially lethal cardiac conditions in young competitive athletes with the goal of better characterizing their experiences, coping mechanisms, and risk factors for adverse emotional consequences.

## Methods

The study followed a qualitative design. Participants in the study included individuals, aged 14–35, diagnosed with a cardiac condition while they were competitive athletes. Athletes were included if they had been diagnosed with a cardiovascular disease that required medical surveillance, further evaluation, or treatment. All participants were >6 months beyond their initial diagnosis to allow for adequate reflection surrounding their experiences. To broadly understand the psychological implications of being diagnosed with a cardiovascular disease, we chose not to limit our study to disqualified athletes only.

Athletes were recruited (February 2013–November 2013) from several sources including community heart screening programs, high school and college team physicians, primary care physicians, and cardiologists. Once athletes agreed to participate, they underwent a recorded semi-structured telephone interview using ten questions to guide dialog (Fig. 1: available online at XXX web address or by request). Interviews lasted 30–60 minutes. Questions investigated the athlete's experiences during and after diagnosis, impact on relationships, coping mechanisms, attitudes toward medical care and treatment, perceived restrictions or limitations, views on screening for cardiac disease, and outlook on life. For consistency, all interviews were conducted by the same individual (IA).

## Data analysis

Audio interviews were transcribed verbatim for analysis. A team of sport psychology experts analyzed each transcript

through consensual qualitative research methods [4]. Each investigator from this team read all interviews several times independently to understand the entire content. The team then met to develop domains, categories, and core ideas across cases (i.e. themes and sub-themes) [4].

Rigor of data analysis was ensured by several means. The sports psychology team was compiled of members from different backgrounds (1 primary care sports medicine physician, 2 doctors of sports psychology, and 3 doctorate students in sports psychology). Each member of the sports psychology team also read all of the interviews individually to avoid potential bias. Disagreements or inconsistencies were discussed during team meetings and resolved by consensus. Additionally, analysis of interviews only occurred once thematic saturation had been achieved (i.e. when no new themes occurred, the data collection was deemed to be complete).

This study received institutional review board approval.

## Results

Twenty-five athletes (52% male; 80% Caucasian, 16% black/African American, 4% other) participated. The median age at diagnosis was 15.2 years, and the median age at the time of interview was 17.7 years. 80% participated in high school sports and 20% college sports. Diagnoses included: Wolff Parkinson White (WPW) syndrome (n = 8), hypertrophic cardiomyopathy (HCM) (n = 5), long QT syndrome (LQTS) (n = 4), atrial septal defect (ASD) (n = 3), supraventricular tachycardia (n = 2), partial anomalous pulmonary venous return (n = 1), bicuspid aortic valve with aortopathy (n = 1), and coronary artery anomaly (n = 1). 3 athletes were disqualified from all competitive sports participation, including 2 college athletes and 1 high school athlete. 1 college athlete twice failed a catheter ablation for SVT and chose self-discontinuation from athletic participation. 1 athlete received an implantable cardioverter defibrillator at the end of high school, but chose not to participate in college athletics. 2 athletes were disqualified from high intensity activity, but still participated in a low intensity sport as an alternative. Specific information for each athlete, including demographics, methods of disease detection, treatment, and sports participation outcome is shown in Table 1 (available online at XXX web address or by request).

Five key domains (themes) emerged from these interviews (Table 2: available online at XXX web address or by request). These domains were incorporated into a new model detailing the *Stages of Psychological Impact for Athletes Diagnosed with Serious or Potentially Lethal Disease* (Fig. 2). The first four domains each comprise a stage within the model, while the fifth domain characterizes the risk factors associated with increased or prolonged psychological morbidity.

### *Stages of psychological impact for athletes diagnosed with serious or potentially lethal disease*

The psychological impact that athletes experienced after learning about their cardiac disease progressed through four successive stages: 1) immediate reaction and challenge to

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