

# **Empowerment of Athletes with Cardiac Disorders: A New Paradigm.**

Rui Providencia <sup>(1)</sup> MD PhD, Carina Teixeira <sup>(2)</sup> PhD, Oliver R. Segal <sup>(1)</sup> MD, Augustus Ullstein <sup>(3)</sup> QC, Kim Mueser <sup>(2)</sup> PhD, Pier D. Lambiase <sup>(1,4)</sup> PhD

<sup>1</sup> - Barts Health NHS Trust, London, United Kingdom; <sup>2</sup> – Centre for Psychiatric Rehabilitation, Boston University, Boston, Massachusetts, United States of America; <sup>3</sup> – 39 Essex Chambers, London, United Kingdom; <sup>4</sup> - University College of London, London, United Kingdom.

**Corresponding author:** Pier D. Lambiase, Professor of Cardiology,

Institute of Cardiovascular Science, University College of London

Barts Heart Centre, Barts Health NHS Trust,

West Smithfield,

London EC1A 7BE, United Kingdom.

e-mail: pierlambiase@hotmail.com

**Telephone number:** +44 020 3765 8647

**Fax:** +44 020 7791 9670

**Perspective**

**Total word count:** 5,313

**Sources of Funding:** CT was funded by the Advanced Rehabilitation Research Training program (Grant #90AR5018) of the National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR), housed within the Agency for Community Living (ACL) at the Department of Health and Human Services (HHS). The contents of this project do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the US Federal Government. PL was supported by University College of London Hospitals Biomedicine Research Centre, a Partnership between University College of London and University College of London Hospitals NHS Trust, funded by the National Institute for Health Research (NIHR); British Heart Foundation.

**Competing Interests** – none.

**Acknowledgements:** none

## **Abstract**

Athletes with cardiac disorders frequently pose an ethical and medical dilemma to physicians assessing their eligibility to participate in sport. In recent decades, patient empowerment has been gaining increasing recognition in clinical decision-making. Empowerment is a process through which people are involved over the decisions and actions that affect their own lives. In the context of a cardiac disorder, empowerment means giving an athlete the chance to participate in the decision about whether or not to remain active in competition. Three models of treatment decision-making are described in this paper, with progressive levels of empowerment: the paternalistic model (the athlete has a passive role), the shared-decision making model (both athlete and physician participate in the decision) and the informed-decision making (the decision is made by the athlete while the role of the physician is solely to provide information). This paper critically discusses the issues involved in disqualification of athletes with cardiovascular disorders and suggests possible ways of incorporating patient empowerment in potentially career-ending decisions. The authors propose a model of empowerment, which gives patients the opportunity to choose how much, and if, they would like to be involved in the decision-making process.

**Key-words:** Shared decision-making; informed decision; paternalism; sudden cardiac death; cardiac disease; sport; arrhythmia.

**Abbreviations:** SCD – sudden cardiac death; ICD – implantable cardioverter defibrillator; AED – automatic external defibrillator.

## **Background**

The diagnosis of a cardiovascular disorder in a competitive athlete very frequently leads to the discontinuation of their sporting career due to concerns of disease progression and exercise-induced sudden cardiac death (SCD) [1]. However, potential career-ending decisions are complex, associated with medical, ethical and legal challenges [2], and may result in significant psycho-social and economic adverse consequences for the athlete [3].

In recent decades, patient empowerment has been gaining increasing momentum in clinical decision-making [4]. In this paper we consider the issue of athletic disqualification in the full spectrum of cardiovascular disease, including cardiomyopathies, channelopathies, congenital heart disease, valvular heart disease, among others. Three subgroups of patients deserve additional considerations, besides the scope of this paper. Firstly, patients with structural conditions such as aortic stenosis, congenital coronary malformations and aortic aneurysms, due to their specific requirements, namely timely diagnosis and appropriate surgical correction. Secondly, patients with coronary artery disease as emphasis should be put on optimization of drug therapy, control of risk factors, and percutaneous or surgical revascularization. Lastly, athletes aged less than eighteen years pose specific challenges as they may not have the maturity or experience to weigh up these complex issues, they are subject to specific legal restrictions, and legal guardians should be involved in the decision-process [5].

### **I. Arrhythmic disorders and the risk of sudden cardiac death**

## 1. To disqualify or not to disqualify?

Disqualification of an athlete with an arrhythmic disorder poses an ethical challenge in that some will not have previous documentation of serious exercise-induced arrhythmia and do not have traditional risk markers (e.g. left ventricular dysfunction) [6]. Therefore, a physician assessing an athlete's risk may face a dilemma: the athlete may have a condition which generally increases the risk for severe ventricular arrhythmia but specific high risk markers may be absent or not known (e.g. some individuals with inherited cardiomyopathy may have a mild phenotype and therefore may have a risk indistinguishable from the general population). On the other hand, by using the HCM risk-SCD risk prediction model, which has a c-statistic of only 0.70, corresponding to moderate discrimination of risk of sudden cardiac death, the 5-year risk for individuals in the highest risk strata is still in the range of >6% over 5years [7], which means that for some of them, even if they were allowed to compete for 1 or 2 years, the chances of *not* experiencing an event are considerable. Other possible criticisms of the risk prediction model, which is still the best tool we have at the moment, reside in the fact that it still lacks validation in athletes.

In some countries, even when doubt about any significant risk exists and this is estimated to be low, the decision to disqualify a person from sport is frequently made due to the potential for future lawsuits in the event of a life-changing (eg. hypoxic brain injury) or fatal outcome [5]. Even when this is not a motivating factor, the decision-making process in this context is heavily biased towards disqualification from a physician's perspective. Physicians have little or nothing to lose personally by being conservative in their recommendations to disqualify athletes, whereas a less conservative approach poses a greater risk to their reputation and to personal feelings of guilt and shame if their athlete has a lethal event. Expert consensus guidance can help mitigate this risk of bias and facilitate informed decision-making.

On the other hand, possible benefits or incentives to the physician by allowing a more active role of the athlete, and even sharing decisions, may be less clear. First, the physician should

acknowledge that athletes are human beings whose rights should be respected, and as such, they are currently entitled to have a word in their health-related decisions. Second, as disqualification in situations of unclear, or uncertain risk can very frequently have disastrous consequences to the individual, physicians should not want to have the onus of destroying individuals' lives and dreams based on scarce evidence, fear of extremely unlikely arrhythmic events (which can now very often be successfully reverted by automatic external defibrillators – AEDs), and resistance to abandoning an old-fashioned and unethical paternalistic approach. Third, allowing athlete participation in the decision-process will enable the development of a more transparent relationship, with better collaboration, truth (avoiding omission of important facts while collecting clinical history) and exchange of information, avoiding the risk of “*doctor shopping*”. Paternalistic physicians should be aware that athletes may be prone to looking for more permissive physicians, instead of physicians with more expertise, who can give them clearer and better information and advice. Lastly, when athletes with “*grey zone*” cardiac conditions (where the risk is uncertain or not known) willingly accept a hypothetical risk, a close physician-athlete relationship will be of utmost importance to advance scientific knowledge in the area, and ascertain the true magnitude of risk and disease progression arising from exposure to competitive sports. Table 1 summarizes the main arguments relating to athlete empowerment.

An intermediate path may constitute an appealing alternative to physicians not willing to follow this dichotomous approach (“*to disqualify or not to disqualify*”). To involve the athlete in a shared-decision comprising continuation of competition with an AED available, and under intensified monitoring through an implantable loop recorder, or an implantable cardioverter defibrillator if the patient meets guideline criteria, may be an option. Another fulfilling option for some athletes would be continuation of a different sport or in a less intensive way, or even transitioning to alternative career paths, like coaching or related.

## 2. What do the Experts say?

Expert Consensus documents from two organisations exist for providing recommendations for sports practice in individuals with different cardiac abnormalities (the *American Heart Association and American College of Cardiology* 2015 scientific statement [8] and the *Working group on Sports Cardiology of the European Society of Cardiology (ESC)* consensus document [9]). However, strong evidence (if any) regarding most of the conditions was absent at the time of writing of the European document, and this is still an issue with the new American document, as it is predominantly based on a consensus of expert opinion..

Some of the recommendations appear to be inconsistent with current knowledge about some of these disorders. For example, most patients with hypertrophic cardiomyopathy will have a normal longevity and many do not develop severe ventricular arrhythmias [10]. A randomized controlled trial demonstrated that moderate-intensity exercise training was associated with a significant increase in exercise capacity, as measured through peak oxygen consumption, in individuals with hypertrophic cardiomyopathy [11]. This improvement occurred at the expense of no ventricular arrhythmia events. However, guidelines are very restrictive for this group of patients if they have any phenotypic expression of the disease. Equally, the authors of the American consensus recognise the limitations of knowledge in this field stating- *“Although this expert consensus report serves as a prudent guideline regarding sports eligibility or disqualification, there will always be tolerance in the system for some degree of flexibility, individual responsibility, and choice in making these decisions for individual student athlete-patients”*. Indeed for recently described entities, like isolated non-compaction of the left ventricle, which might affect as much as 8% of the athlete population [12], recommendations are absent in the European document [9], and in the new American consensus it is stated that, until more evidence is available, participation in competitive sports may be considered in the

absence of left ventricular systolic function impairment, or documented important atrial or ventricular arrhythmias, or unexplained syncope [13].

Even though the new American scientific statement [14] is more liberal regarding channelopathies and supports participation under certain conditions, on the bases of recent findings [15, 16], the 2005 ESC recommendations [9] advise that these individuals should not be involved in competitive sports or should be excluded from most competitive sports, with the possibility of those of low intensity sports (Classification of sports is based on Mitchell et al. [17]).

The changes in the recent update of the American recommendations illustrate how much knowledge in the field of risk stratification, technology (ICDs and AEDs), athlete's heart and sports medicine has evolved in the last few years. However, there are still a lot of unknowns in the field, and the advice physicians can provide to athletes should by no means be regarded as definitive, reinforcing the need for regular assessment of these highly-trained individuals.

### **3. Is there an effective treatment/prevention for sudden cardiac death?**

The results of the *“National Registry for AED Use in Sports”* confirmed the effectiveness of AEDs, providing support for these devices in strategic locations for the prevention of SCD during sports [18]. Analysis of arrests occurring during physical activity in this North American observational prospective study revealed that almost 90% of student athletes and adults who arrested during physical activity survived to hospital discharge. Witnessed arrests, and those happening in the setting of ventricular arrhythmia with cardioversion/defibrillation performed onsite had higher chances of survival to hospital discharge.

A recent retrospective series of 291 children with long QT syndrome managed without ICDs supports the effectiveness of AEDs in this channelopathy, with 100% successful AED rescues

[19]. Events were rare ( $\approx 1\%$ ) during  $> 1,700$  patient-years follow-up (i.e.  $< 0.2$  per 100 patient-years). Only one out of the three events occurred during exercise, indicating that in appropriately treated patients these events are rare and sports restriction still leaves patients exposed to a low risk of life-threatening arrhythmia.

Therefore, provision of AEDs is a key aspect to prevent SCD in patients without known cardiac disease, previous events or an indication for an ICD is now contemplated in the new *American Heart Association* and *American College of Cardiology* scientific statement -AEDs should be made available in sports, whether competition, training, practice, either in schools or other organizations hosting athletic events, or providing training facilities for organized competitive athletic programs [20].

However, some athletes may already have been implanted with an ICD. Should they be disqualified because of concerns regarding the implanted devices in competitive sports? The “*ICD Sports Safety Registry*” has provided very important preliminary data regarding this population [21]. No occurrence of tachyarrhythmic death, externally resuscitated tachyarrhythmia during or after sports, or severe injury resulting from arrhythmia-related syncope or shock during sports was observed in the 372 participants followed during a median of 31 months, suggesting that athletes can engage in sports without physical injury or failure of the ICD to terminate the arrhythmia.

Accordingly, the new *American Heart Association* and *American College of Cardiology* scientific statement now allows the participation of athletes with ICDs in higher intensity sports if certain pre-requisites are met [22], suggesting progression into a more permissive approach across the Atlantic as knowledge in the subject grows and some of the previous concerns are not confirmed. However, if there are other reasons to restrict sports practice, like arrhythmogenic right ventricular cardiomyopathy with documented progression while in



competition, the recommendations state that ICD implantation should not be seen as a way to continue participation.

## **II. Should the patient be involved in the decision?**

### **1.1 The concept of empowerment**

Empowerment is a widely used concept which can be generically defined as a process through which people who are disenfranchised gain more control over the decisions and actions that affect their own lives, acquire rights, decrease marginalization and achieve life goals [4, 23-25]. The verb “empower” means both “conceding power to others”, and “gaining or assuming power” [26]. A seminal definition of power was provided by *Max Weber* who stated that people have power when they can enforce their own will, even if others try to oppose them [27]. Empowerment can be measured as the “existence” of choice, the “use” of choice and the “achievement” of choice [28].

### **1.2 Proposed model of empowerment for competitive athletes**

The process of empowerment requires a reformulation of the discrepancies in power between those who have it and those who do not [29]. According to *Rappaport* empowerment implies a relational dimension and means moving away from a paternalistic/controlling approach to a relationship that emphasizes people’s rights and responsibilities [29]. This is particularly relevant in health services, where empowerment involves a change in power-based relationships between the person who uses services and the health professional [30], where the first have a passive position and the latter exercises the power. Currently, the dominant medical approach towards competitive athletes may be considered paternalistic. Paternalism

is a pattern of behaviours, by a person or organization, which limits liberty or autonomy on an individual for that person's or group's own good, regardless of the will of the individual [31].

*Chamberlin* argues that having decision-making power and access to information are key elements of empowerment [32]. These two aspects are closely related since *"decision-making shouldn't happen in a vacuum. Decisions are best made when the individual has sufficient information to weigh the possible consequences of various choices"* [32]. Thus, empowerment is closely related to choice. Prominent models of treatment decision-making have been described: a) the *Paternalistic* model, as described above, (places the patient in a passive role, a situation traditionally more acceptable in emergency situations); b) the *Informed decision* model (consisting of increasing a patient's knowledge of therapeutic options and possible risks, so they can decide on their own, based on best scientific knowledge and their preferences); and c) the *Shared decision-making* model (where both patient and physician share their preferences, reach agreement, and share responsibility for the final decision) [33, 34]. A shared decision-making model for athletes has previously been suggested by Mitten: *"ideally, the ultimate decision whether to participate in a sport with a cardiovascular abnormality should be the product of mutual agreement between the team physician, consulting cardiologists, team officials, the athlete..."* [35].

Implementation of an informed decision model is supported by *John Stuart Mill's "On Liberty"*: *"the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. Each is the proper guardian of his own health, whether bodily, or mental or spiritual"* [31]. This opinion seems to be shared by *Lampert et al.* in a paper discussing sports participation in athletes with ICDs: *"life is not risk-free, and ultimately an informed choice should lie with the individual athlete and his or her family"* [36].

The role of society also needs to be taken into account as, in some circumstances, society can limit our freedom of choice, and we as members of society are expected to follow its rules,

moral, ethics, and law. It seems indisputable that we need to use a seatbelt while driving (and the law enforces us to do so) even though we are the only ones who may come to harm if we refuse to do it. However, other controversial themes like euthanasia, and abortion, raise the issue of how much freedom of choice an individual should be allowed and how much can society be allowed to choose on behalf of the individual. Also, this dilemma between “freedom of choice” and “freedom from society” may be subject to different interpretations for cultural reasons, which makes it almost impossible to achieve a universal solution for each problem. The same may also occur with empowerment. While the paternalistic approach might be construed as coercive, since the physician has total power for decision-making, the informed choice can also be perceived similarly if a patient declines the responsibility to choose. Forcing individuals to make a decision when they do not feel prepared can potentially be as coercive as imposing a decision. The shared decision-making model can also prove challenging when patient and physician cannot reach agreement. Decision is based on values, dreams, lifestyles and these are idiosyncratic. So, in the shared decision-making model physicians need to be careful in order to avoid imposing their own values system on the person they are treating. The model of empowerment we propose is not about placing the responsibility of decision on the patient (many patients do not want this responsibility), but rather giving patients the opportunity to choose which model of decision-making they prefer. We conceptualize empowerment as giving patients the opportunity to choose how much they would like to be involved in the choice (which could be choosing not to choose and thus empowering the physician, shared-decision making or informed decision) (Figure 1).

## **2. Can career-ending decisions result in severe consequences to the athlete?**

A fundamental principle taught in medical schools is "*primum non nocere*", first, do no harm. This implies that for an existing problem, the most important thing to do is to avoid worsening the condition (or more broadly, the person's functioning) through treatment [37].

Disqualification of athletes may protect their physical health, but can induce harm in other ways and impact on psycho-social function [38]. Athletic retirement is often different from retirement in other occupations due to the age at which this typically happens and therefore the specific characteristics and problems associated with an athlete's identity [39] and ambitions (the possibility of unmet goals and unfulfilled ambitions and objectives as players) [40, 41]. Patients with early or forced retirement fare worse, in terms of post-retirement adjustment and transition than those with control over the timing and circumstances of their retirement [39]. Furthermore, guidance and counselling are important if a patient needs to quit competition, as the decision should not be presented in an overdramatic or negative way. Not infrequently, athletes are highly driven individuals, determined to achieve their goals, and when they are still young, they may be fitted to change their career path if guidance is provided. On the other hand, professional athletes with lower levels of education and few professional skills to transfer to a non-sporting occupation, particularly if they have achieved higher visibility and earned large incomes, may struggle [42].

Negative outcomes resulting from disqualification include loss of identity, lack of perceived control, financial issues (reduction or loss of income and poverty), loss of social support from friends, sporting colleagues and fans [3], unemployment/unemployability, substance abuse, marital break-ups [43-45], depression and emotional adjustment difficulties [46].

Therefore, in situations where the risk of events is not expected to be high and if there is the possibility to establish necessary preventive measures, a premature and possibly unnecessary disqualification may do more harm than keeping an athlete in competition under closer surveillance. However, due to the sometimes rapid and unpredictable progression of these

heart rhythm disorders, sometimes things can go unexpectedly wrong even in low risk individuals, and fatalities, or cases of hypoxic brain injury, can occur. Sports clubs and organizations, athletes and relatives should be made fully aware of this possibility, and the necessary arrangements should be made to deal with and assume responsibility for these situations before and after they happen. AEDs and trained personal should be available at all times, and a chain-of-action with appropriate acute medical management of arrhythmia and other cardiovascular issues should be arranged with rapid transfer to a hospital environment.

### **3. The Fear of Disqualification**

When facing the possibility of an arrhythmic disorder, the fear of disqualification may lead the athlete/team into one of several situations: first, to try to hide or deny the severity of the clinical problem and arrange multiple consultations until the desired recommendation is obtained (known as “*doctor shopping*” [5]). The presence of contradictory opinions amongst experts can cause legal debates and confusion for a patient. Sometimes, only a single physician’s opinion may deviate from accepted or usual medical practice, while in others there may be a relatively equally split [35]. What should the decision be when dealing with conditions without evidence for treatment options and recommendations based on expert consensus? Which opinion and which experts should we value most?

Second, strong economic interests may be involved in the dilemma, influenced by an athlete’s or team’s earning potential, rather than purely by a person’s health and safety [47]. In these circumstances, a great deal of pressure may be brought to bear on the treating physician and even the athlete against disqualification [1]. It should be clear, if empowerment is given to an athlete, whether the decision to accept competition is made out of free will, or only as a result of coercion by the sports team and family. However, differentiating between these two

situations may be difficult, and likely to require a lengthy and thorough discussion between the physician and athlete.

Third, some situations may be transient and resolve after timely detection and appropriate intervention. Denying or hiding health problems (transparency should come first) can potentially lead to disastrous situations.

Lastly, the physician may fear legal action as a result of a disqualification decision. Physicians may be liable for malpractice lawsuits if they deviate from professionally determined standards: failing to perform all appropriate diagnostic tests, not providing sufficiently clear information regarding medical risk associated with competitive athletic participation in patients with particular arrhythmic disorders and/or refusing to follow accepted guidelines for that scenario [35]. A written record regarding the discussion between the physician and athlete is of importance, but its legal value is uncertain in some countries. The issue of informed consent in athletes is discussed in detail elsewhere [48].

This area is made more contentious as guidelines are generally based on expert consensus as opposed to more robust randomised controlled trials (i.e. Class A evidence) and therefore, by their very nature, highly subjective. The particular experience of the guideline committee will heavily influence their published recommendation and guideline committees are usually populated by highly specialised physicians who are referred the most severe and most challenging cases. The country in which the physician practices will also heavily influence their views. Most guideline committees are based in American organizations and societies and American physicians typically work in a much more litigious environment than elsewhere in the world. However, it is important to stress that the recommendations do allow physicians to exercise their medical judgment in individual cases [8]. The American scientific statement recommendations do not, per se, rigidly restrict clinical practice or medical decision-making. A

clinician may still have the flexibility to suggest an alternative decision or strategy, deviating from the recommendations, if he believes it is in the best interest of a patient-athlete [6]

### III. Differences Across the Globe

British law contemplates the concept of “*volenti non fit injuria*” (from Latin: “to a willing person, harm is not done”) [49]. Applied to the athlete with a heart rhythm disorder, this would mean that if the athlete is willing to voluntarily expose himself to a risk, and if he fully knows and understands the extent of the possible consequences, there is no one he can blame in case something happens. The *General Medical Council* provides clear guidance in consenting patients and in the decision-making process, which seems to follow this premise [50]. Individuals with mental capacity to decide for themselves should be allowed to play the main role in the decision-making process, as discussed on point 5 of the document. This should happen irrespectively of the risk of adverse events, whether it is very low (annual risk deemed to be <1%), uncertain or high, as long as athletes can only harm themselves (i.e. if they are not placing other individuals at risk) with the decision of not abandoning their sporting career. In situations of a clearly life-threatening condition the physician can try to have a safeguarding role, but the ultimate decision should be allowed to the individual [50]. In the *Good Medical Practice Document*, issued by The *General Medical Council*, it is stated that doctors should “*respect patients’ right to reach decisions with you about their treatment and care*” [51].

While the United Kingdom has a more liberal approach [52], based on the informed-decision making model, some regions in Europe, tend to be often conservative, and paternalistic. For example, in the Veneto region in Italy, between 1982 and 2004, 879 out of 42,386 young athletes (2.1%) were disqualified from participation in competitive sports. Supra-ventricular arrhythmias, pericarditis, and hypertension were among the causes, and accounted for over 40% of all cases [53]. This also contrasts with the liberal US approach. A survey carried out in

2006 members of the *Heart Rhythm Society* regarding sports participation in patients with an ICD, showed that avoidance of competitive sports was recommended by only less than half of the physicians [54]. Furthermore, Mayo Clinic pioneered a comprehensive shared-decision making process, which allows athletes with genetic heart diseases to return to play [55]. Among 246 assessed athletes, only 46 (19%) chose to quit sports. Preliminary data showed a low rate of cardiac events: one non-lethal event per 100 athlete-years in the whole cohort (which included pre-high school, high-school, college, recreational and professional athletes), and no cardiac events were observed at the post-high school level. Furthermore, one cardiac event also occurred in an athlete who ceased activity. These findings suggest that most athletes are willing to remain in competition, and that an increased level of athletic training may not correlate with a higher rate of cardiac events, thus supporting an empowering approach and the need of guideline re-evaluation.

#### **IV. Current Barriers and Suggestions for the Future**

The American guidelines have been recently updated and the European document should follow the same path in respect to the use of ICDs and AEDs in this population, management of low risk individuals with non-compaction of the left ventricle, and long QT syndrome, following the recent publication of a position paper by the *European Heart Rhythm Association (EHRA)*, *European Association of Preventive Cardiology*, endorsed by the *Heart Rhythm Society*, *Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología*, and *Asia Pacific Heart Rhythm Society* on pre-participation screening [56]. However, models of patient empowerment to make decisions regarding level of activity and sports participation have not yet been included in the 2005 European consensus or in the recent American scientific statement. Interestingly, these concepts are slowly making their way into the arrhythmia field. A recent consensus document on patient's values and preferences for the management of



cardiac tachyarrhythmias was recently published by the EHRA, and the concepts of shared-decision making and informed decision were mentioned in this document, but only in the setting of atrial fibrillation (decisions towards rhythm or rate control and regarding oral anticoagulation) or management of distress in patients with ICDs [57]. Patient-centred care, education, and shared-decision making are also contemplated for the first time in the recent ESC atrial fibrillation guidelines, with an emphasis on addressing the needs, values and preferences of the patient [58]. The aforementioned approach by Mayo Clinic with the implementation of a Shared-Decision approach [55] is also a big step to be acknowledged and followed by other centres.

Empowerment in this field will always face the challenge of uncertainty, how much risk is acceptable for the athlete to be exposed to, and a deeply rooted physician paternalistic behaviour. While moving from a paternalistic approach into a model where the patient has all the liberty to make choices is least likely to be considered in the presence of situations of very high risk or that are worsened by competitive, some physicians may already be more prone to adopting a shared decision making stance regarding situations where the risk is not that well established or even uncertain.

Some situations deserve special attention as potential exceptions to patient empowerment. It is hard to draw a line and predict accurately which patients face imminent risk of life-threatening cardiac events if allowed to compete. Furthermore, in sports like auto-racing, motorcycling or riflery, sudden cardiac arrest or an arrhythmic event may place the patient and other athletes or spectators at risk of physical injury. In these cases, the threshold for disqualifying an athlete must be substantially lower, because athletes should only be empowered and be free to place themselves at risk.

We suggest the following as possible limits to patient empowerment or situations of very high risk where the athlete should be discouraged from pursuing a sports career: (a) risk of harm to

other individuals; (b) individuals without mental capacity to decide for themselves; (c) individuals whose the interference of third parties (relatives, sports club/organization) might affect their freedom to make an individual decision; (d) risk of direct and life-threatening harm resulting from loss of consciousness (i.e. fall from great height, drowning, heavy body or cranial trauma) in the evidence of a very high probability of arrhythmic events during competition; (e) need for temporary removal from competition due to a potentially reversible condition with highly likely benefit for the athlete resulting from temporary cessation of sports practice; (f) documentation of exercise/catecholaminergic driven life-threatening sustained ventricular arrhythmias in patients already on maximal  $\beta$ -blocker dose; (g) obstructive hypertrophic cardiomyopathy with severe dynamic gradient requiring appropriate intervention or (h) athletes previously requiring defibrillation during competition, namely if concerns exist regarding possible refractoriness or resistance of the arrhythmia and the availability of defibrillators.

Some patients are willing to assume the risks resulting from competitive sports even if it includes the possibility of death [2]. As we propose a patient-centred care model, we suggest it is up to the patient to determine what brings quality and what is important to his or her life. If livelihood is the question, which is frequently the case in professional athletes [59]- is the ability of maintaining income considered reason enough to prevail over health concerns and safety?

Paradoxically, there are sports like mountain climbing, auto-racing or extreme sports that place an individual at very high levels of physical risk in the absence of arrhythmic disorders or other health problems and these participants are still allowed to assume this risk without a paternalistic pressure from the society for safeguarding them [2]. If these individuals are permitted freedom to make their own risk-analysis decision on participating in these pastimes, why not the athlete with an arrhythmic disorder?

The question of how much liberty an athlete should have and what is the maximum level of risk they may be allowed to assume when making this decision, or which situations can be classified as too high risk, is still open for debate [59], and may differ among different countries. However, certain athletes with arrhythmic disorders could eventually be considered eligible for sports practice, assuming their conditions are considered stable, the necessary preventive measures are established (either ICDs or AEDs and trained personnel) and patients and sports organisations/teams are willing to take the risk to pursue their dream and assuming their choice doesn't place any others at risk (See Figure 2). This should be regarded as a principle of liberty and personal choice that all of us should respect provided the athlete is truly expressing freewill independent of any coercive influences. We believe the deleterious effects on an individual's personal, professional and psychological well-being should be taken into account in revised recommendations. They should also reflect the importance of sports in motivating these individuals and the conflict that exists between a traditionally paternalistic medical community, an ambiguous and currently mostly unsupportive legal framework and a dynamic public perception of individual choice and risk. Can we deny this choice based solely on a possibility, or potential risk of an event that may never occur and even if it does, can now be effectively managed in most circumstances? The calibration of risk to the athlete requires careful consultation between the athlete, physician and sports team/organisation as well as the athlete's family. This decision & its basis must also be fully documented and recorded for medico-legal purposes with the athlete willing to accept responsibility for the management of his/her condition and associated risks.

## **Conclusions**

The concept of empowerment in the assessment of eligibility of athletes with arrhythmic disorders has been clearly underexplored. The freedom of the individual should be respected

and an athlete's will and freedom of choice should prevail over possible physical or psychological injury arising from prolonged sports practice or restriction in a significant number of cases.

So far, the field of arrhythmic disorders has been a disempowering setting where the athlete has little or no say regarding medical decisions in their sporting career. This article proposes an empowerment approach, where the patients are not forced to decide, but are granted that possibility. Most people are used to a traditional, paternalistic approach in medicine where they have limited responsibility to decide and we expect many patients will still not want this responsibility. However, we also expect that many, particularly young people, will want to exercise their own choice. Future research needs to assess the extent to which people with these conditions would like to be involved in this type of decision.

We believe that empowering the athlete may have several advantages including respect for people's rights, a person-centred care approach, transparency and avoidance of "*doctor shopping*". Ultimately, this will hopefully avoid denial of life-threatening heart conditions, forging a closer relationship between the athlete and specialized health-services and possibly improving the availability of care and chances of survival if a serious event occurs during competition.

**Figure 1** – Proposed model for the empowerment of athletes with arrhythmic cardiac conditions.

Note: \* in some countries the ultimate decision should be allowed to the individual even if the risk is high, as long as considered mentally capable of deciding [50].

**Figure 2** – Authors' suggested approach to Athlete Empowerment according to perceived risk of ventricular arrhythmias.

Legend: CPVT – catecholaminergic polymorphic ventricular tachycardia; HCM – hypertrophic cardiomyopathy; VT – ventricular tachycardia; VF – ventricular fibrillation; ARVC – arrhythmogenic right ventricular cardiomyopathy; EF – ejection fraction; LQTS – Long QT Syndrome; ICD – Implantable Cardioverter Defibrillator; DCM – Dilated Cardiomyopathy; LVNC – Left Ventricular Non-Compaction; VA – Ventricular Arrhythmias. Note: Arrhythmic risk on exercise is a broad estimation due to the unavailable/anecdotal data regarding most of these situations.

**Table 1** – Main arguments regarding athlete empowerment from the Physician’s perspective.

<b>Benefits of Empowerment</b>	<b>Possible Drawbacks</b>
<ul style="list-style-type: none"> <li>• Respecting Athletes’ Liberty as human beings</li> <li>• Avoid destroying athletes’ professional lives and dreams</li> <li>• More transparent doctor-patient relationship, with better collaboration and truth</li> <li>• Avoiding “<i>doctor-shopping</i>” – athletes will seek experts in the area instead of more permissive physicians</li> <li>• Acquiring more knowledge on “<i>grey zone areas</i>” if athletes are allowed to compete in a safe environment</li> </ul>	<ul style="list-style-type: none"> <li>• Concern that athlete’s decision may not follow the Expert Consensus / Recommendations</li> <li>• Risk to reputation or personal feelings if the athlete has an arrhythmic event</li> <li>• Fear of liability</li> </ul>

## References

1. Pelliccia A. Sports Cardiology Casebook. London, United Kingdom: Springer. 2009
2. Maron BJ, Mitten MJ, Quandt EK, Zipes DP. Competitive athletes with cardiovascular disease: the case of Nicholas Knapp. *N Engl J Med.* 1998;339:1623–5.
3. Fortunato V, Marchant D. Forced retirement from elite football in Australia. *Journal of Personal and Interpersonal Loss* 1999;4:269-280.
4. Balcazar FE, Seekins T, Fawcett SB, Hopkins BL. Empowering people with physical disabilities through advocacy skills training. *American Journal of Community Psychology* 1990;18:281-296.
5. Pelliccia A, Zipes DP, Maron BJ. Bethesda Conference #36 and the European Society of Cardiology Consensus Recommendations Revisited. *J Am Coll Cardiol.* 2008;52:1990-6.
6. Maron BJ, Zipes DP. 36th Bethesda Conference: Eligibility recommendations for competitive athletes with cardiovascular abnormalities. *J Am Coll Cardiol.* 2005;45:1313–1375.
7. O'Mahony C, Jichi F, Pavlou M, Monserrat L, Anastasakis A, Rapezzi C, et al. A novel clinical risk prediction model for sudden cardiac death in hypertrophic cardiomyopathy (HCM risk-SCD). *Eur Heart J.* 2014;35:2010-20.
8. Maron BJ, Zipes DP, Kovacs RJ; American Heart Association Electrocardiography and Arrhythmias Committee of the Council on Clinical Cardiology, Council on Cardiovascular Disease in the Young, Council on Cardiovascular and Stroke Nursing, et al. Eligibility and Disqualification Recommendations for Competitive Athletes With Cardiovascular Abnormalities: Preamble, Principles, and General Considerations: A Scientific Statement From the American Heart Association and American College of Cardiology. *Circulation.* 2015;132:e256-61.
9. Pelliccia A, Fagard R, Bjørnstad HH, Anastassakis A, Arbustini E, Assanelli D, et al. Recommendations for competitive sports participation in athletes with cardiovascular disease. A consensus document from the Study Group of Sports Cardiology of the Working Group of

Cardiac Rehabilitation and Exercise Physiology, and the Working Group of Myocardial and Pericardial diseases of the European Society of Cardiology. *Eur Heart J*. 2005;26:1422– 45.

10. Maron BJ. Hypertrophic cardiomyopathy: a systematic review. *JAMA*. 2002;13;287(1):1308-20.

11. Saberi S, Wheeler M, Bragg-Gresham J, Hornsby W, Agarwal PP, Attili A, et al. Effect of Moderate-Intensity Exercise Training on Peak Oxygen Consumption in Patients With Hypertrophic Cardiomyopathy: A Randomized Clinical Trial. *JAMA* 2017; 317:1349-1357.

12. Gati S, Chandra N, Bennett RL, Reed M, Kervio G, Panoulas VF, et al. Increased left ventricular trabeculation in highly trained athletes: do we need more stringent criteria for the diagnosis of left ventricular non-compaction in athletes? *Heart*. 2013;99:401-8.

13. Maron BJ, Udelson JE, Bonow RO, Nishimura RA, Ackerman MJ, Estes NA 3rd, et al. Eligibility and Disqualification Recommendations for Competitive Athletes With Cardiovascular Abnormalities: Task Force 3: Hypertrophic Cardiomyopathy, Arrhythmogenic Right Ventricular Cardiomyopathy and Other Cardiomyopathies, and Myocarditis: A Scientific Statement From the American Heart Association and American College of Cardiology. *J Am Coll Cardiol*. 2015;66:2362-71

14. Ackerman MJ, Zipes DP, Kovacs RJ, Maron BJ; American Heart Association Electrocardiography and Arrhythmias Committee of the Council on Clinical Cardiology, Council on Cardiovascular Disease in the Young, et al. Eligibility and Disqualification Recommendations for Competitive Athletes With Cardiovascular Abnormalities: Task Force 10: The Cardiac Channelopathies: A Scientific Statement From the American Heart Association and American College of Cardiology. *Circulation*. 2015;132:e326-9.

15. Ostby SA, Bos JM, Owen HJ, Wackel PL, Cannon BC, Ackerman MJ. Competitive Sports Participation in Patients With Catecholaminergic Polymorphic Ventricular Tachycardia - A Single Center's Early Experience. *JACC Clin Electrophysiol*. 2016;2:253-262.



16. Azis PF, Sweeten T, Vogel RL, Booney WJ, Henderson J, Patel AR, et al. Sports Participation in Genotype Positive Children With Long QT Syndrome. *JACC Clin Electrophysiol*. 2015;1:62-70.
17. Mitchell JH, Haskell W, Snell P and Van Camp SP. Task force 8: classification of sports. *J Am Coll Cardiol* 2005;45: 1364–1367.
18. Drezner JA, Toresdahl BG, Rao AL, Huszti E, Harmon KG. Outcomes from sudden cardiac arrest in US high schools: a 2-year prospective study from the National Registry for AED Use in Sports. *Br J Sports Med*. 2013;47:1179-83.
19. Pundi KN, Bos JM, Cannon BC, Ackerman MJ. Automated external defibrillator rescues among children diagnosed and treated with long QT syndrome. *Heart Rhythm*. 2015;2012:776-81.
20. Link MS, Myerburg RJ, Estes NA 3rd; American Heart Association Electrocardiography and Arrhythmias Committee of the Council on Clinical Cardiology, Council on Cardiovascular Disease in the Young, Council on Cardiovascular and Stroke Nursing, et al. Eligibility and Disqualification Recommendations for Competitive Athletes With Cardiovascular Abnormalities: Task Force 12: Emergency Action Plans, Resuscitation, Cardiopulmonary Resuscitation, and Automated External Defibrillators: A Scientific Statement From the American Heart Association and American College of Cardiology. *Circulation*. 2015;132:e334-8.
21. Lampert R, Olshansky B, Heidbuchel H, Lawless C, Saarel E, Ackerman M, et al. Safety of Sports for Athletes With Implantable Cardioverter-Defibrillators: Results of a Prospective, Multinational Registry. *Circulation*. 2013;127:2021-2030.
22. Zipes DP, Link MS, Ackerman MJ, Kovacs RJ, Myerburg RJ, Estes NA 3rd. Eligibility and Disqualification Recommendations for Competitive Athletes With Cardiovascular Abnormalities: Task Force 9: Arrhythmias and Conduction Defects: A Scientific Statement From the American Heart Association and American College of Cardiology. *J Am Coll Cardiol*. 2015;66:2412-23.

23. Kuipers, P. Empowerment in Community-based Rehabilitation and Disability-inclusive Development. *DCID*. 2013;24:24-42.
24. Maton KI. Empowering community settings: agents of individual development, community betterment, and positive social change. *Am J Community Psychol*. 2008;41:4-21.
25. Peterson NA. Empowerment theory: clarifying the nature of higher-order multidimensional constructs. *Am Community Psychol*. 2014;53:96-108.
26. Labonte R. Health promotion and empowerment: Practice frameworks. Toronto: Centre for Health Promotion. 1993. Available through: <http://www.utoronto.ca/chp>
27. Swedberg R. The Max Weber Dictionary: Key Words and Central Concepts. Stanford, California: Stanford University Press. 2005.
28. Alsop R, Bertelsen MF, Holland J. Empowerment in practice: from analysis to implementation. Washington DC: The World Bank. 2006.
29. Rappaport J. In praise of paradox: A social policy of empowerment over prevention. *Am J Community Psychol*. 1981;9:1–25.
30. Pulvirenti M, Mc Millan J, Lawn S. Empowerment, patient-centred care and self-management. *Health Expectations*. 2011;17:303-310.
31. Stuart Mill J. On Liberty. New York: Dover Publications. 2002.
32. Chamberlin J. A working definition of empowerment. *Psychiatric Rehabilitation Journal*, 1997;20:43-46.
33. Charles C, Gafni A, Whelan T. Shared decision making in the medical encounter: what does it mean? (Or it takes at least two to tango). *Soc Sci Med*. 1997;44:681–692.
34. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*. 1999;49:651-661.
35. Mitten MJ, Maron BJ. Legal considerations that affect medical eligibility for competitive athletes with cardiovascular abnormalities and acceptance of Bethesda Conference Recommendations. *J Am Coll Cardiol*. 1994;24:861-3.

36. Lampert R, Cannom D. Sports participation for athletes with implantable cardioverter-defibrillators should be an individualized risk-benefit decision. *Heart Rhythm*. 2008;5:861-863.
37. Smith CM. Origin and Uses of Primum Non Nocere — Above All, Do No Harm! *J Clin Pharmacol*. 2005;45:371–377.
38. Asif IM, Price D, Fisher LA, Zakrajsek RA, Larsen LK, Raabe JJ, et al. Stages of psychological impact after diagnosis with serious or potentially lethal cardiac disease in young competitive athletes: a new model. *J Electrocardiol*. 2015;48:298-310.
39. Webb WM, Nasco SA, Riley S, Headrick B. Athlete identity and reactions to retirement from sports. *Journal of Sports Behavior*. 1998;21:338-352.
40. Albion MJ. Restoring the Balance: Women’s Experiences of Retiring from Elite Sport. Toowoomba, Australia: 2007 International Women's Conference: Education, Employment and Everything... the Triple Layers of a Woman's Life. 2007.
41. Cockeril IM. They think it’s all over, but it may not be! *Br J Sports Med*. 2005;39;880-882.
42. McPherson BD, Curtis JE, Loy JW. The Social Significance of Sport: An Introduction to the Sociology of Sports. Champaign, Illinois: Human Kinetics. 1989.
44. Houlston DR. The occupational mobility of Professional athletes. *Inter Rev Sport Soc*. 1982;2(17).
45. Weiss O. Identity reinforcement in sport. *Inter Rev Soc Sport*. 2001;36(4):393-405.
46. Lavallee D, Gordon S, Grove JR. Retirement from sport and the loss of athletic identity. *Journal of Personal and Interpersonal Loss*. 1997;2:129-147
47. Maron BJ. Sudden death in young athletes: lessons from the Hank Gathers affair. *N Engl J Med*. 1993;329:55–7.
48. Providencia R, Teixeira C, Segal OR, Ullstein A, Lambiase PD. Call for joint informed consent in athletes with inherited cardiac conditions *Open Heart* 2017;4:e000516.
49. Jaffey AJE. Volenti Non Fit Injuria. *The Cambridge Law Journal*. 1985;44:87-110.

50. General Medical Council. Consent: Patients and Doctors Making Decisions Together. 2008;6-33. Available at: [www.gmc-uk.org/guidance](http://www.gmc-uk.org/guidance)
51. General Medical Council. Good Medical Practice. 2013;4-24. Available at: <http://www.gmc-uk.org/guidance/>
52. Providência R, Teixeira C, Segal O, Ullstein A, Mueser KT, Lambiase P. Is it time to loosen the restrictions on athletes with cardiac disorders competing in sport? *Br J Sports Med*. 2017 [Epub ahead of Print]
53. Corrado D, Basso C, Pavei A, Michieli P, Schiavon M, Thiene G. Trends in sudden cardiovascular death in young competitive athletes after implementation of a preparticipation screening program. *JAMA*. 2006;296:1593-601.
54. Lampert R, Cannom D, Olshansky B. Safety of sports participation in patients with implantable cardioverter defibrillators: a survey of heart rhythm society members. *J Cardiovasc Electrophysiol*. 2006;17:11-15.
55. Turkowski K, Bos JM, Ackerman MJ. Sports Organization/School/University-Determined Fate of Athletes with Genetic Disease who Received Physician Support for Return to Play after their Shared Decision Making Evaluation. *Heart Rhythm*. 2016;13(Suppl):S536-7.
56. Mont L, Pelliccia A, Sharma S, Biffi A, Borjesson M, Terradellas JB, et al. Pre-participation cardiovascular evaluation for athletic participants to prevent sudden death: Position paper from the EHRA and the EACPR, branches of the ESC. Endorsed by APHRS, HRS, and SOLAECE. *Europace*. 2017;19:139-163.
57. Lane DA, Aguinaga L, Blomström-Lundqvist C, Boriani G, Dan GA, Hills MT, et al. Cardiac tachyarrhythmias and patient values and preferences for their management: the European Heart Rhythm Association (EHRA) consensus document endorsed by the Heart Rhythm Society (HRS), Asia Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE). *Europace*. 2015; 17:1747-69.

58. Kirchhof P, Benussi S, Kotecha D, Ahlsson A, Atar D, Casadei B, et al. 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. *Europace*. 2016;18:1609-1678.

59. Mitten MJ. Enhanced Risk of Harm to One's Self as a Justification for Exclusion from Athletics. *Marq Sports LJ*. 1998;8:189-223.