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ETHICAL ASPECTS OF ATHLETE DISQUALIFICATION FROM COMPETITIVE SPORT DUE TO HEART DISEASE; TIME FOR A HOLISTIC APPROACH

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Abstract

Sudden cardiac death (SCD) in any young person is a tragic event. Following decades of high profile cases, the value of preventative strategies, including cardiac pre-participation screening for athletes, has been debated in the medical community and public health arena. Equally important, but less prominent in the literature, are the possible implications of subsequent disqualification of individuals identified with a condition associated with exercise related SCD from competitive sports. This is critical, given the currently limited knowledge regarding the risk of exercise induced malignant arrhythmias for heterogeneous conditions, poor risk stratification protocols in athletic individuals, and the potential benefits of disqualification in reducing morbidity and mortality. These challenges are reflected in the discrepancies of expert consensus recommendations across the Atlantic. In recognition of the limited evidence, the American Heart Association and the American College of Cardiology take a more liberal approach, while the European Society of Cardiology makes more conservative recommendations. This analysis considers the ethical implications of disqualification of athletes with heart disease from competitive sports in the context of available evidence, contemporary medical recommendations and legal structures, as well as emerging genetic diagnostics.

Key Words: athlete, disqualification, ethics, cardiac screening, sports cardiology

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Introduction

Sudden cardiac death (SCD) in any young person is a devastating event. The value of cardiac pre-participation screening (PPS), in young athletes has been intensely debated in the medical community and public health arena (1). One of the shortcomings of attempting to identify athletes with heart disease is the lack of established risk stratification protocols. Consequently, athletes are offered a “blanket approach”, with a considerable number of athletes being disqualified to save the few at high risk of exercise-associated arrhythmias.

This analysis considers the ethical implications of disqualification of athletes with heart disease from competitive sport in the context of available evidence, contemporary medical recommendations and legal structures, as well as emerging genetic diagnostics.

Eligibility Recommendations for Athletes With Heart Disease

There is a lack of consensus in eligibility recommendations for athletes with heart disease aimed at medical practitioners. The discrepancies relate to multiple factors including: 1. The lack of evidence base relating to risk stratification of athletes for most conditions predisposing to exercise-related sudden cardiac death. As a consequence, the recommendations are expert opinion based (Level C). 2. Cultural differences; and 3. Differences in legal contexts. If physicians are legally liable, disqualification

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decisions tend to be more conservative, as physicians can be held accountable for adverse events (2). In addition, the label of “disqualification” can be tantamount to loss of employment or ‘being fired’ when the athlete receives substantial financial remuneration or has a professional status.

Is Medical Disqualification Ethically Justified?

Ethical arguments in favour of medical disqualification

Precaution Argumentation

Disqualification of athletes with heart disease from competitive sport as a precautionary measure relies heavily on evidence that disqualification of at risk athletes improves morbidity and mortality. In the 36th Bethesda conference the authors state: “The increased risk of sudden death associated with intense athletic participation is a controllable risk factor, and the devastating impact of even infrequent sudden deaths in this young population underscores the wisdom of the conservative nature of these recommendations”(3).

The benefit of disqualification is best supported by landmark studies demonstrating an increased risk of SCD due to exercise in individuals with cardiovascular disease, and a decrease in mortality with the identification (through mandatory PPS) and disqualification of such individuals (4,5). Arrhythmogenic right ventricular cardiomyopathy (ARVC) is a prime example. Contemporary studies demonstrate that

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continuation of high level, strenuous exercise can adversely affect the natural history of ARVC, with athletes experiencing a higher prevalence of arrhythmias and heart failure, compared to individuals who restricted their physical activity (6).

When the risk of athlete SCD is considered to be high, and physician advice against participation in competitive sport is disregarded, there can be a tragic perception of a societal failure to avert a potentially preventable death. These challenges are highlighted by the case of *Penny vs. Sands* (1989). Penny filed a lawsuit against the cardiologist who disqualified him from college basketball on the basis of a cardiomyopathy diagnosis (7). He subsequently moved to England to continue competing professionally, and suffered a SCD one year later at the age of 23(8). This kind of moral rationalization, however, has a consequentialist element in which the goodness of the decision depends upon the outcome, which may have a strong element of chance. Furthermore, it risks characterizing as ‘bad’ any judgment that one may not agree with, and therefore substitutes a physician’s normative evaluation of cardiovascular risk versus the benefit of athletic activity for the individual athlete’s.

Protection from External Pressures and Poor Judgement

It is important to consider the normative argument that the harm to society of a SCD in a young athlete outweighs the individual’s right to autonomy, literally meaning self-governance, and self-determination. In the 36th Bethesda conference the authors recognize that the perception of an individual’s rights is culturally influenced, but state that “the level of importance the individual athlete personally attaches to continuing or resuming competitive sports is not regarded as a primary determinant in formulating

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eligibility recommendations”(3). From an ethical point of view, one may argue that a libertarian approach is not always desirable. Many public health measures are in place for the protection of individuals living within society, such as a legal mandate to wear a seatbelt in a car or a helmet on a bike. These measures take a small amount of choice away from the individual but give a great benefit to society in reducing injuries and associated costs. These measures are known as “soft” paternalism because they strongly incentivise compliance (if you violate the laws you are fined), but don’t take away the ability to be non-compliant. On the other hand, “hard paternalism” takes the choice away from the individual. This is often justified by risk to others, for example regulations against individuals with sickle cell disease flying as pilots. Likewise, it seems short of ethically desirable to implement a model in which society as a whole and sporting organizations in particular wash their hands of all responsibility and duty toward the athletes’ welfare with a disclaimer form.

There may be many socio-economic incentives that could coerce an athlete into making a decision against his or her best interest. Furthermore, not every individual may exercise good or mature judgement. In the case of overwhelming risk or clearly poor judgement in personal lifestyle choice, should there be no mechanism to intervene and overrule personal autonomy?

Ethical arguments against medical disqualification

Undue Restrictions to Autonomy and Self Determination

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Existing recommendations position the physician as the main determinant of eligibility for the athletes. The ESC document states that “individuals with CV disease may not always use proper independent judgement in assessing the overall risk associated with a competitive sports career. This panel believes that the physician has the ethical, medical, and legal obligation to exhaustively inform the candidate of the risks inherent in competitive athletic lifestyle and, when the CV risk appears to be disproportionately high, the physician should be responsible for the final decision, with the aim to prevent adverse clinical events and/or reduce the risk for disease progression”(9). Likewise, the revised recommendations from the AHA/ACC state that “When such athletes are recognized, they are exposed to eligibility and disqualification decisions that become the responsibility of the practicing physician”(10).

These statements are compelling, but pose considerable restriction to the individual’s self-determination. A decision to disqualify an athlete based solely on grounds of cardiovascular risk may be considered as ‘hard’ paternalism. In contrast, smoking cigarettes and excess alcohol consumption are discouraged but not disallowed by society, though known to cause great harm. Risky activities such as sky diving and rock climbing are left to an individual’s discretion.

The weight of autonomy is influenced by cultural factors and differing legal systems and, therefore, practices vary significantly from country to country. Based on examples in the literature, such as that of the Olympic swimmer Fioravanti, who was disqualified after a diagnosis of hypertrophic cardiomyopathy (HCM), as well as numerous lawsuits in the USA, disqualification of high level athletes as a result of a diagnosis of quiescent heart disease during mandated cardiac pre-participation screening is at best problematic

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(7,11).

Lack of an Individualised Approach

Various philosophers have long attested that autonomy is not paramount to all other considerations and may be limited when one intentionally risks his/her own life. An extrapolation of this argument is based, however, on irrefutable proof of the peril of continued athletic activity. Unfortunately, our current understanding of the natural history of the heterogeneous conditions predisposing to SCD during sport, and the influence of strenuous exercise, is limited. Even for well-established conditions, such as HCM, risk stratification of athletes is challenging, and extrapolated data from predominantly non-athletic patient cohorts would classify the great majority of athletes as low risk (6). Yet transatlantic guidelines agree that all athletes with HCM should be disqualified from competitive sports. In addition, contemporary studies of individuals with cardiac diseases that have traditionally been considered to pose a risk of exercise related fatal arrhythmias suggest a low event rate in athletes with long QT syndrome and Catecholaminergic Polymorphic Ventricular Tachycardia (12). Although these studies should be viewed with caution, as they include a small number of professional athletes competing at an elite level, and a relatively short follow-up period, they raise poignant questions about the efficacy of exercise restriction as a preventative strategy.

Furthermore, a recent international registry did not observe any fatalities in high-risk individuals with an implanted cardiac defibrillator (ICD), who continued to perform competitive or high-intensity sports, over a 31-month period (13). Nevertheless, the

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registry confirmed that arrhythmias were more frequent during physical activity and there was an increase of inappropriate shocks during sports, calling for a more individualised approach (13).

Holistic Approach to Beneficence

Interpreting beneficence, that is the ethical imperative to do good, within the narrow perspective of cardiovascular risk alone contradicts the principles of holistic medicine. Even if minimising cardiac risk is the most important consideration from a physician's perspective, that may not be the case for the individual athlete, who may be willing to accept a small risk to ensure his/her psychological, social and financial wellbeing. Disqualification from competitive sport has extensive personal consequences for the athlete, beyond the narrow medical perspective. As such, one may argue that it should not be the physician alone who makes the decision.

Psychological Distress

The diagnosis of a quiescent cardiac condition and subsequent restriction of competitive athletic activity are not innocuous. Asif *et al.* reported increased indicators of psychological distress in athletes diagnosed with a hereditary versus a non-genetic condition (14). Notably, those disqualified from sports were also at a significantly higher risk of psychological morbidity compared with those who had some or no restriction to activity (14). This underscores the potential harm to mental health that disqualification from competitive sport may pose, which needs to be weighed against potential benefits.

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Discrimination

There is no agreement as to what may constitute discrimination from an employment perspective regarding the unwilling medical disqualification of an athlete with heart disease from professional competition. A notable example of a successful discrimination claim in the USA is that of *Mobley v Madison Square Garden LP*, in which the former National Basketball Association Knicks player won his disability discrimination legal claim following a medical disqualification due to HCM, in 2008. To win the case he provided evidence from 3 cardiologists that he was not less fit to play in 2008 than he had been since 1998(7). Conversely, In *Knapp v Northwestern University*, a university student with a prior cardiac arrest and subsequently implanted ICD failed to establish that his disqualification from the basketball team was in violation of federal disability discrimination law(7).

Informed Consent

Informed consent requires that the patient is informed as fully as possible and is able to make an autonomous choice whether he/she wishes to proceed with an investigation or intervention. Yet in the context of PPS informed consent is problematic, given that participation in the initial screening process and subsequent evaluation is mandated by many sporting organisations, and medical clearance is often a prerequisite for employment in a professional athletic capacity. Furthermore, a model of “athlete informed consent” has been proposed whereby a professional athlete deemed at risk of SCD may participate in sport after the risk of participation is explained, therefore allowing more athlete autonomy in participation decisions (7). This seems less than

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ideal ethically, as it leaves athletes open to economic and team pressures to participate against their best interest. As a recent review on the topic has highlighted, “joint informed consent,” that is an agreed understanding and risk reduction approach between all stakeholders, rather than a strictly autonomy based informed consent might be a more ethically desirable approach(15).

The Role of Genetic Testing

Genetic testing is increasingly utilized in the assessment of athletes flagged by PPS (16). However, the interpretation of genetic data in this context is complex, and it is not usually helpful to risk stratification (16). It may also cause legal uncertainty in disqualification decisions for professional athletes, as many nations now have laws forbidding employers from requiring genetic testing as part of pre-employment assessment or occupational health tests (Genetic Information Non-discrimination Act, or GINA, in the USA). It is not clear how these regulations may apply to the context of a professional athlete, particularly in cases where physician guidelines recommend disqualification of genotype-positive, phenotype-negative individuals(2,9).

Conclusion

While PPS may be an ethically justified precaution to offer athletes, there are a number

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of complex ethical issues relating to disqualification decisions. Depending upon the medical society recommendations, sporting body regulations and national legal system, the doctors, team, athletic organization and athletes may have different and potentially conflicting goals and motives as stakeholders.

In our modern, global, and pluralistic, society there is a need to find a common ethico-legal approach. The ultimate goal should be a collaborative decision making process that allows for individualized exercise prescription, respects an individual's self-determination and at the same time offers athletes the necessary protection.

KEY MESSAGES:

- Abstaining from competitive sport has the potential to reduce disease progression and the risk of SCD in some athletes with heart disease.
- The heterogeneity of conditions predisposing to SCD in young athletes and the lack of exercise-specific risk stratification protocols hinder an individualised approach. A considerable number of athletes are being disqualified to save the few at high risk of exercise-associated arrhythmias.
- A “libertarian” approach which respects the individual's right for self-determination must be balanced with the society's obligation to protect potentially vulnerable individuals subjected to external pressures.
- Disqualification from competitive sport has significant psychological, social and financial implications for the athlete and the wider society, underscoring the need

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for an individualised approach that includes input from all stakeholders and carefully weighs the benefits and risks of withdrawal from competitive sports.

Competing interests

We have read and understood the BMJ Group policy on declaration of interests and have none to declare.

CONTRIBUTORS and SOURCES:

EFM is an MD with a Master in Bioethics. She wrote the analysis in collaboration with MP, GF, SS and PB. MP, GF, and SS are clinical cardiologists practicing in sports cardiology and active in a research group in St. Georges University of London cardiovascular research centre (specializing in research on sudden cardiac death). They are involved in pre-participation cardiac screening organized by the charity Cardiac Risk in the Young (CRY). SS is a Professor of Cardiology at St George's University of London. PB is a Professor of Bioethics at the Centre for Biomedical Ethics and Law at the University of Leuven in Belgium. The information used to prepare this analysis came from a review of the published literature. PB is the guarantor of the article.

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