Sudden cardiac death: mandatory exclusion of athletes at risk is a step too far

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ABSTRACT
Sudden cardiac death (SCD) in young athletes is a distressing event and it is not surprising that some physicians working with sports people are proposing that preventive action should be taken. There is a push for a system similar to that established in some countries, which involves screening and mandatory exclusion of those at risk. The authors argue that while screening can provide useful information to at-risk athletes making decisions about their future athletic careers, mandatory exclusion of athletes is paternalistic and such decisions are not rightfully within the domain of medicine.

INTRODUCTION
Sudden cardiac death (SCD) in a young athlete is a distressing event that is often witnessed by a large audience. What makes SCD so distressing is that it strikes people in their prime and challenges our beliefs about the association between sport and good health. It is traumatic for the athlete’s family and community, and concerns have been raised that it may have the effect of discouraging observers and the general public from participating in sport and exercise. Consequently, it is not surprising that many people want to take action to prevent SCD.

SCD can occur without any warning symptoms, so preventive intervention requires instigating a broad cardiac screening programme in an effort to identify those at risk. In some countries, national screening programmes are now in place. When initial screening suggests an abnormality, that athlete undergoes further investigations to confirm a diagnosis. If an athlete is diagnosed with an SCD-linked condition, he/she is excluded from competition. Physicians in other countries are advocating for similar programmes.

The broad principle for initiating a screening programme is to prevent harm to the individual who may be at risk of SCD. Maron et al have voiced this by stating, “there is general consensus that in a benevolent society, a responsibility exists on the part of physicians to initiate prudent efforts to identify life-threatening conditions in athletes for the purpose of minimizing the risk associated with the intersection of sports and cardiovascular disease.”

A benevolent society is concerned about the well-being of its citizens and where methods to identify life-threatening conditions exist, we should arguably make use of them. Doctors have a duty to identify and respond to the health needs of their community, and therefore we broadly agree that if a screening programme can identify health risks, it would be beneficial to adopt it. There are, however, constraints on intrusive beneficence.

Maron et al go on to say that “The devastating impact of even relatively infrequent sudden death events justifies restriction of young athletes from competition to reduce their risk related to silent and unsuspected cardiac disease.” (The term ‘young athletes’ refers to those younger than 35 years. Most screening programmes are aimed at athletes aged between 15 and 35 years). It is this statement and the basis for mandatory exclusion it expresses that is objectionable. There are two grounds on which we object to mandatory exclusion. The first relates to our ability to accurately predict the risk of death during vigorous exercise for those individuals diagnosed with a condition that can lead to SCD. But more importantly, even if we could accurately predict the risk of death, mandatory exclusion is unacceptable medical paternalism. Decisions that limit the choices of an individual in this situation are not rightfully within the domain of medicine.

SCREENING FOR SCD-LINKED CONDITIONS
An effective screening programme is a useful tool for identifying health concerns in a population and is therefore part of the remit of a benevolent society. There is evidence that a well-constructed SCD screening programme can be valuable in identifying those at risk. Screening can provide information to athletes, enabling them to make informed decisions regarding their future sporting career. For example, those with an SCD-linked condition can be informed that vigorous exercise creates a 2.5-fold increased risk of SCD with 90% of events occurring during or just after exercise. Despite the utility of SCD screening and acknowledging that no screening programmes can be expected to be 100% robust, there are some features about SCD screening that are particularly problematic.

The composition of a screening programme itself is contentious. SCD screening is an attempt to detect a cluster of conditions with a common potential outcome, rather than one single condition. Not all of the conditions are equally detectable with one standard screening protocol, and this is compounded by the fact that the prevalence of each of the SCD-linked conditions may vary across ethnic groups.

The European Society of Cardiology recommends that an ECG should be a routine screening practice, whereas the American Heart Association believes ECG should be reserved for athletes with positive findings on history and examination. Good evidence suggests that the history and examination approach is ineffective.
for identifying those at risk of SCD. Eighty percent of athletes with SCD-linked conditions are asymptomatic, and the addition of clinical examination often adds little. In one reported case series of SCD screening, only one athlete of the 115 was correctly identified using history and examination screening. Addition of routine ECG increases the sensitivity of the screening process and is the investigation of choice for Wolfe–Parkinson–White syndrome and the ion channelopathies. It is also highly effective in the detection of hypertrophic and arrhythmogenic right ventricular cardiomyopathies (HCM and ARVC). Follow-up studies have shown that ECG has a sensitivity of 95% and a negative predictive value as high as 99.98% for HCM, while it is also reasonable to assume that ECG will detect 80% of cases of ARVC. However, an ECG is not effective in identifying congenital coronary artery anomalies and premature coronary artery atherosclerosis, which may account for approximately 20% of the causes of SCD. Therefore, while screening with ECG can effectively identify some SCD-linked conditions, others may not be.

The next problem relates to the ability to predict the risk of death for a particular individual. Death is not inevitable for those diagnosed with a SCD-linked condition, nor will abstaining from competitive sport ensure survival. The prevalence of SCD-linked conditions is significantly higher than the incidence of SCD. The best estimate of the rate of SCD in the USA gives a figure of 1 death per 45 000 athletes per year. While there are some justifiable concerns that SCD risk remains underestimated, particularly in certain demographics, there is still a significant discrepancy between this figure and what appears to be the prevalence of potentially lethal cardiovascular condition in young athletes. Screening programmes have consistently shown this prevalence to be between 1 in 500 and 1 in 150 athletes. This suggests that in a cohort of 45 000 athletes, between 90 and 300 will have a potentially lethal condition and one will die each year. So, if an athlete has an SCD-linked condition, he/she has between a 0.5% and 1% chance of dying each year that he/she participates in competitive sport while younger than 35 years. Therefore, mandatory exclusion of at-risk athletes would exclude many who will never go on to suffer an SCD.

Despite the problems identified, the authors consider that effective screening is a useful tool and further improvements in screening will be helpful to provide information to individuals. Although mandatory exclusion based on the findings of current screening methods is problematic in the ways presented, our argument is not solely based on the limitations of the scientific data, but is concerned with the infringement of personal liberty. Even if a screening programme existed that could more accurately predict the risk associated with SCD-linked conditions, mandatory exclusion remains unacceptable.

LIMITING CHOICES OF OTHERS

Forced interference in the lives of competent individuals is generally considered to be unacceptable. This idea is encapsulated in Mill’s ‘harm principle’, which acknowledges a competent individual as the best judge of his/her own interests, where those interests do not infringe upon or cause harm to others. This principle embraces the idea that respecting the individuals’ voluntary judgement and decisions about their life, based on their values, are important for human dignity and self-worth, and therefore people should make their own choices. When others interfere in our lives it is patronising and overbearing because it appears that they know better than we do what is best for us and what shape our lives should take. Such interference is said to be paternalistic and is usually justified on the grounds that others, in this case, healthcare professionals, possess better, or more knowledge about an individual’s best interests than the individual concerned, or that he/she is incapable of making informed choices. Where the actions of others are thought to be involuntary or unwittingly taken and will lead to their harm, or when time is needed to check that this action is indeed voluntary, then intervention is permissible. This is often called ‘soft paternalism’. We object to hard paternalism, which is interference in the voluntary and informed choice of another. We hold that mandatory exclusion of at-risk athletes with the aim of preventing SCD requires the use of unjustifiable hard paternalistic restrictions.

There are several possible objections to our position against the mandatory exclusion of athletes which we will present and discuss.

The first objection is that many people who have a positive screening test are not competent to choose whether or not to participate. Objectors might agree that competent individuals should be left to make their own decision, but some being screened are minors and therefore not legally competent, so a conservative response should be taken to prevent them from taking risks. This could be justified under soft paternalism. Although we agree that some very young people will not be competent to make such a decision, the true number is likely to be low. Many young teenagers are able to make reasoned and sensible choices, including accepting or declining medical treatment, and this is not necessarily age dependent. This concept is accepted in law where we may consider a young person to be Gillick-competent, meaning that despite their age, the young person may be judged capable of making a reasoned decision. (The Gillick principle was developed in relation to young girls being able to decide on contraception.) Therefore, we should not be too hasty in considering young people incapable of weighing up evidence for themselves.

The next objection might be that an athlete’s decision making is not voluntary (or not voluntary enough) when we consider the pressures extant in competitive sport, particularly at the elite level. Athletes are under pressure to compete from coaches, teammates, family and others, and this may result in someone making a decision they would not necessarily wish to make. Pressure to compete can be pervasive and systemic in competitive sports and can distort risk perception. However, the existence of pressure does not necessarily render the decision involuntary. Pressures can and should be managed appropriately in potentially coercive environments. Care must be taken to ensure that the decision is sufficiently voluntary, particularly where the risk element is high and the harm posed is irrevocable. In the case of potential SCD, the possible harm is nearly always irrevocable, and the risks may be considered relatively high so that it is important that athletes are provided with full information about the risks and options associated with participating with their condition, and given time and space to make such a decision. Here, an effective relationship with a doctor is invaluable in providing a clear health-related focus in the face of pressures to participate. Despite such a relationship and the existence of risk, the values that give shape to an athlete’s life may lead some to a decision that may be at odds with medical advice. Interference with such a voluntary and informed decision is a case of hard paternalism and is therefore unjustified.
Objectors may also argue that SCD (especially when televised) causes harm to others and therefore we can legitimately intervene in such circumstances. A legitimate restriction, using ‘harm to others’ arguments, is the suspension of an impaired airline pilot. This action is justified when we consider how many lives would be lost or harmed if an impaired pilot remained in active service. It is hard to see how stopping an athlete from playing sport could prevent comparable harm to others. Nonetheless, objectors might argue that emotional harms are suffered by the millions who may witness an SCD, and the aggregate of these harms could be considered to be greater than that suffered by an individual excluded from participation. We reject the aggregation argument because to take this seriously would lead to absurd positions. Any nasty sports injury, such as broken limbs, that is witnessed by others could potentially lead to incalculable amounts of harm to a vast number of people. To avoid this, our only recourse would be to ban sport or spectators, both of which are unacceptable.

Objectors may challenge the harm principle itself, suggesting that the presence of existing laws that limit self-endangering choice indicates that the harm principle is not inviolable, thereby setting a precedent for interfering in the lives of others. Objectors might point to laws that set conditions on individual actions, such as laws in many countries that force the use of cycle helmets or seatbelts, suggesting that these are imposed in an effort to stop harm we might do to ourselves. These laws do in effect stop people from taking unnecessary risks by reducing the risks involved, but do not prevent participation in the activity. Such laws are not solely there to minimise risk taking, but also to lessen the costs to a publically funded health system should a cyclist be knocked from the bike or a driver hit the windscreen at speed. This is not comparable with SCD where there are no on-going costs to society resulting from disability.

The use of seatbelts and cycle helmets are an attempt to mitigate the risks posed by particular activities. When we consider mitigating the risks posed by sports we focus on the use of safety procedures and protocols. For example, in motor sport, fire-resistant clothing, helmets and rollbars are standardly imposed on all drivers; in mountaineering, most mountaineers will adopt modern safety methods in an effort to mitigate risks involved with the terrain, the weather and the experience of the climber. Despite these attempts, we know that capable and experienced people will die.

In contrast to sports where risk can be mitigated, the risks associated with cardiovascular abnormalities are not capable of being reduced in a similar way (there is no seatbelt equivalent). Objectors may claim that because these risks cannot be mitigated, those with identified cardiovascular abnormalities should therefore be mandatorily excluded from competitive sport. Although we should take steps to reduce risk wherever possible, this does not lead to the conclusion that where this is not possible, the activity, or the at-risk athlete, should be banned. Life contains risk and we all differ in the levels of risks we are personally willing to accept and the activities we are willing to engage in. Challenging ourselves and pushing ourselves to the edges of our physical limits are valued in our society, and being free to do so is an important part of self-expression and identity for some.

THE DOCTOR’S ROLE
While we reject forcing or compelling someone into a course of action that another considers is ‘good’ for him, we also reject the other extreme of leaving the athlete unsupported in such decisions. A good relationship between a doctor and an athlete is centrally important in providing the information required by the athlete to make a decision. But, while the doctor can be the source of support and information, the ultimate decision is the athlete’s. The International Olympic Committee (IOC) supports this approach. Where physicians are carrying out periodic health evaluations (PHEs) of athletes, two important considerations are expressed:

- If PHE evidences that an athlete is at serious medical risk, the physician must strongly discourage the athlete from continuing training or competing until the necessary medical measures have been taken.
- Based on such advice, it is the responsibility of the athlete to decide whether to continue training or competing. This position is reiterated by Dr Douglas in the 26th Bethesda Conference panel discussion. Her comments resonate with the IOC’s position when she states that ‘doctors are advisors, not decision makers’. Dr Levine also involved in the Bethesda discussion agrees, stating:

  I do not think that it is really the role or authority of the physician to literally “permit” an athlete to compete or alternatively to “exclude” an athlete from competition. It may be well meaning and benevolent, but I would regard this view as extending beyond the limits of the usual doctor–patient relationship because it removes from the patient the ultimate right of self-determination.

The IOC PHE Consensus Group acknowledges the ethical, medical and legal difficulties associated with screening and subsequent disqualification, especially the unnecessary exclusion of ‘competitive athletes with non-lethal diseases’. Objectors may suggest that it would be ethically problematic for a doctor to know about a risk of death and not have prevented it by excluding the athlete. The relationship, support and information that skilled medical practitioners provide help inform individuals in making life choices. By informing and educating the athlete of the risks involved with continued participation the doctor has acted ethically, and should not be held responsible for how someone chooses to live his/her life. This fits with the harm principle whereby we can educate or reason with people to encourage them not to engage in activities that might cause them harm, but the final decision rests with them.

CONCLUSIONS
A benevolent society is concerned with the interests of its citizens and in achieving this there are many aspects that such a society needs to consider. These include:

- Caring about the health and well-being of its citizens.
- Enabling citizens to be free to live the kind of life he/she chooses, as long as those choices are freely made by competent people, and their decisions do not directly harm others.

In balancing these two aspects, a benevolent society is required to keep compelled interventions into the lives of others to a minimum.

Medical practitioners have a role in screening for SCD. A robust SCD screening programme will assist athletes to make decisions about their sporting careers in light of what they value. Doctors can also play an important role in educating and


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interpreting the risk for athletes found to have an SCD-linked condition, but they are not the arbiters in deciding what level of personal risk is acceptable for an individual. Doctors can advise, but the final decision is not rightfully within their domain.

SCD is a rare and distressing event, and it is understandable that some members of the medical community wish to respond by excluding athletes identified as being at high risk. However, we should not extrapolate this sense of medical responsibility into paternalistic measures that limit the actions of others in this situation.

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