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Research Paper

Shared decision making for participation in elite athletes with cardiovascular conditions. Where are we now?

Katherine M. Edenfield^{a,*}, James R. Clugston^a, Matthew W. Martinez^{b,c}

^a Department of Community Health and Family Medicine, University of Florida, Gainesville, FL, USA

^b Department of Cardiovascular Medicine, Atlantic Health, Morristown Medical Center, Morristown, NJ, USA

^c Sports Cardiology and Hypertrophic Cardiomyopathy, Morristown Medical Center, Morristown, NJ, USA

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ABSTRACT

Sudden Cardiac Death is a leading medical cause of death in athletes of all ages. Recently there has been a shift from an authoritarian approach to that of using a Shared Decision Making (SDM) model in eligibility decisions of athletes with cardiovascular conditions. SDM in elite athletics can be complex and collaboration amongst the athlete, family, physicians, athletic trainers, and institutional stakeholders is critical. SDM acknowledges the complexities of a collaboration between sports cardiologists bringing disease and sport-specific expertise, and team physicians, in complementary fashion to integrate medical knowledge, clinical uncertainty, athlete and family values, and institutional philosophies and risk tolerance.

1. Background

Sudden Cardiac Death (SCD) is a leading medical cause of death in young competitive athletes [1]. There have been various guidelines over the years to help clinicians make eligibility decisions for athletes with cardiovascular conditions [2,3]. However, these, including the most recent 2015 guidelines [3] are outdated and based mostly on expert opinion, without a full understanding of the natural course and phenotypes of many conditions, and have not typically accounted for varying levels of play.

Historically, expert consensus recommendations have advised a simple yes or no approach to athlete return to play (RTP) after a diagnosis of cardiac disease. Recommendations have been phrased in binary fashion as either “can participate” or “cannot participate” [2]. This approach fostered an authoritarian decision-making methodology, in which physicians and institutions made decisions without input from the athlete and family. In addition, this promoted athlete distrust and avoidance of evaluations for symptoms and disclosure of known personal/family histories of cardiovascular disease.

Recently, there has been a shift from an authoritarian approach to that of using a Shared Decision Making (SDM) model in eligibility decisions of athletes with cardiovascular conditions. This is at least in part due to recent data illustrating positive outcomes and improved risk

assessment tools leading to an increased understanding of risk [4,5]. However, there is no precise definition or standardization of what SDM means or how to execute it uniformly. At a minimum it is intended to involve the patient in the medical decision-making process by assessing their values and preferences, educating them on the condition and treatment options, and taking their preferences into account with recommendations/decisions. When SDM is referred to in the context of cardiovascular conditions it is most often referencing the patient (athlete) and the cardiologist as evidenced by the study by Montembeau et al. [6] published in this special edition of *American Heart Journal Plus: Cardiology Research and Practice*. The concept of shared decision-making (SDM) is now firmly rooted in the medical community and termed the “pinnacle of patient-centered care” [7]. Many procedures now require SDM [8], and a recent meta-analysis found that SDM decreases decisional conflict [9]. Although the concept of SDM might seem simple, applying SDM to elite athletics is very complex. There are often complicated medical situations; varying personal circumstances (physical development, emotional maturity, education level, economic considerations, etc.); and multiple stakeholders with different perspectives of acceptable risk and safety.

* Corresponding author at: University of Florida, Department of Community Health and Family Medicine, Student Health Care Center, 2140 Stadium Road, Gainesville, FL 32611, USA.

E-mail address: kedenfield@ufl.edu (K.M. Edenfield).

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2. Who gets to “SHARE” in the SDM in an elite athlete?

Why do stakeholders outside of the athlete and cardiologist need to share in the decision making regarding elite athlete eligibility with a cardiovascular condition? When a cardiac event such as a Sudden Cardiac Arrest (SCA) occurs, it does not happen in isolation involving only the athlete (and parents) and the cardiologist. If an athlete has a known prior SCA event or has a significant cardiac condition with known risk of SCA; the first responder medical staff (usually a certified athletic trainer (ATC)) would have an additional burden of responsibility to monitor the athlete with the cardiac condition. This may have an unintended consequence of decreasing resources to the rest of the team. In the case where an event has already occurred, and decisions are being made about return, SDM should also consider teammates and staff who witnessed the event and could be affected by another event if participation occurs. If the athlete is part of an organized sport whether professional, national, collegiate, high school, or club level; there are administrators, managers, and owners who will be concerned with liability and legal aspects of RTP. Other considerations include acknowledgement that all involved require significant education to understand the risk. Of interest, the study by Montembeau et al. [6] highlights the need to consider SDM in cardiac eligibility decisions. The authors surveyed sports cardiologists who demonstrated a wide variance in their tolerance of risk for allowing an athlete to participate who was at risk of SCA, ranging from <1 % to >10 % annually. Over half of those surveyed were ok with a >5 % annual risk of SCD in an athlete [6]. This tolerance for SCA is

higher than we might expect amongst the sports medicine team physicians. Although, much has changed since the 1996 Knapp v. Northwestern decision [10], which impacts how RTP decisions are interpreted, the core of the decision—the team physician judgment model remains intact. The team physician is in the best position to coordinate communication between athletes, specialists, athletic trainers, coaches, parents; and is ultimately the person responsible for medical clearance at most levels of play. The Knapp decision explicitly declined to address the question of whether a school *should* allow an athlete with CVD to RTP if that decision involved assumption of risk. Instead it demonstrated that if a determination to disallow participation was based on reasonable medical practice and deliberation, especially if supported by current guidelines, the physician and institution were not liable under the Rehabilitation Act of 1973 for denying participation in a major life activity or a necessary part of learning. All universities can evaluate risk differently, meaning an athlete restricted by one school due to lower risk tolerance could compete at another school that determines risk differently [10,11]. Use of SDM as part of integration of expert opinion and current guidelines in a multidisciplinary fashion with team physicians is consistent with the Knapp ruling. Clinical approaches for an athlete's RTP should be based on most recent data and guidelines which include SDM, as supported by both cardiologists and team physicians. Fig. 1 summarizes the key participants in SDM and their role. The Team Physicians' consensus statement describes the role of SDM in the team-physician-led decision-making process noting physicians are guided by respect for patients' goals/preferences and accounts for risk

WHO	WHY
Athlete	It is their life and medical condition. Vital to understand their values and wishes.
Athletic Trainers	Expertise in first-responder care, most knowledge of the athlete and team dynamics, and emergency-action plans. Central in communication between medical staff, coach, and athlete.
Family	Support network of the athlete. Might have experience if any genetic transmission. If the athlete is a minor, they might ultimately have the ultimate decision-making ability for the athlete.
Institutional Stakeholders	Concern for the institution/organization's well-being as a whole. Knowledge of the applicable laws and need to be agreeable to ultimate risks if athlete allowed to play.
Primary Care Team Physician	Expertise in Primary Care Sports Medicine, Knowledge of the athlete, team, and institution. Ultimately responsible for eligibility decisions for most situations, Central in communication between relevant parties.
Primary treating Cardiologist	Expertise in the athlete heart conditions and often has a good understanding of the patient history for compliance and complications. They are most likely the individual who will continue to follow the athlete for ongoing surveillance and risk stratification.
Team/Institution/League Sports Cardiologist	Expertise in the athlete heart conditions and risk of the athlete based on the sport. Has an independent view of the risks, evaluation of the conditions, and risk mitigation/treatment of the conditions, and most relevant guidelines to those conditions. Is able to provide an objective expert review of the condition without a relationship to the athlete.

Fig. 1. The who and the why of shared decision making in elite athletes.

tolerance of patient, physicians, and organizations [12]. In short, the team physician judgment model is intact, but the input from guidelines/consensus statements/experts has evolved.

The 2018 International Olympic Committee Consensus Statement on pediatric anterior cruciate ligament injuries [13] contains an important discussion on ethical considerations and SDM which can be applied to athletes with cardiovascular conditions. Ultimately there should be consensus amongst all stakeholders when arriving at an eligibility or treatment decision. The clinician's responsibility is to educate and advise the stakeholders with accurate up to date medical information regarding the condition and the potential morbidity and mortality from the condition, how athletics affects the risks, and potential treatment options. When consensus is unable to be reached, there are 6 ethical standards which can be applied to help navigate treatment and eligibility decision:

- Best Interests (what is in the best long-term interests of the athlete)
- Harm Principle (threshold below which the clinician should not acquiesce to a parent-led decision, so that athlete is not harmed)
- Parental Discretion (acceptance of parent preference when it is not harmful over the clinician's threshold)
- Costs/Benefits (risk assessment)
- Not unreasonable (only accounts for appropriateness of decisions and decision-maker)
- Reasonable choice (considers all of the ethical standards into single decision) [13].

3. Risk/benefit assessment; clear as mud

Clinicians often think more in terms of Risk of participating than Benefit of participating when considering the eligibility recommendations of an athlete with a serious cardiac condition. But when restricting an athlete from organized sports, what about the risk of *not* participating? Physical activity is effective in both preventing and treating a multitude of chronic diseases and health conditions while physical *inactivity* causes 9 % of premature mortality [14]. Physical fitness benefits children's cognitive function, brain structure and function and improves academic achievement [14]. Significant mental health benefits, including a 25 % lower risk of depression in adults, achieving the recommended volume of activity/week have been demonstrated [15]. Young athletes excluded from sports for any reason experience decreased quality of life. [16] Amongst Hypertrophic Cardiomyopathy (HCM) individuals excluded, they report a negative impact of restriction on their emotional well-being [17]. For adolescents with defibrillators, athletes indicated restriction from sports was the most devastating aspect of their illness [18]. From the psychological standpoint, sports may provide coping mechanisms, and restriction leads to loss of the support of the team environments and significant psychological distress [19]. Lastly, if an athlete is restricted from organized sports, they very well might participate in unorganized activity such as pick-up basketball where they will not have as many available resources and monitoring as they would in an organized setting. These are important considerations which much be weighed in all SDM situations.

Consider the following example demonstrating the process of SDM in an elite athlete with a serious cardiac condition. A 19 year old women's soccer player had an ICD placed for primary prevention of SCD and would like to be cleared to return to play soccer at her institution. The team physician for the soccer team consults with the sports cardiologist. The sports cardiologist conducts a formal risk assessment of the circumstances surrounding the need for the ICD implant in addition to the data on risk for ICD damage, risk of sustaining a shock from the device and the risk for disease progression and this is discussed in a series of visits and phone calls with various combinations of the athlete, her parents, the sports cardiologist, other consulting cardiologists, the athletic trainer, and the team physician. Visual aids about potential harm and some protective equipment that may help the device remain safe with mild collisions are included. The team physician and athletic

trainer further discuss the recommendations with the institution regarding risk for the player. A safety plan that includes ongoing surveillance for changes in risk and to ensure the ICD was properly functioning is discussed with the institutions' medical team to prepare for possible clearance to play. The local EAP is reviewed and updated. Ultimately, the team physician makes the clearance decision while taking into account the athlete's values and understanding of risk, with the consultants analysis of the risks, and the athletic trainers understanding and comfort as the first responder medical staff, and the institutions tolerance of the risk and ability to provide the necessary and appropriate resources for the athlete.

The results of Montembeau's recent survey of sports cardiologists about SDM [6] highlights the need for a more uniform approach to SDM in elite athletes, ideally leading to a consensus from the entire team invested in the athlete. We agree on the need for a more standardized approach to SDM and recommend an individualized and nuanced approach to elite athlete cardiac condition eligibility decisions utilizing a SDM model which involves a broader group of stakeholders (other healthcare providers, administrators, coaches) so a larger group is in agreement and appropriate resources are provided when indicated such as counseling, monitoring equipment, extra staff) as well as considering the long term health of the athlete. It is important to note that all stakeholders do not necessarily have an equal part in the SDM process and the timing and inclusion of certain stakeholders can be dependent on the situation and athlete's values.

Collaboration amongst the athlete, family, physicians, athletic trainers, and institutional stakeholders is critical. SDM acknowledges the complexities of a collaboration between sports cardiologists bringing disease and sport-specific expertise, and team physicians, in complementary fashion to integrate medical knowledge, clinical uncertainty, athlete and family values, and institutional philosophies and risk tolerance.

CRedit authorship contribution statement

Katherine M. Edenfield: Writing – review & editing, Writing – original draft, Conceptualization. **James R. Clugston:** Writing – review & editing, Writing – original draft, Conceptualization. **Matthew W. Martinez:** Writing – review & editing, Writing – original draft, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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