

An Exercise Plan for HCM patients

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HCM Director
Atlantic Health System/Morristown Med Center

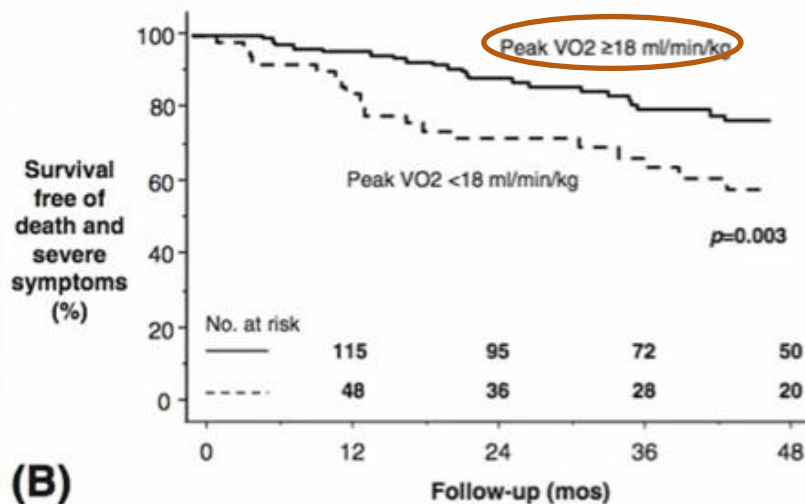


In HCM too!

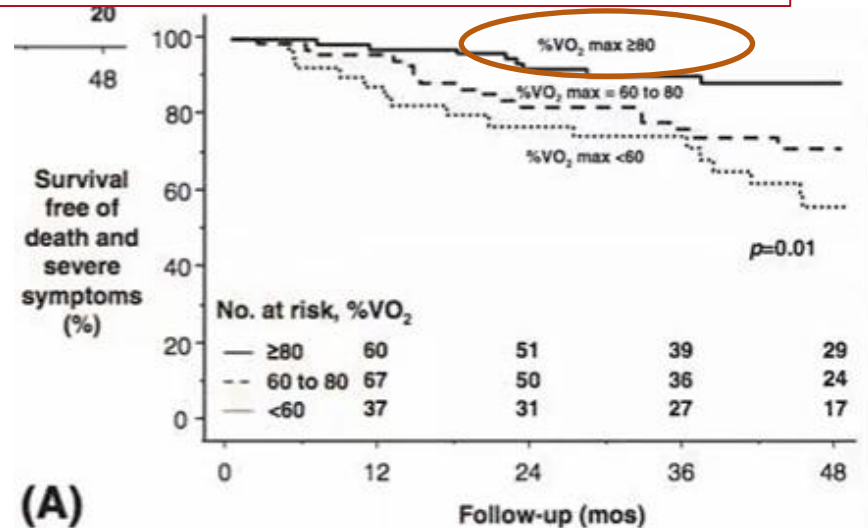
Physical Activity Among HCM Patients

In clinical practice, the message of physical activity has been confusing

Fitness is Associated with prolonged survival and free from HF in those with HCM



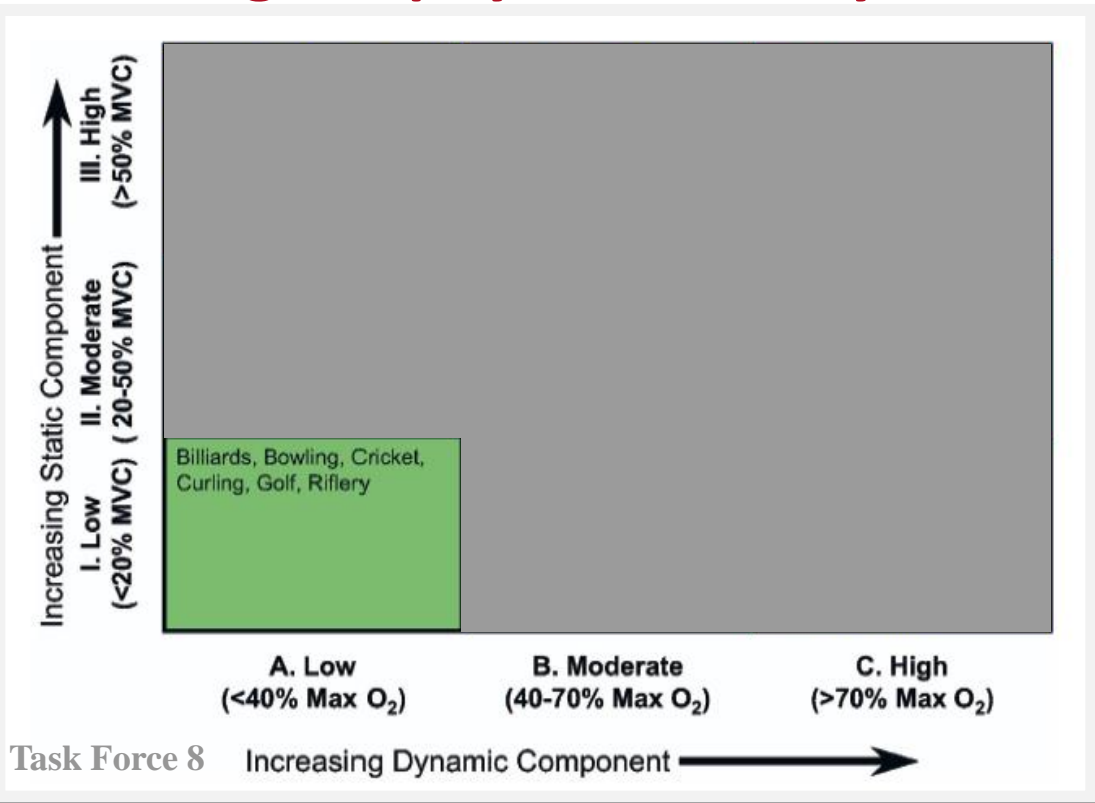
(B)



(A)

Physical Activity Among HCM Patients

In clinical practice, the message of physical activity has been confusing



Physical Activity Among HCM Patients

- HCM patients are less active than the general U.S. population
- 60% believe exercise restrictions negatively impact well-being
- >50% fail to meet minimum guidelines for physical activity

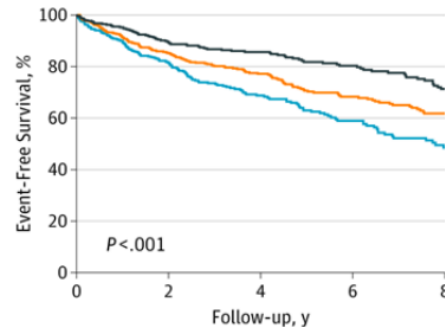


Association of Obesity With Adverse Long-term Outcomes in Hypertrophic Cardiomyopathy

- 3282 patients, 2019 (61.5%) were male. Mean age 47yrs.
 - 1280 patients in the preobesity group (39.0%),
 - 1040 patients in the obesity group (31.7%).

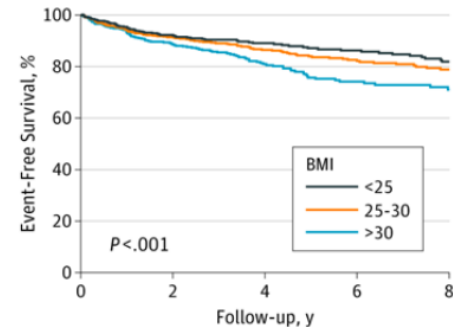
Figure 2. Kaplan-Meier Analysis of the Overall Composite and Heart Failure Composite Outcomes

A Overall composite outcome



No. at risk					
<25	899	627	489	403	314
25-30	1191	841	646	495	390
>30	942	640	483	352	266

B Heart failure composite outcome

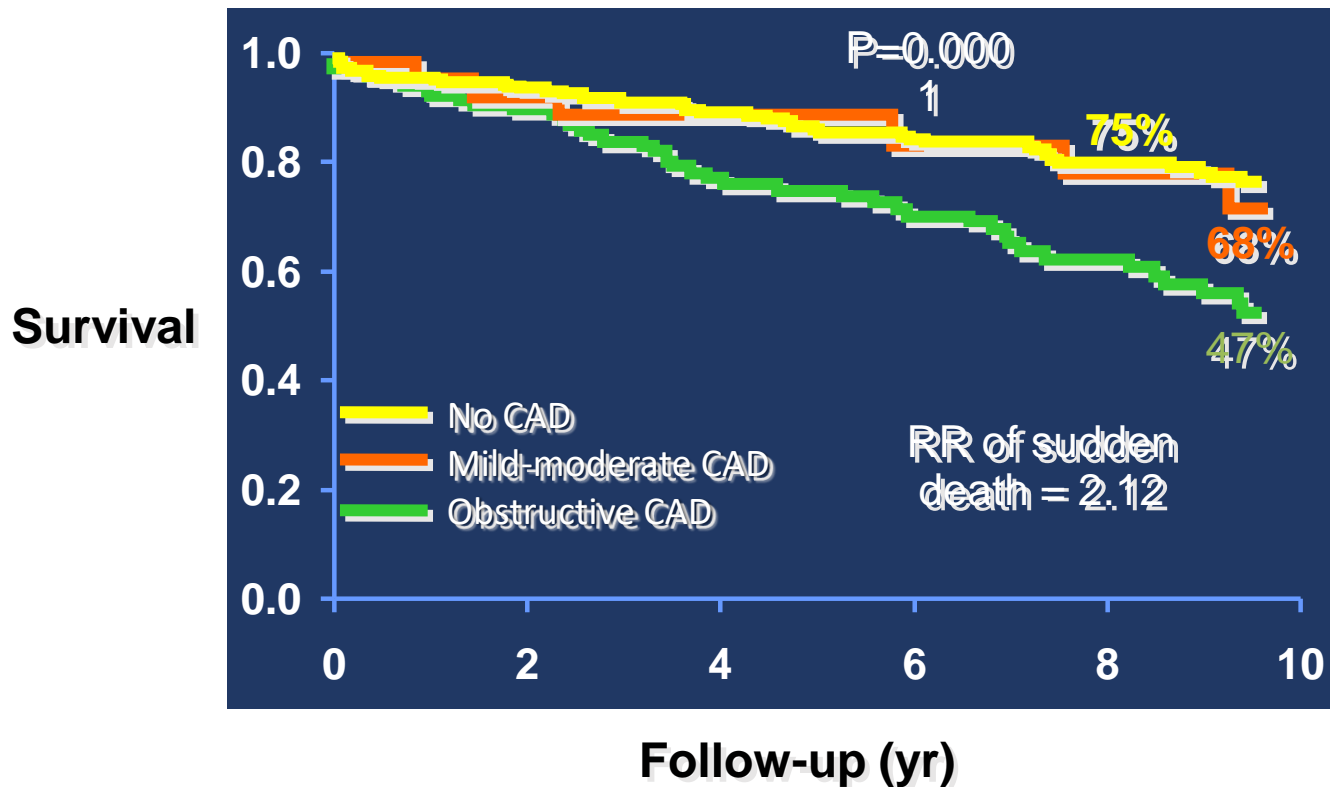


No. at risk					
<25	879	632	510	411	333
25-30	1183	876	685	532	438
>30	964	721	527	397	308

Association of Obesity With Adverse Long-term Outcomes in Hypertrophic Cardiomyopathy

- 3282 patients, 2019 (61.5%) were male. Mean age 47yrs.
 - 1280 patients in the preobesity group (39.0%),
 - 1040 patients in the obesity group (31.7%).
 - Patients with obesity were more symptomatic.
 - At follow-up, obesity was independently associated with the HCM-related adverse outcomes, heart failure and AFIB
 - Irrespective of age, sex, left atrium diameter, obstruction, and genetic status.

CAD & HCM has a poor prognosis



Benefits of Exercise in HCM

Improved exercise tolerance, increased V02 max.¹⁻²

Psycho-social benefits and improved health-related quality of life.⁴

Overall health benefits (weight loss, improved metabolic profile, longevity).

Potential for improved LV remodeling, increase in LV and RV end diastolic volume, improved diastolic function.³

1. Saberi et al. JAMA. 2017;317:1349-57.
2. Klempfner et al. Eur J Prev Cardiol. 2015;1:13-19.
3. Sheikh et al. Circ Cardiovasc Imaging. 2015;8:e003454.
4. Sweeting et al. Am J Cardiol. 2018;122:866-71.

Exercise in HCM

The Randomized Exploratory Study of Exercise Training in Hypertrophic Cardiomyopathy (RESET-HCM)

JAMA | Preliminary Communication

Effect of Moderate-Intensity Exercise Training on Peak Oxygen Consumption in Patients With Hypertrophic Cardiomyopathy
A Randomized Clinical Trial 2017

Sara Saberi, MD, MS; Matthew Wheeler, MD, PhD; Jennifer Bragg-Gresham, MS, PhD; Whitney Hornsby, PhD; Prachi P. Agarwal, MD, MS; Anil Attili, MD; Maryann Concannon, MSW; Annika M. Dries, BA; Yael Shmargad, BS; Heidi Salisbury, RN, MSN, CNS; Suwen Kumar, MBBS; Jonathan J. Herrera, MS; Jonathan Myers, PhD; Adam S. Helms, MD, MS; Euan A. Ashley, FRCP, DPhil; Sharlene M. Day, MD

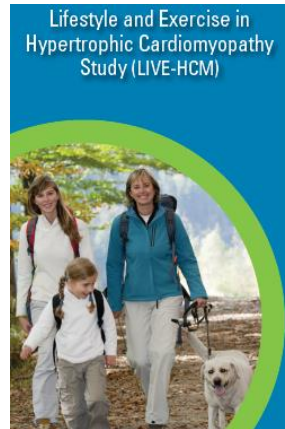
- 136 patients with HCM; **mean age 50.4 years**
- Randomly assigned to **16 weeks of moderate-intensity exercise training** or usual activity
- Moderate-intensity exercise resulted in a significant but **small increase in exercise capacity** (+1.35 mL/kg/min)
- **No adverse events** (sustained ventricular arrhythmia, SCA, appropriate defibrillator shock, or death) in either group

EXERCISE IN GENETIC CARDIOVASCULAR DISEASE (LIVE-HCM)

Aim 1: Incidence **arrhythmic events** over 3 years
Comparison moderate or vigorous exercisers vs sedentary

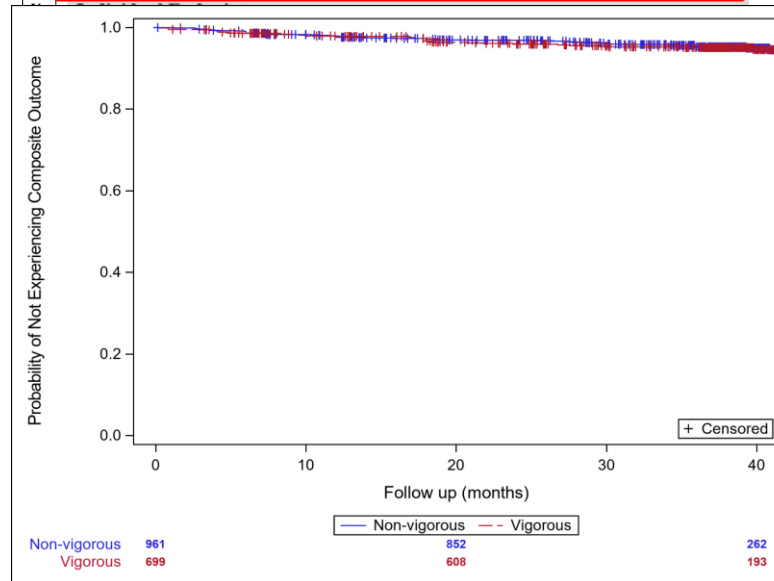
Aim 2: **Quality of life**
Comparison moderate or vigorous exercisers vs sedentary
Age 8-60 years, with OR without ICD
Any level exercise

3 years of follow up



NIH R01 HL125918-01

	Non-Vigorous	Vigorous	Total	
	N=961	N=699	N=1660	
TOTAL composite endpoint				
N	44	33	77	
Rate per 1,000 person-year (95% CI)	15.3 (11.4, 20.5)	15.9 (11.3, 22.4)	15.6 (12.5, 19.6)	P value



Athletes with HCM

Circulation

Volume 137, Issue 5, 30 January 2018, Pages 531-533
<https://doi.org/10.1161/CIRCULATIONAHA.117.031725>



CORRESPONDENCE - RESEARCH LETTER

Does Sport Participation Worsen the Clinical Course of Hypertrophic Cardiomyopathy? 2018

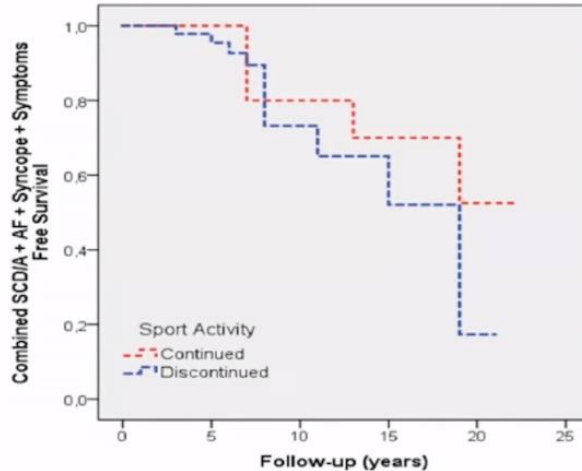
Clinical Outcome of Hypertrophic Cardiomyopathy in Athletes

- 35 athletes with HCM; mean age 32
- 33 (94%) white
- 31 (88%) low risk by ESC risk score
- Mean observation 9 years
- 1 SCA occurred (amateur tennis player while walking)
- **No difference in the incidence of symptoms or events among patients who stopped or continued sport competitions**

HCM in Athletes

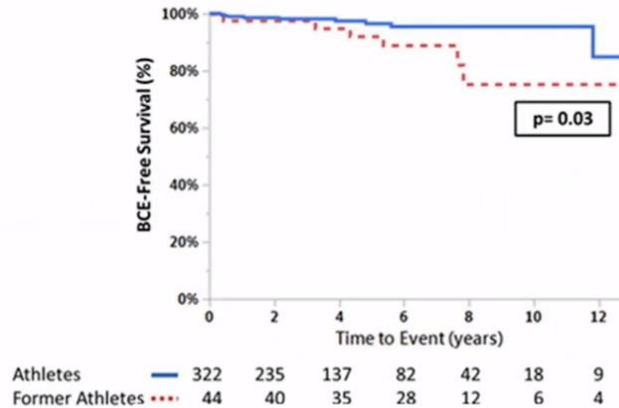
No increase in arrhythmic events for athletes who continue to play versus those who have stopped

88 athletes with HCM
61 stopped, 27 continued



Pelliccia et al., British Medical Journal 2020

366 athletes (23 with HCM)
44 stopped, 322 continued



Turkowski et al. Circulation. 2018

AHA/ACC CLINICAL PRACTICE GUIDELINE

2020 AHA/ACC Guideline for the Diagnosis and Treatment of Patients With Hypertrophic Cardiomyopathy

A Report of the American College of Cardiology/American Heart Association Joint Committee on Clinical Practice Guidelines

COR	LOE	RECOMMENDATIONS
1	B-NR	1. For most patients with HCM, mild- to moderate-intensity recreational* exercise is beneficial to improve cardiorespiratory fitness, physical functioning, and quality of life, and for their overall health in keeping with physical activity guidelines for the general population (1-3).
1	C-EO	2. For athletes with HCM, a comprehensive evaluation and shared discussion of potential risks of sports participation by an expert provider is recommended (4).
2a	C-EO	3. For most patients with HCM, participation in low-intensity competitive sports is reasonable (5,6).

Recommendation Table 31 — Exercise recommendations for patients with cardiomyopathy

Recommendations	Class ^a	Level ^b
All cardiomyopathies		
Regular low- to moderate-intensity exercise is recommended in all able individuals with cardiomyopathy.	I	C
An individualized risk assessment for exercise prescription is recommended in all patients with cardiomyopathy.	I	C

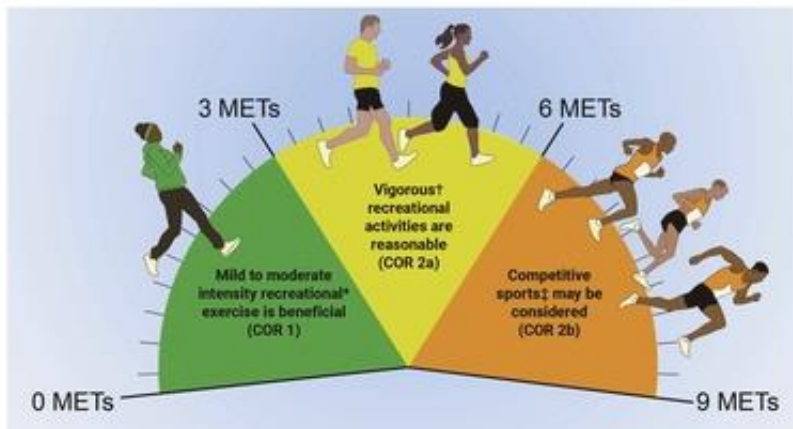


ESC

European Society
of Cardiology

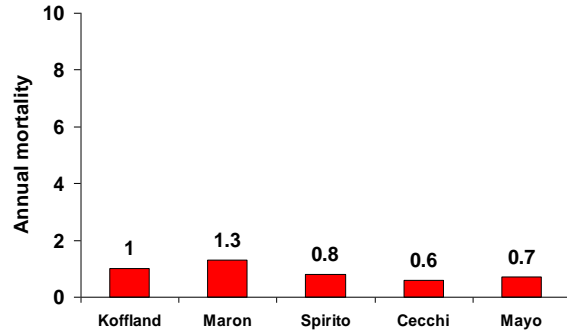
European Heart Journal (2023) 44, 3503–3626
<https://doi.org/10.1093/eurheartj/ehad194>

CENTRAL ILLUSTRATION: 2024 AHA/ACC/Multisociety HCM Guideline

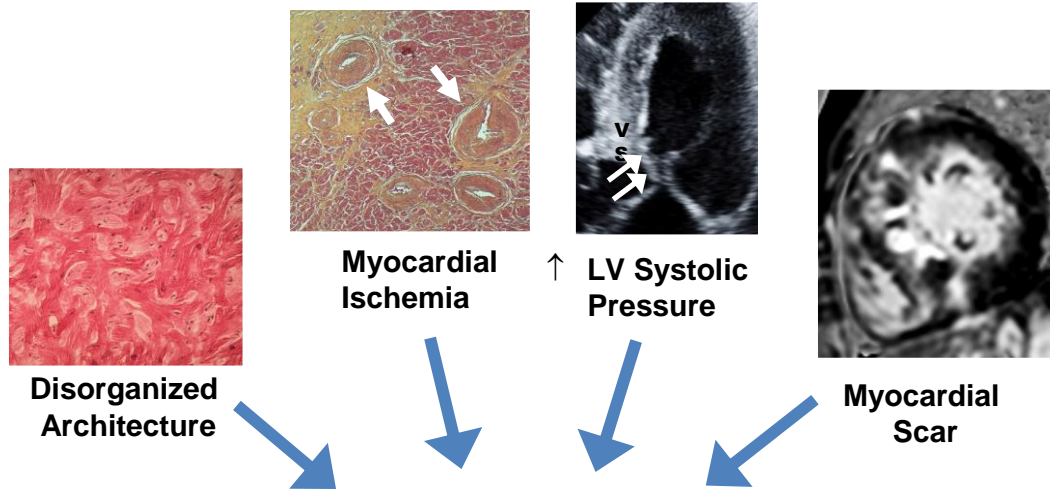


Clinical Dilemma

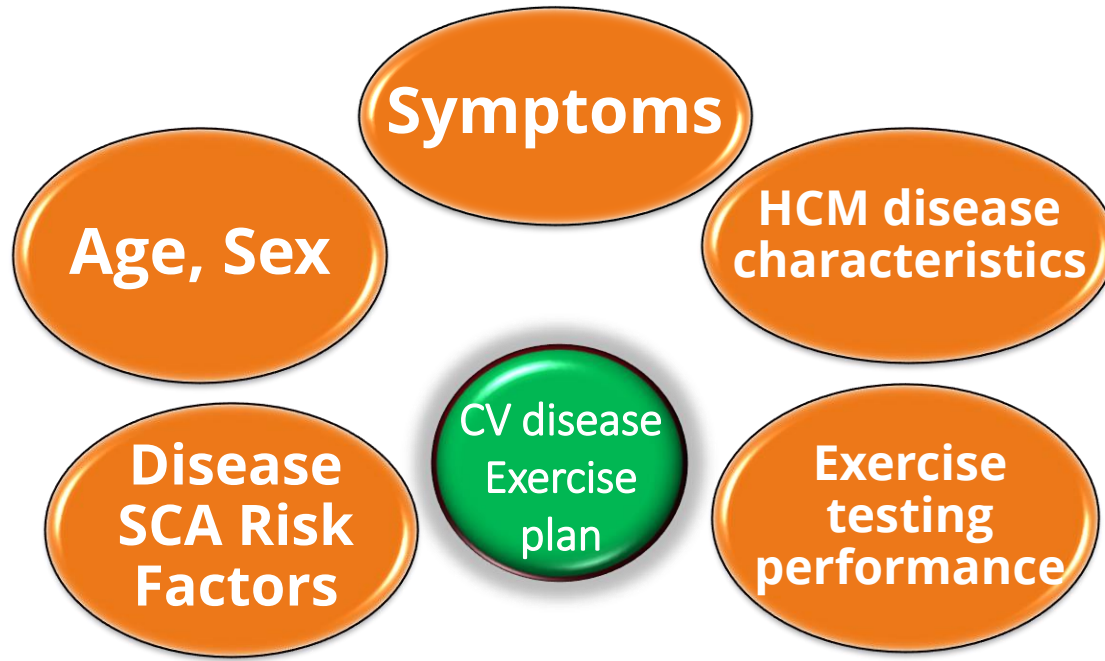
Low Annual Mortality Overall



HCM



Arrhythmic Risk



Clinical Risk Factors for HCM Sudden Cardiac Arrest



Family history of sudden death from HCM

Massive LVH ($>30\text{mm}$)

Unexplained syncope

HCM w/ LV systolic dysfunction ($\text{EF} < 50\%$)

LV apical aneurysm

Extensive LGE on CMR

NSVT on ambulatory monitor

Enhanced American College of Cardiology/American Heart Association Strategy for Prevention of Sudden Cardiac Death in High-Risk Patients With Hypertrophic Cardiomyopathy

Martin S. Maron, MD; Ethan J. Rowin, MD; Benjamin S. Wessler, MD; Paula J. Mooney, RN; Amber Fatima, MD; Parth Patel, MD; Benjamin C. Koethe, MPH; Mikhail Romashko, MD; Mark S. Link, MD; Barry J. Maron, MD

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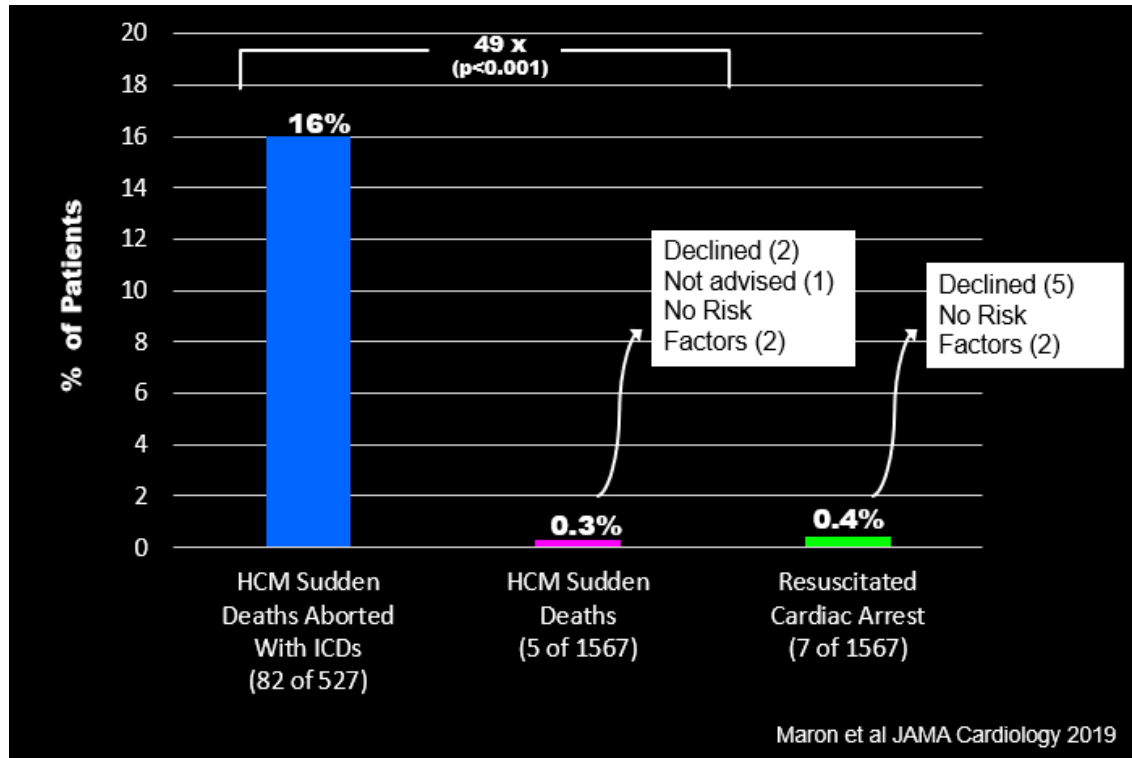
9

- 2094 patients with HCM. Observational data. Single center
- Mean follow-up 4.7 years
- 12 of 1567 (0.8%) had SCA
- 527 received primary prevention ICDs
- Very low annual mortality. 99% survival without ICD
- 16% experienced device therapy-terminated VT/VF;
- 20 patients w/ ICD interventions -> 85% had LGE

Risk stratification and prevention model averted nearly all SCD

Enhanced ACC/AHA clinical risk factor strategy for predicting SCD events was 95% sensitive

Impact of US Guidelines For Risk Stratification in 2094 HCM patients



Sudden Cardiac Death Risk in Hypertrophic Cardiomyopathy Wither Our Cognitive Miser

Steve R. Ommen, MD

of risk tolerance. In the end, the guideline models are not intended nor should they be used to make the final decision to implant an ICD. No cutoff value applies to every patient with HCM. It is the patient's risk tolerance/aversion, stemming from that consultation, that informs the final decision of whether to pursue an ICD. The consultation is not easy and is not the preference of the cognitive miser; the shared decision-making consultation is the domain of healers.

indications.¹ One can infer that expert clinical experience and/or discussions accounting for patient preferences affected the final treatment pathway chosen. The cognitive miser did not dictate the clinical decisions.

Shared Decision-Making



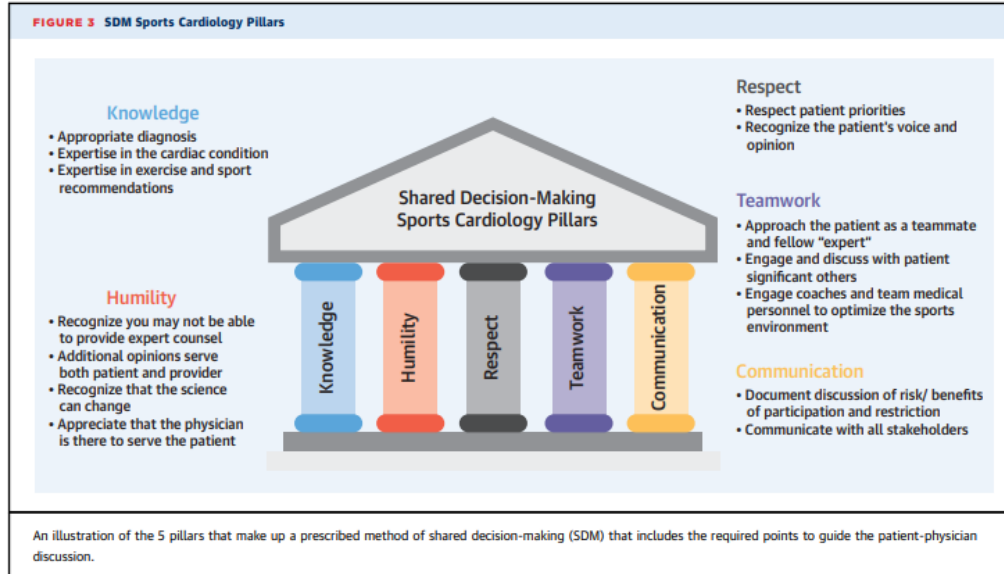
SHARED DECISION-MAKING

Recommendation for Shared Decision-Making

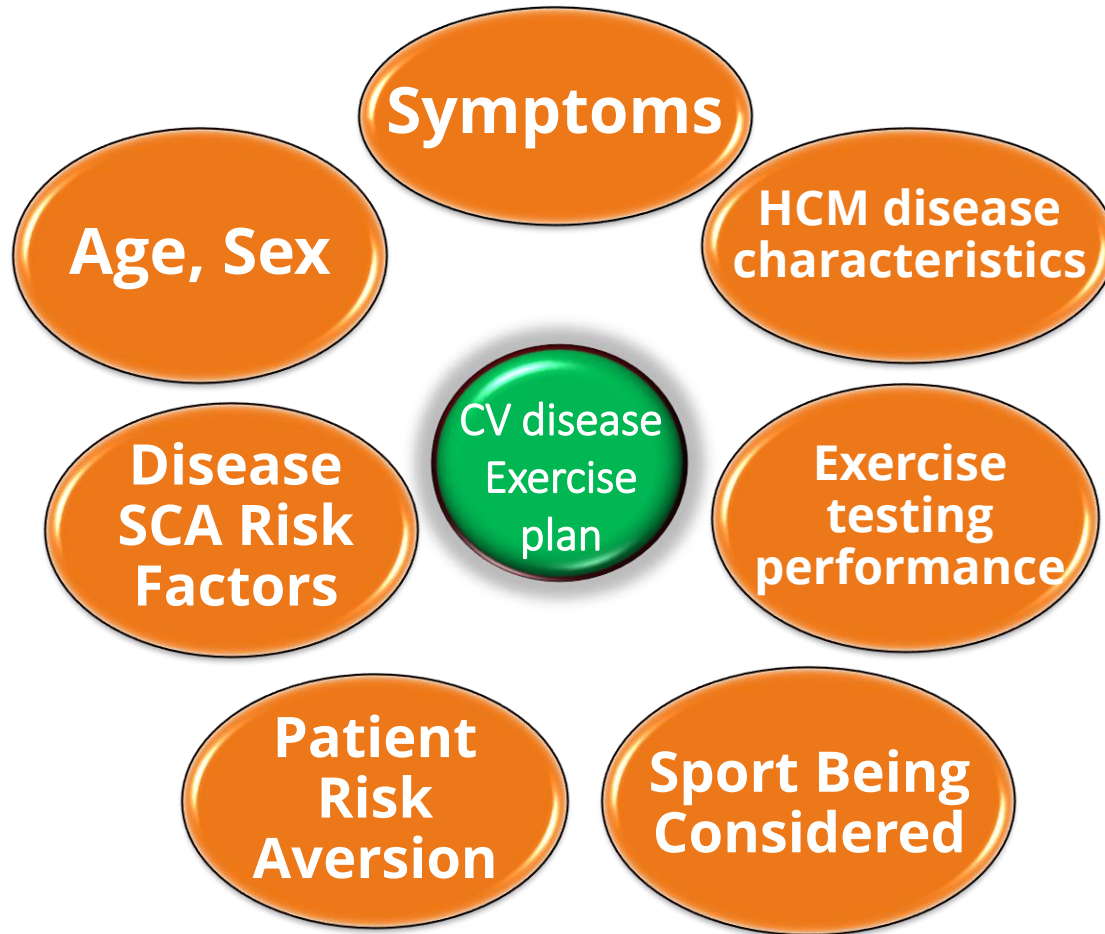
Referenced studies that support the recommendation are summarized in [Online Data Supplement 1](#).

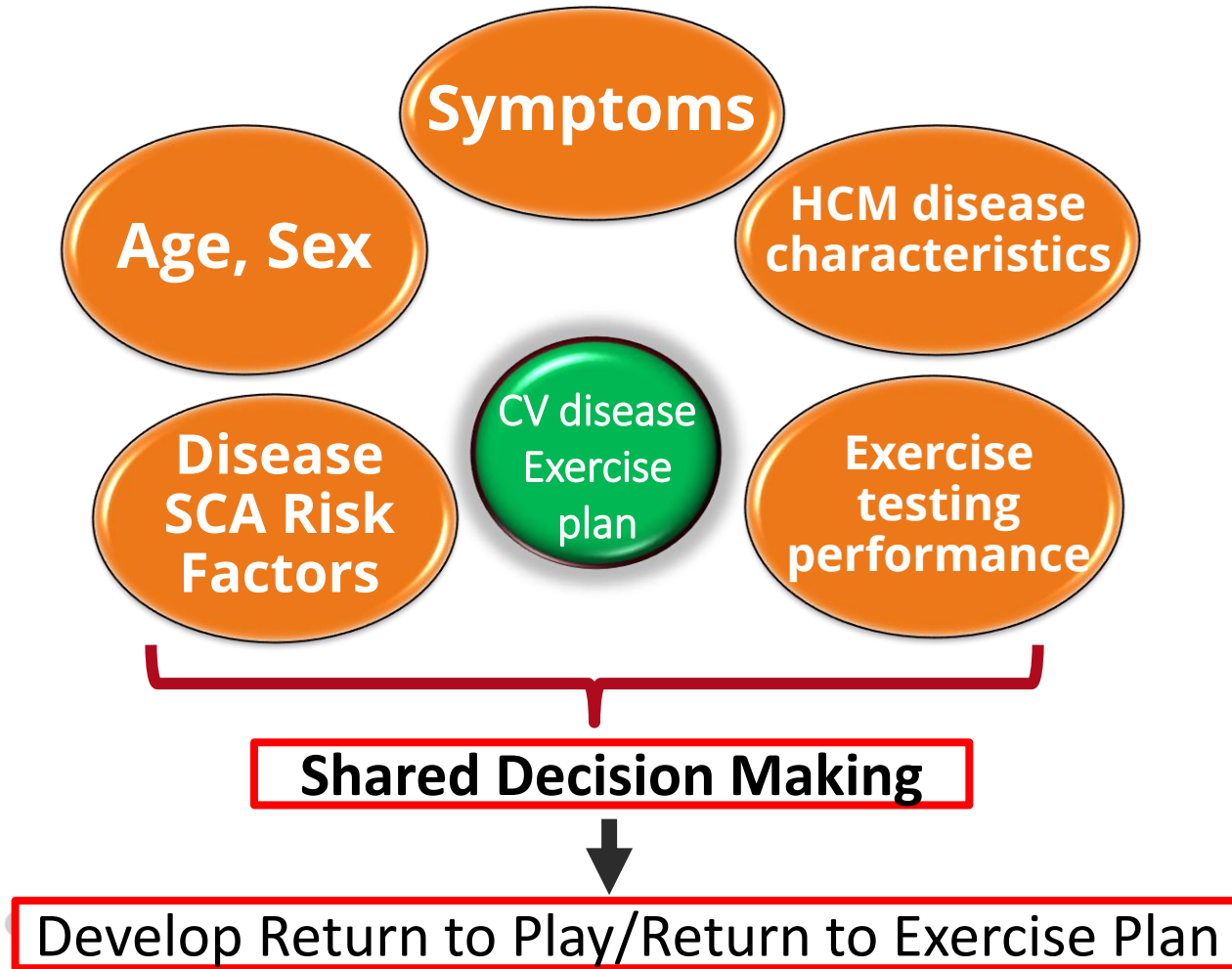
COR	LOE	Recommendation
1	B-NR	1. For patients with HCM or at risk for HCM, shared decision-making is recommended in developing a plan of care (including but not limited to decisions regarding genetic evaluation, activity, lifestyle, and therapy choices) that includes a full disclosure of the risks, benefits, and anticipated outcomes of all options, as well the opportunity for the patient to express their goals and concerns. ¹⁻⁶

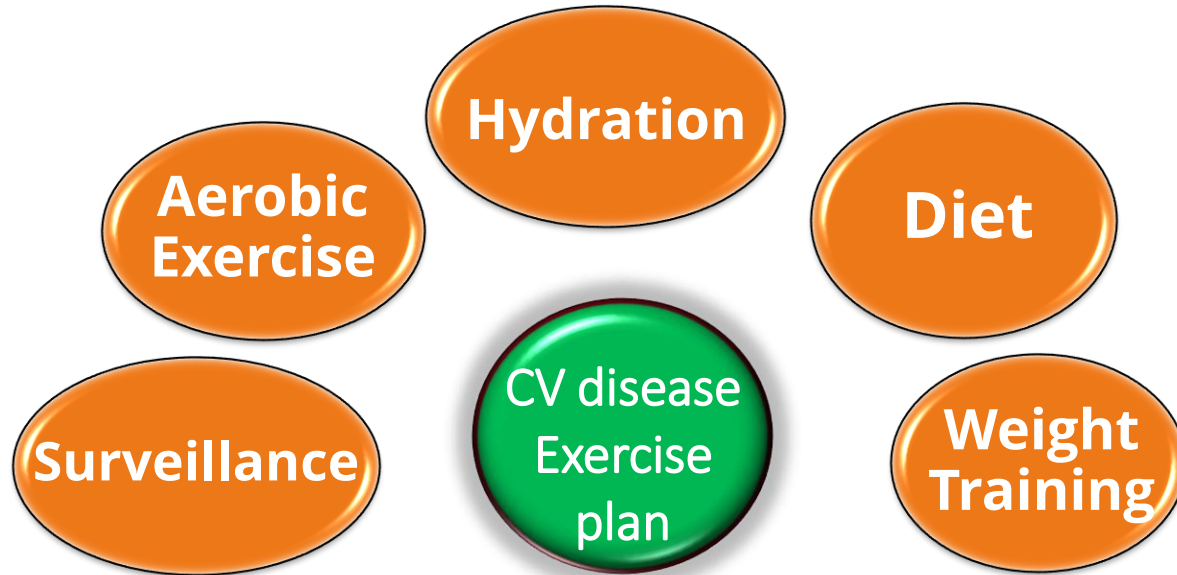
SDM in Sports Cardiology



Is the right provider having the discussion?







Key components to writing a cardiovascular exercise Rx following the "F.I.T.T." model:

FREQUENCY

5 days per week of moderate exercise or 3 days per week of vigorous exercise or a combination of the two

INTENSITY

Light: 30-39% of HRR. THR _____ to _____.

<3.0 METs (Ex: Walking slowly, cooking, light housework, you can talk or sing)

Moderate: 40-59% of HRR. THR _____ to _____.

3.0 to <6.0 METs (Ex: Brisk walking (2.4-4 mph), biking (5-9 mph), active yoga, recreational swimming², you are a little short of breath, sweating and have trouble talking unless in short sentences)

Vigorous: >60-89% of HRR. THR _____ to _____.

≥6.0 METs (Ex: Jogging/running, biking (>10 mph), singles tennis, swimming laps², cannot talk)

Heart Rate Reserve (HRR)=

HRmax - HRrest = _____ - _____ = _____

HRmax = 220 - age = 220 - _____ = _____

Target HR (THR) = (HRR x %intensity) + HRrest =

(_____ x _____) + _____ = _____

TIME

150 min/week of moderate-intensity or 75 min/week of vigorous-intensity or a combination

100+ minutes/week

TYPE

Continuous, regular and purposeful exercise involving major muscle groups (see examples under Light, Moderate, and Vigorous)

Learn more at [ACC.org/LearnHCM](https://acc.org/LearnHCM)



Just move your body!

Mild to Moderate exercise for all



Exercise Prescription for all

4-5 days a week of some physical activity

Dr. Benjamin Levine

(these can be done in any order)

1 Day
1 hour - something **fun!**



1 Day
4 mins **high intensity**
3 mins recovery repeat 4x



2 - 3 Days
30 minute **moderate intensity**



Plus
Any day - 30 minute **strength** training



Get a Dog!



Owning a dog = large, health improving effect!!
22 min additional time spent walking, 95%CI (12, 34)
2760 additional steps per day, 95%CI (1667, 3991)



- 1-2 days a week
- No true maximum weight
 - Max repetitions - >12 per muscle group
 - Toning, fitness, cross training
 - Avoid sustained Valsalva
 - > "grunting", "swinging or bouncing the weights"

Aerobic
Exercise

Weight
Training



The American Heart Association Recommendations for Physical Activity in Adults

At least **30** minutes of moderate-intensity aerobic activity At least **5** days per week for a total of **150** minutes



OR

At least **25** minutes of vigorous aerobic activity At least **3** days per week for a total of **75** minutes

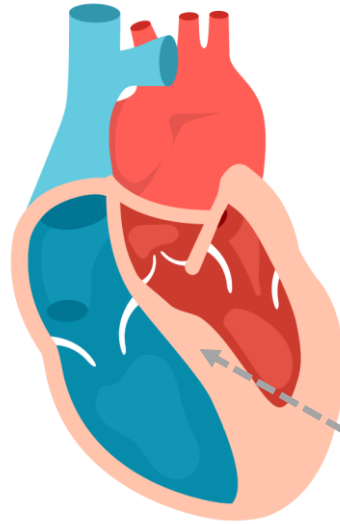


or a combination of the two

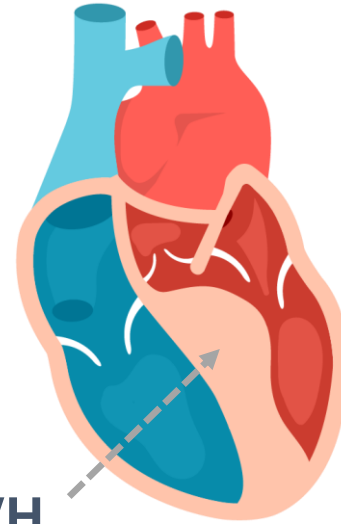
AND

Moderate to **HIGH INTENSITY** muscle-strengthening activity At least **2** days per week for additional health benefits





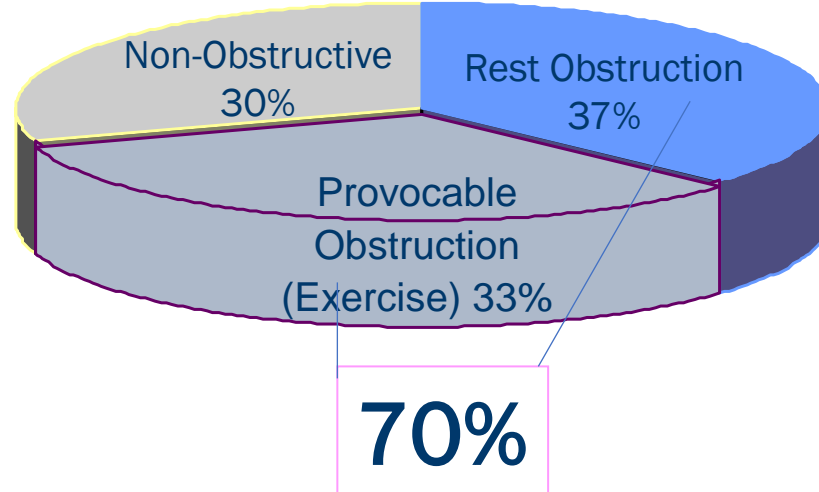
**Nonobstructive
HCM**

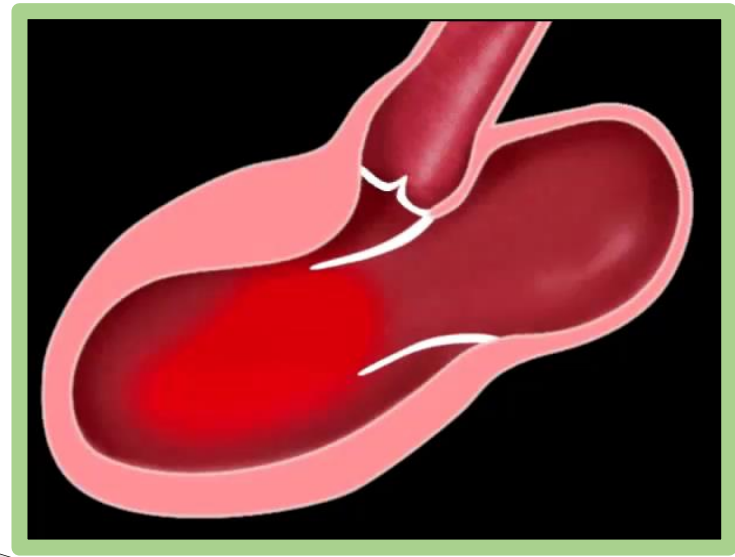
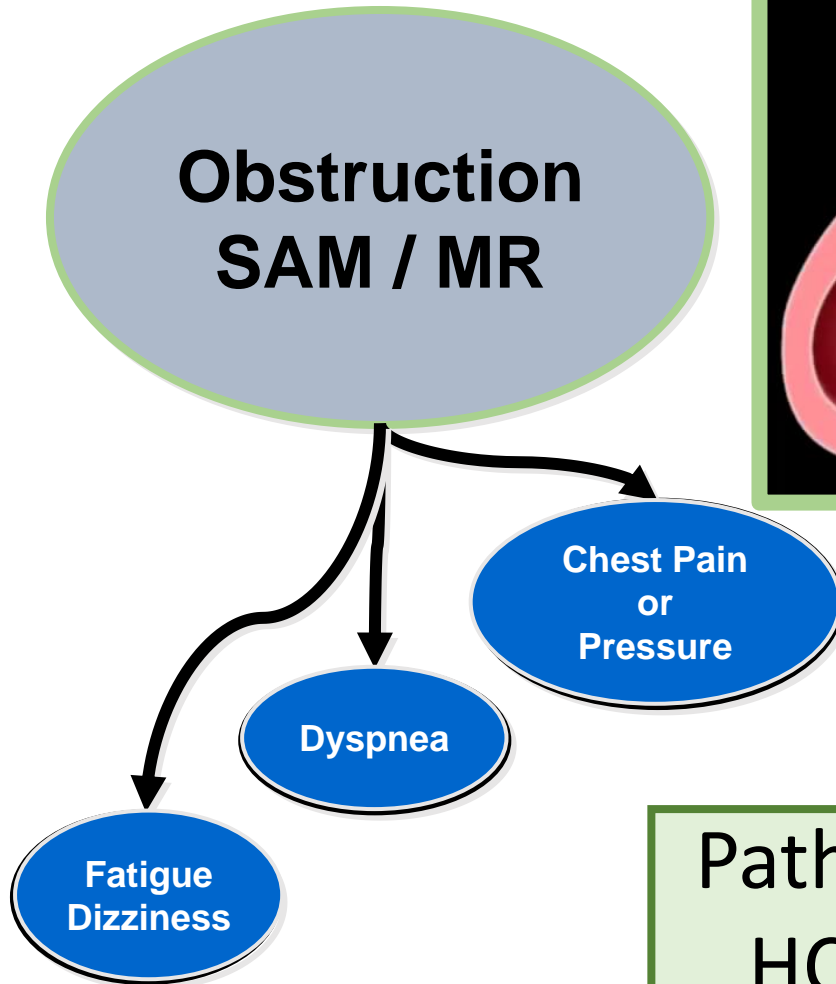


**Obstructive
HCM**

LVH

Prevalence of LV Outflow Obstruction (based on rest and exercise gradients)





**Pathophysiology of
HCM Symptoms**

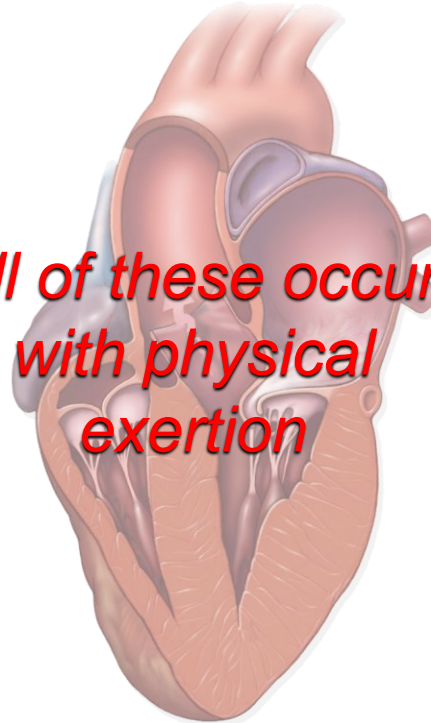
Obstruction gets worse if...

**More Vigorous
Contraction**

Decreased Resistance

Decreased Volume

***All of these occur
with physical
exertion***



Hydration

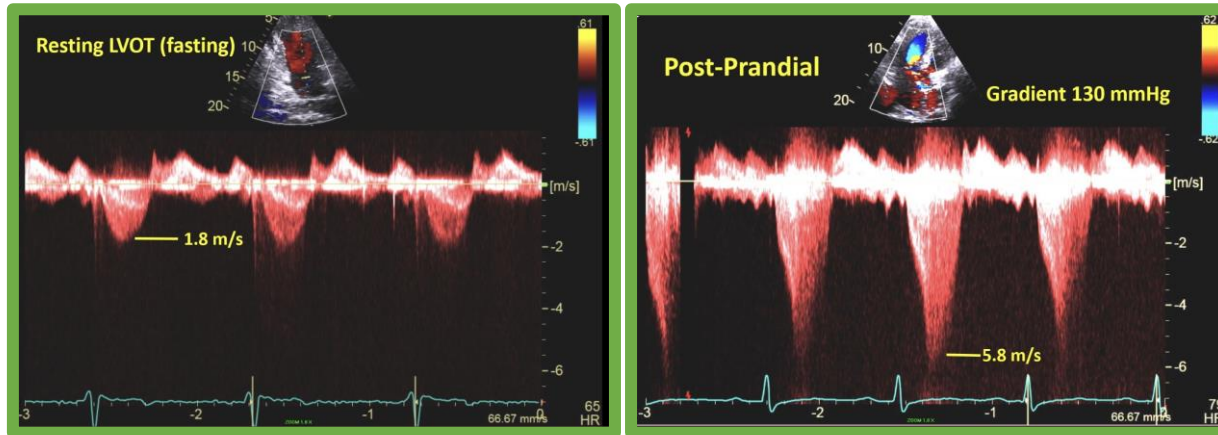


Diet

➤ Am J Cardiol. 2010 Nov 1;106(9):1313-6. doi: 10.1016/j.amjcard.2010.06.061. Epub 2010 Sep 9.

Drink more, and eat less: advice in obstructive hypertrophic cardiomyopathy

Mayank M Kansal¹, Farouk Mookadam, A Jamil Tajik





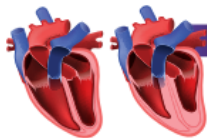
Diet

- Lean body mass is better
- Watch your calories –weight/weight loss
- Sleep and exercise for weight management.



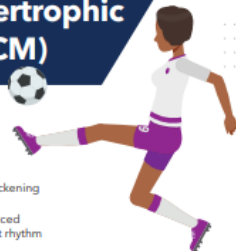
AMERICAN
COLLEGE of
CARDIOLOGY

Exercising with Hypertrophic Cardiomyopathy (HCM)



What is HCM?

- HCM = Hypertrophic Cardiomyopathy
- Affects 1 in 200 - 500 people worldwide
- HCM is a genetic heart condition that causes thickening of the heart muscle
- HCM can result in abnormal heart function, reduced blood flow out of the heart or an abnormal heart rhythm



Exercise and HCM

Exercise is encouraged for people with HCM, even in those with ICDs.¹

Mild to moderate physical activities improve fitness, quality of life, and lowers traditional cardiac risk factors (high blood pressure, high cholesterol), even in those with HCM.²

High intensity activity/ competitive sports may be possible after evaluation and guidance by an expert HCM cardiologist.



See your doctor: Physician expert provides a personal exercise prescription



A comprehensive EAP is required to manage a possible cardiac emergency (including player gear removal such as football, hockey)



Proper hydration and replenishment of electrolytes for exercise
Increase hydration for hotter days and longer activities



SAFE PERFORMANCE STRATEGIES



Make AEDs accessible and usable within 3-5 min



CPR and AED training is imperative for coaches, officials, and athletic medical staff (all key stakeholders in athletics)



WHEN TO WORRY

Worsening shortness of breath
Dizziness or fainting
Chest pain
Heart palpitations or fluttering

5 Things to Remember For Your Student Athlete

1

Each HCM patient requires an individualized exercise program.

2

Some HCM patients may need a defibrillator.

3

Avoid dehydration and advise no medicines with stimulants and no exercise during viral illnesses.

4

Initiate and maintain communication with the patient and the treating cardiologist.

5

HCM patients' 1st degree relatives are at risk to have HCM.

Abbreviations:
ICD: Implantable Cardioverter-Defibrillator
EAP: Exercise Assessment Program
AED: Automated External Defibrillator
CPR: Cardiac Resuscitation Program

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Educational

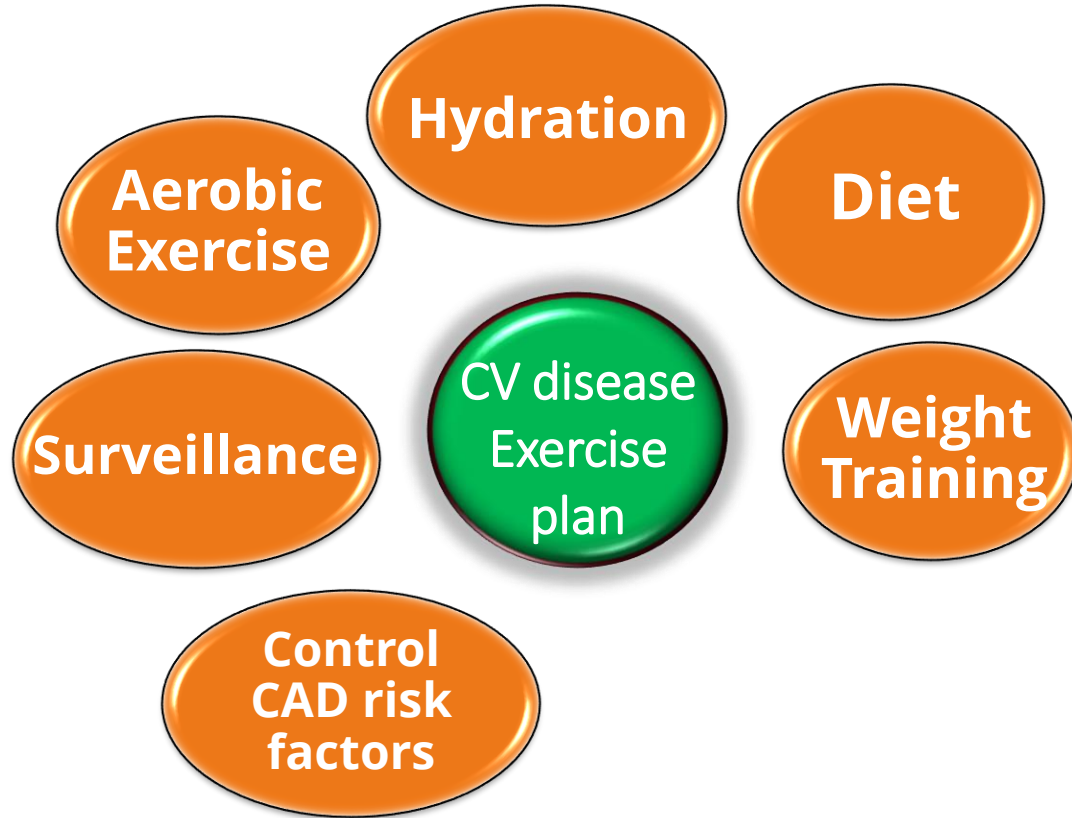
Learn more at [ACC.org/LearnHCM](https://www.acc.org/LearnHCM)



[ACC.org/LearnHCM](https://www.acc.org/LearnHCM)

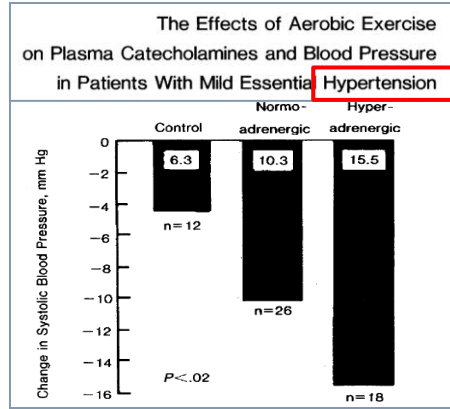
Faculty:

Chad Asplund, MD
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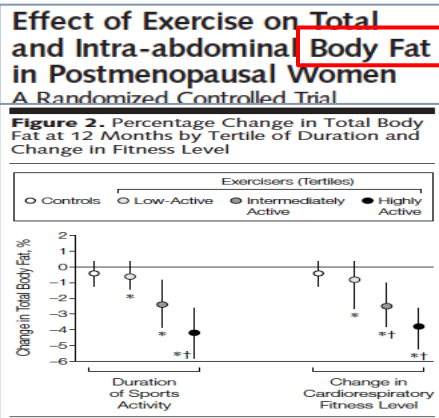


Exercise modifies CV Risk Factors

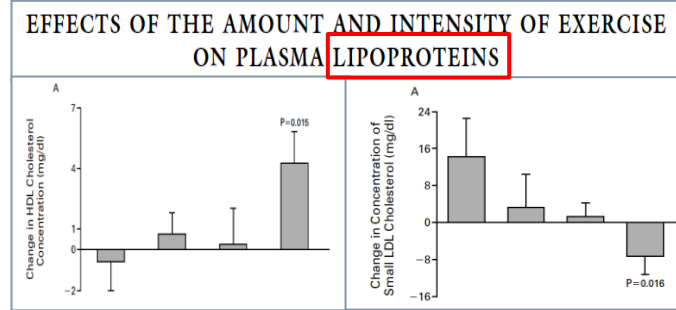
JAMA 1985



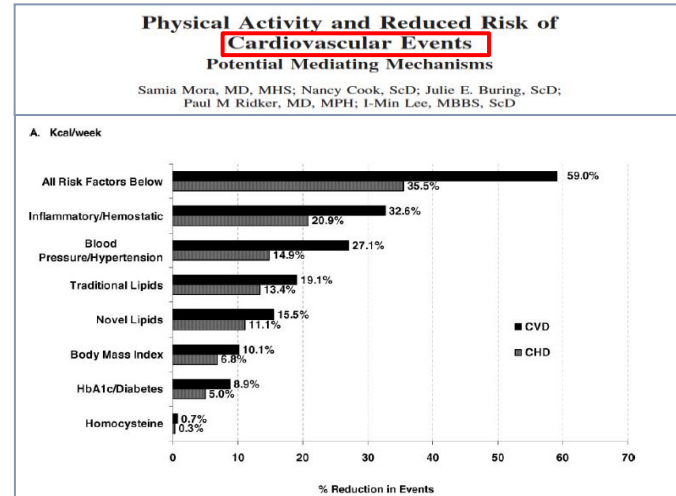
JAMA 2003



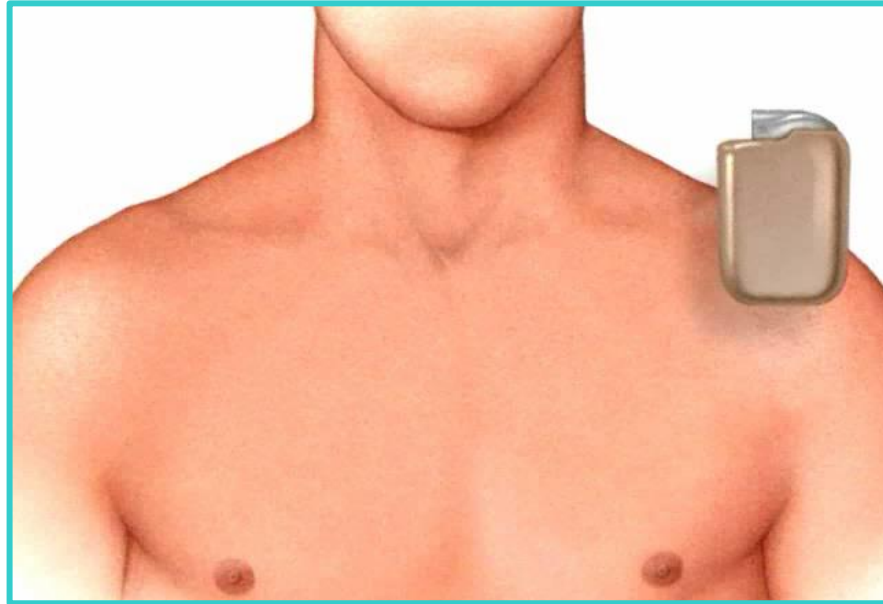
NEJM 2002



Circulation 2007



What if you have an ICD?



Safety of Sports for Athletes With Implantable Cardioverter-Defibrillators : Results of a Prospective, Multinational Registry

Rachel Lampert, Brian Olshansky, Hein Heidbuchel, Christine Lawless, Elizabeth Saarel, Michael Ackerman, Hugh Calkins, N.A. Mark Estes, Mark S. Link, Barry J. Maron, Frank Marcus, Melvin Scheinman, Bruce L. Wilkoff, Douglas P. Zipes, Charles I. Berul, Alan Cheng, Yan-Li, Michael L. Esposito, Chantal Barth, Cynthia Brugada, James Dorian, Eusebio L. Fernandez, David J. ...

RESEARCH LETTER

Safety of Sports for Athletes With Implantable Cardioverter-Defibrillators

Long-Term Results of a Prospective Multinational Registry

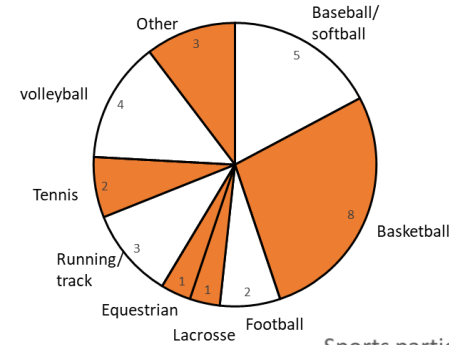
Circulation. 2017;135:00–00. DOI: 10.1161/CIRCULATIONAHA.117.027828

440 subjects with 44 month follow-up

RESULTS: PRIMARY ENDPOINTS

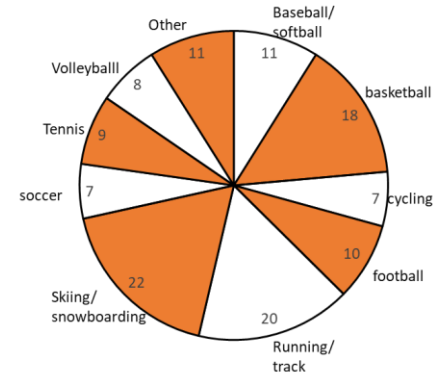
- Tachyarrhythmic death or externally resuscitated tachyarrhythmia during or after sports: 0
- Injury due to arrhythmia or shock during sports: 0

Sports Participation: Varsity/traveling team athletes



**ICD
SPORTS
REGISTRY**

Sports participation: All athletes



AHA/ACC Guideline for the Diagnosis and Treatment of Patients With Hypertrophic Cardiomyopathy

A Report of the American College of Cardiology/American Heart Association Joint Committee on Clinical Practice Guidelines

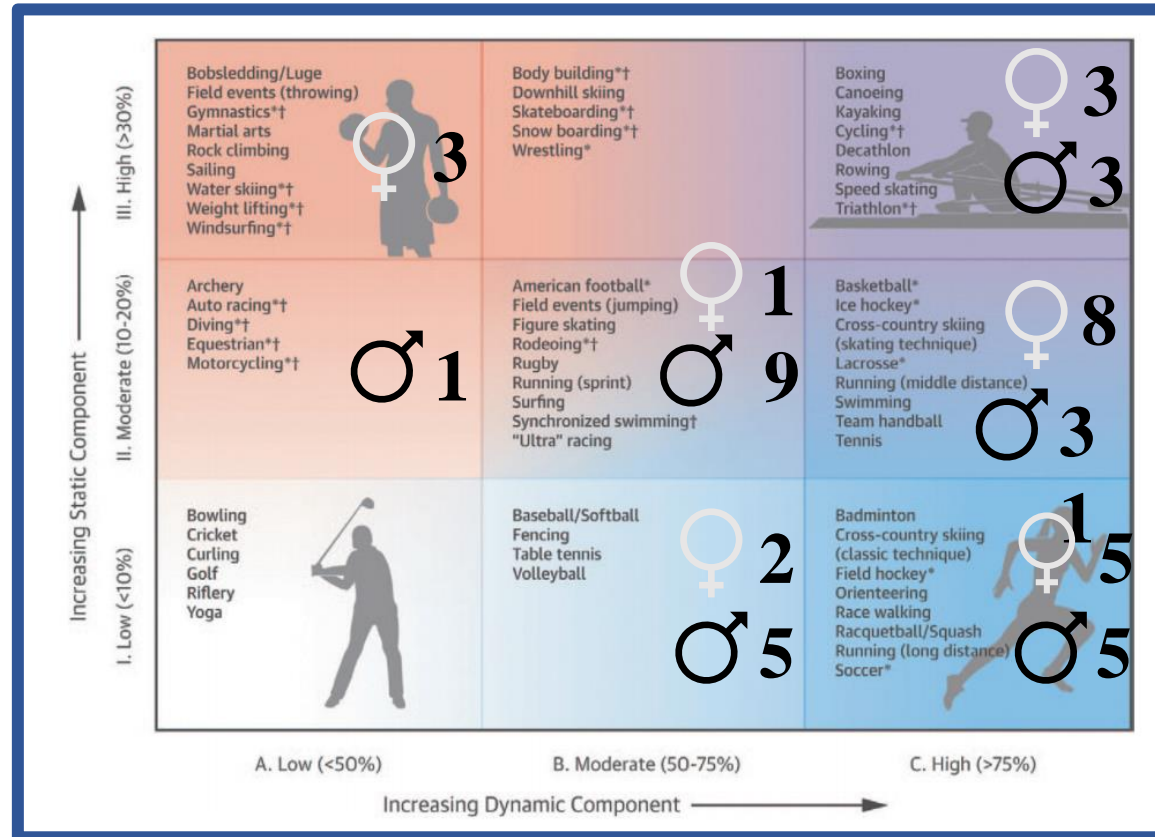
COR	LOE	RECOMMENDATIONS
1	B-NR	1. For most patients with HCM, <u>mild- to moderate-intensity recreational* exercise is beneficial</u> to improve cardiorespiratory fitness, physical functioning, and quality of life, and for their overall health in keeping with physical activity guidelines for the general population (1-3).
1	C-EO	2. For athletes with HCM, a <u>comprehensive evaluation and shared discussion of potential risks of sports participation by an expert provider is recommended</u> (4).
2a	C-EO	3. For most patients with HCM, participation in low-intensity competitive sports is reasonable (5,6).
2b	C-LD	5. For patients with HCM, participation in high-intensity recreational activities or moderate- to high-intensity <u>competitive sports activities may be considered</u> after a comprehensive evaluation and shared discussion, <u>repeated annually with an expert provider who conveys that the risk of sudden death and ICD shocks may be increased, and with the understanding that eligibility decisions for competitive sports participation often involve third parties (e.g., team physicians, consultants, and other institutional leadership) acting on behalf of the schools or teams</u> (4,7-11).

RTP for Elite Level Athletes With Sudden Cardiac Death Predisposing Heart Conditions

Demographics	Total Cohort
Total Number of Athletes	76
Mean Age at Return-to-Play (years)	19.9 ± 5.0
Female (%)	21 (28)
Race (%)	
White	38 (50)
Black	28 (37)
Not Disclosed/Unknown	4 (5)
Other	2 (3)
Asian	1 (1)
Hispanic	1 (1)
Indian	1 (1)
Pacific Islander	1 (1)
Diagnosis (%)	
HCM	40 (53)
LQTS	20 (26)
DCM	5 (7)
Other	5 (7)
ARVC	4 (5)
IVF	2 (3)
Symptomatic Prior to Diagnosis (%)	28 (37)
Syncope	10 (13)
Other	6 (8)
SCA	6 (8)
Irregular Heart Rate / Palpitations	4 (5)
Sustained VT	2 (3)

- 49 (64%) Division I and 27 (36%) professional athletes.
- 55 athletes (72%) were initially disqualified but opted to RTP after comprehensive clinical evaluation and SDM.
- 73 out of 76 athletes (96%) chose to RTP.

Return-to-Play for Elite Athletes With Genetic Heart Diseases Predisposing to Sudden Cardiac Death



RTP for Elite Level Athletes With Sudden Cardiac Death Predisposing Heart Conditions

Demographics	Total Cohort
Total Number of Athletes	76
Mean Age at Return-to-Play (years)	19.9 ± 5.0
Female (%)	21 (28)
Race (%)	
White	38 (50)
Black	28 (37)
Not Disclosed/Unknown	4 (5)
Other	2 (3)
Asian	1 (1)
Hispanic	1 (1)
Indian	1 (1)
Pacific Islander	1 (1)
Diagnosis (%)	
HCM	40 (53)
LQTS	20 (26)
DCM	5 (7)
Other	5 (7)
ARVC	4 (5)
I/VF	2 (3)

- 49 (64%) Division I and 27 (36%) professional athletes.
- 55 athletes (72%) were initially disqualified but opted to RTP after comprehensive clinical evaluation and SDM.
- 73 out of 76 athletes (96%) chose to RTP.
- 1 patients (1.3%) had ≥ 1 breakthrough cardiac event (BCE) with exercise, 2 (2.6%) without exercise. NO deaths.

Conclusion:

After careful evaluation by an expert, risk stratification, and SDM, an exercise plan can be put into place for Division I and professional athletes to RTP.

Playing with HCM

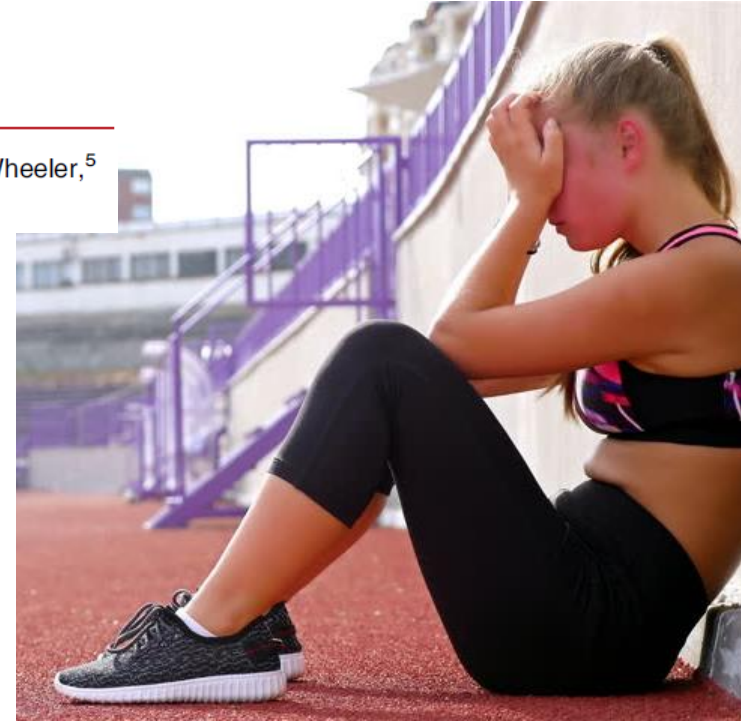
- Patient/player autonomy in health care decisions is important
- Absolute risk is difficult to quantify for all
- Risk avoidance/acceptance is individual decision
- Potential harms of disqualification
 - Loss of self-identity
 - Loss of scholarship/education
 - Loss of income
 - Depression/mental health concerns

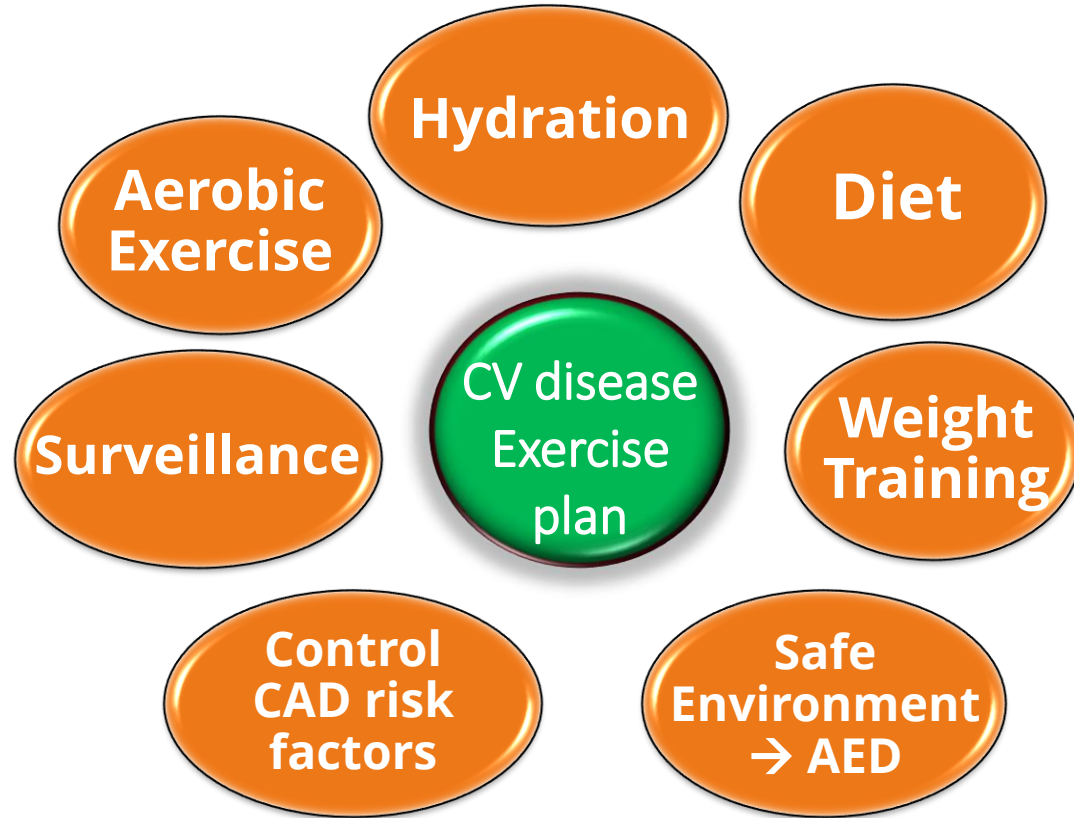


openheart Exercise restrictions trigger psychological difficulty in active and athletic adults with hypertrophic cardiomyopathy

Rebecca C Luiten,¹ Kelly Ormond,² Lisa Post,³ Irfan M Asif,⁴ Matthew T Wheeler,⁵ Colleen Caleshu⁵

Data reveal that active and athletic adults experience multifaceted, lasting psychological distress in response to being advised to restrict their exercise regimen





Patients who stop exercising at still have risk

Low risk → decided to stop sports

Low risk → decided to play



With Permission
& By Request

An 18-Year-Old Athlete Almost Dropped Dead, but Friends Saved His Life: 'It's Really a Miracle'

In May, high school wrestler jumped on the treadmill at a teammate's house for a routine workout — and five minutes later, the 18-year-old went into cardiac arrest.



With
Permission

Sudden Cardiac Arrest “Drill”



SCA in athletes is largely a **survivable event** through prompt treatment and access to an AED



Take Home Points

- Exercise in HCM patients is needed and should be discussed with ALL HCM patients
- HCM patients who exercise have a better quality of life and improved outcomes.
- In treatment compliant patients, an exercise plan can be developed, even for elite athletes.
- An individual risk assessment, exercise plan, hydration and safety strategy are required.
- No absolute decisions – ongoing risk assessment is required.



An Exercise Plan for HCM patients

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Thank you