




Impact of patient support group on middle-aged recreational and competitive athletes with aortic disease

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Received 21 April 2025; revised 18 August 2025; accepted 5 September 2025; online publish-ahead-of-print 23 September 2025

Aortic disease is an uncommon but important cause of adverse events among athletes of all ages.^{1–5} Medical guidance regarding sports and exercise participation among individuals with aortic disease is highly variable and constrained by a lack of rigorous clinical evidence.^{1,2} A diagnosis of aortic disease has historically led to exercise/sport restriction and can often be associated with feelings of fear among both athletes and medical teams. In this context, the advent of patient-driven online support provides an opportunity for individuals with uncommon diagnoses to connect, provide peer support, and share/disseminate targeted medical information.⁶ However, the effect of peer support groups on exercise/sport participation and attitudes towards exercise among individuals with aortic disease remains unknown.

'Aortic Athletes' is a Facebook group that was established in March 2023 (approximately 1200 members as of 23 January 2025) with the goal of providing community and support to self-identified athletes, both competitive and recreational, with aortic disease. Group participation consists primarily of unstructured discussion among members regarding their medical and athletic circumstance, in addition to intermittent informational sessions (typically one to five annually) with national physician experts on exercise and aortic disease, including both lecture and question/answer components. A voluntary internal group survey was conducted from 1 July 2024–23 January 2025 to explore impacts of group membership on exercise habits and attitudes. Inclusion criteria were self-identification as having an aortic aneurysm, prior aortic surgical intervention, or prior acute aortic syndrome (AAS). All data were de-identified and are reported using standard descriptive statistics. Study approval was waived by the Massachusetts General Hospital Institutional Review Board.

A total of 224/226 (99%) survey respondents met inclusion criteria (average age 57 ± 9.7 years). This included 78/224 (35%) individuals with prior AAS, 44/224 (20%) with prior elective aneurysm repair, and 102/224 (46%) with aortic aneurysm undergoing surveillance.

Average age at diagnosis was 54.0 ± 10.3 years. Most respondents (185/224, 83%) were from North America, with 26/224 (12%) from Europe and 12/224 (5%) from Australia. Respondents reported diverse forms of exercise as their primary activity, including walking/hiking (85/224, 38%), cycling (48/224, 21%), running (27/224, 12%), and weightlifting (27/224, 12%).

A total of 49/224 (22%) athletes reported having received either no or unclear exercise guidance from their physicians. Of the individuals who received exercise recommendations, specific heart rate and/or weight limits were common (80/175, 46%), as was advice to limit oneself to moderate intensity (50/175, 29%) and to avoid heavy weights and Valsalva manoeuvres during resistance exercise (74/175, 42%). Only 11/175 (6%) were advised to avoid weight training/resistance exercise entirely.

Prior to diagnosis, 194/224 (87%) individuals reported having met guideline recommendations for physical activity of 150–300 min weekly of aerobic exercise. Since joining 'Aortic Athletes,' 64/224 (29%) indicated that they had increased exercise volumes (*Figure 1*), 145/224 (65%) reported similar volumes of exercise, and 15/224 (7%) reported less exercise than prior to group membership. Group membership was also correlated with reports of subjectively reduced exercise intensity (92/224, 41%), with a decrease of those reporting vigorous exercise from 81/224 (36%) to 8/224 (3%) and a corresponding increase in moderate intensity exercise from 104/224 (46%) to 165/224 (74%).

A substantial majority of participants (160/224, 71%) reported experiencing fear of exercise prior to joining 'Aortic Athletes'. Of these, 103/160 (64%) reported reduced fear of exercise since joining the group (*Figure 1*), with 54/90 (34%) reporting similar and only 3/160 (2%) increased fear. Finally, when individuals reporting reduced fear were queried as to the reason(s) underlying this change, peer support from fellow group members was the most commonly cited factor (66/103, 64%), followed by medical information provided via the group (33/103, 32%) and personal experience (18/103, 18%).

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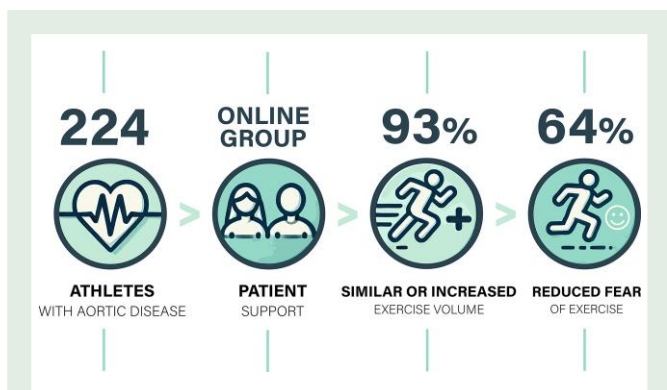


Figure 1 Impact on participation in a patient support group on exercise habits and attitudes among middle-aged athletes with aortic disease. Participation in an online patient support group was associated, based on patient-reported data, in similar or increased exercise volume in nearly all individuals as well as reduction of fear of exercise in almost two-thirds.

We report here data detailing patient-reported outcomes related to participation in an online support group centred on self-identified athletes with aortic disease, with the following key findings. First, physician guidance on exercise recommendations was highly variable and non-existent for over one-fifth of respondents. Second, 93% of individuals increased or maintained a similar exercise volume after joining the group, with self-reported exercise intensity also decreasing among many individuals. Third, fear of exercise was common before joining the support group (>70%), but nearly two-thirds (64%) of individuals noted reduced fear after participation in the group, a change most often attributed to peer support from other group members. These data represent, to our knowledge, the first report of the impact of online peer support groups on attitudes and disease-related behaviours among individuals with aortic disease, building on limited prior cardiovascular disease literature.^{7,8}

There are clear benefits to regular physical activity amongst individuals with aortic disease. Nonetheless, despite guideline recommendations supporting habitual exercise in this population,⁹ our findings demonstrate that there are many limiting barriers including patient fear and conflicting medical advice. Patient-driven support groups may offer an important pathway towards addressing these challenges, and our data suggest that the peer support may be particularly important for doing so. Such groups also offer unique opportunities for national experts to deliver niche medical information to patients who might otherwise not reach specialized care, with important implications for improving disparities in access to care.

We note important limitations including limited demographic data (including absence of data on sex/gender), a culturally and geographically specific (83% from North America) and predominantly middle-aged population, lack of data defining both aortic disease severity and athletic participation, and a retrospective study design raising the possibility of recall bias. All data including specifics of aortic disease, sport participation/athlete status, and exercise habits/intensity are additionally patient-reported, subjective, and not clinically verified. Both group participation and survey response may also be subject to selection bias, with the resultant possibility of overestimation of changes associated with group participation. Finally, our data are cross-sectional and cannot assess causality in any associations between group participation and exercise habits/attitudes. Despite these limitations, these findings represent a novel lens into an emerging feature of the patient care landscape and

highlight important opportunities for delivering patient-centred care among patients with cardiovascular conditions. Future work should ideally leverage controlled experimental designs, more detailed clinical data, and prospective data capture with control groups to assess the impacts of support groups on relevant patient-centred outcomes.

Acknowledgements

We gratefully acknowledge the administrators of Aortic Athletes as well as all survey participants.

Author contribution

B.J.P. and T.W.C. contributed to the conception and design of the work, interpretation of data, and manuscript drafting. K.M.S., K.F., and J.C. contributed to acquisition of data and critically revised the manuscript. N.M., H.D., J.S.G., E.C., and A.L.B. critically revised the manuscript. All authors gave final approval and agree to be accountable for all aspects of the work ensuring integrity and accuracy.

Funding

None declared.

Conflicts of interest: A.L.B. has received funding from the National Institute of Health/National Heart, Lung, and Blood Institute, the National Football Players Association, the American Heart Association, and the American Medical Society for Sports Medicine to study cardiovascular outcomes among elite athletes and receives compensation for his role as team cardiologist from the US Olympic Committee/US Olympic Training Centers, US Soccer, and US Rowing. T.W.C. has received funding from the National Institutes of Health/National Heart, Lung, and Blood Institute to study cardiovascular outcomes among athletes and receives compensation for his role as team cardiologist for the Boston Bruins. The other authors report no disclosures.

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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