All Party Parliamentary Group on Women's Health

All-Party Parliamentary Group on Women's Health: Inequalities Series
Closing the Gap
Spotlight on Cardiovascular Disease: Aortic Stenosis for Women

Overview

Data published at EuroPCR 2022 has highlighted that women are less likely to receive lifesaving treatment for Aortic Stenosis (AS) than men.[1]

AS is a cardiovascular condition, and there are both open surgical and minimally invasive treatment options available. Both men and women are equally affected[2], and in 2019 there were almost 70,000 patients who were eligible for treatment with severe AS[3].

There is no valid reason why women should be less likely to receive treatment than men. This APPG has spoken to experts and those affected to find out what the barriers are that women are facing accessing treatment, and what can be done to ensure women get equal access to this lifesaving treatment.

Recommendations

The APPG is calling for:

1) Strengthening the **'Make Every Contact Count'** programme. Widen stethoscope checks to be included in annual checks that women may receive. This could include blood pressure and cholesterol checks, breast screening, NHS Health Check and when attending for vaccination.
2) **National awareness** drive to raise awareness of symptoms of Aortic Stenosis, including:
    - Posters in GP surgeries, hospital waiting rooms, mammogram clinics and menopause clinics.
    - Encourage patients to ask someone to "have a listen".
    - NHS adverts in public places – including supermarkets, hairdressers, public toilets and dentist waiting rooms.
3) Training and education for female-specific presentation of AS symptoms and treatment options across clinical specialties including primary care doctors and nurses, Accidents and Emergency, geriatricians and cardiologists. The APPG is calling for **inter society action** – for The British Association for Nursing in Cardiovascular Care (BANCC), British Cardiovascular Intervention Society (BCIS), British Cardiovascular Society (BCS), Royal College of Physicians (RCP), Royal College of General Practitioners (RCGP) and Royal College of Nurses (RCN) - to come together, with support from Professor Nick Linker, National Clinical Director for Heart Disease, NHS England to tackle this issue.

What is the issue?

- Women and men have similar rates of AS and AS related events.[4]
- AS is a treatable condition.

[1] A. Farmer et al, 'Differences in access to aortic valve replacement (surgical or transcatheter) across gender, ethnicity and deprivation status - a retrospective database study of patients in England'. EuroPCR 2022.
[2] D. Cramariuc, BP. Rogge, MT Lønnebakken et al, 'Sex differences in cardiovascular outcome during progression of aortic valve stenosis', *Heart,* 101 (2014), 209 - 214.
[3] G. A. Strange et al, 'Uncovering the treatable burden of severe aortic stenosis in the UK', *Open Heart,* 9:1 (2022).
[4] Cramariuc et al, 'Sex differences in cardiovascular outcome during progression of aortic valve stenosis'.

- Outcomes for severe AS is worse than metastatic cancer.[5]
- Data has been published highlighting that women are not receiving the same access to treatment for AS as men.[6]
- There are more significant delays for women using the pathway and there are more delays to diagnosis.[7]
- Women, if treated with minimally invasive treatment options, have better outcomes than men.[8]

Why is this important?

- Women deserve to receive treatment and should not miss out or suffer delays due to the way (or to whom) they present.
- Patients who are misdiagnosed spend longer navigating complex referral systems increasing the pressure on NHS capacity and resources.
- There is significant impact to patients who do not progress to treatment. This can affect the patient's quality of life as they are left untreated in the system.
- Women who do not receive timely diagnosis and treatment for AS will have their quality of life deteriorate and may die prematurely.[9]

Barriers

1) Awareness

- Low patient and community awareness of the symptoms of AS, including breathlessness and fatigue, can delay all patients seeking help, however, anecdotal evidence highlights that low awareness is particularly detrimental for women seeking help.
- Women are likely to delay presenting at primary care, even if they are aware of symptoms. This can be for a variety of reasons. Some examples from women we spoke to included:
    - They did not think their symptoms needed checking and were just a sign of ageing.
    - They had caring responsibilities and were too busy to seek help.
    - Women needed someone to accompany them to fully disclose the severity of their symptoms and push them to take action.
    - Women did not want to burden the health service and needed someone to support them in appointments to indicate the severity of their symptoms.
- Patients and clinicians reported that women underplay their symptoms and are too stoic. Anecdotal evidence highlighted that:
    - Women needed to have the severity of their symptoms analysed by the clinician in more detail for a full understanding.

[5] Ali N, Faour A, Rawlins J, et al, 'Valve for Life: tackling the deficit in transcatheter treatment of heart valve disease in the UK', *Open Heart*, 8 (2021).
[6] Farmer et al, 'Differences in access to aortic valve replacement'.
[7] ESC, '2021 ESC/EACTs Guidelines for the management of valvular heart disease', *European Heart Journal,* 43, (2022), 587.
[8] D. Bienjonetti-Boudreau et al, 'Impact of sex on the management and outcome of aortic stenosis patients', *EHI,* 42:27 (2021), 2683–2691; V. F. Panoulas et al, 'Female-specific survival advantage from transcatheter aortic valve implantation over surgical aortic valve replacement: Meta-analysis of the gender subgroups of randomised controlled trials including 3758 patients', *International Journal of Cardiology,* 250:1 (2018), 66-72.
[9] ESC, '2021 ESC/EACTs Guidelines for the management of valvular heart disease'.

- Women were more likely to be dismissive of the impact of their symptoms, and clinicians needed to ask probing questions to gather insights. For example, asking what could you do six months ago that you can't do now, or do you struggle to carry your shopping?

2) Healthcare professionals

- There is a lack of understanding and awareness that women are not getting the same treatment as men for AS.
- There is a lack of awareness of symptoms of AS in the community and in primary and secondary care.
- Primary care physicians have a lack of awareness of the symptoms for severe AS, or that women may downplay the impact of their symptoms in discussion. Questions need to be asked to tease out symptoms for women in particular.
- Clinically, women present with different clinical indicators to men, such as with low flow and low gradient, and clinicians who are not aware of the differences in how women present may not believe treatment is appropriate.
- The male default is used in education and training in terms of valve size, and clinical factors.

3) Pathway

- The pathway for AS can be lengthy, and women experience delays once on the pathway[10], in part due to the way they describe their symptoms. Anecdotal evidence also highlights men appear more willing to seek help urgently and escalate for further help.
- Evidence shows women are slower to get onto the pathway.[11]
- Delays result in deterioration and frailty which impacts treatment options. Women appear frail if they present at a later stage, which may impact how clinicians view women and deter them from offering treatment.

Solutions

- Raising patient awareness of the symptoms and impact of AS in women. Women need to be empowered to recognise their symptoms and seek appropriate treatment. This can be achieved through raising general awareness of AS and also targeted advertising at women over the age of 65. This can include:
  - Media adverts.
  - Magazines – articles highlighting women's experience of AS, in national and women's magazines.
  - Social media campaigns on AS awareness targeted as the right profile.
  - Collaboration with third sector to raise the profile of AS.
  - Making Every Contact Count – asking about breathlessness/fatigue at other health touch points, such as at mammogram clinics, pharmacies, and blood pressure checks.
  - National government awareness campaign – like FAST for stroke e.g. 'Think Heart' or 'Stop, look and listen'.
- Raising clinical awareness and education.
  - Use data to show that there is an issue with women accessing treatment for AS and raise awareness with clinical professionals of variation by local area in England.

[10] ESC, '2021 ESC/EACTs Guidelines for the management of valvular heart disease'.

[11] C. Tribouilloy et al, 'Excess Mortality and Undertreatment of Women with Severe Aortic Stenosis', *Journal of American Heart Association,* 10:1 (2021).

  - Drive clinicians to contextualise symptoms in women by asking the right questions at the right time to ensure that women are able to access the right treatment at the right time.
  - Encourage primary care professionals to ask women over the age of 65 if there is anything else of concern, or anything else that they would like to discuss – to open conversation up and encourage them to raise questions about potential AS symptoms.
  - Increase GP awareness of AS symptoms, through symptoms alert boxes when patients present with breathlessness of fatigue over the age of 65.
  - Ensure further training of all healthcare professionals regarding female presentation of AS, including how valves are different and how there are different clinical indicators. This could include training new healthcare professionals, and then targeted current geriatricians, A&E doctors, primary care professionals and cardiologists.
  - Ensure training at cardiologist level and specialists regarding the benefit to women of intervention with AS, even at an older age.
- Ensure that there is a dedicated valve clinic within every ICS to ensure prompt pathway referral and treatment.
- Funding for increased research on gender differences for cardiovascular disease, both in presentation and treatment.

Conclusion

The *'Gender Health Gap'* is clear in AS. More needs to be done to raise awareness of this issue with the general public and with clinicians. Currently women are being failed by the system when there are treatments available. This APPG believes there are solutions that would dramatically improve outcomes for women, focusing on targeted AS awareness and clinician education.

Patient Stories

Brenda Walker

Brenda was fortunate enough to have the transcatheter aortic valve implantation in November 2011. She was then 77. Feeling something was wrong and believing in 'listening in' to her body's needs she approached the local doctor who dismissed her symptoms, (left ankle swelling, breathlessness, and feeling tired) without using a stethoscope, saying quite pleasantly that he did not think she 'presented as someone with a heart problem'.

A few weeks later, Brenda saw an advertisement for a Saturday morning appointment with a cardiologist at the Leicester Nuffield for just £50. She attended and was found to have Aortic Stenois with a possible life expectancy of just two and a half years. She had looked too young and outwardly well, to take up the local physician's time, but the situation was resolved successfully and within three months she was able to complete her doctorate, conferred at Loughborough University in 2013; move house with her new partner to Somerset and involve herself once again in education and the arts. She was lucky that she had fifty pounds to spare and the practitioners were able to act fast enabling her to manage her condition and get on with life. She states how she was indebted to Professor Jan Kovak and his team at Glenfield Hospital, Leicester for their careful explanation of the procedure beforehand and the confidence they inspired. The decision was hers to choose and she chose TAVI.

'I knew the risks but was in the middle of my doctorate and the thought of having my energy back in 2-3 days rather than convalescing for weeks was very appealing. At that time there was no question

of more men than women being offered the procedure. The question was whether your situation was severe enough to get on the list for TAVI without going privately. Mine was not quite severe enough'.

After 13 years, a recent left ventricle systolic dysfunction and double pneumonia, Brenda says with confidence that her transcatheter aortic valve is still in place and working well.

Brenda believes that patient awareness and education are two of the main routes to unlocking the fear that many women possess which prevents them from seeking and pursuing medical attention. Women must be equipped with the knowledge to raise their symptoms and make informed choices about the right treatment for them.

When treatment is delayed, due to the long patient pathway, patients suffer and outcomes worsen. It is critical that patients are picked up swiftly in primary and community care and treated in a timely manner.

Morgan Lee-Stephens

Morgan received treatment for AS a year ago and has been able to get back to health with no additional medication or complications. Morgan is calling for swifter treatment once a patient receives a diagnosis to ensure they are given better outcome opportunities.

Before the COVID-19 pandemic, Morgan was very active, going to the gym and boxing regularly. During lockdown, Morgan found she was getting increasingly out of breath and dizzy when walking. With no family history of heart disease, she put this down to being unfit and avoided visiting her GP.

Morgan's AS was only discovered when she visited her GP for a urine infection. There was a trainee doctor present who requested that they listen to her heart with a stethoscope as part of their learning. The doctor found Morgan had a strong heart murmur and she was rushed to hospital, however she was shocked to be told she would have to wait six weeks for an echocardiogram.

Morgan was due to be travelling abroad and was keen to get her echocardiogram before this to ensure she was covered by her insurance. Morgan sought a scan privately and found she had severe AS and would need heart surgery. However, because she was not presenting symptoms, Morgan was told that she would have to wait four to six months for surgery on the NHS and would have to be very careful in the meantime. Morgan would have to quit her job and put her life on hold to ensure her condition did not worsen before surgery.

Morgan decided to go through private care and was treated within a few weeks. Her surgeon told her that her heart valve was the size of a polo hole, instead of the size of a 50 pence piece it is supposed to be. He told her that if she had not received treatment, Morgan would have survived a matter of weeks.

Through her journey, Morgan was told that as she was not suffering with symptoms, her treatment was not a priority. To maintain her quality of life and to survive her condition, Morgan was forced to go privately and spend her life savings on treatment.

For Morgan, it is crucial that patients have the knowledge and tools to make informed decisions about the right treatment for them and must be made aware of all the medical options available to them.

Background

Working Groups

The APPG brought together working groups of patients and clinicians to understand the barriers and solutions for women when accessing treatment for AS. With the support of these experts, the APPG has put together this Call to Action.

Thank you to those who contributed:
Dr Clare Appleby, Consultant Cardiologist, Liverpool Heart and Chest Hospital
Professor Dan Blackman, Consultant Interventional Cardiologist, Leeds Teaching Hospitals NHS Trust
Lauren Deegan, Heart Valve Clinicial Nurse Specialist, University Hospitals Coventry and Warwickshire NHS Trust
Judith Hearn, patient representative
Dr Cara Hendry, Consultant Interventional Cardiologist, Manchester University Hospitals NHS Foundation Trust
Dr Ee Ling Heng, Consultant Cardiologist, Harefield Hospital
Morgan Lee-Stephens, patient representative
Dr Ghada Mikhail, Consultant Cardiologist, Imperial College Healthcare NHS Trust
Dr Vasileios Panoulas, Consultant Cardiologist, Harefield Hospital
Janet Rathbone, patient representative
Brenda Walker, patient representative

Data highlighting differences in access to AS treatments

The publication of Farmer et al 'Differences in access to aortic valve replacement (surgical or transcatheter) across gender, ethnicity and deprivation status - a retrospective database study of patients in England' has highlighted the significant variation in access to Aortic Stenosis (AS) treatment in various demographics, including women, ethnicity, and deprivation. The study aimed to assess the inequity of access to aortic valve replacement (AVR) at a national level for patients of different genders, ethnicities and levels of deprivation in England**.**

Researchers found that women with AS had significantly reduced odds of receiving any AVR when compared to men. The data shows that of the 52.39% of men who received a diagnostic code for AS in hospital, 63.01% received an aortic valve replacement. However, the same data shows that of the 47.60% of women who received a diagnostic code for AS in hospital, only 36.98% of those received an aortic valve replacement.[12]

The 2021 ESC/EACTS Guidelines for the management of valvular heart disease similarly found that "Women with aortic stenosis have higher mortality than men, resulting from late diagnosis and initial specialist assessment followed by less frequent and delayed referral for intervention. Measures are needed to improve this situation and ensure that both sexes receive equivalent care".[13]

NICE recommendations

https://www.nice.org.uk/guidance/ng208/chapter/recommendations

Treatments for AS are fully commissioned and available on the NHS.

[12] A. Farmer et al, 'Differences in access to aortic valve replacement (surgical or transcatheter) across gender, ethnicity and deprivation status - a retrospective database study of patients in England'.
[13] ESC, '2021 ESC/EACTs Guidelines for the management of valvular heart disease', *European Heart Journal,* 43, (2022), 587.

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For more information

If you have any questions or queries, please contact the secretariat via appgwh@healthcommsconsulting.co.uk.