




Creating a better journey of care for patients with heart valve disease

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Received 19 July 2021; revised 14 September 2021; editorial decision 3 November 2021; accepted 3 November 2021; online publish-ahead-of-print 9 November 2021

Handling Editor: Patrizio Lancellotti

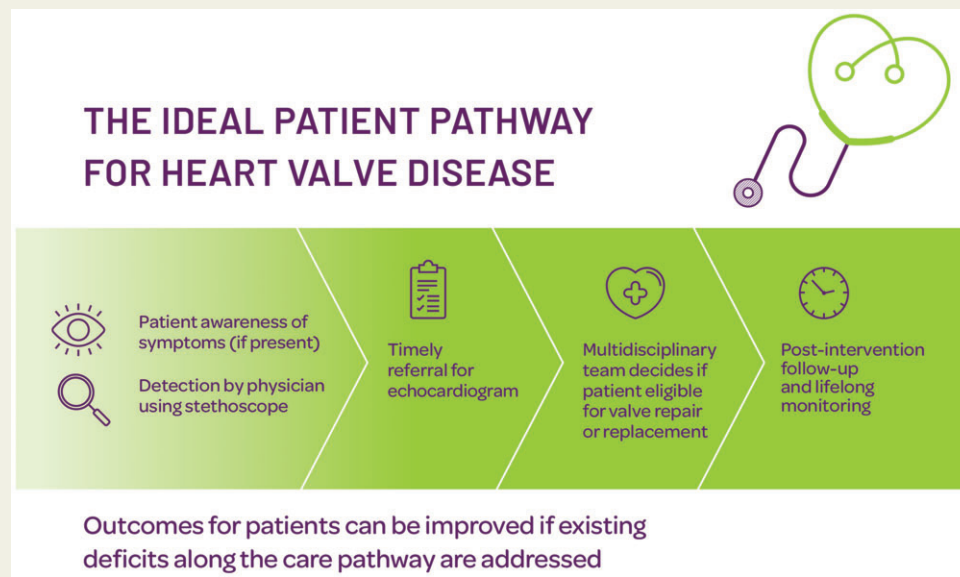
Heart valve disease has been described as ‘the next cardiac epidemic’, with prevalence expected to double by 2040 and triple by 2060 due to the ageing of the population. Yet until now, it has been characterized by scarce data, limited research, and low general awareness compared with other cardiovascular diseases. Effective treatment options exist for heart valve disease, and early detection and treatment can dramatically change disease progression, improve quality of life, and reduce mortality. Unfortunately, in too many patients, heart valve disease is undetected, undiagnosed, untreated, or treated too late, leading to avoidable deaths and costs, and significant compromises to people’s quality of life. These gaps in the patient pathway can be remedied through appropriate policy action, with a focus on: early detection and diagnosis; timely intervention; patient-centred follow-up care; patient engagement and empowerment; psychological support; and better data to guide practice. Ensuring all patients have access to appropriate diagnosis and care without delays is imperative as we look towards rebuilding stronger and more resilient health systems, and ‘build back better’ after the coronavirus disease-19 pandemic.

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Graphical Abstract



Keywords

Heart valve disease • Valvular heart disease • Patient pathway • Psychological support • Timely intervention

Heart valve disease has been described as ‘the next cardiac epidemic’, with prevalence expected to double by 2040 and triple by 2060 due to the ageing of the population.¹ Yet until now, it has been characterized by scarce data, limited research, and low general awareness compared with other cardiovascular diseases. In early 2020, the Global Heart Hub, an international coalition of patient organizations working in cardiovascular health, gathered a multidisciplinary group of clinical and patient experts in heart valve disease from around Europe to raise awareness of unmet needs of patients with heart valve disease. Findings were collated into a policy report, which proposes actions that could be taken at each stage of the care pathway to improve patient outcomes.² These findings are summarized below.

Heart valve disease: the importance of prompt diagnosis and treatment

Heart valve disease can present in several forms, and each type of heart valve disease requires its own diagnostic and treatment pathway.³ Effective treatment options exist for most types of heart valve disease that can alleviate disease progression, improve quality of life, and reduce mortality in many patients.³ For example, the rate of mortality in untreated, severe, symptomatic aortic stenosis—the most common type of heart valve disease—is between 25% and 50% per year.⁴ In contrast, timely and appropriate aortic valve replacement can lead to normal life

expectancy.⁵ Most patients with aortic stenosis who undergo valve replacement still have a well-functioning valve 10 years after the intervention, allowing them to enjoy a normal, if not improved, quality of life.⁶

Unfortunately, significant disparities in care and outcomes exist both between and within countries.⁷ In too many patients, heart valve disease is undetected, undiagnosed, untreated, or treated too late, leading to avoidable deaths and costs, and significant compromises to people’s quality of life.⁸ Much of this burden could be alleviated by addressing gaps that exist along the patient care pathway (Figure 1).

Awareness, early detection, and diagnosis

Under-detection is a key problem in heart valve disease. The Ox-Valve study in the UK found that, among a group of 2500 people over the age of 65 who were registered in primary care centres, 11.3% had moderate to severe heart valve disease, but over half of these cases had not been previously diagnosed.⁹ In many patients, symptoms of heart valve disease are difficult to identify and may be confused with general signs of ageing, leading to under-detection. Heart valve disease can also be asymptomatic. Limited knowledge about heart valve disease and its symptoms by non-specialist physicians, particularly those in primary care, can also contribute to under-detection,¹⁰ and systematic auscultation of

OVERARCHING RECOMMENDATIONS ALONG THE ENTIRE CARE PATHWAY

- Embed patient education and shared decision-making into all stages of care
- Configure care around multidisciplinary teams centred in heart valve clinics
- Facilitate integration of digital and remote technologies into care
- Invest in data collection and research on quality of life and patient outcomes

SPECIFIC RECOMMENDATIONS AT KEY STAGES OF THE CARE PATHWAY



Figure 1 Recommendations.

all patients over 65 presenting with a possible heart murmur is therefore recommended.³

Delays in referral for an echocardiogram are a significant issue in many European countries. Ideally, all patients with suspected heart valve disease should be referred for an echocardiogram within set time frames, which in turn should be embedded in national standards

and local care protocols and regularly monitored through clinical audits. For example, guidance in the UK is that patients with symptomatic heart valve disease should be referred within 2 weeks of presenting to their physician, and asymptomatic patients within 6 weeks.¹¹ The use of other diagnostic tools, such as cardiac magnetic resonance, computed tomography, stress testing, and biomarkers,

should be adapted to each patient's presentation of symptoms and disease aetiology.³

Timely intervention

The timing of interventions for heart valve disease is a key determinant of their effectiveness. The selection of the most appropriate intervention (transcatheter or surgical) depends on the person's risk profile³ and their individual preferences.¹² If a person is not deemed ready or eligible for an intervention, they are put on active surveillance. A 'watch and wait' approach is taken,³ with the understanding that regular reviews, including echocardiograms, are needed to make sure patients can be offered heart valve replacement or repair should their condition deteriorate.

Person-centred follow-up care

Clinical teams tend to think of heart valve repair or replacement as the endpoint in patients' care—but a patient's journey to recovery does not end after a successful intervention. Individualized follow-up by a multidisciplinary team in a heart valve clinic is needed to assess a person's evolving needs and tailor care and support to each person over time.^{13,14} Regular echocardiograms are also key to check for potential deterioration of prosthetic valves, ensure early detection of any disease in another valve and adapt treatment plans accordingly.³

Patient engagement, education, and empowerment

Better information is needed to guide patients through all aspects of their care, ensuring they feel empowered to recognize potential signs of deterioration of their condition and seek help accordingly. For example, patients often think they have to wait until their 6-monthly visit to see the cardiologist, and by the time they present at their next scheduled appointment, their disease has worsened. Clinical teams should explain clearly to their patients what signs and symptoms could indicate that their condition may have changed, so that they can quickly consult their physician and have their treatment plan revised as appropriate. A shared decision-making approach should also be integral to all steps and decisions in a person's care.

Addressing the psychological dimension of receiving a diagnosis of heart valve disease

As for many chronic conditions, the diagnosis of heart valve disease and its impact on quality of life can have a profound psychological impact on patients. Appropriate support to help them develop suitable coping mechanisms and address their psychological needs must be part of the multidisciplinary care offered to them, ideally from diagnosis onwards. Ongoing collection of patient-reported outcomes data can ensure clinical teams are aware of the psychological and quality-of-life status of their patients over time and can offer tailored support accordingly.¹²

Better data to guide practice

Despite the fact that there has been considerable research on different types of surgery and catheter-based information, there are still gaps in the evidence base. For example, research on other important aspects of the patient journey is needed as well—such as early detection, appropriate symptom management, and selection of the best treatment approach.¹⁵ Research priorities include how best to identify and treat asymptomatic illness⁷; standardized assessment tools to confirm diagnosis³; and gathering patient perspectives and preferences with respect to their care.¹² All of these data then need to be brought into the formulation of clinical guidelines and optimization of care pathways.

Addressing the impact of coronavirus disease-19

As for other cardiovascular diseases, the coronavirus disease (COVID) pandemic has had a marked impact on patients with heart valve disease, in terms of delayed diagnosis and disruptions to care. The redeployment of echocardiography machines and personnel towards the pandemic response exacerbated often long waiting lists for echocardiograms, delaying confirmation of diagnosis in many patients. As health systems look beyond the pandemic, dealing with the backlog of cases will be a key priority, and continuation of some of the approaches adopted to deal with the COVID crisis may prove useful in charting out future care models—such as virtual multidisciplinary care teams, virtual clinics, and use of severity or stage grading systems to prioritise patients based on the urgency of their condition.¹⁶

In conclusion, heart valve disease presents a clear case for person-centred, timely care, patient engagement, a multidisciplinary approach, and early intervention built into all facets of care. Putting in place these recommendations will have tangible benefits to a growing population of people living with heart valve disease in Europe, and help attenuate the predicted public health impact of this condition on our future societies. It will also translate into lower use of scarce healthcare resources, which we must protect and manage efficiently as we re-build for greater sustainability post-pandemic: the cost of poor management of heart valve disease is much higher than the cost of managing it appropriately.^{14,15} Making changes today represents a wise investment and should be viewed as an opportunity not to be missed.

Lead author biography



Marta Sitges has been staff cardiologist since 2001 at the Cardiovascular Institute in Hospital Clinic in Barcelona, Head of Cardiac Imaging from 2013 to 2015 and Director of the Cardiovascular Institute since October 2015. Her main research interests currently consist in cardiac imaging, valvular heart disease, and cardiac remodelling. She has published more than 300 peer reviewed

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Acknowledgements

This manuscript was developed by the co-authors, all of whom contributed to its drafting and validated the final version. It is based on a report developed by the same authors, which was commissioned by the Global Heart Hub. None of the co-authors received any funding for the drafting of this manuscript. However, the development of the initial report was supported by a grant from Abbott, Edwards Lifesciences, and Medtronic to the Global Heart Hub.

Conflict of interest: none declared.

Data availability statement

No new data were generated or analysed in support of this research.

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