CLINICAL HEART FAILURE (T.E. MEYER, SECTION EDITOR)



Missed Opportunities in the Diagnosis of Heart Failure: Evaluation of Pathways to Determine Sources of Delay to Specialist Evaluation

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Accepted: 25 April 2022 / Published online: 6 June 2022 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

Abstract

Missed opportunities are incidents where different actions by those involved could have resulted in more desirable events. Heart failure is a complex clinical syndrome presenting as symptoms and signs common to other diagnoses, in patients frequently with multiple co-morbidities. Heart failure itself is not a diagnosis, but is the common clinical presentation of a variety of cardiac conditions. Correct diagnosis involves amalgamation of the clinical presentation, the results of general and specific investigations, and the clinician's ability to synthesize the overall picture. It is not surprising therefore that misdiagnosis can occur at any level of the heart failure journey and can occur because of patient, clinician, and health economy related factors. Delayed diagnosis leads to excess morbidity and mortality in these patients. In this review, we define the pathways for diagnosis of heart failure and then highlight missed opportunities related to delay and misdiagnosis. In addition, we consider how the earlier opportunity may impact patients, clinicians and health services.

Keywords Heart failure · Diagnosis · Pathways · Missed opportunities

Introduction

Heart failure is a global pandemic causing considerable morbidity and mortality [1]. With an estimated 64.3 million people living with heart failure worldwide, it affects 1–2% of the adult population in high-income countries and has an incidence of between 1 and 9 per 1000 person-years in Europe and the USA [2]. Its impact on patients can be significant causing various physical and psychological symptoms, limitation to physical and social activities, and poor quality of life [3]. The care of patients with heart failure results in a substantial burden to healthcare systems [4] with costs related to outpatient, primary care, secondary, mental health, and social services as well as the increasingly complex potential treatments.

This article is part of the Topical Collection on *Clinical Heart Failure*

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Current specialist care is the culmination of decades of research and the current guidelines recommend treatments including lifestyle advice, pharmacological treatments, device therapy, mechanical circulatory support, and heart transplant [5, 6]. As this care is well defined in guidelines, the biggest challenges are around early diagnosis and initiation of disease-modifying medication as well as access to specialist input. A variety of factors contribute to suboptimal care, including delays at the level of patients, primary care, and secondary care where delays to diagnosis and potential misdiagnoses occur along the diagnostic pathway. These represent important missed opportunities in early identification of heart failure. The aim of this review is to systematically consider the different pathways to which a patient presents with suspected heart failure diagnosis and how delay may at each stage represent missed opportunities for better patient care.



Defining the Diagnostic Pathways for Suspected Heart Failure

Clinical pathways are a sequence of events [7]. In the case of an eventual diagnosis of heart failure, the starting point is usually the patient in the community. Depending on the type of symptoms a patient experiences and their personal decision making, they may end up seeing a general practitioner or present to an emergency department in hospital. Both the general practitioner and emergency department team act as the gatekeeper to evaluation and testing for suspected heart failure which may then lead onto referral to specialist care.

In a straightforward linear pathway (Fig. 1), a patient develops symptoms of heart failure such as shortness of breath, fatigue, and leg swelling and recognizes there is a problem. They then proceed to a consultation in primary care and is reviewed by the general practitioner (GP) or family doctor and suspected to have heart failure. At this point, the GP can refer the patient to specialist care where they may be reviewed by a hospital cardiologist or nurse specialist. Alternatively, the GP may investigate the patient themselves with a NT-pro-BNP level, chest X-ray, or transthoracic echocardiogram to confirm the suspected diagnosis or refer the patient to secondary care either as outpatient or inpatient for further assessment.

However, there may be missed opportunities or delays along the way which could be related to patient presentation, GP, or emergency department evaluations. The diagrammatic representation of pathways for patients with mild or atypical symptoms is shown in Fig. 2. A key consideration in the pathway is that the starting point is not when a patient presents to the doctor but actually when

the symptoms occur. This creates the often overlooked but important consideration of whether the patient delays seeking help or misinterprets their symptoms and there is a delay to seeking healthcare (Path A). The linear pathway of Fig. 1 resembles that which is presented as Path B but there is also Path C where alternative diagnoses are explored which represents another important missed opportunity for earlier identification of heart failure. It is important to be aware that some patients may not have any symptoms although having significant left ventricular dysfunction such as a patient's post-myocardial infarction that is no longer followed up by cardiology. These patients would benefit from disease-modifying therapies, but are often picked up incidentally.

The pathways that may occur for patients with severe symptoms is shown in Fig. 3. In this case, there may be no delay and the first point of contact with healthcare professionals may be the Accidents and Emergency department instead of the GP. Again, Path B represents the linear diagnosis of heart failure while Paths A and C illustrate how opportunities are missed for more rapid care from the GP and A&E respectively.

Patient-Related Diagnostic Opportunities

Fundamental to the ability to diagnose and treat a patient is their willingness and awareness of the need to present to healthcare professionals. A patient must first recognize they have symptoms that need medical attention. Despite experiencing symptoms, patients may not make arrangements to visit healthcare professionals for help. In modern society, people are busy with work, caring responsibilities,

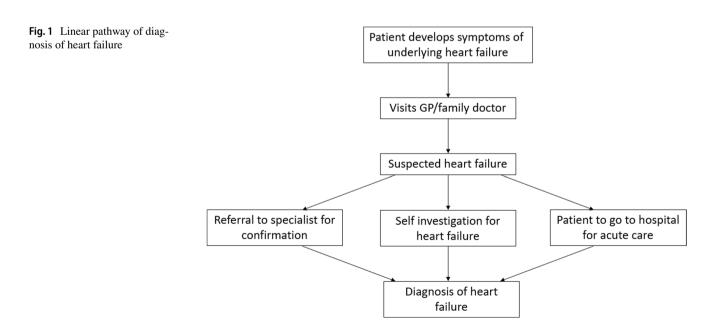




Fig. 2 Pathways for mild symptoms and the eventual diagnosis of heart failure

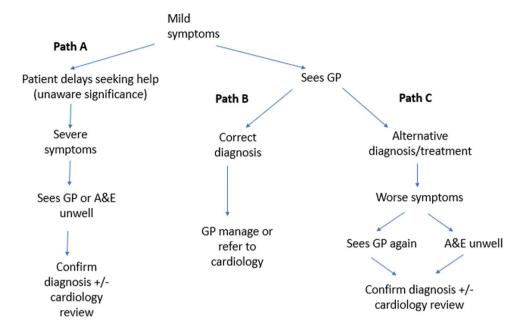
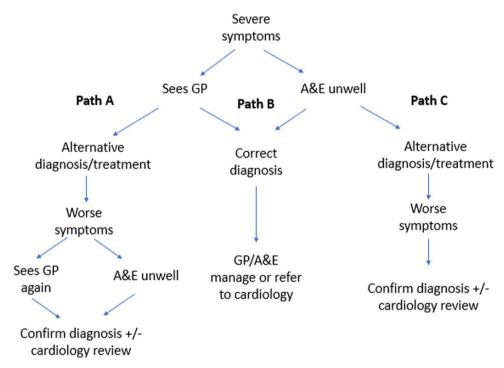


Fig. 3 Pathways for severe symptoms and the eventual diagnosis of heart failure



hobbies, and other activities which make seeing a doctor about ailments less of a priority. This is particularly true for minor symptoms which may progress to interfere with a person's ability to carry out daily tasks. In the elderly, limited exercise capacity due to frailty and comorbidities may result in limited exertion so mild symptoms may not manifest and symptoms of heart failure may be falsely attributed to getting old and therefore not acknowledging there is an issue. On the other hand, young patients have a stronger physiological reserve which can enable them to

compensate physiologically so that minor symptoms will not affect them significantly. There are other complicated factors such as the healthcare setting. In countries where there is cost associated with healthcare, there may be reservations in seeking help because of the financial impact. The current COVID-19 pandemic also may have an impact on a patient's willingness to seek help from professionals because of the fear of contracting the virus. Even if a patient has symptoms, they may not attribute its origin to the actual underlying cause. For example, shortness of



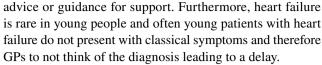
breath, weight gain, and ankle swelling may be attributed to obesity, poor fitness, or aging when it is actually early onset of heart failure.

In the case of heart failure, this can present a problem. The chronic onset of heart failure can cause an insidious onset of symptoms such as tiredness and weight gain from fluid retention over days to months. Furthermore, it may result in shortness of breath initially on exertion with the greatest impact on exercise tolerance and at night when lying flat. Depending on the patient's personal understanding and awareness of their health together with the combination of symptoms will they consider why they are experiencing symptoms. At some point, the symptoms progress such that they will take action and see a health professional. This raises the questions that at what point in the initial stages or when the symptoms become too disabling and they require emergency care.

This is important because often healthcare professionals would prefer to see patients with early symptoms before they progress. The types of intervention that could reduce missed opportunities related to delay presentation of patients to professions rely on education and public health promotion. It may be important to educate the society about heart failure as many people will get it and it can be treated with better outlook for those who have earlier treatment.

Missed Opportunities When Patients Present to Primary Care

The GP or family doctor may be the first doctor to assess a patient with underlying heart failure. The challenge is that fatigue and shortness of breath are common complaints for a range of diagnoses that include heart failure. During the COVID-19 pandemic, many GP surgeries moved towards telephone consultations and patients often report not being seen face-to-face by their doctor, which may have negatively impacted upon the occurrence of missed diagnoses of patients with heart failure. In addition, consultations can be short and primary care clinicians have limited access to tests and investigations. Even the tests they are able to arrange do not necessarily happen right away. Additional symptoms, such as orthopnea and leg swelling, may be more suggestive of underlying heart failure but these symptoms may not be apparent in the early stages of heart failure. Investigating alternative diagnoses is not unexpected as heart failure may be mistaken for COPD, especially in smokers, and nocturnal breathlessness overlaps with asthma diagnosis. In addition, detection of crackles on precordial examination may prompt a GP to diagnose a chest infection [8]. While tests such as electrocardiogram can be helpful in detecting underlying ischemic heart disease, this relies on the GP having access to it and interpreting it correctly or being able to access expert



An approach of GPs may be to consider conditions which are common and treatable in the first instance. Response to treatment can help support a diagnosis in the absence of diagnostic tests. Symptomatic resolution with a trial of antibiotics in a patient with shortness of breath and crackles on the chest may support a diagnosis of chest infection. This approach is different from that which aims to determine the exact diagnosis before instigating treatment. This is further complicated by potential financial incentives for GP not to refer patients to hospitals without first trying to treat themselves. While the clinical condition of heart failure is well known to majority physicians and most GPs will have several cases in their population, they may not have up to date knowledge or extensive experience in early detection of patients with the condition. The important factor is that in order to detect heart failure it must have been considered as a potential cause for the symptoms. In current practice where BNP and echocardiography are readily available in most hospitals most GP can arrange for these tests which when abnormal may prompt referral to specialist [6, 9]. However, they are not always available especially in rural centers and waiting times for both echocardiogram and specialist review may be prolonged due to limited resources.

This requires specialist input but if heart failure was not considered, then patients will not get access to such input. There are other issues related to leg swelling which is a common complaint. It is very easily managed with furosemide at first instance. Some GPs may feel they can manage heart failure. However, patients who are seen by cardiologists may receive different care compared to those who are seen by the general practitioner or general medical physician alone. The report from the National Heart Failure Audit in the UK suggests that specialist input or care improves survival [10]. This may be because cardiologists have access to investigations to determine the etiology of heart failure such as coronary angiography and cardiac magnetic resonance imaging as well as more experience with second-line therapies such as sacubitril/valsartan, dapagliflozin, and cardiac resynchronization therapy as this is their area of expertise.

Missed Opportunities When Patients Present as an Acute Emergency

Heart failure patients can be clinically unstable. When acutely unwell, the first contact may be from the paramedic. The combination of respiratory distress and crackles on the chest may make sepsis high on the list of potential diagnoses especially when the patient is tachycardic and hypotensive.



However, in a patient with acute pulmonary edema, the administration of intravenous fluids will make the situation worse. Even in emergency departments, there is evidence that patients with heart failure are frequently inappropriately given fluids. This misdiagnosis occurs despite having access to tests such as chest X-ray and BNP. However, often there are clues which even in the absence of these tests would help make the diagnosis like pitting peripheral edema and an elevated jugular venous pressure. The key is considering heart failure in the differential diagnosis for a patient who presents.

Should We Care About Diagnostic Delay?

Delay in the diagnosis of heart failure places patients at risk of harm from prolonged exposure to congestion. First, the congested state is distressing for patients. In acute pulmonary edema, the lungs fill with fluid which resembles that of drowning despite being in a room full of air. The psychological impact of this creates unavoidable anxiety especially when patients do not improve. In addition, the reduction in gas changes in the lung causes compensatory tachypnea and respiratory distress. A significant amount of energy is expended to maintain the respiratory effort and a patient's exercise tolerance is reduced eventually making them sedentary. The subsequent imbalance of energy expenditure relative to input results in decondition with muscle loss and malnutrition. This can contribute to worsening symptoms and frailty which can have long-term consequences such as predisposition to infections such as chest infections and cellulitis. Moreover, prolonged congested state may worsen cardiac function and in certain states such as severe or critical aortic valve disease, constriction and cardiac dysfunction secondary to causes such as thyroid disease and nutritional deficiencies can results in irreversible cardiac impairment. Furthermore, prolonged exposure to the congested state places patients at risk of multiorgan dysfunction such as the brain, liver, and kidneys, and even sudden death.

What Is the Impact of Diagnostic Delay?

Considering the patient, clinician, and health service perspective is a systematic approach to analyzing patient pathways [7] and diagnostic delay can be considered the same way.

From the patient perspective, the response to the bad news of a diagnosis of heart failure varies depending on the individual. Equally, the response to awareness that there was diagnostic delay can have variable reactions. Some patients will feel regret because if they should have taken actions differently. This may be the case for patients who delayed seeking healthcare professionals for mild symptoms until

they were too troublesome. Another group of patients may feel anger because they may attribute the delay to diagnosis related to the quality of care they received. Patients put trust in advice that is given by healthcare professionals and when there are misdiagnoses or delays to correct diagnosis there can be a breakdown of the relationship between doctor and patient. In some cases, this can even lead to medicolegal action and investigations into fitness to practice so this is not something that physicians should ignore. From a practical perspective, nothing can be done to reverse activities so reflection can provide constructive feedback to improve future practice and for the patient it should be about helping them cope what has happened. Some individuals may be more understanding that no doctor is perfect and delays and misdiagnosis occur even in the best practitioners. Helping patients come to terms and move on from what has happened may not be easy but should be an aim for professionals when undesirable events happen.

The clinician perspective on diagnostic delay is complex. It is clear that delays to diagnosis and misdiagnosis do adversely impact the experience of illness. As with the patient response, the clinician will consider if it was avoidable or unavoidable. For example, delay related to patient not recognizing the significance of the symptoms is something that occurs regularly and is difficult to present. When the delay may be related to the physician's actions, the immediate reaction may be defensive with suspicion that they did nothing wrong. Physicians are in positions where they need to be correct and confident in their decision making in order to gain the trust of patients. Even if their actions led to delay and potential harm to patients, they may suspect that it is not their fault or unavoidable. For instance, one approach is to consider whether given the same information they would have done anything differently. Based on the information at the time, it may be that the course of action that the doctor took was appropriate. For example, a GP seeing a patient with a shortness of breath and crackles in the chest may suspect they had a chest infection and try a course of antibiotics. This might actually be heart failure but retrospectively evaluating the situations the GP may stand by instigating the same plan as they did. However, only considering and reflecting on these events can clinicians learn from their mistakes and improve the care they deliver. The impact of considering missed opportunities advantage of looking at missed opportunities such as diagnostic delay of heart failure in local practice is that the information gathered can be local instruments that drive changes that improve practice.

In general, the healthcare service perspective on missed opportunities is that they represent inefficiencies and poor quality of care that need to be minimized. Diagnostic delay results in wasted resources from clinical contacts, investigations, treatments, and hospital admissions. This translates into unnecessary and potentially avoidable costs that should



be minimized. The cost of caring for someone who is seen in the community and diagnosed with heart failure by their GP which is then confirmed by a hospital specialist is much cheaper compared to a patient who saw their GP and was given the alternative diagnoses and ended up going to hospital for prolonged inpatient stay. In the latter case, there may be irreversible consequences for patients including worsening severity of their heart failure and existing comorbidities. This may place them at risk of future readmissions as loss of independence as well as the downstream consequences such as disability and the need for care or change of living situation to residential or nursing facilities. One approach of trying to reduce this problem is developing pathways specifically designed for patients with suspected heart failure. Specialist teams may be developed such as community heart failure nurse or rapid access heart failure clinics so that patients can be seen quickly before missed opportunities occur and patients deteriorate. Whether to develop or implement pathways depends on the burden of illness in the local area. The key for health services is investing effort to conduct audits and evaluate services performance. This is particularly important as the best value for care is specific to the area and demographics of the population as rural and urban areas. The type of healthcare system also has impact on how missed opportunities are considered. In private healthcare systems where there is fee for service, there may be a pecuniary interest that poor care results in greater need for care and increased profit. This is particularly dangerous when substandard care is not investigated as a problem will never be there if it was never identified. Another challenge related to heart failure from a service perspective is that the reality is that heart failure patients are high risk and expensive to care for but when they die these costs disappear.

Missed Opportunities as Ways to Improve Patient Care

Missed opportunities are a good starting point for clinical audit and service evaluation. Setting standards that patients should receive certain diagnostics if suspected to have heart failure within defined timeframes and then auditing them to provide evidence to substantiate suspicions can enable care to be improved. From the audit findings, an intervention could be introduced to increase the patients meeting the standards and closing the loop of the audit will demonstrate how the intervention has affected clinical practice. Health service evaluation is also possible for heart failure patients to evaluate any missed opportunities for earlier diagnosis. Interventions such as public education and health promotion may be used to minimize delays related to patients unaware of the significance of their symptoms. There may also be opportunities for specialists to design pathways for heart

failure and work together with GP and A&E doctors to maximize the use of such pathways to benefit patients. Through an iterative cycle of investigation of missed opportunities a local level, implementation of changes for patient benefit and re-evaluation can care for heart failure patients be improved.

Conclusions

In the diagnostic pathway for patients with an eventual diagnosis of heart failure, there may be many missed opportunities. These may occur because of a patient's inability to recognize that their symptoms may be a serious problem and seek medical attention or a GP or A&E doctor failure to attribute clinical features of the patient with heart failure. The impact of missed opportunities causing delay to diagnosis in heart failure can be significant with consequences on the patient, clinicians, and healthcare service.

Acknowledgements None.

Author Contribution CSK designed the study and concept and wrote the first draft of the manuscript. All the authors contributed to the writing of the paper.

Compliance with Ethical Standards

Conflict of Interest The authors have no conflicts of interest to declare. CDM has received funds from Bristol Myer Squibb for academic support for a non-pharmacological atrial fibrillation screening trial but this is not related to this work.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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