

The lived experience of cardiac disease

Stephen A Margolis

*Your vision will become clear only
when you can look into your own heart.
Who looks outside, dreams; who looks
inside, awakes.*

– Carl Jung¹

I find it interesting that the notion of chest pain transcends a broad range of disciplines. As clinicians, we tend to narrow this to cardiac disease (or, more specifically, coronary artery disease [CAD]) until proven otherwise. Yet, historically, chest pain was more closely aligned with emotion rather than disease, encapsulated in the notion of a ‘broken heart’, as typified in a play by John Ford, published in 1633.² The concept appears to have first appeared in Pharaonic Egypt, third millennium BCE, when the vital force of the soul was in the heart.³ As recently as the nineteenth century, there remained substantial opposition to the idea of a physical rather than a psychological basis for heart pain.⁴

Medical training was still firmly fixed in the mechanical age when I began nearly a half century ago, somewhat akin to the Meccano sets that championed the industrial revolution of the nineteenth through early twentieth century. Diseases were still viewed as damaged or broken parts that required fixing, regardless of the context of the person whose body was affected. Perhaps this was an overreaction to the earlier emphasis on the metaphysical and an attempt to place the science at the centre. The scientific advances in cardiology since the 1970s are nothing short of astounding.

We have profoundly moved from the earliest stirrings of primary prevention counterpointing limited diagnostic modalities and treatment for acute events. Cardiac investigations are now extraordinarily sophisticated, whereby pathological changes can, for the most part, be identified and quantified through safe and non-invasive techniques.⁵ Cardiac failure management is now increasingly focused and effective following the arrival of the latest medications.⁶

Yet, perhaps the most profound recent change is our expanding exploration of the ‘lived experience’ of our patients who experience these pathophysiological changes. Consideration of the lived experience developed through maturation of the biopsychosocial model of healthcare, first advocated by Engel in 1977.⁷ With the progressive acceptance of multidisciplinary care (initially in cancer management), it became increasingly apparent that each patient’s personal journey affected the choices and implementation of the team’s deliberations. Formalisation of this process is perhaps the nidus for personalised medicine, an exciting new area that is progressively developing. Gurgenci and Good explore lived experience in the context of end-stage heart failure, helping to demonstrate how this new paradigm can be incorporated into care.⁸

Cardiac care has grown exponentially in the past half century. Initially the focus was on identifying and treating pathophysiology. Today, the addition of personalised care is now gaining acceptance alongside the traditional approach and perhaps will be truly integrated in the near future.

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