Communicating with our patients for shared decision making

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doi:10.1136/heartjnl-2018-313114

Current guidelines for treatment of patients with cardiovascular disease often recommend we consider 'patient preferences and values' and involve the patient in 'shared decision making'. However, there are few objective published data on the patient's perspective and little guidance for effectively involving patients in decision making. Although research on these issues might seem like 'soft' science, we urgently need solid evidence for these terms to be more than empty words.

Treasure and colleagues\(^1\)\(^{, 2}\) present the first steps toward a decision support framework for timing of aortic root surgery in adults with Marfan syndrome. Patients, family members and providers were asked to rank the importance of several factors including timing of surgery (postpone vs get it over with); avoiding anticoagulation (particularly if pregnancy is being considered); avoiding other medications, hospital tests or noise from the prosthetic valve; and having an active lifestyle. The results indicate that lifestyle is more important to men compared with women. Both not deferring surgery and avoiding anticoagulation in the interest of childbearing were more important to patients than to physicians. The authors conclude: “Given the cogency of these viewpoints, people anticipating root replacement surgery should have ample opportunity to express them and to have them acknowledged ahead of a consultation when they can then be fully explored in a mutually informed forum. If they differ from local medical practice, they can then be discussed in the process of reaching shared and individualised decisions.”

In an accompanying editorial, Groenink and Koolbergen\(^3\) discuss the complexities of timing of surgery in Marfan patients including the type of aortic root surgery, heterogeneity in disease progression rates, reliance on expert opinion alone for current recommendations about timing of intervention and variability in measuring aortic size with various imaging modalities (figure 1).\(^4\) In addition, we still have large knowledge gaps in individual risk assessment, despite recent insights into genotype-phenotype correlations.\(^5\) They also remind us that undertaking earlier surgery, even in a patient who want to 'get it over with' entails risks that might not be appreciated by the patient. Besides overall surgical mortality and morbidity, other considerations include the potential need for a prosthetic valve rather than a valve-sparing procedure and the effects of aortic cross-clamping. Our patients may wishfully imagine that surgery is curative, when, in fact, they will still have Marfan syndrome and thus require life-long medication and periodic aortic imaging, regardless of surgical timing. Thus, we need 'to take a deliberated and shared decision in a process that supports the patients, as well as the physicians, to learn and accept the uncertainties that go with it'.

Patient involvement also is important in management of patients with atrial fibrillation (AF) both for the choice of rhythm versus rate control and for decisions about anticoagulation. Kaufman and colleagues\(^6\) measured patient's understanding of rhythm control, ablation, anticoagulation and cardioversion in 1004 patients at baseline and again 6 months after diagnosis. Overall, patient understanding increased from less than 50% at baseline to 60%–70% at 6 months for stroke risk and anticoagulation; was high but unchanged at 6 months for rhythm control; and remained low for AF ablation at both time points. Higher levels of understanding were associated more patients undergoing AF ablation, but not with increased use of other therapeutic options (figure 2). Although the authors conclude that these results 'suggest a need for ongoing patient education', it is difficult to reconcile the discordance between patients' self-perceived levels of understanding and continued failure to agree to guideline-based therapies, such as anticoagulation.

In an editorial, Bhave\(^7\) suggests we ask three questions when we care for patients with a chronic condition, such as AF:

- First—do patients' self-assessment of their understanding of their disease bear any correlation to their actual comprehension of the disease process and its management?

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**Figure 1** Aortic MRI images in a patient with Marfan syndrome. (A) Long-axis view of the thoracic and abdominal aorta, with aortic diameter measurements at multiple anatomical locations (lines). (B) Short-axis view of the aortic root, with diameter measurements between the right coronary cusp (RCC) and left coronary cusp (LCC), and the right and left coronary cusps to the non-coronary cusp (NCC).\(^8\)

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Second—what strategies can we employ to improve our patients’ understanding of their disease?

Third—will better patient understanding of their disease lead to an improvement in the healthcare that they receive?

As he points out, patient self-assessment of knowledge may not be accurate especially given that typical patient ‘education’ only occurs verbally in a short clinic visit.

As with any type of learning, repetition and serial assessments are essential. The barriers to patient education are myriad—perhaps topping the list is the medical equivalent of ‘fake news’: misinformation from sources such as television commercials, well-meaning friends and relatives, and unvetted websites. Frequent physician reinforcement of accurate information can help curb the influence of unreliable sources.”

Clearly there are many challenges in ensuring our patients have accurate information to participate meaningfully in shared decision making.

There is little data on long-term outcomes in patients admitted for syncope or orthostatic hypotension (OH) in the absence of prevalent cardiovascular disease. In a population-based study of over 29 000 adults (mean age 58 years), 3.45% were hospitalised for unexplained syncope or OH before any cardiovascular event over 15 years of follow-up. Compared with those without syncope/OH, affected patients had a higher risk of coronary events, heart failure, AF, aortic stenosis and mortality—both all cause and cardiovascular (figure 3).

In an editorial, Ruwald8 discusses the strengths and limitations of this study and puts the importance of this data in context. Even so, he asks, “How effective are we to find and select the high-risk patients and how much effort and costs should be used to find very infrequent cases of true high risk (unknown underlying severe cardiac disease) among a very large number of low-risk healthy patients with benign syncopal events?”

The Education in Heart article 9 in this issue provides a quick overview of new-generation coronary stents with the

Figure 2  SATELLITE patient understanding of role or options for atrial fibrillation therapies at baseline and use of therapy at 6 months. Notes: the relationship between patient understanding and therapy at 6 months was assessed only for the subset of patients not on the treatment at baseline. Ablation therapy was defined as use of pulmonary vein isolation. Rhythm control therapy was defined as antiarrhythmic medication.

Figure 3  Long-term cumulative incidence of cardiovascular (CV) mortality rates according to incident syncope-related and orthostatic hypotension (OH)-related hospital admission (n=29129). Kaplan-Meier curves with regard to CV mortality stratified according to incident syncope-related (blue) and OH-related (red) hospital admissions: inpatients showed a significantly lower survival rate (Log-rank test P<0.001) compared with those never hospitalised for syncope or OH (green). The black vertical line at 12 years is a landmark point indicating mean time between baseline and first-ever OH/syncope hospital admission. Thereafter, survival curves for OH/syncope-related hospital admission and non-hospitalised patients begin and continue to diverge.
three main categories being permanent polymer drug-eluting stent (DES), biodegradable polymer DES and polymer-free DES. The antiproliferative drug used in stents now mainly are analogues of rapamycin which induce a reversible arrest of the cell cycle with a broader therapeutic window than previous agents. Polymer coatings, which control the timing of drug release, now have improved biocompatibility (less inflammatory response) with some polymers being biodegradable and some stents not requiring a polymer at all. Data from clinical trials with newer stent designs are summarised concisely followed by a discussion of indications for use for each stent type.

Competing interests None declared.

REFERENCES