

Needs and Preferences of The Patient with Valvular Heart Disease

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Introduction

A decision regarding the conduct aiming at good quality of life of patients with chronic valvular heart disease during the natural history of the disease is supported by four good clinical practice pillars^{1,2}: 1 - Identification of the patient's clinical need; 2 - useful and effective recommendation selection according to the state-of-the-art; 3 - Strictly ensured organic harmony when applying the conceptual benefit; 4 - Realities of the patient's preference.

The identification of the patient's clinical need comprises: a) updated valvular and nonvalvular cardiodiagnosis; b) prognostic evaluation of evolution stage; c) identification of comorbidities for the heart disease. The direct use of the senses (hearing, palpation and inspection) and information acquired through tracings, figures and images are responsible for obtaining the patient's clinical needs, which is essentially associated to etiological peculiarities and the physiopathological course of valvular heart disease

The selection of useful and effective recommendations, according to the state-of-the-art includes: a) drug prophylaxis of rheumatic disease, of infective endocarditis and thromboembolism; b) cardiovascular pharmacotherapy to relieve hemodynamic load and control effects on body water distribution, myocardial function and cardiac rhythm; c) change of lifestyle; d) corrective surgery on the quality of valve opening and closing. The same method (valve replacement surgery, for instance) is distributed in distinct dimensions of usefulness during the evolution of clinical need (important degree of aortic regurgitation still in functional class I/II or already developed into significant quality of life restriction, for instance), supported by probability of certainty supported, in most recommendations, by expert opinion (level C in guidelines).

The strictness regarding the patient's clinical safety when applying the conceptual benefit for the moment of valvular heart disease requires that prevention and treatment occur with maximum preservation of healthy organs and the best support regarding chronic comorbidities. In the last two decades, more points were included in risk scores of Brazilian patients with valvular heart disease, due to the progressive increase in the mean age at the time of invasive interventions³.

Keywords

Heart Valve Diseases; Quality of Life; Patient Participation; Bioethics.

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Focus on the patient

The identification of the clinical need, recommendation selection and safety stringency give quality to the process of triangulation between the rapidly renewable body of scientific and technological medical knowledge, the moral basis of assistance related to indispensable professional training and expertise of cardiologists and the clinical expression of patients with valvular heart disease. Indicative data, suggestive facts and favorable evidence, thus recognized through the collective experience of literature and/or bedside experience, maintain the excellence of the essential link Medicine-doctor-patient with a valvular heart disease.

In the combinations of attention to the disease, thus determined, patient participation is fundamentally that of an emitter of diagnostic signs and symptoms and a receiver of therapeutic countermoves aimed at the etiopathogenic and physiopathological. But the human being with a valvular heart disease goes beyond, by presenting with attitude preferences^{4,6} manifested by: a) initiative for the initial consultation, b) accuracy of clinical subjectivity c) choice of valve prosthesis d) consultation and follow-up attendance; and e) adherence to the consented conduct, both pharmacological and nonpharmacological. They are the result of a mental process on the merits of the abovementioned triangulation at each step of treatment and the willingness to submit.

This fourth decision component admits the right that patients with valvular heart disease have to consent or not to what would be applicable in the short term to their clinical need, including reviewing the decision at any time, and to do or not to do "for the rest of their lives" each conduct to which they consented, very often repeatedly.

It should be noted that many aspects of the rational management of valvular heart disease - interfaces between prevention, treatment and prognosis, for instance - are not so natural for non-experienced humans. After all, cardiologists apprehend them during graduation, are subject to the relearning due to professionalism and explanations do not always make them understood in their essence by those who have the disease, but do not know the singularities.

It is at least singular as the conduct in valvular heart disease - during many years of its natural history, already at the stage of significant lesion, but with preserved quality of life (labeled as 'asymptomatic') differently from what is done with many other diseases - is to "take advantage" of significant pathological changes in cardiac architecture - the so-called natural remodeling - as good enough benefit for good patient quality of life^{1,2}. It is classical reasoning in the process of choosing the conduct, because: a) there is no feeling of being sick, b) there are no drugs acting on the valvular tissue c) valvular prostheses have not reached the ideal level and d) the expectant management does not compromise

the prognosis. As a result, several questions arise on the relative importance of the physician's professional responsibility to identify and the patient's personal responsibility to inform.

Thus, cardiologist's complex knowledge – which gives him/her skills as diverse as subject to ethical and legal constraints – is at the disposal of the pluralism of a population that, although ill, is not obliged to make use of Medicine. And as negligence and recklessness related to the care of valvular disease do not have the same sense of professional breach, the patient's "clinically inappropriate" behaviors, expressions of free will, must be tolerated by the same cardiologist who appreciates zeal and prudence as much as possible.

Consent and refusal, adherence and noncompliance to the same offered state-of-the-art represent the patient's wishes, subordinate to his affective states and from them come sufficient reasons for a universe of patients - a minority, it is true, but numerically significant - that no longer wants to go through the monthly discomforts antibiotic prophylaxis of rheumatic disease, who is satisfied with the beneficial effects of the first pills of a drug that reduces the hemodynamic load and fights the idea of periodic laboratory control of oral anticoagulation. In other words, the daily determination and compliance by patients with valvular heart disease includes dealing with heterogeneities of the willingness to be affected by medical technoscience and which have nothing to do with trust in the physician.

Nowadays, the principle of autonomy reaffirms how much the affectivity of the human condition is an essential component of ethical appropriateness⁷. It has been learned that the search for a former "offensive" second opinion makes it easier for the patient to accept an equal first opinion, due to personal changes in the unpleasant initial impact, which occur through the "time of impact absorption" factor between the two opinions. As a counterpoint, and emphasizing that the physician also has the right to autonomy, hypochondriac disorder and Munchausen's syndrome (factitious disorder with the aim of generating medical care related to the need to be sick)⁸ one recalls that when the patient's thoughts are oriented toward diagnostic unrealities, they become unacceptable to be accepted by the physician.

Thus, the patient's preference lies in a dimension of decision-making complementary to the availability of science and technology resources in the presence of the clinical needs. The first is related to the individual and second, to the collective.

In this sense, the affectivities of each patient with valvular heart result in an increase or decrease of the power to act against the technoscientific factor. Clinical worsening tend to responsiveness to the recommended actions, whereas improvements tend to inaction.

Hot-cold empathy gap

The influence of affective states on the patient's compliance "oscillations" is attributed to the so-called "hot-cold empathy gap"⁹. They include: a) the perception of having a clinical need, b) the recalling of how much he/she has suffered with discomfort c) the leading of the goals that desire a conduct d) capability to analyze risks and benefits, e) degree of satisfaction with the present health status, f) intensity of future appreciation.

When patients with valvular heart disease are in a "hot" situation, being affected by symptoms that make them feel

an impaired quality of life, their preference tends to search for consultation, consent to medical recommendation, the urgency of applying the therapeutic method and the momentary reduction of the importance of their life routine. There is one ethical aspect to consider, because the "hot" situation brings difficulty to envision an immediate change to "cold" and the patient with valvular heart disease becomes vulnerable to any propositions on the margin of good practice.

In the reverse situation, in which the patient with valvular heart disease is "cold", comfortable despite the illness, there is a lack of prospective nature that tends to inhibit the perception of future aspects in the natural history of valvular heart disease and that cardiologists know about and which they strive to make arrangements for.

It is noteworthy the parallelism that occurs between, on the one hand, the affection of the patients and the perception of their needs and on the other side, the medical distinction between good and poor quality of life as the classical foundation for decision-making in valvular heart disease. It reinforces the line of thought that discredits a recommendation for routine surgery during the oligosymptomatic phase of the natural history of valvular heart disease, just because there are certain scientific conclusions of good results.

In the real world, disharmony regarding the relationship cardiology-cardiologist-patient with heart-valve replacement, dictated by the patient's affective state most commonly occur during the extended validity of consensual conducts, resulting in a paradox between the desire for better prognosis and the desire to live well. The "watchful waiting" that would qualify as negligence of the doctor becomes the reality, and only belatedly the cardiologist will learn about the breach of commitment by the patient at the time of the inexorable deterioration of the natural history of valvular heart disease.

Conclusion

Analyses of moral value of decision-making at different times of valvular heart cannot ignore the inevitable encounters between rationality of scientific evidence, with heteronomous connotations, and affective-dependent oscillatory autonomic movements of patient preferences. A transdisciplinary culture by the cardiologist facilitates the application of knowledge beyond medical science in favor of assuming/correctly deciding/communicating well, the triad that provides good justification for maintaining the physician-patient relation ship in the midst of variations of convergence between human behavior and state-of-the-art.

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