Patient engagement in cardiology – nice or necessary?

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It has long been known that a positive interaction between doctor and patient is of great importance for the recovery from illness. While doctors are experts in how best to treat a disease, patients are experts by experience, and mostly have very specific ideas about how they would like to be treated and what the treatment goals are [1]. Importantly, patients can develop innovative approaches of fighting a disease, advocate to achieve healthcare goals or may fund healthcare facilities and scientific units [2, 3].

Although definitions of the term patient engagement lack homogeneity, it is widely agreed that it describes “a set of behaviors by which patients take more responsibility for their own health care, and health care professionals take more account of patients [1].” It implies an ethos of shifting from medical dominance within the health care environment to one of equality that facilitates patient involvement in their health care. As a central feature it combines a patient’s knowledge, skills, ability and willingness to manage his/her own health care with interventions designed to increase activation and promote positive patient behavior. In addition to education, patient engagement ultimately means inclusion of patient representatives in the development of treatment guidelines. Healthcare professionals have expertise in the best treatment but may not necessarily be expert in knowing what patients actually wish for or need, in terms of being able to understand treatment options outlined in guidelines, or in participating in healthcare decisions.

The idea of partnership between doctors and patients to achieve specific healthcare goals has previously also been described as co-design and has proven to be of great impact for both sides [4].

The shift from the traditional paternalistic model to the concept of patient engagement and shared decision making was driven by clinical evidence for better healthcare outcomes if the latter is pursued. Krumholz et al. [5] for instance elegantly demonstrated, that in heart failure patient knowledge 1) of the illness, 2) of the relation between medications and illness, 3) of the relation between health behaviors and illness, 4) of early signs and 5) symptoms of decompensation and where and when to obtain assistance led to significantly improved outcomes.

If one takes a closer look at these facts, one may be surprised that the cardiology community, namely national and international scientific societies, only became involved with patient engagement in recent years.

Accordingly, recent guidelines on the management of blood cholesterol by the American Heart Association [6] expressed the need to actively involve patients as recommendations for guideline-directed management and treatment would be most effective when they are followed by both doctors AND patients. The European Society of Cardiology (ESC) guidelines for the diagnosis and management of atrial fibrillation [7] state that “exploring patient’s values, goals, and preferences should be the first step of shared decision making”. The importance of a disease-educated patient to prevent stroke as well as major bleeding and enable optimal management strategies is expressively declared.

Nevertheless, many national cardiac societies still lag behind and have so far not even considered patients as important partners in their activities.

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Fig. 1 Outline of the European Society of Cardiology Patient Committee aims (from Fitzsimons [3], GL indicates guidelines. Reprinted by permission of Oxford University Press)

In 2017, the constitution of patient engagement was defined as a strategic priority of the ESC by the ESC board. Since then, great efforts were made to involve patients at many different levels. Fig. 1 shows the objectives of the ESC Patient Committee as published in 2019. Several of these have already been implemented.

Although the advantages by far outweigh the disadvantages, there are also important obstacles to effective patient engagement. The concept is clearly challenging to clinicians and also patients educated in the traditional, doctor knows best model. When it comes to participation in the development of guideline recommendations, it may be difficult to find patients or indeed people, who can articulate a balanced group perspective of a specific condition without their individual experience dominating. It is also evident that some patient groups are supported by funding from industry which may raise questions about the independence of their input and conflict of interest concerns.

Within the next years, patient involvement and engagement is destined to play an increasingly important role not only in the treatment of cardiovascular diseases but also in the preparation of guideline recommendations. This positive development will cer-

tainly improve patient outcomes as well as satisfaction of patients and healthcare professionals.

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