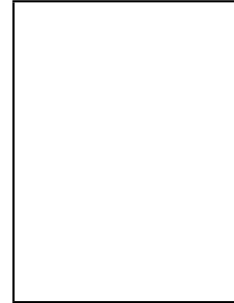


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Rui Anjos



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Knowledge and perception of disease – time to empower the needy and change the world!

Rui Anjos*

Department of Pediatric Cardiology, Hospital de Santa Cruz, Carnaxide, Portugal

Reference Center for Congenital Heart Disease CHLO/CHULN

Member of the European Reference Network, ERN GUARD-Heart

*Corresponding author:

E-mail address: ranjos@ulslo.min-saude.pt (R. Anjos)

Albuquerque et al.'s paper published in this issue (1), addresses a hot topic for all those who deal with adult congenital heart disease (ACHD). The theme of patients' knowledge and perception of disease is contemporary and has a major impact on outcomes. And this is true not only for ACHD, but also applies to all areas of Cardiology and Medicine.

The authors conducted a survey adapted from the Leuven Knowledge Questionnaire for ACHD (1), in a tertiary center for ACHD. Their conclusions are very interesting, although not unexpected. Patients had a significant lack of knowledge on their type of heart defect, drug side effects, symptoms of clinical deterioration, including signs of endocarditis, and risk of clinical deterioration during pregnancy. Patients with a higher education level had a more accurate knowledge in several areas.

We are all aware of the drive toward patient-centered approaches in modern health care systems. All quality improvement programs stress the importance of focusing on the patients, particularly on their needs, concerns, knowledge of the disease and therapeutic options. Patient education is an important and integral part of this concept and should be undertaken through a multidisciplinary approach, adapted to the patient's and family's educational level, culture, and age, among others. This applies to research as well, an essential component of our activity.

Strong patient involvement and good knowledge is an essential part of healthcare research, improving its quality and impact. Some countries, like the United Kingdom, have set Standards for Public Involvement in Research (2), which include communication, inclusive opportunities, support and learning. Concerning patient educational needs, these standards raise detailed issues on the type of support available, specific resources designated, where to go for information, and the presence of a culture of learning and sharing with the public.

The benefits of patient education, particularly in chronic diseases, have been recognized for decades (3). Although several educational strategies are used universally, they are not always effective, and the message is frequently not well understood (4). The World Health Organization has recently published a guide on this subject, "Therapeutic Patient Education" (5). It guides those responsible for designing and delivering effective therapeutic education for patients with chronic conditions. Outcomes of educational programs can be assessed by evaluating basic empowerment and competencies, adherence to self-management behaviors, clinical

outcomes, patient quality of life, care perception and satisfaction. Instruments like the Leuven Knowledge Questionnaire for ACHD are important tools for the assessment of these programs. The authors of the current study (1) propose a structured nurse and physician-directed educational program, and improvements in the transition program from adolescent to adult care to increase patients' knowledge of ACHD. This is paramount and will certainly make a difference. One of the most important features of this approach is the focus on multidisciplinary involvement, including physicians, specialized nurses, and other health professionals.

The other part of this equation is the role of patient and family organizations. These groups, technically supported by professionals, provide an even more comprehensive approach to this issue. In the area of ACHD, patient organizations have a long way to go, when compared with areas such as diabetes. But the European Patient Advocacy Group (ePAG) of the European Reference Network for Rare Diseases of the Heart (ERN-Guard Heart) is building its network and leading the way by joining organizations from different countries, providing patients' perspectives and showing clinicians the unmet needs of their patients (6). In terms of educational activities, apart from disease-specific brochures, meetings and podcasts, this ePAG is sponsoring a particularly interesting program, translating into "laymen language" a summary of selected scientific papers. Many other forms of educational approach can be used by and with the patients for educational purposes. As an example, at our center, we are providing a mutual help group, joining online families of children with congenital heart disease, under the guidance of specialized professionals (7).

As health professionals, we must engage in patient education and health literacy, defined as the individual knowledge and skills that enable people to access, understand, evaluate, and use health information to promote and maintain their health (8). We must provide patients and families with more time and offer more opportunities for interaction. We also need to improve our communication style and method, avoid medical jargon, and spend less time looking at the computer and more time facing the patient. Direct interfacing with health professionals is the most important source of health care education for most patients but high quality written educational material should be provided at least for the more frequent conditions. We should consider guiding patients and families in their internet search, "prescribing" reliable online information (9), adapted to their literacy level, age group, and cultural background.

Only with a multidisciplinary, comprehensive and personalized approach we will be able to provide effective educational support, leading to a real improvement in health literacy. Patient empowerment leads to better outcomes!

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