



Editorial

Impact of a centre and home-based cardiac rehabilitation program on the quality of life of teenagers and young adults with congenital heart disease: the QUALI- REHAB study rationale, design and methods



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The proposed study by *Amedro et al* touches a very important aspect of the care of patients with congenital heart disease (CHD) which is the “cardiac rehabilitation” or in other word the guidance toward exercise and diet (life style) provided by experts in the field. As also the authors state, advances in surgical and medical management have resulted in a growing number of patients born with a heart defect to survive to adulthood, however the majority of these patients requires life-long care and often further re-interventions for residual haemodynamic lesions [1,2]. This often results in reduced exercise capacity and impacts on patients' quality of life. As patients get older, their cardiac health is also often aggravated by the constellation of acquired cardiovascular risk factors (i.e. obesity, smoking, hypertension, diabetes) commonly seen in the general population highlighting the need for primary prevention. Whereas historically patients with CHD were refrained from exercising and many do still experience fear of “pushing too much”, it is now widely recognized the role and the benefits from regular exercise with improvement in skeletal muscle function, vascular health, immune system function, obesity prevention, and complex psychological, cognitive and social function [3–7]. Most of the published studies report short term exercise programs, mostly lasting 8 to 12 weeks, and yet improvement is seen in patients' exercise capacity and well-being with no concerns with regards to safety [7].

Assessment and encouragement for habitual physical activity should be part of CHD patient's routine clinical evaluation and counselling [8,9], however to date there is still need for structured programs that can assist clinicians in guiding and advising patients on lifestyle choices and physical activities according to their needs rather than relying on referral to individuals or organizations that hold widely recognized certifications.

The authors rightly highlight that the current trend in the medical research field, after focusing on the survival of patients with CHD, is now opening on primary and secondary prevention and on patient-related outcomes or, in other words, patient's perceived quality of life.

Primary prevention is a crucial aspect of health which is still not adequately addressed mainly due to lack of resources. It is well known that chronic stress, which nowadays is experienced by most of the population, causes changes in the body composition leading to osteosarcopenia and obesity, a substrate of disease associated with distinct disorders, such as anxiety, depression, obesity, metabolic syndrome, autoimmune disorders, diabetes, with psychological and somatic manifestations [10]. Patients who suffer from chronic conditions such as CHD are more vulnerable and predisposed to the negative effects of chronic stress and osteo-sarcopenic elements exist even in very young populations. The possibility to control and modify chronic stress and body composition with lifestyle intervention, is key to minimize the burden on their long term chronic cardiac condition.

A very important aspect of the rehabilitation program suggested by *Amedro et al* is the multidisciplinary approach to patients. Understanding the complexity of this population, its heterogeneity and therefore the complexity of these programs is paramount for their success and should be sought by any centre who wishes to embark in similar projects. The program is based on the collaboration between trained physiotherapists who understand CHD, clinicians who know the patients and who can advise on type of exercise and exercise intensity, clinical psychologists who can support the patients and their family, nutritionists who can guide on diet plans, and specialist nurses who are often the first contact for patients. It is only through this collaboration that the complex physical and mental health aspects of life style intervention plans in CHD can be adequately addressed.

The proposed plan includes high level of supervision for the enrolled patients including a 5-days hospitalization with individual and group education sessions, followed by 12 weeks of home-based training program consisting of 2 × 1 h each session per week supervised by a physical education teacher, with motivation reinforcement and three recall sessions at the rehabilitation centre, for 1 day each. Patients will also be equipped with a stationary bike which will be used for their interval training type of exercise. Whereas this setting is very likely to obtain a good level of adherence and to provide information about the effects of exercise training on physical and psychological health, it is however difficult to reproduce, due to limited resources, the same

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provision in the routine clinical setting. Studies addressing the feasibility of life style intervention programs which do not involve such extensive use of resources but rely more on patients' own motivation following adequate guidance and training by experts, will provide important information on how best to implement life style changes in patients' daily routine.

Acceptability, which the authors set as secondary outcome, is another important aspect of any life style intervention plans. This should be particularly emphasised by the authors especially given that the program involves a 5-days hospitalization with 3 further, 1-day long, recall sessions. In this early phase of research studies assessing the effects, feasibility and acceptability of life style intervention programs, obtaining feedback from the enrolled patients' using semi-structured interviews, carried as one to one by an independent researchers, would add value and key information for their success and future planning.

Finally, it is anticipated that primary and secondary prevention will lead to a significant saving for the health care providers so that, after initial investment of resources, the anticipated improvement in patients' physical and mental well-being will result in reduced NHS costs. Studies assessing the effects of life style plans should see the involvement of health economists in order to identify key information to obtain cost-effectiveness, including QALY, estimates. All this will help in planning further studies which should see also the involvement of older patients with CHD. It will take many years however, before the long term effects of "cardiac rehabilitation" can be fully appreciated but the trajectory of its benefits will be clear and strong enough since early stages to support implementation of such programs in the routine patients' care.

Conflict of interest

The author reports no relationships that could be construed as a conflict of interest.

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