Letters to the Editor

doi:10.1016/j.ehj.2003.06.009

Psychosocial functioning of adults with congenital heart disease: a neglected area

We read with great interest the paper by van Rijen et al. on the psychosocial functioning of adults with congenital heart disease, but feel that the importance of their paper has been underplayed. It is estimated that 1% of all live births have congenital heart disease, and that in the United States alone, there are 500 000 adults with congenital heart disease. Because medical intervention is continuously improving, the long-term outlook of these patients who have had either curative or palliative treatment is getting better, and many of these patients are followed up regularly. Nonetheless, their psychosocial problems and psychosocial functioning have been relatively neglected. Indeed, we recently demonstrated worse quality of life scores amongst grown up congenital heart disease patients attending our outpatient clinic, with lower scores surprisingly amongst patients who were surgically cured than those who had received palliative treatment. Certainly, most of the patients had significantly poorer physical functioning and overall general health perception than the general population, especially the groups which had inoperable or cyanotic congenital heart disease.

In addition, we recently completed a Cochrane systematic review of the literature to identify research relevant to interventions for depression in adolescents and adults with congenital heart disease. There was a dearth of information on the incidence and prevalence of depression in congenital heart disease, as well as a serious lack of studies on the optimal treatment of depression in this group of patients.

Our findings are of course rather concerning since individuals who survive with congenital heart disease will increase, and because of this, we anticipate an increase in psychosocial disorders in this group of patients. Nonetheless, van Rijen et al. suggest that these patients overall seem to do well, despite a high proportion of patients who attain lower social, academic and occupational levels than controls. Furthermore, there was a high number of patients with special needs, and females appeared to suffer more psychological disturbance. Although the authors do not comment about the incidence of depression in this cohort, one can speculate that the incidence of depression is probably significant, especially in the latter group of individuals who are ‘lower achievers’.

Why is the recognition of psychosocial problems and the availability of appropriate treatments in patients with congenital heart disease important? The needs of patients with congenital heart disease are complex, especially since a significant number require continuous medical intervention. Therefore, therapists will need to take account of their complex medical condition, intelligence, in the case of patients with learning disabilities) when providing treatment. Although the latter statement is plausible, our Cochrane review suggests that we lack randomised trial data to back it up.

van Rijen et al. are to be congratulated for undertaking this large and unique study, but the authors should comment on specific problems, such as the prevalence of depression, in their cohort. Although they suggest most patients appear to develop well, a large number probably still suffer psychiatric distress. Thus, more work is urgently required to identify the group(s) at highest risk, and to develop and administer effective holistic psychological and psychiatric interventions for such patients.

References