Letters to the Editor
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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 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 psychological 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 psychological 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 (e.g. 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

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Reply to: Psychopathology in adults with congenital heart disease: the attribution of longitudinal cohort studies

In accordance with the comment of Tayebjee and Lip on our article concerning psychosocial functioning in a cohort of adults with congenital heart disease, we agree with the importance of assessing psychopathological symptoms and development of optimal psychological treatment.

About a decade ago, our research group investigated a broad range of psychiatric problems in children, adolescents and young adults in the first follow-up of this same cohort. A broad range of psychiatric problems was investigated. Besides symptoms of depression and anxiety, somatic complaints (without medical cause), withdrawn behaviour, delinquent behaviour, aggressive behaviour, social problems, thought problems and attention problems were examined. Results of psychiatric problems in children were unfavourable, whereas, in contrast, those of the young adults were favourable overall.

We agree with Tayebjee and Lip about the scarcity of information regarding depression. In literature, the prevalence of depression might be overrated since many studies consisted of relative small samples of patients with severe congenital heart disease. Often, response rates were low, thereby enlarging the chance of selection bias. To get a clear view of prevalence of psychopathology, cohort studies with consecutive series of patients provide an important contribution. The strength of both our present and previous cohort studies are the large sample size and high response rate. Moreover, patients with severe as well as less severe cardiac diagnoses are represented.