

Editorial Comment

Do we need cardiac camps?

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FOR DECADES, CHILDREN AND ADOLESCENTS OF ALL ages have enjoyed participating in residential summer camps.¹ These are very well established in North America, and are increasing in popularity in Europe. Many of these include programmes which have been designed specifically to include participants with chronic medical conditions, including some children with congenital cardiac disease.

These camps frequently share a common ethos around developing goals of independence, improving self esteem, and encouraging social interaction. So, in addition to providing a “good time”, camps have been promoted as being of positive benefit to the medical state of the child, and in effect can be considered as a therapeutic intervention.^{2–4}

Although the first report of such a camp for children with congenital heart disease was as long ago as 1953, there has been very little research conducted into the potentially beneficial impact these camps might have. Simons et al.⁵ therefore, are to be congratulated for their paper in this issue which seeks to provide evidence that beneficial psychosocial changes are associated with participation at this type of camp.

The group from the United States of America⁵ have used an innovative approach to explore how changes in levels of anxiety are associated with the camp experience. One of the important themes they looked at was the level of parental anxiety associated with separation from their child and attendance at the camp.

As well as showing that levels of anxiety were lower at the end of the camp, they also demonstrated

that children whose parents had the most negative feelings associated with attendance at camp benefited the most. The theme of parental overprotection has been shown to be very relevant to patients, particularly adolescents, with congenital cardiac disease, with social inclusion and independence identified as important factors in perceived health.

Another major factor that has been shown to be linked to the perceived state of health is the perception of physical ability. Some residential camps are designated as “sports camps”, and have specific programmes designed for children with congenital cardiac disease, with goals of increasing exercise levels and participation in physical activities. Recent research by Moons and colleagues⁶ was the first of its kind to explore the potential benefits of this type of camp. They demonstrated significant improvements in the perception by the participant of physical functioning, self esteem, and general behaviour, following attendance at a designated sports camp. Further work by the same group⁷ demonstrated that the improvements in the perceived state of health were sustained in the short term three months after the sports camp. Habitual physical activities, in contrast, remained unchanged.

Although Simons et al.⁵ and Moons et al.^{6,7} advocated that children with congenital cardiac disease should be encouraged to participate in such camps, both groups raised important questions that highlight a lack of good quality research in relation to the need for, and impact of, interventions designed to improve self-perceived health. Such interventions often fall outside the conventional range of medical and surgical treatments currently offered.

With the development of disease-specific instruments to evaluate the state of health of these patients, it has become clear that identification of healthcare needs, and health-related measures of outcome, are becoming increasingly important in

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the management of children with congenitally malformed hearts. The factors relating to self-perceived health are complex, and are not necessarily related to functional ability or severity of disease. As a consequence, they are less likely to be addressed within conventional surgical or medical interventions.

Alternative interventions that are currently being explored involve individual or group programmes, which include patient education, psychological support and physical training. In this respect, residential camps may be considered as having a head start, in that they have been fulfilling many of these requirements for some time. Important questions around issues of accessibility, selection of patients, long term benefits, and the different nature of camps, however, remain unanswered. Consequently, the lack of data makes it is very difficult to assess what impact participation at these camps might have on the health of our patients, and the role they have in their management.

Accessibility

Residential camps are not accessible for all patients with congenitally malformed hearts. Currently, only a very a small minority are able to attend. Capacity is likely to be the biggest factor restricting access, and this may include financial and geographical constraints. Patient and parental motivation are also important. The results of the paper published in this issue⁵ may lead to an improvement in confidence to use these camps for those parents experiencing doubts about being separated from their child.

Selection of patients

The study⁵ demonstrated that children whose parents were the most anxious gained the most benefit. The authors commented that there will almost certainly have been children that potentially had even more to gain, but whose parents were too anxious to allow them to attend.

In the various studies cited,⁵⁻⁷ a range of improvements associated with camp attendance was reported, with some of the patients showing minimal or no gain in perceived health. It is possible that the children attending the camps are already well motivated, whilst those refusing may have the greater need, and greater potential for benefit, as reported in the current study.⁵

It is evident that not all patients benefit equally, and whilst places at camps remain limited, it is important that the health care professional involved in referring patients select those that are likely to

benefit the most. The difficulty may lie in how to identify those with the greatest need.

It is not clear from any of the cited studies,⁵⁻⁷ how representative the patients with congenitally malformed hearts benefiting from these camps were compared with the much larger population of patients with congenital cardiac disease that did not attend. The groups studied were very small, and although there was a reasonable cross-section in terms of functional ability and severity of disease, the differences in characteristics between participants and non-participants is unknown.

One indirect observation from these studies⁵⁻⁷ relates to the methodological difficulties in researching with younger children, with the lowest age group studied being 8 years of age. It is clear, though, that some children attending these and other camps are much younger than this. At this time, it would be difficult to make recommendation on the therapeutic role of camps in very young children.

Long term effects

One of the important questions applicable to all interventions is whether any observed short term benefits are sustained? Neither of the studies^{6,7} presents evidence relating to the long-term impact of these camps. The group from Rotterdam^{6,7} has highlighted this as an important point, and is currently carrying out a longer term evaluation. The group involved in the present study⁴ had a number of participants that were returning from previous years. Whether repetition of such camps is necessary to achieve sustained improvements needs further evaluation, but accessibility is likely to be an issue, with financial and capacity issues being important factors.

The evidence obtained from other groups of children with chronic conditions participating in specialist residential camps report similar short term benefits to physical functioning and self-esteem, but recommend further research to determine whether any benefits are maintained in the long term.^{3,4,8}

All the investigators⁵⁻⁷ have stressed that, although their results were clear in reporting observed beneficial effects associated with participation in camps, none of the studies was designed to be able to conclude that a definite causal relationship exists. Unanswered questions are how any benefits are achieved, and whether some aspects of a camp experience are more likely to be of benefit than others. Camp programmes may differ significantly, as demonstrated by the experience at the European camp, described as "a special sports camp",⁶ with a much greater emphasis on sporting

activities and participation than provided at the camp described by Simons and colleagues.⁵ It may be important to be able to match a child with specific needs to a certain type of camp. Currently the evidence available to make such an informed choice is lacking.

There are alternatives for children unable or unwilling to attend camps. Educational and exercise programmes developed for adults with chronic heart failure are well established, with proven benefit for some patients. There has been some limited work in this area with children. Problems include motivating patients to attend, and difficulties in resourcing the programmes, which are often individualised, which limits their accessibility and overall effectiveness in patient management. In this respect, the residential camps may have an advantage, in that their programmes are usually based on groups rather than individually delivered, with “therapy” provided in more subtle ways, with an emphasis of having fun as opposed to “treatment”.

Finally, is there any evidence that might suggest that participation in camps is harmful? The risk of sudden death relating to exercise and physical activity for patients with certain types of congenitally malformed hearts is well recognised. The recommendations for the levels of activity patients should pursue, however, are regularly updated, so compliance with these guidelines should help prevent this happening.

It is probable that, for some children, an experience at camp could have some negative psychological effects. Anecdotal feedback from patients who have declined the opportunity to attend such camps have reported that the thought of spending time with other children with similar conditions was unappealing, and would only serve to highlight any differences and exclusion from their peer group. Others have similarly observed that interaction amongst children with previous medical experience may have detrimental effects, especially in terms of conveying information and anxiety levels concerning medical conditions.⁹ For these patients, an experience at camp integrating with healthy children might have been a preferred option. Further research would provide guidance in these areas.

In conclusion, although children with congenitally malformed hearts have been attending residential camps for over 50 years, it is only very recently that studies have shown some of the beneficial effects which can be associated with participation. Should those involved in the care of children with congenital cardiac disease be advocating active participation, as suggested by the advocates of these camps^{5,6} as part of their overall management? It is very likely that many children will derive much benefit from this suggestion, but at the current time it should be recognised that a lot more research is needed to guide the clinician who is still faced with important questions such as, which child should attend, which type of camp is best, and what to do for the child that is unable, unwilling, or not permitted to attend.

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