Illness narratives from school-age children with congenital heart defects: children’s perspectives on life experiences and coping strategies related to severity of cardiac diagnosis.

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Introduction: Understanding children’s own views about living with congenital heart defects (CHDs) is key to supporting their successful participation in daily life, school and peer relationships. In this paper we explored children’s narratives about living with CHDs and compared qualitatively the views of children with defects that are often surgically corrected during infancy (less severe) and those with complex, palliated defects (more severe).

Methods: A UK-wide cohort of school-age children with CHDs, aged 10-14 years, and their parents completed postal questionnaires about children’s health and quality of life; children also answered an open question about what it is like to be a child with ‘a heart problem’. Through collaborative thematic content analysis using NVivo software, we explored how children characterise their experiences of living with a CHD and coping strategies they have developed, as well as differences in response by cardiac severity group.

Results: Written narratives and/or drawings were returned by 436 children (248 boys [56.9%]; mean age 12.1 years [SD 1.0; range 10-14]); 313 had less severe and 123 had more severe cardiac diagnoses. Key themes included medical care, positive and negative emotions, social interaction and coping strategies. Within these themes, there were important qualitative differences in the way children in the two severity groups characterised their CHD and some coping strategies were clearly emphasised by one severity group. A key issue for many children was managing revealing their scar in order to minimise the risk of social exclusion.

Conclusion: Children’s perceptions of living with CHDs were only partly related to the severity of their cardiac diagnosis, and associated physical limitations. Parents, healthcare staff and teachers responsible for children with CHDs should be aware of and understand the child’s perspective of their condition in order to actively support the coping strategies they develop. Managing information-sharing about their condition may be an important step for school-age children with a CHD in taking responsibility for their future health. We have shown that children’s written narratives, collected through a postal survey, can be a helpful, innovative child-centred method for capturing these perspectives and adaptive strategies.

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