

Early morbidities following paediatric cardiac surgery: a mixed-methods study

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Plain English summary

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Plain English summary

Over 5000 heart surgery procedures are performed in children in the UK each year and early survival has improved to > 98%. Although early survival is important, most people now think that this does not provide enough information. Therefore, we aimed to study health-related issues following surgery that are generally considered as 'bad for the patient'. The medical term for these issues is 'morbidity', but often they are called 'complications'.

We reviewed existing literature, ran three family focus groups and undertook a family online discussion forum. A group of health professionals and family representatives then considered the possible 'morbidity' and decided on a list of the nine most important ones, which were defined by a group of specialists. This included medical complications, such as needing support with a mechanical pump after the operation, but also 'morbidity' that were particularly serious to families, such as feeding difficulties.

Working in five of the UK centres, we involved children aged < 17 years with congenital heart disease and their parents to:

- successfully test a new method for nurses to check child development in 1200 children (we found that this worked in children aged between 4 months and 5 years old)
- measure how often 'morbidity' happened after 3090 operations (we found that 21.8% experienced at least one)
- measure the impact of 'morbidity' in 666 children over 6 months (one important finding was that although patient quality of life was reduced when these happened, over 6 months it improved in survivors).

We developed new ways to inform parents and the organisation that monitors the results of children's heart surgery (national audit) about complications, with a view to empowering parents. Monitoring 'morbidity' is more difficult than monitoring mortality, so it requires resources and clinician commitment. Further research is needed to work out how best to help children with feeding problems and delays in development.

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