#### **Abstract Info**

Impact of congenital heart disease on siblings – a review

Oral or poster presentation is requested.

Keywords: Heart Defects, Congenital; Siblings; Health Impact Assessment; Literature review

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## Introduction

Affecting 9/1000 births worldwide, congenital heart disease (CHD) is the most common birth defect. Medical and surgical advancements ensure that 95% of children reach adulthood. Due to required changes to daily life, CHD can often be referred to as a chronic condition. Chronic conditions among children and young people have been found to negatively, and sometimes positively, affect siblings and increase the risk of psychological distress. Maturity, patience, responsibility and independence were described by siblings. Having a child with CHD in the family can impact finances, relationships, parent and sibling health related quality of life (QOL). For children with CHD they have improved quality of life if they have a sibling. However, little is known about being a sibling of a child with CHD.

### Aim

To identify and synthesise empirical evidence regarding effects of having a sibling with CHD

### Methods

Databases searched were CINAHL, AMED, MEDLINE, PsychARTICLES, SocINDEX, PsychINFO, PubMed, Web of Knowledge, Education research complete, ERIC, and GreenFILE. Two researchers independently screened articles and discrepancies resolved by a third. Included studies were subject to a data extraction and quality appraisal process.

# **Results**

As detailed in figure 1, 11 articles were finally included. Three themes emerged.

## 1. Changes in normal life

Siblings experienced changes in parenting, specifically in available time and attention for the well child reducing family activities. Discipline was more relaxed with the child with CHD. Siblings were undertaking more chores, increased caretaking requirements and less social activities with friends.

## 2. Impact on siblings

Parents recognised and siblings confirmed feeling jealous, resentful, insecure and having low self-esteem. School performance and attendance were negatively affected. Entire family QOL was low but siblings self-reported QOL was higher than controls. Parents also reported anxiety, depression and displays of anger and intolerance among siblings. Birth order may play a role as older children had less behavioural problems in one study. Younger siblings were reported by parents to be more withdrawn.

# 3. Factors affecting the extent of impact on siblings

Parents rated a greater impact on siblings depending on CHD classification. Higher impact was found in cyanotic lesions and in heart transplant siblings. However, heart disease classification and impact were not statistically significant. More symptoms of psychological distress were noted in children whose sibling required less intense treatment for CHD. High restrictions on family life and previous family trauma were risk factors for a more negative sibling outcome.

## Conclusion

Siblings of children with CHD experience negative life changes. Evidence to understand mitigating factors is inconclusive. Further research is required to gain a better understanding of CHD sibling's experiences and outcomes.

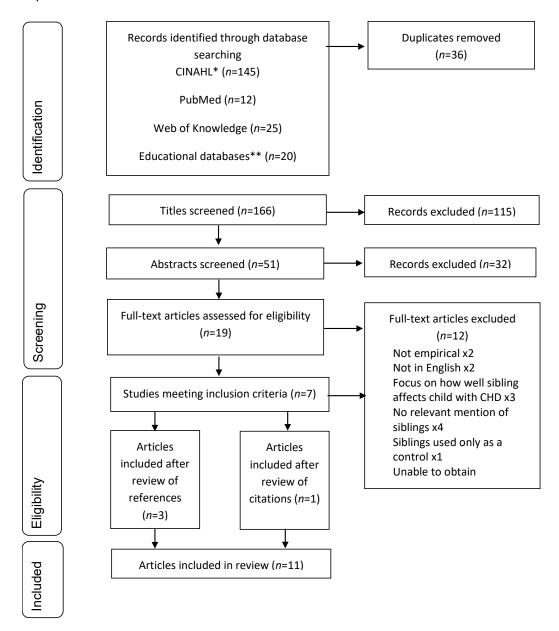


Figure 1: PRISMA diagram showing study selection