

# Impact of congenital heart disease on siblings – a review

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## Background

Chronic conditions in children have been found to negatively impact all aspects of family life, including siblings (O'Brien, Duffy, & Nicholl, 2009)  
Cancer (Grootenhuis & Last, 1997)  
Sickle cell disease (Thompson et al., 2003)  
Epilepsy (Rodenburg, Marie Meijer, Deković, & Aldenkamp, 2006)  
... and more

Congenital heart disease can become a chronic condition (Loup et al., 2009)

Should we be doing more to support ♥ siblings?

## Aim

To identify and synthesise empirical evidence regarding effects of having a sibling with congenital heart disease

## Methods

Independently screened (RP, SH, EB)  
Discrepancies mostly resolved by discussion  
Non agreement resolved (SM)  
Hawker, et al (2002) quality appraisal tool developed for reviewing research from range of methodologies, disciplines, and paradigms

## Databases searched

CINAHL, AMED, MEDLINE, PsychARTICLES, SocINDEX, PsychINFO, PubMed, Web of Knowledge, Education research complete, ERIC, and GreenFILE

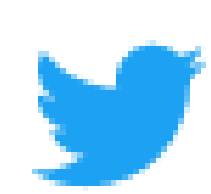
## Literature search terms

•"Congenital heart disease\*" OR "CHD" OR "acquired heart disease\*" OR "heart defect\*" OR "cardiac surgery" OR "heart surgery"  
•AND  
•"sibling\*" OR "brother\*" OR "sister\*"  
•AND  
•"experien\*" OR "impact\*" OR "perception\*" OR "effect"



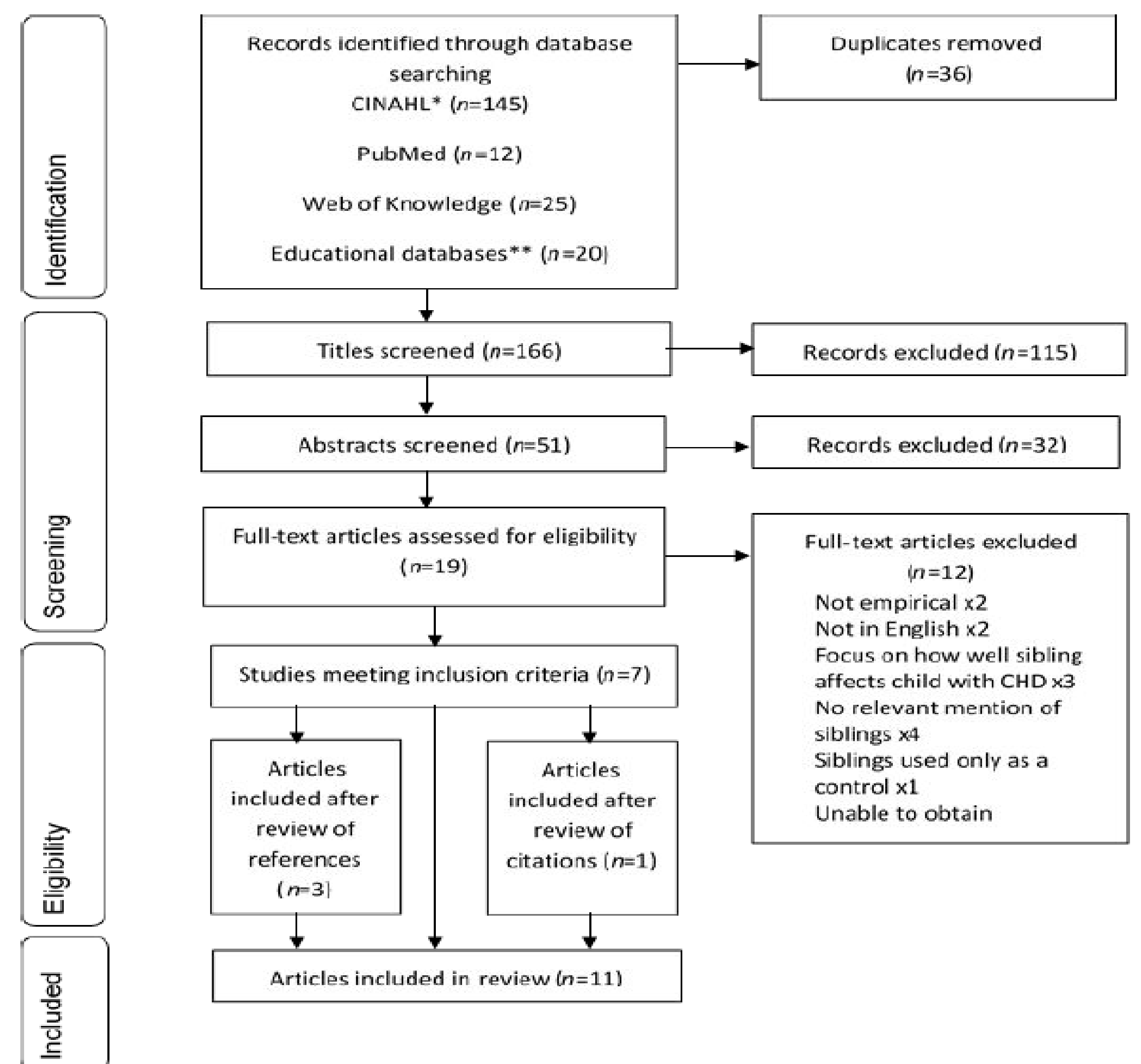
## Further Information

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## PRISMA diagram



## Results

6 /11 studies conducted in the past 20 years

Publication dates range from 1967 – 2019

Three studies were conducted in the UK and USA. One study was conducted in each of Australia, Canada, Belgium, Lahore, Philippines, and Saudi Arabia.

### One intervention

Parents reported that the Heart Beads Programme enabled siblings to feel included (Redshaw and Wilson, 2012)

## Themes

### Changes in normal life

Siblings experienced changes in parenting, specifically in available time and attention for the well child reducing family activities (Wray & Maynard, 2005)

Discipline was more relaxed with the child with congenital heart disease (Wray & Maynard, 2005)

Siblings (particularly sisters) were undertaking more chores (mean difference -0.5, t 2.32 p <.05)

less social activities with friends (mean difference 0.99, t 5.39 p <.01)

less school activities (mean difference 0.17, t 2.36 p <.05) (Williams, Lorenzo, & Borja, 1993)

### Impact on siblings

Parents recognised and siblings confirmed feeling jealous, resentful, insecure and having low self-esteem. (Wray & Maynard, 2005; Azhar et al., 2016)

School performance and attendance were negatively affected. Entire family QOL was low. Aspects self-reported QOL was varied when compared to controls, cystic fibrosis or cancer siblings. (Azhar et al., 2016; Havermans et al., 2015; Mughal et al., 2011; Williams et al., 1993)

Parents also reported anxiety, depression and displays of anger and intolerance among siblings. (Wray and Maynard, 2005; Havermans et al., 2015; Apley et al., 1967)

Birth order, older children had less behavioural problems. Whilst younger siblings were reported to be more withdrawn. (Knight, 2018; Lavigne and Ryan, 1979)

### Factors affecting the extent of impact on siblings

Parents rated a greater impact on healthy siblings depending on congenital heart disease classification.

16% in families where the child had an acyanotic lesion,

43% where the child had cyanotic lesion,

60% where the child had undergone transplant (Wray and Maynard, 2005)

More symptoms of psychological distress were noted in children whose sibling required more intense congenital heart disease treatment. (Janus and Goldberg, 1997; Apley et al., 1967)

## Conclusion

Evident lack of contemporary understanding of impact of congenital heart disease on siblings

## Article

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