Characteristics, barriers, and enablers of models of care supporting neurodevelopmental follow-up of children with congenital heart disease: a scoping review

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Background

Children with congenital heart disease (CHD) are at increased risk for developmental deficits. Despite the importance of neurodevelopmental follow-up in long-term CHD care, limited research considers the design and implementation of such programs. An improved understanding of best program approaches has been identified as a critical element of the congenital heart disease research agenda to guide implementation and evaluate impacts in practice [1].

To support this, we performed a scoping review which aimed to identify and describe characteristics of neurodevelopmental follow-up programs for children with CHD and highlight contextual factors impacting implementation.

Lessons & next steps

These findings will be combined with qualitative interview data to inform the development of a taxonomy of neurodevelopmental models of care for children with CHD, which can be used to support simulation modelling of service delivery and subsequent implementation planning at local and national levels.

However, published descriptions of neurodevelopmental follow-up programs, their implementation, and impact are limited, and constrained to a small number of geographical regions. As a result, defining components of a successful program and understanding how they may be adapted to different contexts is challenging. Neurodevelopmental follow-up providers should be encouraged to evaluate and report on their programs to provide critical insights into the gaps identified in this review.

Methods

1: review question

What are the characteristics of models of care for neurodevelopmental follow-up of children with CHD?

2: systematic search

Databases: OVID Medline, EMBASE, CINAHL and SCOPUS

Citation tracking

Expert clinician recomendations

5427 records retrieved
1012 duplicates removed

3: study selection based on inclusion criteria

At least two reviewers independently completed title, abstract, and full text screening for publications that:

- Described program characteristics or components of developmental follow-up processes for children with CHD
- Of any study design (RCT, qualitative, pre-post, cohort)
- No language or date restrictions

4405 title/abstracts screened
170 full text screened

4: data extraction

Data extraction was piloted and two authors extracted care model characteristics; study characteristics; outcomes reported; implementation barriers and enablers reported

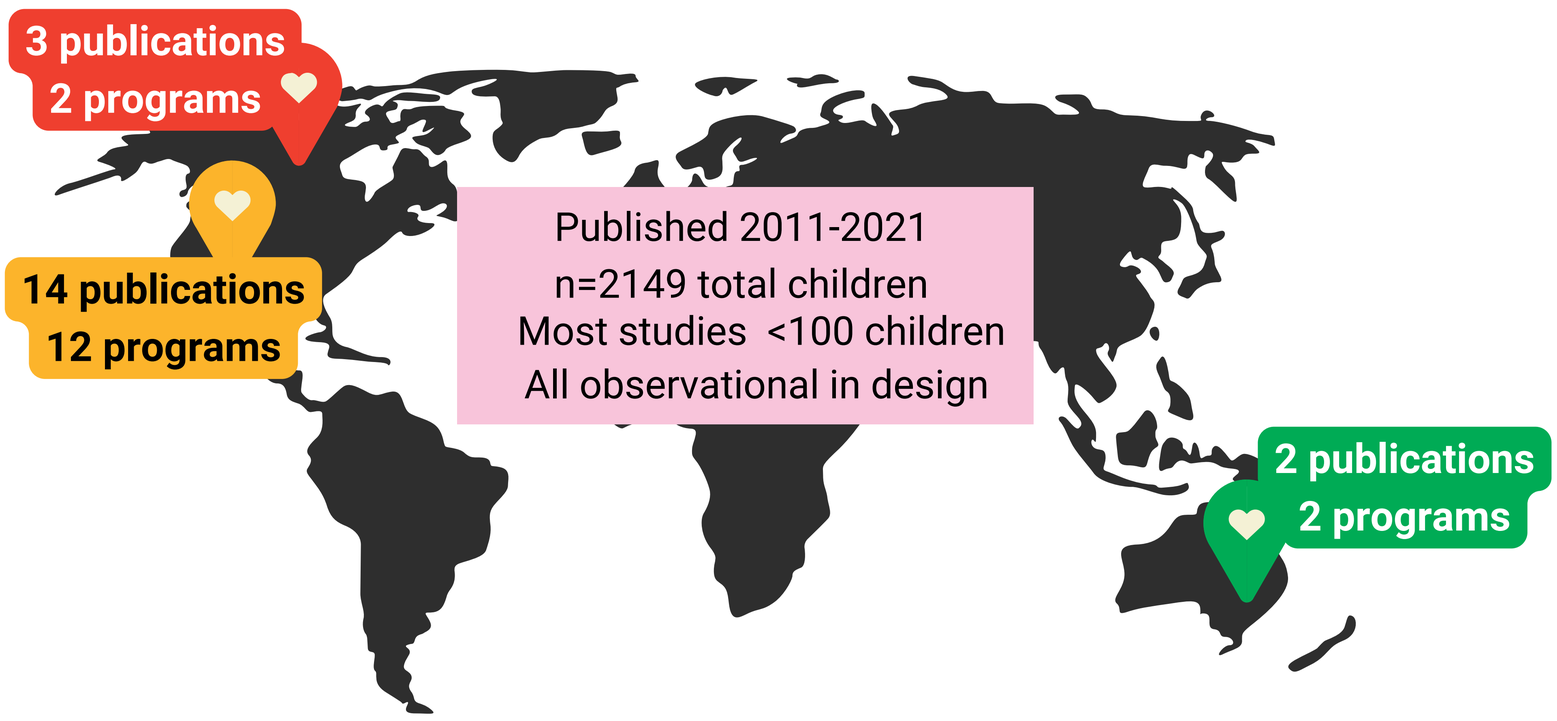
19 publications included in review

5: data summary

Summary tables and narrative synthesis created

Care model/program characteristics were coded using framework analysis [2]

What were the characteristics of the included publications?



Published 2011-2021
n=2149 total children
Most studies <100 children
All observational in design

How many publications reported each outcome?

14/19 **Effectiveness**
lead to new diagnosis or referral/access to ND evaluation, therapy or intervention

4/19 **Acceptability**
"high levels of parent satisfaction"

0/19 **Cost/cost-efectiveness**

12/19 **Adoption/uptake**
(median rate 77%)

What were the common neurodevelopmental follow-up program elements?

REFERRAL & INTAKE APPOINTMENTS

Before inpatient discharge (56%)
Via Cardiology outpatient's clinic (22%)
By regular/primary care provider (17%)
After inpatient discharge (11%)
Self-referral (6%)

SERVICE STRUCTURE

Centralised at one location (72%)
Centralised with some decentralised elements (17%)
Decentralised across region (11%)

FOLLOW-UP FREQUENCY

Fixed ages + adhoc (44%)
Every 6-12 months (17%)
Every 2 years (6%)

LOCATION

Children's hospital (72%)
Children's healthcare system (11%)
Hospital/healthcare network (11%)
School (6%)

PROVIDERS

Nurse/nurse practitioner (71%)
Allied health (67%)
Psychologist (67%)
Paediatrician (50%)
Cardiologist (39%)

TOOLS

Bayley Scales of Infant and Toddler Development (50%)
Child Behaviour Checklist (28%)
PedsQL™ (22%)
Ages & Stages (22%)

What were the challenges and enablers to delivering neurodevelopment follow-up programs?

Dedicated, skilled, collaborative interdisciplinary team
Leverage existing resources/clinics
Scheduling appointment before discharge
Institutional support and program leadership
Schedule ND visits to align with other appointments for patient

Lack of skilled/qualified personnel to perform follow-up
Lack of resources, time and assessment tools
Providers lack knowledge about ND/guidelines
High cost of service delivery
Travel/transport to clinic for families & time involved
Lack of insurance coverage/reimbursement

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2. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC medical research methodology. 2013 Dec;13(1):1-8.

Learn more about CHD LIFE+ and how we are co-designing sustainable cardiac neurodevelopmental models of care for CHD

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