Vol. 15(5), pp. 42-49, September 2023
DOI: 10.5897/AATCVS2023.0055
Article Number: DC13C3E71292
ISSN 1994-7461

http://www.academicjournals.org/AATCVS

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African Annals of Thoracic and Cardiovascular Surgery

Review

Current status of the pediatric congenital heart disease management pathway in low and low-middle income countries: A review

Mark Nelson Awori[1]*, Daniel Ojuka[1], Diana Marangu[2] and Paul Bannon[3]

[1]Department of Surgery, School of Medicine, University of Nairobi, P.O. Box 19676-00202, Nairobi, Kenya.
[2]Department of Paediatrics and Child health, School of Medicine, University of Nairobi, P.O. Box 19676-00202, Nairobi, Kenya.
[3]Department of Cardiothoracic Surgery, University of Sydney, NSW 2006, Australia.

Received 23 April, 2023; Accepted 17 July, 2023

There is evidence that children with congenital heart disease (CHD) in low and low-middle income countries (LMICs) do not have access to timely intervention. The concept of the 'Management Pathway' (MP) for CHD has been developed to facilitate a pragmatic assessment of the quality of care. The MP is comprised three phases: diagnosis, treatment (intervention) and follow-up. Best practice recommendations regarding how each phase should be executed have been published. The fundamental tenets of these recommendations can be summarised as follows: timely diagnosis, timely treatment and robust follow-up. We aimed to examine the status of the MP in LMICs. Google Scholar and PUBMED were searched between January 1st 1966 and August 31st 2022. Twenty-nine articles, representing 43,082 patients were included: sixteen (55.2%) were from Asia; eight (27.6%) were from Africa; three (10.3%) were regional and two (6.9%) were from the Middle East. Twelve (41.4%) studies examined two phases of the MP: eleven examined diagnosis and treatment; one examined treatment and follow-up. Eight (27.6%) studies did not examine the MP at all and only one (3.4%) examined all three phases of the MP. The majority of studies found that MP phases had not been executed as recommended. No study found that all the three phases of the MP had been executed as recommended. Most papers revealed that best practice goals for the MP were not achieved; it is likely that most children with CHD in LMICs do not receive optimal surgical intervention.

Key words: Congenital heart, disease, treatment, low, middle income, countries.

INTRODUCTION

Congenital heart disease (CHD) refers to congenital malformations of the heart and great vessels. The prevalence of CHD is approximately 10 per 1000 live births (Liu et al., 2019). Critical congenital heart disease (CCHD) refers to patients who require intervention (surgical or by cardiac catheterisation) within the first year of life; this represents about a quarter of patients born with CHD (Glidewell et al., 2015). The majority of patients

*Corresponding author. E-mail: aimekiriouakamenan@gmail.com. Tel: 00225 07 07 11 89 31.

Table 1. Search strategy.

Search	Strategy
GS	Congenital, heart, disease, developing
GS	Pediatric, cardiac, surgery, developing
PM	Title/abstract- congenital, heart, disease, developing, country
PM	Title/abstract-pediatric, cardiac, surgery, developing

GS=Google Scholar; PM= Pubmed.

with CCHD who do not receive care within the first year of life die (Samánek et al., 1992). In patients who do not have CCHD, the pathological process often progresses to the point where patients become inoperable (Gan et al., 2014). Optimal care of patients with CHD requires timely surgical or catheter intervention. High income countries have generally achieved this; however, this may not be the case in LMICs nations (GBD, 2017; Congenital Heart Disease Collaborators, 2020).

The objective of this study was to assess the current status of the pediatric congenital cardiac 'Management Pathway' in LMICs. The management pathway considers three aspects of service delivery: diagnosis, treatment (surgery or catheter intervention) and follow-up (Awori et al., 2007). For the purposes of this review, a LMIC was defined as a country with a Gross National Income (GNI) per capita of less than or equal to USD 4,045 and HIC was defined as a country with a GNI per capita of greater than USD 12,535 (Fleming, 2020). Evidence based standards of care have generally been established for most types of CHD; these are conveniently captured by Park (2007). These standards of care are essentially based on data relating to the diagnosis, the age at diagnosis, the type of intervention, the age at intervention, the outcome of intervention and the proportion of patients followed-up. Arbitrarily, if 80% of patients in a particular country are diagnosed, receive required surgery (or catheter intervention) and are followed-up according to these standards of care; the service in that country can be thought to be well developed.

MATERIALS AND METHODS

Google Scholar (GS) and PUBMED (PM) were searched between January 1st 1966 and August 31st 2022 (Martin-Martin et al., 2018; Teo and Maurice, 2020). Titles and abstracts were reviewed; full-text papers were read when there was a possibility that data pertinent to CHD diagnosis, treatment and follow-up in LMICs could be present within the text. Additional relevant full-text papers were located using the references from retrieved full-text papers. Only English language studies where included; non-human studies were excluded. Global studies that did not have any data from developing countries were also excluded. All searches used the 'AND' function; the details of the search strategy are shown in Table 1 and the search flow is shown in Figure 1. Papers that were included in this review are shown in Tables 2 and 3.

RESULTS

Our search yielded 355 records; 64 full-text papers were reviewed by the primary investigator (Waffenschmidt et al., 2019). Twenty nine full-text papers, representing 43,082 patients were included: sixteen (55.2%) papers were from Asia; eight (27.6%) papers were from Africa; three (10.3%) papers were regional, and two (6.9%) papers were from the Middle East. These 29 papers included data from 20 countries; the details of these studies are shown in Tables 2 and 3.

Tables 2 and 3 contain exactly the same 29 studies; however, Table 2 contains data about specific portions of the MP and how well these portions were executed with reference to accepted current best practice. Table 3 contains data about a specific aspect of a particular portion of the MP that was examined in a particular study. By combining the data provided by the two tables, it is possible to deduce how well a specific aspect of a particular portion of the MP was executed. Twelve (41.4%) studies examined two phases of the MP: eleven examined diagnosis and treatment; one examined treatment and follow-up. Eight (27.6%) studies did not examine the MP at all and only one (3.4%) examined all three phases of the MP. No study found that all the three phases of the MP had been executed in the fashion recommended.

DISCUSSION

The global prevalence of CHD has generally remained the same over the years (CHD Collaborators, 2020). CHD is the leading cause of heart failure in children in Sub-Saharan Africa (Yuyun et al., 2020). The first successful repair of a congenital heart lesion on cardiopulmonary bypass was performed by Gibbon et al., (1953); this also happened to be the first successful repair of any cardiac lesion on cardiopulmonary bypass (Kurusz, 2012). The first cardiac surgery utilising cardiopulmonary bypass in Africa, was performed in South Africa in 1958 (Brink and Hassoulas, 2009). Since then, cardiac surgery utilising cardiopulmonary bypass has spread to the rest of Sub-Saharan Africa (Yankah et al., 2020) beginning with Ghana in 1964 (Vervoort and Kpodonu, 2020); reports show good surgical outcomes

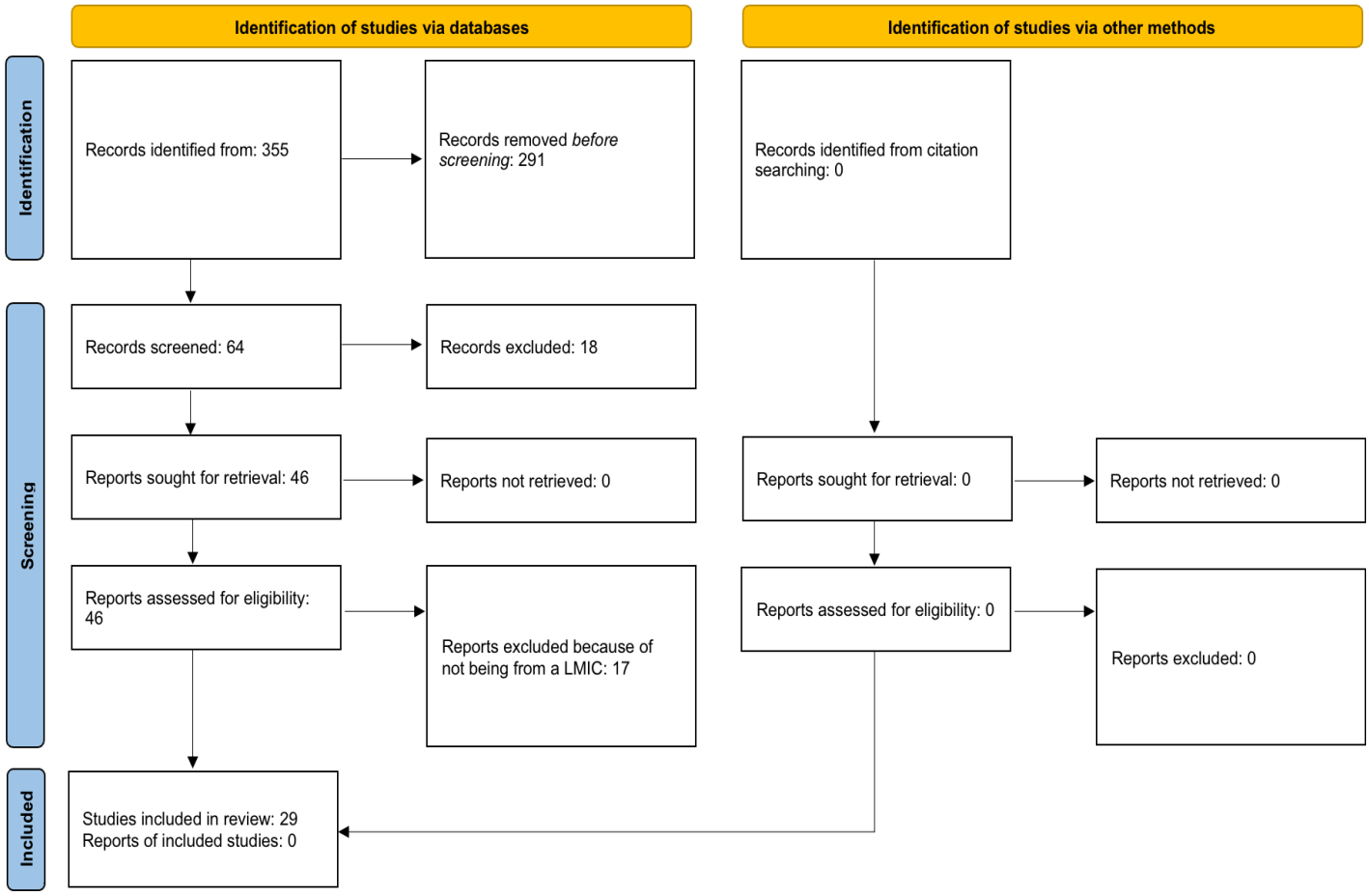

Figure 1. Search flow diagram.

(Yangni-Angate et al., 2016). Prior to the availability of cardiopulmonary bypass, only 20% of infants born with CHD reached their first birthday; now 90% survive into adulthood (Reid et al., 2006). Furthermore, the average life expectancy of these patients is now 75 years, only 4 years less than the normal healthy population (Reid et al., 2006). To achieve this level of positive outcome, CHD must be diagnosed and treated in a timely fashion (Awori et al., 2007).

Consideration of the MP is a pragmatic way to assess the quality of care. The MP comprises 3 phases: diagnosis, treatment and follow-up (Awori et al., 2007). Attempts to improve the quality of care should be guided by specific, measurable, achievable, relevant and time-bound' (SMART) goals; the MP facilitates this. Less than half of the studies included in this review examined more than one aspect of the MP and about one quarter did not examine the MP at all. Although cardiac surgery started in LMICs just a decade later than it did in HICs, there is little evidence to suggest that the service in LMICs has grown at the same rate as it has in HICs (Saxena, 2018). It would be difficult to set SMART goals without examining the MP. This may partly explain the apparent deceleration in growth of the services in LMICs; the studies included in this review demonstrate that the MP generally was not the focus of investigation. The cost of surgery (Giamberti et al, 2018) and the lack of infrastructure and personnel (Phuc et al., 2015) may also have contributed to the apparent poor growth of health care systems that deliver care to children with CHD. With respects to pediatric congenital cardiac surgery (PCCS) there are essentially three ways in which children with CHD in LMICs receive corrective surgery: 1) 'Referal abroad' (Rebolledo et al, 2020); 2)'Surgical Safaris'(Leon-Wyss et al., 2009); 3) Through a 'local PCCS service'(Phuc et al., 2015). 'Referal abroad' refers to a strategy where children are taken to a HIC to have their surgery. Although the surgical results are good, it is generally thought that this approach can only serve a small number of patients and is likely not sustainable. A 'Surgical Safari' refers to a strategy where a 'team' of health care workers from a HIC travel to a LMIC to operate on children. This strategy can deliver good surgical results, and if organised well can contribute

Table 2. Studies included.

Author	Country	(n)	MP phase(s) discussed	MP phase(s) executed as recommended
Abbas et al. (2022)	Pakistan	65	None	N/A
Mostafa et al. (2021)	Pakistan	438	D,T	None
Marianesch et al. (2021)	Cambodia	128	T	No
Elshazali et al. (2020)	Sudan	120	None	N/A
Dehghan et al. (2020)	Iran	1600	None	N/A
Rakha (2020)	Egypt	200	None	N/A
Slitine et al. (2020)	Morocco	8013	D	Yes
Mohsin et al. (2019)	Pakistan	1650	D	Yes
Younis et al. (2019)	Pakistan	44	T	Yes
Rahman et al. (2019)	Regional	24917	None	N/A
Giamberti et al. (2018)	Cameroon	302	None	N/A
Cardarelli et al. (2018)	Regional	446	D,T	Yes(D,T)
Eberly et al. (2018)	Rwanda	134	D	No
Hwang et al. (2017)	Laos	213	D,T	None
Khan et al. (2017)	Pakistan	721	D,T	Yes(D,T)
Aliku et al. (2017)	Uganda	254	T	Yes
Rashid et al. (2016)	Pakistan	354	D	No
Shahabuddin et al. (2016)	Pakistan	195	D,T	None
Phuc et al. (2015)	Vietnam	179	None	N/A
Akhtar et al. (2015)	Pakistan	8	D,T	None
Reddy et al. (2015)	India	1028	D,T	Yes(D,T)
Akhtar et al. (2014)	Pakistan	71	D,T	None
Mohsin et al. (2014)	Pakistan	34	D	No
Tomita et al. (2013)	Mongolia	255	None	N/A
Balachandran et al. (2011)	India	643	D,T	Yes(D,T)
Mocumbi et al. (2011)	Mozambique	534	D,T	None
Awori et al. (2008)	Kenya	313	D,T	None
Awori et al. (2007)	Kenya	214	D,T, F	None
Khan et al. (2003)	Pakistan	8	T, F	Yes(F)

D = Diagnosis; F = Follow-up; MP = Management pathway; T = Treatment.

significantly towards the development of a ‘local PCCS service’; primarily through ‘skills transfer’. However, like ‘Referal abroad’, this strategy may only serve a limited number of patients and is likely not sustainable. A ‘local PCCS service’ refers to a strategy where a LMIC starts a local PCCS service. This service is essentially run by local healthcare workers and is ideally funded locally. When designed well, this strategy has the potential to grow and eventually serve the whole nation. In terms of funding a local PCCS service, the ‘3P’ approach has proven to be effective (Phuc et al., 2015) and sustainable (Lajos and Carpentier, 2016). The ‘3P’s’ refer to: Philanthropy, Public (state) and Patient. It is a model that has delivered sustainable funding for delivering PCCS locally: the patients’ family and friends (Patient) contribute what they can to the cost of surgery. The government (Public) contributes a certain amount to the cost of surgery (usually as a state health insurance scheme with affordable premiums). The private sector (Philanthropy) contributes an amount to the cost of surgery (usually through charitable contributions). Phuc et al, 2015 did not discuss any other forms of funding. Over time, the local PCCS capacity develops and confidence grows in the local service. ‘Twinning’ describes a strategy where a centre of excellence in a HIC partners with a LMIC PCCS centre to provide support; in whatever way the centre thinks they require (Caneo et al., 2022). For example, after starting a relationship with a local LMIC PCCS service through an initial surgical safari, a team from a centre of excellence may continue to participate in patient care through virtual multidisciplinary team patient discussions. Combining ‘Twinning’ and the 3P approach has the potential to be very effective at developing local PCCS services in LMICs. However, it has been suggested that there should be an ‘Exit Strategy’ for the HIC partner to avoid LMIC partner dependence (Murala et al., 2019). Central to a successful partnership is appropriate ‘patient selection’: good surgical outcomes early in the program are essential for sustainability (Cvetkovic, 2018). Our own experience in Kenya has

Table 3. Focus of studies included.

Author	Country	(n)	Focus
Abbas et al. (2022)	Pakistan	65	Postoperative treatment protocols
Mostafa et al. (2021)	Pakistan	438	Cost of surgery
Marianesch I et al. (2021)	Cambodia	128	Cost of DALYs averted
Elshazali et al. (2020)	Sudan	120	Parents knowledge about CHD
Dehghan et al. (2020)	Iran	1600	CHD registry
Rakha (2020)	Egypt	200	Parental awareness of fetal ECHO
Slitine et al. (2020)	Morocco	8013	Pulses oximetry screening
Mohsin et al. (2019)	Pakistan	1650	Pulses oximetry screening
Younis et al. (2019)	Pakistan	44	Surgical outcome
Rahman et al. (2019)	Regional	24917	Surgical outcome
Giamberti et al. (2018)	Cameroon	302	Cost of surgery
Cardarelli et al. (2018)	Regional	446	Cost effectiveness of surgery
Eberly et al. (2018)	Rwanda	134	Cause of heart failure
Hwang et al. (2017)	Laos	213	Age at Diagnosis and surgical outcome
Khan et al. (2017)	Pakistan	721	Surgical outcome
Aliku et al. (2017)	Uganda	254	Surgical outcome
Rashid et al. (2016)	Pakistan	354	Age at diagnosis
Shahabuddin et al. (2016)	Pakistan	195	Types of CHD
Phuc et al. (2015)	Vietnam	179	Infrastructure and personnel
Akhtar et al. (2015)	Pakistan	8	Postoperative fast-tracking
Reddy et al. (2015)	India	1028	Surgical outcome
Akhtar et al. (2014)	Pakistan	71	Postoperative fast-tracking
Mohsin et al. (2014)	Pakistan	34	Outcomes of unoperated patients
Tomita et al. (2013)	Mongolia	255	Catheter intervention outcomes
Balachandran et al. (2011)	India	643	Early postoperative care
Mocumbi et al. (2011)	Mozambique	534	Age at diagnosis
Awori et al. (2008)	Kenya	313	Surgical outcome
Awori et al. (2007)	Kenya	214	Age at diagnosis
Khan et al. (2003)	Pakistan	8	Surgical outcome

CHD=congenital heart disease; DALYs=Disability adjusted life years.

shown that an experienced team from the HIC is required to optimise patient selection.

There has always been a concern that the cost of performing pediatric congenital cardiac surgery (PCCS) cannot be justified in LMICs. The core of the argument is summarised as follows: ‘you can treat a lot more children and save more lives by spending money on public health measures rather than by spending the money on one expensive surgery’. The concept of a DALY (disability adjusted life year) was developed to facilitate cost-benefits analysis in health care spending (Marianeschi et al., 2021). The cost of DALYs averted shows that PCCS is as cost effective as some common public health measures (Grimes et al., 2014). In fact, it has been suggested that PCCS should be listed as an essential pediatric surgical procedure (Saxton et al., 2016). The introduction of the DALY is significant because it allows governments in LMICs to justify resource allocation towards the development of a PCCS service. Strategic planning is necessary to ensure that services that used to be adequate do not become overwhelmed (Hoosen et al., 2022). Patient care protocols have been shown to reduce costs and improve outcomes (Balachandran et al., 2010). Good surgical results are achievable in LMICs (Rao, 2007).

In one LMIC country, most of the diagnoses of CHD were made in private institutions that required the patient to pay for services rendered. This study found that lower parent income was associated with late diagnosis of CHD; presumably because the patients had to ‘acquire the funds’ to seek a diagnosis (Awori et al., 2007). Level of paternal education was not found to be associated with ‘age at diagnosis’ in this study. Two studies found that parents were reasonably knowledgeable about CHD (Elshazali et al., 2020; Rakha 2020). One Kenyan study found that the average age at referral to paediatric cardiologist was 16.9 months (Awori et al., 2007). This implies that patients with critical CHD are likely to die

before receiving treatment for CHD in this country. This situation seems to be supported by studies that reported intervention on patients with non-CCHD (Awori and Ogendo, 2008), (Aliku et al., 2017). Lack of awareness of CHD signs/symptoms and treatment options on the part of parents/guardians, may contribute to delayed diagnosis/treatment. In this regard, coordinated efforts to spread awareness of CHD diagnosis and treatment are important. It was interesting to note that postoperative care techniques prevalent in HICs, such as 'fast tracking' could be successfully applied in LMICs (Akhtar et al., 2014). Although Table 2 provides data regarding how well a specific portion of the MP executed, and Table 3 provides data on the specific aspect of the MP examined, the aim of the current study was to provide a broad overview of the current status of the CHD-MP in LMIC as depicted in available literature. It was beyond the scope of this review to give a detailed analysis of the results of each study included in the review.

CONCLUSION

In summary, we found that the majority of studies from LMICs did not examine all three phases of the MP; about one quarter did not examine the MP at all. Although strategies have been proposed to improve the service in LMICs, the lack of data on the state of local MPs makes it difficult to set SMART goals for service development. We recommend that future studies in LMICs examine all three phases of the MP. In particular, the diagnosis, the age at diagnosis, the type of intervention, the age at intervention, the outcome of intervention and the proportion of patients followed-up should be recorded. Despite the fact that most children are diagnosed late, good surgical results are achievable in LMICs; some LMICs even perform complex PCCS with acceptable results. Although limited resources remain an obstacle to development of local PCCS programs in LMICs, the '3P' model is capable of delivering a sustainable PCCS that can scale to serve the nation. PCCS is cost effective and LMIC governments can justify allocating resources towards the development of a local PCCS service.

CONFLICT OF INTERESTS

The authors have not declared any conflict of interests.

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