Cardiology in the Young

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Effects of transition programmes to adulthood for adolescents and young adults with CHD: a systematic review with meta-analysis

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Review

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Abstract

Background: The increased survival rate among individuals with CHD has sparked interest in their transition to adult healthcare. Although there is a general agreement on the importance of transition interventions, the empirical evidence supporting them is insufficient. Therefore, this study aimed to conduct a systematic review and meta-analysis of transition interventions for adult healthcare in adolescents and young adults. *Methods and results:* A literature search was conducted for studies comparing the quantitative effects of transition interventions with control groups, published up to March 15, 2023, in major databases (CENTRAL, Embase, PubMed, Web of Science, CINAHL, KISS, and KMbase), major clinical trial registries, academic journal sites related to the topic, and grey literature databases. Ten studies involving a total of 1,297 participants were identified. Transition interventions proved effective in enhancing disease-related knowledge (Hedge's $g = 0.89$, 95% CI = 0.29−1.48) and self-management (Hedge's $g = 0.67$, 95% CI = 0.38−0.95), as well as reducing loss to follow-up (OR = 0.41, 95% CI = 0.22−0.77). The certainty of evidence for the estimated values of each major outcome was low or very low. *Conclusions:* This study supports the implementation of transition interventions by demonstrating that they can improve patients' disease knowledge and self-management, while also promoting treatment continuity. However, since the available data on transition interventions for adolescents and young adults with CHD remain limited, the widespread adoption of structured transition interventions in the future may alter the conclusions of this study. *Registration:* URL: https://www.crd.york.ac.uk/PROSPERO. Unique identifier: CRD42023399026.

Introduction

The discontinuation of follow-up among individuals with CHD predominantly occurs during the transition from paediatric to adult care,[1] and studies have reported that approximately 26.1% of individuals with CHD at the transitional age discontinue their medical follow-up.[2] Patients who discontinue their follow-up often do not seek medical attention until their heart failure symptoms have significantly worsened, to the point of being life-threatening in some cases.[3,4] Therefore, it is of vital importance for individuals with CHD to acquire the necessary knowledge and skills for managing their disease in adulthood at the appropriate time, enabling them to independently manage their condition. Additionally, they should transition from paediatric to adult care to ensure they receive lifelong follow-up care.[5,6]

The process through which individuals with CHD attain independent adult disease management, while simultaneously accomplishing medical, psychosocial, educational, and vocational developmental tasks, is referred to as the transition.[6,7] Those who undergo a suitable transition process gain an understanding of their disease, make informed decisions regarding necessary disease management and a healthy lifestyle (which includes physical activity, diet, career choices, sexual health, and contraception), and are able to utilise the social resources required for adult disease management.[5,6] Consequently, heart associations across the globe recommend providing transition programmes for adolescents and young adults with CHD.[6]

However, the actual impacts and effectiveness of transition programmes provided to individuals with CHD are not well-established. Despite growing interest in these programmes and related research, their practical implementation for CHD patients is not yet commonplace,[8,9] and there is a clear need to establish evidence supporting the use of CHD transition programmes. Consequently, this study aimed to systematically review the literature on the effectiveness of transition programmes for adolescents and young adults with CHD, comparing their outcomes with control groups. Furthermore, through a meta-analysis of various effects, it is hoped that this study will contribute to the evidence base for transition programmes for CHD patients.

Methods

Search for studies

The literature search was conducted in accordance with the COre, Standard, Ideal search model.[10] On February 26, 2023, keyword searches were executed across seven academic databases: CENTRAL, Embase, PubMed, Web of Science, CINAHL, KISS, and Kmbase. From February 26, 2023, to March 15, 2023, additional searches were carried out in clinical trial databases (ClinicalTrials.gov, ICTRP), on relevant academic journal websites, and through grey literature sources (ERIC, ProQuest, RISS, OPENGREY.EU). The search keywords comprised combinations of the following terms: "adolescent/puberty/young adult/pediatrics/child," "heart defects, congenital/congenital heart malformation," and "patient transfer/continuity of patient care/health transition/transition to adult care/self-management/patient transport/patient care/population dynamics/transition to adult care/self-care."

Inclusion and exclusion criteria

The studies included adolescents (aged 10–17 years) and young adults (aged 18–29 years) who had simple, moderate complexity, or severe complexity CHD. Studies that involved non-structural cardiac conditions or individuals outside the age range of 10–29 years were excluded.

The experimental group (or exposure group) participated in a transition programme that incorporated five key components: an introduction to transition, medical knowledge, living with CHD, self-management, and self-advocacy. The goal of this programme was to foster independent adult health management, following the guidelines set forth by the American Heart Association (Table 1).[5,6] The intervention (or exposure) was deemed to have been provided if one or more topics within each component were addressed. The control group (or non-exposure group) either received no intervention or usual care. This control group comprised individuals who had not participated in a structured transition programme or received any other form of intervention, as defined in the literature.

The inclusion criteria encompassed randomised controlled trials, non-randomised controlled trials, cohort studies, and case-control studies, provided they included a control group. Cohort studies, single-group pre-test-posttest studies, cross-sectional studies, and descriptive studies that did not feature a control group were not considered.

Data extraction

Two researchers, BRL and SL, independently carried out literature selection. Following this, one researcher (BRL) extracted the data using a predefined data coding form, while two other researchers independently reviewed the data that had been extracted. The findings from the study selection and data extraction were shared among the researchers, with any discrepancies being resolved through discussion.

Quality evaluation

Quality evaluation was conducted using the Revised Tool to Assess the Risk of Bias in Randomized Trials (RoB 2.0)[11] and the Risk of Bias Assessment tool for Non-randomized Study.[12] This evaluation was performed by two researchers, BRL and SL. The interrater reliability of the quality evaluation among the researchers was assessed using Cohen's kappa statistics. In the event of any discrepancies in the assessments between the researchers, these were resolved through discussion and consensus. The certainty of evidence pertaining to each major outcome was analysed using the Grading of Recommendations Assessment, Development, and Evaluation approach.

Table 1. Transition programme components for adolescents and young adults with CHD

Components	Topics
Introduction to transition	Description of the transition, need for lifelong care, need to transfer to an adult health care setting
Medical knowledge	Anatomical-haemodynamic considerations, complications, catheter and surgical interventions
Living with CHD	Educational/vocational considerations, physical activity, pregnancy and birth control, diet and weight management, smoking/alcohol/drugs, anxiety and depression, connecting with others who have CHD, parent support, insurance
Self-management	Medical appointments, managing medication
Self-advocacy	Communication with the healthcare provider, use of community resources

CHD: congenital heart disease.

Statistical analysis

Effect sizes were analysed using the meta package in R software version 4.2.1. Due to variation in participant age, as well as the composition and methods of interventions across the selected literature, a random-effects model was used to calculate the pooled effect sizes.[13] When three or more studies reported the same outcomes, the intervention effect estimates were combined.[14] The effect size for continuous data was calculated using Hedges' g, while odds ratios were used for dichotomous data. Additionally, 95% confidence intervals for effect sizes were computed.[15] Hedges's g is interpreted based on effect size as follows: small effect size (0.34 or lower), moderate effect size (0.35–0.74), and large effect size (0.75 or higher).[16] Heterogeneity was assessed using Cochran's Q test,[16] and the extent of heterogeneity was determined using Higgins I^2 statistic.[13] Subgroup analyses were performed to investigate whether the timing of effect measurement contributed to heterogeneity and to examine potential differences in loss to follow-up observations based on parental involvement. Publication bias was assessed using funnel plots, the Egger test, and trim-and-fill analysis.[13,17,18]

Results

Study selection results

We conducted a keyword search and reviewed the titles and abstracts of 13,429 papers, excluding any duplicates. From these, we selected 20 studies. However, four of these studies were abstracts for which the full text was not available, two clinical trials did not report their results, and two clinical trials were still ongoing, thus providing insufficient information about the characteristics or outcomes of transition programmes. Additionally, two papers were not related to transition programmes, and two were descriptive studies, leading to their exclusion from the analysis. This left eight studies in the initial selection. We also performed a manual search, which yielded an

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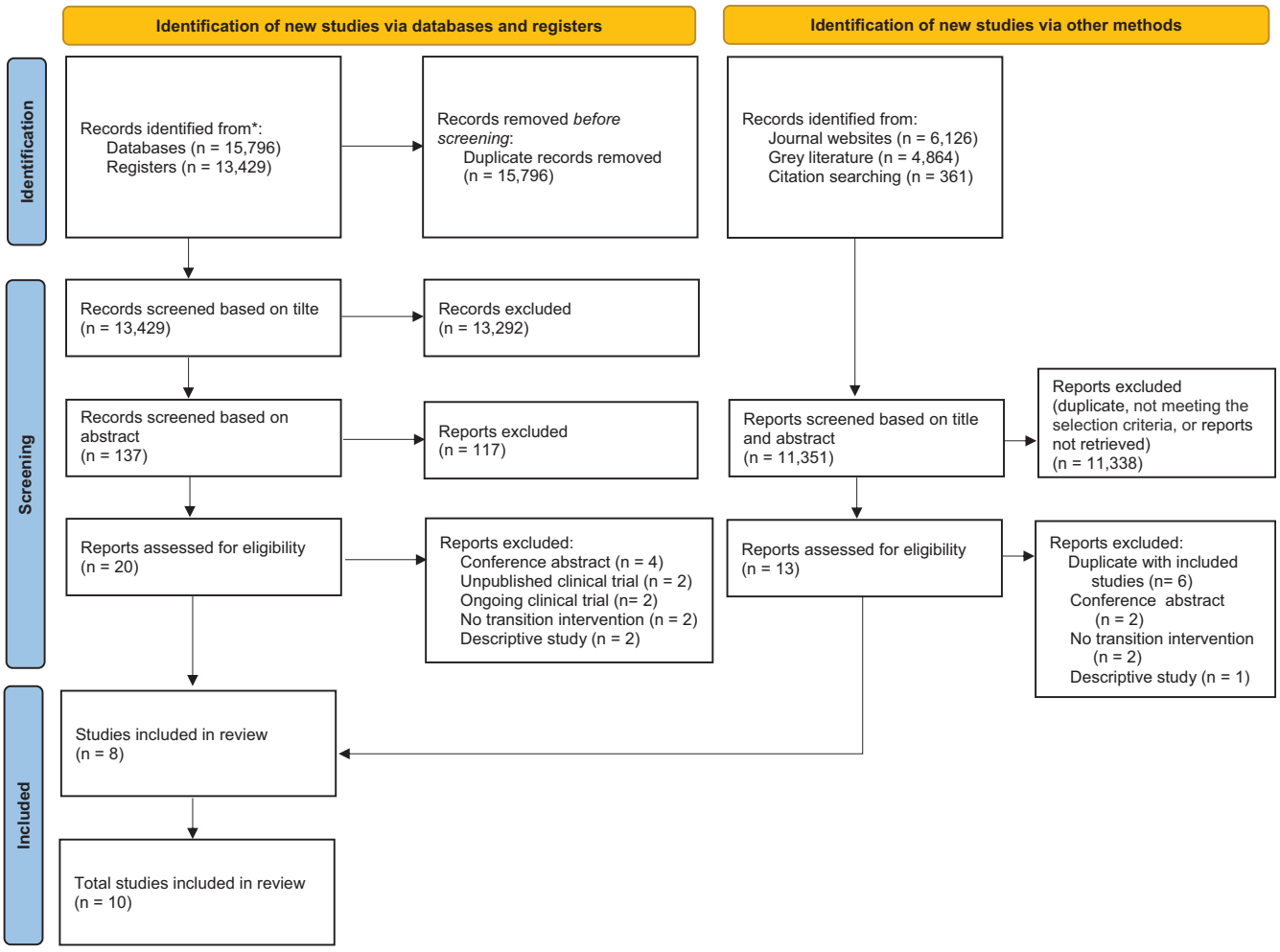

Figure 1. PRISMA flow diagram of the study selection process. PRISMA = Preferred reporting items for systematic reviews and meta-analyses.

additional 11,351 papers. After reviewing the titles and abstracts of these papers, we selected 13 studies. Among these, six had already been chosen in the initial selection, two did not have full text available, two were not related to transition programmes, and one was a descriptive study. This resulted in the inclusion of two additional studies. In total, we selected and analysed 10 studies (Fig. 1).

Intervention outcomes

In the 10 studies, outcomes were reported for disease-related knowledge,[19,20,23,24,28] loss to follow-up,[22,23,25,26] self-management,[19,23,24,28] quality of life,[21,24,27] excess time between paediatric and adult CHD care,[22,23] self-advocacy,[19,23] health and health risk behaviour,[20,27] transition to adult CHD care,[26] unplanned cardiac hospitalisations,[26] and deterioration of heart failure status[22] (Table 2). Among these, disease-related knowledge was the most frequently measured outcome, assessed in five studies. Conversely, outcomes related to the impact on participants' health, such as unplanned cardiac hospitalisations and deterioration of heart failure status, were each evaluated in only one study. Detailed outcome statistics for each specific study can be found in Table S1.

Intervention characteristics

The characteristics of interventions are summarised and presented in Table 3. Among the included transition programmes, six were not based on any specific model or theory. One study utilised guidelines and tools from GotTransition© (https://www.gottransition.org/),[25] two were based on Bandura's[29] self-efficacy theory,[24,27] and one applied the five psychosocial factors of resilience.[21]

The frequency of interventions varied, with four studies offering interventions once,[19–21,28] one study providing two interventions,[23] one study conducting interventions weekly for 4 weeks,[27] and one study offering interventions weekly for 6 weeks.[24] Two studies had varying intervention frequencies, with one providing interventions annually until the transfer to adult CHD care was complete,[26] and one providing interventions at least every 6 months until completion of the transfer.[25] One study did not report the exact frequency of interventions.[22]

Seven studies provided individualised transition programmes tailored to each patient's condition and needs,[19,20,22,23,25,26,28] while three provided group transition programmes that involved group activities such as sharing experiences and exercising together among individuals with CHD.[21,24,27] Among the group transition programmes, two involved creating self-management plans and providing one-on-one coaching from nurses via phone or email during the self-management process.[24,27]

The topics covered by almost all (9 or 10) of the transition programmes comprised anatomical-haemodynamic considerations (n = 10), managing medications (n = 10), medical appointments (n = 9), and communication with the healthcare provider

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Table 2. General characteristics of the included studies

No	First Author (year), Country	Design	Setting	Participants			Comparison	Outcomes	Data Collection
				Age	Number	Classification of CHD			
1	Bushee (2021), USA	Case-control study	Single centre Pediatric cardiology clinic (offline)	>16 years*	Exp. 350 Cont. 303	Simple to severe	Usual care: routine clinic visits with a paediatric cardiologist	Unplanned cardiac hospitalisations ↓* Transition to ACHD care ↑* Loss to follow-up ↓*	For 3 years Clinical record review
2	Gaydos (2020), USA	Case-control study	Single centre Transition clinic (offline)	>11 years* (mean = 18)	Exp. 53 Cont. 54	Simple to severe	Usual care: paediatric cardiology clinics	Loss to follow-up ↓*	For 26 months Clinical record review
3	Goossens (2015), Belgium	Cohort study	Single centre ACHD clinic (offline)	14–18 years	Exp. 106 Cont. 104	Simple to severe	No intervention: not exposed to patient education	Disease-related knowledge ↑* (LKQ-CHD) Health risk behaviours (HBS-CHD) (n)	Pre and 27-month follow-up Clinical record review, mailed structured questionnaire
4	Hergenroeder (2018), USA	Cohort study	Single centre Pediatric cardiology clinic (offline)	≥ 16 years*(Exp. mean = 18.5, Cont. mean = 20.3)	Exp. 15 Cont. 30	Moderate to severe	Usual care: having transitioned out of adult care before introduction of the transition planning programme	Excess time to ACHD care (month) ↓* Loss to follow-up ↓ Deterioration of heart failure (NYHAFS)↓*	For 3 years Clinical record review
5	Hwang (2022), South Korea	RCT	Community-based (online)	12–19 years	Exp. 14 Cont. 14	Moderate to severe	No intervention	Health self-efficacy (SRAHP) ↑* Health behavior (item of KYHBS, actigraph) ↑* Disease-related QoL (PCQLI) ↑	Pre, post, and 1 month follow-up Online self-reporting surveys
6	Lee (2019), South Korea	NRCT	Community-based (on-offline)	≥ 19 years* (Exp. mean = 25.1, Cont. mean = 25.9)	Exp. 27 Cont. 25	Moderate to severe	No intervention	Disease-related knowledge (Korean version LKQ-CHD) ↑* Self-management (Self-care Heart Failure Index) ↑* QoL (PedsQL) ↑	Pre and post Structured questionnaire
7	Lee (2017), South Korea	NRCT	Community-based (offline)	14–22 years	Exp. 25 Cont. 31	Moderate to severe	No intervention	Resilience (the Resilience Scale) ↑* Disease-related QoL (PCQLI) ↑	Pre, post, and 6-month follow-up Structured questionnaire (face to face, mail, or post)
8	Mackie (2022), Canada	RCT	Single centre Pediatric cardiology clinic (offline)	13–14 years	Exp. 27 Cont. 25	Moderate to severe	Usual care: attending cardiology clinic without transition intervention	Self-management (TRANSITION-Q) ↑* Disease-related knowledge (MyHeart) ↑*	Pre, 1, and 6-month follow-up Structured questionnaire

Table 2. (*Continued*)

9	Mackie (2018), Canada	RCT	Two centres Pediatric cardiology clinic (on-offline)	16–17 years	Exp. 58 Cont. 63	Moderate to severe	Usual care: attending cardiology clinic without transition intervention	Excess time to ACHD care (month) ↓* Disease-related knowledge (MyHeart) ↑* Self-management (TRAQ) ↑* Self-advocacy (TRAQ) ↑ Loss to follow-up (for 2 years) ↓	Pre, 1, 6, 12, and 18-month follow-up Clinical record review, structured questionnaire
10	Mackie (2014), Canada	RCT	Single centre Pediatric cardiology clinic (offline)	15–17 years	Exp. 24 Cont. 26	Moderate to severe, cardio-myopathy	Usual care: attending cardiology clinic without transition intervention	Self-management (TRAQ) ↑* Self-advocacy (TRAQ) ↑* Disease-related knowledge (MyHeart) ↑*	Pre, 1, and 6-month follow-up Structured questionnaire

ACHD = adult congenital heart disease; CHD = congenital heart disease; Cont. = control group, Exp. = experimental or exposure group; HBS-CHD = Health Behavior Scale-Congenital Heart Disease, KYHBS = Korean Youth Health Behavior Survey, LKQ-CHD = Leuven Knowledge Questionnaire for Congenital Heart Disease; NRCT = non-randomized controlled trial; NYHAFS = The New York Heart Association Functional Classification of Heart failure; PedsQL = Pediatric Quality of Life; PCQL = Pediatric Cardiac Quality of Life Inventory; QoL = quality of life; RCT = randomised controlled trial; SRAHP = Health Self-Efficacy Measure; TRAQ = Transition Readiness Assessment Questionnaire; USA = United States of America.
*Upper age limit not determined.
Reporting statistical significance: ↑* Increase and a statistically significant result; ↑ Increase and not a significant result; ↓ Decrease and not a significant result; ↓* Decrease and a statistically significant result; (n) Not significant.

Table 3. Characteristics of the interventions of the included studies

First author (year), country	Model or theory	Frequency (duration)	Type	Key components					Provider	Participation of parents	Other characteristics
				Introduction to transition	Medical knowledge	Living with CHD	Self-manage-ment	self-advocacy			
Bushee (2021), USA	–	1 session or more, yearly (NR)	IP	b,c	d,e,f	o	p,q	r	Transition team: ACHD nurses, physicians, and a social worker	Family included	–
Gaydos (2020), USA	GotTransi-tion© guideline	1 session or more, minimum 6 months interval (NR)	IP	a,c	d,e	h,i,m	p,q	s	Transition team: paediatric cardiologist and ACHD NP	Family included	Used an electronic registry to track patients' progress and continuation of care
Goossens (2015), Belgium	–	1 session (15–30 min)	IP	c	d,e,f	g,h,i,j,k	p,q	r	ACHD APN team	Not included	Used a computerised checklist in education
Hergenroe-der (2018), USA	–	NR	IP	a,c	d	o	p,q	r	Two research nurses	Not included	Used an electronic medical record-based transition planning tool to navigate patient's transition
Hwang (2022), South Korea	Self-efficacy theory	4 sessions, 1 session/week (60 min/session)	GP	a,b	d,f	g,h,j,l,m,n	q	r	Nurse	Not included	Performed self-management and 1:1 coaching
Lee (2019), South Korea	Self-efficacy theory	6 sessions, 1 session/week (10–90 min/ session)	GP	b	d,e	h,i,j,l,m	p,q	r	Nurses	Not included	Performed self-management and 1:1 coaching
Lee (2017), South Korea	Resilience (psycho-social factor)	1 session (300 min)	GP	b	d,f	g,h,i,j,k,m	p,q	r	Doctors, nurses, NPs, researchers	Not included	Included a group exercise programme
Mackie (2022), Canada	–	1 session (1 hr)	IP	a	d,e,f	l	p,q	r,s	Two nurses	Not included	Used a MyHealth passport for the creation of a portable health summary
Mackie (2018), Canada	–	2 sessions, 2-month interval (1–1.5 hr/session)	IP	a	d,e,f	i,k	p,q	r,s	Two nurses	Not included	Used a MyHealth passport for the creation of a portable health summary

Table 3. (*Continued*)

Mackie (2014), Canada	–	1 session (1 hr)	IP	a	d,e,f	i,k	p,q	r,s	Cardiology nurses	Not included	Used a MyHealth passport for the creation of a portable health summary

ACHD = congenital heart disease; APN = advanced practice nursing; CHD = congenital heart disease; GP = group programme; IP = individual programme; NP = nurse practitioner; NR = not reported; USA = United States of America.
[a]Description of the transition.
[b]Need for lifelong care.
[c]Need to transfer to adult health care setting.
[d]Anatomical-haemodynamic considerations.
[e]Complications.
[f]Catheter and surgical interventions.
[g]Educational/vocational considerations.
[h]Physical activity.
[i]Pregnancy and birth control.
[j]Diet and weight management.
[k]Smoking/alcohol/drugs.
[l]Anxiety and depression.
[m]Connecting with others who have CHD.
[n]Parent support.
[o]Insurance.
[p]Medical appointments.
[q]Managing medications.
[r]Communication with the healthcare provider.
[s]Use of community resources.

(n = 9). In contrast, lifestyle topics, such as educational/vocational considerations (n = 3), anxiety and depression (n = 3), insurance (n = 2), and parent support (n = 1), were covered in three or fewer transition programmes.

Nurses were the primary providers of the interventions in seven studies,[19,20,22–24,27,28] while in two studies, the intervention was delivered by both nurses and physicians.[21,25] Additionally, one study involved a multidisciplinary team,[26] and in all cases, nurses were part of the intervention delivery. Two studies included parents in the transition programme, considering their opinions when determining the timing of transferring to an adult care environment or providing brochures on transferring health management responsibilities to their children.[25,26]

Three studies used electronic tools to efficiently manage participants during the transition process. Gaydos et al.[25] created an electronic registry to manage the progress of the transition programme and follow-up. Goossens et al.[20] used a computerised checklist during education to differentiate information that had been discussed with participants or that participants were already aware of. Furthermore, Hergenroeder et al.[22] developed an electronic medical record-based transition planning tool to track and assess participants, which served as the basis for providing the transition programme.

Risk of bias assessment

Out of the 10 selected studies, four randomised controlled trials[19,23,27,28] were evaluated using RoB 2.0 (5 domains), while the remaining six studies[20–22,24–26] were assessed using Risk of Bias Assessment tool for Non-randomized Study (6 domains). The Cohen's kappa for quality assessment across a total of 56 domains was 0.75 (95% CI = 0.61–0.85), indicating moderate agreement.[30]

Randomised controlled trials

Mackie et al.[19] employed random allocation, clustering by the week of attendance in the cardiology clinic. However, a detailed description of the allocation sequence was not provided, resulting in a rating of "some concerns." In all four randomised controlled trials,[19,23,27,28] there were no deviations from the intended interventions, and the risk of bias in terms of missing data and outcome measurement was low. Two studies by Mackie et al.[23,28] had follow-up durations ranging from 6 to 18 months, and some mean and standard deviation values were not reported. This raised concerns about potential bias. The overall bias assessment indicated that one study[27] had a low risk of bias, while three studies[19,23,28] were rated as having some concerns regarding the risk of bias (Fig. 2).

Non-randomised controlled trials, Cohort studies, and case-control studies

The cohort studies conducted by Goossens et al.[20] and Hergenroeder et al.[22] did not report baseline differences in outcome variables or utilised a historical control group, resulting in a high risk of bias in the selection of participants. Bias due to confounding variables was low in all six studies[20–22,24–26]. Two studies[21,24] collected all outcomes using self-reported tools, which raised concerns about the risk of bias. Lee and Jung's study[24] did not provide details about blinding of outcome assessors, leading to an unclear risk of bias. The study of Goossens et al.[20] reported detailed results only for some participants who participated in all outcome measurements within the control group, resulting in an unclear risk of bias. The study of Goossens et al.[20] did not report the

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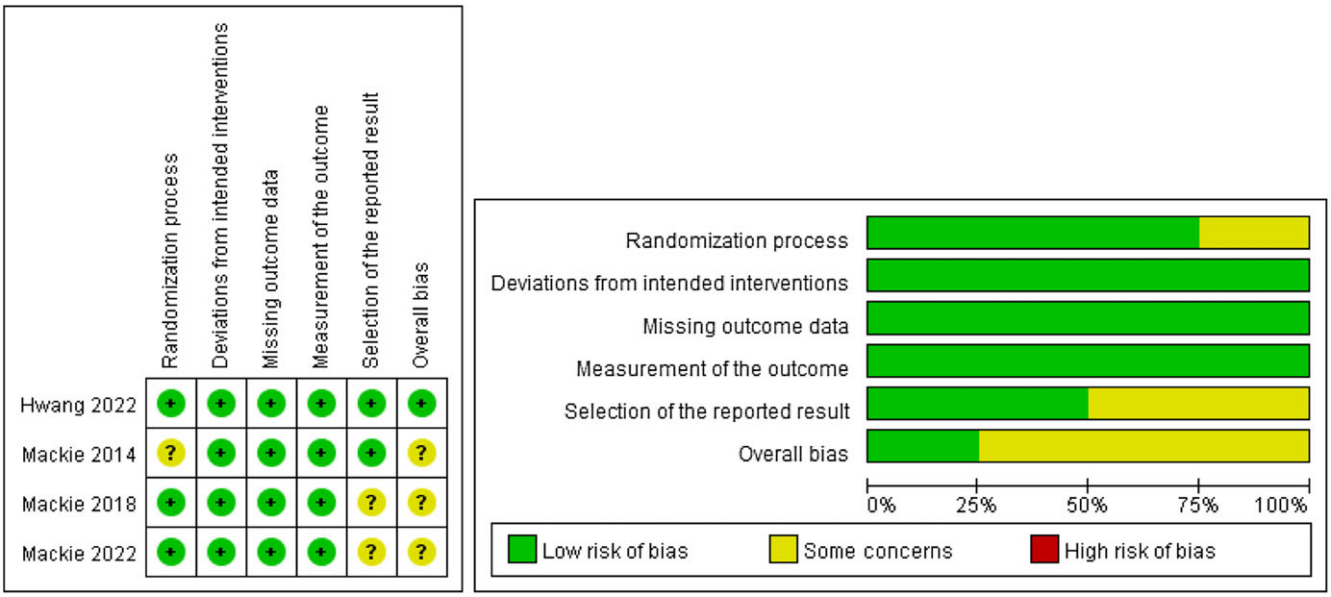

Figure 2. RoB 2.0 for randomised controlled trials. ROB = risk of bias assessment using a revised tool to assess the risk of bias in randomisedtrials.

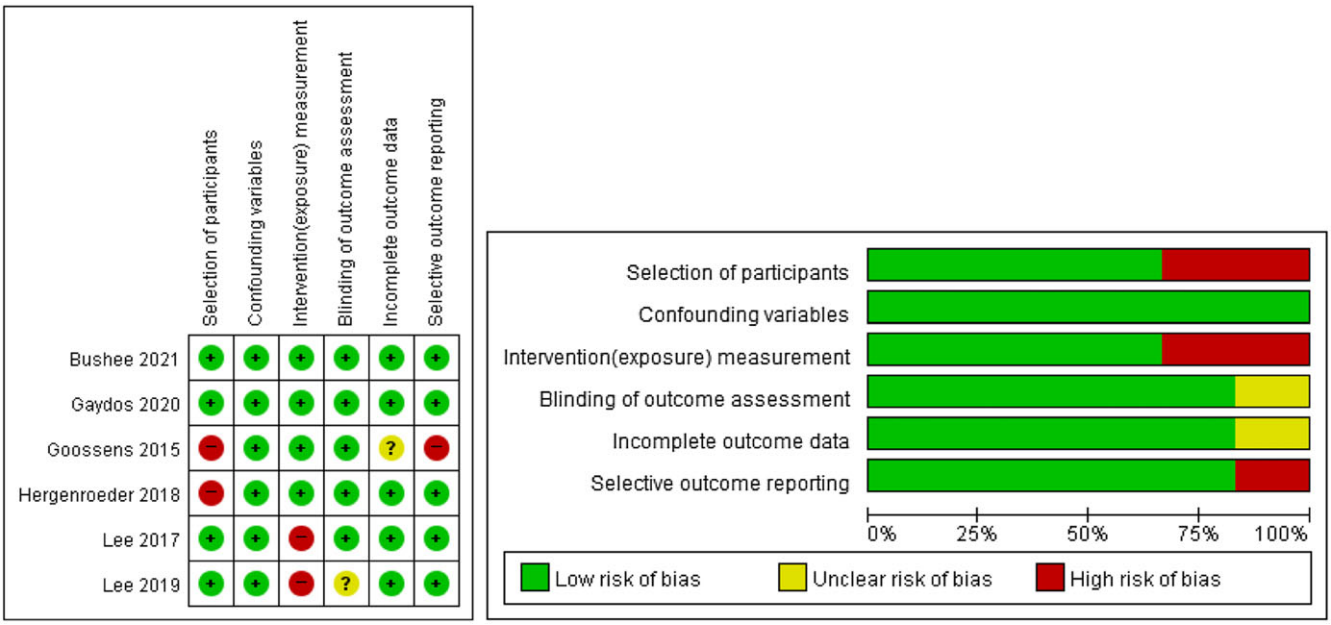

Figure 3. Risk of bias assessment using RoBANS. RoBANS = Risk of Bias Assessment tool for Non-randomized Study.

mean and standard deviation for secondary outcomes, leading to a high risk of bias (Fig. 3).

Results of the meta-analysis

Disease-related knowledge

In the five studies reporting disease-related knowledge, Hedge's g was 0.89 (95% CI = 0.29–1.48), indicating a large effect size that was statistically significant. Heterogeneity testing revealed a Cochran's Q value of 32.7 ($p < .001$, df = 4), indicating heterogeneity in effect sizes across studies, and the degree of heterogeneity was substantial (Higgins $I^2 = 87.8\%$; Fig. 4). Since the timing of outcome measurements varied among the included studies, a subgroup analysis was conducted by dividing studies into those reporting immediate post-intervention results and those reporting results from follow-up assessments (Fig. 5). Disease-related knowledge showed a significant increase in the experimental group compared to the control group when measured immediately after the intervention (Hedge's g = 2.26, 95% CI = 1.57–2.95). Furthermore, in follow-up assessments of 6 months or more, the experimental group exhibited a significant increase in disease-related knowledge compared to the control group (Hedge's g = 0.55, 95% CI = 0.18-0.93), and this difference in effect sizes between the two groups was also significant ($F^2 = 18.07$, df = 1, $p < .001$).

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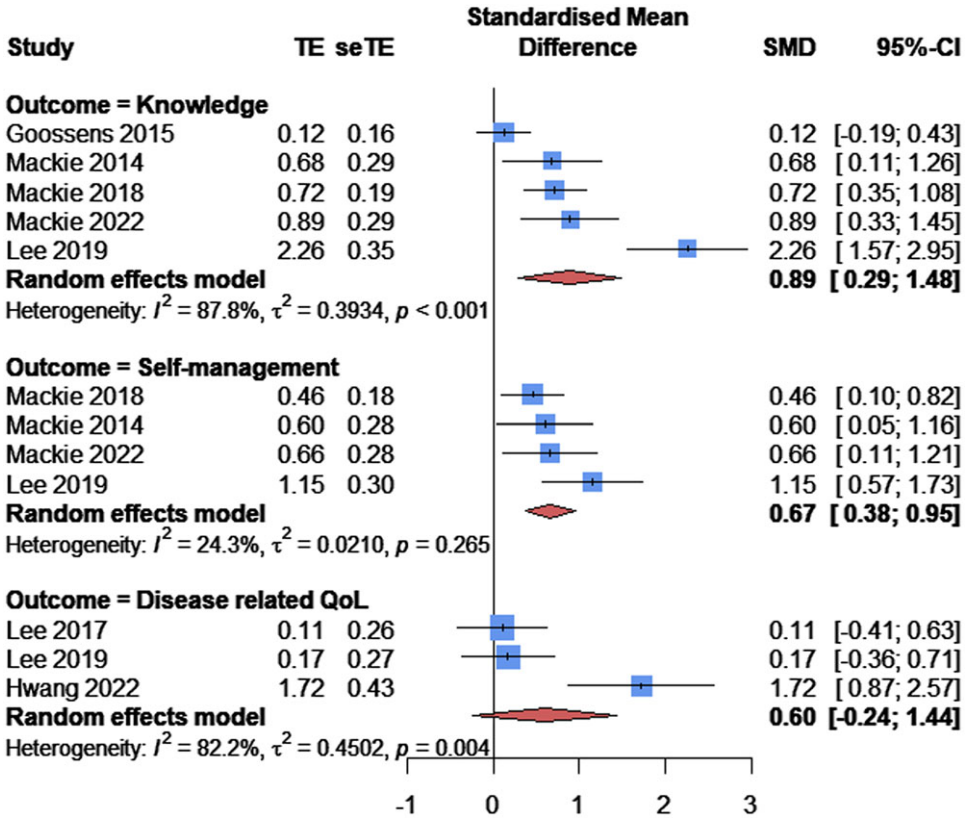

Figure 4. Forest plot of the effects of transition programmes for adolescents and young adults. TE = estimate of treatment effect; seTE = standard error of treatment estimate; SMD = standardised mean difference; CI = confidence interval; QoL = indicates quality of life.

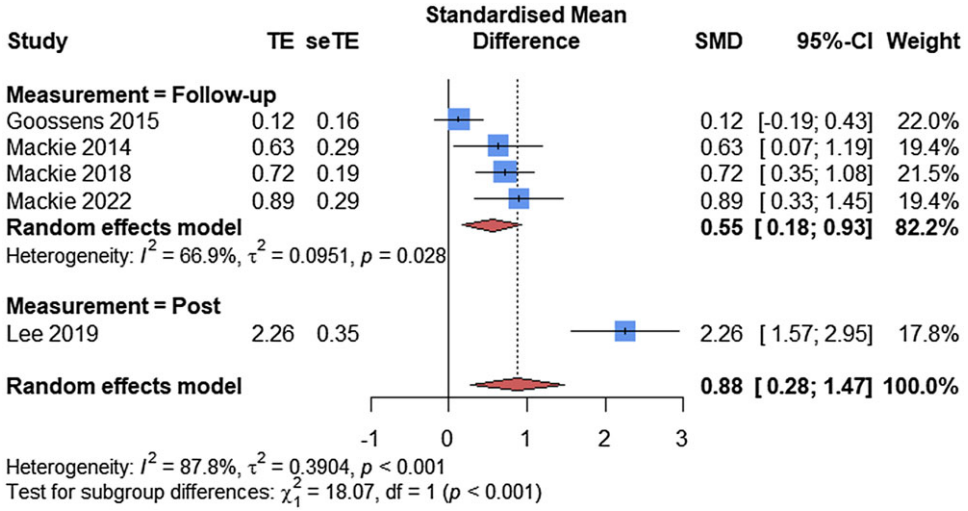

Figure 5. Forest plot of the disease-related knowledge effect of transition programmes for adolescents and young adults according to the timing of measurement. TE = estimate of treatment effect; seTE = standard error of treatment estimate; SMD = standardised mean difference; CI = confidence interval.

Self-management

In the four studies reporting self-management, Hedge's g was 0.67 (95% CI = 0.38–0.95), indicating a moderate effect size that was statistically significant. Heterogeneity testing showed a Cochran's Q value of 3.97 (p = .265, df = 3), suggesting that the effect sizes across studies were not heterogeneous, and the degree of heterogeneity was low (Higgins I^2 = 24.3%; Fig. 4).

Disease-related quality of life

In the three studies reporting disease-related quality of life, Hedge's g was 0.60 (95% CI = −0.24 to 1.44), indicating a moderate effect size that was not statistically significant. Heterogeneity testing showed a Cochran's Q value of 11.22 (p = .004, df = 2), indicating heterogeneity in the effect sizes across studies, and the degree of heterogeneity was substantial (Higgins I^2 = 82.2%; Fig. 4). However, since the number of studies included in the effect size synthesis was less than four, a moderation analysis could not be conducted.[14]

Loss to follow-up

The pooled effect size for loss to follow-up, reported in four studies, showed that the experimental group receiving the transition programme had a 0.41-fold (95% CI = 0.22−0.77) lower rate of loss to follow-up compared to the control group, and this difference

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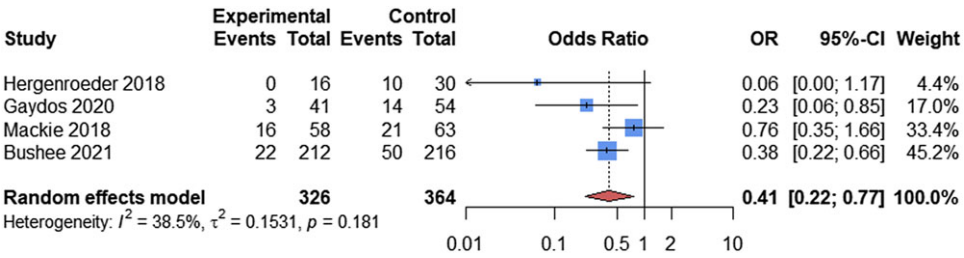

Figure 6. Forest plot of the effect of transition programmes for adolescents and young adults on loss to follow-up. CI = confidence interval; OR = odds ratio.

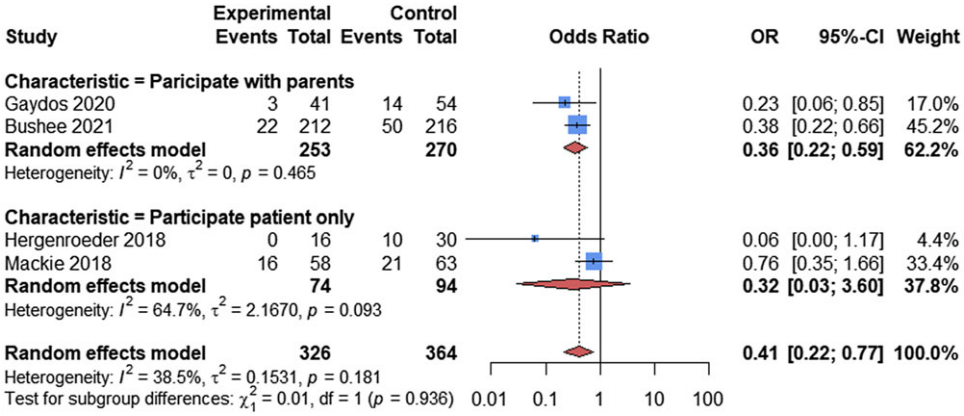

Figure 7. Forest plot of the effect of transition programmes for adolescents and young adults on loss to follow-up according to parents' participation. CI = confidence interval; OR = odds ratio.

was statistically significant. The converted value for this effect size, represented by Hedge's g, was 0.49 (95% CI = 0.15–0.83), indicating a moderate effect size. Heterogeneity testing revealed a Cochran's Q value of 4.88 (p = .181, df = 3), indicating no heterogeneity in effect sizes across studies, and the degree of heterogeneity was moderate (Higgins I^2 = 38.5%; Fig. 6). In line with the recommendation to include parents in transition programmes to facilitate the transfer of self-management responsibilities,[6,31] we analysed differences in the effect of loss to follow-up according to parental involvement. The results showed that when parents participated in the transition programme, the experimental group had a 0.36-fold (95% CI = 0.22–0.59) reduction in the loss to follow-up rate compared to the control group, and this was statistically significant. However, when parents did not participate, the OR for loss to follow-up was not statistically significant, and the difference in effect size between the two groups was also not significant (χ^2 = 0.01, df = 1, p = .936; Fig 7).

Publication bias

Publication bias was assessed using the effect size of the primary outcome for each study. A right-skewed funnel plot was observed, and the Egger test indicated that the regression equation was not statistically significant (t = 2.20, p = .059). The Hedge's g, adjusted using the trim-and-fill method, decreased compared to the unadjusted Hedge's g. However, both effect sizes remained statistically significant. It was concluded that even though publication bias was present, it did not have a significant impact on the results of the studies (Figure S1; Figure S2).

Quality of evidence

The quality of evidence for the outcome variables included in the meta-analysis—namely, disease-related knowledge, loss to follow-up, self-management, and disease-related quality of life—was assessed. Disease-related knowledge and loss to follow-up were evaluated as having low-quality evidence, indicating limited reliability of effect estimates. Self-management and disease-related quality of life were assessed as having very low-quality evidence, suggesting that there is almost no certainty regarding the effect estimates. Detailed results are provided in Table S2.

Discussion

Research characteristics

Transition programmes for CHD patients have been implemented in the USA, Canada, South Korea, and Belgium since 2014. These programmes primarily target adolescents and young adults, with an average age range of 13–25 years. They encompass a broad age spectrum, from adolescents to young adults (n = 6), with the majority focusing on those with moderate to severe complexity CHD (n = 7).

Among the 10 transition programmes reviewed, over nine studies incorporated topics related to the anatomical-haemodynamic considerations of CHD (n = 10), medication management (n = 10), medical appointments (n = 9), and communication with healthcare providers (n = 9). The anatomical-haemodynamic considerations of CHD are part of the medical knowledge component of the transition programme, while medication management and medical appointments fall under the self-management component. Communication with healthcare providers, in contrast, is part of the self-advocacy component.[5] In other words, transition programmes for adolescents and young adults with CHD focus on enhancing their independent self-management and self-advocacy skills, grounded in a thorough understanding of the disease. Experts in the field of transition concur that acquiring skills related to medical knowledge, self-management, and self-advocacy is vital among the various topics

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covered in transition programmes.[31–33] Self-management and self-advocacy skills can bolster a CHD patient's medical independence, decision-making capacity in healthcare, and control over their psychosocial environment.[31] A lack of medical knowledge can hinder patients from developing self-management and self-advocacy skills.[34] Therefore, it is crucial for transition programmes to incorporate education and role supplementation concerning medical knowledge to understand the condition, self-management skills for managing the condition, and self-advocacy skills to enhance decision-making and communication.

Interventions related to educational/vocational considerations (n = 3), anxiety and depression (n = 3), and parent support (n = 1) were relatively underrepresented in transition programmes for lifestyle management. Education for patients with CHD is closely linked to adult employment and income.[5] Adolescents and young adults with CHD often encounter educational delays and face difficulties in making career choices.[31,35] They are less likely to pursue higher education or vocational training compared to their peers without CHD.[36] Therefore, transition programmes for adolescents and young adults with CHD should consider incorporating additional educational and vocational interventions. Moreover, individuals with CHD have a higher lifetime prevalence of anxiety and depression compared to the general population,[37] especially during the adolescent and young adult years when the transition process involves shifting disease management responsibilities from parents to the individual. This shift can intensify psychological distress in these individuals.[35] Parent support is also recognised as a crucial factor in the psychosocial well-being of CHD patients.[38] Therefore, when developing transition programmes, it is important to include psychological interventions that are based on assessments of anxiety and depression. Additionally, considering parental support during the process of empowering patients to manage their own healthcare decisions can prove beneficial.[5,39]

Among the 10 transition programmes analysed, seven were individual programmes, outnumbering the group programmes. This contrasts with the findings of a systematic review of transition programmes for paediatric patients with chronic conditions, where individual and group programmes were reported to be equally represented.[9] This discrepancy may be due to the diverse nature of cardiac diseases within CHD, which vary in severity, characteristics, and management strategies based on individual patients.[40] The studies included in this analysis targeted various CHDs, ranging from simple to severe complexity or moderate to severe complexity. Consequently, a more personalised approach is often favoured. Notably, all three transition programmes reported in South Korea were group programmes. This could be because, in South Korea, adult CHD care is not distinct from paediatric care.[41] Therefore, these programmes tend to focus more on enhancing the general disease management of adult CHD in a community-based group setting rather than individual, hospital-based approaches primarily aimed at transitioning to adult CHD care.

Among the transition programme studies analysed, four were observational studies, while seven demonstrated a risk of bias. The primary sources of bias included the omission of some outcome values when measurements were taken multiple times, the use of historical control groups, the failure to clearly report baseline differences in outcome variables, and self-reporting. Therefore, it is crucial to consider these biases when examining the effects of transition programmes in future research. Additionally, some studies did not provide detailed descriptions of programme aspects such as the exact age of participants, programme frequency, and duration. Consequently, future studies should adhere to reporting guidelines to ensure that transition programmes can be replicated.

Effects of transition interventions

After the transition programmes, the participants showed a substantial increase in disease-related knowledge, with a large effect size. In this context, disease-related knowledge refers to understanding medical aspects related to CHD, including its complications, medical interventions, and disease management strategies.[42,43] Youth with CHD often have limited knowledge about topics such as physical activity, diet, and sexual health related to disease management,[44–46] and they frequently struggle to accurately locate their specific cardiac abnormalities and comprehend the complexities of cardiac defects and complications.[44,46] During the transition programme, it is recommended to employ strategies such as creating portable electronic files like the MyHealth passport to provide information about heart conditions and using diagrams to educate patients about anatomical defects.[5] In the transition programmes included in this study, similar approaches were likely employed. These programmes likely utilised visual materials, such as MyHealth passports and anatomical diagrams, to educate participants about medical knowledge, contributing to the improvement in disease-related knowledge. Notably, the study conducted by Lee and Jung[24], which reported the largest effect size, was based on self-efficacy theory. In addition to written educational materials, they produced successful disease management videos to provide audio-visual materials. Unlike other studies that delivered the intervention 1–2 times, they implemented the programme over 6 weeks and augmented knowledge comprehension by offering weekly phone and email support to address participants' queries.

Disease-related knowledge showed a larger effect size immediately after the intervention than in follow-up assessments conducted after the intervention. According to the Forgetting Curve Theory[47], knowledge tends to be forgotten at a rate of approximately 80% within 1 month. Therefore, it is plausible that the effect size diminished in assessments conducted after a period of 6 months or more. Given that the effectiveness of intervention on disease-related knowledge may wane over time, regular re-evaluations and supplementary education are essential. However, in this meta-analysis, the follow-up periods across the studies varied from 6 to 26 months, highlighting inconsistencies between studies. Further research is required to ascertain the optimal timing for reassessment.

Self-management among participants saw a moderate increase following the transition programme. This concept of self-management includes behavioural aspects such as obtaining prescribed medications when necessary, arranging follow-up appointments, and attending medical consultations.[48] To encourage changes in health behaviour, interventions that not only impart knowledge but also promote self-monitoring, risk communication, and social support have proven effective. As such, interventions should incorporate behaviour change strategies that combine knowledge, awareness, and facilitation.[49] The transition programmes analysed in this study utilised various role supplementation techniques for awareness and facilitation. These included discussions, encouragement, sharing and providing experiences, and offering relevant resources. Of particular note is the study by Lee and Jung,[24] which reported a large effect size. This study provided participants with a self-management diary to encourage

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self-monitoring of medication adherence and symptoms. They also offered one-on-one telephone counselling to promote self-management and mailed necessary resources to participants. Additionally, the programme facilitated discussions among participants, allowing them to share their self-management experiences.

Loss to follow-up decreased after the transition programmes, with a moderate effect size. In a previous meta-analysis by Moons et al.,[1] the effect size for discontinuation of follow-up in CHD patients after transition programmes was not statistically significant. However, in this study, the addition of one more study to the effect size pooling conducted by Moons et al.[1] yielded a significant effect on loss to follow-up. Furthermore, a meta-analysis by García-Rodríguez et al.,[50] which included various chronic disease populations, also found a significant effect size for clinic drop-out. By combining the results of the previous meta-analysis with the findings of this study, it can be deduced that transition programmes may help reduce loss of follow-up. A recent systematic review identified structured transition programmes led by nurses and formal handovers to adult CHD care as strategies to decrease treatment discontinuation in CHD patients.[51] The transition programmes evaluated for loss to follow-up in this study employed structured transition programmes, which included guidelines from Got Transition©, electronic medical record-based transition planning tools, and shared patient information among healthcare providers. These programmes were primarily nurse-led or included nurses as part of the transition team. Notably, the study by Mackie et al.,[23] which reported a significant effect size on the reduction in loss to follow-up, involved paediatric cardiac nurses visiting an adult CHD outpatient clinic with patients and directly transitioning them, thereby reducing the rate of loss to follow-up.

The analysis found no statistically significant differences in loss to follow-up based on parental involvement. However, it's important to note that the number of studies included in this meta-analysis was limited, and the specific roles of parents and the details of their interventions in transition programmes were not thoroughly described. The reason is that when parents become overly involved in the transition process and hinder their child's acquisition of independence, parental involvement can actually diminish the effectiveness of transition programmes. Ideally, parents can play a significant role in the follow-up process during transitions by engaging in discussions with their children about the follow-up before visiting the outpatient clinic, preparing a list of questions for healthcare providers, and encouraging their children to communicate directly with these providers and ask questions.[6] Therefore, a structured transition programme that involves parents from the planning stage of transitions, providing them with relevant information, is necessary. This will enable parents to participate appropriately and play a positive role in the transition process. Subsequently, an analysis can be attempted to evaluate the effectiveness of parental involvement.

The effect of the transition programmes on disease-related quality of life was not statistically significant. The disease-related quality of life in adolescents and adults with CHD is influenced by the complexity of the CHD, clinical symptoms, and complications, with only limited associations with demographic and socio-economic factors.[52–54] Therefore, to enhance disease-related quality of life in individuals with CHD, the focus should be on alleviating clinical symptoms and complications associated with CHD. A prior meta-analysis indicated an improvement in disease-related quality of life when individuals with CHD participated in an exercise programme lasting from 10 weeks to 3 months, which improved cardiac function and reduced the need for medication.[55] In this study, the transition programmes that evaluated disease-related quality of life also incorporated topics aimed at improving cardiac health through lifestyle factors such as physical activity, diet, and weight management. These programmes were intended to motivate participants to actively participate in exercise and make dietary modifications. However, these programmes were relatively brief, lasting only 1 day or 6 weeks. To effectively improve disease-related quality of life, future programmes should include topics related to lifestyle management, focusing on enhancing cardiac function and clinical symptoms, and should be implemented over longer periods, such as 10 weeks or more, to evaluate their effectiveness.

This study marks the first attempt to conduct a meta-analysis of the varied effects of transition programmes for individuals with CHD, by identifying five key components of CHD-targeted transition programmes and analysing appropriate programmes based on these components. By defining transition programmes clearly and conducting an exhaustive literature search with heightened sensitivity, this research sought to strengthen the validity of effect assessment. This was achieved by selecting studies that included control groups and analysing their outcomes to yield meaningful conclusions. Consequently, this study carries significant importance as it provides a current overview of transition programmes for adolescents and young adults with CHD. This serves as an evidence base for researchers and practitioners interested in developing and implementing transition programmes for CHD patients in the future.

Limitations

This study has several limitations: First, the specific topics included within the transition programme components and the structures of the programmes themselves varied, resulting in significant heterogeneity among the studies. Alternatively, most studies had similar characteristics, such as the classification of CHD and providers. Therefore, due to a lack of studies for each outcome, we could not perform subgroup analysis on characteristics with substantial diversity and identical characteristics. As a result, there were limitations in understanding which factors had a positive impact on specific outcomes. Second, there was a dearth of studies reporting actual health-related outcomes, such as emergency room visits, hospitalisations, and disease or complication status, which precluded an analysis of their effects. Third, methodological weaknesses in the included studies (risk of bias), high heterogeneity between studies, and small sample sizes resulted in low or very low levels of certainty in the evidence produced by the meta-analysis. Therefore, these limitations should be taken into account when interpreting the results of the analysis.

Conclusions

This study conducted a systematic review of transition programmes designed to aid adolescents and young adults with CHD in managing their condition as they transition into adulthood. To evaluate the effectiveness of these programmes, a comprehensive search of research literature, clinical trials, and grey literature was undertaken. Ten studies that met the selection criteria were ultimately analysed. The transition programmes for adolescents and young adults with CHD focused on providing education and role supplementation to enhance their medical knowledge to understand the disease, their self-management skills, and their self-

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advocacy skills to improve decision-making and communication. The impact of these transition programmes was evident in the improvement of disease-related knowledge, self-management, and a reduction in loss to follow-up. However, there was no significant effect on improving disease-related quality of life. It is important to acknowledge that the studies included in this review had methodological weaknesses (risk of bias), a high degree of heterogeneity, and limited sample sizes. As a result, the evidence supporting the effect estimates was of low or very low certainty. Therefore, caution should be exercised when interpreting these results, and further replication studies are recommended for the future.

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