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The effectiveness of transition care models in patients with congenital heart disease: a systematic review of the literature and implications for nursing practice

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INTRODUCTION

Over the past few decades, advances in prenatal diagnosis, cardiac surgery, and perioperative management have substantially improved survival among individuals with congenital heart disease (CHD). As a result, CHD has evolved from a predominantly pediatric condition into a lifelong chronic disease requiring specialized follow-up tailored to disease complexity to prevent long-term complications, including arrhythmias, heart failure, and infective endocarditis [1]. The transition from pediatric to adult healthcare services represents a critical stage in the care pathway. Many adolescents transfer to adult care through unstructured processes, increasing the risk of discontinuity of care, loss to follow-up, and adverse clinical outcomes. Transition care is defined as a purposeful, planned, and coordinated process that ensures continuity of care, promotes patient autonomy, and facilitates transfer to specialized adult congenital heart disease (ACHD) services [2]. Although international guidelines strongly recommend structured transition programs, considerable heterogeneity persists regarding the timing of transition, intervention components, and the healthcare professionals involved. Consequently, standardized models and evidence-based recommendations for clinical practice remain limited. Therefore, a comprehensive synthesis of the available evidence is needed. The aim of this systematic review was to evaluate the effectiveness of transition care interventions for adolescents and young adults with CHD, with particular emphasis on clinical, educational, and organizational outcomes.

MATERIALS AND METHODS

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement. The research question was developed using the Population–Intervention–Outcome (PIO) framework.

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The target population comprised adolescents and young adults with CHD undergoing transition from pediatric to adult healthcare services. Eligible interventions included structured transition care programs and organizational models designed to facilitate this process. Outcomes of interest included follow-up adherence, continuity of care, self-management skills, disease-related knowledge, and patient satisfaction. Primary quantitative, qualitative, and mixed-methods studies evaluating structured transition care interventions in adolescents and young adults with CHD were eligible for inclusion. No restrictions were applied regarding publication year or geographical setting. Articles published in English or Italian were included, whereas secondary studies and studies not addressing the predefined population, interventions, or outcomes were excluded. Electronic searches were performed in MEDLINE, CINAHL, and Scopus. Additional manual searches of reference lists (snowballing) and grey literature searches through Google Scholar and institutional websites were conducted. Although no additional eligible studies were identified through grey literature, these sources were used to contextualize the findings. The final search was performed on December 18, 2025. Search terms were identified through a preliminary literature review and combined using Boolean operators (AND/OR). Outcome-related terms were intentionally omitted from the search strategy to maximize sensitivity. Complete search strategies for each database are provided in Appendix A. All retrieved records were imported into Rayyan software for duplicate removal and study selection. Screening was performed by a single reviewer in two sequential stages: title and abstract screening followed by full-text assessment. Data extraction was carried out using a standardized extraction form that included bibliographic information, study design, participant characteristics, intervention details, and outcomes. Methodological quality was assessed using the appropriate Joanna Briggs Institute (JBI) Critical Appraisal Checklists according to study design. Risk of bias was classified as low, moderate, or high. Because of substantial methodological and clinical heterogeneity among the included studies, findings were synthesized narratively.

RESULTS

The literature search identified records from MEDLINE, CINAHL, and Scopus that were screened according to the predefined eligibility criteria. Following title, abstract, and full-text assessment, 15 studies were included in the systematic review. The study selection process is presented in the PRISMA 2020 flow diagram (Figure 1). Characteristics of the included studies are summarized in Table 1. Study designs included randomized controlled trials, quasi-experimental pre–post studies, observational studies, and mixed-methods studies. Transition care interventions varied considerably in content, duration, delivery modality, and healthcare professionals involved, and were categorized as educational interventions, self-management interventions, multifaceted programs, and case management models. Overall, methodological quality was moderate across all included studies (Table 2). Structured transition care interventions, particularly those incorporating educational components or delivered by nurses, consistently improved disease-related knowledge among adolescents and young adults with CHD. However, these benefits appeared less pronounced in individuals with cognitive impairment. Several studies also demonstrated improvements in self-management skills, transition readiness, self-efficacy, and patient empowerment, with the greatest benefits observed in nurse-led interventions. Transition care interventions were associated with improved continuity of care, lower rates of loss to follow-up, and more timely transfer to specialized ACHD services. Although some studies reported improvements in selected domains of health-

related quality of life, health behaviors, and psychosocial outcomes, these findings were inconsistent and generally limited.

DISCUSSION

The findings of this review indicate that structured transition care interventions improve several proximal outcomes among adolescents and young adults with CHD, supporting the concept that transition is a gradual process requiring individualized, multidisciplinary care. One of the most consistent findings is the pivotal role of nurses. Nurse-led interventions, whether brief or multicomponent, were feasible, well accepted, and associated with significant improvements in patients' ability to manage their condition independently [3-6]. However, most studies had relatively short follow-up periods, and the widespread use of patient-reported outcome measures limits conclusions regarding objectively measured behavioral and clinical outcomes. Alongside conventional transition programs, emerging approaches such as web-based interventions, mobile health applications, and virtual peer support demonstrated good feasibility and acceptability. Nevertheless, evidence supporting these approaches remains preliminary and is largely derived from small studies [7-9]. Continuity of care emerged as the outcome with the strongest and most consistent evidence. Successful transition appears to depend on multiple factors, including patient age, disease complexity, cognitive impairment, and effective coordination between pediatric and adult healthcare services, emphasizing the importance of integrated multidisciplinary models. The findings are consistent with current international recommendations advocating structured, patient-centered, multidisciplinary transition programs. Both the European Society of Cardiology guidelines and the International Society for Adult Congenital Heart Disease (ISACHD) recognize the ACHD nurse coordinator as a key professional responsible for promoting continuity of care, patient education, self-management, and self-advocacy [10]. Within the Italian healthcare setting, experiences such as the Transition Clinic at IRCCS Policlinico San Donato and the multicenter TELEMACO project further demonstrate the feasibility of structured transition pathways while highlighting the need for stronger long-term evidence [11]. The available evidence also highlights the need to clearly define the competencies, responsibilities, and scope of practice of nurses dedicated to transition care through specific educational pathways and organizational models that fully recognize their contribution. Furthermore, organizational factors—including standardized referral protocols, shared transition pathways, joint pediatric–adult clinics, and dedicated healthcare resources—appear essential for successful implementation of transition programs. Overall, the evidence supports the development of standardized, multidisciplinary, and adaptable transition care models that strengthen the nursing role, integrate innovative approaches, and foster sustained collaboration between pediatric and adult healthcare services to improve continuity of care and optimize long-term outcomes.

CONCLUSIONS

Structured transition care interventions for adolescents and young adults with CHD improve disease-related knowledge, self-management skills, transition readiness, and continuity of care while reducing the risk of loss to follow-up. Although the available evidence is limited by methodological heterogeneity, these findings provide important implications for clinical practice and healthcare organization. Integrating innovative approaches, strengthening specialized nursing competencies, and implementing standardized transition pathways represent promising strategies to enhance the quality of

transition care. Future multicenter studies with larger sample sizes, standardized outcome measures, and longer follow-up are required to determine the long-term impact of transition care interventions on clinical outcomes and continuity of care. Overall, this review underscores the importance of well-designed, multidisciplinary transition programs supported by adequate organizational resources to ensure effective lifelong care and improve long-term outcomes for individuals with CHD.

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Appendix A – Database search strategies

The search strings are reported verbatim to ensure transparency and reproducibility.

Search string used in MEDLINE

("Adolescent"[MeSH terms] OR adolescen*[tiab] OR "Adult"[MeSH terms] OR adult*[tiab] OR "Young Adult"[MeSH terms] OR "young adult*"[tiab])

AND

("Congenital Heart Disease"[MeSH terms] OR "Heart Defects, Congenital"[MeSH terms] OR "congenital heart disease"[tiab] OR "congenital heart defect*"[tiab] OR "adult congenital heart disease*"[tiab])

AND

("transition to adult care"[tiab] OR "transition to adulthood"[tiab] OR "transfer of care"[tiab] OR "transfer to adult care"[tiab] OR "transition program"[tiab] OR "transition care"[tiab] OR "continuity of care"[tiab] OR "health care transition"[tiab] OR "Continuity of Patient Care"[MeSH terms])

Search string used in CINAHL

(MH "Adolescence" OR MH "Adult" OR MH "Young Adult" OR XB (adolescen* OR adult* OR "young adult*"))

AND

(MH "Heart Defects, Congenital" OR XB ("congenital heart disease" OR "congenital heart defect*" OR "adult congenital heart disease"))

AND

(MH "Transitional Care" OR MH "Continuity of Patient Care" OR XB ("transition to adult care" OR "transition to adulthood" OR "transfer of care" OR "transfer to adult care" OR "transition program" OR "transition care" OR "health care transition" OR "continuity of care"))

Search string used in Scopus

(TITLE-ABS-KEY(adolescen* OR adult* OR "young adult*"))

AND

(TITLE-ABS-KEY("congenital heart disease" OR "congenital heart defect*" OR "adult congenital heart disease"))

AND

(TITLE-ABS-KEY("transition to adult care" OR "transition to adulthood" OR "transfer of care" OR "transfer to adult care" OR "transition care" OR "health care transition" OR "continuity of care"))

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Figure 1. PRISMA Flow-chart.

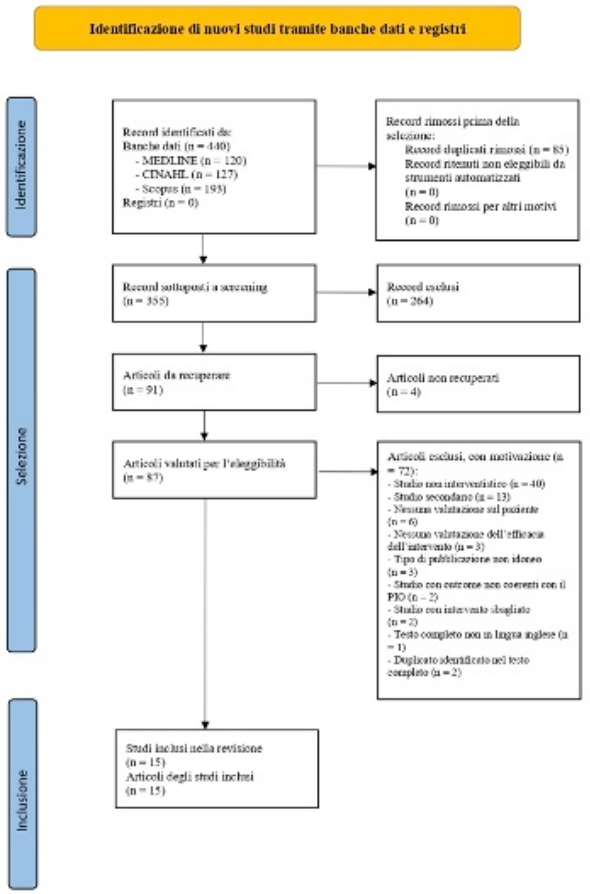

Table 1. Literature review summary table

Studio	Paese	Disegno dello studio	Campione (n)	Tipo di intervento	Età	CHD	Follow-up
Mackie et al., 2018	Canada	RCT multicentrico	121	Programma educativo guidato da infermieri	16-17 anni	Moderata o severa	Fino a 18 e 24 mesi
Mackie et al., 2022	Canada	RCT multicentrico	60	Programma educativo guidato da infermieri	13-14 anni	Moderata o severa	Fino a 6 mesi
Bratt et al., 2023	Svezia	RCT multicentrico longitudinale	139	Programma strutturato, multifattoriale e centrato sulla persona	16-18,5 anni	Semplice, moderata o severa	Fino a 30 mesi
Mackie et al., 2014	Canada	Quasi-sperimentale	58	Programma educativo guidato da infermieri	15-17 anni	Moderata o severa, cardiomiopatia	Fino a 6 mesi
Bredy et al., 2024	Francia	RCT multicentrico	200	Programma strutturato e multifattoriale	13-17 e 18-25 anni	Diversi livelli di complessità	Fino a 12 mesi
Hwang et al., 2025	Corea del Sud	RCT	29	Programma online centrato sull'autogestione	12-19 anni	Severa	Non specificato
Charles et al., 2021	Canada	Metodi misti	57	Programma educativo guidato da infermieri	16-17 anni	Moderata o severa	Non specificato
Killackey et al., 2025	Canada	Metodi misti	76	Programma virtuale di supporto tra pari centrato sull'autogestione	13-18 anni	Prevalentemente severa	Fino a 6 mesi
Burger et al., 2024	Stati Uniti d'America	Osservazionale di coorte retrospettiva	65	Programma di case management basato sull'ordine di invio	Pari o superiore a 17 anni	Moderata e severa	Fino a 24 mesi (retrospettivo)
de Hosson et al., 2024	Paesi Bassi	Quasi-sperimentale longitudinale pre-post	124	Programma multifattoriale guidato da infermieri	Pari o superiore a 12 anni	Moderata o severa	Da 24 a 36 mesi
Han et al., 2023	Canada	RCT	68	Programma digitale guidato da infermieri, centrato sull'autogestione	16-18 anni	Semplice, moderata o severa	Fino a 6 mesi
Ricci et al., 2023	Regno Unito	Osservazionale di coorte retrospettiva longitudinale	592	Programma educativo guidato da infermieri, basato su una clinica di transizione	12-21 anni	Semplice, moderata e severa	Fino a 3 mesi
Guydos et al., 2020	Stati Uniti d'America	Osservazionale retrospettivo caso-controllo	107	Programma multifattoriale basato su una clinica di transizione	Pari o superiore a 11 anni	Complessità variabile	Fino a 26 mesi (retrospettivo)
Flocco et al., 2019	Italia	Quasi-sperimentale longitudinale pre-post	224	Programma multifattoriale basato su una clinica di transizione	11-18 anni	Semplice, moderata e severa	Fino a 12 mesi
Ladouceur et al., 2017	Francia	Osservazionale trasversale	115	Programma educativo strutturato	14-19 anni	Prevalentemente severa, ma anche semplice e moderata	Non previsto (studio trasversale)

Abbreviazioni: RCT = randomized controlled trial; CHD = congenital heart disease.

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Studio	Disegno dello studio	Strumento JBI (checklist)	Principali limiti	Rischio di bias
Mackie et al., 2018	RCT multicentrico	Checklist JBI per RCT	Assenza di mascheramento; strumenti parzialmente validati; perdita al follow-up	Moderato
Mackie et al., 2022	RCT multicentrico	Checklist JBI per RCT	Assenza di mascheramento; "intention-to-treat" incompleta; perdita al follow-up	Moderato
Bratt et al., 2023	RCT multicentrico longitudinale	Checklist JBI per RCT	Assenza di mascheramento; outcome autoriportati	Moderato
Mackie et al., 2014	Quasi-sperimentale	Checklist JBI per studi quasi-sperimentali	Assenza di randomizzazione; assenza di mascheramento	Moderato
Berdy et al., 2024	RCT multicentrico	Checklist JBI per RCT	Eterogeneità del campione; assenza di mascheramento; dati autoriportati incompleti	Moderato
Hwang et al., 2025	RCT	Checklist JBI per RCT	Parziale mascheramento; campione ridotto	Moderato
Charles et al., 2021	Metodi misti	Checklist JBI per studi qualitativi	Prospettiva filosofica non dichiarata; ruolo e influenza dei ricercatori non discussi; voci indirette dei partecipanti	Moderato
Killackey et al., 2025	Metodi misti	Checklist JBI per studi quasi-sperimentali	Assenza di gruppo di controllo; campione ridotto	Moderato
Burger et al., 2024	Osservazionale di coorte retrospettiva	Checklist JBI per studi di coorte	Follow-up incompleto; studio retrospettivo monocentrico; campione ridotto	Moderato
de Hosson et al., 2024	Quasi-sperimentale longitudinale pre-post	Checklist JBI per studi quasi-sperimentali	Assenza di randomizzazione; dati basali mancanti; campione ridotto; studio monocentrico	Moderato
Han et al., 2023	RCT	Checklist JBI per RCT	Assenza di mascheramento; follow-up incompleto e di breve durata; campione ridotto; studio monocentrico	Moderato
Ricci et al., 2023	Osservazionale di coorte retrospettiva longitudinale	Checklist JBI per studi di coorte	Strumenti parzialmente validati; perdita al follow-up	Moderato
Gaydos et al., 2020	Osservazionale retrospettivo caso-controllo	Checklist JBI per studi caso-controllo	Selezione non omogenea dei gruppi; follow-up breve; studio monocentrico; campione ridotto	Moderato
Flocco et al., 2019	Quasi-sperimentale longitudinale pre-post	Checklist JBI per studi quasi-sperimentali	Assenza di randomizzazione; assenza di gruppo di controllo; studio monocentrico; dati clinici limitati	Moderato
Ladouceur et al., 2017	Osservazionale trasversale	Checklist JBI per studi trasversali analitici	Campionamento consecutivo dei partecipanti; campione ridotto; studio monocentrico; disegno trasversale; mancato controllo dei confondenti	Moderato

Abbreviazioni: RCT = randomized controlled trial; JBI = Joanna Briggs Institute.

Table 2. Results of the risk of bias assessment using the JBI checklists.