International Journal of Cardiology 310 (2020) 51–57

Contents lists available at ScienceDirect

International Journal of Cardiology

journal homepage: www.elsevier.com/locate/ijcard

Outpatient volumes and medical staffing resources as predictors for continuity of follow-up care during transfer of adolescents with congenital heart disease

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ARTICLE INFO

Article history:
Received 28 May 2019
Received in revised form 6 September 2019
Accepted 8 January 2020
Available online 17 January 2020

Keywords:
Adolescent
Continuity of patient care
Heart defects, congenital
Patient transfer
Young adult
Transition to adult care

ABSTRACT

Background: Providing continuous follow-up care to patients with congenital heart disease (CHD) remains a challenge in many settings. Previous studies highlight that patients with CHD experience discontinuation of follow-up care, but mainly describe a single-centre perspective, neglecting inter-institutional variations. Hospital-related factors above and beyond patient-related factors are believed to affect continuity of care. The present multicentre study therefore investigated (i) proportion of "no follow-up care"; (ii) transfer destinations after leaving paediatric cardiology; (iii) variation in proportions of no follow-up between centres; (iv) the association between no follow-up and outpatient volumes, and (v) its relationship with staffing resources at outpatient clinics.

Methods: An observational, multicentre study was conducted in seven university hospitals. In total, 654 adolescents with CHD, born between 1991 and 1993, with paediatric outpatient visit at age 14-18 years were included. Transfer status was determined 5 years after the intended transfer to adult care (23y), based on medical files, self-reports and registries.

Results: Overall, 89.7% of patients were receiving adult follow-up care after transfer; 6.6% had no follow-up; and 3.7% were untraceable. Among patients in follow-up care, only one remained in paediatric care and the majority received specialist adult CHD care. Significant variability in proportions of no follow-up were identified across

Abbreviations: CHD, congenital heart disease; ACHD, adult congenital heart disease; CI, confidence interval; OR, odds ratio; F, Fischer's exact test; χ^2, Chi-square test; ADOLE7C, ADOLEsCents reCeiving Continuous Care for Childhood onset Chronic Conditions; CONCOR, CONgenital COR Vitia; SWEDCON, Swedish Registry of Congenital Heart Disease.

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https://doi.org/10.1016/j.ijcard.2020.01.016
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centres. Higher outpatient volumes at paediatric outpatient clinics were associated with better continued follow-up care after transfer (OR = 1.061; 95% CI = 1.001 – 1.124). Medical staffing resources were not found predictive. *Conclusion:* Our findings support the theory of hospital-related factors influencing continuity of care, above and beyond patient-related characteristics.
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1. Introduction

Advances in paediatric cardiology and congenital cardiac surgery have resulted in increased survival rates for patients born with congenital heart disease (CHD). To date, >90% of patients with CHD survive to adulthood [1,2]. However, the risk of developing complications is still substantial, even after initial surgery and despite long symptom-free intervals, therefore, the majority of these patients require life-long follow-up care [3]. International guidelines describe the characteristics of recommended follow-up care for patients with CHD, both in terms of recommended level of care and time intervals for follow-up visits [3–6].

Delivery of continuous follow-up care to adult CHD patients is however still a challenge in many healthcare settings [3]. Both absence and disruption of follow-up care are frequently reported in published literature, but also follow-up care provided at non-recommended care levels [7–19]. These issues could be referred to as "discontinuation of follow-up care" and have been shown to be associated with adverse outcomes [9,14,20,21]. There is a wide range of proportions of patients with discontinuation of follow-up care ranging from 7% to 76% [7–19]. Reasons for this fluctuation in proportions are not fully clarified. The phase of transfer from paediatric to adult care seems to be particularly vulnerable for discontinuation of follow-up care.

The majority of previous studies investigating discontinuation of follow-up care have been conducted in North America, leaving other healthcare systems less addressed. In addition, a majority of these studies were single centre studies which do not account for possible inter-institutional variations [7–19,22]. Furthermore, only patient-related factors in relation to discontinuation of follow-up care have been studied. Indeed, a systematic review of risk factors and protective factors for care gaps found that all factors investigated so far were related to patient characteristics [23]. However, it is assumed that hospital-related factors can also predict discontinuation of care. It could be hypothesized that dedicated CHD centres with high outpatient volumes and abundant staffing resources are better equipped to reduce the proportion of patients experiencing discontinuation of care.

Considering characteristics of previous studies, we conducted a multicentre study involving all seven university hospitals in Sweden. The aims of the study were (i) to investigate the proportion of CHD patients with no follow-up after leaving paediatric cardiology; (ii) to determine transfer destinations of patients who continued follow-up care; (iii) to identify possible variation across centres in proportions of patients with no follow-up; (iv) to investigate if there is an association between outpatient volumes at centre level and proportion of no follow-up; and (v) to study if medical staffing resources in paediatric and adult cardiology outpatient clinics are related to proportion of no follow-up.

2. Method

2.1. Setting and study population

As part of the ADOLE7C-project (ADOLEsCents reCeiving Continuous Care for Childhood onset Chronic Conditions), a descriptive, observational, multicentre study was conducted in all seven university hospitals in Sweden: Gothenburg, Linköping, Lund, Örebro, Stockholm, Umeå, and Uppsala. These seven university hospitals have paediatric cardiology and adult CHD programs available. They provide specialist care for a majority of patients with CHD in Sweden [24]. Paediatric cardiac surgery is centralized in Gothenburg and Lund [25]. Formal transition programs for transferring patients to adult care were lacking in all centres. However, it was standard practice at all centres to transfer patients at the age of 18 years, as well as providing a formal transfer letter. In all centres, patients were actively invited for their outpatient appointment, and in case of missed appointments, all centres offered the patients a new appointment.

The study population comprised adolescents born 1991–1993, diagnosed with CHD, defined as "*structural abnormalities of the heart and/or intrathoracic great vessels that are actually or potentially of functional significance*" [26]. To be eligible for inclusion, adolescents should have at least one registered outpatient visit in paediatric cardiology within the five year period before intended transfer to adult congenital heart disease (ACHD) care, meaning January 1st 2005–December 31st 2011, depending on year of birth. Adolescents were excluded if they underwent a heart transplantation, died or moved abroad prior to inclusion or during the inclusion period. We also excluded patients with genetic disorders, in which there was no documented cardiac involvement. Patients who had written documentation in the medical file by a cardiologist dismissing the patient from further follow-up were not included.

2.2. Procedure

At the end of 2016, included patients were 23 years of age or older, and could therefore be expected to receive care within an adult-focused facility. An observation window of 5 years after intended transfer was selected based on international guidelines that stipulate that patients with mild conditions require follow-up once every 3–5 years [3–6]. Data collection officers (DCOs) at each of the seven specialist ACHD clinics were provided a list of eligible patients in order to determine if patients had continued or ceased follow-up care after intended transfer. DCOs searched patient administrative system and medical files for requested variables: year of birth; sex; current follow-up status within ACHD care (including the date of the first visit in ACHD care); primary and secondary CHD diagnosis; CHD complexity; cardiac surgery and/or previous catheter interventions.

Patients who had no documented ACHD visit were contacted by postal mail (n = 58), of which 19 (33%) responded. For patients who did not reply, the Swedish Registry of Congenital Heart Disease (SWEDCON) [24] was searched for documented visits to adult care facilities.

To appraise outpatient volume and medical staffing resources of participating centres, a questionnaire was completed by a member of staff with good understanding of the organization of the clinic during the requested period. The questionnaire addressed the average number of outpatient visits per year during 2008–2012, number of full time equivalents (FTE) of cardiologists and fellows available for outpatient consultations during 2008–2012, and other hospital characteristics and processes of care.

The Regional Ethics Review Board in Gothenburg approved the study protocol (number: 632–15). The study was performed in accordance with the 2013 Helsinki declaration [27].

2.3. Definitions

Patients were categorized according to their primary CHD using a modified version [28] of the CONCOR (CONgenital COR Vitia) hierarchy

[29]. Furthermore, patients were categorized according to the anatomical complexity of their heart disease, being of either mild, moderate or severe complexity, as described by Task Force 1 of the 32nd Bethesda Conference [4].

The follow-up status was categorized as: in follow-up care, not in follow-up care, or untraceable. In follow-up care was defined as the patient having at least one documented or self-reported cardiac follow-up visit within the five-year period after intended transfer. Not in follow-up care was defined as no documented or self-reported follow-up care visit within the five-year period after intended transfer. When there was no information on follow-up status in the medical file and no self-report was provided by the patient, the patient was considered untraceable. It can be assumed that the likelihood for no follow-up is high in untraceable patients, although this cannot be firmly confirmed.

Transfer destinations and level of care were defined according to the three levels described by Deanfield and co-workers as specialist care, shared care and non-specialist care [5]. Specialist care is follow-up provided by an ACHD specialist cardiologist at a tertiary care centre. Shared care is follow-up provided by a general cardiologist in collaboration with an ACHD specialist cardiologist. Non-specialist care is follow-up provided by a general cardiologist or general practitioner. In the present study, specialist care was further divided into paediatric cardiology care and specialist ACHD care.

Medical staff were defined as cardiologists and fellows available for outpatient consultations in the outpatient units for CHD.

2.4. Statistical analysis

Descriptive statistics are presented as absolute numbers and percentages. For identification of differences in proportions between the centres we used Fisher's exact test. For comparing patient characteristics between centres, we used Chi-square test. Multivariate logistic regression models were applied to investigate if the medical staffing resources or outpatient volumes were associated with continued follow-up care. The analysis was adjusted for known patient-related risk factors for discontinuity of care: sex, complexity of CHD and previous interventions [8,9,13,17]. Outpatient volumes are expressed as average number of visits to the outpatient clinic per year. In paediatric care, outpatient volumes include consultant referrals and screenings, as well as CHD patients. In adult care, outpatient volumes reflected only CHD patients. Regarding outpatient volumes, one scale-step in the regression model corresponded to 500 paediatric outpatient visits and to 50 adult outpatient visits. To make an accurate comparison of available medical staffing resources across centres, a ratio was calculated representing full-time equivalent medical staff per 1000 outpatient visits. The assumptions of the regression models were not violated, including variance of influence (VIF) for independent variables. All tests performed were two-sided and a p-value <0.05 was considered as statistically significant. Data were analysed using IBM SPSS Statistics for Windows, version 24 (IBM Inc., Armonk, NY, USA).

3. Results

In total, 688 patients were identified, of whom 34 patients were excluded. Reasons for exclusion included: heart transplant (n = 1; 0.1%); genetic disorders with no documented cardiac involvement (n = 1; 0.1%); patient moved abroad (n = 2; 0.3%); no CHD (n = 17; 2.5%) and dismissed from follow-up care (n = 13; 1.9%).

3.1. Sample characteristics

In total, 654 patients were considered eligible, 70% of which were included from, Gothenburg, Lund and Stockholm. The sample consisted of 59.9% men. The proportions of mild, moderate and severe complexity lesions were 36.9%, 48.9%, and 14.2%, respectively. Demographic and clinical characteristics are given in Table 1. Significant differences in patient characteristics were identified across centres regarding complexity of heart disease, ($\chi^2 = 21.971$; $p < 0.038$) and previous interventions, ($\chi^2 = 23.007$; $p < 0.001$) (Table 1).

3.2. Proportions of patients in follow-up care

Overall, 587 of 654 patients (89.7%) had continued follow-up care five years after intended transfer. In contrast, 43 patients (6.6%) were not in follow-up care and 24 patients (3.7%) were untraceable (Fig. 1). The characteristics of patients not in follow-up care (6.6%) can be found in Table 2.

3.3. Transfer destinations

Of the 587 patients in follow-up, 549 patients (83.9%) were followed up at specialist care level (Fig. 1). Of these, 548 patients received ACHD care, and one patient (0.2%) was still seen at paediatric cardiology. Twenty-one patients (3.2%) received shared care, and 12 patients (1.8%) received follow-up care in a non-specialist setting. For 5 patients (0.8%), the level of care was unclear (Fig. 1).

3.4. Differences in proportions of patient not in follow-up care across centres

Although the overall proportion of patients not in follow-up care was 6.6%, we observed a large variability across centres ($F = 14.880$; $p < 0.014$) ranging from 0% to 12.7%, with one centre at 0%, a cluster of three centres around 5% and three centres around 11% (Fig. 2, Panel A).

3.5. The relationship between continued follow-up care and outpatient volumes

At paediatric cardiology, outpatient volumes ranged from 400 to 8400 (Fig. 2, Panel B). At the ACHD clinics, a range from 120 to 1100 outpatient visits per year was observed (Fig. 2, Panel C).

A multivariable logistic regression model, adjusting for patient-related factors (i.e. sex, prior interventions, and complexity of heart disease), showed that paediatric outpatient volumes were significantly predictive for continued follow-up care after transfer (OR = 1.061; 95%CI = 1.001–1.124). The higher outpatient volumes, the higher the odds of continued follow-up care. One scale step in the regression model corresponded to 500 outpatient visits, meaning that an additional 500 visits to the paediatric outpatient clinic would increase odds of continued follow-up by 6.1%. Outpatient volumes in the adult setting were not found to be predictive for continued follow-up care. Neither sex, prior interventions, nor complexity of heart disease was found predictive in the regression models.

Given the higher likelihood of untraceable patients having no follow-up, we built a second logistic regression model, in which no follow-up and being untraceable was used as outcome. Adjusted for patient characteristics, no follow-up or being untraceable was predicted by paediatric outpatient volumes (OR = 1.072; 95%CI = 1.021–1.125) and adult outpatient volumes (OR = 1.036; 95%CI = 1.000–1.073). An additional 500 visits to the paediatric outpatient clinic would increase odds of continued follow-up by 7.2% and an additional 50 visits to the adult outpatient clinic would increase odds of continued follow-up by 3.6%.

3.6. The relationship between medical staffing resources and follow-up care

In paediatric and ACHD clinics, medical staffing resources ranged from 0.8–3.0 FTE and 0.25–2.75 FTE. When linking staffing resources to outpatient volumes, the staffing ratio at paediatric and adult cardiology ranged from 0.4–2.3 FTE medical staff per 1000 visits, and 2.1–6.1 FTE medical staff per 1000 visits, respectively. When adjusted for patient factors, the multivariable logistic regression model showed no

Table 1
Clinical characteristics of 654 patients with CHD.

	Complete sample	Centre 1	Centre 2	Centre 3	Centre 4	Centre 5	Centre 6	Centre 7	Chi-square
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Total cohort, n	654	200 (30.6)	142 (21.7)	120 (18.3)	59 (9.0)	55 (8.4)	39 (6.0)	39 (6.0)	
Year of birth									
Year 1991	206 (31.5)	64 (32.0)	44 (31.0)	39 (32.5)	20 (33.9)	17 (30.9)	12 (30.8)	10 (25.6)	
Year 1992	226 (34.6)	69 (34.5)	51 (35.9)	33 (27.5)	22 (37.3)	21 (38.2)	14 (35.9)	16 (41.0)	
Year 1993	222 (33.9)	67 (33.5)	47 (33.1)	48 (40.0)	17 (28.8)	17 (30.9)	13 (33.3)	13 (33.3)	
Sex									p <0.852
Male	392 (59.9)	115 (57.5)	92 (64.8)	71 (59.2)	35 (59.3)	35 (63.6)	22 (56.4)	22 (56.4)	
Female	262 (40.1)	85 (42.5)	50 (35.2)	49 (40.8)	24 (40.7)	20 (34.4)	17 (43.6)	14 (43.6)	
Primary CHD diagnosis									
Hypoplastic left heart syndrome	2 (0.3)	0 (0.0)	1 (0.7)	1 (0.8)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Univentricular physiology*	11 (1.7)	3 (1.5)	3 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	3 (7.7)	2 (5.1)	
Tricuspid atresia	8 (1.2)	1 (0.5)	0 (0.0)	3 (2.5)	1 (1.7)	2 (3.6)	0 (0.0)	1 (2.6)	
Tetralogy of Fallot	58 (8,8)	14 (7.0)	12 (8.5)	16 (13.3)	0 (0.0)	6 (10.9)	7 (17.9)	3 (7.7)	
Pulmonary atresia with VSD	2 (0.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.8)	0 (0.0)	0 (0.0)	
Pulmonary atresia without VSD	5 (0.8)	0 (0.0)	1 (0.7)	3 (2.5)	1 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	
DORV	14 (2.1)	3 (1.5)	7 (4.9)	2 (1.7)	0 (0.0)	0 (0.0)	1 (2.6)	1 (2.6)	
DILV	5 (0.8)	0 (0.0)	2 (1.4)	1 (0.8)	2 (3.4)	0 (0.0)	0 (0.0)	0 (0.0)	
Truncus arteriosus	7 (1.1)	1 (0.5)	2 (1.4)	3 (2.5)	0 (0.0)	1 (1.8)	0 (0.0)	0 (0.0)	
TGA	32 (4.8)	10 (5.0)	9 (6.3)	6 (5.0)	2 (3.4)	3 (5.5)	2 (5.1)	0 (0.0)	
ccTGA	6 (0,8)	3 (1.5)	2 (1.4)	0 (0.0)	0 (0.0)	1 (1.8)	0 (0.0)	0 (0.0)	
Coarctation of aorta	70 (10.7)	23 (11.5)	11 (7.7)	12 (10.0)	9 (15.3)	9 (16.4)	2 (5.1)	4 (10.3)	
AVSD	49 (7.5)	13 (6.5)	11 (7.7)	14 (11.7)	1 (1.7)	4 (7.3)	2 (5.1)	4 (10.3)	
ASD type 1	11 (1.7)	4 (2.0)	3 (2.1)	2 (1.7)	2 (3.4)	0 (0.0)	0 (0.0)	0 (0.0)	
Ebstein malformation	5 (0.8)	1 (0.5)	1 (0.7)	1 (0.8)	0 (0.0)	1 (1.8)	1 (2.6)	0 (0.0)	
Pulmonary valve abnormality	56 (8.6)	27 (13.5)	17 (12.0)	2 (1.7)	3 (5.1)	3 (5.5)	4 (10.3)	0 (0.0)	
Aorctic valve abnormality	107 (16.4)	37 (18.5)	14 (9.9)	23 (19.2)	16 (27.1)	8 (14.5)	4 (10.3)	5 (12.8)	
Aorctic abnormality	5 (0.8)	0 (0.0)	0 (0.0)	2 (1.7)	0 (0.0)	0 (0.0)	1 (2.6)	2 (5.1)	
ASD type 2	18 (2.7)	3 (1.5)	4 (2.8)	3 (2.5)	1 (1.7)	1 (1.8)	2 (5.1)	4 (10.3)	
VSD	113 (17.3)	41 (20.5)	21 (14.8)	18 (15.0)	10 (16.9)	8 (14.5)	7 (17.9)	8 (20.5)	
Mitral valve abnormality	37 (5.7)	10 (5.0)	12 (8.5)	2 (1.7)	7 (11.9)	4 (7.3)	2 (5.1)	0 (0.0)	
Pulmonary vein abnormality	5 (0.8)	2 (1.0)	1 (0.7)	1 (0.8)	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.6)	
Other	28(4.3)	4 (2.0)	8 (5.6)	5 (4.2)	3 (5.1)	3 (5.5)	1 (2.6)	4 (10.3)	
Complexity of heart disease									**p <0.038**
Simple	241 (36.9)	68 (34.0)	54 (38.0)	38 (31.7)	35 (59.3)	18 (32.7)	13 (33.3)	15 (38.5)	
Moderate	320 (48.9)	110 (55.0)	62 (43.7)	63 (52.5)	17 (28.8)	29 (52.7)	19 (48.7)	20 (51.3)	
Severe	93 (14.2)	22 (11.0)	26 (18.3)	19 (15.8)	7 (11.9)	8 (14.5)	7 (17.9)	4 (10.3)	
Prior interventions									**p <0.001**
No interventions	261 (39.9)	92 (46.0)	49 (34.5)	30 (25.0)	33 (55.9)	25 (45.5)	16 (41.0)	16 (41.0)	
Interventions	393 (60.1)	108 (54.0)	93 (65.5)	90 (75.0)	26 (44.1)	30 (54.5)	23 (59.0)	23 (59.0)	

CHD = congenital heart disease; VSD = ventricular septal defect; DORV = double-outlet right ventricle; DILV = double-inlet left ventricle; TGA = transposition of the great arteries; ccTGA = congenitally corrected transposition of the great arteries; AVSD = atrioventricular septal defect; ASD = atrial septal defect.
*Unspecified univentricular heart defects or Fontan procedure.

significant associations between medical staff ratio in paediatric cardiology or ACHD care and continued follow-up care.

4. Discussion

The aim of the study was to provide a multicentre perspective on discontinuation of care and investigate if outpatient volumes or medical staffing resources were predictive for continued follow-up care. The majority (89.7%) of patients had continued follow-up 5 years after leaving paediatric cardiology. Significant differences in proportions of no follow-up care were nevertheless identified across centres. Outpatient volumes were positively associated with continued follow-up care after transfer, suggesting that bigger centres, have higher odds of keeping patients in follow-up. The medical staff ratio was not found

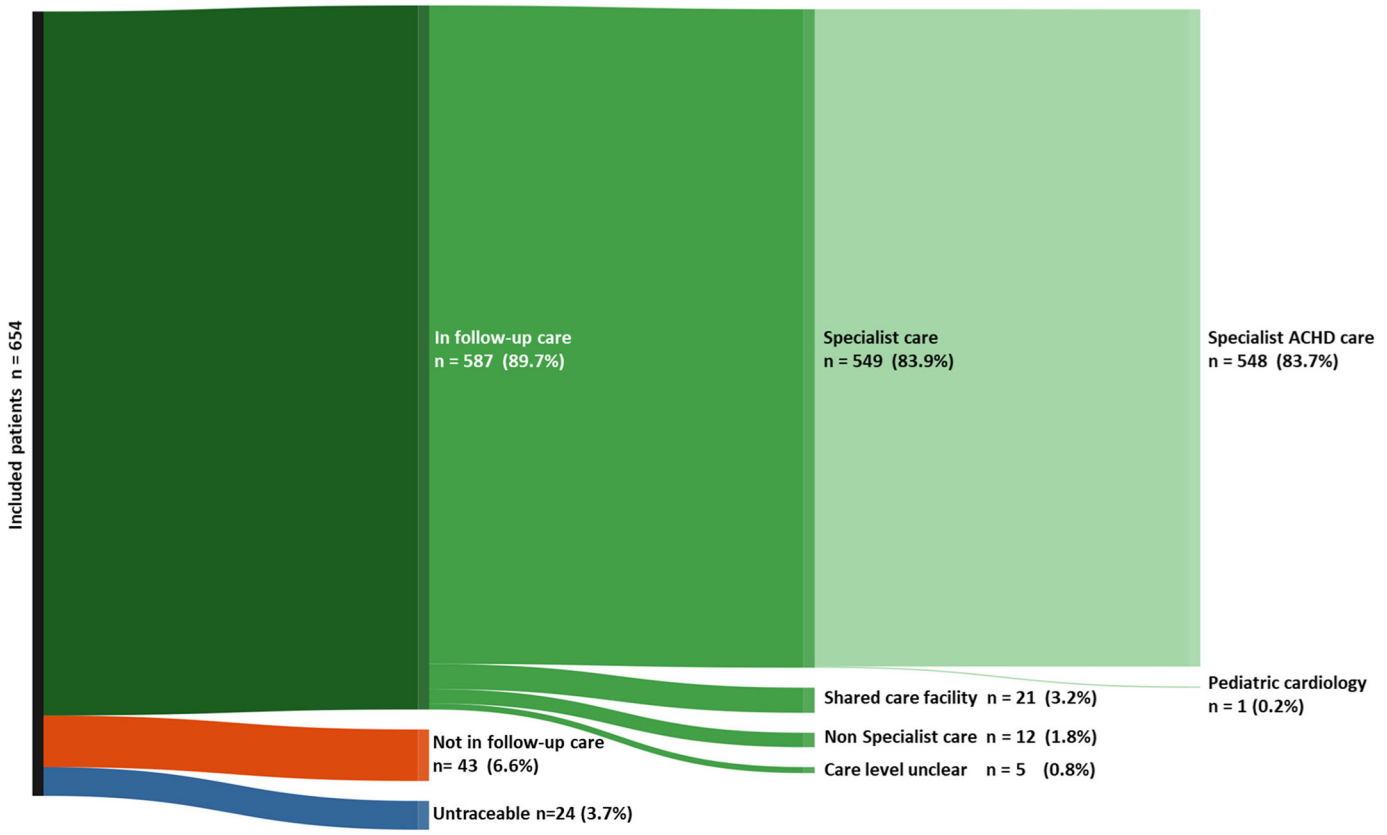

Fig. 1. Follow-up status and transfer destinations of the included 654 patients.

predictive of continued follow-up care. Lack of time and staffing should therefore not be hypothesized as the sole barrier for quality transfer care, based on the current findings.

Two previously identified risk factors for no follow-up are male sex, as well as non-severe lesions [8,9,13]. This is in line with our results where no patients with severe lesions were without follow-up and 65.1% of patients with no follow-up were male. However, sex and complexity were not significantly predictive in our multivariable regression models.

Table 2
Clinical characteristics of 43 patients with no follow-up.

	n (%)
Total cohort, n	43
Sex	
Male	28 (65.1)
Female	15 (34.9)
Primary CHD diagnosis	
Tetralogy of Fallot	3 (7.0)
Coarctation of aorta	4 (9.3)
AVSD	4 (9.3)
Pulmonary valve abnormality	3 (7.0)
Aorctic valve abnormality	4 (9.3)
ASD type 2	1 (2.3)
VSD	18 (41.8)
Mitral valve abnormality	2 (4.7)
Other	4 (9.3)
Complexity of heart disease	
Simple	18 (41.9)
Moderate	25 (58.1)
Severe	0 (0%)
Prior interventions	
No interventions	23 (53.5)
Interventions	20 (46.5)

CHD = congenital heart disease; VSD = ventricular septal defect; ASD = atrial septal defect; AVSD = atrioventricular septal defect.

Although a direct comparison with previous findings cannot be made, our proportion of no follow-up is substantially lower than prior studies [7–19]. Pooling results of previous investigations [7–19] a median proportion of 39% of adolescents with CHD were shown not to be in follow-up care [7–19]. Similarly low proportions have only been found in a Belgian study, where 6.2% of patients had no follow-up and 1.1% were untraceable [11]. In both Sweden and Belgium, health insurance is compulsory and covers the entire population, thus eliminating financial and insurance barriers to follow-up care and transfer. Suggested explanatory factors for the low proportions in Belgium have been high population density, resulting in short travelling distances to care, but also the fact that paediatric and adult CHD care were located in the same building. Compared to Belgium, Sweden has a lower population density, resulting in quite long travelling distances to specialist CHD care, particularly in the northern areas. Distance between paediatric and adult outpatient clinics in Sweden varies among centres, and in contrast to Belgium, many clinics are located in separate hospital buildings [11]. Consequently, in Sweden, other factors may have played a role in yielding the low proportion of patients not in follow-up. Possible explanations for the low proportions of no follow-up in both countries could be hospital-related, but it is even more likely they are healthcare system related. The compulsory insurance system is one such factor but also sufficient access to specialist care, low out-of-pocket cost for patients and dedicated administrative work to keep the patients in the system.

Significant differences in proportions of no follow-up were identified among the centres. To our knowledge, only one study has previously provided a multicentre perspective. Gurvitz and colleagues reported on a study comprising 12 centres and observed that 42% of patients self-reported gaps in their follow-up care and variability across centres was found [10]. This supports the theory of hospital-related factors such as organization, staffing and administration influencing continuity in follow-up care, in addition to previously identified patient-

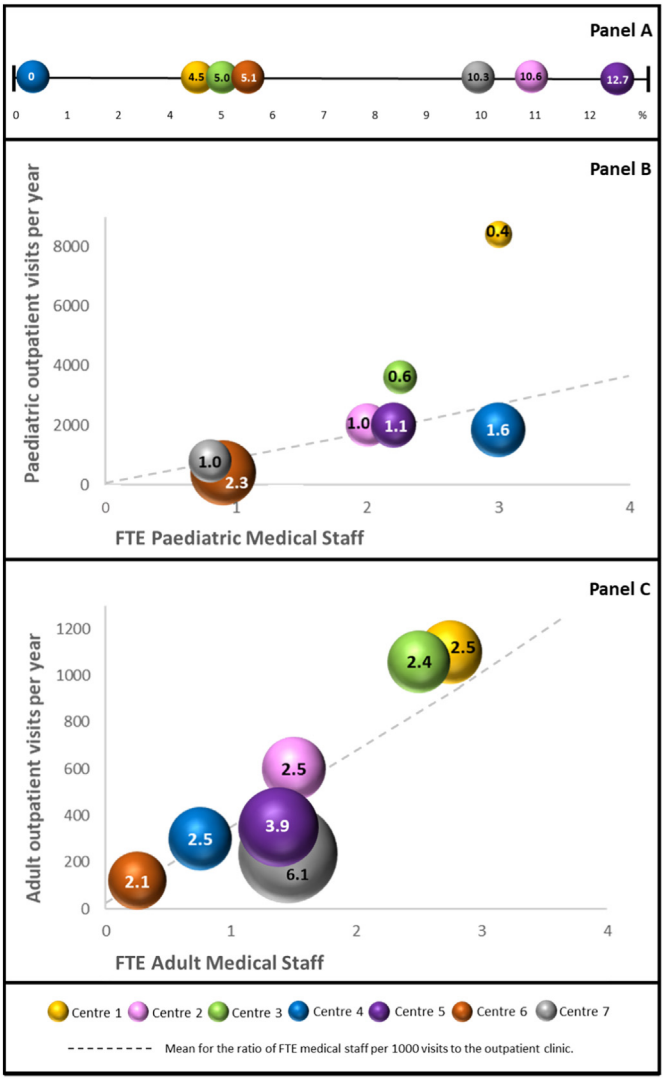

Fig. 2. Patient volumes, medical staffing resources and proportions of No follow-up across the seven centres. Panel A: Proportion of patients with No follow-up five years after intended transfer in each of the seven centres. Panel B: Bubble graph of the full-time equivalent (FTE) of paediatric medical staff vs the number of outpatient visits per year in each centre, including all paediatric cardiology related visits. The size of the bubbles and the number within the bubble represent the ratio of FTE paediatric medical staff per 1000 visits to the outpatient clinic. Panel C: Bubble graph of the full-time equivalent (FTE) of adult medical staff vs the number of outpatient visits per year in each centre, including CHD related visits. The size of the bubbles and the number within the bubble represents the ratio of FTE adult medical staff per 1000 visits to the outpatient clinic.

related factors: sex, complexity of heart disease and previous interventions [8,9,13,17].

After adjusting for patient factors, outpatient volumes at paediatric outpatient clinics were significantly associated with continued follow-up, inasmuch as an additional 500 annual outpatient visits to the paediatric clinic would increase odds of continued follow-up by 6.1%. This association between outpatient volumes and continued follow-up could be explained by the fact that centres with high outpatient volumes are more likely to provide full-time dedicated staff for their CHD patients compared to centres with lower volumes, where staff often need to combine care of CHD patients with care for patients with other conditions. Full time dedicated staff, including physicians, nurses and administrators, could however improve quality of transfer care and coordination. When including untraceable patients in the regression model, outpatient volumes at the adult outpatient clinic were found predictive for continued follow-up care, also here the opportunity to provide dedicated staff could be an explanatory factor. The positive impact of outpatient volumes could also be related to increased clinical exposure for staff practising within these centres, with high outpatient volumes generating greater experience and increased competence. This theory is nevertheless challenged by Centre 4, where 100% of patients were in follow-up. Furthermore, the majority of patients in Centre 4 had mild conditions (59.3%), which is a known risk factor for discontinuation [8,9,13]. Success factors of Centre 4 cannot be identified within this study and indeed other hospital related factors than the ones investigated in this study could be influencing continued follow-up care. Hypothesized influencing factors within the Swedish setting could be related to organizational and administrative activity aimed to keep patients in follow-up. Future studies should therefore investigate the role of administrative staff and programme managers in prevention of discontinuity of care.

Continuity of care has a wider perspective. From the present study's disease-focused perspective, the type of continuity addressed could be considered *Management continuity*, concerned with timely and complementary delivery of care [30,31]. However, the concept of continuity also includes a person-focused perspective, and the perceived experience of patients [30], which is not addressed in this study.

4.1. Methodological considerations

The strengths of the present study are the multicentre perspective and the fact that the majority of eligible patients were identified, either through medical files and registries or through postal mail. However, there are also some methodological limitations that ought to be considered when interpreting the findings.

First, we focussed on discontinuity of care during transfer because it is known to be a vulnerable period. However, the current study design might not provide full coverage of all eligible patients. This could be due to the fact that some patients receive paediatric follow-up care outside university hospital setting. It could also be that we lose patients from follow-up care earlier in life. Indeed, Mackie and colleagues found that 47% of patients aged 13–17 years failed to attend outpatient consultations [13]. A study on discontinuity of care throughout the life spectrum would give a complete picture of phases in which patients most likely drop out of follow-up.

Second, the observation window of 5 years is a prerequisite to capture the follow-up status of patients with mild conditions, however, it might result in underestimation of no follow-up for moderate and severe conditions.

Third, the associations found in the present study should not be interpreted in causal terms. Indeed, the cross-sectional, observational design does not allow us to draw causal conclusions.

Fourth, information on outpatient volumes and full-time equivalent of medical staff were provided by the clinics themselves. However, there is no uniform documentation of this kind of information. This makes these data vulnerable to estimation errors or recall bias.

Fifth, number of events of no follow-up care was small. This reduces the power of multivariable analysis. Limited number of events also reduces the possibility for sensitivity analysis and thereby confirmation of robustness of the statistical models. Hence, no definite conclusions should be drawn from the current results, and more studies on hospital-related factors are needed. Ideally, hospital-related factors should be investigated within a sample with higher prevalence of no follow-up. Furthermore, the impact of healthcare system factors should also be investigated, which would require large-scale multicentre international studies.

5. Conclusion

The proportion of patients no longer in follow-up was low in Sweden. Adjusting for patient-related factors, outpatient volumes within paediatric care was found associated with continued follow-up care, inasmuch as an increase of 500 annually visits to the paediatric

outpatient clinic would increase the odds of continued follow-up care after transfer by 6.1%. When including untraceable patients in the regression model, outpatient volumes in adult care were also found predictive. Medical staffing resources were not predictive in our sample. These findings support the theory of hospital-related factors influencing continuity of follow-up care during transfer from paediatric-focused to adult-focused health care facilities, above and beyond patient-related characteristics.

Funding

This study was supported by research grants provided by the Swedish Heart-Lung Foundation and the Swedish Research Council for Health, Working Life and Welfare-FORTE (grant 2016-07259); and the Institute of Health and Care Sciences of the University of Gothenburg: LJZ is funded by the South African Medical Research Council through a collaborative grant with FORTE and the National Research Foundation of South Africa.

Declaration of competing interest

The authors report no relationships that could be construed as a conflict of interest.

Acknowledgments

We would like to thank. **Ann Asp**: *Skåne University Hospital*, *Lund*, *Sweden*, **Åsa Burström**: *Karolinska Hospital*, *Stockholm*, *Sweden*, **Helena Dellborg**: *Sahlgrenska University Hospital*, *Gothenburg*, *Sweden*, **Eva Furunäs**: *Sahlgrenska University Hospital*, *Gothenburg*, *Sweden*, **Anette Gylling**: *Linköping University Hospital*, *Linköping*, *Sweden*, **Anna Karin Hammarstedt**: *Karolinska Hospital*, *Stockholm*, *Sweden*, **Karin Johansson**: *Örebro University Hospital*, *Örebro*, *Sweden*, **Anders Jonzon**: *Uppsala University Hospital*, *Uppsala*, *Sweden*, **Thomas Kronvall**: *Örebro University Hospital*, *Örebro*, *Sweden*, **Annika Maxedius**: *Skåne University Hospital*, *Lund*, *Sweden*, **Lena Larsson**: *Umeå University Hospital*, *Umeå*, *Sweden*, **Görel Hultsberg Olsson**: *Sahlgrenska University Hospital*, *Gothenburg*, *Sweden*, **Linda Ternrud**: *Skåne University Hospital*, *Lund*, *Sweden* and **Ingegerd Tiblad**: *Queen Silvia's Children's Hospital*, *Gothenburg Sweden*, for their contribution to the data collection.

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