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TRANSITION AND TRANSFER IN CONGENITAL HEART DISEASE

Experiences and perspectives of young people with
CHD and their parents/caregivers

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Forward

Without chocolate, teamwork, and our supervisor Mariela Acuña Mora, this thesis would never have been completed. Thank you for all your help!

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Abstract:

Children born today with congenital heart disease (CHD) will most likely live into adulthood and as such need to transition their care from the paediatric cardiac clinic to the adult cardiac clinic. How young people and their parents/caregivers perceive this process of transition is not well understood. Also not well understood are their understanding of the transition process. This literature review of qualitative studies aimed to investigate the experiences of young people with CHD and their parents/caregivers around transition to adult care. Searches were performed in PubMed, Scopus, CINAHL and an EndNote library of transition literature. Four themes and nine sub-themes were found. The results indicated that young people and their parents/caregivers want and need more information about their health, lifestyle factors and the transition process. Trust in the care team was important as was peer-support and peer-learning. Parents had a hard time letting go of responsibility for care, though they understood that the shift in responsibility was a natural and normal part of growing up. Timing of transition was also considered important, with preferences for individualisation of timing according to maturity. Young people and their parents also perceived the young people's self-management and communication skills were lacking, causing concern for the parents in particular. Young people with CHD and their parents/caregivers need person-centred care during the transition to adult care. A care environment that fosters trust in the care team and supports them to become capable of self-management and with sufficient communication skills to be able to advocate for themselves.

Keywords: transition, transfer, transition to adulthood, CHD, perspectives, experiences, parents, young people, adolescents

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Introduction

Chronic conditions are an increasing factor in today's society as medical science has advanced and survival has increased. Of the children born today with chronic conditions, 90% are expected to reach adulthood (Lykkeberg et al., 2020, Moons et al., 2010). As such, they will need to transition from paediatric to adult healthcare. We are interested in how young people with congenital heart disease experience this transition process. By knowing more about their experiences, we, as future registered nurses, should be better able to meet these expectations and ensure quality of care.

Background

Congenital heart disease

Congenital heart disease (CHD) is a term used to describe conditions that consist of various anatomical heart defects which begin during pregnancy, while the heart is developing (Sunnegårdh, 2014). These cardiac structural malformations, and the differences between them, are based on anatomy, and can consist of holes in the heart's septum, chambers and atria, but also vascular structures (Sunnegårdh, 2014). The worldwide prevalence of CHD is 8 per 1000 newborns and is the most common congenital anomaly (van der Linde et al., 2011). In Sweden, approximately 2000 of the 115 000 children born every year are born with a CHD (Socialstyrelsen, 2022, Hjärt-Lungfonden, 2021).

Conditions that are included in the term CHD range from simple to complex, with the most common types of simple diagnoses including, among others, ventricular septum defects and pulmonary stenosis (Lykkeberg et al., 2020). Those that fall into more complex conditions include tetralogy of Fallot, atrioventricular septal defect, and pulmonary atresia (Lykkeberg et al., 2020).

Due to improved diagnostic tools and the development of more sophisticated surgical procedures, about 90% of individuals born with heart defects will reach adulthood (Lykkeberg et al., 2020, Moons et al., 2010). Although survivorship has increased in patients with CHD, there remains an increased risk of developing pulmonary hypertension and heart rhythm problems amongst other complications, and this requires life-long follow-up care (Mayo Clinic, 2020). This follow-up care is scheduled based upon the severity of the CHD, with simple heart defects having a check-up every 3-5 years, every 1-2 years for patients with moderately severe CHD lesions and every 6 months to 1 year for patients with complex defects (Landzberg et al., 2001). Because the majority of children born with CHD now reach adulthood, there is a greater need for transfer of patients from paediatric to adult cardiac care in order for them to receive age and developmentally appropriate care.

A cohort study performed in 2004 showed that only 48% of young people with CHD had undergone a successful transfer to adult care, defined as attending follow-up care at an adult facility (Reid et al., 2004). When CHD patients are lost to follow-up care, there is an associated significant increase in the risk of morbidity, with a 3-fold increase in the need for urgent cardiac care (Yeung et al., 2008). A study looking at a group of patients lost to follow-up CHD care found that more than a third of these lost to follow-up patients had an imperative need of follow-up care (Iversen et al., 2007). Discontinuity of care amongst young

people with CHD has been shown to be significant, with a greater proportion of patients with simple heart defects discontinuing care (Moons et al., 2021). Though formal transition programmes have been shown to decrease the proportion of discontinued care (Moons et al., 2021).

Transition and transfer

The literature surrounding transition and transfer often use the terms interchangeably, but these words have distinct meanings that warrant clarification in relation to young people with CHD and their continued care.

Transfer

Transfer is often a single event where care of young people with chronic health conditions, such as CHD, is moved from a paediatric to an adult health care system (Meadows et al., 2009). It has primarily to do with the transfer of responsibility from the paediatric physician and treatment team to the adult physician and treatment team, and not about the process surrounding this transfer. Timing of transfer for young people with CHD is variable between countries and healthcare systems with some people transferring at 16 years old, 18 years old or even 20 or 21 years old (Sable et al., 2011).

Transition

The process surrounding transfer is known as transition, which as a concept within healthcare was defined in 1986 by Chick & Meleis as “a passage from one life phase, condition, or status to another...” (Chick & Meleis, 1986, p 239). Transition “refers to both the process and outcome of complex person-environment interactions. It may involve more than one person and is embedded in the context and the situation” (Chick & Meleis, 1986, p239-240). Nurses are key players in a number of transitions, medical or otherwise. They have a clear and fundamental role in health education, as well as being a consistent point of contact for patients, often seeing patients for longer and more often than medical doctors and specialists. In fact, transition and the facilitation of transition has been described as the fundamental mission of nurses (Meleis & Trangenstein, 1994).

According to Meleis & Trangenstein (1994), there are four kinds of transitions in life that nurses are involved in. These are: 1) developmental (e.g. adolescence or becoming a parent, 2) situational transitions (e.g. professional role transitions), 3) health transitions (e.g. changing health status, diagnosis, discharge from care), and 4) organisational transitions (e.g. implementation of new policies or practices, or changes in nursing as a profession) (Meleis & Trangenstein, 1994).

Considering this framework for viewing transitions that nurses are involved in, it can be stated that young people with CHD transitioning to adult healthcare are not only experiencing an individual developmental transition from childhood, through adolescence to adulthood, with the associated physical, psychological and emotional changes of puberty (Patton & Viner, 2007), but also a health transition to adult healthcare. In the context of young people with chronic illness, this transition is defined as “the process by which adolescents and young adults with chronic illnesses are prepared to take charge of their lives and their health in adulthood.” (Meadows et al., 2009, p292).

So what does transition actually entail? Meadows et al (2009) discuss the stages of a successful transition. There is ideally an initial pre-transition phase, where young people are informed that they will need long term follow-up care. Following the pre-transitional phase, comes transition proper (Meadows et al., 2009). At this point formal education would begin about their diagnosis and medical history, the signs and symptoms to watch out for and how to access care in the adult system (Meadows et al., 2009). Furthermore, this phase of transition would ideally include education about contraception, lifestyle factors and skills training for self-advocacy (Meadows et al., 2009).

Transition is considered a family process, with parents/caregivers having a role in encouraging the young person to increase their independence and take on more responsibility for their own care (Meadows et al., 2009). Parents can include mothers, fathers, step parents, and foster parents. The term caregiver expands the title parent to include those who have primary responsibility for care who may not be parents, including grandparents. Parents/caregivers of young people with CHD are the people primarily responsible for ensuring that the young person with CHD has access to appropriate medical care, as well as, for example, managing medications, recovery from surgery post discharge from hospital (Clarizia et al., 2009). Parents of children with CHD are often overprotective, in part likely due to the parents' higher than average symptoms of depression, stress and anxiety (Cohn, 1996, Lawoko & Soares, 2006, Uzark & Jones, 2003). Parental styles have been shown to contribute to how well a young person with CHD understands their disease and their own limitations, with more realistic views of living with CHD leading to young people with CHD being more able to cope with their disease than those parents who perceived the CHD as disabling (Claessens et al., 2005).

Nurses can also play an important role in all phases of transition, through providing continuity of care and education about the process itself and relevant health related information (Meadows et al., 2009). Many times a transition coordinator is used to ensure this continuity of care between healthcare systems, and this coordinator, more often than not, is a nurse (Meadows et al., 2009).

Nurses who built trust and a good relationship with patients were shown to be a key factor in a positive experience of transition and transfer (Gabay (Gillie) & Tarabeih, 2020). A fundamental part of creating and maintaining trust and a good relationship between caregivers and patients is the utilisation of person-centred care (Hendren & Kumagai, 2019).

While transfer of care for young people with CHD happens regularly and increasingly often due to the increased survival of this patient group, transition is not always carried out well and can lead to a loss of patients to follow-up. How a successful transition programme is created and assessed has been discussed. An international panel of experts was used to establish the key elements, and indicators of successful transition (Suris & Akre, 2015). Elements were defined as things that should be included in a transition programme, and indicators were measurable outcomes of a transition programme's success (Suris & Akre, 2015). Included in the key elements considered as essential or very important were: "Assuring a good coordination (such as timing of transfer, communication, follow-up...) between paediatric and adult professionals", "discussing with patient and family about self management", "including young person's views and preferences to the planning of transition", "tailoring the transition plan to the needs of the patient and family", "identifying someone within the team who will play the role of transition manager or coordinator", "parents should be included in the process

of transition”, and “discussing with patient about risk behaviours and their influence on health” (Suris & Akre, 2015). And of the key indicators of successful transition, the following three were included: “Patient not lost to follow-up”, “patient building a trusting relationship with adult provider”, and “patient and family satisfaction with transfer of care” (Suris & Akre, 2015). By using these elements to build transition programmes and indicators to evaluate them, healthcare professionals should be able to better manage transition and transfer of young people from paediatric to adult care.

Person-centred care

Person-centred care (PCC) emerged from a desire to move away from a form of healthcare provision that was patriarchal, top-down and prescriptive, based on the opinions of healthcare providers, largely ignoring the opinions, knowledge, and capabilities that people in need of healthcare possess. The type of healthcare that sees patients as passive recipients of care, instead of participants in their care. Person-centred care is an overarching term that perceives a person in a healthcare context as something more than a patient, upon whom care is enacted (Ekman et al, 2011a).

PCC seeks to involve patients in the decision making process, and take an active part in their own care (Leplege et al., 2007). The three cornerstones of PCC are patient narratives, partnership with caregivers, and documentation (Ekman et al., 2011a). These three can be further explained as follows:

Patient narratives

Through dialogue and active listening to the patient the healthcare provider can more readily determine the resources and capabilities of the patient and effectively address any obstacles the patient may face (Britten et al., 2020).

Partnership with caregivers

By using the narrative as the basis for a partnership between caregivers and patients, this collaborative partnership seeks to find a health plan that is in line with the identified goals, resources, capabilities and obstacles (Britten et al., 2020). Partnership supports self-management through paying attention to the patient’s own priorities and enhancing/making use of their resources and capabilities (Britten et al., 2020).

Documentation

By documenting the health plan, it is then possible to adapt it as changes in the patient’s life or goals happen over time (Britten et al., 2020).

Person-centred care has not only been discussed as a theoretical way to approach healthcare provision, but studies have shown that there is evidence that it improves patient outcomes, for example, by shortening hospital stays, improving health related quality of life scores, and improving the discharge from hospital process (Ekman et al., 2011b, Wallström et al., 2019, Ulin et al., 2015).

Problem formulation

When transition to adult care is not successful, patients are lost to follow-up care, which leads to poorer health outcomes for this group. This lack of follow-up can lead to increased costs to the healthcare system in the form of increased hospitalisation. There is some evidence from

the literature that formalised transition programmes reduce discontinuation of care (Moons et al., 2021). Yet, it is still unknown which aspects of transition and transfer, as they are performed currently, are working, or not working, according to young people with CHD and their parents/caregivers. A collated investigation of how transition and transfer are experienced by this patient group and their parents/caregivers is needed to better direct the efforts of the healthcare professionals providing transitional care. This information would allow healthcare professionals to better meet the needs of young people with CHD and their families and reduce the gaps that lead to discontinuation of care.

Aim

This study aims to investigate the experiences of young people with congenital heart disease, going through transition to adult care, as well as the experiences of their parents/caregivers with relation to the process of transition and transfer.

Methods

Study design

In order to assess the available research surrounding the experiences of young people with CHD and their parents/caregivers, a critical examination of the existing literature was performed. The aim was to give a broad overview of the current state of research in this area and collate the data and find common themes.

Search process

The following databases were searched: CINAHL(EBSCO), Scopus and PubMed (MEDLINE). An Endnote library, provided by our supervisor, including the search results from a scoping review was also searched to complement the database searches (Acuña Mora et al., 2019).

Search terms were decided upon by analysing search terms used in other reviews of related research (Acuña Mora et al., 2019, Lykkeberg et al., 2020) and selecting those that were most relevant to the aim. Search terms chosen are listed in Table 1. To obtain an efficient search strategy and find terms specific to the aim, a SPICE framework was used. SPICE stands for S- setting, P- perspective, I- intervention, C- comparison and E- evaluation (Booth, 2006). This is shown in Table 2.

Table 1: List over search terms used

parent/caregiver/mother/father

Congenital heart disease

GUCH

ACHD

Transfer

Transition
 Transition to adult care
 experience/s
 perspective/s
 Expectations
 Chronic condition
 pediatric*/child/children/adolescent/teen/teenager
 Care transitions
 Patient attitudes/experiences/perspectives
 heart*
 CHD

MESH: Heart defects, congenital, transition, transitional

Table 2: The SPICE framework used in this study

S- Setting	P-Perspective	I-Intervention	C-Comparison	E-Evaluation
Care transitions	Patients with CHD and their parents/caregivers	Transition from paediatric to adult care	Not applicable	Experience/s, perspective/s and expectation/s

The process of finding the right search terms was conducted in different ways. Search terms were chosen that were relevant to the aim. Search terms were then chosen from different articles relevant to the research. More search terms were found using the MESH database. After search terms were selected Boolean terms “AND” and “OR” were used for every search block. According to Karlsson, (2017) by using Boolean terms you achieve an exhaustive result that is also specific. To further improve the search strategy phrase searching was used when searching, for example, “chronic condition” using quotation marks ensures that the words are not separated. Truncations were used to include all variations of words such as adolescent, or experience (Karlsson, 2017).

Inclusion criteria

Inclusion criteria include peer reviewed research articles, published within the last 10 years, written in English, from high income countries providing transitional care for young people born with CHD. Qualitative articles that cover experiences, expectations and perceptions of parents (parents includes mothers, fathers, other types of primary caregivers, such as step-

parents or foster parents) as well as young people with congenital heart disease (CHD), around the transition process.

According to the World Health Organisation (WHO), people between the ages of 10 and 19 years old are referred to as adolescents (WHO, 2019). Further to this definition, the WHO defines “youth” as between 15 and 24 years old, and uses the collective term “young people”, to cover both adolescents and youth, i.e. people from 10-24 years old (WHO, 2019). The articles included in this literature review commonly use two terms to describe their participants, either adolescents or young adults, or a combination referred to as AYAs (adolescents and young adults). For the sake of consistency, the term used in this thesis is “young people”, in accordance with the WHO definition.

Exclusion criteria

Excluded literature were articles that included needs of young people who were yet to transfer to adult care, unless used in comparison to young people who had already transferred.

Study selection

All identified citations for each search were uploaded to Endnote 20 (Clarivate Analytics, PA, USA) and placed in their own Endnote group titled with the search engine and date, (e.g. CINAHL 9/3). Each collected group of citations had the titles and abstracts reviewed by both authors individually against the inclusion and exclusion criteria. Once reviewing the relevance of articles individually, the authors met to compare ratings. Any disagreement between authors was resolved by asking for external review by the supervisor.

Relevant citations based on the abstract were assigned 5 stars in the rating system in Endnote, and, subsequent to review of the abstract, all citations with a 5-star rating were moved into an Endnote group labelled “relevant citations”. Table 3 describes the search strings used, limitations placed on searches, number of hits, number of relevant abstracts, full text articles reviewed, and chosen articles.

Duplicates were removed after review of the relevant abstracts of each search, after which 15 articles remained for full text review. Full text assessment was then performed by both authors and following this, 8 articles remained to be included in the study. There was consistency of opinion between the authors on the quality and content of the 8 remaining full text articles.

To ensure that there was a sufficient breadth and depth of research included in the thesis, a secondary search in the references of the 8 included articles was performed. In this search one further article was identified for inclusion. This article was outside the inclusion criteria of “published within the last 10 years”. However, it was decided that due to the exceptional relevance of the article to the aim, as well as the fact that 5 of the 8 already included articles included this article in their reference list, that it should be included. The process for study selection is described in a PRISMA flowchart in Figure 1.

Table 3: Description of search strategy including search strings and databases searched

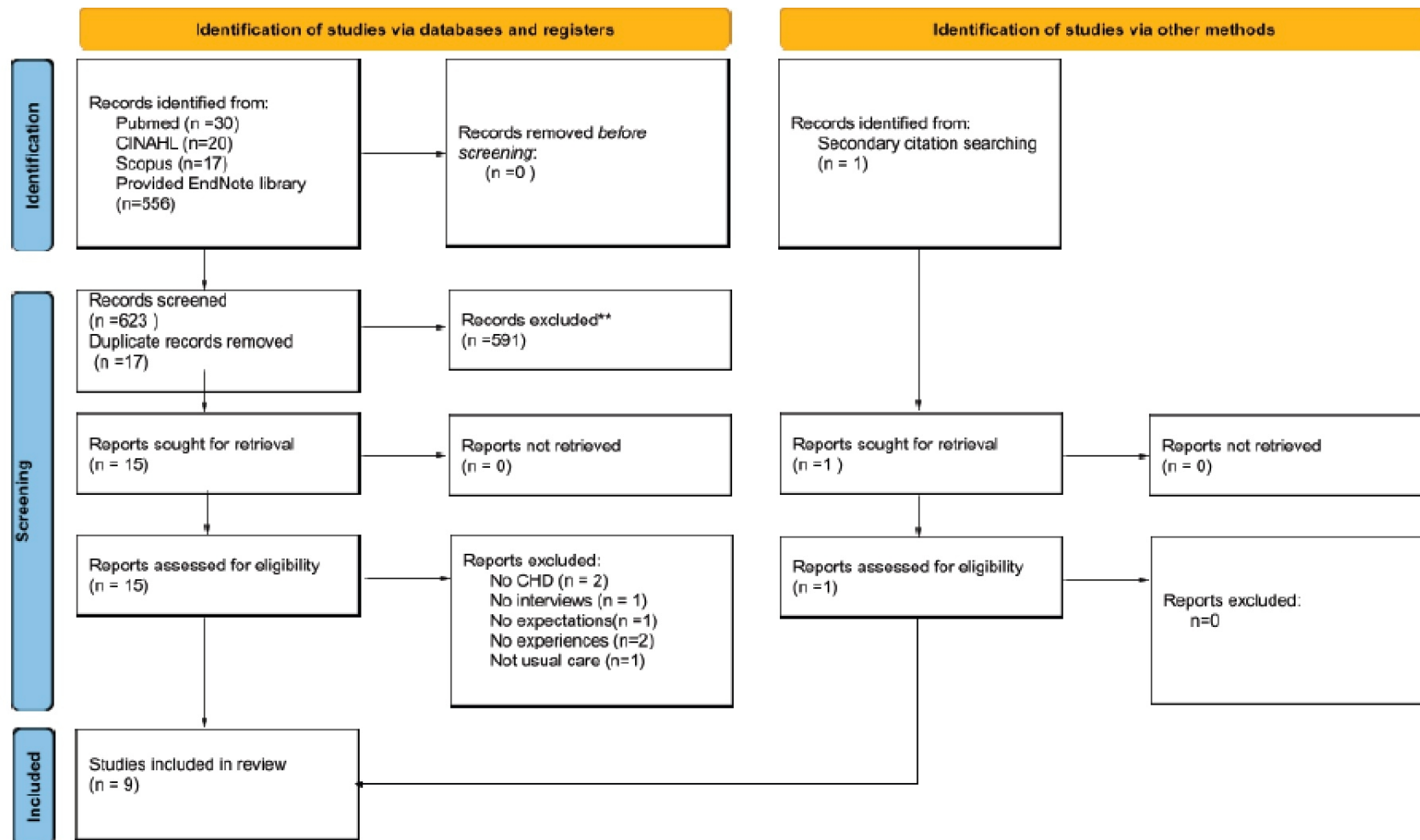
Date & database	Search string	Limits	Number of hits	Relevant abstracts	Articles read	Chosen articles
7/3/22 - pubmed	((((((((parent) OR caregiver) OR mother) OR father)) AND (((((((("congenital"[All Fields] AND "heart"[All Fields] AND "disease"[All Fields]) OR "congenital heart disease"[All Fields])) OR "Heart Defects, Congenital"[Mesh]) OR congenital heart defect) OR congenital heart malformation)) OR GUCH) OR ACHD)) AND (((Transfer) OR transition) OR Transition to adult care)) AND (((((((experience) OR experiences) OR perspective) OR perspectives) OR "expectations"[All Fields])) NOT (infant)) NOT (fetal*))	10 years	30	7	7	<p>Do not forget the parents-Parents' concerns during transition to adult care for adolescents with congenital heart disease Bratt et al., 2018</p> <p>"Not such a kid thing anymore": Young adults' perspectives on transfer from paediatric to adult cardiology care Catena et al., 2018</p> <p>Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences Coyne et al., 2019</p> <p>Needs and Experiences of Adolescents with Congenital Heart Disease and Parents in the</p>

						Transitional Process: A Qualitative Study de Hosson et al., 2021
9/3/22 - scopus	(ABS) (transition OR transfer OR transition AND to AND adulthood) AND ALL (chronic AND condition) AND ALL (heart*) AND TITLE-ABS-KEY (pediatric*))	Nursing English 10 years	17	3	3	Needs and experiences of adolescents with congenital heart disease and parents in the transitional process: A qualitative study de Hosson et al., 2021 Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences Coyne et al., 2019 Transfer to Adult Care- Experiences of Young Adults with Congenital Heart Disease Asp et al., 2015
9/3/22- CINAHL	(AB (transitional care or care transition or care transitions) AND TX (chronic conditions or long term conditions or chronic disease) AND TX (pediatric or child or children or adolescent or teen or teenager) OR TX transfer AND MW (chd or congenital heart defects or congenital heart disease)	10 years Peer Reviewed Research Article adolescent: 13-18 years	20	2	2	Adolescents with congenital heart disease: their opinions about the preparation for transfer to adult care Burström et al., 2017

	AND MW "transitional care" AND MW (patient attitudes or patient experiences or patient perspectives)) AND MW (parents or caregivers or mother or father or parent)	English				
10/3/22-scoping review #1	Title contains "Congenital heart"	10 years	73	6	6	<p>Adolescents With Congenital Heart Disease and Their Parents Needs Before Transfer to Adult Care Burström et al., 2016</p> <p>Adolescents with congenital heart disease: their opinions about the preparation for transfer to adult care Burström et al., 2017</p> <p>Do not forget the parents-Parents' concerns during transition to adult care for adolescents with congenital heart disease Bratt et al., 2018</p>
11/3/22-scoping review #2	Keyword contains "heart disease"	10 years	14	1	1	<p>Traversing the liminal: what can Fontan adults' transition experiences and perspectives teach us about optimizing healthcare? du Plessis et al., 2018</p>

11/3/22- scoping review #3	Abstract contains CHD	10 years	49	7	7	<p>Traversing the liminal: what can Fontan adults' transition experiences and perspectives teach us about optimizing healthcare? du Plessis et al., 2018</p> <p>"Not such a kid thing anymore": Young adults' perspectives on transfer from paediatric to adult cardiology care Catena et al., 2018</p> <p>Adolescents With Congenital Heart Disease and Their Parents Needs Before Transfer to Adult Care Burström et al., 2016</p> <p>Adolescents with congenital heart disease: their opinions about the preparation for transfer to adult care Burström et al., 2017</p> <p>Do not forget the parents- Parents' concerns during transition to adult care for</p>
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						adolescents with congenital heart disease Bratt et al., 2018
11/3/22-scoping review #4	Abstract contains experience* OR perspective	10 years	420	6	6	<p>Traversing the liminal: what can Fontan adults' transition experiences and perspectives teach us about optimizing healthcare? du Plessis et al., 2018</p> <p>Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences Coyne et al., 2019</p> <p>"Not such a kid thing anymore": Young adults' perspectives on transfer from paediatric to adult cardiology care Catena et al., 2018</p>



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71.

Figure 1: PRISMA flowchart showing study selection

CHD = congenital heart disease

Assessment of methodological quality

According to Mårtensson & Fridlund (2017), to ensure the quality of the chosen articles it is appropriate to use a review template. Forsberg & Wengström (2016)'s quality review template, translated into English by one author (KB, a native English speaker) and turned it into a Google Form so that both authors could independently review the methodological quality of the articles, was used. All selected articles were reviewed by filling in the Google Form and based on the results were divided into the following categories: high, medium and low.

To further review the quality Mårtensson & Fridlund (2017) points out to look for terms such as "credibility", "transferability", "dependability" and "confirmability" as this indicates quality. This information was then used to search through the articles for evaluation. Credibility was detected in all articles when data analysis was reviewed by different people before it was finalised. The articles also showed signs of dependability as they had clear descriptions of the data collection and data analysis process (Mårtensson & Fridlund, 2017).

Ethical considerations

All included articles had ethics approval from appropriate ethics committees. Participants all gave informed consent to participation. The authors attempted to be aware of their own preconceived notions and lived experiences when assessing the data. Every attempt was made to ensure that the data was interpreted in line with the intentions of the reviewed articles' authors. All work not that of the authors was referred to in the text and included in the reference section of the thesis.

Results

Overview of study population demographics

Included studies are from six different countries, four articles from Sweden (Asp et al., 2015, Bratt et al., 2017, Burström et al., 2016, Burström et al., 2017), two from Belgium (de Hosson et al., 2021, Moons et al., 2009) and one from Canada (Catena et al., 2018), one from Ireland (Coyne et al., 2019), and one from Australia/New Zealand (du Plessis et al., 2018). Included ages of young people with CHD was between 14 and 30 years old. Demographic data is presented in Table 4.

Table 4: Overview of study demographics

Study	Age (Young adults / parents)	Number of participants	Chronic illness
Asp et al 2015	19-24	16	CHD
Bratt et al 2017	14-18 / 45-56	34	CHD
Burström et al 2016	16-18	25	CHD
Burström et al 2016	14-18	17	CHD
Catena et al 2018	14-18	21	CHD
Coyne et al 2019	14-25	116	CHD, Cystic fibrosis, Type 1 diabetes
de Hossons et al 2021	Average age 17.8	21	CHD
du Plessis et al 2018	18-30	18	CHD
Moons et al 2009	15-17	14	CHD

CHD = Congenital heart disease

Themes identified in the literature review

An analysis of the literature revealed four main themes and nine sub themes. These are described in Table 5.

Table 5: Summary of themes and sub-themes

Themes	Sub-theme
1: Information about, participation in, and timing of transition	<ul style="list-style-type: none"> • <i>Information about the transition process provides a sense of security</i> • <i>Increased involvement of young people in their care</i> • <i>Timing of transfer - maturity or chronology?</i>
2: Shifting roles and responsibilities	<ul style="list-style-type: none"> • <i>the role of parents in the transfer of responsibility</i> • <i>Young people taking on more responsibility for their care</i>

3: Feeling uncertain about transfer to a new care facility/system	<ul style="list-style-type: none"> • <i>Trust in the care team</i> • <i>Meeting the new care team before transfer helps</i>
4: Health knowledge and lifestyle factors impact on daily life	<ul style="list-style-type: none"> • <i>Young people need more information</i> • <i>Use of peer-support and education in groups</i>

Theme 1 : Information about, participation in, and timing of transfer

Young people were clear in many studies about a need to be more involved in the planning of their future care, experiencing it as positive when they were involved and negative when they felt excluded from the planning process. Being informed about what is going to happen and being allowed to be a participant in planning was important for young people.

Both parents and young people expressed that the time of transfer should be tailored to the individual and their needs.

Sub-theme: information about the transition process provides a sense of security

Studies showed that young people wish to receive information about the transition process at an early stage, as it leads to a sense of security (Asp et al., 2015, Moons et al., 2009).

Participants in Asp et al's (2015) study reported that by receiving the information they needed beforehand led to feeling more secure. This was also emphasised in the Burström et al (2017) study where the participants wanted information as early as two or three years in advance of transfer to adult care. Participants that did not receive adequate information about the transfer felt insecure and were left with a lot of questions (Burström et al., 2017, de Hosson et al., 2021). Furthermore, sometimes the young adults received information at their very last appointment surrounding the transition to the adult clinic (Coyne et al., 2019, de Hosson et al., 2021). Some participants experienced that a lack of information and preparation resulted in them not attending their appointments at the adult clinic (du Plessis et al., 2018).

Sub-theme: increased involvement of young people in their care

Young people reported that their involvement in their care and transition process was limited (de Hosson et al., 2021). Participants in the Asp et al (2015) study felt positive towards being more involved. They had been offered the opportunity to have a consultation without their parents with their cardiologist and perceived this as positive, but only when it was a choice (Asp et al., 2015). This solo consultation was seen as an opportunity to practice communication skills (Asp et al., 2015). Young people wanted paediatrics to direct information about managing their medication and addressing their concerns to them rather than their parents as a way of increasing their involvement in their care (Burström et al., 2017). On the other hand, participants could feel negative towards being involved in their care when they felt that the cardiologist had too high expectations of their ability to understand difficult medical terms (Asp et al., 2015).

Sub-theme: Timing of transfer- maturity or chronology?

Parents discussed that they thought that transfer should be decided on the basis of maturity and not chronological age and that transition shouldn't start as early as 11-12 but closer to 15-16 years old, subject to the maturity of the young person in question (Bratt et al., 2017). This is also described by de Hosson et al, with some participants feeling that they were too old for the paediatric setting and that their personality and degree of maturity should be taken into account when making a decision about when to transfer to adult care (de Hosson et al., 2021). In one study, the young adults considered that leaving paediatrics was normal, they were unable to say exactly what made them ready to leave beyond that they were too old for paediatric care (Moons et al., 2009). Flexibility in timing of transfer to adult care was described as positive for this group of young people (Moons et al., 2009).

Theme 2 : Shifting roles and responsibilities

As young people began the transition process it was clear for both them and their parents that the responsibility for their care needed to shift from their parents to themselves. This theme discusses parents seen as both a resource and/or a hindrance to this shift in responsibility, and that throughout transition young people do eventually start to take more responsibility for their own care.

Sub-theme: the role of parents in the transfer of responsibility

Both parents and young people described transition as difficult for parents (Catena et al., 2017, Coyne et al., 2019, Moons et al., 2009). The parents were ambivalent about the transition, they acknowledged that they had difficulty giving up responsibility for their child's health, despite knowing that it was developmentally appropriate for their child to be responsible going forward (Coyne et al., 2019, de Hosson et al., 2021). This ambivalence was also felt by parents in Burström et al's (2016) study, though they expressed it as sadness at not being needed anymore and a loss of identity as the parent of a child with CHD. Similarly, parents in Bratt et al's study struggled with their own transition from being the parent of a child to the parent of an adult and felt grief at the loss of that role, knowing that this shift was a natural one and included a shift of responsibility for their child's healthcare to their, now, adult child (Bratt et al., 2017) . Though most studies that interviewed parents described parents as believing that stepping back was a natural step for them (Bratt et al., 2017, Coyne et al., 2019), some parents felt that this stepping back was thrust upon them when the cardiologist in the adult setting forced an individual consultation with the young person, without their parent/s (de Hosson et al., 2021). Parents in Coyne et al's (2019) study worried about how much more responsibility their child would have once they transferred to the adult clinic and whether they would be capable to effectively communicate with the adult team. Young people described their parents as a resource and support, especially with regards to making care decisions, and that their parents had a greater knowledge of their child's heart condition (Asp et al., 2015, Burström et al., 2017, Catena et al., 2017). Young people felt that continued parental support helped them to feel safe during transition (Asp et al., 2015). As they grew older, they felt more comfortable attending appointments on their own, but liked knowing that their parents were nearby (Burström et al., 2017). While participants took on more responsibility for their care, they still expressed a desire for their parents to be involved in their care, with some expressing it as wanting their parents "in charge" of their care (Burström et al., 2016), others wanted their parents' involvement but for that involvement to

reduce over time (de Hosson et al., 2021) and some expected information about their care to be directed to them, but still expected their parents to be involved (Moons et al., 2009). Young people perceived their parents as supportive, but some also described that transition as harder for their parents than for them (Moons et al., 2009) and that mothers in particular were overly involved or 'protective' (Catena et al., 2017).

Sub-theme: young people taking on more responsibility for their care

Young people were aware that they needed to take more control of their own care after transfer to adult care (Asp et al., 2015, Catena et al., 2017), despite this knowledge, some young people felt a lack of confidence in their self-management and communication skills prior to transfer (Coyne et al., 2019). Young people took on more responsibility for some aspects of their care, such as ensuring that they took their medication, and considered this both an appropriate level of responsibility (Burström et al., 2016) and a way for them to increase their general responsibility for their care (Burström et al., 2017). The age at which young people took more responsibility for their care was variable, with the majority of participants in du Plessis et al's (2018) study taking responsibility for their care by the age of 25.

Theme 3 : Feeling uncertain about transfer to a new care facility/system

Young people and their parents were often uncertain about the transfer to the new care facility and the sub themes that emerged had to do with trust in the care team, both the established trust in the paediatric setting as well as establishing trust in the new setting.

Sub-theme: trust in the care team

Several articles highlighted that they were concerned about losing the relationship they had developed with their paediatric care team, the participants expressed that the lack of relationship would mean a loss of security (Burström et al., 2016, Catena et al., 2018, Coyne et al., 2019). This loss of relationship to the paediatric setting led to some young people wanting a formal goodbye from that setting before moving onto the adult one, though this was not expressed by all of them (Moons et al., 2009).

Young people and parents expressed different ways to gain trust in the new care team. The young adults' trust in the new care team increased when they were allowed to discuss their fears with staff members with whom they were familiar (Asp et al., 2015).

Sub-theme: meeting the new care team before transfer helps

Young people and their parents wanted more information about the adult clinic specifically on an organisational level (Moons et al., 2009). Young people explained that it was important to be familiar with the new cardiologist and care team, as doing so led to an increased sense of security (Asp et al., 2015). Similarly, parents expressed that allowing their young people to become familiar with the adult clinic beforehand and visiting the new caregivers would be beneficial (Bratt et al., 2017). In du Plessis et al's (2018) study, participants described factors that led to negative experiences surrounding transition including the lack of a formal introduction to the adult clinic. Participants suggested that a joint meeting between the paediatric team and adult team would be an integral part of a well-handled transfer (du Plessis et al., 2018). In another article, parents indicated that meeting the adult clinic team that was

arranged by the transition coordinator (TC) led them to gain trust and confidence in the new care team (de Hosson et al., 2021). In contrast to this, young people lost trust in the care team when there was a lack of continuity of care and insufficient information about the transfer process (Asp et al., 2015).

Theme 4 : Health knowledge and lifestyle factors impact on daily life

The final theme pertained to the provision of health and lifestyle related information to young people with CHD, before, during and after transfer. Providing specific information on lifestyle factors and disease factors that affect health was considered important. The way the information was provided to young people and their parents/caregivers was also important, with a preference for group and peer-based learning.

Sub-theme: young people need more information

Many young people do not have sufficient knowledge about their CHD (Asp et al., 2015, Burström et al., 2016, Burström et al., 2017, du Plessis et al., 2018, Moons et al., 2009). While some young people wanted more information about their condition, as their lack of knowledge about their medical history created uncertainty about how to manage symptoms or even what symptoms to be aware of (Asp et al., 2015), some felt that the information they had was sufficient, even when it was not complete (Burström et al., 2016). Participants in du Plessis et al.'s (2018) study who had not been given sufficient information about their health and need for follow-up care had often disengaged from care. The authors concluded that cardiac specific health education needs to continue after transfer to adult care and that healthcare providers should not assume this education is complete post transfer (du Plessis et al., 2018).

Information about lifestyle factors, such as alcohol, smoking, sex and pregnancy/contraception as well as information about heredity and genetics was important to young people with CHD and perceived by them as lacking in paediatric care (Burström et al., 2016, Burström et al., 2017, Catena et al., 2017). One participant said that the risks of pregnancy should be discussed in the early teens because it was a surprise to find out at 18 years old and it is relevant to younger people, because people can be sexually active before the age of 18 (Burström et al., 2016). In line with the young people, their parents expressed the same concerns around information about lifestyle factors and their effects on health, as well as concerns that their child/ren would not have sufficient disease relevant information to be able to manage daily life (Bratt et al., 2017).

Sub-theme : use of peer-support and education in groups

Young people in three studies described peer-learning activities and peer-support groups as positive and useful (Burström et al., 2017, du Plessis et al., 2018). Parents who were interviewed said that information about CHD provided in group settings was beneficial, allowing them to benefit from questions asked by others in the same situation (Bratt et al., 2017). The same group of parents also thought that peer-support was positive, allowing their young people to meet others with the same condition (Bratt et al., 2017).

Discussion

Results discussion

In investigating and collating the common themes amongst the studies presented in this literature review, it is clear some areas of transition and transfer for young people with CHD, as it looks today, are working well, and other areas need improvement. A summary of themes discovered in this review is included in Table 5.

In this discussion, the themes will be discussed with relation to the key elements and indicators of a successful transition, as described by Suris & Akre (2015). As well as in the context of research around transition and transfer of young people with chronic health conditions.

Participants in the included studies in this review viewed getting sufficient and timely information about the transition process as important, and when information wasn't provided about transfer to patients in time, felt insecure about their future care (Burström et al., 2017, de Hosson et al., 2021) or ended up not coming to appointments anymore (du Plessis et al 2018).

Getting information about their CHD, the impacts of lifestyle choices, such as smoking, sex, drugs, or the implications of heritability of their condition was also considered important by the young people with CHD and also their parents/caregivers. But many did not have sufficient information about their health status (Asp et al., 2015, Burström et al., 2016, Burström et al., 2017, du Plessis et al., 2018, Moons et al., 2009) and felt the lifestyle factor information in particular was lacking in the paediatric care setting (Burström et al., 2016, Burström et al., 2017, Catena et al., 2017). This is in line with other studies that have shown that young people with chronic congenital diseases perceive information about their health and lifestyle factors to be insufficient in transitional care (Fernandes et al., 2014). These results are also in line with the key elements of a transition programme “discussing with patient about risk behaviours and their influence on health”, “assuring good coordination between paediatric and adult professionals”(shortened hereafter to “assuring good coordination”), and “tailoring the transition plan to the needs of the patient and family” (Suris & Akre, 2015). Meadows et al (2009), also described clearly that education is a key part of the transition process, with information specifically about the process itself, as well as health related and lifestyle factor education. Not only that, but that nurses play a key role in this education for young people in transition (Meadows et al., 2009).

Important for “assuring good coordination” is the timing of transfer (Suris & Akre, 2015). This aspect was discussed by young people and their parents/caregivers in this study, with an emphasis on maturity rather than chronological age as the determinant of transfer timing. This is in line with previous research and a scientific statement from the American Heart Association (Sable et al., 2011, Viner, 1999). Viner (1999), suggests that timing should be based on developmental milestones of adolescence. Meadows et al (2009) also state that timing of transfer should be flexible and come at the end of a well performed transition process. The desire of young people and their families to tailor the timing of transition and transfer is also in agreement with the key element of “tailoring the transition plan to the needs of the patient and family” (Suris & Akre, 2015). Despite the recommendations and desires of

young people and their families, the authors were unable to find data on whether delaying or speeding up transfer to adult care leads to better transitional success.

The elements of “assuring good coordination” and “tailoring the transition plan to the needs of the patient and family” are also important when it comes to how young people feel about participating in their own care and planning of their transition (Asp et al., 2015, Burström et al., 2017, de Hosson et al., 2021). Also important here is the key element “including young person’s views and preferences to the planning of transition” (Suris & Akre, 2015). Young people wanted to participate more in their own care, but wanted the option to choose how much they did this (Asp et al., 2015). When the expectations on them were too high, they experienced a negative reaction towards increased participation (Asp et al., 2015). Patient participation is an often discussed theme in nursing, and has been identified as a core component of PCC (Kitson et al., 2012). By utilising PCC, healthcare providers should be in a good position to increase patient participation and contribute to successful transition programmes, as defined by Suris & Akre (2015). An example of the use of a PCC model to provide transition care is the STEPSTONES (Swedish Transition Effects Project Supporting Teenagers with chrONic mEdical conditionS) transition programme for young people with CHD (Acuña Mora et al., 2017, Saarijärvi et al., 2019). In this programme, young people and their parents were given in depth information about the transition process, as well as tailored information about their health and lifestyle factors (Saarijärvi et al., 2021) In an evaluation of the programme, young people described that they gained more confidence in how their future care would be in the adult setting (Saarijärvi et al., 2021). Young people were also positive about the opportunity to have the connection with a transition coordinator (a nurse) to be able to ask repeat questions about things related to their CHD (Saarijärvi et al., 2021).

The element “tailoring the transition plan to the needs of the patient and family” is also present when considering how the information is provided. Learning through group activities, and the use of peer-support were mentioned as favourable by both young people with CHD and their parents/caregivers (Bratt et al., 2017, Burström et al., 2017, du Plessis et al., 2018). This is in agreement with a study showing that less peer-support was correlated with worse feelings around transition for young people with other chronic conditions (Zimmerman et al., 2022). Participants in the STEPSTONES transition programme described that meeting others with the same condition made them feel less alone (Saarijärvi et al., 2021).

The transition success key element “Identifying someone within the team who will play the role of transition manager or coordinator”, as well as the key indicator “Patient building a trusting relationship with adult provider” were also relevant to the participants in this review. They expressed the importance of feeling secure and trusting their new care team. By establishing a trusting relationship patients are more likely to engage in their care (Leslie & Lonneman, 2016). Leslie & Lonneman (2016) also mention different ways to ensure trust and security such as “communication” and “connection”. By utilising PCC and its collaborative planning and active listening, a trusting relationship can be built in line with the results from Leslie & Lonneman (Leslie & Lonneman, 2016). This is consistent with the results in this review, the participants described that when they had a chance to meet the new care team, either through a meeting arranged by the transition coordinator (de Hosson et al., 2021) or otherwise (Asp et al., 2015), it helped them feel secure and gain trust in the new team but also communicating their worries was another way to establish trust (Asp et al., 2015). This security and trust was lost when meeting the new care team didn’t happen (du Plessis et al.,

2018, Asp et al., 2015). These also relate to having a successful transition. A study investigating how to improve transition and transfer found that meeting the adult care team before transition would have been helpful (Tuchman et al., 2008). This approach is further highlighted in the STEPSTONES programme where both a planned transfer that includes a transfer meeting where doctors and nurses participate, as well as an opportunity to view the adult clinic, contributed to a sense of security (Saarijärvi et al., 2021). The use of a transition coordinator in the STEPTSONES programme was perceived as positive for both young people and their parents and enhanced the feelings of trust in the care team (Saarijärvi et al., 2021). The use of a transition coordinator has also been suggested by many as a means of better assisting the transition process (Madge & Byron, 2002, Meadows et al., 2009, Viner, 2001).

The key indicator of a successful transition “patient and family satisfaction with the transfer of care” and the key elements of “parents should be included in the process of transition” and “discussing with patient and family about self-management” are relevant to the experiences of the participants in this review (Suris & Akre, 2015).

The parents in this study experienced an ambivalence about leaving responsibility of care over to their young person. Repeatedly parents expressed that their young person being responsible for their care in the future was a normal and natural progression, but the ambivalence came about due to a variety of factors (Bratt et al., 2017, Burström et al., 2016, Coyne et al., 2019, de Hosson et al., 2021) Both young people and their parents/caregivers experienced that transition was difficult for the parents, and young people were clear that their parents were a support, but could also be perceived as overprotective (Asp et al., 2015, Burström et al., 2017, Catena et al., 2017, Moons et al., 2009). Parents were also reluctant to give up control in relation to the young person taking over responsibility for their own care (Coyne et al., 2019, de Hosson et al., 2021).

When taking more responsibility for their care, young people were all aware that they needed to do it but some had a lack of confidence in their self-management and communication skills (Coyne et al., 2019). These results are in direct agreement with Meadows et al (2009), who described parents as sometimes being a barrier to transfer, with parents perceiving transfer as a loss of control and having concerns that the young person will not have sufficient self-management skills. Previous research has shown that parents are less scared to let go of control over the young person’s care when they perceive that the young person has sufficient self-management skills to manage on their own (Fernandes et al., 2014). This is in line with the recommendations from Suris & Akre (2015) that discussions of self-management are a key element of a successful transition programme. These skills that have been highlighted by other research as key factors to be included in a formalised transition programme (Clemente et al., 2016, Grant & Pan, 2011, McDonagh, 2005, Meadows et al., 2009, Paine et al., 2014, Rapley & Davidson, 2010, Sable et al., 2011).

One way of helping parents cope with the shift in responsibility could be participation in a formalised transition programme. Both patient and family satisfaction has been shown to increase when a formalised transition programme is implemented (Shaw et al., 2007). Participating parents in the STEPSTONES transition programme described that they were taught how to take a step back to become a support system rather than a caregiver (Saarijärvi et al., 2021). Though some parents also felt that they didn’t have enough participation in the

programme and wanted more information about their young person's care, which they felt was lacking (Saarijärvi et al., 2021).

By implementing transition programmes, parents who feel conflicted may be afforded the opportunity to learn how to take a step back while at the same time having support from other parents in the same situation.

Method discussion

A literature review was chosen as the method to investigate experiences and expectations of young people with CHD and their parents/caregivers. It felt appropriate to only choose qualitative studies in this literature review due to the fact that qualitative methods are used to answer questions about experience, meaning, and perspective, primarily from the participant's perspective (Hammarberg et al., 2016).

Multiple academic databases were searched, such as PubMed that includes an extensive amount of data but also CINAHL and Scopus to ensure that all the relevant data would be found within the area of interest (Östlundh, 2017). According to Henricsson (2017) by doing so this achieves trustworthiness in the review. An EndNote library was also used as the database came from a group that had done a scoping review of available literature on the topic of transition of care with chronic illnesses (Acuña Mora, 2019). This was felt to be a good complement to the existing searches and ensured that articles were not missed that might be excluded by the inexperienced search skills of undergraduate students. The search terms used for literature searches were developed based on a SPICE structure and to further expand the terms synonyms were used. The usage of Boolean terms, truncation and phrase searching contributed to us getting an exhaustive and appropriate amount of articles for this review by using these different approaches in order to establish trustworthiness (Willman & Stollts, 2017).

Inclusion and exclusion criteria were introduced and were necessary for obtaining valid data that would answer the aim, inclusion criteria such as articles being peer reviewed also strengthens credibility in this study (Henricson, 2017). It was considered appropriate to choose studies from high-income countries due to the lack of infrastructure and resources in low-income nations, services to this patient population are limited and there are many fewer people who survive to adulthood to make use of a formal transition programme (Webb et al, 2015). Not only that, the majority of research is undertaken in high-income countries and data from low-income countries may not be readily available (Acuña Mora et al., 2019). While the authors did their best to be cognisant of their own preconceived notions and lived experiences when interpreting the data, there is always a risk for bias when humans perform research and this should not be discounted.

8 articles were found for inclusion that were published within the last 10 years and an article from 2009 was chosen for inclusion to increase the breadth of included data. There is certainly a risk that more relevant research may have been missed by the use of this inclusion criterion in the last 10 years. However, by including an article that was referred to in 5 of the 8 already included articles, that was from more than 10 years ago increased the breadth of data included while not flooding the pool of relevant research. This could have been a risk if the inclusion criterion was, for example, 15 years.

The article from 2009 was found using a secondary search, which according to Östlund (2017) is an effective method to get a good result. An article was included that had participants that were up to the age of 30 years old (du Plessis et al., 2018). This is also outside the framework set up around the notion of “young people”, defined as those between the ages of 10 and 24 (WHO, 2019). However, according to Knauth et al (2006) transition starts before adolescence and continues “until they are capable of taking full responsibility for their care”. While the du Plessis article included participants beyond the age that was chosen for inclusion, it could be argued that adults up to the age of 30 may not be capable of taking full responsibility for their care, especially considering that young people with chronic illnesses often have an infantilised self-image, promoting dependence (Meadows et al., 2009).

Another factor to consider is that one article (Coyne et al., 2019) included participants that had other chronic illnesses as well as CHD participants. This could potentially cause the results to be less transferable or appropriate for the aims of the study. Despite this, it was considered important to include this study, as it had important information about parents’ perspectives on transition and transfer, perspectives that are not represented in many studies. While not exclusively the perspectives of young people with CHD and their parents/caregivers, the participants in Coyne et al(2019)’s study all had chronic illnesses (cystic fibrosis, type 1 diabetes and CHD), and many of the same issues around education, information, timing, parental roles, trust, uncertainty, and self-management are applicable to these patient populations (Chiang et al., 2021, Zack et al., 2003). The authors reviewed and compiled the results together, highlighting the similarities found in the articles in collaboration with one another and creating new themes and sub-themes. Credibility is further applied when the assigned supervisor reviewed the results descriptions.

Clinical implications

The results of this study indicate that communication, security and trust are key factors for young people and parents’ satisfaction for a successful transition. Nurses play a very important role in the transition process and for that reason it could be suggested that nurses should be given proper guidance to make sure they make use of a person-centred care model to deliver improved transition care, preferably in a formalised transition programme. The focus should also be on providing extra training for nurses to facilitate their role as specialised transition coordinators. By providing this training for nurses, they can be involved in educating young people about the transition process, CHD specific education and acting as a bridge, and trusted caregiver, between care teams.

Future research

Person-centred care as discussed in the background is not about patients being passive recipients of care, but is about taking into consideration that which constitutes a person is more than just a patient, by being aware of the person's social circumstances (Ekman et al, 2011a). Social determinants of health are discussed in the literature as factors that affect a person's health that are determined by education, income, racial and ethnic background amongst other things (Lopez et al., 2022). One example is that people in North America can experience health disparities due to structural racism that appears at different levels, such as on an *individual level* that comes down to microaggression and implicit bias but also on a

populational level where the access to specialised care and prenatal care is limited along with the high cost of care and missing insurance leads to poorer outcomes (Lopez et al., 2022). These factors are associated with higher mortality and morbidity amongst people with congenital heart disease (Lopez et al 2022). So while this study looked at the population of young people with CHD more generally, it is of interest to put efforts into investigating within subgroups of this population. Lopez et al (2022) highlight the issues of social determinants of health amongst people with CHD in the US, but how this looks in the rest of the world, and in particular Sweden has yet to be investigated. It would be of interest to look at how the social determinants of health may impact on healthcare provision amongst young people with CHD in Sweden. And further what role nurses can play in providing equitable care, in line with their ethical duty (International Council of Nurses, 2012).

Conclusion

Young people with CHD and their parents/caregivers need person-centred care during the transition to adult care. Care that considers them as individuals with their own strengths, weaknesses, resources and capabilities. Care that provides them with information at the right time. A care environment that fosters trust in the care team and supports them to become capable of self-management and with sufficient communication skills to be able to advocate for themselves.

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Attachment

Author Year Country	Title	Aim	Method	Selection	Results	Quality according to Forsberg & Wengström
Asp <i>et al</i> 2015 Sweden	Transfer to Adult Care- Experiences of Young Adults with Congenital Heart Disease	The aim of the study was to explore the experiences of young adults with congenital heart disease in Sweden after transfer from the paediatric cardiac clinic to the adult congenital heart disease clinic	Qualitative descriptive study Open ended questions using an interview guide	31% male, 20-24 years old 44% moderate lesion grade 56% complexity grade lesion 100% had had surgery transitioned between 18 and 21 years old <i>Clinical visiting frequency</i> every 6 months:31% every year 31% every two years 25% every 3-5 years 12%	Categories: Feeling secure during the transfer process Experiencing trust in the care Expecting to be involved Assuming responsibility for one's health is a process Lack of knowledge leads to uncertainty	High

Burström <i>et al</i> 2016 Sweden	Adolescents With Congenital Heart Disease and Their Parents Needs Before Transfer to Adult Care	To identify and describe the needs of adolescents with CHD and their parents during the transition before transfer to adult care	Qualitative study Exploratory design Individual semi structured interviews	13 adolescents (6 boys, 7 girls) and 12 parents (5 fathers, 7 mothers)	<i>Adolescent categories:</i> -change of relationships -knowledge and information -daily living <i>Parent categories:</i> -change of relationships -daily living	High
Bratt <i>et al</i> 2018 Sweden	Do not forget the parents- Parents' concerns during transition to adult care for adolescents with congenital heart disease	To explore parents' expectations and needs during their adolescents' transition to adult care	Qualitative Semi structured interviews, analysis with qualitative content analysis	Parents: median age 49,5 (45-56 range), 83% mothers, Adolescents 56% female, median age 16(14-18 range), disease complexity 81% complex, 19% moderate	Theme 1: feeling secure the importance of being prepared and informed subcategories: -being involved, prepared and informed -being assured the adolescent gets essential information - preferred information channels and methods Theme 2: recognising when to hand over at the right time Subcategories: -start of transition process and shift in roles -the process of handing over responsibility	High

Burström <i>et al</i> 2017 Sweden	Adolescents with congenital heart disease: their opinions about the preparation for transfer to adult care	The aim of the study was to explore what adolescents with CHD view as important in preparation for transfer to adult care	Qualitative Content analysis with a manifest approach from focus group interviews	n =17 Male 7, female 10 Age 14 years: 5 15 years: 4 16 years :2 17 years: 2 18 years: 4 Mean age 15.8 <i>Moderate lesions:</i> 2 <i>Complex grade :15</i>	Main category: <i>Becoming a manager of the condition</i> Sub categories: Sufficient knowledge about the health Be a participant in the care Parental Support Communicating with others about the health	High
Catena <i>et al</i> 2018 Canada	"Not such a kid thing anymore": Young adults' perspectives on transfer from paediatric to adult cardiology care	To assess perspectives on transfer in 18-25 year olds followed in paediatric vs ACHD clinics	Qualitative Interviews performed in a separate cross sectional study were used as content for analysis Included both patients in paediatric and adult care	21 adults (9 women), 13 in adult care, 8 via paediatric care	Participants called their paediatric care "a little home" "a personal connection, a comfort thing" - paediatric cardiology healthcare team -parents have a hard time letting go of control -but parents are also a resource and are often wanted at appointments/for advice -negative experiences happened when patients were forced to transition to adult care before they felt ready -positive experiences were coupled with independence gained in other areas of life	High

					and questions around adult topics were brought up at adult clinics, with regards to pregnancy for example	
Coyne et al 2019 Ireland	Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences	To explore AYAs, parents and healthcare professionals' views regarding transition from paediatric to adult services within one health system	Qualitative Thematic analysis from semi structured interviews	<i>Cystic fibrosis</i> - patients 14, parents 11, HCP 11 <i>Type 1 Diabetes</i> - patients 17, parents 13, HCP 15 <i>CHD</i> - patients 16, parents 13, HCP 6	Four themes, and 13 categories Theme 1: Transition process and preparation -practices and preparations for transition -timing of transition Theme 2: Expectations of adult services: acceptance and loss -a culturally different environment -acceptance of the move -loss of security and relationships -concerns over shift in responsibility Theme 3: Transition to adult services- a culture shock -no man's land -culture shock -shift in responsibility Theme 4: Flourishing or floundering in new roles -facilitating the shift in roles	Medium: included -Cystic fibrosis patients, diabetes patients and HCP -no description of questions asked -selection method not described

					-flourishing or floundering in new roles -challenges of 'stepping back' for parents	
de Hosson <i>et al</i> 2021 Belgium	Needs and Experiences of Adolescents with Congenital Heart Disease and Parents in the Transitional Process: A Qualitative Study	To further explore the experiences and care needs of adolescents with CHD and a group of parents of adolescents with CHD in the entire transitional process, including the post-transfer period.	Qualitative Phenomenological analysis from semi structured interviews	Adolescents: 9 Average age 17.8 3/6 female/male Parents: 12 Average age of child: 18.4 9/3 female/male child gender: 6/6 female/male	Five themes 1. having mixed feelings about leaving paediatric care 2. being prepared and informed 3. shifting responsibilities and roles 4. being accompanied during consultations 5. gaining trust in new healthcare	High
du Plessis <i>et al</i> 2018 Australia and New Zealand	Traversing the liminal: what can Fontan adults' transition experiences and perspectives teach us about optimizing healthcare?	To explore young adults' (18-30) transition experiences and perspectives with the aim of informing systems to empower and engage young people with Fontan circulation in their healthcare as they move to adulthood	Qualitative study Thematic analysis Interviews conducted over a period of 6 months	Participants' contact details were obtained from a registry of patients with Fontan circulation and 20 people were randomly contacted from that list who met the inclusion criteria (aged 18-30)	Six themes : 1. The adult congenital care experience is undeniably different from paediatric care 2. Suboptimal preparation for transition to adult care contributes to patient disengagement 3. Ongoing cardiac health education in the adult setting (and about the adult health setting) is important	Medium: No discussion of methodological weaknesses/deficiencies or risk for bias

					<p>4. Ideally, transfer should occur in the context of joint sessions between the paediatric and adult teams</p> <p>5. Consultations with highly specialised adult congenital cardiologists are ideal</p> <p>6. Support networks are helpful</p>	
Moons <i>et al</i> 2009 Belgium	Expectations and Experiences of Adolescents with Congenital Heart Disease on Being Transferred from Pediatric Cardiology to an Adult Congenital Heart Disease Program	To investigate the expectations and experiences of adolescents on transferring from a paediatric cardiology program to an adult congenital heart disease program.	Qualitative study Semi-structured interviews Interpreted with a phenomenological approach	<p>14 participants</p> <p><i>Age:</i> 15 years: 2 16 years: 8 17 years: 4</p> <p><i>Frequency of follow up:</i> 6 months: 2 1 year: 7 2 years: 5</p>	<p>6 themes:</p> <p>1. Leaving paediatric cardiology is seen as normal</p> <p>2. Leaving behind familiar surroundings</p> <p>3. A positive wait-and-see attitude toward the adult congenital heart disease program</p> <p>4. Adjusting to a new environment</p> <p>5. A need for better information</p> <p>6. A shift in roles between the adolescent and the parents</p>	High