


BMJ Open Qualitative study of facilitators and barriers for continued follow-up care as perceived and experienced by young people with congenital heart disease in Sweden

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ABSTRACT

In-depth understanding of factors perceived by young people with congenital heart disease (CHD) to affect continued follow-up care is needed to tailor preventive strategies for discontinuation of follow-up care. To identify facilitating factors, low-prevalence settings in terms of discontinuation should be investigated.

Objective This qualitative study describes factors affecting continued follow-up as perceived and experienced by young adults with CHD.

Participants Using a mixed purposive sampling technique, 16 young adults with CHD were included. Three participants had discontinued follow-up care and 13 had continued follow-up care after transfer.

Setting Participants were recruited from all seven university hospitals in Sweden, which is considered a low-prevalence setting in terms of discontinuation.

Design Individual interviews were performed and subjected to qualitative content analysis.

Results The analysis resulted in three main categories, illuminating factors affecting continued follow-up: (1) motivation for follow-up care; (2) participation in care and sense of connectedness with healthcare provider (HCP) and (3) care accessibility. The choice of continuing follow-up or not was multifactorial. Knowledge of your CHD and the importance of continuing follow-up care was a central factor, as well as experiencing CHD-related symptoms and having ongoing or planned medical treatment or interventions. Sensing a clear purpose with follow-up care was facilitating, as was feeling well treated and cared for by HCPs. Practical aspects, such as travel distance was also stressed, as well as active invitations and reminders for visits.

Conclusion Factors on both patient, hospital and healthcare system level were raised by participants, stressing the importance of holistic approaches when developing preventive strategies for discontinuation. There is a need for improved skills and competencies among HCPs, as well as a person-centred approach to follow-up care. In addition, specific healthcare needs and remaining transitional needs after transfer to adult care require careful consideration to prevent discontinuation.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study was performed within a low prevalence setting of discontinuation of follow-up care and provides a unique opportunity to identify facilitators for continued follow-up care.
- ⇒ Interviews gave an opportunity to explore young people's own perceptions and experiences of barriers and facilitators for continuing follow-up care after transfer.
- ⇒ Diversity of patient characteristics is a strength, considering both congenital heart disease complexity and the fact that both participants with and without follow-up care were included.
- ⇒ The geographical spread of participants is a strength, covering all university hospitals in Sweden.
- ⇒ A limitation is that few participants were without follow-up, which gives this perspective less robust data.

INTRODUCTION

To safeguard future health of a rapidly expanding population of young people with congenital heart disease (CHD), timely delivery of appropriate follow-up care across the life spectrum and healthcare settings is required.¹⁻³ Follow-up guidelines and adult CHD (ACHD) programmes have been established.¹⁻⁵ However, despite the recommendation that the vast majority of CHD patients receive continued follow-up care,^{1,3} high rates of discontinuation of care among young people with CHD are being reported.⁶⁻²³ In this paper, the term discontinuation of care is used as an overarching term for describing 'a disrupted chain of follow-up care'. Terms and definitions in this area differs greatly and often included aspects such as inappropriate time intervals, care levels or complete disruption of follow-up care.^{13,24}

Discontinuation of care is a concern as it is associated with adverse outcomes, such as increased morbidity and need for urgent (re)interventions.^{6 25} There is a need to prevent discontinuation of follow-up care to safeguard the future health of this young generation.

Proportions of discontinuation differ across countries and settings, ranging from 3.6% to 62.7% of patients experiencing some degree of discontinuation.¹³ The reasons for this broad ranges in proportions are still undetermined, however, factors such as healthcare access or implementation of systematic and mandatory transfer of care could be of influence.¹³ Predictors for discontinuation from a patient-level perspective have previously been investigated and generated opposing findings in terms of which factors are to be considered as predictors.²⁴ Few studies have addressed young peoples' perceptions and experiences of factors affecting continued follow-up care after transfer. Three of the existing studies have identified self-reported reasons for discontinuation, missed appointments²⁶ and reasons for returning to follow-up care.⁹ Reasons for discontinuation were for example, being told that follow-up care was not needed, feeling well,⁶ fear of bad news, insurance issues,^{6 9} losing track of time and parents being less involved.⁹ Self-reported reasons for missing appointments included, missed appointment letters due to unstable housing, weather conditions making travel difficult, difficulty scheduling appointments and anxiety about cardiac health.²⁶ Reasons for returning to care were, for example, new symptoms and the desire to prevent complications.⁹

In-depth understanding of factors perceived by young people as affecting continued follow-up care is needed to tailor effective preventive strategies for discontinuation. The majority of prior studies have been performed within cohorts characterised by large proportions of discontinuation of follow-up care, ranging from 25% to 62.7%.^{6 9 26} Settings characterised by low proportions of discontinuation should be investigated to identify facilitators for successful delivery of follow-up care. Based on results from a previous multicentre study,¹⁴ Sweden could be considered a low prevalence setting where only 6.6% of patients failed to attend 'at least one adult outpatient visits within 5 years after intended transfer to adult care'.¹⁴ The reasons for the low proportions in Sweden remains unknown, however, significant differences across the seven hospitals indicate influence of hospital related factors.¹⁴ Specific factors of relevance in this setting could be highlighted through inquiry about young people's perceptions and experiences of facilitators and barriers to continue follow-up care.

Aim

The aim of this study was to describe factors affecting continued follow-up care after transfer, as perceived and experienced by young adults with CHD.

METHOD

Study design

A qualitative descriptive study was performed in Sweden, based on perceptions and experiences of Swedish young adults living with CHD and who had previously transferred follow-up care from paediatric to adult healthcare providers (HCPs). This study adheres to a qualitative research design, whereby individual interviews were conducted and subjected to qualitative content analysis, based on Graneheim and Lundman's methodological description.²⁷

Patient and public involvement

Neither patients nor the public was involved in the design, conduct, reporting or dissemination plans of our research.

Setting and eligibility

In Sweden, patients with CHD transfer from paediatric to adult care at 18 years of age. Eligible participants for this study were included from a cohort previously recruited for a Swedish multicentre study.¹⁴ This cohort comprised 654 patients diagnosed with CHD and born between 1991 and 1993 and seen at one of the seven specialist paediatric CHD centres in Sweden during 2005–2011. Follow-up status in the adult settings was determined through hospital administrative systems or registries at 23 years of age, meaning 5 years after intended transfer to adult care.¹⁴

In this study, both patients with and without follow-up care 5 years after intended transfer were included. Patients previously confirmed to have 'at least one adult visit within 5 years after intended transfer'¹⁴ were eligible for inclusion as 'in follow-up care' participants. Patients confirmed to have 'no adult visit within 5 years after intended transfer'¹⁴ were eligible for inclusion as 'no follow-up care' participants. Participants were included from all seven university hospitals. Patients with cognitive impairment were excluded, as well as patients who were not able to understand and speak Swedish.

Sampling

A mixed purposive sampling technique was used, in which several sampling strategies were combined.^{28 29} Different approaches were used for participants with and without of follow-up care.

Sampling of participants 'in follow-up care'

For patients 'in follow-up care' a combination of maximum variation and random sample techniques was applied. In a maximum variation approach, key dimensions are identified, and cases selected to create variation across these dimensions. In a random sample approach cases are randomly selected from a larger sample.^{28 29}

First, the maximum variation approach was used.^{28 29} Three key dimensions were considered: 'sex', 'clinical location' and 'complexity of CHD' (categorised as either mild, moderate or severe complexity).² These dimensions were chosen as they were previously reported as

Table 1 Demographics and clinical characteristics

	n (%)
Follow-up status	
‘No follow-up care’ group	3 (19)
‘In follow-up care’ group	13 (81)
Year of birth	
1993	8 (50)
1992	4 (25)
1991	4 (25)
Sex	
Female	8 (50)
Male	8 (50)
Complexity of CHD	
Mild complexity	5 (31)
Moderate complexity	8 (50)
Severe complexity	3 (19)

CHD, congenital heart disease.

predictive for discontinuation.^{9 10 14 15 18 30} We strove to keep proportions of included participants from each dimension as similar as possible to the previous multicentre study¹⁴ in order to make our sample reflect the cohort of the previous multicentre study.¹⁴ Second, the random sampling approach was used,^{28 29} where participants from each key dimension were randomly selected.

Sampling of participants with ‘no follow-up care’

For participants with ‘no follow-up care’ a convenience sample approach was used where cases are selected based on easy access.^{28 29} The convenience sample approach was chosen as the number of patients with no follow-up care was limited.

Participant demographics

Study information and invitations were sent to 27 young adults, of which 59% (n=16) replied and consented to participate, 19% (n=3) had no follow-up during the 5 years period after intended transfer to adult care and the remaining 81% (n=13) attended at least one adult outpatient visit during the same 5-year period. All participants who replied consented to participate. No participants actively refused participation. Participants were included from all university hospitals in Sweden (n=7). Age at the time of interview ranged from 27 to 29 years of age. Proportions of severe, moderate and mild complexity lesions were 18%, 50% and 31%, respectively, and 50% of participants were women (table 1).

Data collection procedure

Participants received a study invitation by post, accompanied by a consent form and stamped response envelope. Individuals who agreed to participate were contacted by telephone. Data saturation for participants ‘in follow-up care’ was attained after 16 interviews. All participants

with ‘no follow-up care’ who replied were included. All interviews were conducted privately on the telephone and scheduled when convenient for participants. Participants gave their consent for all interviews to be audio-recorded. Field notes were taken during the interviews. No repeated interviews were performed. The first author (Registered Nurse, PhD-student) conducted all the interviews and had no prior relation to any of the participants.

A semistructured interview guide developed by the authors was used, containing open-ended questions about transfer from paediatric to adult care and questions related to factors affecting continued follow-up (online supplemental material_interview guide). The interview guide was evaluated after the first interview and considered satisfactory. Examples of questions were, ‘Can you tell me about your transfer from paediatric to adult care?’, and ‘What made you attend your first appointment in adult care?’. Participants retrospectively described and reflected on factors perceived or experienced to affect continued follow-up. Interviews lasted 13–56 min with participants speaking freely—questions were only asked if they became silent.

Data analysis procedure

Interviews were transcribed verbatim by the first author and read through repeatedly to attain a deeper understanding. Transcripts were not returned to participants for comments. Qualitative content analysis, as described by Graneheim and Lundman,²⁷ was performed, using an inductive approach. Meaning units addressing study purpose were identified, condensed and coded by the first author. In an iterative process, codes were clustered into tentative categories, which were considered descriptive. Next, subcategories and main categories were formulated (table 2). No software was used. Continuous shifting between the complete text and its parts ensured trustworthiness, as well as reflection and discussion between first and last author during the analysis process. Participants did not provide feedback on the findings.

Ethical considerations

The study was performed in accordance with the 2013 Helsinki declaration.³¹ Gothenburg regional ethics review board approved the study (application numbers: 632-15 and T917-16). Participants received information about the study and means of participation and were informed of its voluntary nature and their right to terminate participation at any time. All participants signed consent forms. The integrity of participants was protected through coding of data material.

RESULTS

Three categories illuminated factors affecting continued follow-up care (figure 1). Participants with and without follow-up care are presented as a whole. Differences between participants with and without follow-up within each (sub)category are described if relevant. This

Table 2 Example of coding structure

Category	Care accessibility	
Subcategory	Practical and flexible follow-up	Expenses and distance to care
Codes	Long-term planning of follow-up is important	Travel distance to care can be a barrier
	Flexibility with time for appointments can ease follow-up	Travel distance to care is less of an issue when follow-up is less frequent
	Accessibility affects continued follow-up	Travel expenses can be a barrier
	Follow-up care should be easy	Patient fees is not a barrier
	Follow-up care should be practical	Patient fees can be a barrier
	Leave from work can be a barrier to follow-up	Limited access to ACHD clinic can be a barrier
	Less comprehensive controls can ease follow-up	Follow-up care can limit resettlement
	The time of the appointment is not a barrier	Follow-up care affects life

ACHD, adult congenital heart disease.

approach was chosen since few differences between participants with and without follow-up were identified.

Motivation for follow-up care

Feeling motivated was a facilitating factor for continuing follow-up care. Factors related to motivation are presented in two subcategories, the first being perception of the heart defect and the second being acceptance or denial.

Perception of heart defect

Participant described how experiencing heart related symptoms increased motivation for follow-up care. Future intervention needs and ongoing treatment such as a pacemaker or prescriptive medication could increase motivation as well as the desire to know your current status and prevent future complications. Participants described how

Perceived and experienced barriers and facilitators for continued follow-up care			
Categories	Sub-categories	Barriers for continued follow-up	Facilitators for continued follow-up
Motivation for follow-up care	Perception of heart defect	<ul style="list-style-type: none"> Lack of motivation for follow-up Feeling no purpose with follow-up Experiencing few CHD related symptoms Having a stable condition Receiving the same information at every visit Lack of knowledge about CHD Feeling no risks with CHD Fear of dying and high levels of anxiety Attitudes towards follow-up influenced by parents Trust in the health care system to discover discontinuation 	<ul style="list-style-type: none"> Feeling motivated for follow-up Desire to prevent future complications Fear of dying and moderate anxiety Prescriptive medications Ongoing treatment Knowledge about future intervention needs Interaction with HCP's about CHD Knowledge about CHD Information about purpose with follow-up Information about risks with discontinuation
	Acceptance or denial	<ul style="list-style-type: none"> Denial of CHD Ambivalence towards CHD CHD and follow-up is not part of every day life 	<ul style="list-style-type: none"> Acceptance of CHD Develop tools for acceptance of CHD
Participation in care and sense of connectedness with healthcare provider	Support and self-management	<ul style="list-style-type: none"> Insufficient information about follow-up Participating parents reducing self-management skills Personal responsibility for care Forgetfulness Not being invited for follow-up Having missed appointments Not knowing whom to contact Not knowing if you are being expected to schedule the appointment yourself 	<ul style="list-style-type: none"> Active invitation to clinic Reminders before appointments Encouragement from clinic and family Extra encouragement when missing appointments Information about follow-up intervals and follow-up need
	Safe and holistic care	<ul style="list-style-type: none"> Sense of not belonging to the clinic Stressful environment Less of regard for fear and anxiety from HCP's Lack of information and participation in care Disrupted care-relationships Shallow connection with adult HCP's Anxiety about transfer Poor experiences of care Not feeling well treated Lack of CHD specific competencies in HCP's Lack of attentions for emotional and mental issues from HCP's 	<ul style="list-style-type: none"> Sense of belonging to the clinic HCP continuity Emotional bonds with HCP Quick establishment of relationship with adult HCP's Clear and sufficient information about follow-up care and transfer Meeting adult HCP's before transfer Feeling well treated and cared for Collaboration with other health care settings
Care accessibility	Practical and flexible follow-up	<ul style="list-style-type: none"> Follow-up arrangements feels unpractical 	<ul style="list-style-type: none"> Long term planning of follow-up Flexibility with appointments Opportunity to reschedule appointments Follow-up planned after individual preferences
	Expenses and distance to care	<ul style="list-style-type: none"> Travel distance to care Patient fees Limited number of ACHD clinics in the country 	<ul style="list-style-type: none"> Manageable travel distance Manageable amount of time allocated to travel Being informed about patient fees

Figure 1 Categories and subcategories of factors perceived and experienced by young people to affect continued follow-up care. Identified barriers and facilitators for continued follow-up care. CHD, congenital heart disease; HCP, healthcare provider.

their condition could deteriorate without their noticing, and that they attended follow-up to detect changes and intervention needs well in advance and also to gain a sense of relief. Interaction with HCP about the condition and receiving information about the purpose of follow-up, as well as risks related to discontinuation, were perceived to increase motivation.

In contrast, lack of symptoms was perceived to decrease motivation. Some participants described follow-up care as important and natural. However, lack of perceived purpose to follow-up and perceiving low or no risk decreased motivation and was related to the stability of the condition, and lack of new information from HCP (quote 1 and 2, [table 3](#)). In addition, participants described lack of knowledge and understanding of their CHD and its long-term effects as reducing motivation. Thus, knowledge of CHD and risks related to discontinuation were emphasised as important in increasing motivation, particularly if symptoms were only experienced to a low degree. Fear of dying and a moderate degree of anxiety was perceived to increase motivation. However, high levels of anxiety could create a barrier where the young person did not want to know the status of their condition (quote 3, [table 3](#)). Many participants took the matter of being invited to follow-up very seriously and some participants described great trust in the adult clinic and follow-up system and did not consider it their place to question follow-up needs. They would let several years pass before reaching out to the clinic themselves (quote 4, [table 3](#)).

Some participants indicated that parental influence could decrease their motivation to attend follow-up, since parental attitudes towards follow-up care and transfer could influence their own attitudes (quote 5, [table 3](#)).

Acceptance or denial

As follow-up was not part of everyday life, some participants only reflected on the consequences of being without follow-up when confronted with it. Both participants with and without follow-up stated struggling with acceptance and ambivalence towards disease and follow-up as a barrier. While follow-up was facilitated by acceptance, the young people required tools to develop this. Denial was described as a barrier in that the young person did not want to be reminded about CHD (quote 6, 7 and 8, [table 3](#)).

Participation in care and sense of connectedness with HCP

Participation in care and sense of connectedness with HCPs was facilitating for continued follow-up care. Related factors are presented in two subcategories, the first being support and self-management and the second being safe and holistic care.

Support and self-management

Both participants with and without follow-up mentioned aspects of support as facilitating. Active invitation to follow-up by post and text-message reminders a few days

ahead of the appointment were facilitating and important to both groups of participants (quote 9, [table 3](#)). As CHD and follow-up did not have a place in everyday life, forgetfulness and not being invited were perceived as barriers. In case of a no show for a scheduled appointment, extra encouragement from the clinic was particularly important. One patient without follow-up described the decision of whether or not to continue follow-up as highly multifactorial and that getting back into care once you have fallen out was particularly challenging, as it demands personal responsibility (quote 10, [table 3](#)).

Extra reminders or encouragement from family were perceived as facilitating, although involved parents could create a barrier for personal participation and self-management.

Insufficient information was perceived as a barrier (quote 11, [table 3](#)). Not knowing who to contact and whether you were expected to schedule appointments yourself created uncertainty. Information about follow-up intervals, CHD and the need for follow-up was perceived as facilitating.

Safe and holistic care

A sense of being in safe hands was described as facilitating, as were informed adult HCPs with access to paediatric records and knowledge of CHD and specific healthcare needs. Feeling well treated and cared for was also described as facilitating, whereas having poor experiences of care or treatment was a barrier.

The care-relationship between patient and HCP was perceived as facilitating. Seeing the same physician for years within paediatric care could provide security and a sense of personal connectedness. However, when the relationship was disrupted by transfer, this could induce stress or anxiety. Emotional bonds could lead to obligations, and when bonds were disrupted, participants described experiencing less purpose related to follow-up (quote 12, [table 3](#)). For some participants, upcoming transfer induced anxiety, although meeting adult HCP within a paediatric setting prior to transfer could ease this. Establishing contact with adult HCP as soon as possible on transfer was described as important, as was receiving clear information about joining the adult clinic.

A contrast in the behaviours and attitudes of HCP in paediatric and adult clinics was described. Some participants in follow-up care perceived contact between patient and HCPs in the adult setting as more shallow and expressed a desire to feel that HCPs cared (quote 13, [table 3](#)). Some participants also described receiving less information and being less included in medical discussions. Several participants described how visits to adult care were conducted at a high pace, creating stress and difficulty posing questions (quote 14, [table 3](#)). Behaviours and attitudes of the HCP were perceived as stricter, and the young people's fear and anxiety were perceived to receive less attention. Adult HCPs were perceived as less equipped for conversations about emotions, fear of dying and mental issues compared with paediatric HCPs. Some

Table 3 Quotes of participants

Subcategory	Quote no.	Participant	Quotes
Perceptions of heart defect	1	Participant 1	<i>'During my entire upbringing...all memories I have are like... nothing happens...there is no risk...there is no reason for me to do this....'</i>
	2	Participant 1	<i>'If there is something to relate to...some statistics or something...that we do checks to avoid or ensure you have not reached a state... for me it doesn't feel like there ever was a risk for anything... my partner asked me what the danger is with my heart defect...and I was like....no it is not dangerous...there is nothing...nothing can happen... but if I would have known that there is a risk of having a heart attack for example, or that some impairment of my heart could emerge, then I would have had reason to make sure it didn't happen...'</i>
	3	Participant 2	<i>'I experience that either you're not worried and don't go, or you're so worried and don't want to know how things are and don't go...or you have just enough worry...well I take this seriously and make sure to do it when you are summoned instead of postponing....'</i>
	4	Participant 3	<i>'I think a lot of time would pass before I would've acted...I do... because I have great trust in the hospital and care in Sweden ...I would expect to be summoned...'</i>
	5	Participant 1	<i>'I wish and believe that it would've been different if someone had questioned my mother being with me every time...I believe the more you can handle and plan by yourself...the more power you get ...and then I probably would've related to it differently...now everything was related to my mother and it was hard for me to feel motivated....since I had no other reason to do it...'</i>
Acceptance or denial	6	Participant 8	<i>'well, like... I am born with this defect... or this issue... then I will go for checks for the rest of my life... that is just how it is...'</i>
	7	Participant 8	<i>'...accept the situation, a bit difficult to say but that's how it is... everyone is not born the same... unfortunately...'</i>
	8	Participant 4	<i>'Well if I don't go...the problem doesn't exist... then it is all fine.... though it may not be that good...'</i>
Support and self-management	9	Participant 7	<i>'I think that it is important to you receive an invitation, otherwise I think it is easy to forget... so it should be the hospital that keeps track on when you.... when it is time to come back... and that it's not up to... me as a patient, that I should keep track of... well now it has been three years... now it is time to book an appointment'</i>
	10	Participant 5	<i>'If you... lost track along the way, or it just ebbed away somehow...then it becomes ... a larger step and something you forget...'</i>
	11	Participant 3	<i>'...that you either should have received more information on the last visit at the paediatric clinic or that you should have received a letter or something from the adult clinic stating that well from now onwards you will be summoned this many times...where.... year....and explain a little what it is based on or something...I don't know...but somehow you should receive a little more information on how it should be...'</i>

Continued

Table 3 Continued

Subcategory	Quote no.	Participant	Quotes
Safe and holistic care	12	Participant 2	<i>'...I believe social relations or emotional bonds leads to obligations. That... here is something.... someone... people who care about me...where I feel safe...and of course this would be...if it was all down to this and it gets replaced... you could feel...shit the same, since it's not the same person who summons me....'</i>
	13	Participant 6	<i>'Participant: Connection with physician....is more evident than with nurses....in adult care that is... Interviewer: did you feel differently in paediatric care? Participant: Yes, there I had a good connection with everything and everyone'</i>
	14	Participant 6	<i>'If I were to snap my fingers, that quick...it is really like 'dish, dish, dish' ...it is not the same peace and quiet as the paediatric ward... it could probably induce stress within some...(...)I think they're just doing it quicker...but that way...as patient...you feel like nothing more than a check in the protocol...'</i>
	15	Participant 6	<i>'Something that surprised me was ... (...) well the heart defect can affect you mentally some times and how bad they are at discussion feelings...really (...) I think it is a great barrier, now that you mention it, it could probably make those who have the opportunity to stop going...'</i>
	16	Participant 4	<i>'In the beginning I felt...maladapted....why am I here...I don't fit here....basically they just stood and looked at me and wondered what I was doing there...you who are so young...it was really... it felt a bit strange...I'm sure it felt like I'm too big to go to paediatric care but I am too young to go to adult care... so I felt... well I feel... now it doesn't come every time I go but it's like you feel a bit more in the way...'</i>
Practical and flexible follow-up care	17	Participant 7	<i>'... also that they are flexible, so that it can be adapted to fit with my schedule and that I can reschedule it if it doesn't fit with my work or my appointments or my school...'</i>
	18	Participant 1	<i>'There should be alternatives to make examinations more varying... so they don't need to be as comprehensive every year... my physician told me the major concern is my blood pressure, and I am like, do I have to spend 350 Swedish crowns to have a heart physician check my blood pressure... when I could have visited my local health centre?'</i>
Expenses and distance to care	19	Participant 9	<i>'ehhh... no if I were younger it would probably have been an issue then... eh... because it is not a verry long travel distance, it is not... 20 miles or 10 miles or anything like that, but it is a travel distance and if you are a little younger and insecure as I was back in time... then it could have been a bit of an issue...'</i>
	20	Participant 2	<i>' I recall seeking care after turning 18...realising...that I have to pay for it, and I was not prepared for it...I was sometimes completely broke... and needed to ask for an invoice... and... for me specifically, I had, I have parents which I could have turned to or which I have been able to turn to in such situations...but...this is absolutely something...something that changes after turning 18...'</i>

participants described how fear of dying and mental issues in themselves could be facilitating for continuing follow-up, although when needs were unmet, they became a barrier. Participants described how lack of initiative, interest, and concern from physicians regarding these topics generated frustration. Questions were seldom asked, and simply completing forms felt insufficient

(quote 15, table 3). Participants also described that cooperation between the ACHD clinic and psychiatric HCPs could be a possible facilitator, as well as engaged and observant HCPs who referred patients to alternative facilities if needed.

Sharing a waiting room with older people was described as a barrier, making some participants feel misplaced and

not belonging, which was reinforced by receptionists asking if they had come to the right clinic. Feelings of not belonging anywhere, as they were too old for paediatric care and too young for adult care were expressed (quote 16, table 3).

Care accessibility

Care accessibility was considered facilitating for continued follow-up care. Related factors are presented in two subcategories, the first being expenses and distance to care and the second being practical and flexible follow-up care.

Practical and flexible follow-up care

Participants in follow-up raised long-term planning and being informed well in advance about clinic appointments as facilitating. Flexibility regarding the time of day was desired, as was the option to reschedule since appointments had to fit in with patients' daily life, schedule and work arrangements. If participants perceived follow-up as planned after individual preferences and as practical and effective, this was described as facilitating (quote 17, table 3). They described how follow-up care sometimes could be more practical through coordination with other healthcare facilities (quote 18, table 3)

Expenses and distance to care

Travel distance and time allocated to travel were described as a potential barriers and was raised by both participants with and without follow-up. Travel distance between their residence and an ACHD clinic was described as a potential issue, due to being young and insecure or no longer being offered a lift (quote 19, table 3). Participants in follow-up raised increased distance to care as an issue when living temporarily somewhere else for study purposes. The limited number of ACHD clinics in the country was also described as a potential barrier, as it could mean long travel distances for the patients and a sense of curtailed choice regarding where to attend follow-up.

Some participants in follow-up mentioned that travel expenses and patient fees were a barrier. Expenses were described as a barrier if unexpected or when participants did not understand the need for follow-up, leading to frustration and a disinclination to spending money on it (quote 20, table 3).

DISCUSSION

Previous studies investigating predictors for discontinued follow-up highlight patient-related factors.²⁴ It is very likely that hospital-related factors also affect discontinuation, as significant differences in proportions exist across hospitals.^{9 14} The results obtained in this study identified both patient-related, hospital-related and healthcare system-related factors, highlighting the complexity of factors perceived to contribute to continued follow-up care for young people transferring their care from paediatric to adult healthcare facilities in Sweden.

Patient-related factors

Participants described their intrinsic motivation as facilitating continued follow-up and a lack of motivation as a barrier. Being in a stable condition and having no symptoms or not seeing the purpose of follow-up were described to decreased motivation. This indicates that low-risk, asymptomatic patients with stable conditions might be particularly vulnerable to discontinuation. Previous studies have confirmed this finding, highlighting either milder disease complexity as a significant risk factor for discontinuation or complex disease complexity as a protective factor.^{10 15 18 30} The results indicate a need to support patients in finding motivation for follow-up. Such motivation could be achieved through interaction with HCPs and the provision of clear information about the purpose of follow-up and the risks patients may face if they discontinue follow-up in the long run. If patients are reassured about the stability of their condition but receive no information on the importance of continuing follow-up, there could be an increased risk of discontinuation. However, too much emphasis on risks could hypothetically induce anxiety, which was described as both a barrier and facilitator for continuing follow-up. Individual assessment of information needs is recommended, and sufficient time should be allocated to address patients' level of disease-related knowledge and information needs. The majority of participants who expressed lack of motivation were 'in follow-up care', indicating a need for support in finding motivation, even when patients are already attending clinic.

Taking responsibility for follow-up could be challenging, as participants 'without follow-up care' described failure in this regard and stressed the need for extra support, especially when they had missed appointments. Forgetfulness and uncertainty about being expected to schedule your appointments were described by both participants with and without follow-up. These results highlight challenges with self-management and a need for support, both of which could be seen as persisting transitional needs. Indeed, when transitioning from childhood to adulthood and when transferring to a new adult HCP, transitional needs arise. Examples of transitional needs in this context include a need for education regarding CHD, future need for follow-up and treatment, symptoms to be aware of, lifestyle restrictions, family planning and support in how to navigate the healthcare system independently.³² Providing information at the point of transfer and expecting young people to recall this information several years later, during this vulnerable life-phase, is probably optimistic. The evaluation of persisting transitional needs could be improved in both paediatric and adult settings, with transition programmes spanning both settings being one possible solution.³²

Quality of the care relationship with HCPs was an important factor for continuing follow-up and could to some extent be considered patient related. Participants described emotional bonds between patient and HCPs, leading to obligations. However, when bonds were

disrupted by transfer, they experienced less purpose related to follow-up. Perceiving strong bonds with paediatric HCPs is in line with findings from a previous study assessing barriers to ACHD-referral, as perceived by paediatric cardiologists, which highlights strong relationships between patient, parents and paediatric physician as a barrier.³³

Participants emphasised their perceived differences between paediatric and adult settings in terms of the care environment and HCP behaviours and attitudes, which is highly influenced by HCPs. Participants described, a shallower connection and stricter behaviours and attitudes in adult care with less regard for fear or anxiety as well as a high tempo that generated stress and made it difficult to pose questions, as barriers. Some participants perceived contact with nurses as less evident in adult care. Although this perception was not shared by all participants, the description was reoccurring, without any clear pattern. The contrast between paediatric and adult care has been previously described. Patients in a recent study²⁶ provided comments, which they thought, could improve care for young people with CHD. For example, when attending the adult clinic, patients described feeling rushed and like they were nothing more than a number in the system. They also felt out of place in the adult setting due to the mix with elderly patients. In contrast, at the paediatric clinic, they experienced the HCPs as having more time for information and building relationships.²⁶ There seems to be a need for increased knowledge about the developmental phase of adolescence and emerging adulthood and how to communicate with young people and address their specific needs. The results also indicate a need for improved transitional work. Clinical nurse specialists are central in the transition process, guiding young people through the process and providing education.^{32 34} Considering the perceived differences between paediatric and adult care, it is important to ensure that HCPs in both paediatric and adult settings are equipped and prepared to meet all the needs of these young patients. For example, mental health should be inquired, not assumed or generalised, and enough time should be allocated to consider the 'whole' patient.³⁵

Hospital and healthcare system-related factors

Explanations for the low prevalence of discontinuation in the Swedish setting warrant further investigation, however, aspects such as public health insurance as well as efforts made by administrators to retain patients in care could be of relevance.¹⁴ Indeed, in this study, active invitation and reminders were raised by participants as facilitating factors, as well as encouragement from clinic, especially when missing appointments. Administrative staff, programme managers or HCPs could probably prevent some cases of discontinuation if they actively kept track of patients within reach of their clinic. This would help them react quickly to missed appointments and, if possible, register if patients moved to a new location. If patients moved, active invitation to the nearest

ACHD clinic at this respective location would be ideal. Active invitation and reminders are factors that could be considered stable across hospitals in Sweden but could vary across countries. Providing active invitations for patients and text-message reminders ahead of appointments should be standard practice at all clinics.

Participants stated patient fees and the number of available ACHD clinics in the country as a potential barrier, these are aspects inherent to the Swedish healthcare system. The fact that participants mentioned the scarcity of ACHD clinics as a barrier indicates a need to ensure the provision of accessible care, not only from a medical point of view but also from the patients' point of view, throughout the country. For example, taking into account geographical location and travel distances when planning follow-up could ensure that care is accessible for all patients. In Sweden and many other countries, ACHD programmes are run at tertiary hospitals. Increasing the number of consultant-clinics where patients can consult an ACHD cardiologist at their local hospital could be an option to make follow-up care more accessible. Another alternative is to increase opportunities to provide ACHD competence at a distance, using digital tools when consultant-clinics are not an option. Both options have been previously suggested by the national board of health and welfare in Sweden as strategies to ensure adequate follow-up care of these patients.³⁶

Methodological considerations

One methodological strength of the study is the geographical spread of participants, covering all university hospitals in Sweden. Another strength is the variation in CHD complexity among participants. In contrast to previously reported studies, this study's representation of patients both with and without follow-up provides a broader perspective on perceived factors affecting continued follow-up care.

Telephone interview is considered a valid approach to data collection and has the advantage that geographical barriers are lifted³⁷ which was useful in this study with participant being spread all over Sweden. A possible limitation with telephone interviews is the lack of non-verbal communication, however, voice elements such as intonation and pauses also provides rich information.³⁷

When interpreting these results some methodological limitations should be considered. Only 3 out of 16 participants were without follow-up since the number of eligible patients confirmed to be without follow-up were limited. No data on socioeconomic characteristics of participants were collected in this study. Moreover, participants recalled perceived and experienced factors for continuing follow-up care after transfer as far back as approximately 9–11 years, meaning their answers should be seen as processed memories affected by later experiences.

CONCLUSION

Young adults described their choice to either continue or discontinue follow-up care after transfer to be personal

and multifactorial, and often related to CHD knowledge and purpose to follow-up. Factors on patient, hospital and healthcare system level were identified, stressing the importance of a holistic approach when developing preventive strategies. HCPs need sufficient skills and competencies to care for young people in a holistic way. Specific healthcare needs, as well as persisting transitional needs after transfer, require careful consideration in order to prevent discontinuation.

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