Transition of young people with chronic conditions: a cross-sectional study of patient perceptions before and after transfer from pediatric to adult health care

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What is known – What is new:

What is known: Consensus statements about transition to adult health care provide expert guidance about how best to support young people with chronic disorders during the transition process. However, there is evidence that many young people continue to find transfer to AHC difficult

What is new: This is one of the few papers comparing cohorts of young people with chronic disorders before and after transfer from pediatric to adult health care. In contrast to other papers with either disease-specific focus or small sample sizes, this paper is one of very few larger cohorts with a non disease-specific approach. We showed that there are few differences reported by young people before and after transfer with regard to barriers to successful transfer (e.g. lack of appropriate information, anxiety) as well as the perceived most preferred age to transfer (18-19 years and older). The fact that there are basically no differences between the two groups is clinically important, as it emphasizes the need for an optimized transition process. Also, we highlighted the discrepancy between the adolescents' perception about preferred age to transfer to adult health care and the upper age limits of the national regulations for pediatric access in many countries in Europe.

ABSTRACT

The aim of this study was to compare perceived barriers to and the most preferred age for successful transition to adult health care between young people with chronic disorders who had not yet transferred from pediatric to adult health care (pre-transfer) with those who had already transferred (post-transfer). In a cross-sectional study, we compared 283 pre-transfer with 89 post-transfer young people, using a 28-item questionnaire that focused on perceived barriers to transition and beliefs about the most preferred age to transfer. Feeling at ease with the pediatrician was the most important barrier to successful transition in both groups, but was rated significantly higher in the pre-transfer compared to the post-transfer group (OR: 2.03; 95%CI: 1.12-3.71). Anxiety and lack of information were the next most important barriers, rated equally highly by the two groups (OR: 0.67; 95%CI: 0.35-1.28 and OR 0.71; 95%CI: 0.36-1.38 respectively). More than 80% of respondents in both groups reported that 16-19 years was the most preferred age to transfer; more than half of all respondents reported 18-19 years and older as the most preferred age. *Conclusion:* Better transition planning through the provision of regular and more detailed information about adult health care providers and the transition process could reduce anxiety and contribute to a more positive attitude to overcome perceived barriers to transition from young people's perspective. Young people's preferences about transferring to adult health care provide a challenge to those children's hospitals that transfer to adult health care at a younger age.

Keywords: adolescence, young adults, chronic disease, transition to adult health care, quality health care, adolescent friendly health care

Abbreviations:

- *AHC* = adult health care
- *post-transfer* = sample of young people who had transferred from pediatric to adult health care
- *pre-transfer* = sample of young people who had not yet transferred from pediatric to adult health care

INTRODUCTION

Consensus statements about transition to adult health care (AHC) provide expert guidance about how best to support young people with chronic disorders during the transition process [2,5,34]. However, there is evidence that many young people continue to find transfer to AHC difficult [20,23,31,38,47,48]. For example, a retrospective review of the medical records of 14 recently transferred pediatric liver transplant recipients showed poorer adherence after transfer to AHC [3]. Callahan et al. reported significant changes in ambulatory health care during transition to adulthood with a higher proportion of emergency department visits for young adults 19-24 years of age compared to adolescents aged 13-18 years [9]. In a recent study of adolescents and parents prior to transfer to AHC, we showed that anxiety and lack of information about AHC were among the most frequently reported barriers to successful transition, and that a majority of adolescents who had not yet transferred to AHC perceived the ages of 18-19 years and even older as the most preferred age to transfer [35].

It can be argued, however, that the predominant focus of adolescents' perceptions prior to their transfer to AHC may be influenced by the emotional challenge of the upcoming transfer. A different perspective may be gained from young people after they have transferred to AHC. Few studies have approached this in a systematic manner however, with the published literature characterized by small sample sizes and/or a disease-specific approach [4,7,11,16,28,43,44]. For example, Tuchman et al. reported fears of adolescents with chronic illness before transition (n=22), but only six participants had transferred to AHC during the 18-month survey period which does not allow conclusions to be drawn about the young people's view *after* transfer [43]. Boyle et al. surveyed 60 patients with cystic fibrosis prior to and after transfer to AHC [7]. They showed that the two areas of greatest concern prior to transfer were potential exposure to infection and having to leave their previous caregivers. They also showed significantly lower levels of concern when the adult cystic fibrosis team was introduced prior to transfer to AHC. The fact that anxiety about exposure to infection was such a high concern in these adolescents with cystic fibrosis shows the value of disease-specific transition surveys. However, these concerns would not be generalizable to other conditions. Therefore, in addition to disease-specific surveys there is also a need for studies that provide a broader picture across different conditions.

In this cross-sectional study, we set out to compare what young people with various chronic health conditions, prior to and after transfer to AHC, perceive as the most important barriers to successful transition and what they think is the most preferred age to transfer. This comparison aimed to examine whether perceptions of adolescents prior to transfer may be influenced by their upcoming transfer and modified by their experiences after transfer.

METHODS

We recruited young people with chronic disorders aged 14-25 years who had not yet transferred to AHC (pre-transfer) and those in the same age range who had transferred during the two years preceding the study (post-transfer). Data were collected from patients attending (pre-transfer) or having attended (post-transfer) seven subspecialty clinics at two university children's hospitals in Switzerland, including cardiology, endocrinology (diabetes only), nephrology, neurology, pulmonology (cystic fibrosis only), gastroenterology, and rheumatology. These subspecialties were chosen because of their large numbers of long-term patients with chronic disorders. In pulmonology, only patients with cystic fibrosis were chosen, as for patients with asthma it is not always possible in middle adolescence to know who will need ongoing treatment by adult specialists. There was no consistent approach to transition to AHC among these programs; different approaches were utilized by the different clinical programs.

A 28-item questionnaire (29 items for post-transfer group) was sent to all patients of the above listed subspecialties by postal mail (detailed methodology published previously [35]). The item selection of the questionnaire development included a literature search, expert opinion and focus group interviews with adolescents with chronic disorders. The questionnaire was designed as a descriptive tool for this specific purpose with content validity having been assessed as part of the questionnaire development process. The response options were designed to suit the purpose of this study, with Likert-scale response options offered where appropriate. Within the pre- and post-questionnaires, a set of 24 core items enabled comparison between the pre-transfer and the post-transfer group. Self-perceived health status, rate of school/work absenteeism, and hospitalization rates during the last 12 months were used as indicators of disease severity. Two waves of reminder letters were mailed. The questionnaires were completed anonymously. Exclusion criteria were if the patient did not have appropriate language skills (German or French), had cognitive disability, was younger than 14 or older than 25 years, and if the patient no longer perceived that they suffered from a chronic disorder. Consent was obtained from patients as well as their parents for those younger than 18 years of age. Ethics approval was obtained from the regional ethics committees of the two university children's hospitals.

Data were analyzed using SPSS 19.0 (SPSS Inc., Chicago). Some item responses were dichotomized, depending on the question under investigation. For example, the item "most important barrier" consisted of a list of several potentially important barriers (derived by the item selection process) with each response dichotomized into yes (most important barrier) or no (not the most important barrier). Statistical analysis included frequency analysis for descriptive comparison of pre- and post-transfer data, applying t-test for continuous variables and Pearson chi-square for categorical variables. The analysis of the outcome variables 'most important barriers' and 'most preferred age to transfer' included logistic regression analysis for dichotomous outcomes and multinomial regression analysis for non-dichotomous categorical/ordinal outcomes. Multivariate analyses were adjusted for gender, congenital disorder, health status, recruiting hospital and specialty.

Within the survey, we differentiated the terms transfer and transition. Transfer referred to the *event* of geographically or physically transferring from pediatric to adult health care (e.g.

most preferred age to transfer to adult health care). The term transition was used when referring to the *process* of transition or if the transfer was to be seen as part of this transitional process [6,39] (e.g. barriers to transition). Within this paper, when citing individual studies, we have used the term in accordance with how it was used in each paper. Transition was defined as successful if the transfer to AHC had occurred and the patient felt comfortable with treatment in AHC, as reported by the patient.

RESULTS

In the pre-transfer group, 298 patients agreed to participate in the study (participation rate 62%). Of these, 15 participants were excluded from the study, mainly because of language difficulties and because four patients were not yet 14 years old. A total of 283 pre-transfer patients were included in the final analysis. In the post-transfer group 92 patients completed the questionnaire (participation rate 54%). Of these, three patients were excluded from the final analysis because of being older than 25 years, yielding a total of 89 post-transfer patients. In both pre-transfer and post-transfer groups, the main reasons for not participating were lack of interest and the patient's perception of not suffering from a chronic disorder anymore.

The mean age was 16.3 (2.2) years in the pre-transfer group and 19.7 (2.3) years in the post-transfer group. Pre- and post-transfer participants did not differ with regard to gender, hospital, rate of congenital disorders, and severity of disease (see table 1). While all the pre-transfer patients were treated at one or other of the recruiting pediatric hospitals, 23.6% of the post-transfer patients consulted their AHC specialist in his or her private practice. In the pre-transition group, all the patients had seen a family doctor as well as their pediatric specialist at least once during the last 12 months and 59% of them had seen the pediatric specialist three times or more often during the last 12 months. In contrast, in the post-transfer group 48.3% reported they had not seen their family doctor during the last 12 months, and 22.5% said they had not seen the adult specialist at all during the last 12 months. With regard to the doctor-patient relationship, 91.9% of the pre-transfer group indicated they felt very much or at least quite at ease with their pediatric specialist, while in the post-transfer group 73% said they felt at ease with their adult specialist.

Fifty-one percent of pre-transfer young people indicated that their pediatrician had ever talked to them about the transition to AHC. In the post-transfer group, 10% of respondents recalled this to have happened before the age of 16 years, 38.2% reported the first talk about transition was at 16-17 years and 25.8% at 18-19 years of age. Mean age at time of transfer was 18.1±2.3 years, and 72% felt very much or quite ready to transfer at the time they transferred. Seventy-nine percent of the post-transfer young people said the transfer to AHC was very easy or quite easy for them to manage, and 50.5% felt very well or quite well supported during the transfer to AHC.

Feeling at ease with the pediatrician was the most important barrier to transfer, reported by 48% of the pre-transfer group and 32% of the post-transfer group. Yet, the odds that young people reported feeling at ease with the pediatrician as the most important barrier were two times higher for the pre-transfer group (OR=2.03; 95%CI: 1.12-3.71). Anxiety and lack of information were rated as similarly important in both groups (OR=0.67; 95%CI: 0.35-1.28 and OR=0.71; 95%CI: 0.36-1.38 respectively). Participants were given the opportunity to provide additional information on what contributed to their anxiety: the main reasons mentioned were the potentially different therapies in AHC, lack of information, concerns about loss of information about their condition, and non-specific anxieties about AHC. In the pre-transition group there was a statistically significant correlation between age and perceived lack of information (Spearman rho=0.15; p=0.01), but not with anxiety (Spearman rho=0.02; p=0.71). In the post-transition group there was neither a statistically significant correlation between age at transition and lack of information (Spearman rho=-0.16; p=0.16), nor with anxiety (Spearman rho=-0.13; p=0.25). Parents' preference for ongoing treatment by the pediatric team was perceived as the most important barrier by 1% of the pre-transfer group and 9% of post-transfer young people (OR=0.15; 95%CI 0.04-0.58). A small number of respondents (6 pre-transfer, 4 post-transfer) cited other reasons that were not comparable because of only being relevant for one or other group (e.g. loss of information of AHC provider after transfer). Four post-transfer respondents indicated no particular barrier was the most important.

Eighteen to 19 years was most frequently identified as the preferred age to transfer to AHC, rated by 52% of the pre-transfer group (see table 2). The post-transfer group equally rated 16-17 years (43%) and 18-19 years (40%). Three-point-seven percent of pre-transfer respondents and 5.7% of post-transfer respondents reported below 16 years as the most preferred age to transfer, while 14.2% of the pre-transfer group and 11.5% of the post-transfer group reported 20 years and older as the most preferred age to transfer to AHC.

DISCUSSION

Few differences were reported about barriers to successful transition to AHC between the groups before and after transfer. The extent of similarities in the pre- and post-transfer groups provides evidence that the perceived barriers by young people prior to transfer are not simply the result of anxiety about the upcoming changes. Rather, it highlights the significance of this event for young people, and the need for greater attention to this issue.

Most important barriers to successful transition: The most important barrier reported by both groups was feeling at ease with the pediatrician, although this was more frequently rated among young people who had not yet transferred. Given the long-term relationship that young people with a chronic condition (and their parents) develop with their pediatrician and care team, the perceived importance of this relationship is not surprising as a barrier to leaving pediatric health care and engaging with AHC services. This is consistent with Reiss et al. who suggest that an appropriately planned termination of pediatric relationships should be part of the transition process [32]. Barriers are typically thought to be preventable or at least modifiable. In this case, knowing the value of feeling at ease with the pediatrician underlines the importance of individual pediatricians helping the young person establish a trusting relationship with the AHC provider, for example, by supporting young people develop self-management skills and by ensuring that young people have sufficient information about the AHC provider and the AHC service.

Lack of information and anxiety were equally important barriers for young people before and after transfer. Our results show that anxiety was in part related to lack of information, but it was also caused by specific fears such as potentially different therapies in AHC, loss of information about the patient's condition during the transfer process, and non-specific anxiety about the transfer to AHC. Anxiety was not statistically correlated with age. This finding in our non disease-specific sample confirms the results of Boyle et al. in their study of young people with cystic fibrosis which showed that neither age, gender nor severity of lung disease were predictive of the level of concern about transfer to AHC [7]. Lack of information has been previously identified as a barrier to successful transition in a number of studies with smaller sample size and/or qualitative study design [11,25,44,8,30] which is confirmed in our larger quantitative study that utilized a generic rather than disease-specific approach. It is notable that the post-transfer respondents equally complained about lack of information. This suggests that the pre-transfer group's perception of lack of information is not just caused by anxiety or due to the transition process being still in progress. Our finding of lack of information confirms preliminary evidence in the existing literature that provision of information during the transition process needs to be optimized [8,11,30]. A positive attitude by young people about the transfer process has been reported [46]. However, it is important that pediatricians do not interpret a 'wait-and-see' attitude as a sign of transition-readiness per se. Providing opportunities for young people to meet staff from the AHC service prior to transfer, such as joint consultations with both the pediatric team and the AHC team, has the potential to reduce anxiety and transition concerns, as shown in several studies. For example Boyle et al. reported a reduction in transition concerns after introducing the AHC team to cystic fibrosis patients prior to transfer to AHC [7]. Similarly, in a qualitative study of 22 adolescents with chronic illness, of whom one-third transferred to AHC during the study period, participants suggested that earlier discussions about transition, opportunities to meet the adult care team and visits to the adult-oriented services prior to transition might have aided their transition process [43,41,14]. Introduction of the AHC team and/or location has also been perceived as important by others [40]. In our recent publication focusing on perceptions of adolescents and their parents prior to transfer to AHC, 48% of adolescents and 57% of parents reported that joint meetings with pediatric and adult health professionals would facilitate transfer to AHC [35]. Interestingly, Chaudhry et al. showed that while their structured transition program for patients with cystic fibrosis did not decrease patient anxiety during the transition period, it seemed to improve patient satisfaction, perceived health status and patient independence [12]. This suggests that equipping young people with the skills that support self-management would enable them to better negotiate AHC and could be expected to help reduce anxiety both before and after transfer. As reported in a study of 954 patients aged 12-19 years with chronic conditions, 48% of the variance in transition readiness was explained by perceived self-efficacy in skills for independent hospital visits, perceived independence during consultations, attitude towards transition and having had more frequent discussions regarding transition [45].

Most preferred age to transfer to AHC: Despite consensus statements recommending that the transition process should start several years before the actual transfer to AHC [2,34], only half of the pre-transfer adolescents indicated that their pediatrician had ever talked to them about the transition to AHC and only 10% of post-transfer respondents recalled that their first discussion about transition to AHC had happened before the age of 16 years. This suggests there is much room for improvement in Swiss clinical practices, consistent with other studies that show that discussions with patients and parents start too late. For example, McLaughlin et al. showed in post-transfer patients with cystic fibrosis that initial discussion of transition did not start until two years before transfer, which provides limited time for development of the necessary self-care skills [27]. Providing more detailed information about the transition process on a regular basis, including addressing adolescent anxieties and transition concerns, and supporting the acquisition of self-management skills should start early during the transitional process, several years before the transfer to AHC [2,26,47], and should also continue after transfer to AHC.

Different ages have been suggested for transfer to AHC. Sixteen and 18 years have been most frequently proposed based on historical norms around health care systems in different countries [33]. In our study, more than 80% of respondents in both groups reported 16-19 years was the most preferred age to transfer to AHC; more than half of all respondents in each group perceived the ages of 18-19 years and older as the most preferred age to transfer. Perhaps not surprisingly, given the high reports of anxiety and lack of information, more young people who had not yet transferred to AHC preferred a slightly higher age of transfer (18-19 years) compared to those who had already transferred, who equally preferred 16-17 years and 18-19 years. However, national pediatric health care regulations in many countries do not allow continued access to pediatric health care once young people turn 16 (i.e. access to pediatric care is restricted for those older than 15 years). Ercan et al. showed that 12 out of 29 European countries have an official upper age limit of 16 years for access to pediatric inpatient care; six of these countries restrict access to 14 years [18]. The two recruiting Swiss pediatric hospitals in this study allow patients with chronic disorders to be transferred to AHC beyond 15 years of age, with the mean age at time of transfer being 18.1 years in the post-transfer group. This may help explain the relatively high percentage (72%) of post-transfer respondents who felt ready at the time they transferred. However, even in Switzerland, the upper age limit for access to pediatric hospitals varies from hospital to hospital, between subspecialties at the same hospital, and between outpatient and inpatient services. Access to pediatric services is even more reduced for young people without a chronic illness. Perhaps one reason for this confusing situation is that the historical upper age limit of 16 years (i.e. access to pediatric hospitals up to 15 years) has not yet officially been changed. This contrasts with young people’s preferences, as only 3.7% of pre-transfer respondents and 5.7% of post-transfer respondents preferred below 16 years as the most preferred age to transfer. Effectively, this suggests that only around 5% of young people support the current upper age policies of the 12 European countries with pediatric access restricted beyond 15 years of age.

There is some evidence that higher age at transfer increases the rate of successful transfer to AHC with potential effects on health outcomes. A study of young people with congenital heart disease reported that transferring at a later age was associated with more successful transition, resulting in more timely consultations in AHC [31]. Similarly, a large study of pediatric renal transplant recipients showed that the graft failure rate was 58% higher in patients who transferred to AHC before the age of 21 years compared to those who transferred at an older r age [19]. In another study, again with renal transplant recipients, while no increase in allograft loss was observed during the transition period, patients were transferred to AHC between the ages of 18 and 20 years [22]. Beyond chronological age, timing for transfer to AHC should also take psychosocial maturation and personal circumstances into account. Thus, within a certain age range, the most preferred age to transfer may vary between individuals with the same condition. Additional assessment of transition readiness, based on self-management efficacy and advocacy skills, could be a more effective way to promote successful transition to AHC than solely relying on chronological age [15,32,33,42,45].

Cultural differences may also be of significance when exploring patient expectations with regard to the most preferred age to transfer and transfer readiness. For example, in contrast to European hospitals, the upper age limit for patients in pediatric care in the USA is 21 years [13,24], with transition clinics and adolescent clinics being available in many large pediatric hospitals. Despite these cultural differences the perception of our Swiss participants did not vary much from US young people in regard to the most preferred age to transfer [7]. In contrast, transfer to AHC between 15-17 years of age was perceived as normal in a small qualitative study of adolescents who attended a pediatric cardiology clinic in Belgium where the standard transfer age was 16 years [29]. Further studies are required to investigate whether and how much national upper age regulations influence young people's expectations about the age to transfer to AHC.

A major concern in this study was the reduced frequency of consultations with the specialist doctor and general practitioners after transfer to AHC. Low frequency of specialist consultations in AHC will obviously make it more difficult for the transferred patient to establish a trusting relationship with the adult specialist, and especially when associated with reduced primary care visits as in this study also threatens adherence with medication. It is disappointing how consistent these results are with other studies [8,11,21]. One exception is a French multi-site study of patients with cystic fibrosis that reported increased outpatient visits in the year after transition [17]. This may reflect more consistent health care delivery between the pediatric and adult cystic fibrosis services as reflected by shared clinical practice guidelines. Alternatively, it might reflect greater patient self-efficacy (e.g. to make clinical appointments), as the mean age of transfer was 21.6 years which is much older than in most European centres. This is consistent with studies that show continued brain maturation well beyond the age of 20 years that could be expected to be associated with higher self-efficacy [10].

A strength of the study was that the non disease-specific (generic) recruitment strategy enabled a relatively large sample to be recruited. This study also has a number of limitations. Firstly, the cross-sectional nature prevents any conclusion regarding causality. A longitudinal cohort study would be ideal at tracking how the opinions of individual patients vary as they traverse the transition years, and how these opinions might be influenced by different approaches to transition within their clinics. The long duration required for such a study was beyond our available resources. Secondly, generalizability is limited as the results are based on two Swiss pediatric university hospitals and may not be representative of pediatric health care more widely. However, these two pediatric hospitals are among the largest pediatric hospitals in Switzerland and are most likely comparable to specialized pediatric health care in many other high-income countries with regard to the transition from pediatric to ACH. Thirdly, no conclusions can be drawn about the transition approach of the two recruiting pediatric hospitals, as different transition models were utilized by different subspecialties across the two hospitals. Ideally, a randomized controlled trial comparing younger and older age at transition or testing different models of transition support within either pediatric or AHC could start to address some of the wider questions raised within this study.

The improved survival of adolescents with previously fatal conditions provides a challenge to both pediatric and adult health care systems to provide more adolescent friendly health care, including older age of transfer to AHC [1,36,37]. Our results of young people’s preferences, when taken with recent evidence that suggests that higher age at transfer is associated with better health outcomes and less anxiety, endorse the need for a more carefully planned, developmentally appropriate approach to transfer to AHC. In terms of timing, there is little rationale for pediatric hospitals to transfer adolescents prior to 16 years of age and much greater rationale to transfer adolescents to AHC after the age of 18 years.

In conclusion, this study suggests that more successful transition to AHC could be achieved by greater attention to transition planning, especially through interventions that help adolescents build trust with the adult health care provider, that provide greater information and reduce anxiety.

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Table 1: Sample characteristics of patients, pre-transfer and post-transfer

	pre-transfer (n= 283)	post-transfer (n=89)	p-value
	n (%) or mean (SD)	n (%) or mean (SD)	
Age (years)	16.3 (±2.2)	19.7 (±2.3)	n.a.
Gender (% female)	157 (55.5%)	39 (43.8%)	0.06
Recruiting hospital			0.07
Lausanne	103 (36.4%)	42 (47.2%)	
Zurich	180 (63.6%)	47 (52.8%)	
Duration of chronic disorder (years)	9.0 (±5.6)	13.0 (±6.3)	n.a.
Participants with a congenital disorder	60 (21.3%)	31 (35.3%)	0.06
Self-perceived health status (very good to excellent)	140 (49.3%)	44 (48.9%)	0.95
Missed school/work past month (≥1 day/month)	65 (22.9%)	21 (24.1%)	0.81
Hospitalization in past 12 months (≥1)	71 (25.1%)	18 (20.2%)	0.35

Table 2: Comparison of barriers and most preferred age to transfer between young people, pre- and post-transfer

	bivariate analysis				multivariate analysis		
	pre-transfer (n= 283)		post-transfer (n=89)		pre- / post-transfer (n=372)		
	n (%)	95%CI	n (%)	95%CI	adjusted OR	95%CI	p-value
Most important barrier to successful transfer							
feeling at ease with the pediatrician	136 (47.7%)	42.2-53.8	29 (32.1%)	21.7-42.5	2.03*	1.12-3.71	0.02*
anxiety	61 (21.6%)	16.8-26.4	25 (28.6%)	18.2-39.0	0.67*	0.35-1.28	0.23*
lack of information	56 (19.7%)	15.1-24.3	21 (23.8%)	13.4-34.2	0.71*	0.36-1.38	0.31*
parent's preference#	4 (1.4%)	0.0-2.8	8 (9%)	3.1-15.0	0.15*	0.04-0.58	0.006*
Most preferred age to transfer to AHC							
15 years and younger	10 (3.7%)	1.5-5.9	5 (5.7%)	0.0-16.1	0.55**	0.10-2.97	0.49**
16-17 years	87 (30.7%)	25.3-36.1	38 (42.5%)	32.1-52.9	0.55**	0.22-1.38	0.20**
18-19 yrs	146 (51.5%)	46.2-57.8	36 (40.2%)	29.8-50.6	1.07**	0.44-2.59	0.89**
20 years and older	40 (14.2%)	10.0-18.0	10 (11.5%)	1.1-21.9	1.00***		

*Logistic regression, and **multinomial regression; odds ratios & p-values for pre-transfer / post-transfer after having controlled for: gender, congenital disorder, health status, recruiting hospital and specialty; *** reference category

parent's preference as perceived by the young person