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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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1 **What is known – What is new:**

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

6

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

18

19 **ABSTRACT**

20 The aim of this study was to compare perceived barriers to and the most preferred age for
21 successful transition to adult health care between young people with chronic disorders who
22 had not yet transferred from pediatric to adult health care (pre-transfer) with those who had
23 already transferred (post-transfer). In a cross-sectional study, we compared 283 pre-transfer
24 with 89 post-transfer young people, using a 28-item questionnaire that focused on perceived
25 barriers to transition and beliefs about the most preferred age to transfer. Feeling at ease
26 with the pediatrician was the most important barrier to successful transition in both groups,
27 but was rated significantly higher in the pre-transfer compared to the post-transfer group
28 (OR: 2.03; 95%CI: 1.12-3.71). Anxiety and lack of information were the next most important
29 barriers, rated equally highly by the two groups (OR: 0.67; 95%CI: 0.35-1.28 and OR 0.71;
30 95%CI: 0.36-1.38 respectively). More than 80% of respondents in both groups reported that
31 16-19 years was the most preferred age to transfer; more than half of all respondents
32 reported 18-19 years and older as the most preferred age. *Conclusion:* Better transition
33 planning through the provision of regular and more detailed information about adult health
34 care providers and the transition process could reduce anxiety and contribute to a more
35 positive attitude to overcome perceived barriers to transition from young people's
36 perspective. Young people's preferences about transferring to adult health care provide a
37 challenge to those children's hospitals that transfer to adult health care at a younger age.

38

39

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

42

43

44 **Abbreviations:**

45 • *AHC* = adult health care

46 • *post-transfer* = sample of young people who had transferred from pediatric to adult health
47 care

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

50

51 INTRODUCTION

52 Consensus statements about transition to adult health care (AHC) provide expert guidance
53 about how best to support young people with chronic disorders during the transition process
54 [2,5,34]. However, there is evidence that many young people continue to find transfer to AHC
55 difficult [20,23,31,38,47,48]. For example, a retrospective review of the medical records of 14
56 recently transferred pediatric liver transplant recipients showed poorer adherence after
57 transfer to AHC [3]. Callahan et al. reported significant changes in ambulatory health care
58 during transition to adulthood with a higher proportion of emergency department visits for
59 young adults 19-24 years of age compared to adolescents aged 13-18 years [9]. In a recent
60 study of adolescents and parents prior to transfer to AHC, we showed that anxiety and lack
61 of information about AHC were among the most frequently reported barriers to successful
62 transition, and that a majority of adolescents who had not yet transferred to AHC perceived
63 the ages of 18-19 years and even older as the most preferred age to transfer [35].

64
65 It can be argued, however, that the predominant focus of adolescents' perceptions prior to
66 their transfer to AHC may be influenced by the emotional challenge of the upcoming transfer.
67 A different perspective may be gained from young people after they have transferred to AHC.
68 Few studies have approached this in a systematic manner however, with the published
69 literature characterized by small sample sizes and/or a disease-specific approach
70 [4,7,11,16,28,43,44]. For example, Tuchman et al. reported fears of adolescents with chronic
71 illness before transition (n=22), but only six participants had transferred to AHC during the
72 18-month survey period which does not allow conclusions to be drawn about the young
73 people's view *after* transfer [43]. Boyle et al. surveyed 60 patients with cystic fibrosis prior to
74 and after transfer to AHC [7]. They showed that the two areas of greatest concern prior to
75 transfer were potential exposure to infection and having to leave their previous caregivers.
76 They also showed significantly lower levels of concern when the adult cystic fibrosis team
77 was introduced prior to transfer to AHC. The fact that anxiety about exposure to infection was
78 such a high concern in these adolescents with cystic fibrosis shows the value of disease-

79 specific transition surveys. However, these concerns would not be generalizable to other
80 conditions. Therefore, in addition to disease-specific surveys there is also a need for studies
81 that provide a broader picture across different conditions.

82

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

88

89 **METHODS**

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

102

103 A 28-item questionnaire (29 items for post-transfer group) was sent to all patients of the
104 above listed subspecialties by postal mail (detailed methodology published previously [35]).
105 The item selection of the questionnaire development included a literature search, expert
106 opinion and focus group interviews with adolescents with chronic disorders. The

107 questionnaire was designed as a descriptive tool for this specific purpose with content
108 validity having been assessed as part of the questionnaire development process. The
109 response options were designed to suit the purpose of this study, with Likert-scale response
110 options offered where appropriate. Within the pre- and post-questionnaires, a set of 24 core
111 items enabled comparison between the pre-transfer and the post-transfer group. Self-
112 perceived health status, rate of school/work absenteeism, and hospitalization rates during
113 the last 12 months were used as indicators of disease severity. Two waves of reminder
114 letters were mailed. The questionnaires were completed anonymously. Exclusion criteria
115 were if the patient did not have appropriate language skills (German or French), had
116 cognitive disability, was younger than 14 or older than 25 years, and if the patient no longer
117 perceived that they suffered from a chronic disorder. Consent was obtained from patients as
118 well as their parents for those younger than 18 years of age. Ethics approval was obtained
119 from the regional ethics committees of the two university children's hospitals.

120

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

132

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

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

141

142 **RESULTS**

143 In the pre-transfer group, 298 patients agreed to participate in the study (participation rate
144 62%). Of these, 15 participants were excluded from the study, mainly because of language
145 difficulties and because four patients were not yet 14 years old. A total of 283 pre-transfer
146 patients were included in the final analysis. In the post-transfer group 92 patients completed
147 the questionnaire (participation rate 54%). Of these, three patients were excluded from the
148 final analysis because of being older than 25 years, yielding a total of 89 post-transfer
149 patients. In both pre-transfer and post-transfer groups, the main reasons for not participating
150 were lack of interest and the patient's perception of not suffering from a chronic disorder
151 anymore.

152

153 The mean age was 16.3 (2.2) years in the pre-transfer group and 19.7 (2.3) years in the
154 post-transfer group. Pre- and post-transfer participants did not differ with regard to gender,
155 hospital, rate of congenital disorders, and severity of disease (see table 1). While all the pre-
156 transfer patients were treated at one or other of the recruiting pediatric hospitals, 23.6% of
157 the post-transfer patients consulted their AHC specialist in his or her private practice. In the
158 pre-transition group, all the patients had seen a family doctor as well as their pediatric
159 specialist at least once during the last 12 months and 59% of them had seen the pediatric
160 specialist three times or more often during the last 12 months. In contrast, in the post-transfer
161 group 48.3% reported they had not seen their family doctor during the last 12 months, and
162 22.5% said they had not seen the adult specialist at all during the last 12 months. With

163 regard to the doctor-patient relationship, 91.9% of the pre-transfer group indicated they felt
164 very much or at least quite at ease with their pediatric specialist, while in the post-transfer
165 group 73% said they felt at ease with their adult specialist.

166
167 Fifty-one percent of pre-transfer young people indicated that their pediatrician had ever
168 talked to them about the transition to AHC. In the post-transfer group, 10% of respondents
169 recalled this to have happened before the age of 16 years, 38.2% reported the first talk about
170 transition was at 16-17 years and 25.8% at 18-19 years of age. Mean age at time of transfer
171 was 18.1 ± 2.3 years, and 72% felt very much or quite ready to transfer at the time they
172 transferred. Seventy-nine percent of the post-transfer young people said the transfer to AHC
173 was very easy or quite easy for them to manage, and 50.5% felt very well or quite well
174 supported during the transfer to AHC.

175
176 Feeling at ease with the pediatrician was the most important barrier to transfer, reported by
177 48% of the pre-transfer group and 32% of the post-transfer group. Yet, the odds that young
178 people reported feeling at ease with the pediatrician as the most important barrier were two
179 times higher for the pre-transfer group (OR=2.03; 95%CI: 1.12-3.71). Anxiety and lack of
180 information were rated as similarly important in both groups (OR=0.67; 95%CI: 0.35-1.28 and
181 OR=0.71; 95%CI: 0.36-1.38 respectively). Participants were given the opportunity to provide
182 additional information on what contributed to their anxiety: the main reasons mentioned were
183 the potentially different therapies in AHC, lack of information, concerns about loss of
184 information about their condition, and non-specific anxieties about AHC. In the pre-transition
185 group there was a statistically significant correlation between age and perceived lack of
186 information (Spearman $\rho=0.15$; $p=0.01$), but not with anxiety (Spearman $\rho=0.02$;
187 $p=0.71$). In the post-transition group there was neither a statistically significant correlation
188 between age at transition and lack of information (Spearman $\rho=-0.16$; $p=0.16$), nor with
189 anxiety (Spearman $\rho=-0.13$; $p=0.25$). Parents' preference for ongoing treatment by the
190 pediatric team was perceived as the most important barrier by 1% of the pre-transfer group

191 and 9% of post-transfer young people (OR=0.15; 95%CI 0.04-0.58). A small number of
192 respondents (6 pre-transfer, 4 post-transfer) cited other reasons that were not comparable
193 because of only being relevant for one or other group (e.g. loss of information of AHC
194 provider after transfer). Four post-transfer respondents indicated no particular barrier was the
195 most important.

196

197 Eighteen to 19 years was most frequently identified as the preferred age to transfer to AHC,
198 rated by 52% of the pre-transfer group (see table 2). The post-transfer group equally rated
199 16-17 years (43%) and 18-19 years (40%). Three-point-seven percent of pre-transfer
200 respondents and 5.7% of post-transfer respondents reported below 16 years as the most
201 preferred age to transfer, while 14.2% of the pre-transfer group and 11.5% of the post-
202 transfer group reported 20 years and older as the most preferred age to transfer to AHC.

203

204 **DISCUSSION**

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

210

211 *Most important barriers to successful transition:* The most important barrier reported by both
212 groups was feeling at ease with the pediatrician, although this was more frequently rated
213 among young people who had not yet transferred. Given the long-term relationship that
214 young people with a chronic condition (and their parents) develop with their pediatrician and
215 care team, the perceived importance of this relationship is not surprising as a barrier to
216 leaving pediatric health care and engaging with AHC services. This is consistent with Reiss
217 et al. who suggest that an appropriately planned termination of pediatric relationships should
218 be part of the transition process [32]. Barriers are typically thought to be preventable or at

219 least modifiable. In this case, knowing the value of feeling at ease with the pediatrician
220 underlines the importance of individual pediatricians helping the young person establish a
221 trusting relationship with the AHC provider, for example, by supporting young people develop
222 self-management skills and by ensuring that young people have sufficient information about
223 the AHC provider and the AHC service.

224

225 Lack of information and anxiety were equally important barriers for young people before and
226 after transfer. Our results show that anxiety was in part related to lack of information, but it
227 was also caused by specific fears such as potentially different therapies in AHC, loss of
228 information about the patient's condition during the transfer process, and non-specific anxiety
229 about the transfer to AHC. Anxiety was not statistically correlated with age. This finding in our
230 non disease-specific sample confirms the results of Boyle et al. in their study of young people
231 with cystic fibrosis which showed that neither age, gender nor severity of lung disease were
232 predictive of the level of concern about transfer to AHC [7]. Lack of information has been
233 previously identified as a barrier to successful transition in a number of studies with smaller
234 sample size and/or qualitative study design [11,25,44,8,30] which is confirmed in our larger
235 quantitative study that utilized a generic rather than disease-specific approach. It is notable
236 that the post-transfer respondents equally complained about lack of information. This
237 suggests that the pre-transfer group's perception of lack of information is not just caused by
238 anxiety or due to the transition process being still in progress. Our finding of lack of
239 information confirms preliminary evidence in the existing literature that provision of
240 information during the transition process needs to be optimized [8,11,30]. A positive attitude
241 by young people about the transfer process has been reported [46]. However, it is important
242 that pediatricians do not interpret a 'wait-and-see' attitude as a sign of transition-readiness
243 per se. Providing opportunities for young people to meet staff from the AHC service prior to
244 transfer, such as joint consultations with both the pediatric team and the AHC team, has the
245 potential to reduce anxiety and transition concerns, as shown in several studies. For example
246 Boyle et al. reported a reduction in transition concerns after introducing the AHC team to

247 cystic fibrosis patients prior to transfer to AHC [7]. Similarly, in a qualitative study of 22
248 adolescents with chronic illness, of whom one-third transferred to AHC during the study
249 period, participants suggested that earlier discussions about transition, opportunities to meet
250 the adult care team and visits to the adult-oriented services prior to transition might have
251 aided their transition process [43,41,14]. Introduction of the AHC team and/or location has
252 also been perceived as important by others [40]. In our recent publication focusing on
253 perceptions of adolescents and their parents prior to transfer to AHC, 48% of adolescents
254 and 57% of parents reported that joint meetings with pediatric and adult health professionals
255 would facilitate transfer to AHC [35]. Interestingly, Chaudhry et al. showed that while their
256 structured transition program for patients with cystic fibrosis did not decrease patient anxiety
257 during the transition period, it seemed to improve patient satisfaction, perceived health status
258 and patient independence [12]. This suggests that equipping young people with the skills that
259 support self-management would enable them to better negotiate AHC and could be expected
260 to help reduce anxiety both before and after transfer. As reported in a study of 954 patients
261 aged 12-19 years with chronic conditions, 48% of the variance in transition readiness was
262 explained by perceived self-efficacy in skills for independent hospital visits, perceived
263 independence during consultations, attitude towards transition and having had more frequent
264 discussions regarding transition [45].

265

266 *Most preferred age to transfer to AHC:* Despite consensus statements recommending that
267 the transition process should start several years before the actual transfer to AHC [2,34],
268 only half of the pre-transfer adolescents indicated that their pediatrician had ever talked to
269 them about the transition to AHC and only 10% of post-transfer respondents recalled that
270 their first discussion about transition to AHC had happened before the age of 16 years. This
271 suggests there is much room for improvement in Swiss clinical practices, consistent with
272 other studies that show that discussions with patients and parents start too late. For
273 example, McLaughlin et al. showed in post-transfer patients with cystic fibrosis that initial
274 discussion of transition did not start until two years before transfer, which provides limited

275 time for development of the necessary self-care skills [27]. Providing more detailed
276 information about the transition process on a regular basis, including addressing adolescent
277 anxieties and transition concerns, and supporting the acquisition of self-management skills
278 should start early during the transitional process, several years before the transfer to AHC
279 [2,26,47], and should also continue after transfer to AHC.

280

281 Different ages have been suggested for transfer to AHC. Sixteen and 18 years have been
282 most frequently proposed based on historical norms around health care systems in different
283 countries [33]. In our study, more than 80% of respondents in both groups reported 16-19
284 years was the most preferred age to transfer to AHC; more than half of all respondents in
285 each group perceived the ages of 18-19 years and older as the most preferred age to
286 transfer. Perhaps not surprisingly, given the high reports of anxiety and lack of information,
287 more young people who had not yet transferred to AHC preferred a slightly higher age of
288 transfer (18-19 years) compared to those who had already transferred, who equally preferred
289 16-17 years and 18-19 years. However, national pediatric health care regulations in many
290 countries do not allow continued access to pediatric health care once young people turn 16
291 (i.e. access to pediatric care is restricted for those older than 15 years). Ercan et al. showed
292 that 12 out of 29 European countries have an official upper age limit of 16 years for access to
293 pediatric inpatient care; six of these countries restrict access to 14 years [18]. The two
294 recruiting Swiss pediatric hospitals in this study allow patients with chronic disorders to be
295 transferred to AHC beyond 15 years of age, with the mean age at time of transfer being 18.1
296 years in the post-transfer group. This may help explain the relatively high percentage (72%)
297 of post-transfer respondents who felt ready at the time they transferred. However, even in
298 Switzerland, the upper age limit for access to pediatric hospitals varies from hospital to
299 hospital, between subspecialties at the same hospital, and between outpatient and inpatient
300 services. Access to pediatric services is even more reduced for young people without a
301 chronic illness. Perhaps one reason for this confusing situation is that the historical upper
302 age limit of 16 years (i.e. access to pediatric hospitals up to 15 years) has not yet officially

303 been changed. This contrasts with young people's preferences, as only 3.7% of pre-transfer
304 respondents and 5.7% of post-transfer respondents preferred below 16 years as the most
305 preferred age to transfer. Effectively, this suggests that only around 5% of young people
306 support the current upper age policies of the 12 European countries with pediatric access
307 restricted beyond 15 years of age.

308

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

324

325 Cultural differences may also be of significance when exploring patient expectations with
326 regard to the most preferred age to transfer and transfer readiness. For example, in contrast
327 to European hospitals, the upper age limit for patients in pediatric care in the USA is 21 years
328 [13,24], with transition clinics and adolescent clinics being available in many large pediatric
329 hospitals. Despite these cultural differences the perception of our Swiss participants did not
330 vary much from US young people in regard to the most preferred age to transfer [7]. In

331 contrast, transfer to AHC between 15-17 years of age was perceived as normal in a small
332 qualitative study of adolescents who attended a pediatric cardiology clinic in Belgium where
333 the standard transfer age was 16 years [29]. Further studies are required to investigate
334 whether and how much national upper age regulations influence young people's
335 expectations about the age to transfer to AHC.

336

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

351

352 A strength of the study was that the non disease-specific (generic) recruitment strategy
353 enabled a relatively large sample to be recruited. This study also has a number of limitations.
354 Firstly, the cross-sectional nature prevents any conclusion regarding causality. A longitudinal
355 cohort study would be ideal at tracking how the opinions of individual patients vary as they
356 traverse the transition years, and how these opinions might be influenced by different
357 approaches to transition within their clinics. The long duration required for such a study was
358 beyond our available resources. Secondly, generalizability is limited as the results are based

359 on two Swiss pediatric university hospitals and may not be representative of pediatric health
360 care more widely. However, these two pediatric hospitals are among the largest pediatric
361 hospitals in Switzerland and are most likely comparable to specialized pediatric health care
362 in many other high-income countries with regard to the transition from pediatric to ACH.
363 Thirdly, no conclusions can be drawn about the transition approach of the two recruiting
364 pediatric hospitals, as different transition models were utilized by different subspecialties
365 across the two hospitals. Ideally, a randomized controlled trial comparing younger and older
366 age at transition or testing different models of transition support within either pediatric or AHC
367 could start to address some of the wider questions raised within this study.

368

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

377

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

382

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387

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389

390 **REFERENCES**

391 1. Ambresin A, Bennett K, Patton G, Sanci L, Sawyer S (2013) Assessment of youth-
392 friendly health care: a systematic review of indicators drawn from young people's
393 perspectives. *J Adolesc Health* 52:670-681

394 2. American Academy of Pediatrics, American Academy of Family Physicians, American
395 College of Physicians-American Society of Internal Medicine (2002) A consensus
396 statement on health care transitions for young adults with special health care needs.
397 *Pediatrics* 110:1304-1306

398 3. Annunziato RA, Emre S, Shneider BL, Barton C, Dugan C, Shemesh E (2007)
399 Adherence and medical outcomes in pediatric liver transplant recipients who
400 transition to adult services. *Pediatr Transplant* 11:608-614

401 4. Anthony S, Kaufman M, Drabble A, Seifert-Hansen M, Dipchand A, Martin K (2009)
402 Perceptions of transitional care needs and experiences in pediatric heart transplant
403 recipients. *Am J Transplant* 9:614-619

404 5. Blum RW (2002) Improving transition for adolescents with special health care needs
405 from pediatric to adult-centered health care: introduction. *Pediatrics* 110:1301-1303

406 6. Blum RW, Garell D, Hodgman C, Jorissen T, Okinow N, Orr D, Slap G (1993)
407 Transition from child-centered to adult health care systems for adolescents with
408 chronic conditions: a position paper of the Society for Adolescent Medicine. *J Adolesc*
409 *Health* 14:570-576

410 7. Boyle MP, Farukhi Z, Nosky ML (2001) Strategies for improving transition to adult
411 cystic fibrosis care, based on patient and parent views. *Pediatr Pulmonol* 32:428-436

412 8. Busse F, Hiermann P, Galler A, Stumvoll M, Wiessner T, Kiess W, Kapellen T (2007)
413 Evaluation of patients' opinion and metabolic control after transfer of young adults

- 414 with type 1 diabetes from a pediatric diabetes clinic to adult care. *Horm Res* 67:132-
415 138
- 416 9. Callahan S, Cooper W (2010) Changes in ambulatory health care use during the
417 transition to young adulthood. *J Adolesc Health* 46:407-413
- 418 10. Casey BJ, Jones RM, Hare TA (2008) The adolescent brain. *Ann NY Acad Sci* 2008
419 1124:111-126
- 420 11. Chaturvedi S, Jones C, Walker R, Sawyer S (2009) The transition of kidney
421 transplant recipients: a work in progress. *Pediatr Nephrol* 24:1055-1060
- 422 12. Chaudhry S, Keaton M, Nasr S (2013) Evaluation of a cystic fibrosis transition
423 program from pediatric to adult care. *Pediatr Pulmonol* 48:658-665
- 424 13. Council on Child and Adolescent Health (1988) Age limits of pediatrics. *Pediatrics*
425 81:736
- 426 14. Crowley R, Wolfe I, Lock K, McKee M (2011) Improving the transition between
427 paediatric and adult healthcare: a systematic review. *Arch Dis Child* 96:548-553
- 428 15. David T (2001) Transition from the paediatric clinic to the adult service. *J R Soc Med*
429 94:373-374
- 430 16. Dovey-Pearce G, Hurrell R, May C, Walker C, Doherty Y (2005) Young adults' (16–25
431 years) suggestions for providing developmentally appropriate diabetes services: a
432 qualitative study. *Health Soc Care Community* 13:409-419
- 433 17. Duguépérroux I, Tamalet A, Sermet-Gaudelus I, Le Bourgeois M, Gérardin M,
434 Desmazes-Dufeu N, Hubert D (2008) Clinical changes of patients with cystic fibrosis
435 during transition from pediatric to adult care. 43:459-465
- 436 18. Ercan O, Alikasifoglu M, Erginoz E, Janda J, Kabicek P, Rubino A, Constantinopoulos
437 A, Ilter O, Vural M (2009) Demography of adolescent health care delivery and training
438 in Europe. *Eur J Pediatr* 168:417-426
- 439 19. Foster B, Platt R, Dahhou M, Zhang X, Bell L, Hanley J (2011) The impact of age at
440 transfer from pediatric to adult-oriented care on renal allograft survival. *Pediatr*
441 *Transplant* 15:750-759

- 442 20. Kennedy A, Sloman F, Douglass J, Sawyer S (2007) Young people with chronic
443 illness: the approach to transition. *Intern Med J* 37:555-560
- 444 21. Kipps S, Bahu T, Ong K, Ackland F, Brown R, Fox C, Griffin N, Knight A, Mann N,
445 Neil H, Simpson H, Edge J, Dunger D (2002) Current methods of transfer of young
446 people with type 1 diabetes to adult services. *Diabet Med* 19:649-654
- 447 22. Koshy S, Hebert D, Lam K, Stukel T, Guttman A (2009) Renal allograft loss during
448 transition to adult healthcare services among pediatric renal transplant patients.
449 *Transplantation* 87:1733-1736
- 450 23. LaRosa C, Glah C, Baluarte H, Meyers K (2011) Solid-organ transplantation in
451 childhood: transitioning to adult health care. *Pediatrics* 127:742-753
- 452 24. Litt I (1998) Age Limits of Pediatrics, American Academy of Pediatrics, Council on
453 Child Health, *Pediatrics*, 1972;49:463. *Pediatrics* 102:249-250
- 454 25. Lugasi T, Achille M, Stevenson M (2011) Patients' perspective on factors that
455 facilitate transition from child-centered to adult-centered health care: a theory
456 integrated metasummary of quantitative and qualitative studies. *J Adolesc Health*
457 48:429-440
- 458 26. McDonagh J (2007) Transition of care from paediatric to adult rheumatology. *Arch Dis*
459 *Child* 92:802-807
- 460 27. McLaughlin S, Diener-West M, Indurkha A, Rubin H, Heckmann R, Boyle M (2008)
461 Improving transition from pediatric to adult cystic fibrosis care: lessons from a national
462 survey of current practices. *Pediatrics* 121:e1160-e1166
- 463 28. Miles K, Edwards S, Clapson M (2004) Transition from paediatric to adult services:
464 experiences of HIV-positive adolescents. *AIDS Care* 16:305-314
- 465 29. Moons P, Pinxten S, Dedroog D, Van Deyk K, Gewillig M, Hilderson D, Budts W
466 (2009) Expectations and experiences of adolescents with congenital heart disease on
467 being transferred from pediatric cardiology to an adult congenital heart disease
468 program. *J Adolesc Health* 44:316-322

- 469 30. Pacaud D, Yale JF, Stephure D, Trussell R, Davies HD (2005) Problems in transition
470 from pediatric care to adult care for individuals with diabetes. *Can J Diabetes* 29:13-
471 18
- 472 31. Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Siu SC, Webb GD (2004)
473 Prevalence and correlates of successful transfer from pediatric to adult health care
474 among a cohort of young adults with complex congenital heart defects. *Pediatrics*
475 113:e197-e205
- 476 32. Reiss J, Gibson R, Walker L (2005) Health care transition: youth, family, and provider
477 perspectives. *Pediatrics* 115:112-120
- 478 33. Rosen DS (2004) Transition of young people with respiratory diseases to adult health
479 care. *Paediatr Respir Rev* 5:124-131
- 480 34. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM (2003) Transition to adult
481 health care for adolescents and young adults with chronic conditions: position paper
482 of the Society for Adolescent Medicine. *J Adolesc Health* 33:309-311
- 483 35. Rutishauser C, Akre C, Suris JC (2011) Transition from pediatric to adult health care:
484 expectations of adolescents with chronic disorders and their parents. *Eur J Pediatr*
485 170:865-871
- 486 36. Sawyer S, Drew S, Yeo M, Britto M (2007) Adolescents with a chronic condition:
487 challenges living, challenges treating. *Lancet* 369:1481-1489
- 488 37. Sawyer S, Proimos J, Towns S (2010) Adolescent-friendly health services: what have
489 children's hospitals got to do with it? *J Paediatr Child Health* 46:214-216
- 490 38. Sawyer SM, Aroni RA (2003) Sticky issue of adherence. *J Paediatr Child Health* 39:2-
491 5
- 492 39. Sawyer SM, Blair S, Bowes G (1997) Chronic illness in adolescents: transfer or
493 transition to adult services? *J Paediatr Child Health* 33:88-90
- 494 40. Scott L, Vallis M, Charette M, Murray A, Latta R (2005) Transition of care:
495 researching the needs of young adults with type 1 diabetes. *Can J Diabetes* 29:203-
496 210

- 497 41. Sonneveld H, Strating M, van Staa A, Nieboer A (2012) Gaps in transitional care:
498 what are the perceptions of adolescents, parents and providers? *Child Care Health*
499 *Dev* 39:69-80
- 500 42. Stinson J, Kohut S, Spiegel L, White M, Gill N, Colbourne G, Sigurdson S, Duffy K,
501 Tucker L, Stringer E, Hazel B, Hochman J, Reiss J, Kaufman M (2013) A systematic
502 review of transition readiness and transfer satisfaction measures for adolescents with
503 chronic illness. *Int J Adolesc Med Health*. Doi:10.1515/ijamh-2013-0512
- 504 43. Tuchman L, Slap G, Britto M (2008) Transition to adult care: experiences and
505 expectations of adolescents with a chronic illness. *Child Care Health Dev* 34:557-563
- 506 44. Valenzuela J, Buchanan C, Radcliffe J, Ambrose C, Hawkins L, Tanney M, Rudy B
507 (2011) Transition to adult services among behaviorally infected adolescents with
508 HIV—a qualitative study. *J Pediatr Psychol* 36:134-140
- 509 45. van Staa A, van der Stege HA, Jedeloo S, Moll HA, Hilberink SR (2011) Readiness to
510 transfer to adult care of adolescents with chronic conditions: exploration of associated
511 factors. *J Adolesc Health* 48:295-302
- 512 46. van Staa A, Jedeloo S, van Meeteren J, Latour J (2011) Crossing the transition
513 chasm: experiences and recommendations for improving transitional care of young
514 adults, parents and providers. *Child Care Health Dev* 37:821-832
- 515 47. Viner R (2008) Transition of care from paediatric to adult services: one part of
516 improved health services for adolescents. *Arch Dis Child* 93:160-163
- 517 48. Wiener L, Kohrt B, Battles H, Pao M (2011) The HIV experience: youth identified
518 barriers for transitioning from pediatric to adult care. *J Pediatr Psychol* 36:141-154
- 519
520

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 (\pm 2.2)	19.7 (\pm 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 (\pm 5.6)	13.0 (\pm 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 (\geq 1 day/month)	65 (22.9%)	21 (24.1%)	0.81
Hospitalization in past 12 months (\geq 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



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