

# Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers

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## Abstract

**Background** Transition from paediatric to adult healthcare has received little attention in the Netherlands. This study aimed to: (i) map experiences with the transfer to adult care of young adults with chronic conditions; and (ii) identify recommendations for transitional care of young adults, their parents and healthcare providers.

**Methods** Semi-structured interviews with 24 young adults after transfer (aged 15–22 years; diagnosed with haemophilia, diabetes mellitus, spina bifida, congenital heart disorders, cystic fibrosis, juvenile rheumatoid arthritis or sickle cell disease), 24 parents and 17 healthcare providers. Thematic analysis was performed.

**Results** Only the haemophilia department offered a structured transition programme, most patients had not been prepared for transition. Experiences and views of patients, parents and professionals mainly overlapped and were condensed into four core themes. Two are related to moving to adult care: (1) 'leaving paediatric care is a logical step'. Leaving familiar surroundings was harder for parents than for young adults who displayed a positive 'wait-and-see' attitude; and (2) 'transition is complicated by cultural gaps between paediatric and adult services'. Young adults and parents felt lost after transfer and recommended their peers 'to be alert and involved'. Providers also recognized the cultural chasm between both services and worried about non-compliance, lost to follow-up and lack of independence. Two other themes indicated priorities for improvement: (3) 'better patient and parent preparation' for differences between healthcare settings and for new roles and responsibilities with respect to self-management; and (4) 'more collaboration and personal links' between paediatric and adult care providers.

**Conclusions** Action is required to cross the chasm between paediatric and adult-oriented care. Preparation for transition should start early and focus on strengthening adolescents' independency without undermining parental involvement. Building bridges between services, gaining trust and investing in new personal relations is a challenge for all parties involved: transition is about responding and bonding.

## Keywords

adolescent,  
adult-oriented care,  
chronic illness, complex  
healthcare needs,  
transfer, transition

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## Introduction

Moving from paediatric to adult healthcare is an essential process in the lives of all young people with chronic conditions. It is one of the many and often concurrent transitions in their lives. In addition to becoming socially independent, young people must move from parental control of their healthcare needs to self-care (Kirk 2008). Thus, parents are important partners in transition as well.

We have gradually begun to understand the challenges of realizing a successful transition to adult life where optimal social participation is the ultimate goal. There is more to it than just transfer to adult healthcare services: major changes in both the organization and content of adolescent healthcare are required. Three elements must be pursued: a cultural shift in staff's attitudes, effective transition programmes and teaching adolescents to become active partners in their own care (Viner 2008).

Ideally, transition of care is a purposeful, planned process – as advocated in policy documents, professional guidelines and expert opinion articles (Blum *et al.* 1993; American Academy of Pediatrics *et al.* 2002; Rosen *et al.* 2003). The term 'transition' refers to the process prior to and after the 'transfer' event, that is, the actual shift from paediatric to adult healthcare (Kennedy & Sawyer 2008). Only few experimental studies have evaluated transition programmes and services (Hilderson *et al.* 2008), mostly conducted in the UK (McDonagh *et al.* 2006, 2007). There is no evidence that particular models of transition are more effective than others (While *et al.* 2004; Binks *et al.* 2007). Nevertheless, there is a growing evidence base on key elements of transitional care (McDonagh 2006; McDonagh & Viner 2006; Christie & Viner 2009). Especially, the need to improve care in different chronic conditions has been documented well in various countries with different healthcare systems. Several empirical, mostly qualitative, studies explored user expectations and experiences around their transfer to adult services (Stewart *et al.* 2001; Shaw *et al.* 2004a; Reiss *et al.* 2005; Stabile *et al.* 2005; Östlie *et al.* 2007; Kirk 2008; Tuchman *et al.* 2008; Anthony *et al.* 2009; Clarizia *et al.* 2009; Moons *et al.* 2009; Young *et al.* 2009; Valenzuela *et al.* 2011).

There is much communality in the themes described in these studies – across issues and conditions. Recurrent themes are: the challenges facing patients and parents alike while *moving to adult services* (going into the unknown, going into a different world, disrupted relationships and ways of working), recognition of the *opportunities for personal growth* (a shift in roles and responsibilities between adolescent and parents) and *recommendations* for improving both process and outcomes.

Unfortunately, daily clinical practice has not kept up with the current evidence and recommendations. In the Netherlands there are no national standards or policy documents advocating transitional care, and few professional guidelines address this issue. A recent survey showed that only a minority of Dutch institutions offered any transitional services to their adolescent patients (van Staa *et al.* 2010), while the experiences and effects of transition to adult services on patients and their parents have hardly been studied (Verhoeven & van Staa 2006; Hilberink *et al.* 2007; Geerts *et al.* 2008). Therefore, we designed an explorative study with a twofold aim: (1) to map experiences with the recent transfer to adult care of young adults (YA) with chronic conditions receiving care in one university hospital in the Netherlands; and (2) to identify recommendations to improve the transition process from the perspectives of YA, their parents and healthcare providers (HCP).

## Methods

### Design and setting

A qualitative study was conducted between 2004 and 2007 in the Erasmus University Medical Center – Sophia Children's Hospital, a tertiary referral centre, among YA diagnosed with haemophilia (HP), diabetes mellitus (DM), spina bifida (SB), congenital heart disorders (CHD), cystic fibrosis (CF), juvenile rheumatoid arthritis (JRA) or sickle cell disease/thalassaemia (SCD). They were eligible for participation if they had no record of intellectual disabilities and had been transferred to adult care in the past 2 years. There was one exception, however: at the time of the research (2004), 25 CF patients over 18 had not been transferred yet. Hence, those to be transferred within 6 months were listed. The term 'young adults' refers to those already or about to be transferred to adult care (aged over 16), to be distinguished from 'adolescents' still receiving paediatric care.

The study consisted of semi-structured interviews conducted with YA, parents and HCP from paediatric and adult care.

### Sampling

In each diagnostic group, three YA were randomly selected from a list of patients officially discharged in the previous 2 years (and in CF from the waiting list). Parents were approached after the YA had given consent. When YA did not reply within 2 weeks, they were sent a reminder letter and a few days later, they were called by telephone. When no consent was given or the YA could not be reached, new patients were approached – until three in each group had consented in an interview. During the

interviews it appeared that three SB patients had not visited adult care yet, so we invited three extra participants.

For the HCP interviews, paediatric providers were first interviewed and asked to suggest participants from adult care.

### Data collection

All interviews were carried out by a trained nursing or physiotherapy student after extensive training by the research team (authors of this paper). The patient and parent interviews were conducted at home and lasted 45 to 120 min. Parents and YA were interviewed separately along the lines of an interview guide developed by the researchers. The interviews focused on expectations and experiences with transfer and perceived quality of care in paediatric and adult services (Table 1). Disease-specific questions were added to gain more in-depth information on specific healthcare needs.

In the HCP interviews, attitudes towards transition and current transfer practices were explored. They were interviewed at their workplaces and interviews lasted from 25 to 60 min.

**Table 1.** Interview guide: young adults' and parents' experiences with care provision in the transitional period

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How did the transfer from paediatric to adult care turn out?

- Positive and negative experiences and feelings about transfer
- Timing of the transfer
- Preparation of the transfer
- Felt readiness at time of transfer
- Experiences with care co-ordination
- Suggestions to improve transitional care

How did you experience and value paediatric care?

- Positive and negative aspects of paediatric care
- Roles of parents, young persons and healthcare providers during consultations
- Experiences with different professionals in the healthcare team
- Last visit, leaving paediatric care
- Experiences with inpatient facilities
- Age-appropriate care: attention paid to psychosocial aspects, coping with condition, career, future
- Suggestions to improve paediatric care

How do you experience and evaluate adult care?

- Positive and negative aspects of adult care
- Perceived differences with paediatric care
- Roles of parents, young people and healthcare providers during consultations
- Experiences with different professionals in the healthcare team
- First visit, reception
- Experiences with inpatient facilities
- Age-appropriate care: attention paid to psychosocial aspects, coping with condition, career, future
- Suggestions to improve adult care

What advice would you give to others in the same circumstances?

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### Data analysis

Interviews were digitally recorded, transcribed verbatim and then imported into the qualitative software package ATLAS.ti 5.0 (<http://www.atlasti.com>). Thematic analysis was chosen for its flexibility and theoretical freedom, and applied in several phases (Braun & Clarke 2006). All interviews were reviewed and coded by A. v. S. who read them repeatedly to familiarize herself with the data. Initial codes (subthemes) were formulated on the basis of the interview guide. Subsequently, these were modified, expanded or merged as new issues emerged during the analysis. The third step was collating subthemes to identify potential themes; emerging themes were checked iteratively in other interviews. Possible relations between respondents' experiences and relevant (demographic) characteristics were identified. The research team examined the coding process and the emerging themes were discussed continually until consensus was reached.

### Validity and reliability

To enhance credibility we used both peer debriefing in the research team as well as respondent validation. The recommendations for transitional care were presented to 27 paediatric HCP from the same hospital in three focus groups (van Staa *et al.* 2007; data not reported here).

### Ethical aspects

The study protocol was approved by the Institutional Review Board of the Erasmus University Medical Center. All study participants gave written informed consent. Researchers had no access to hospital charts and all participants were assured of confidentiality and anonymity.

## Results

### Study population

Table 2 presents the characteristics of the 65 participants: 24 YA (mean age 18.7 years, range 15–22), 24 parents and 17 HCP. Six YA (25%) were about to transfer; 18 had already been transferred to adult care. One-third of them were now being treated in non-academic hospitals. Twenty YA gave permission to invite their parents for an interview; all parents consented, so 20 pairs were interviewed. Of four YA, parents were not interviewed. Three SB patients and one CHD patient who did not wish to participate gave permission to interview their parents.

**Table 2.** Background characteristics of 65 study participants

	Response rate (%)*	Total	Young adults	Parents	Healthcare providers
Number of participants		65	24	24	17
Male/female			13/11	3/21	6/11
Treatment setting: paediatric care/adult care			6/18	9/15	11/6
Chronic condition					
Diabetes mellitus	60	8	3	3	2
Haemophilia	60	7	3	2	2
Spina bifida	30	17	6	9	2
Congenital heart disorders	23	7	3	3	1
Cystic fibrosis	100	8	3	3	2
Juvenile rheumatoid arthritis	27	12	3	3	6
Sickle cell disease	60	6	3	1	2
Young adults' characteristics					
Age (years)					
15–18			13		
19–22			11		
Non-Dutch ethnic background			3		
Living independently			5		
Studying/working/unemployed			19/2/3		
Educational level: higher/lower			10/14		
Healthcare providers characteristics					
Medical specialist					10
Nurse specialist/nurse practitioner					6
Physiotherapist					1

\*Percentage of young adults that consented to participate after initial approach.

Response rates varied between the various conditions. The three approached CF patients all consented, but in SB, RA and CHD the initial response rates were 30% or less. Non-participation was mostly related to lack of interest, as 'I do not go to the hospital very often' and 'my disease does not bother me'. Those under 18 and those with limited disease activity were less inclined to participate. Also, 60% of all selected SCD patients and 38% of DM patients could not be reached through mail or phone.

### Transfer practices in seven chronic conditions

Table 3 gives an overview of transfer practices as reported by HCP. At the time, only the HP department offered a structured transition programme in which patients learned about their medication and were taught to make appointments and to take responsibility for self-management of their medical condition. HP patients also had the opportunity to meet their new providers during holiday camps.

The other departments started discussing the impending transfer no earlier than 6 to 12 months in advance. Timing of the transfer differed between the chronic conditions: SB patients were discharged at 15–16 years; other YA were usually transferred between 16 and 18 years, by the time they graduated from secondary education. Although many claimed that timing

depended upon adolescents' developmental readiness and not on a fixed age, only the HP department tested knowledge and self-management skills.

Transfer usually was to specialists of the same university hospital; only patients with DM were transferred to other hospitals for organizational reasons. Those with JRA and SB were offered the option of a specialist closer to home. For CF, SCD and JRA centralization of care was still at a preliminary stage and joint treatment protocols were not yet in place. The CF Centre was the first to formulate a joint mission statement, but protocols and procedures had not been aligned yet and many YA were still on the waiting list for transfer.

Even though the children's hospital and the adult facilities are located at the same premises, most professionals in paediatric and adult care of the same specialty did not know each other. Joint consultations were not organized and there was no formalized consultation between paediatric and adult healthcare. The HP department offered a farewell meeting and personal handover of patients after crossing the bridge that connects the children's and adult hospital, a ritual some other HCP thought of as 'perhaps a bit over the top'.

Both settings differed largely in treatment protocols and working methods. The multidisciplinary team approach, providing more holistic care, was standard in paediatric care. Most adult care facilities had higher patient load, less consultation

**Table 3.** Overview of transfer practices in seven subspecialties at time of research

	HP (2004)	DM (2004)	CHD (2004)	CF (2004)	SB (2004)	JRA (2006)	SCD (2007)
Written medical transfer document	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Personal links between paediatric and adult care	Yes	No	Yes	No	Yes	No	No
Dedicated professional for treating young persons in adult care	Yes	No	Yes	No	Yes	No	No
Joint mission statement/written policy	No	No	No	Yes	No*	No	No
Flexible moment of transfer possible	Yes	No	No	Yes	No	Yes	Yes
Transfer always within same institution (including transfer of medical dossier)	Yes	No	Yes	No	No	No	Yes
Meeting new HCP in advance	Yes	No	No	No	Yes	No	No
Joint medical treatment protocol with adult team	Yes	No	Yes	No*	No	No	No
Alignment of procedures and approach of young persons/parents	Yes	No	Some	No	No	No	No
Multidisciplinary team approach in both settings	Yes	No	No	Yes	Yes	Yes	Limited
Structural consultation between paediatric and adult care	Yes	No	No	No	No	No	No
Structured transition programme, including early preparation	Yes	No	No	No	No	No	No
Joint consultations, transition clinic	No	No	No	No	No	No	No

\*In preparation at time of research.

HP, haemophilia; DM, diabetes mellitus; CHD, congenital heart disease; CF, cystic fibrosis; SB, spina bifida; JRA, juvenile rheumatoid arthritis; SCD, sickle cell disease; HCP, healthcare provider.

time and fewer supporting staff. For example, in CHD, the adult specialist was dedicated to congenital heart diseases, but he worked alone, and did not consult with the paediatric team. In the SCD department, psychosocial support was not always continued after transfer.

### Moving on to adult services

Two core themes related to the process of 'moving on to adult care' emerged from the interviews with YA, parents and HCP:

- 1 Leaving paediatric care is a logical step.
- 2 Transition is complicated by cultural gaps between paediatric and adult services.

#### 1. Leaving paediatric care is a logical step

Parents and YA shared many common views. Moving on to adult care is not only 'inevitable' but also appropriate for grown-ups. Even (parents of) YA with serious, life-threatening conditions recognized the necessity. Many YA said they had 'grown out of the children's hospital', whereas few did not feel ready yet.

Before transfer, YA did not know what to expect, but most did not seem too worried about it (displaying a positive, wait-and-see attitude) – in contrast to their parents. Several parents said they had been sorry to leave, as they felt 'safe' in the children's hospital:

I didn't want to leave the trusted environment where everything is familiar and where you're in charge. [. . .] Still, raising kids implies that you have to let them go and accept that they make their own choices. I didn't like it that he had to go, but I saw the necessity. And now I see it's good. (Parent of 18-year-old male, HP)

Another parent was opposed to transfer because her son did not adhere to treatment; besides, in paediatric care they knew their situation very well. The son himself had a different attitude:

I'll need to get used to it. I've known my doctor awfully long, for 18 years. But I'll just see what's going to happen. [. . .] Actually, I'm getting too old now for a children's hospital. Seems to be the right age [for transfer] because I'm an adult now, aren't I? (19-year-old male, CF)

Healthcare providers recognized transfer as 'a natural process' that is 'age-appropriate'. They had different views on the proper age to transfer. Some considered 18 years as 'the upper limit'. Paediatric HCP tended to stress that age boundaries should be flexible, depending upon the adolescent and his parents. Adult HCP felt that 'most young people are ready' to be more involved in their healthcare. YA need to be 'pushed' a little, as leaning back comes naturally to them. This may create tension with 'overprotective' parents. A paediatric rheumatologist felt that parents were 'being sidetracked in adult care' as consultants 'are not used to conducting triadic consultations',

but she also acknowledged that ‘we are pampering those children too much’. All HCP were convinced that parents have more difficulty in leaving behind the trusted paediatric environment than YA themselves, and that the YA are tired of being ‘patronized’ by paediatric staff and parents.

## 2. Transition is complicated by cultural gaps between paediatric and adult services

Some parents and YA looked back at transfer as ‘no big deal’ and even as ‘peanuts’, when the process had been smooth or ‘seamless’. But most YA and especially parents said it had been more stressful and difficult than anticipated. Those who had had frequent contact with paediatric HCP found it hard to establish trust and familiarity with the new staff, as reflected by metaphors like ‘being lost’, ‘falling into a deep hole’, ‘feeling abandoned’ and even ‘waking up in a horror movie’. However, this was seen as temporary; transition was perceived as a rite of passage: ‘you have to get used to it, that’s all’.

Parents and YA described paediatric surroundings and relationships with the staff as warm, familiar, cosy and trusted (‘feels like a second home’, ‘they are family’). They were mostly negative about the look-and-feel of the adult-oriented surroundings (‘treated like a number’, ‘sterile environment’).

All YA and parents, except those in the HP department, said they had been uninvolved in transfer decisions and had not been prepared for the differences. Two of the three YA with HP and their parents were positive about the transition programme; one felt unprepared. However, also HP patients noticed differences in way of working. The farewell ceremony was seen as a clear demarcation of ‘bridging services’, but one YA thought this was ‘more for parents than for us boys’.

All participants could easily identify upsides and downsides of both settings (Table 4). Advantages of paediatric care (‘it’s familiar, home-like’) contrasted with disadvantages of adult care (‘everything is new and feels different’). At the same time, perceived disadvantages of the children’s hospital (‘some treat you as if you’re still a child’) were compensated for in the new setting (‘you take more control of your own affairs’). YA liked it that they were ‘more involved as an adult’ and that consultations were more business-like. Still, all had to get used to new staff, procedures and protocols, and a different care culture.

Most challenging for parents and YA is the role shift with respect to self-management and responsibility. Parents found it difficult to step aside, even though they agreed it was necessary. They wondered whether their children could take up the full responsibility for their treatment. YA, too, had noted that more independence and self-reliance was expected of them. They

**Table 4.** Advantages and disadvantages of paediatric and adult care, as perceived by young adults and their parents

Advantages of paediatric care	Disadvantages of adult care
<ul style="list-style-type: none"> <li>• Familiar</li> <li>• Cosy, relaxed atmosphere</li> <li>• Child-friendly</li> <li>• Parents involved</li> <li>• Respect for parent’s and patient’s expertise</li> <li>• Trusted providers’ expertise</li> <li>• Good collaboration between care providers</li> <li>• Multidisciplinary teamwork</li> <li>• Holistic approach</li> <li>• Excellent conditions for inpatient care</li> <li>• Everything is arranged for you</li> </ul>	<ul style="list-style-type: none"> <li>• Unfamiliar</li> <li>• Formal, stand-offish, strict</li> <li>• Not focused on young people</li> <li>• Parents less welcome</li> <li>• Lack of respect for patient’s and parent’s expertise</li> <li>• Expertise not always trusted</li> <li>• Poor co-ordination with paediatric care/with other specialist providers</li> <li>• Team approach is not self-evident</li> <li>• Less attention paid to psychosocial issues</li> <li>• Poor conditions for inpatient care</li> <li>• Confronted with older patients</li> <li>• Different methods and treatment procedures than in paediatric care</li> <li>• You have to arrange everything yourself</li> </ul>
Advantages of adult care	Disadvantages of paediatric care
<ul style="list-style-type: none"> <li>• Age-appropriate (adult-like)</li> <li>• Business-like, matter-of-fact atmosphere</li> <li>• More focus on responsibility &amp; self-management</li> <li>• Young adult more involved in decision making</li> <li>• Exciting to build new relationships; make a fresh start</li> <li>• Information relevant to adult issues</li> <li>• Possibility to chose hospital closer to home</li> <li>• New treatment options possible</li> </ul>	<ul style="list-style-type: none"> <li>• Childish, not age-appropriate</li> <li>• Confronted with young children</li> <li>• Less encouragement of independence &amp; self-management</li> <li>• Adolescent less involved in decision making; presence of parents limits freedom to speak/ youth participation</li> <li>• ‘Fixed’ relationships</li> <li>• Lack of information on adult issues</li> <li>• Doctors reluctant to treat aggressively and to try new options</li> </ul>

were positive about their potential to achieve this, even though they found it hard ‘to be fully responsible now’. Gaining trust in your child was the major challenge for parents; gaining trust in your own capacities and developing trusted relations with new HCP that for YA.

All HCP recognized cultural differences between the paediatric and adult-oriented specialities that complicated transfer. These are summarized in Table 5. The adult care ‘business-like approach’ was often contrasted with the paediatric ‘holistic, system-oriented approach’. HCP in both settings felt there is truth in the stereotypes about paediatrics being a ‘pampering’ environment where ‘everything is arranged for’, and that parents and patients in adult services ‘fall into a deep hole when they have to do things by themselves’. The haematologist said that SCD patients were ‘somewhat spoilt in paediatrics’, while his paediatric colleague stressed that intensive surveillance is needed because of poor adherence, high no-show rates and

**Table 5.** Cultures of care: typical differences between paediatrics and adult specialist medicine, according to interviewed healthcare professionals

Paediatrics	Adult care
Typical patient is healthy, only a minority is chronically or terminally ill	Typical patient has complex, chronic and often progressive condition
Patient seen as fragile, vulnerable, dependent	Patient seen as co-responsible, self-reliant
Family-centred care: parents always involved	Individual-based care
Shared decision making and education focuses on parents rather than on patients	Empowerment of patient by means of being with information and expectations of self-reliance
Informal, relaxed communication style; empathic but also more paternalistic	Formal and direct communication style; more distant and 'business-like'
Holistic care: attention to developmental and learning issues, social functioning	Disease-oriented care: strong focus on treatment complications and adherence
Interdisciplinary team approach	Specialist orientation, less team work and care co-ordination

(psycho)social problems. In turn, this was accredited for by the haematologist, who felt that social work should be continued after transfer. Paediatric HCP worried that their long-standing bonds would be severed after transfer, and those in adult services saw failure to adhere to treatment and loss to follow-up as the major risks of transition.

Generally, HCP saw the large cultural gaps as unwanted. Differences in treatment protocols and procedures should be smoothed, but on the other hand, a paediatric rheumatologist felt: 'We should not pamper transition as well! Patients could handle this very well themselves'.

### Recommendations for better transition

Table 6 summarizes recommendations from the study participants. Two core themes emerged:

- 3 Better patient and parent preparation.
- 4 Better organization and communication between paediatric and adult care.

#### 3. Better patient and parent preparation

Young adults and parents would have appreciated more information, at an earlier stage, and more time to make choices: 'give young people more time to decide when they want to leave. Do not tell them: now you're 16, you have to go.' Both wished to be involved in the decision making. Several YA suggested it would

be nice to meet the new HCP before transfer and all wanted to be prepared for differences in ways of working.

Healthcare providers generally supported these recommendations. Almost all felt that the present process of transition should be improved; only the HP nurses were content because they already worked in that way. Transfer now often is too abrupt, with patients and parents not being well prepared. However, transitional care goes beyond the mere transfer of information:

It is a pathway in which patients are ready to take on full responsibility for their healthcare at the moment they transfer, while the parental role is declining. (Paediatric pulmonologist)

Healthcare providers mentioned that YA therefore needed to know more about their condition, and should improve self-management skills. Involvement during consultations should be encouraged, as 'we deal with patients, not parents' (adult rheumatologist). Since parents are almost always present in paediatric consultations, this poses an enormous challenge.

Healthcare providers proposed concrete interventions such as seeing adolescents independently (without parents), using checklists and individual transition planning, developing a transition protocol and organizing joint consultations. Differences in care should be smoothed, whenever possible.

Parents and YA indicated that preparation for transfer requires action from all actors involved, not only from HCP. YA advised their peers to be involved and more alert: 'make sure you set the facts straight'; 'get familiar with your medication, prepare a to-discuss list before you see your doctor'. Parents acknowledged the expert role of YA, but also stressed that parents' involvement during transition remains crucial. Their advice to other parents was: 'be alert, don't make yourself dependent upon professionals', 'hang on there'.

#### 4. Better organization and communication between paediatric and adult care

A common view was that the logistics and organization of the transfer itself would benefit from resources to develop transition clinics or joint clinical pathways. Nevertheless, enhanced communication is most needed. Not only between doctors and nurses of paediatric and adult services, but also with social workers and other allied professionals. YA and parents stressed that adult care should be more accessible and responsive to their needs: 'make us feel welcome'.

Almost all HCP regretted that they did not know their counterparts personally but only through 'paper'. Closer personal

**Table 6.** Recommendations from young adults, parents and healthcare providers to improve transitional care

<b>Better patient and parent preparation</b>	
<p><b>Young adults</b></p> <ul style="list-style-type: none"> <li>• Start preparation earlier</li> <li>• Allow more time and more choice</li> <li>• Give more information enabling informed choices</li> <li>• Prepare in advance for differences in care</li> <li>• Try to become more independent</li> <li>• Prepare yourself and be more involved in your own care</li> </ul> <p><i>Be alert and involved: do it yourself</i></p> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• Start preparation earlier</li> <li>• Allow more time and more choice</li> <li>• Adjust transfer to other life transitions</li> <li>• Give more information, also on paper</li> <li>• Involve parents</li> <li>• Make young people responsible; they are the experts</li> </ul> <p><i>Don't leave this to professionals, do it yourself, be alert and hang on there</i></p>	<p><b>Healthcare providers</b></p> <ul style="list-style-type: none"> <li>• Preparation should start early and transition should be gradual</li> <li>• Timing of transfer should be flexible, adjusted to other life transitions and to patient readiness</li> <li>• Set up transition clinics/young adult teams; introducing new providers early</li> <li>• Involve adolescents more in their own care and listen to their opinions</li> <li>• Have parents stay involved, but in a different role</li> <li>• Prepare patients and parents for differences between paediatric and adult care</li> <li>• Work systematically on the fostering of adolescents' independence; use checklists and transition readiness assessments</li> <li>• Encourage more independent behaviours during consultations; see adolescents without parents</li> <li>• Less is more: less pampering, but more self-management of young people</li> <li>• Pay attention to adult issues such as career, sexuality and intimate relations, etc.</li> </ul> <p><i>Do not pamper; prepare patients to take care in their own hands</i></p>
<b>Better organization of transition, more communication between providers</b>	
<p><b>Young adults</b></p> <ul style="list-style-type: none"> <li>• Arrange a meeting with adult healthcare providers before transfer; organize a period of joint care</li> <li>• Improve logistics of the transfer process</li> <li>• Improve communication and alignment between paediatric and adult care</li> <li>• Make young adults feel welcome in adult services</li> <li>• Give patients access to their own dossier</li> <li>• Respect patient expertise</li> </ul> <p><i>Make transfer safe, smooth and simple; respect patient expertise</i></p> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• Appoint someone who co-ordinates care</li> <li>• Organize transition clinic/period of joint care</li> <li>• Procedures in adult care should be the same as in paediatric services</li> <li>• Improve logistics of the transfer process</li> <li>• Improve communication and alignment between paediatric and adult care</li> <li>• Improve communication with parents in adult services</li> <li>• Make parents feel welcome in adult services</li> </ul> <p><i>Make transfer safe, smooth and simple; keep parents involved</i></p>	<p><b>Healthcare providers</b></p> <ul style="list-style-type: none"> <li>• Invest in personal relationships between providers in paediatric and adult care</li> <li>• Exchange knowledge and experiences through clinical lectures, patient rounds, internships and staff exchange</li> <li>• Formulate a joint mission statement</li> <li>• Smoothen differences in working ways and treatment protocols as best as possible</li> <li>• Appoint as a go-between professional in adult healthcare who is trained/interested in treating young adults</li> <li>• Involve doctors and consultants, do not leave transition to nurses and social workers</li> <li>• Organize joint medical consultations/transition clinics</li> <li>• Organize regular consultation (transition meetings) between paediatric and adult care about patients to be transferred</li> <li>• Design a structured transition programme</li> <li>• Paediatric care should provide multidisciplinary referral notes timely; adult care should provide feedback on transferred patients</li> <li>• Invest in building good communication and relations with young adults: it pays back</li> </ul> <p><i>Invest in relations between paediatric and adult services and with patients and parents</i></p>

bonds and enhanced integration between adult and paediatric services were seen as key conditions for better communication and collaboration. Professionals recommended having more staff exchange, holding consultation meetings about patients before and after transition and setting up joint clinics.

## Discussion

This was the first study in the Netherlands to explore the lived experiences of YA transferring to adult care, their parents and

paediatric and adult-oriented providers. Although a multi-actor perspective is recommended (Moons *et al.* 2009), few qualitative studies have included adult-oriented HCP views (Shaw *et al.* 2004b; Reiss *et al.* 2005; Östlie *et al.* 2007). Transitional care should not be confined to a paediatric paradigm and be disconnected from the principles and practice of adolescent medicine (Kennedy & Sawyer 2008). Our study showed that HCP were well aware that transition poses challenges to patients and parents, and were motivated to initiate change. This is exemplified by the recently improved collaboration between



paediatric and adult HCP in the Erasmus University Medical Center, where transition programmes are now being implemented for adolescents with CF, JRA, SB and SCD.

Adolescents with any kind of chronic condition are facing the same challenges with respect to their transition to adulthood (Reiss *et al.* 2005; Sawyer *et al.* 2007). We studied seven patient populations and the type of condition hardly seemed to influence practices, attitudes and concerns. This supports generic, inter-specialty developments in transitional care (McDonagh & Viner 2006).

All actors in our study considered moving to adult services as 'normal' and even desirable for young people with chronic conditions, as reported in other studies as well (Östlie *et al.* 2007; Tuchman *et al.* 2008; Moons *et al.* 2009). Nevertheless, parents and adolescents may have different perceptions before transfer: parents will typically be anxious, whereas adolescents display a wait-and-see attitude (Anthony *et al.* 2009; Moons *et al.* 2009). Still, the prevailing belief of our YA and parents after transfer was that transition was desirable and well timed. In another study, we found that a majority of adolescents still in paediatric care already felt 'ready for transfer' (van Staa *et al.* 2011).

Time is an essential element in transition (Reiss *et al.* 2005), and therefore longitudinal studies are required to explore the initial phase, midcourse experience and outcome of the transition experience (Kralik *et al.* 2006). The only longitudinal study performed so far established that feelings about the desirability of transfer, the appreciation of medical care, the relationships with HCP and the parent's role changed over time during the stages of transition (Tuchman *et al.* 2008). Adolescents anticipating transfer to adult care had ambivalent feelings, but after transfer they acknowledged benefits of the adult-oriented system. Paediatric HCP may therefore overestimate reluctance to transfer or anticipated difficulties.

Our study confirmed that YA and parents often experience the transfer period as challenging, because moving to adult services implies going into a different world and adjusting to the new environment while leaving behind familiar surroundings and trusted HCP (Stewart *et al.* 2001; Kirk 2008; Young *et al.* 2009). Especially sudden and unprepared transfer will affect YA and parents (Shaw *et al.* 2004a). Paediatric providers and their patients are often assumed to be strongly attached (Wray & Maynard 2008), but this is not always the case. It seems that the strength of the relationship depends on the duration and intensity of contact. Transition is not only a time of losses, but also of gains (Kralik *et al.* 2006): new relations offer new opportunities and it is a period for disease-related learning and personal growth for adolescents and parents (Valenzuela *et al.* 2011). Transition should therefore be incorporated in a comprehen-

sive, lifespan perspective on healthcare for young people with chronic conditions (Roebroek *et al.* 2009).

According to HCP in our study, cultural and organizational differences between paediatric and adult-oriented services should be smoothed out, as they inhibited transition. For YA, however, it seemed most important to anticipate on these differences so they could adapt to them. Also, the change from family-oriented to patient-oriented care was not unwelcome for them. YA preferred healthcare staff addressing just them rather than their parents, being spoken to in an adult manner and being responsible for their own care (Stabile *et al.* 2005; Tuchman *et al.* 2008). The shift from parental care to self-care in roles between adolescents and parents is the most decisive element for successful transition (Shaw *et al.* 2004a; Kirk 2008; Moons *et al.* 2009).

With respect to transitional care, all actors in our study agreed that the move from paediatric to adult services should be better prepared for, that young people's views should be listened to and that they should be taught self-management skills. Meeting providers alone during consultations is often seen as a useful intervention to encourage self-efficacy and self-reliance in adolescents (McDonagh 2006; Clarizia *et al.* 2009, van Staa & On Your Own Feet Research Group 2011). Also, earlier discussions about transition, opportunities to meet new providers and visits to adult-oriented venues prior to transition might aid in the transition process (Shaw *et al.* 2004a; Reiss *et al.* 2005; McDonagh 2006; Östlie *et al.* 2007). Positive attitudes towards transition and more discussions have a positive effect on follow-up (Reid *et al.* 2004) and on transfer readiness (van Staa *et al.* 2011).

The key challenge for health services relates to bridging the differing cultures of paediatric and adult healthcare. More communication and collaboration between HCP is essential (Anthony *et al.* 2009; Valenzuela *et al.* 2011). These issues seem universal features of the Western biomedical system characterized by high specialization and fragmentation of services. According to Rosen (1995), physicians in all specialties develop unique styles of care, reinforced by stereotypes, socialization and the working environment. However, cultural differences between paediatric and adult care are also functional: the clear role for parents, the supportive practice style and the awareness of developmental issues in paediatrics are geared to the care of young children, but these attributes become dysfunctional and self-limiting for older adolescents and YA. This is confirmed by our YA assertion that they 'grew out' of paediatric care. As adolescents must become self-efficacious partners in their own care, self-reliance should be encouraged and parents' roles must be redefined (Rosen 1995).

The experiences and recommendations we collected from Dutch YA, parents and HCP were quite similar to those reported in international studies. An example are the similarities between the (dis)advantages of paediatric and adult care reported in Table 4 and the findings of Wray and Maynard (2008) on specialist cardiac services in the UK. There is also close agreement between the experiences and challenges in transition, and solutions for improving the process – as suggested by patients and parents in our study and in studies from the UK, the USA, Canada and Australia – despite the large differences in healthcare systems. We think it unlikely that international parent-to-parent or youth-to-youth communication influenced or shaped our respondents' experiences. At least, it was never mentioned. Since less than 10% of interviewed parents or YA were members of a patient organization, we do not feel that they were influenced by experiences of others, especially not from abroad.

Nevertheless, we encountered some differences in experiences cross-culturally. For example, our respondents never reported problems related to accessibility of healthcare services because adult-oriented medical care is fully covered by insurance in the Netherlands – in contrast to US-based studies such as Reiss and colleagues (2005) and Tuchman and colleagues (2008). This demonstrates that system-related variables are indeed important in transition, although they did not raise barriers in the Netherlands.

Our results firmly support the key elements for transitional care (McDonagh & Viner 2006) as well as the need for action (Christie & Viner 2009). These Dutch professionals had little awareness of and designated attention to adolescent health issues. Most had only just begun to think about transition of care and did not use protocols or other interventions to smoothen the process.

With the findings of this study, it is now possible to direct paediatric and adult HCP in the Netherlands towards better organization of multidimensional and multidisciplinary healthcare transition.

### Limitations of the study

A limitation of this study is that in some chronic conditions, non-response and refusal rates were high, implying that there could be a selection bias. YA with mild health complaints may have been less inclined to participate, which may have resulted in an overrepresentation of more severe conditions and an overestimation of the reported difficulties during transfer. On the other hand, many YA with SCD and DM could not be reached. We do not know whether they have dropped out of care.

Furthermore, the small numbers of participants in each diagnostic group did not allow for detecting differences between the conditions. Also, possible benefits of a structured transition programme could not be established, as only one department offered this at the time. This study was conducted at one university hospital with short communication lines because the paediatric and adult services are located on the same premises. Most YA were transferred within this hospital. However, they complained of the same lack of co-ordination and differences in care as those transferred to other hospitals.

### Conclusion

Preventing adolescents becoming lost in the transfer between paediatric and adult health services is a major challenge in view of the cultural chasm between paediatric and adult-oriented services. Until recently, the specific needs of YA and their parents during healthcare transition have been largely ignored in the Netherlands. The directions emerging from this study are clear: better preparation for transition, early start and involvement of adolescents and parents. The focus should be on strengthening adolescents' independency and changing parents' roles. HCP's first priority is building bridges through enhanced communication between paediatric and adult-oriented care. Gaining trust and investing in new personal relations is the way forward for all parties involved: transition is about responding and bonding.

### Key messages

- Moving on to adult care is a welcome and positive challenge for young adults with chronic conditions and their parents, despite inherent insecurities.
- Young adults and parents wish to be involved in the transition process and be better informed about the changes.
- The key to successful transition is strengthening independency and encouraging self-management right from childhood.
- Gaining trust in each other and building new personal relations is essential for successful transition, not only for patients and their parents, but also for paediatric and adult-oriented healthcare providers.
- From a lifespan care perspective, providing comprehensive transitional care is a necessity: so let's just do it.

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