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

AnneLoes van Staa, Susan Jedeloo, Jetty van Meeteren, Jos M. Latour

Child: Care Health and Development. 2011;37(6):821-832.

Abstract

BACKGROUND: Transition from pediatric to adult health care 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, (ii) identify recommendations for transitional care from the perspectives of young adults, their parents and health care providers.
METHODS: Semi-structured interviews with 24 young adults after transfer (aged 15-22 years; diagnosed with hemophilia, diabetes mellitus, spina bifida, congenital heart disorders, cystic fibrosis, juvenile rheumatoid arthritis, or sickle cell disease), 24 parents, and 17 health care providers. Thematic analysis was performed.
RESULTS: Only the hemophilia department offered a structured transition program, 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 pediatric 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 pediatric 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 noncompliance, lost to follow-up, and lack of independence. Two other themes indicated priorities for improvement: (3) 'better patient and parent preparation' for differences between health care settings and for new roles and responsibilities with respect to self-management; and (4) 'more collaboration and personal links' between pediatric and adult care providers.
CONCLUSIONS: Action is required to cross the chasm between pediatric 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.

1 Introduction

Moving from pediatric to adult health care 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 health care needs to self-care.[1] 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 health care services: major changes in both the organization and content of adolescent health care are required. Three elements must be pursued: a cultural shift in staff's attitudes, effective transition programs, and teaching adolescents to become active partners in their own care.[2]

Ideally, transition of care is a purposeful, planned process – as advocated in policy documents, professional guidelines and expert opinion articles.[3, 4, 5] The term "transition" refers to the process prior to and after the "transfer" event, that is, the actual shift from pediatric to adult health care.[6] Only few experimental studies have evaluated transition programs and services,[7] mostly conducted in the UK.[8, 9] There is no evidence that particular models of transition are more effective than others.[10, 11] Nevertheless, there is a growing evidence base on key elements of transitional care.[12-14] Especially the need to improve care in different chronic conditions has been documented well in various countries with different health care systems. Several empirical, mostly qualitative, studies explored user expectations and experiences around their transfer to adult services.[1, 15-25]

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,[26] while the experiences and effects of transition to adult services on patients and their parents have hardly been studied.[27-29]

Therefore, we designed an explorative study with a twofold aim: (1) to map experiences with the recent transfer to adult care of young adults 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 young adults, their parents, and health care providers.

2 Methods

2.1 Design and setting

A qualitative study was conducted between 2004-2007 in the Erasmus University Medical Center - Sophia Children's Hospital, a tertiary referral centre, among young adults diagnosed with hemophilia (HP), diabetes mellitus (DM), spina bifida (SB), congenital heart disorders (CHD), cystic fibrosis (CF), juvenile rheumatoid arthritis (JRA), or sickle cell disease / thalassemia (SCD). They were eligible for participation if they had no record of intellectual disabilities and had been transferred to adult care in the past two 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 six months were listed. The term 'young adult' refers to those already or about to be transferred to adult care (aged over 16), to be distinguished from 'adolescents' still receiving pediatric care.

The study consisted of semistructured interviews conducted with young adults, parents and health care providers from pediatric and adult care.

2.2 Sampling

In each diagnostic group, three young adults were randomly selected from a list of patients officially discharged in the previous two years (and in CF from the waiting list). Parents were approached after the young adult had given consent. When young adults did not reply within two weeks, they were sent a reminder letter and a few days later, they were called by telephone. When no consent was given or the young adult 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 health care provider interviews, pediatric providers were first interviewed and asked to suggest participants from adult care.

2.3 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 minutes. Parents and young adults 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 pediatric and adult services (Table 1). Disease-specific questions were added to gain more in depth information on specific health care needs.

In the health care provider interviews, attitudes toward transition and current transfer practices were explored. They were interviewed at their workplaces and interviews lasted from 25 to 60 minutes.

2.4 Data analysis

Interviews were digitally recorded, transcribed verbatim and then imported into the qualitative software package ATLAS.ti 5.0 (www.atlasti.com). Thematic analysis was chosen for its flexibility and theoretical freedom, and applied in several phases.[30]

All interviews were reviewed and coded by AvS 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.

2.5 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 pediatric health care providers from the same hospital in three focus groups (data not reported here).[31]

2.6 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.

3 Results

3.1 Study population

Table 2 presents the characteristics of the 65 participants: 24 young adults (mean age 18.7 years; range 15-22), 24 parents, and 17 health care providers. Six young adults (25%) were about to transfer, 18 had already been transferred to adult care. One-third of them was now being treated in nonacademic hospitals. Twenty young adults gave permission to invite their parents for an interview; all parents consented, so 20 pairs were interviewed. Of four young adults, parents were not interviewed.

Three SB-patients and one CHD-patient who did not wish to participate, gave permission to interview their parents.

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. Nonparticipation 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.

3.2 Transfer practices in seven chronic conditions

Table 3 gives an overview of transfer practices as reported by health care providers. At the time, only the HP department offered a structured transition program 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 young adults 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 Center was the first to formulate a joint mission statement, but protocols and procedures had not been aligned yet and many young adults 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 pediatric and adult care of the same specialty did not know each other. Joint consultations were not organized and there was no formalized consultation between pediatric and adult health care. The HP department offered a farewell meeting and personal hand-over of patients after crossing the bridge that connects the children's and adult hospital, a ritual some other health care providers 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 pediatric care. Most adult care facilities had higher patient load, less consultation 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 pediatric team. In the SCD-department, psychosocial support was not always continued after transfer.

3.3 Moving on to adult services

Two core themes related to the process of 'moving on to adult care' emerged from the interviews with young adults, parents, and health care providers:

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

3.3.1 Leaving pediatric care is a logical step

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

Before transfer, young adults 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 pediatric 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)

Health care 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".* Pediatric providers tended to stress that age boundaries should be flexible, depending upon the adolescent and his parents. Adult providers felt that *"most young people are ready"* to be more involved in their health care. Young adults need to be *"pushed"* a little, as leaning back comes naturally to them. This may create tension with *"overprotective"* parents. A pediatric 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 health care providers were convinced that parents have more difficulty in leaving behind the trusted pediatric environment than young adults themselves, and that the young adults are tired of being *"patronized*" by pediatric staff and parents.

3.3.2 Transition is complicated by cultural gaps between pediatric and adult services

Some parents and young adults looked back at transfer as *"no big deal"* and even as *"peanuts",* when the process had been smooth or *"seamless".* But most young adults and especially parents said it had been more stressful and difficult than anticipated. Those who had had frequent contact with pediatric providers 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 young adults described pediatric surroundings and relationships with the staff as warm, familiar, cozy 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 young adults 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 young adults with HP and their parents were positive about the transition program, 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 young man 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 pediatric 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").* Young adults 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 young adults 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. Young adults, too, had noted that more independence and self-reliance was expected of them. They 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 health care providers that for young adults.

All health care providers recognized cultural differences between the pediatric and adult-oriented specialties that complicated transfer. These are summarized in Table 5. The adult care *"business-like approach"* was often contrasted with the pediatric *"holistic, system-oriented approach"*. Health care providers in both settings felt there is truth in the stereotypes about pediatrics 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 hematologist said that SCD-patients were *"somewhat spoilt in pediatrics"*, while his pediatric colleague stressed that intensive surveillance is needed because of poor adherence, high no-show rates, and (psycho)social problems. In turn, this was accredited for by the hematologist, who felt that social work should be continued after transfer. Pediatric providers 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, health care providers saw the large cultural gaps as unwanted. Differences in treatment protocols and procedures should be smoothened, but on the other hand, a pediatric rheumatologist felt: "*We should not pamper transition as well! Patients could handle this very well themselves".*

3.4 Recommendations for better transition

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

1. Better patient and parent preparation.
2. Better organization and communication between pediatric and adult care.

3.4.1 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 young adults suggested it would be nice to meet the new health care provider before transfer and all wanted to be prepared for differences in ways of working.

Health care provides 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 health care at the moment they transfer, while the parental role is declining*. (Pediatric pulmonologist)

Health care providers mentioned that young adults 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 pediatric consultations, this poses an enormous challenge.

Health care 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 smoothened, whenever possible.

Parents and young adults indicated that preparation for transfer requires action from all actors involved, not only from health care providers. Young adults 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 their children, 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"*.

3.4.2 Better organization and communication between pediatric 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 pediatric and adult services, but also with social workers and other allied professionals. Young adults and parents stressed that adult care should be more accessible and responsive to their needs*: "make us feel welcome"*.

Almost all health care providers regretted that they did not know their counterparts personally but only through ‘paper’. Closer personal bonds and enhanced integration between adult and pediatric 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.

4 Discussion

This was the first study in the Netherlands to explore the lived experiences of young adults transferring to adult care, their parents, and pediatric and adult-oriented providers. Although a multi-actor perspective is recommended,[25] few qualitative studies have included adult-oriented health care providers’ views.[17, 19, 32] Transitional care should not be confined to a pediatric paradigm and be disconnected from the principles and practice of adolescent medicine.[6] Our study showed that health care providers 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 pediatric and adult providers in the Erasmus University Medical Center, where transition programs 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.[17, 33] 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.[13]

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.[19, 20, 25] Nevertheless, parents and adolescents may have different perceptions before transfer: parents will typically be anxious, whereas adolescents display a wait-and-see attitude.[21, 25] Still, the prevailing belief of our young adults and parents after transfer was that transition was desirable and well-timed. In another study, we found that a majority of adolescents still in pediatric care already felt 'ready for transfer'.[34]

Time is an essential element in transition,[17] and therefore longitudinal studies are required to explore the initial phase, midcourse experience, and outcome of the transition experience.[35] The only longitudinal study performed so far established that feelings about the desirability of transfer, the appreciation of medical care, the relationships with health care providers, and the parent's role changed over time during the stages of transition.[20] Adolescents anticipating transfer to adult care had ambivalent feelings, but after transfer they acknowledged benefits of the adult-oriented system. Pediatric providers may therefore overestimate reluctance to transfer or anticipated difficulties.

Our study confirmed that young adults 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 health care providers.[1, 15, 22] Especially sudden and unprepared transfer will affect young adults and parents.[16] Pediatric providers and their patients are often assumed to be strongly attached,[36] 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[35]: new relations offer new opportunities and it is a period for disease-related learning and personal growth for adolescents and parents.[24] Transition should therefore be incorporated in a comprehensive, lifespan perspective on health care for young people with chronic conditions.[37]

According to health care providers in our study, cultural and organizational differences between pediatric and adult-oriented services should be smoothened out, as they inhibited transition. For young adults, 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. Young adults preferred health care staff addressing just them rather than their parents, being spoken to in an adult manner, and being responsible for their own care.[18, 20] The shift from parental care to self-care in roles between adolescents and parents is the most decisive element for successful transition.[1, 16, 25]

With respect to transitional care, all actors in our study agreed that the move from pediatric 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.[12, 23, 38] 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.[12, 16, 17, 19] Positive attitudes toward transition and more discussions have a positive effect on follow-up,[39] and on transfer readiness.[34]

The key challenge for health services relates to bridging the differing cultures of pediatric and adult health care. More communication and collaboration between health care providers is essential.[21, 24] These issues seem universal features of the Western biomedical system characterized by high specialization and fragmentation of services. According to Rosen,[5] physicians in all specialties develop unique styles of care, reinforced by stereotypes, socialization, and the working environment. However, cultural differences between pediatric and adult care are also functional: the clear role for parents, the supportive practice style and the awareness of developmental issues in pediatrics are geared to the care of young children, but these attributes become dysfunctional and self-limiting for older adolescents and young adults. This is confirmed by our young adults' assertion that they *"grew out"* of pediatric care. As adolescents must become self-efficacious partners in their own care, self-reliance should be encouraged and parents' roles must be redefined.[5]

The experiences and recommendations we collected from Dutch young adults, parents and health care providers were quite similar to those reported in international studies. An example are the similarities between the (dis)advantages of pediatric and adult care reported in Table 4 and the findings of Wray & Maynard on specialist cardiac services in the UK.[36] 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 health care 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 young adults 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 health care services because adult-oriented medical care is fully covered by insurance in the Netherlands – in contrast to US-based studies such as Reiss *et al*[17] and Tuchman *et al.*[20] 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,[13] as well as the need for action.[14] 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 pediatric and adult health care providers in the Netherlands toward better organization of multidimensional and multidisciplinary health care transition.

4.1 Limitations of the study

A limitation of this study is that in some chronic conditions, nonresponse and refusal rates were high, implying that there could be a selection bias. Young adults 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 patients 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 program 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 pediatric and adult services are located on the same premises. Most young adults were transferred within this hospital. However, they complained of the same lack of coordination and differences in care as those transferred to other hospitals.

5 Conclusion

Preventing adolescents becoming lost in the transfer between pediatric and adult health services is a major challenge in view of the cultural chasm between pediatric and adult-oriented services. Until recently, the specific needs of young adults and their parents during health care 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. Health care providers' first priority is building bridges through enhanced communication between pediatric 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 pediatric and adult-oriented health care providers.
- From a lifespan care perspective, providing comprehensive transitional care is a necessity: so let's just do it.

Acknowledgements

No external funding was available; Rotterdam University & Erasmus University Medical Center supported the study. Wil de Groot and Bert van der Heijden from Erasmus MC - Sophia are thanked for giving access to medical and nursing staff. We thank all young adults, their parents and health care professionals who participated in the study. Thanks also go out to the former students of Rotterdam University who helped collecting the data: Sofia Asvesta, Angelie Faber, Annemieke Figee, Linda van der Meijs, Marjolein Mostert, Janet Nobel, Marieke van Oorschot, Laura van Pappelendam, Yvette van Strien, and Maaike Zijderveld.

References

1. Kirk S. Transitions in the lives of young people with complex health care needs. *Child Care Health Dev.* 2008;34(5):567-575.
2. Viner RM. Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Arch Dis Child.* 2008;93(2):160-163.
3. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adol Health*. 1993;14(7):570-576.
4. American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics.* 2002;110(6 Pt 2):1304-1306.
5. Rosen D. Between two worlds: bridging the cultures of child health and adult medicine. *J Adolesc Health*. 1995;17(1):10-16.
6. Kennedy A, Sawyer S. Transition from pediatric to adult services: are we getting it right? *Curr Opin Pediatr.* 2008;20(4):403-409.
7. Hilderson D, Westhovens R, Wouters C, Moons P. Transitional care for adolescents with rheumatic diseases: urgent need for more research. *Child Care Health Dev.* 2008;34(3):401-402.
8. McDonagh JE, Shaw KL, Southwood TR. Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care program for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *J Child Health Care*. 2006;10(1):22-42.
9. McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care program on adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford)*. 2007;46(1):161-168.
10. While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child Care Health Dev.* 2004;30(5):439-452.
11. Binks JA, Barden WS, Burke TA, Young NL. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabil.* 2007;88(8):1064-1073.
12. McDonagh JE. *Growing up ready for emerging adulthood. An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities*. Paper read at Conference 26th March 2006. Department of Health Publications, London, UK; 2006. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137427
13. McDonagh JE, Viner RM. Lost in transition? Between paediatric and adult services. *Brit Med J*. 2006;332(7539):435-436.
14. Christie D, Viner R. Chronic illness and transition: time for action. *Adolesc Med State Art Rev.* 2009;20(3):981-987,xi.
15. Stewart DA, Law MC, Rosenbaum P, Willms DG. A qualitative study of the transition to adulthood for youth with physical disabilities. *Phys Occup Ther Pediatr.* 2001;21(4):3-21.
16. Shaw KL, Southwood TR, McDonagh JE. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford).* 2004;43(6):770-778.

17. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics.* 2005;115(1):112-120.
18. Stabile L, Rosser L, Porterfield KM, et al. Transfer versus transition: success in pediatric transplantation brings the welcome challenge of transition. *Prog Transplant.* 2005;15(4):363-370.
19. Östlie IL, Dale O, Moller A. From childhood to adult life with juvenile idiopathic arthritis (JIA): a pilot study. *Disabil Rehabil*. 2007;29(6):445-452.
20. Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev.* 2008;34(5):557-563.
21. Anthony SJ, Kaufman M, Drabble A, Seifert-Hansen M, Dipchand AI, Martin K. Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation.* 2009;9(3):614-619.
22. Young NL, Barden WS, Mills WA, Burke TA, Law M, Boydell K. Transition to adult-oriented health care: perspectives of youth and adults with complex physical disabilities. *Phys Occup Ther Pediatr.* 2009;29(4):345-361.
23. Clarizia NA, Chahal N, Manlhiot C, Kilburn J, Redington AN, McCrindle BW. Transition to adult health care for adolescents and young adults with congenital heart disease: perspectives of the patient, parent and health care provider. *Can J Cardiol.* 2009;25(9):e317-322.
24. Valenzuela JM, Buchanan CL, Radcliffe J, Ambrose C, Hawkins LA, Tanney M, et al. Transition to Adult Services among Behaviorally Infected Adolescents with HIV--A Qualitative Study. *J Pediatr Psychol*. 2011;36(2):134-140.
25. Moons P, Pinxten S, Dedroog D, Van Deyk K, Gewillig M, Hilderson D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health.* 2009;44(4):316-322.
26. van Staa AL, Eysink Smeets-van de Burgt AE, van der Stege HA, Hilberink SR. Transitie in zorg van jongeren met chronische aandoeningen in Nederland nog onder de maat. [Transition in care for young people with chronic conditions: substandard in the Netherlands]. *Tijdschr Kindergeneeskd.* 2010;78(6):227-236.
27. Verhoeven L, van Staa AL. ''Vanzelfsprekend, maar niet vanzelf''. Transitie in zorg: ervaringen van adolescenten met Cystic Fibrosis en hun ouders [Transition of care: a matter of course, but no plain sailing. Experiences of adolescents with Cystic Fibrosis and their parents]. *Verpleegkunde.* 2006;3:186-195.
28. Hilberink SR, Roebroeck ME, Nieuwstraten W, Jalink L, Verheijden JM, Stam HJ. Health issues in young adults with cerebral palsy: towards a life-span perspective. *J Rehabil Med.* 2007;39(8):605-611.
29. Geerts E, van de Wiel H, Tamminga R. A pilot study on the effects of the transition of paediatric to adult health care in patients with haemophilia and in their parents: patient and parent worries, parental illness-related distress and health-related Quality of Life. *Haemophilia.* 2008;14(5):1007-1013.
30. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res in Psychol.* 2006;3(2):77-101.
31. van Staa AL, Jedeloo S, Kuijper M, Latour JM. *Op Eigen Benen. Jongeren met chronische aandoeningen: wat willen en kunnen zij in de zorg? [On Your Own Feet. Young people with chronic conditions: what are their preferences and competencies for health care?]*. Rotterdam: Hogeschool Rotterdam; 2007. ISBN 978-90-8017-769-7.

32. Shaw KL, Southwood TR, McDonagh JE. Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. *Rheumatology (Oxford).* 2004;43(8):1000-1006.
33. Sawyer SM, Drew S, Yeo MS, Britto MT. Adolescents with a chronic condition: challenges living, challenges treating. *Lancet.* 2007;369(9571):1481-1489.
34. van Staa AL, van der Stege HA, Jedeloo S, Moll HA, Hilberink S. Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors. *J Adolesc Health.* 2011;48(3):295–302.
35. Kralik D, Visentin K, van Loon A. Transition: a literature review. *J Adv Nurs.* 2006;55(3):320-329.
36. Wray J, Maynard L. Specialist cardiac services: what do young people want? *Cardiol Young.* 2008;18(6):569-574.
37. Roebroeck ME, Jahnsen R, Carona C, Kent RM, Chamberlain MA. Adult outcomes and lifespan issues for people with childhood-onset physical disability. *Dev Med Child Neurol.* 2009;51(8):670-678.
38. van Staa A, On Your Own Feet Research Group. Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: The added value of mixed methods research. *Patient Educ Couns.* 2011;82(3):455–464.
39. Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Siu SC, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*. 2004;113(3 Pt 1):e197-205.

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

How did the transfer from pediatric 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 coordination
  - Suggestions to improve transitional care

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

How do you experience and evaluate adult care?
  - Positive and negative aspects of adult care
  - Perceived differences with pediatric care
  - Roles of parents, young people, and health care providers during consultations
  - Experiences with different professionals in the health care 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?

Table 2
Background characteristics of 65 study participants

	Response rate[a]	Total	Young adults	Parents	Health care providers
Number of participants		65	24	24	17
Male / female			13 / 11	3 / 21	6 / 11
Treatment setting: Pediatric care / Adult care			6 / 18	9 / 15	11 / 6
Chronic condition					
Diabetes Mellitus	60%	8	3	3	2
Hemophilia	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					
15-18 years			13		
19-22 years			11		
Non Dutch ethnic background			3		
Living independently			5		
Studying / working / unemployed			19 / 2 / 3		
Educational level: Higher / lower			10 / 14		
Health care providers characteristics					
Medical specialist					10
Nurse specialist / Nurse Practitioner					6
Physiotherapist					1

[a] Percentage of young adults that consented to participate after initial approach.

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 pediatric 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[1]	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 health care providers in advance	Yes	No	No	No	Yes	No	No
Joint medical treatment protocol with adult team	Yes	No	Yes	No[a]	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 pediatric and adult care	Yes	No	No	No	No	No	No
Structured transition program, including early preparation	Yes	No	No	No	No	No	No
Joint consultations, transition clinic	No	No	No	No	No	No	No

[a] In preparation at time of research

Note: HP, hemophilia; DM, diabetes mellitus; CHD, congenital heart disease; CF, cystic fibrosis; SB, spina bifida; JRA, juvenile rheumatoid arthritis; SCD, sickle cell disease.

Table 4

Advantages and disadvantages of pediatric and adult care, as perceived by young adults and their parents

Advantages of pediatric care	**Disadvantages of adult care**
familiar	unfamiliar
cozy, relaxed atmosphere	formal, stand-offish; strict
child-friendly	not focused on young people
parents involved	parents less welcome
respect for parent’s and patient’s expertise	lack of respect for patient’s and parent’s expertise
trusted providers’ expertise	expertise not always trusted
good collaboration between care providers	poor coordination with pediatric care / with other specialist providers
multidisciplinary teamwork	team approach is not self-evident
holistic approach	less attention paid to psychosocial issues
excellent conditions for inpatient care	poor conditions for inpatient care
	confronted with older patients
	different methods and treatment procedures than in pediatric care
everything is arranged for you	you have to arrange everything yourself
Advantages of adult care	**Disadvantages of pediatric care**
age-appropriate (adult-like)	childish, not age-appropriate
business-like, matter-of-fact atmosphere	confronted with young children
more focus on responsibility & self-management	less encouragement of independence & self-management
young adult more involved in decision making	adolescent less involved in decision making; presence of parents limits freedom to speak / youth participation
exciting to build new relationships; make a fresh start	“fixed” relationships
information relevant to adult issues	lack of information on adult issues
possibility to chose hospital closer to home	
new treatment options possible	doctors reluctant to treat aggressively and to try new options

Table 5
Cultures of care: typical differences between pediatrics and adult specialist medicine, according to interviewed health care professionals

Pediatrics	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 coresponsible, self-reliant
Family-centered 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 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 coordination

Table 6

Recommendations from young adults, parents and health care providers to improve transitional care

<table>
<tr><td colspan="2">Better patient and parent preparation</td></tr>
<tr><td>Young adults
• Start preparation earlier
• Allow more time and more choice
• Give more information enabling informed choices
• Prepare in advance for differences in care
• Try to become more independent
• Prepare yourself and be more involved in your own care
<i>Be alert and involved: do it yourself</i></td><td rowspan="2">Health care providers
• Preparation should start early and transition should be gradual
• Timing of transfer should be flexible, adjusted to other life transitions and to patient readiness
• Set up transition clinics / young adult teams; introducing new providers early
• Involve adolescents more in their own care and listen to their opinions
• Have parents stay involved, but in a different role
• Prepare patients and parents for differences between pediatric and adult care
• Work systematically on the fostering of adolescents' independence; use checklists and transition readiness assessments
• Encourage more independent behaviors during consultations; see adolescents without parents
• Less is more: less pampering, but more self-management of young people
• Pay attention to adult issues such as career, sexuality and intimate relations, etc.
<i>Do not pamper; prepare patients to take care in their own hands</i></td></tr>
<tr><td>Parents
• Start preparation earlier
• Allow more time and more choice
• Adjust transfer to other life transitions
• Give more information, also on paper
• Involve parents
• Make young people responsible, they are the experts
<i>Don't leave this to professionals, do it yourself, be alert and hang on there</i></td></tr>
<tr><td colspan="2">Better organization of transition, more communication between providers</td></tr>
<tr><td>Young adults
• Arrange a meeting with adult health care providers before transfer; organize a period of joint care
• Improve logistics of the transfer process
• Improve communication and alignment between pediatric-adult care
• Make young adults feel welcome in adult services
• Give patients access to their own dossier
• Respect patient expertise
<i>Make transfer safe, smooth and simple; respect patient expertise</i></td><td rowspan="2">Health care providers
• Invest in personal relationships between providers in pediatric and adult care
• Exchange knowledge and experiences through clinical lectures, patient rounds, internships, and staff exchange
• Formulate a joint mission statement
• Smoothen differences in working ways and treatment protocols as best as possible
• Appoint as a go-between a professional in adult health care who is trained / interested in treating young adults
• Involve doctors and consultants, do not leave transition to nurses and social workers
• Organize joint medical consultations / transition clinics
• Organize regular consultation (transition meetings) between pediatric and adult care about patients to be transferred
• Design a structured transition program
• Pediatric care should provide multi-disciplinary referral notes timely; adult care should provide feedback on transferred patients
• Invest in building good communication and relations with young adults: it pays back
<i>Invest in relations between pediatric and adult services and with patients and parents</i></td></tr>
<tr><td>Parents
• Appoint someone who coordinates care
• Organize transition clinic / period of joint care
• Procedures in adult care should be the same as in pediatric services
• Improve logistics of the transfer process
• Improve communication and alignment between pediatric-adult care
• Improve communication with parents in adult services
• Make parents feel welcome in adult services
<i>Make transfer safe, smooth and simple; keep parents involved</i></td></tr>
</table>