# 18 Transitional Medicine, from Childhood to Adulthood

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## 18.1 Definitions of Health Care Transition

Several definitions exist to describe Health care transition (HCT). In its simplest term, the transition is defined as "the planned process of chronically ill adolescents from a child-centred to an adult-centred system of care" [1]. In a more detailed way, we could also define HCT as "a purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical conditions, as they advance from a paediatric and family-centred to an adult, individually focused health care provider" [2], but for us, HCT is "the process of moving from a child/family-centred model of health care to an adult/patient-centred model of health care, with or without transferring to a new clinician."

Concerning the apparent contradiction of being able to carry out the HCT process without changing the reference clinic, this fact can be explained not so much by the existence of dedicated services capable of taking care of a specific pathology in all phases of life, but rather by the possibility that some pathological fragility conditions occur after the age of 10, that is, in an adolescent age group that can be taken care of by services dedicated to adult medicine. The latter, however, should not underestimate the need to structure HCT courses for the population thus taken care of.

It is clear, that even a healthy child would have the right to transition to adult medicine in a gradual and planned way, but this aspect is beyond the scope of this volume dedicated to frailty and therefore to HCT in the strict sense. However, it is essential to emphasize, especially here, that at present, transitional medicine still deals almost exclusively with the transition to adult medicine of a paediatric subject (10–18 years) suffering from a chronic disease and/or the long-term side effects of the treatment received for that disease.

I therefore feel it is useful to draw the reader's attention, first of all, to the subject of adolescence, since it is the lack of knowledge of the peculiarities of this complex age which causes the greatest difficulties in planning and realizing the transition.

## 18.2 Adolescence

Adolescence can be defined as the 'transition phase between childhood and adulthood'. This definition could be reductive if one considers that adolescence is a rather long and important period

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of life consisting of complex and specific dynamics with important physical and psychological changes that can be at the basis of organic and behavioural pathologies. It is not necessarily a 'difficult' period of life, but it certainly requires special attention, bringing into play elements that may affect the future development of the young person. It is recognized that many of the biological and neuropsychological characteristics of adolescents, as well as their main causes of morbidity and mortality, have their specificities, which differentiate them from both childhood and adult life [3, 4].

The many physical, sexual, cognitive, social, and emotional changes that occur during adolescence determine a profound reshaping of the boy's identity. These changes are rapid and often radical: the boy finds himself unconsciously passing, most of the time in an inadequate way, from a carefree phase, such as the childhood period, to a phase of growing uncertainties from which worries arise. So, we can say that adolescence is that phase of life during which the individual begins to acquire the skills and requirements necessary to assume the responsibilities typical of adulthood. In the process of transitioning to adulthood under normal health conditions, biological, psychological, and social factors come into play and interact with each other.

Classically, adolescence is the age between 10 and 18 years, although the American Society of Adolescent Medicine identifies the upper limit at 21 years … and beyond! This extension of the upper limit is because today's youth, due to a variety of social changes over time, require more time to educate themselves, access the world of work, and achieve economic independence later, as well as the responsibilities and roles of adult social life, such as marriage and parenthood.

**Adolescence is generally divided into three phases**

– Early adolescence (10–12 years). It is the phase characterized by rapid somatic growth and the beginning of pubertal development. Group life and the search for greater independence within the family begin. On a cognitive level, the capacity for abstraction and depth of thought increase, and on a behavioural level, the search for one's own identity predominates.
– Second adolescence (13–15 years). In this phase, somatic and pubertal development is completed. Group life is consolidated and risk behaviour begins (alcohol, smoking, early sex, eating disorders). There are the first sexual relationships, often with unstable partners. On a cognitive level, there is a greater definition of one's goals, and contrasts with the adult world begin.
– Third adolescence (16–18 years). At this stage, concerns about social inclusion and economic independence begin. Risk behaviours are reduced and couple ties become more stable. More mature and responsible behaviour is accompanied by a resumption of dialogue with the family.

We can consider adolescence as a change that can be considered a real rebirth, in which the individual is completely renewed in appearance and personality, with changes so rapid that it often makes it difficult to understand them, especially for educators distracted by the rhythms of life and values that in many societies of industrialized countries do not allow sufficiently dedicated parenting.

Physical change begins at a varying age, usually earlier for females (11–13 years) and later for males (12–14 years), and continues until reaching adulthood, that is, until about age 21. Full brain maturation occurs even later, completing at the age of 24. From the biological point of view, some processes—hormonal, metabolic, and neuronal—are typical of this time window and cannot be properly associated either with childhood or adulthood. The body changes quickly and in a disharmonious way, the adolescent sees his stature grow and increase. His physique matures, with the development of secondary sexual characteristics: there is an increase in the odour of body secretions, the oiliness of skin and hair, and the appearance of acne. It is clear, therefore, that this period presents complex dynamics and requires multidisciplinary attention. It goes

towards a full somatic maturation and completion of sexual development. The adolescent is aware of this, of the progressive independence implemented primarily with the detachment from parental figures, as well as the search for his own identity and self-esteem, in relation to new guiding figures. As far as cognitive development is concerned, the adolescent reaches the operant-formal stage, can systematically organize knowledge and thinks in hypothetical-deductive terms, acquiring the ability to formulate abstract thought. With a new self-awareness, the adolescent is no longer intent on understanding the rules to accept them, but wants to understand, to know, to affirm his precise identity in the group as well as in society. It is the era of experimentation with one's own body: clothing, haircuts, tattoos, piercings. A recent survey shows that adolescents face their sexual life knowing the risks of HIV, but not of other sexually transmitted infections; they hardly orient themselves through a multitude of information, sometimes erroneous, and rarely practice contraception correctly. Changes from the physical sphere explode and involve the sphere of instincts and emotions, which are perceived more intensely, but confusedly. Adolescents are poised between the need for independence and the lack of autonomy, they are conceited and shy, selfish and generous at the same time, they enjoy going against traditions, they can't stand constraints, they demand their independence, they defend their ideas, the more vigorously they are hindered by parental authority. The adolescent is in an unstable mood, may have moments of verbal or physical rebellion and then suddenly turn in on himself, to the point of isolation. He may take extreme positions with the use of smoking, alcohol, and drugs and may manifest mood disorders, aggression towards his body, and eating disorders. All this generates confusion and bewilderment in those around him: the parents, astonished spectators of this metamorphosis, do not recognize in this "strange and alien" boy, the son who was until that moment. Being a parent of an adolescent imposes the fundamental task of reassuring, welcoming, understanding, transmitting trust and security, being ready to listen "on demand", to "walk beside", and to dialogue when possible. Adolescents, in fact, still need more and more to be recognized, to enjoy their rightful freedom, but also to have precise boundaries within which to stay and feel protected. In any case, everyone will have his or her personal path, but after a variable period, the unstable attitude of the adolescent will give way to the attainment of a maturation stage typical of the adult, in which the subject is capable of taking care of himself or herself in daily life and assumes an independent and responsible role in society. Finally, adolescents cannot be lumped together in terms of diagnosis, therapy, and need for psychological support with any of the other ages of life and, therefore, constitute a specific management difficulty. It is inferred, moreover, precisely because of the completion of pubertal development and, therefore, of sexual differentiation, that the approach to gender medicine begins in adolescence. Associated with this is the phenomenon, already described, of experimentation and identification with new figures, a phenomenon that can complicate the management of a cure where a chronic condition is present. All these aspects are further complicated by the process of acceptance of one's body image and the exercise of sexuality, with possible concerns about future fertility. Adolescence, therefore, carries within itself the germ of physical and psychological change, with the search for new lifestyles in keeping with one's identity. If we consider that lifestyle is the cornerstone of future health and impacts on treatments in the presence of pathologies already established, we understand how, even in terms of prevention, this phase of life is associated with important health issues. Although there is the idea that the adolescent is a healthy individual, some studies have observed that about 20–25% of subjects may have medical problems, suggesting that this age of life needs a path and/or dedicated and specific knowledge (**Adolescent medicine**) [5].

Adolescents with a long-term illness generally experienced well-being like everyone else. Three themes were found to be important for feeling well: "a feeling of acceptance of illness/disability as a natural part of life," "a feeling of support,"

and "a feeling of personal growth." Adolescents with long-term illnesses or disabilities experience well-being when they are allowed to prepare to live a normal life with respect to their new value system that allows for their integration into society. In other words, even the normal canons of quality of life assessment must be re-evaluated specifically for different diseases and age groups. Health care providers, however, need to focus on the care of the young person rather than the illness.

Present-day society has produced changes in family living patterns and conditions, and this has resulted in new stressors and health problems. Most children and adolescents with chronic diseases and disabilities, who were previously cared for at hospitals and institutions for long periods, are now integrated into society and they are expected to live a normal life in the conditions that currently prevail.

## 18.3 Health Care Transition

The issue of HCT is of absolute importance and topicality, because of its repercussions on the care plan. For this reason, it must be the object of careful reflection by paediatricians, who represent a fundamental component of the transition process. Paediatricians must deal with transition in a more conscious and effective way because some studies have shown that an inadequate transition process for adolescents affected by chronic diseases is associated with a worsening of their health status.

The goal of HCT is twofold, namely: (1) to ensure an organized process in paediatric and adult health care practices to facilitate transition preparation, transfer of care, and integration into adult-centred health care; and (2) to improve the ability of youth and young adults with and without special health care needs to manage their health care and effectively use health services.

It is clear, as explained in the second objective, that even a healthy child would have the right to transition to adult medicine in a gradual and planned way, but this aspect is beyond the scope of this volume dedicated to frailty and therefore to HCT in the strict sense.

The number of young people with long-term illnesses/disabilities has increased worldwide during the last decades. There is a lack of studies relating to the way young people regard their daily lives and factors that are important for their well-being. Improvements in chronic disease management have led to increasing numbers of fragile youth transitioning to adult healthcare. Poor transition can lead to high risks of morbidity and mortality for these citizens. For the child with a chronic or rare disease, who needs continuous care for his frailty, it is particularly delicate, the transition from paediatric care to those of the general practitioner and the specialist of the hospital centre of reference for adults, in a period of life already affected by risk behaviours typical of adolescence. Some international studies document that in this phase is higher the risk that children "get lost", abandon treatments, and do not undergo periodic check-ups, with the real danger of facing long-term complications and increased mortality [6–8]. Hence the growing attention of the medical and scientific community to the so-called "transition" of adolescents suffering from chronic diseases from a child-centred care system to an adult-oriented one. Transition is intended to prevent the loss of these patients to follow-up, which is frequently reported during this period, as well as ensure the autonomy of care. Unfortunately, in the current state of the art, the process is usually not well coordinated and is still too little widespread and standardized. Typically, a formalized transition programme is often associated with significantly lower pre-transition anxiety and greater post-transition satisfaction.

The process of health care transition (HCT) includes initial planning, the transfer itself, and the support provided during adulthood. The crucial steps to be taken for this type of medical practice are shown in Table 18.1. The steps shown in Table 18.1 are in part those proposed by The American Academy of Pediatrics and American Society of Internal Medicine consensus [9] modified according to the author's experience and

**Table 18.1** Steps in the transition from child-oriented to adult-oriented healthcare

| Step | | Comment |
|---|---|---|
| 1. | Identify a healthcare professional who attends to the care coordination and future healthcare planning | Small group work is preferable |
| 2. | Identify the foundational knowledge and skills required to provide developmentally appropriate health transition services to the chronically ill patient with a specific disease | Disease-specific knowledge acquisition in transition curriculum does not necessarily correlate to task-completion skills |
| 3. | Prepare a medical summary that provides the common knowledge base for collaboration among health care professionals engaged on both the paediatric and adult fronts | A formalized transition programme is often associated with significantly lower pre-transition anxiety and higher post-transition satisfaction |
| 4. | Establish a written health transition plan by age 14–16 involving the youth and their caregivers and family in its development | Teams should partner with young adults to choose the right transition time considering that age at transfer initiation is not associated with satisfaction or perceived readiness to transfer |
| 5. | Try as much as possible to move along the same guidelines adopted by the primary and preventive care service for all adolescents and young adults | Evidence-based medicine is key to optimizing resource allocation |
| 6. | Plan periodic checks on the application of the agreed programmes, intervening on critical issues with appropriate corrective actions, with particular attention in the peri-transitional period | It is essential not to take for granted the success of the transition at the time of handover and appropriate to periodically monitor the cases entrusted to the adult specialist with whom a periodic epicritic evaluation is appropriate, especially concerning the resources dedicated |

supplemented with specific comments deduced from the literature in the field.

To facilitate the implementation of HCT Programmes, Got Transition's Six Core Elements of Health Care Transition™ 3.0 is the widely adopted approach called for in the 2018 Clinical Report on Health Care Transition from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians. The Six Core Elements considered define the basic components of a structured transition process and include customizable sample tools for each core element. The Six Core Elements are tailored to the type of practice facilitating the health care transition and are presented in three distinct packages [10].

A recent review strengthens the evidence that a structured HCT process for youth with special health care needs can show improvements in adherence to care, disease-specific measures, quality of life, self-care skills, satisfaction with care, health care utilization, and HCT process of care [11].

Currently, most countries have no guidelines on health care transition based on systematic evidence research and the process is primarily organized in local settings, partly based on disease-specific guidelines.

The existing guidelines have important limitations. Most of the actual recommendations for the HCT of young people are disease-specific, but not evidence-based, and are conducted on many chronic diseases, conditions, and intellectual and developmental disabilities, including HIV/AIDS [12, 13], type 1 diabetes [14], sickle cell disease [15], chronic kidney disease [16], autism spectrum disorder [17], and cancer [18], among others less relevant.

Only a few high-quality studies, i.e. RCTs, are available on HCT [19, 20], so evidence-based statements are possible for some, but not all, areas. Moreover, only three adult patient representatives and no adolescents/young adults themselves were involved in the Delphi consensus process. This could have strengthened the quality of the guidelines, especially in terms of their applicability and transferability.

Recently a National Institutes of Health Workshop titled Navigating Paediatric to Adult Health Care Transition has been published. The terms, criteria, standards, and actions to be taken for the planning of HCT are set in a kind of milestone for the future [21].

Transition is too often treated as an event, instead of being viewed as a gradual process of empowerment of all parties, including the patient and his or her caregivers, involved in the various care settings. Regarding this point, it is clear that during and also following the transfer, therapeutic education for the parents, as well as the young adults, requires reinforcement [22].

Risk and vulnerability encompass many dimensions of the transition from adolescence to adulthood, and the transition from paediatric, parent-supervised health care to more independent, patient-centred adult health care is no exception. There is evidence for increases in emergency hospital visits when young people with life-limiting conditions transition to adult health care. These changes are not observed for comparator groups—young people with diabetes and young people with no known long-term conditions, suggesting they are not due to other transitions happening at similar ages [23]. Special attention must therefore be paid to the most fragile cases at risk of life-threatening critical episodes.

Recently, HCT has evolved from a focus on paediatric care responsibility to a shared responsibility of paediatric and adult clinicians (physicians, nurses, social workers, and other health care providers working together to provide patient care). The crucial role of adult care clinicians in accepting and collaborating with young adults is still not only an issue of dedicated resources, but rather a challenge of education and professional training. Indeed, young adults are increasingly recognized as a vulnerable population not only in terms of their high rates of behavioural health risks but also their susceptibility to the emergence or worsening of chronic health conditions and traditionally low health care utilization.

In addition, many young adults view health care as a low priority compared to other dimensions of their adult transition (education, employment, housing, relationships, and recreation). Coordinated and dedicated HCT efforts are therefore needed to increase awareness among youth, young adults, and their families that health maintenance and continuity of care are central to achieving broader adult goals [24].

In conclusion, the transition from paediatric to adult health care represents a critical time in an adolescent's developmental trajectory, regardless of background. For youth with chronic conditions and/or developmental disabilities, this changeover can be even more critical with significant and lifelong implications. Future efforts to improve available resources and provider preparedness are and will be increasingly essential to meeting the unmet needs of frail patients.

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