



## EDITORIAL

## Transition in adolescents with chronic disease. It is an integral care



## Transición en adolescentes con enfermedad crónica. Se trata de una atención integral

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The transition from paediatric to adult care involves a change from a child-centred health care system to one focused on the adult, which are necessarily different.<sup>1,2</sup> It must be organised, planned, gradual and coordinated in order to optimise health outcomes and help adolescents and young adult achieve their full potential.<sup>1–4</sup>

At present, adolescent care is not adequately organised in Spain. There are differences between care settings in the age boundary: in primary care, paediatric/adolescent care ends at 14–15 years, compared to 16, 18 or even 21 years in inpatient or emergency care settings.<sup>1,3</sup> The training and skills in adolescent care of health care professionals is heterogeneous and could be improved. In addition, the approach to adolescent care is frequently not holistic (addressing physical, psychological, emotional and social aspects). Since 2014,<sup>5</sup> the WHO has been underscoring the need to offer adolescents age-appropriate care different from paediatric and adult care to address their specific needs.

Adolescence is “a period characterized by rapid physical, cognitive and social changes, including sexual and reproduc-

tive maturation; the gradual building up of the capacity to assume adult behaviours and roles involving new responsibilities requiring new knowledge and skills” (Convention on the Rights of the Child, 2003). Adolescence is a stage in which there is an enormous potential for positive changes, intense learning and exposure to new and diverse situations,<sup>2,6</sup> during which young individuals must find their talents and assume dynamic roles. It is also a period of uncertainties, vulnerability and personal health problems in which risk behaviours and behavioural disorders may develop.<sup>1–3</sup>

According to official data endorsed by the Instituto Nacional de Estadística (National Institute of Statistics), in Spain, out of the total population of 47.43 million people in 2022, 14% were aged 0–14 years and 15.6% were aged 15–29 years (total of 7 431 973, with approximately 200 000 fewer women than men).

In Spain, the legal age of majority is 18 years, as established by article 315 of the Civil Code. Since 2022, the age of consent for medical purposes is 16 years, as established by Law 41/2002, of 14 November on the autonomy of the patient and the capacity to make decisions concerning health care. When it comes to adolescent care,<sup>7</sup> we must also take into account the “mature minor doctrine” in assessing the capacity of patients from age 12 years to assent or even consent. Important approaches for decision-making in the care of adolescents with chronic disease or disabil-

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ity include the shared, supported and proxy decision-making models.

In neighbouring countries, between 15% and 20% or more of the adolescents in the population have some form of chronic health problem. This percentage has been increasing in recent decades<sup>1-4,7</sup> due to advances in the treatment of diseases that used to be fatal before adulthood or significantly impair quality of life, chronic diseases involving special health care needs or technology dependence or the increased prevalence of lifestyle diseases like obesity, mental health disorders and their comorbidities. And we cannot forget diseases with onset in adolescence.

The transition to adult care has been subject to extensive research in the 21st century. In *Anales de Pediatría*, an article published in 2014 by Martín-Frías et al.<sup>8</sup> presenting the findings of a study conducted in Madrid evinced the need of improving the planning of the transition to adult care of paediatric patients with type 1 diabetes. Various hospitals, scientific societies and expert groups have proposed and developed recommendations for care transition focused on specific conditions<sup>3,4,7</sup>: diabetes, cancer and haematological diseases (tumours, sickle cell anaemia), gastrointestinal diseases (inflammatory bowel disease, coeliac disease, liver transplantation, cystic fibrosis), cardiovascular diseases (congenital heart disease, Kawasaki disease), renal diseases, neurologic diseases (epilepsy, autism spectrum disorder, attention-deficit hyperactivity disorder, cerebral palsy, chromosomal disorders), neurosurgery and psychiatric and mental health disorders.

The article by Moreno-Galdó et al.<sup>9</sup> in the current issue of *Anales de Pediatría* provides a detailed review of care transition and developmentally appropriate care depending on the maturity of the patient. The statements in this article—a truly 'special' one, given its relevance and its proposals—are consistent with the recent literature<sup>2,4,6,7</sup> in describing the transition to adult care as an educational and therapeutic process that must be planned and negotiated with the patient and discussed with the family and the paediatric and adult care teams to minimise its potential deleterious effects and benefit the patient and other involved parties. It must include the preparation for transition in the paediatric care system, the transfer of the patient and the completion of transition with the integration of the patient in the adult care system. The hospital of the authors has adopted the 6 core elements of the GOT Transition model.<sup>3,4,6,9</sup>

The authors noted that care transition protocols can and should be developed for specific diseases, depending on the condition of the patient (level of complexity and severity, which is also a consideration in determining the age of transition) and the organization and structure of the local health care system. But they also underscored the paramount importance of a general care transition programme with teams specialised in transitions to coordinate the programme and support the different care teams involved, which can be a great help, in addition to promoting and strengthening the role of primary care teams. As health care professionals, we must reach out to adolescents and engage them, listen to them, develop rapport. These programmes must also be allocated the necessary administrative and ICT support staff. Patients with severe intellectual disability constitute a special case.

The authors used the Transition Readiness Assessment Questionnaire (TRAQ), an instrument used in previous publications, to assess the readiness of the adolescents.<sup>3,4,10</sup> Between 16% and 19% of adolescents were adequately prepared for the transition.

Nursing staff plays an important role in the transition to adult care. Patient associations, support groups, and the support of the adolescent by peers, groups of friends and adults are also important. In both primary and speciality care settings, efforts should be made to investigate, disseminate and generate technological resources<sup>6</sup> that are accessible and user-friendly for adolescents and young adults: apps with information to facilitate the joint management of their health, information on what to do in particular situations, websites, maps or charts of local and supralocal resources.

The authors underscored the value of the requisite quality assessment of care transition programmes, in addition to monitoring and research.

These programmes can drive change<sup>10</sup> in every setting in the hospital involved in the care of young patients and other hospitals of similar characteristics. The development of regional and even nationwide strategic plans has been proposed in other areas.<sup>6</sup>

The transition to adult care is just one of the many transitions (social, cultural and economic) that individuals undergo during adolescence.

The social and cultural context shapes the lives of individuals, including adolescents. At present, we are living under the paradigm of postmodernity.<sup>11</sup> It promotes individualism, diversity, fragmentation, relativism and a break with "classical" references. It is characterised by complexity and a marked dynamism, prioritizes the present, with a certain scepticism toward the future, which appears bleak. It brings attention to contradictions, creating a difficult environment. It is developing concurrently with emerging information and communication technologies in the framework of globalization, environmental protection and protests against social injustice. This sociocultural context is also giving rise to currents like gender perspective, overcoming the boundaries of binarism, to vital experiences that extend beyond the body, as the real world grows into a virtual world, with access to social networks and artificial intelligence. Expressions of identity are constantly evolving, fluid (the "liquid society" of Bauman, 2006), shifting and precarious, and it is difficult to find stable identity models shared by large groups of people.<sup>11</sup> This is the postmodernity in which adolescence unfolds, a stage that is more than a transition or a liminal state (in the sense of boundary, not of invisibility). At a crucial juncture in life, that of identity formation, young individuals are the subject of reflection or criticism by adults. They are often perceived negatively. Adolescents need to adapt to this society. They clearly require the support of families, guardians, emotional attachment figures, peer groups, communities and also the government.

The Sociedad Española de Medicina de la Adolescencia (SEMA, Spanish Society of Adolescent Medicine) was founded in 1987 on the initiative of Blas Taracena del Piñal (1924–2002) within the Asociación Española de Pediatría (AEP, Spanish Association of Pediatrics). The mission of the SEMA is to improve the care and integral health of ado-

lescents and young adults, taking into account biological, psychological, emotional and social aspects, in addition to educational, ethical and legal aspects. Its core objective is the training of health care professionals. The association holds congresses and training courses biannually. Since 2013, it publishes *Adolescere*, a continuing education journal that is the main communication platform of the SEMA. It had its roots in the bulletin of the Section of Adolescent Medicine of the AEP, launched in December 1994 and coordinated by Josep Cornellá y Canals (1950–2014).

The SEMA has also developed the manual “Medicina de la Adolescencia. Atención integral” (Adolescent Medicine. Comprehensive Care. M.I. Hidalgo Vicario et al. Eds.); the third edition of which was published in 2021. It has also collaborated with the AEP in the development of its White Book of Paediatrics and its Specialities (*Libro Blanco de las ACES Pediátricas*) describing the specific requirements and scopes of practice of each of the paediatric speciality fields recognised in Spain as well as internationally. Information regarding the SEMA can be found at [www.adolescenciasema.or](http://www.adolescenciasema.or).

Last of all, the proposal of Moreno-Galdó published in this issue offers a key update in adolescent care. Its framework, that is, our journal *Anales de Pediatría*, along with the AEP and paediatric speciality societies, must take on leadership roles. Paediatric scientific societies in Spain also act as advocates for the development of comprehensive adolescent care, addressing public administrations and other institutions, scientific societies and mass-media and cultural agents, in addition to promoting and upholding continuity across levels of care, and with the cultural and educational milieu as well as patients.

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