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NEURODEVELOPMENTAL DISORDERS AND CHILDHOOD-ADOLESCENT PSYCHOPATHOLOGY TESTED BY TRANSITION. CASE REPORT AND LITERATURE REVIEW

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ABSTRACT

Background: This contribution summarizes the critical issues and operational and cultural difficulties of the transition of skills from services for children and adolescents to services for adults regarding neurodevelopmental disorders and psychopathology. Obstacles inherent to services and patients often create a void in this phase which, instead, represents the one with the most marked care needs. It appears that there is a concrete risk of exiting the care circuits.

Purpose: The authors report the case of a patient in transition from child care to adult care, highlighting the clinical and care peculiarities. The methodologies shared in the literature are also represented.

Results: Recent literature and the reported case confirm the organizational and methodological difficulties that hinder the transition from child services to adult services, highlighting possible solutions and shared methodologies.

Conclusions: Despite a large literature, the transition of a patient from childhood and adolescent services to adult services is still a source of difficulty and sometimes disorientation for the family, so this contribution summarizes the methodologies and recommendations of the most accredited recent works. It is necessary to insist on procedures and shared training between the two types of services, not sparing resources to treat this important care need.

KEYWORDS: transition, neurodevelopmental disorders, psychopathology, case report, adult services

INTRODUCTION

Current epidemiological data report alarming numbers regarding the mental health of children and adolescents.

Social transformations, new family models, the outcomes of the COVID-19 pandemic, feelings of uncertainty resulting from political instability and international conflicts, have profoundly affected the mental health of families and minors. Globally, there is data that 1 in 7 individuals between the ages of 10 and 19 have a mental health problem (WHO 2021), among which the most frequent are anxiety and depression (40% of the total) according to the 2021 UNICEF report on the mental health of children and young people [1]. Approximately 75% of adult mental disorders first appear before the age of 24 [2]; [3].

Meanwhile, the growth in the prevalence of some neurodevelopmental disorders appears notable, including autism, for which in Italy we speak of 1 case in every 77 children between 7 and 9 years old, while the CDC in Atlanta reports a figure of 1 in 36 [4].

Data from the World Health Organization indicate a risk of neurodevelopmental disorders of approximately 20% among minors.

These critical issues are obviously laying the foundations for access to Adult Services for a significant number of users with particular and complex needs and with care pathways to be built in a tailor-made manner.

Welcoming and dealing with this enormous amount of suffering is a mission that can no longer be avoided by mental health services, beyond the standard operations classically polarized on serious and chronic cases of psychosis, which will require specific and peculiar training for all staff of the Services for adults.

THE TRANSITION

Transition is understood as the transfer of competences from services for mental health and disability of childhood and adolescence to services for adults [5]; [6].

The transition phase is recognized as a critical step with respect to the risk of interruptions and dispersion of care; it is believed that at least 6 out of 10 patients lose contact with the care teams and the continuity of care in this transition phase [7]. Other data report that approximately 50% of patients suffer from a discontinuity of care processes [8];[9]. Several studies show that the dropout rates of mental health services for children and adolescents at any age range from 28% to 75% depending on the methodology [10].

Furthermore, milder conditions often receive less attention, while more serious and frankly psychiatric conditions, such as psychosis or bipolarism, often manage to maintain a certain continuity of care in adult services, which are already prepared for these very care needs.

It should also be added that complex disability conditions, perhaps syndromic, with a strong neurological and/or genetic imprint, diagnosed in early childhood, and subject to specific care in

dedicated services, do not have the possibility of corresponding care in specific services for adults, with the same attitude and competence. Perhaps the acute or extemporaneous needs will be mainly given attention, often inappropriately, and the various and numerous functional limitations determined by these conditions will be managed with difficulty and considerable burden for the family and the community.

Obviously, discontinuity in care can lead to a worsening of symptoms and a serious sense of abandonment and loneliness on the part of the family. In the long term, an inadequate transition leads, in addition to clinical worsening, to an often-inappropriate reliance on emergency services and an increase in hospitalizations, the chronicization of the condition and a global reduction in QoL [6].

Several reasons for the failure of the transition have been described: poor awareness of the problem and failure to ask for help, disappointment with the responses received from the healthcare system in terms of quality and competence, or effectiveness, or the fear of stigma and the choice of self-management by the child or the family [11]; [12].

SCOPE

The aim of this contribution is to present a clinical case and highlight the critical elements of this phase, outlining and summarizing the recommendations and methodologies suggested in recent literature.

Case Report

The patient comes to clinical observation close to the age of majority (17.0 years) in January 2023.

The clinical history begins in the second year of high school where an initial social withdrawal is accompanied by a decline in mood and infrequent school attendance due to difficulty in going to school. Somehow the boy manages to recover the year but during the following year the situation worsens until complete withdrawal. The previous year in 2022 he had already manifested physical symptoms with headache and difficulty falling asleep, whose checks (brain MRI and specialist visit) had not revealed significant data. The NPI prescribed pharmacological therapy and sent him to a psychotherapy program.

During the evaluation for inclusion in the Psychotherapy program, the patient accompanied by his mother, although asking for help due to the intrapsychic and interpersonal discomfort experienced for some time, shows difficulty in trusting and accessing introspective work; the lack of compliance is also evident in the intake of drugs. It is highlighted in subsequent interviews in an initial refusal of drugs, a difficulty in accepting the discomfort/illness both in the boy and in the parents and consequently the belief of being able to "heal" with one's own strength.

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The boy is an only child, born after ten years of marriage, he is very attached to his mother and maternal grandfather, he reports feeling very sad because he does not want to disappoint his parents, since he was previously competent and effective in everything. In the family there is a maternal grandfather with a serious illness, and his care significantly engages Francesco's mother and causes him a lot of anxiety. It is clear that the boy is desperately searching for his own identity and involved in issues of self-esteem and self-efficacy. In this period the boy's withdrawal from the environmental context is almost total: he does not attend school, does not see his friends, does not even participate in chat discussions anymore, the only activities that give him tranquility and well-being are those of a solitary household nature such as gardening.

The brief psychotherapeutic work that was possible to carry out was essentially focused on the therapeutic alliance with the boy and the family in order to create an awareness of the present problems and the objectives to be achieved, first and foremost the acceptance of the diagnosis and the relative treatment.

Furthermore, as he approached the age of majority, the issue of transition to the Adult Service arose, with which a collaboration for the specific case began, with meetings of the two teams and alternating checks in the two services.

In the end, the boy (and his parents) accept the drug therapy but not the psychotherapeutic path, and in the transition to the Adult Service, after an initial phase, they appear more collaborative and compliant with the drugs.

Over time, the boy resumes his studies privately and with the help of his schoolmates, he also slowly resumes his social life.

The peculiarities of the case are to be referred to the age closer to adulthood, the psychopathological characteristics, the rather simple cultural context, the effectiveness of the social network especially of peers that allowed a relatively good recovery of relational skills, even if it is necessary to evaluate the long-term outcomes. The clinical diagnosis may refer to "social anxiety disorder" in comorbidity with "major depressive disorder".

ADOLESCENCE, SERVICES FOR DEVELOPMENTAL AGE, SERVICES FOR ADULTS: CRITICAL ISSUES and SOLUTIONS

The transition must be an operating mode that aims at continuity of care with a planned and personalized process that responds to the specific individual needs of each user.

Adolescence represents a period of extreme vulnerability, in which constitutional, emotional and social factors modulate in a specific way for each individual a construct of health or disease conditioned by these variables in a manner that is often difficult to predict. On a neurofunctional

level, the equivalent of the adolescent phase is represented by the phenomenon of synaptic pruning, which increases myelination and connectivity, mainly in the areas involved in cognitive modulation, in the processing of social information and in the search for pleasure [13].

It is a shared opinion that in adolescence and before the age of 18, the activities of care and therapy for neurodevelopmental disorders and childhood psychopathology mark a difficult time, as a remodulation of objectives is necessary and family mourning occurs: when peers begin to separate and process sexual and socio-affective maturation, these patients highlight their difficulties as much as, if not more than, those of previous ages.

Parents' feelings of frustration, failure, and depression are heightened and are accompanied by a sense of confusion due to the loss of case managers and the lack of clarity about the areas of healthcare in which the necessary assistance will be provided to their children.

The advancement and completion of school careers deprives children of this age of a system, that of school, which, despite all its weaknesses, represents, especially in Italy, an experience of protection, inclusion, and anchoring to sociality and relational exchange with peers. The question of possible job placement or a pre-work training process arises, where possible.

Furthermore, adolescence is often the age of onset of most psychiatric pathologies, mood disorders and psychotic disorders. It is often at this age that it is necessary to make a diagnosis and set up therapies, multimodal, including pharmacological, even demanding in terms of global management. This is also the age of the prodromes or onset of schizophrenia, an absolutely central theme in mental health management policies.

There are national and international programs that have identified the criticality of the transition and have provided operational guidelines for the correct management of this phase. Among these, the Milestone program has certainly been the most far-reaching. 2 “Tram” tools have been suggested (Transition readability and appropriateness Measure) and “Trom” (Transition related Outcome measure) [14] to assess the readiness and appropriateness of transition processes.

In Italy, the transition and its critical issues also have to do with the cultural and operational peculiarities of NPIA and adult psychiatry.

In Italy, [15] the NPIA has maintained together the neurological and psychiatric skills of developmental age, with a strong rooting in the psychological and pedagogical models of child development. The comparison between Psychiatry and NPIA can be profitable for both disciplines provided that it is equal, respectful of the characteristics of each discipline and characterized by the availability for a reciprocal formative exchange and learning.

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There are frequent operational opportunities for a comparison between the 2 branches: The data published in 2022 in the Lancet, which recalls how mental disorders are neurodevelopmental disorders that characterize the growth of the child, document that the peak incidence of onset of a mental disorder coincides with late adolescence (17-19 years) [16].

It is therefore inevitable that cases are transferred from NPIA mainly to Adult Psychiatry when they reach 18 years of age; emergency hospitalizations of minors in adult psychiatry facilities are frequent, given the lack of beds dedicated to developmental psychiatry.

In the Health Authorities, the organizational affiliation of the NPIA to the Department of Mental Health is reported in several Italian Regions, while in other regions the NPIA belongs to the Maternal and Child Departments. This possible improvement aspect, however, still encounters cultural and educational obstacles, even within the same DSM, both from the context and from individuals, due to the specificities and peculiarities of the NPIA, so close, but also so far, often in terms of operational practices, from adult psychiatry.

It should also not be forgotten that in many regions, the NPIA, which prescribes a very large share of the services of all rehabilitation services delegated to accredited private centres, is placed or administratively connected to the rehabilitation assistance units, which often have a neurological and strictly organicist methodological approach.

Furthermore, there are enormous cultural differences between psychiatry and NPIA: NPIA is oriented towards an evolutionary dimension of care and diagnosis, the often blurred relationship between diagnosed and at-risk conditions is highlighted, as is the relationship with cognition and academic paths, which are essential for the branch; furthermore, there is a frequent difficult relationship with emergencies and complex cases, often managed with difficulty and reluctance due to resources distributed in a diversified manner across the territory; the reference law for NPIA is represented by 104/92, which underlies much of the daily operations, often to the detriment of new epidemiological conditions and new care needs.

Italian psychiatry, moreover, born and raised on the trail of law 180/78, which decommissioned psychiatric hospitals, oriented towards psychosis and chronicity, has had to manage the overcoming of an uncomfortable role of social control, and has had to deal gradually with new users, such as young people, the elderly, addictions , immigrants, and still has difficulty accepting nuanced pictures, so-called minor disabilities, and the whole quota of specific pathologies, with high burdensome care, such as serious disabilities and autism, which arise and manifest themselves in pre-school and school age; these in fact have only recently been included in the operational horizon of adult psychiatry, despite what is recommended by various documents and programs developed at an international level.

In summary, let's review the critical factors in the late adolescent phase in patients with psychopathology or neurodevelopmental disorders:

Poorly planned interruption of care; Scarcity of information provided to families and poor involvement of family members in care projects; Poor continuity between services for cultural, logistical, operational and communication reasons [17]; Difficult communication between child and adult services, often with mutual prejudices regarding their respective peculiarities; differences between the operators' curricula and their training and operations, with respect to developmental age, chronicity, developmental psychopathology, relational dimension, use of psychotropic drugs and management of emergencies, type of access threshold.

Often the transition to adult services is driven by the formal diagnosis rather than the specific needs of the patient.

There is also a problem of marked care burden, high bureaucracy and scarcity of resources, which hinders virtuous transition processes, which are often experienced as a "luxury" by different operators of both services; the Italian NPIA is only recently building a coherent and strong model in negotiation with adjacent branches.

Another issue is the poor integration with social services resources and other resources in the area that could act as a glue and a "bridge" between the various care agencies. It is also necessary to define the role of GPs, paediatricians and basic psychology, as well as hospital and university departments, which are often privileged interlocutors in different phases of the care pathway, especially if there is a clinical complexity of the picture, which may also require a hospitalisation phase, or on the contrary vague symptoms that may worsen.

As regards the timing of the transition process, it is sometimes dramatically reduced to the last 2-3 months of the path in the child care service, when the family and even less the child are ready or adequately informed.

It is also necessary to identify a dedicated team in both services and, if necessary, a case manager for both teams, who at a certain point can work together profitably.

On a clinical level, what operational models should be implemented for adolescence? One hypothesis could be to form mixed micro teams that work on cases for a parallel management for a given period, starting from an adequate reporting and transmission of information from CAMHS to AMHS; or to structure specific outpatient services dedicated to adolescence in the interface between services, in defined and recognizable places and times.

The establishment of NPIA UOs on Italian territory must in any case provide spaces and teams dedicated to the pathology of adolescents, who cannot always be recognized in settings dedicated to

mothers and young children, due to the proximity to adulthood issues and the particular sensitivity to recognizing themselves as growing and detaching children.

To summarize, what could be the elements of success of the transition? From systematic reviews it emerges [18] that there is still little data on the subject, a criticality that has been maintained over the years, despite the vastness of studies and operational recommendations on the subject. The quality transition remains a process often left to the initiative and will of those responsible for the services and to the goodness of their mutual health and organizational culture.

According to Singh, the success of the transition depends on 4 elements: Transfer of information with written report and assessment of psychopathological risk; Parallel period of taking charge in both services.

Planning: a meeting of at least the caregiver with a child care provider and an adult team physician; Continuity and transfer of care.

Globally, the components of the transition on an organizational and methodological level, as per the review of the literature on the subject, now extensive [19] wanting to develop a model to be implemented, can be simplified as follows:

- Adequate organizational policies in services, implementation of resources and training of operators;
- Adequate tracking and monitoring of patients, with attention to databases and computerization of procedures
- Preparation of the patient and the family in adequate time with detailed information and processing of the separation; involvement of the boy and parents in this action and in the therapeutic choices.
- Gradual and flexible transition timing.
- Planning of interventions by identifying operators and roles with precision, including the case managers to refer to; personalized treatment plan oriented to objectives. The 2 services must be considered in continuity, with transmission of information and periodic meetings; parallel assistance work between the 2 services.
- Formal transition of the care offer and completion of the transfer of the care action, with maintenance of sharing of clinical information with continuous contacts between the 2 services; involvement of the patient and the family in the post-transition, tendency to the autonomy of the boy in decisions and in consenting to therapies as much as possible.

On a methodological and cultural level, in our country, the practices described are identified with the possibility of applying the community psychiatry model to the transition, an intervention that must take into account the fundamental variables such as individual and family bio-organic components;

ways in which the intra and intersubjective relationships of the boy were formed; micro and macro social context of reference; which is based on the possibility of creating an integrated network of services and facilities capable of providing articulated and complex responses to the needs of the individual patient.

Therefore, this type of cultural approach deals with the global care of the patient and his family, as is necessary in neurodevelopmental disorders, creating the necessary continuity in the transition.

Last but not least, we must address the problem of identifying indicators of the outcome of the transition. We can hypothesize evaluations pertaining to the adaptive functions, or to the level of severity, or to specific symptoms of the different clinical pictures.

Apart from specific scales for psychotic symptoms, adaptive functions, social skills, theory of mind, ADHD, in adolescence and early adulthood we can use instruments such as the CGI (Clinical Global Impression) [20]. The CGI allows the formulation of a global judgment in 3 areas, the severity of the disease, the global improvement and the index of therapeutic efficacy; also worth mentioning is the Disability Scale - DISS, [21] a scale for self-assessment, on an analog scale from 0 to 10, of the degree of impairment due to mental disorders in the areas of work, relationship and family life. The DISS has proven to be easy to apply and sensitive in discriminating between different therapeutic interventions. The GAF scale (Global Assessment of Functioning) [22], a numerical scale used in mental health to subjectively assess an individual's psychosocial functioning, later replaced by the more detailed WHODAS scale in the DSM-5 [23];[24]. The GAF has been successfully used in Italian experiences to measure transition [25].

CONCLUSIONS

NPIA services must dedicate part of their resources, their methodological vision and their operations to the transition process. It is not enough to report patients or inform parents in brief about the continuation of the paths, but it is necessary to structure adequate practices for an adequate time.

The dedicated literature describes many experiences and many operational practices, however there is still a notable weakness regarding both the transition as a whole and the quality and outcome indicators of the processes, and this appears to be a line to be developed both in research and in clinical practice.

If care in developmental age is a crucial component in safeguarding the mental health of a population, even more so is the optimization of interventions in adolescence and early adulthood and the guarantee of continuity of care. A community psychiatry perspective, which safeguards global care by paying attention to the specificities of each individual child, his context and his family, can be of great help in this management.

Above all, we believe that it is necessary to overcome the current cultural and organizational limitations of services to make truly feasible the majority of the operational models now widely described in international literature.

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