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QUALITY OF LIFE AND ASSISTANCE OF MINOR WITH CHRONIC DISEASE: FROM PRE-BIRTH TO ADOLESCENCE

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LECT 1

THE EXPERIENCE OF PEDIATRIC PSYCHOLOGY IN MATERNAL AND CHILD DEPARTMENT

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The contribution, that it is oriented by the constructs of Pediatric Psychology and by a neuroscientific perspective, addresses the complexity of taking care of pediatric conditions characterized by the presence of chronicity within the relational space that is defined between the vertices of the “field” (family system, care system, school system) with which a pediatric condition is identified and which can be connected to a maternal-child dimension [1]. Within this relational space, the possible pathway of any pediatric condition with a chronic illness develops. We identify three major phases: the communication of diagnosis, the stabilization of frailty, and the dysfunctional identity identification.

The phase of the diagnosis communication represents a catastrophic neurocognitive event for the entire pediatric condition [2, 3]; in this sense, it gives rise to a deconstruction of model scripts, with which the child's reference adults, often including physicians, look at the future of the child's developmental trajectory. This deconstruction directly regards the older children and adolescents involved in the communication, who may develop processes of overgeneralization, even denial, disqualification of positive thinking, and catastrophizing reality. The communication of the diagnosis tests the proactive brain function, unbalancing the child's functioning in a reactive sense, as well as executive functions related to paying attention, self-monitoring etc., as well as cognitive control over the environment, directing maladaptive behaviors and toxic responses to stress. This becomes a psychosocial risk condition to the extent that it combines a condition of internal risk to the person (undermining of certainties, beliefs, etc.) and external riskiness, represented

by the taking charge of this communication by the family and further contexts of reference. The stabilization of frailty phase follows this, often, unfortunately, subjected to simplification, or reductionism by professionals; instead, frailty indicates a developmental emergency [1, 3] that is defined through an alteration of internal operating models and a neuropsychological dysregulation of developmental domains (identity, emotions, relationships); not least, there are the possible dysregulation of parenting competence and dysfunctionality in the response by local services. The stabilization of frailty is followed by the phase of the possible dysfunctional identity configuration, in which the self-representation as a person with chronic illness is stabilized and chronicized. In this dangerous phase, a Traumatic Developmental Disorder and/or an Adjustment Disorder (DSM-5) can be developed. That being said, for Pediatric Psychology, taking care of the pediatric condition with chronicity will have to develop through a helping relationship crossed by: acceptance, as active listening to the story of the child/adolescent and contact to make him feel safe and be able to go further; orientation, as an indication to the child/adolescent of traces, possible paths; accompaniment, to stand by him and support him in the management of difficulties; and side-by-side, to observe him as he activates change and “be a fan of” him [3]. This specific taking charge identifies its reference perspectives: in the strengthening, in the strategic function of intercepting useful resources to manage the risk condition (problem-solving, perspective taking, motivational profile, etc.), in the rehabilitative perspective, and in the inclusive integrated work, which implies first the sharing among the involved professionals of a vision of the pediatric condition with chronicity.

All the actors involved must take on this charge, each with their specifics: the physicians with their expertise and availability, the psychologist in the clinical intervention, the teacher in the educational intervention and so on.

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LECT 2

PEER RELATIONSHIPS AND ADOLESCENTS WITH CHRONIC DISEASE

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Adolescence is a critical time for the development of peer relationships and the presence of a chronic disease complicates this process. There are four key aspects of youths' peer relationships: close friendships; one's position in the larger peer group; the presence of peer victimization (PV); and romantic relationships. There are bidirectional influences between peer relationships and chronic disease. Specifically, in each of the four areas, youths' relationships can interfere with disease management, and having a chronic disease can interfere with relationship development.

First, close friendships provide youth with support, companionship, and intimacy. They buffer the impact of stress and enhance self-esteem. Importantly, youths' close friends are a key source of support for chronic disease; they also provide companionship for lifestyle aspects of disease management (e.g., eating, exercising) and help youth feel accepted. However, youth with certain conditions, like neurological disorders or obesity, find it harder to establish close friendships than healthy youth and thus may be limited in their friendships.

Second, adolescents need to "fit in" with peers and find their position within the larger peer group. The peer group contributes to a sense of identity and belonging and provides opportunities for developing friendships and romantic relationships. However, peers can affect health behaviors. For example, youth who align with the "jocks" (athletes) or "brains" (studious youth) are likely to engage in healthy eating and exercise, which can positively affect a chronic disease. In contrast, youth who affiliate with a "problem" crowd are more likely to drink, smoke, or engage in risky sexual behavior, with potential adverse health consequences. Also, youths' chronic disease might limit their ability to affiliate with other peers. Youth with visible defects or cognitive impairment, or who cannot participate in typical peer activities due to their illness, may find themselves neglected or rejected by peers.

Third, adolescents may experience stress from PV. The most common forms of PV are relational victimization (i.e., being left out or excluded by

friends) and reputational victimization (i.e., being the target of rumors or efforts to damage one's reputation). PV can occur online and through social media. Not only does PV contribute to youths' psychological distress (e.g., feeling anxious and depressed) but also to sleep problems and somatic complaints, all of which could interfere with disease management. In turn, youth with certain chronic conditions are more likely to experience PV than others; this includes youth with visible illnesses or disabilities, such as craniofacial conditions, obesity, epilepsy, chronic skin disease, or visual impairments.

Finally, adolescents' romantic relationships are important. By 16 years of age, most youth have had a romantic relationship, which sets the stage for intimate adult relationships and provides considerable social support. However, romantic relationships can be a source of stress and conflict, especially when a breakup occurs. For youth with chronic conditions, romantic partners are an important source of support and can facilitate youths' disease management. Like friends, they can support either healthy or unhealthy behaviors. However, romantic conflict and breakups are associated with poorer self-care and greater psychological distress in youth with chronic conditions. Although less well-studied than other types of peer relationships, youth with visible illnesses or disabilities may likely have a harder time developing romantic relationships than other youth.

In general, chronic conditions that are visible or associated with cognitive impairment may trigger PV or rejection and affect youths' peer acceptance and romantic appeal. Conditions with complex management tasks that affect one's lifestyle (e.g., eating, exercise) can limit youths' participation in normal peer activities. Similarly, conditions with intensive or extended treatments can limit youths' friendships and normal social activities.

To address the above concerns, providers are encouraged to monitor youths' peer relationships to better understand how they may affect disease management. First, ask about youths' friendships and romantic relationships (e.g., Who are their friends and romantic partners? How do they help or interfere with disease management?) and consider inviting youths' friends and romantic partners to assist with disease management and support. Second, ask about youths' peer acceptance and the crowds they affiliate with; help youth manage their chronic disease while also "fitting in" with peers. Third, ask youth if they experience PV or bullying,

and if so, help them get help. Finally, ask about romantic relationships and breakups. In general, providers should help youth develop connections that promote peer support and positive relationships.

LECT 3

PARENTAL ETHNOTHEORIES AND CHILD CARING IN MIGRANT FAMILIES

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Parental ethnotheories involve cultural models of parents' beliefs on how to raise and nurture their offspring, including necessary measures for effective parenting. When different parental ethnotheories converge within the same social system, such as in the case of migrant families, parents face the task of adjusting their original parenting approach while still prioritising the essential objective of parenting: the physical and psychological development of the child.

Immigration and related issues have gained significant importance in recent years. Immigration became a permanent feature in Italy, rather than a temporary or sporadic occurrence. Over the past decade, there has been a significant shift in immigration patterns in Italy, with a great increase of family-based immigration rather than work-based immigration, as many seek to settle permanently in the country.

According to scholars [1], a crucial measure of stabilization is the fact that, despite varying frameworks, most immigrants in Italy currently reside in a conventional household arrangement, comprising of at least one parent and one or more children. Additionally, more emphasis should be placed on addressing the particular requirements of distinct cultural groups to facilitate the substantial diversity of geographical origins, nationalities and religious affiliations. In this case, it is essential to understand these families' needs, expectations, and perceptions better. This understanding will enable us to plan social and health services better and promote their genuine integration into our country. However, little research has been conducted on the challenges immigrant parents face in bringing up their children in modern-day Italian society. The available literature indicates that ethnic minority parents share some beliefs, attitudes, values, and

behaviors with the majority group, while differing significantly in other ways [2].

Migrant parents develop specific attitudes and behaviors, referred to as “culturally standardized formulas,” to encourage their child's skills and behavior to align with the norms of the host country [3]. Therefore, analyzing parents' ethnotheories is a valuable approach to understanding their experiences and helping to implement effective support techniques beyond temporary measures. Recent research suggests that maternal beliefs vary depending on their country of origin. The duration of time that immigrant mothers spend in Italy can influence the formation of their beliefs, indicating an acculturation process towards their new context.

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LECT 4

THE CENTRALITY OF THE CHRONIC CHILD IN ACCOMPANIMENT TO TREATMENT

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The Italian Society of Pediatric Primary Care (*Società Italiana delle Cure Primarie Pediatriche – SICuPP*) represents the pediatricians of the pediatric community care in Italy. Since its starting, SICuPP has repeatedly addressed the issue of chronic conditions (CC), which today takes a large part of the work of the territorial pediatrician and represents the health challenge of our century. WHO, in 1948, framed health as a state of complete physical, psychological, and social well-being, while in 2011, considering the evolution of the global picture, health is the ability to adapt and self-manage in the face of social, physical, and emotional challenges. An adequate healthcare system must offer treatment paths that suit all the patient's needs and be shared by all

healthcare professionals who work on CC regardless of the patient's age and in full awareness that the sole treatment path is not sufficient. Still, building and sharing relationships that must be an integral part of the therapeutic plan is also essential. At the basis of this health revolution, there is the integrated work between the figures that revolve around the patient: pediatrician, tertiary center doctor, nurse, health assistant, psychologist, school, and social services, which must put the child and his family at the center. Positive experiences and interactions with the health system can establish the foundation for a future of positive health-seeking behaviors in a family with CC, who must continually reorganize life in a problematic and progressively changing everyday life. Dealing with treatment means seeking shared and sustainable solutions for the patient and the family. Palliative care for children means active care of the body, mind and spirit. Also, it includes support for family and siblings experiencing a state of mental distress that needs psychological support, starting from when the disease is diagnosed and continuing whether or not a child receives treatment for his or her illness. The pediatrician who works territorially needs to be trained on the following topics: innovations in medicine, therapeutic techniques, diagnostic and therapeutic programs, family integration and awareness of social and health rules, ability to manage complex relationships, burn-out prevention and siblings care.

LECT 5

THE PEDIATRIC PSYCHOLOGIST IN DERMATOLOGICAL CHRONICITY. MULTIDISCIPLINARY WORK EXPERIENCE IN THE CLINIC OF ATOPIC DERMATITIS

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The theoretical framework of this work regards the importance of “skin” (physical and emotional), “contact,” and “touch” since neonatal and pre-natal experiences and their psychological implications in dermatological diseases [1-3]. Atopic dermatitis represents one of the most common dermatoses. The predominant age of onset is 0-5 years, with approximately 60% of cases starting by the age of 1 year [2]. Manifestation of atopic dermatitis is complex and heterogeneous, characterized by a

broad spectrum of clinical symptoms, severity and course, with a significant “burden of disease” [3] and impact on health-related quality of life (HRQoL) in patients and their families. HRQoL measurement has become an integral aspect of monitoring the clinical progress of the disease and of the efficacy of the therapy in dermatology and is one of the most cited constructs in the international literature in the biomedical field and generally is identified as one of the main patient-reported-outcomes (PROs), a key element of diagnosis and treatment (from “disease-oriented” to “patient-oriented” perspective). Psychosocial factors seemed to affect the course of atopic eczema. The bio-psycho-social interactions between stress, protective factors, the clinical course of atopic eczema, and the psychoneuroimmunological mechanisms underlying these interactions are considered fields for future research contributions. The early onset of the pathology leads to keeping the focus on interventions age-specific according to an evolutionary trajectory.

All these elements underline the need for a multidisciplinary approach and research strategies that effectively integrate epidemiological, immunological and genetic research to improve clinical settings, therapeutic management, patient assistance, and intervention based on the methodology of Therapeutic Education. According to all these premises, the clinic dedicated to dermatitis implemented a work entitled “*Atopic dermatitis: establishment of a clinical registry for the multidimensional evaluation of adult and pediatric patients with a view to an integrated approach to care.*”

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LECT 6

COULD THE NUTRITION OF THE PREGNANT WOMAN PREVENT DIFFERENT FORMS OF CHRONICITY?

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The study is interested in understanding the factors determining the eating behavior of pregnant women

using the Capability, Opportunity, Motivation - Behavior model (COM-B model) [1] and the tool of a questionnaire for the first time in the Italian context. The final purpose is to be able to make contributions on the topic of eating behavior in pregnancy, improving the outcomes of interventions on the development of healthy eating habits and consequently impacting certain chronic diseases starting from pre-birth.

The general objective of the research is to contribute to advancing the state of knowledge on the eating behavior of pregnant women.

The specific objectives refer to the verification of the effectiveness of the COM-B model, selected as the reference model for the study of factors affecting eating behavior during pregnancy for the first time in the Italian context; identifying a questionnaire for data collection concerning the model, which is characterized as an innovative tool; and being able to communicate results that can help operators in the sector understand the complexity of the phenomenon.

The research is longitudinal (three years), and the sample of interest will be theoretically founded, consisting of a hundred women in their third month of pregnancy at the Hospital-Territory, ASP Palermo, Italy.

The COM-B model represents the reference model [1], demonstrating how behavior results from three conditions: ability, opportunity, and motivation. Skills and opportunities can affect motivation, and the resulting behavior can influence the three factors.

The hypothesis is that the COM-B model can be a valid reference for understanding the factors impacting eating behavior during pregnancy. The first phase of research will focus on the drafting of the questionnaire about the model, investigating the variables of capacity (physical, psychological, and knowledge), opportunities (external stimuli), and motivation (habitual processes, emotional responses, and analytical decision-making processes). The questionnaire is structured as a battery of closed-ended questions assessed through a Likert scale. The second phase will include the administration of the questionnaire and the statistical data analysis. The third phase will analyze the validity and reliability. The last phase will be based on communicating the results.

The data analysis must demonstrate a positive correlation between healthy food choices and medium-high levels in measuring capacity, opportunities, and motivation. In contrast, less

adequate food choices must correspond to lower levels of measurement of the three variables. A medium-high level of motivation must correlate with medium-high skills and opportunities.

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LECT 7

QUALITY OF LIFE AND CARE OF A CHILD WITH CHRONIC PATHOLOGY: FROM PRE-NATAL LIFE TO ADOLESCENCE

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In March 2015, an international congress entitled “*Enhancing the Competencies of the Child, Adolescent and Parenting Couple*” was held in Rome to honor the work of T. Berry Brazelton, a great pediatrician and child psychiatrist, who placed relationship, attention to resources, flexible professional boundaries and multidisciplinary collaboration at the center of care. All of the papers by pediatricians, psychologists, neuropsychiatrists, educators, and health care providers emphasized how supporting parenting goes through the recognition and promotion, in both parents and providers, of the child’s resources, skills, and creative intentionality from birth.

Development is a complex process, the result of reciprocal action between child and context over time, in which the state of one influences the subsequent state of the other in a continuous dynamic process [1]. Chronic illness constitutes an ongoing traumatic situation that violates expectations, destabilizes relationships, undermines the sense of trust and hope, and often causes dissociation between cognition and affect. Psychobiological storms, caused by traumatic disruptions of the sense of continuity, require therapeutic, psychological and medical minds, alive and curious to search tirelessly for connections between the medical and relational histories, to go where, in the present, the child and his or her parents risk finding themselves imprisoned in illness. In a child’s life, hospitalization is an event of a very complex and delicate nature. The experience of illness, physical and psychological pain, separation from the family and the routines of daily life, and the transition from a familiar environment to

the potentially threatening and unusual setting of ward life make hospitalization a traumatic event that can have negative consequences.

The basic assumption is to consider the child in his globality, not only in his pathology but also in his emotions, family history, and the needs of his evolving psychophysical personality.

In perinatal medicine and psychology, it is about grasping not only and not so much the organic and environmental randomness but also the sketches and signs of the subject's response: it is about letting the child go to the unpredictable dimension of his choices without the problems that surrounded his conception and birth becoming the only sign board that represents him [2, 3].

Clinical intervention, both medical and psychological, aims not to erase the effects of cumulative trauma but to recreate a space of freedom so that what is upstream does not continue to absorb what is downstream.

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LECT 8

TO CARE OF THE MINOR WITH NEURO-DEVELOPMENTAL DISORDERS IN THE TRANSITION TO THE ADULT PHASE

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The transition from pediatric care to adult health facilities is often difficult for the patients and their families. It can lead to a breakdown in medical follow-up and, therefore, serious complications with risk and vulnerability for young adults with neurodevelopmental disorders and their caregivers [1-3]. The increasing number of young adults with neurodevelopmental disorders transitioning from child-centered to adult-oriented healthcare services has highlighted gaps in the availability and quality of "transition services." Organizational deficiencies of health, social,

and disability systems and their fragmentation exacerbate the difficulties in managing and caring for this frail population, leading to feelings of disconnection with existing services in young patients and their caregivers.

The Territorial Psychiatric Services for the management of neurodevelopmental disorders in adulthood have:

- to assist patients in transitioning to adulthood, promoting a better quality of life, and offering specific developmental needs. According to this perspective, specific multidisciplinary teams for the "age of transition" should be trained and organized within the territorial services of the various Italian regions;
- to value neurodiversity and neurodivergence, defining a specific life project built on the subject's identity and functioning profile. This also involves structuring listening and training spaces for parents and families to share the educational project;
- to promote life skills development to cope with daily challenges and orient oneself independently in one's living environment through non-pharmacological and cognitive-behavioral habilitation interventions that implement problem-solving strategies.

Therefore, transition services must include any support sources to train young adults and their families better and guide them as they move between pediatric and adult services.

Several issues include poor communication between pediatric and adult services, limited resources, lack of knowledge of transition practices among adult care practitioners, and inadequate transition planning [1].

Developing new skills, adopting a new routine in the clinical practice, and building communication spaces between services and operators belonging to the various services involved appear to be necessary [3].

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LECT 9

THE POWER OF EPIGENETICS IN PERINATALITY

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Genetics and epigenetics are closely interconnected. The structural genome is comparable to the hardware of a computer and determines, in practice, the boundaries of what is possible to do, while the epigenome acts as an operating system, without which the genome does not receive the operational instructions to function. A few examples can further the understanding of the interactive mechanisms between genetics and epigenetics. I propose some of them below.

- Genetics is written in pen and cannot be erased, while epigenetics is written in pencil and can be edited.
- Genetics proposes, but epigenetics disposes.
- Genetics is a very long piano keyboard with about 25,000 keys that are always the same (our genes). Epigenetics, on the other hand, involves the choice and succession of keys: which keys I play and with what sequence. This can result in Mozart's *Symphony No. 40* or Stravinsky's *The Firebird*, with a very different impact on the listener.

We cannot change our past (the genes we inherited from our parents), but we can try to influence or change our future by modifying epigenetic factors: for example, using proper nutrition, defending ourselves from environmental pollution, avoiding, limiting and personalizing the use of drugs, modulating lifestyle. Within epigenetic factors, the most important one is

nutrition. Prevention strategies can be implemented through dietary and lifestyle modifications. Already Thomas Edison, the inventor of the light bulb and more than a thousand other patents, predicted many years ago that doctors of the future would treat and prevent disease through nutrition.

In pediatrics and neonatal care, these findings are even more important because the child is a dynamic organism that is constantly growing. Consider, for example, the growth in stature and weight in the first year or the morpho-functional growth and maturation of the encephalon in the first three years of life: at no other age are such important changes occurring in such a concentrated time duration. Moreover, an increasingly important body of experimental, clinical, and epidemiological data underscores the relevance of perinatal programming in determining the health or disease status of an adult subject. Everything, or much, is decided in the early ages of life or, even, in the womb. The determinism of many diseases begins during this period of life and their prevention begins during pregnancy itself: the power of epigenetics in perinatality.

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