



S.I.P.U.O.



Ordine degli Psicologi
della Regione Siciliana

Tempi di transizione. Supportare le transizioni del bambino e dell'adolescente in condizione pediatrica

Transition times.
Supporting the child
and adolescent's
transitions
in pediatric condition



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The Italian Society of Pediatric Psychology (S.I.P.Ped.)



The Italian Society of Pediatric Psychology (S.I.P.Ped.) was founded on May 12th, 2016 and today includes members from 15 Italian regions. S.I.P.Ped. is a member of the Italian Federation of Association and Scientific Societies in Pediatric area (FIARPED), it is registered in the list of Scientific Societies and Technical-Scientific Associations of health professions (Ministerial Order 06/11/2018) - Ministry of Health, according to the Ministerial Order 2/08/2017, and it is a member of the Council of Scientific Societies in Psychological field set up by the National Council of the Order of Psychologists (Resolution n. 37 of 21/06/2019). S.I.P.Ped. is also affiliated to the Society of Pediatric Psychology and it is a member the board of International Committee of Society of Pediatric Psychology.

The aim of the S.I.P.Ped. is to promote the spread of Pediatric Psychology, through a mission that is identified with the pediatric psychologists' training: Pediatric Psychology promotes a specific expertise of support and of psychological rehabilitation in the Maternal-Infant Healthcare, in addition to the implementation of Psychology in Pediatrics. In this sense, the expertise of Pediatric Psychology is identified with the care of the dynamics of Development in pediatric conditions of children with chronic or acute diseases, of children in emergency, children with rare diseases and syndromes, premature babies, and women in high risk pregnancy.

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Sense and Meaning of Evolutionary Transitions in Pediatric Psychology

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President of the Italian Society of Pediatric Psychology

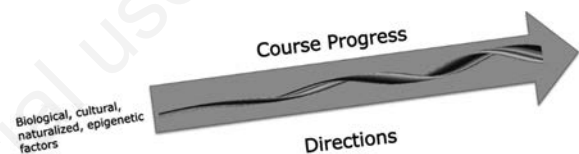
Preface

When it comes to *transitions*, we usually think of important progressions, momentous historical events, peoples' unforgettable memories, or significant changes in the individual's life. More rarely, we refer to the feature of *simplicity*. The Second International Congress of the Italian Society of Pediatric Psychology, in order to focus on and open a debate about the evolutionary transitions in pediatric conditions, emphasised simplicity as essentiality, repeatability, reproducibility and comprehensibility of these progressions. It is an identity attribution that recognises these characteristics in terms of their potential, which are unique for the development of every evolutionary trajectory,^{1,2} and by which we identify every individual evolutionary path/process (*there is no development without transitions*). We speak about reproducible phases since the transformation mechanism trait is in all evolutionary life-cycle trajectories and, adhering to the theme of the Congress, also in acute or emergency pediatric conditions, either in hospitalization or along the care path, albeit with different ways, in different spaces and situations. And as different as the processes and trajectories of individual development are (Figure 1), the evolutionary trend, for Pediatric Psychology, *develops in a neuroconstructivist perspective*.^{3,4} At the same time, these inner workings can be thoroughly analysed and interpreted according to the potential and meaning that they have in terms of development and change.

Through the metaphor "Hercules' labors", the Congress focused on the commitment, the self-regulation, the agency, and the conscious and non-conscious investment that children and adolescents find, during these transitions, as evolutionary tasks among their growth targets in pediatric conditions (Figure 2).^{1,2,5}

Children with pediatric conditions at different levels depend on these specific tasks to develop agency, meant as the ability to act actively and transformatively within the reference social system, regardless of the outcomes;⁶ of self-perceiving as able to influence the environment,⁷ such as the care system, to maintain the sense of control of the personal actions implied. Therefore, agency is as an

adjustable state of mind like metacognitive mastery,⁸ through which children/adolescents (c/a) develop an awareness of their ability to direct or modify "the organization of their internal script".^{9,10}

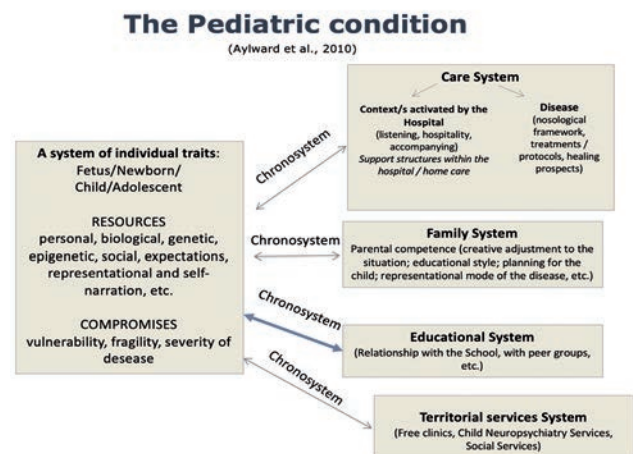


COURSE PROGRESS: mentalization of disease experience, treatment pathways, diagnostic experience, relationship with caregivers along the path of care, expectations, fears, etc.

DIRECTIONS: developmental dimensions with their evolutionary state (cognitive, motor, emotional, social, language development, etc., and characteristics of this development) before and during the disease; the type of disease with its possible sequelae and related treatments, etc.

Adapted from Perricone Briulotta, 2019.

Figure 1. Developmental trajectory: individual developmental trend.



(adapted from Perricone Briulotta, 2019)

Figure 2. The pediatric conditions.

The evolutionary tasks to which c/a in pediatric conditions have to be able to respond are:

- to redefine self-understanding, self-concept, and self-image;
- to manage an experiential self in the here-and-now of the disease;
- to mentalise their own experience of disease as part of the self;
- to build integrated mappings to represent themselves;
- to create other links and redefine the previous ones;
- to recognize their own resources;
- to redefine meanings on their own resources;
- personal planning.

C/a who have developed agency can change the mentalisation of the treatment experience. As new childhood studies have pointed out,¹¹ they can have an adequate social competence – nevertheless, such studies should better clarify the correlation between specific competence and age.¹² For Pediatric Psychology, the theme of transitions is one of the priority areas of reference, since every child and adolescent in the pediatric condition is metaphorically on the shore of a complex crossing. That is the crossover from the representation of self as healthy children to the one in which the pathology has induced other emotions and thoughts; from living within borders, relationships, and systems where they felt protected and safe, to new settings where they feel threatened and in danger. Not to mention children/adults' complicated trauma condition, for example in emergency, when the organic and psychological traumas are pervasively concomitant, causing a dysfunctional and deregulatory holistic nucleus that, however, can be still "dissipated" through the enhancement of the adaptive tendency that prevails over avoidance and escape.¹³⁻¹⁵

In this monographic issue, the contributions gathered from the Congress sessions – proposed below – are supposed to be reading patterns, perspectives, criteria, and functional paths, which Pediatric Psychology reckons suitable to ease the evolutionary steps that every c/a has to experience in pediatric conditions. Such functionality must be traced back to the constructs of this specific know-how and expertise that *translates* it at the level of pediatric psychologist's professional practice. The transition becomes the process through which c/a's evolutionary and psychosocial needs are met, as the real chance to *normalise* the self-representation, even when the developmental path is atypical.

Pediatric psychology among perspectives, constructs, and tools

The theoretical reference frame of the Italian Society of Pediatric Psychology, and the background of the Congress as well, is the heuristic path of Pediatric Psychology, defined as a specific international epistemological field (note 1). In Italy, it finds some reference contributions in the application of psychology to Pediatrics in some hospital settings (note 2). It develops through an epistemological *framework* that identifies it as Developmental Psychology – based on "clinical evolutionary" vertices – whose object of study is the developmental health, and which finds methods, techniques and tools in clinical contributions (note 3). This synthesis originates from some perspectives, starting with the promotion of *strengthening*,¹⁶⁻¹⁸ that is reinforcing the stability and the enhancement^{19,20} of the child under treatment. A functional clinical evolutionary assessment identifies the

resources on which it is necessary to "insist" and orient c/a's energy towards the decline in the impairments that the pediatric condition has induced. The orientation is implemented through the promotion of a restorative processes^{21,22} of the inner space,²³ which becomes the first step to reconnect after the discontinuity represented by the non-normative evolutionary crisis^{24,25} with the emotional resonances and the related developmental tasks, posed by the critical event of pathology.

The reference to the identification and support of resources, which are a further perspective of Pediatric Psychology, is marked explicitly at two levels. On one side, investing in resources means, in terms of perspective, the intentional, systematic, organised, and psycho-diagnostic searching for processes, ways, and so on. On the other, it refers to the specific areas where children's and adolescents' resources are to be intercepted. The investigation of the resources must be performed while listening the child, as it allows the reception of the message within a specific context in which the pediatric psychologist participates by interacting and adopting techniques that are imaginative, referencing,²⁵ and detecting.²⁶ The resources must be investigated in the following reference areas:

- motivation (e.g. the c/a can set performance targets);
- problem-solving (the c/a uses solutions experienced in other similar situations);
- ability to get out of self-referentiality;
- to associate;
- attention shifting.²⁷

Among the resources, reference has to be made to the perspective-taking, which is c/a's ability to build a circularity between the point of view used by the care system to recognise them and their own emotions. For the recovery of evolutionary impairments, some types of c/a's thinking are significant resources. The divergent thinking²⁸⁻³⁰ allows c/a to see other non-obvious possibilities even under pediatric condition, and the narrative thinking, through which c/a define the reality, fantasise about other aspects, connect events (e.g. care and healing), and redefine the treatment in terms of an event, grasping the personal relationship with it.

The resource mapping, as a perspective of Pediatric Psychology, is an inescapable step of the pediatric psychologist's intervention. It also helps the pediatrician initiate a medical history at the beginning of the treatment and, besides granting a more complete "prospective diagnosis, it constitutes a kind of "hub" for any individual pediatric condition." During the diagnosis revelation, we can encourage a therapeutic alliance with children (e.g. *since s/he likes to use metaphors, let's use the guidelines that help explain by talking about...*).

Therefore, it should be stressed how necessary the knowledge of c/a's resources is, for the organic, biological, and psychological functioning, according to a holistic approach. These perspectives (strengthening and exploration of resources) are transversal to the whole caring process. They are contextualised within a representation of health, beyond the idea of the absence of disease, where there are correspondences and overlappings between health, well-being, and mental health,³¹ being aware that well-being cannot be "placed" in the same continuum of mental distress.³² These "basics" of Pediatric Psychology are operational theoretical markers that help inscribe this know-how among the knowledge oriented by the Positive Developmental Psychology,³³ since they exhaustively represent the subjective, individual, and group levels. At the individual level, Pediatric Psychology guides the reading of children's resources, and consequent self-awareness, as real strengths that are useful for overcoming the risk of the developmental blackout brought by the disease. With regard to the group level, the intervention of Pediatric Psychology emphasises the social responsibility of c/a's developmental health, despite the

1 Such know-how and expertise started in Italy in the 90s, following the development of the sector in the United States, from 1967 to the founding of the 54th Division of the APA (1980), called "Pediatric Psychology".

2 The Hospital Unit of Pediatric Psychology - Bambino Gesù Hospital in the 2000s in Rome, and the UOC of Pediatric Psychology - Meyer Hospitals in Florence.

3 Research Unit in Pediatric Psychology - University of Palermo.

pathology/illness, sharing with them the knowledge of the resources and favouring are percussion on the curing process and related care. Finally, the subjective level can be identified as a further effect of such exploration, which induces c/a to be optimistic and enhances their awareness about the possibility to manage pathology and treatments. Thereby, the treatment management switches from the *negative* (among pathology and consequent evolutionary impairments) to the *positive* perspective, emphasising c/a's resources and self-awareness.³⁴ A "language of strength" is developed, the "positive" and the "negative" are balanced and strategies, which make children and health care providers more confident, are built by sharing the sense of well-being.³⁵ C/a experience their agency⁷ and master their personal growth, planning the everyday and future life despite the pathology. Children respond autonomously with the acceptance of self and the disease. Furthermore, positive relationships are built in the interaction with the care system.^{36,37}

If pediatric psychology is inspired by positive psychology

Including Pediatric Psychology as part of the epistemological sphere of Positive Developmental Psychology means – along the treatment process – to counteract the negative approach in favour of positive events, whose impact on the patient's life are far more significant. That concerns, quite rightly, with the transition that c/a face at the evolutionary level while being either in the acute or emergency phase. At the same time, this challenge can be contextualised within the developmental path of c/a under chronic pathology – with early onset or shifted over time – when discontinuity gives rise to atypical development. And the challenge, which guides every transition, might make the transition itself a psychosocial risk condition.⁵ It may be the result of the integration between c/a's vulnerability, albeit oriented by the pediatric psychologist towards the awareness of personal resources and external support that are not focused on stability and enhancement, so peculiar to strengthening. When the treatment system adopts this perspective, but only leans towards treatment, a psychosocial risk condition may be set. Therefore, Pediatric Psychology brings such risk condition back to the need of involving the community, the field made up of the relationship between the systems representing the reference vertices of the pediatric conditions and c/a.³⁸⁻⁴⁰ The classification as a case is replaced with a state of life^{18,22} and c/a in the "field" of the pediatric condition are seen as a system of individual traits, defined in terms of thoughts and emotions that have been developed in the relationship between the single vertices and the representations they have of c/a, of their caregiving, as well as of their ability of caregiving, at a precise time in c/a life in which the pathology and the probable disease occurred. In this way, one or more chronosystems – a temporal dimension that characterizes the transition and its development – are created. It is precisely in the relationship between the individual traits and the chronosystems that the pediatric condition and its development are defined with regard to pathology/healing and stabilisation or to the emotional resonances, self-regulation, and energy that c/a develop. These reflections give us a profile of extremely changeable transitions in the occurrence of pediatric pathology, which are not directly and definitively inscribable in a case study not because there are no variables, but because c/a cannot be considered only by virtue of the pathology and its severity.

Treatment management among virtues and strengths

Therefore, the transitions of our c/a with pathologies are part of the complexity of pediatric conditions. Considering them is an act of care, support, and rehabilitation to be oriented, in the evolutionary-clinical practice, within the relationship of virtues and strengths⁴¹ that the Positive Developmental Psychology indicates, and in which it finds

the operating lines of an intervention that is supposed to be within the organization and community. Still, for the reference organization and community of every pediatric condition, this intervention is aimed at representing open-mindedness, strength, social intelligence, teamwork, temperance, self-regulation, hope, and the intimate dimension of every relationship like closeness and empathy. Such operativeness leads to prevent the *compassion fatigue*⁴² of the health-care community and the erosion of empathy, imposing the aesthetics of humanization.

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Pediatric Psychology in the World: Significant Characteristics and Trends

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Introduction

Pediatric Psychology emphasizes the integration of pediatric medicine and psychological science and practice to remedy medical and physical health problems presenting in childhood. The field has developed around the globe in different stages as professionals recognize the need for (a) psychosocial services for issues related to pediatric health conditions; (b) psychological services for mental health problems appearing in medical settings along with a pediatric problem; and (c) assessment and treatment for psychological problems that present in a medical setting without a concomitant medical condition.¹ The field is well established in the USA with training

sequences and programs, professional organizations, and positions within medical inpatient and outpatient units in children's hospitals, pediatricians' offices, and developmental clinics. The scientific evidence-base for clinical applications for promoting children's healthy development is very strong. Psychologists in other countries have developed pediatric collaborations in clinical services and research activities adapted to their cultural heritage, financial resources, and institutional infrastructure. This is an encouraging evolution for the psychology profession in the provision of behavioral services to fulfill the mental health needs of children, youth, and their families worldwide. The second conference of the Italian Society of Pediatric Psychology (Società Italiana di Psicologia Pediatrica) held in Palermo, Sicily, in November 2019 offered the opportunity to reflect on where the field is now, on the evolutionary steps to this stage, and on projections for the future advancement of these trends of clinical applications and scientific understanding of children's healthy development.

Significant characteristics and trends in pediatric psychology over time

Whereas chronic illnesses were once life-threatening, there has been a shift to long-term management of chronic diseases such as diabetes, cancer, and cystic fibrosis. These medical advances have necessitated professional attention to improving adherence to medical regimens, adjustment to disease and treatment of concomitant behavioral and emotional problems, management of procedural and chronic pain, treatment for posttraumatic stress, etc. Pediatric medicine has insufficient time and training to address these issues. Recognition of the need for Pediatric Psychology has grown. The scientific evidence-base for the field demonstrates the cost-effectiveness of services leading to improvement of health care and health outcomes.

Historical developments inform the development of the field internationally

Logan Wright's² prescription guided this development: (a) establish an identity through a formal organization; (b) construct new knowledge through applied research; (c) focus on professional training in the field. Organizational development and penetration of the field into medical settings took time, people, and resources. Over a 50 year period, the US developed its field through organization of its Society of Pediatric Psychology. Communication and research demonstrating the benefits and value of Pediatric Psychology in hospitals produced more opportunities. Concomitantly, Pediatric Psychology created change in health care organizations. These changes took considerable effort. Acceptance by health care leadership or policy makers was not guaranteed. This was the experience of many at hospitals across the US. Progress occurred by (a) finding exemplars to serve as program models, (b) using data to support recommended changes, (c) finding allies and opinion leaders in the medical establishment to serve as advocates, and (d) utilizing expertise and competence to fill the immense needs for services in health care settings.

Inter- and trans-disciplinary relationships for pediatric psychology

By its very nature, Pediatric Psychology has to be inter-, trans-, and multi-disciplinary. Diverse elements converge within training and practice serving as background and knowledge, including child development, family and peer processes, and developmental psychopathology. The pediatric psychologist needs knowledge of the biological, cognitive, social, affective, sociocultural, and lifespan developmental influences on children's health and illness. Basic knowledge of disease processes and medical treatments is needed.³ The psychologist needs to understand and appreciate the roles of other

disciplines in health service delivery systems. The various professions and disciplines have different ways of thinking; each has also developed its own language and jargon to communicate within themselves. Where this is not a regular part of the university education of psychology students, extra effort must be applied to insure learning. Although medicine and the pediatrics specialty is the most obvious discipline requiring knowledgeable interactions, there are many other disciplines including psychiatry, social work, nursing, school specialists, juvenile justice, and law enforcement. As a member of an interdisciplinary team, the psychologist can facilitate communication for all parties and educate other team members about psychosocial development, adherence barriers, and behavioral strategies to enhance functioning. The pediatric psychologist can “study” these professional orientations in the same way they would learn about disease or illness (e.g., seek informational resources) through coursework, practicum, and internship experiences. Mentors can provide opportunities for working within the variety of settings and for interactions with other disciplinary professionals. Ideally, this would occur through an educational function with supportive supervision. Interdisciplinary collaboration and consultation has historically been one of the cornerstones of research and clinical innovation in the field of pediatric psychology, so this experience leading to expertise is essential. Often overlooked, however, is that a psychologist’s functioning in a clinical team, in addition to being a contributor of expert techniques of assessment and intervention, includes serving as a *relational leader*. The psychologist is often cast into the middle of these interactions with presumed expertise to resolve conflicts among team members or with the families receiving services from the team. This expertise requires careful development to help hospital teams to function at their best to provide quality care.

Pediatric psychology in the future

Past editors of the *Journal of Pediatric Psychology*⁴ articulated their view of future issues in the field including attention to: (a) technology and health; (b) clinical and research teamwork; (c) primary care settings; (d) new interventions, and (e) emphasis on prevention and health promotion. Future efforts also need to focus on health care disparities and poverty that create health concerns and on the adaptation of interventions for the diversity of patients. These will involve biopsychosocial concerns associated with immigrants and refugees. Internationally, it is clear that Pediatric Psychology is expanding in various ways in different countries with practitioners and researchers. Pediatric Psychology may be different across countries because of politics, culture, history, resources, professional identities, health care organization, and financing arrangements. Different models of training, knowledge transmission, and experiential learning will inevitably result. Small and large studies in their own countries need to prove the worth of pediatric psychology and demonstrate improvement in both medical and psychological outcomes. Pediatric psychologists are not going to be all the same, but can be committed to the same goal of applying psychology to enhancing children’s health and functioning.

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A Long Term Experience in Childhood Leukemia: Psychosocial Aspects

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Background

The experience of Giuseppe Masera (GM) from 1965 and Momcilo Jankovic (MJ) from 1976 in treating childhood leukemia specifically addressed to psychosocial aspects is described in a narrative way. GM, following a research and study training time at Kinderspital in Bern (1964), promotes and chairs the Hematology-Oncology Center at the Pediatric Clinic in Milan. From 1984 he moves to Monza, where he chairs the University Pediatric Clinic until 2009.

MJ becomes part of the Hemato-Oncology group from the end of 70’s and, with great commitment and dedication, cooperates with GM in developing for the following years the different psychosocial issues.

Indeed since 70’s our Center has been among the pioneers in implementing and promoting the holistic and psychosocial approach in pediatric oncology at clinical, research and training at national and international level.

A success story

At the beginning of 60’s In Pediatric Oncology particularly in leukemias the results are very poor. In 1965, when GM starts his activity in Milan, the concept of cure of leukemia doesn’t exist. It is the time of resignation and despair.

1967: A surprising message comes from Donald Pinkel,¹ of St. Jude Children’s Research Hospital in Memphis: with the association of multiple drugs (Total Therapy), we are achieving positive results. We believe that acute lymphoblastic leukemia, the most frequent form, can be cured. Indeed it must be approached with this goal: the hope is born.

1968 Lorena, a 10-years old child, is the first young patient treated with the new therapy. She asks to speak to the doctor: “Doctor, you must tell me what leukemia is and if I can be cured”.... She gives us an important lesson: even children, or some of them, wish to know directly from the doctor, with adequate and truthful words, what is happening. Lorena is our first cured, happily married, mother of two children, and resilient grandmother of a nice baby.

After 1970: important progress is made on the medical and psychosocial level. In ALL, an increasing percentage (from 50 to 80%) of children are successfully treated and cured. Many clinical research studies through the Italian Association of Pediatric Hemato-Oncology (AIEOP) are promoted both in Italy as well as at international level (International BFM Study Group). Milan and Monza actively participate with responsibility roles.

1972: by interacting with the parents of children affected by various hemopathies, a strategy is created which will be fundamental for developments in the following years: the Therapeutic Alliance between family and multidisciplinary health-care team (Figure 1).

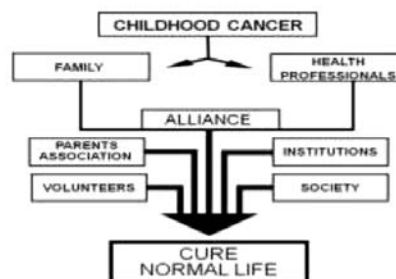


Figure 1. The Therapeutic Alliance between Family and Multidisciplinary Health Care Team.

1975-77: two outstanding oncologists, Giulio J. D'Angio from Philadelphia, and Jan van Eys from Houston, both promote the importance of the holistic, psychosocial approach in Pediatric Oncology, with two important statements: "Cure is not enough"² and "the aim of Pediatric Oncology: the truly cured child".³

1978: despite having limited resources, the "school in hospital" program is launched in Milan. This program will have a significant development in Monza from 1984 and will be structured with a formal agreement between the school authorities, the Municipality of Monza and Hospital S. Gerardo.

1979: Maria Letizia, a 3-years old child, dies from leukemia, and her parents sublimate the great pain creating the Parents Association "Comitato Maria Letizia Verga" (CMLV) for research and care of childhood leukemia. The parent, for the first time, has an important place in the total psychosocial approach (Figure 2). Giovanni Verga, Letizia's father, becomes the President: he will dedicate a relevant part of his energies to the development and growth of CMLV. After more than 40 years he is continuing his mission with renewed enthusiasm. The annual supporters of CMLV are so far more than 6000.

At the present the CMLV celebrates 40 years of activity giving voice to parents and supporters contributing in a relevant way to the growth of the Center and development of many research and welfare initiatives.



Figure 2. Psychosocial organization.

1984: the Pediatric Clinic of the University of Milano moves to Monza at San Gerardo Hospital, Pediatric Clinic of the University of Milano-Bicocca, shortly followed by the creation of a Bone Marrow Transplant Unit. By combining total care and research, the Monza Center will be recognized of great value at national and international level.

1985: a psychosocial Working Group is activated, directly coordinated by physicians (GM and MJ), with an essential role played by psychologists and social workers.⁴

80's: an international cooperation is activated; John J. Spinetta (JJS),⁵ Psychologist at San Diego State University, an International leader in the Psychooncology starts the collaboration with our Working Group and for more than 15 years at least 2-3 weeks per year attends the Pediatric Clinic implementing the growth of the group and doing research. Mark Chesler (MC)⁶, Sociologist from University of Michigan, who met many times during the SIOP Congress, introduces us in the basic concepts of Resilience, Post-Traumatic Growth (PTG) and Post-Traumatic Stress Disorders (PTSD).⁷ Based on these concepts GM and MJ edit a book "Noi Ragazzi Guariti" (We Cured Guys)⁸ where 100 narratives were collected from young-adults (age 18-50 years) formerly affected by leukemia at least 5 years from diagnosis.

An important part of the psychosocial program is "Communication" in general, but in particular that of the diagnosis, both to the family and to the child. The attending physician of the ward makes a preliminary communication to the family followed by the psychologist and the

social worker for giving an overview of the different needs and aspects related to the disease. A few days later the Director meets both parents to illustrate the different aspects of the "Project of care". Regarding the communication of diagnosis to the child MJ elaborated a formula where the doctor talks to the child alone without parents present with a dialogue modality, using a metaphor and including also the siblings.^{9,10}

1991-2008: the SIOP commits GM to chair the Psychosocial Committee (co-chaired by MJ and JJS). We aim to prepare some guidelines on the major psychosocial topics, and 13 documents are written as Guide-Lines/Recommendations with the contribution of experts (physicians and psychologists) from international Centers. These documents, coming out from annual meetings held in different countries worldwide with different senior experts (Pediatric Oncologists, Psychologists, Sociologists, Nurses, Epidemiologists Parents, Survivors), and other members of International Centers, are published in Medical Pediatric Oncology and Pediatric Blood and Cancer.¹¹⁻¹⁴

To better define some important issues, we promote a collaboration with Riccardo Haupt (from Gaslini Hospital in Genoa). An International workshop on psychosocial cure and care after childhood cancer is held in Erice (Sicily) in 2006 (repeated ten years later - 2016)^{15,16} with the attendance of 48 experts from 15 European and North America Countries. Two important concepts came out:

1. Cure: it should be referred to the original cancer, regardless of any potential for, or presence of remaining disabilities or side-effects of treatment.
2. The goal: treatment for childhood cancer should have the aim to form a resilient, fully functioning, autonomous adult, accepted in the society at the same level of his/her peers

Moreover the Center should offer a counseling service for medical and psychosocial problems and to develop a specific and specialized clinic-oriented toward the preventive medical and psychosocial care of long-term survivors. This program should facilitate the transition from Pediatric Cancer Unit to community family physicians by organizing an individualized survivorship care plan.

Palliative Care and end-of-life phase always received special attention in our Center. MJ coordinated this specific care area following an original initiative, *i.e.* meeting both parents 3-4 months after the death of their child/adolescent from leukemia. He performed in about 20 years more than 200 meetings giving the parents the opportunity of clarify aspects still unsolved and expressing perplexity on the terminal phase of the disease. Parents confirmed the utility of this type of approach.

MJ attended for some time training courses about end-of-life with Elisabeth Kubler-Ross¹⁷ well learning that child does not need either "therapeutic renouncing" or "ruthless obstinacy" approach.

Veronica, a 13 years-old girl before dying leaves us an important message in her poems; another child states: "My parents do not know that I know I have to die: I did it".

2000's: Following a collaboration program of Monza with the Oncology Center of Managua-Nicaragua, started in 1986, Ernesto Cardenal, poet, priest and exponent of Liberation Theology, begins the "Talleres de Posia" ("Poetry workshops") with free verse with children of La Mascota Hospital in Managua.¹⁸ The program is successful and allows the publication of two books. An example is a poem by Ibis Palacios, 8 year-old girl.

Conclusions

At the end of this long-lasting and passionate commitment we can well say: "It was worth it". And never burn-out had touched us. Now more than 2500 young adults are cured and well integrated into society. Most of them could be defined "resilient" having obtained the "true cure". We are grateful to them, to those who died and to their

parents, for what they taught us helping our growth. And based on these aspects the story is going on.

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Understanding Childhood Neglect in Pediatric Contexts

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Introduction

Neglect in childhood is an increasing problem for health practitioners, policy makers and public health experts. In the UK neglect reported to child protection services is increasing whilst other types of childhood abuse are decreasing¹ (note 1) and community investigation shows neglect to have the highest maltreatment rate.² This is in part due to problems with its identification and threshold for intervention as well as for associated maltreatments such as emotional abuse. The UK policy definition of child neglect is: *A persistent failure to meet a child's*

basic physical and or developmental needs.¹ Childhood neglect occurs in 1 in 5 children or adolescents and is highly related to affective disorder. It leads to a nearly threefold risk of major depression or anxiety and as much as eight-fold increase in deliberate self-harm in adolescence.³ This article will consider four key issues in relation to child neglect, it will then discuss the implications of child neglect in a pediatric health context.

i) **Neglect and emotional abuse:** Material neglect of the child is highly related to emotional abuse. This has varied definitions but encompasses '*Antipathy*' from mother or father, which involves parental hostility, criticism, rejection and unfavourable comparison with siblings. It is highly correlated with neglect. *Psychological abuse* is sadistic control of the child involving terrorising, humiliation, deprivation of needs or valued objects which is a rarer experience and often concurrent with sexual or physical abuse as means of control, and it is also associated with neglect.⁴ Another related experience is *role reversal*, which usually occurs in a neglect context. It involves the child taking care of the parent and/or siblings in a way that can be material (eg housework, babysitting) or emotional (hearing confidences, keeping secrets). This is also highly related to affective disorder and deliberate self-harm.^{3,5}

ii) **Neglect and dose-effects:** Dose-effects occur when multiples of childhood neglect and abuse lead to higher rate of both psychological⁶ and physical⁷ problems in later life as indicated by the Adverse Childhood Experience (ACE) studies.⁸

iii) **Neglect and attachment insecurity:** Childhood maltreatment is mediated through insecure attachment style. Parental maltreatment damages a child's cognitive-emotional development, which includes the ability to trust others, to emotionally regulate and to have self-worth.⁹ Neglect relates particularly to anxious styles causing lack of long term social support and more conflictual partner relationship.¹⁰

iv) **Neglect and measurement issues:** Self-report childhood questionnaires are brief and easy to administer but can be oversimplistic, e.g. ACE questionnaire (notes 1-2). Interviews eg Childhood Experience of Care and Abuse (CECA)^{6,11} are validated and create more in-depth and varied data.¹² However, these are time consuming and require expert use. None are used with primary school age children but can be used with adolescents.

Neglect and pediatric health: There has been relatively little research into childhood neglect in families where a child has a serious health problem. The child presenting with a serious illness will usually attract greater parental concern and anxiety. This leads to certain scenarios: (i) that parental anxiety is an unintentional form of emotional abuse for the child – who may feel responsible for their parent's psychological distress; (ii) that siblings in the household may experience neglect or emotional neglect when the focus is solely on the ill child, (iii) siblings, and the affected child, may experience role reversal in trying to alleviate the parental anxiety and provide support for the parent. All of these will have negative impacts on the affected child's future affective health. However, in addition there is a small research literature on the effect of childhood maltreatment itself on physiological conditions such as chronic pain¹³ with a common role for serotonin, norepinephrine and pain perception.¹⁴ Indeed the child abuse-depression model has been compared to models for chronic pain¹⁵ and treatments being similar for both in later life.¹⁶ Neglect or abuse in childhood certainly relates to poor emotional regulation and physiological stress response, which increase vulnerability to pain. Thus chronic pain is considered 'the next frontier in child maltreatment research'.¹⁷

1 <https://www.ons.gov.uk/peoplepopulationandcommunity/crimeandjustice/articles/childneglectinenglandandwales/yearendingmarch2019>

2 <http://traumadissociation.com/ace>

Conclusions

It is becoming increasingly important for health experts to acknowledge the role of child maltreatment in a range of health issues involving later disease. Increased distress for a neglected child with a pediatric condition, and siblings, is likely. It is important for child and family psychologists to be involved in the health care of children with to dissipate the associated effects of emotional issues.

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Ecological Transitions and Identity Building at School

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Introduction

The School - as is well known - is one of the fundamental places where children and adolescents can co-build their own Identity by feeding from the relationship with the Other (adults, peers, group, institutional

rules). It is a place where important "ecological transitions" are experienced and that require the predisposition of adequate psycho-social-educational support to avoid "adaptive risks" related to the transition itself.

As Bronfenbrenner has long reminded us, "an ecological transition occurs when an individual's position in the ecological environment changes as a result of a change in role, environmental situation or both".¹

The first passage/transition of the child from the family microsystem to the group-class/section microsystem, the following transitions between school orders are all examples of important "ecological transitions" lived and experienced by children in the relationship between themselves, School and Family. If - as Bronfenbrenner reminded us - the "ecological transition" is both a "consequence" and a "determining factor" of the subject's developmental process, then it becomes fundamental, in a global and dynamic ecosystemic perspective, to be able to identify the "risk factors" present in each transition in order to outline Operational Support Plans for the Promotion of Wellbeing and Identity Development.

Methods

The theoretical-methodological perspective to assume, therefore, can only be global, dynamic and inter-institutional, just in an attempt to "keep together" the evolutive influences of the various ecosystemic levels involved in the Person's development (Figure 1). An approach coherent with a "vision of the Whole"^{2,3} and towards a "new wisdom"⁴ still ought to be understood and practiced. A vision of the School able to understand what really needs to be taught to young people today in order to survive in a society of "uncertainty" and "discontinuity".

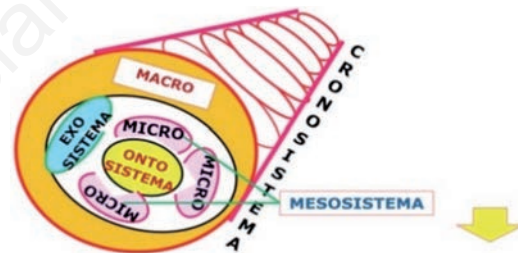


Figure 1. Chrono-procedural ecosystem model.

The figure - adapted from a work by Absil and Vandoorne⁵ - also tries to show the temporal dimension introduced by U. Bronfenbrenner in 1986. To better understand and act more effectively on the risks involved in "ecological transitions", it is necessary to move from a synchronic approach centered on the here-and-now to a more dynamic one that also includes temporality.

Chronosystems are made up by the "life time" of the different systems that welcome people (biological time, time of the family system), time of the school scan, time psychologically "lived" by the individual person) in a complex and dynamic dimension, to better understand with what psychosocial and educational "equipments" the child arrives when he has to deal with his "developmental tasks". It is from this model of complexity that we have re-read the different phenomenologies of dropout that occur within the school system, especially in the presence of ecological transitions both experienced by students and "determined" by the school organization itself.

Results

The data in our possession - processed by the Observatory on School Dropout (USR Sicilia) relating to the school year 2017/2018 - mercilessly confirm the adaptive risks associated with the "Ecological-School Transition", as illustrated in the following Tables 1 and 2 and Figures 2 and 3:

Table 1. Raw data of general index of early school leaving in Sicilian region,, in school transition from fifth class of primary school to first class of secondary school.

School order	Registered	Evasors	Abbandons	Not admitted to the next class	Index general dispersion (IDG)
Fifth class primary school	46725	28	35	91	155
First class secondary school	50587	256	259	939	2270

Table 2. Raw data of early school leaving in Sicilian region (%), in school transition from third class of secondary school (first level) to first class of secondary school (second level).

School order	Registered	Evasors	Drop out	Non-validated school year (irregular frequency)	Not admitted to the next class	Index general dispersion (IDG)
Third class secondary school	52146	110	240	512	875	1899
First class secondary school second degree	48986	438	1181	2989	3461	9381

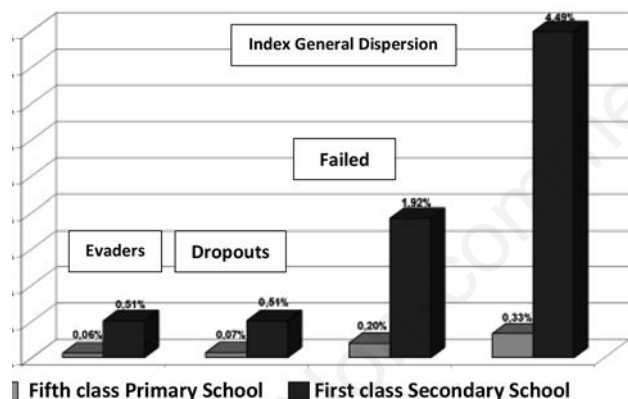


Figure 2. General index of early school leaving in Sicilian region (%), in school transition from fifth class of primary school to first class of secondary school.

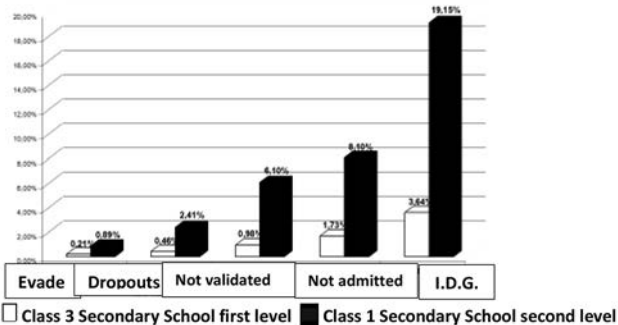


Figure 3. General index of early school leaving in Sicilian region (%), in school transition from third class of secondary school (first level) to first class of secondary school (second level).

As can easily be seen from the data referring to the total number of students in the state public school throughout the Sicilian region, the phenomena of *school drop-out* (evasion, early school leaving, irregular attendance, real failures) are particularly evident in the classes of *transition* from one school order to another. The "school transition - if not adequately thought out, organized and supported - makes *discomfort* explode and significantly hinders the Identitarian construction of minors. But what *identity* are we talking about?

Coherently with the ecosystemic and complexity approach, the identity construction to which we refer is to be seen as a dynamic process of multiple co-construction, starting from the Relationship with the Other within specific ecological and socio-cultural contexts.

Collaboration and coherence between the different ecosystem levels are fundamental to prevent psycho-social-educational risk and to promote a healthy identity building (Adaptive Balance). A *deficit of interconnection* among the various microsystems in which our children's lives take place is at the origin of the malaise and discomfort. And so, if there is a problem in the interconnection among the various *contexts of life* that, causing fragmentation and ruptures, it becomes necessary to develop Integrated Strategies to support children.

The *support strategies* can only be conceived in an Ecosystemic Optics, with the involvement of all the actors (Parents, Teachers, Managers, Healthcare, Social Workers, etc...) who interact responsibly with and for children in a dynamic, global approach modelled on the ecology of human development. It is a complex Model that strives to hold together both the synchronic axis (the context in which the Person lives in the here and now) and the diachronic axis of human experience (temporal processuality).

It is not accidental that the model is named by U. Bronfenbrenner⁶ PPCT MODEL (Process/Person/Context/Time). It is an "operational" model that allows us to understand how development is achieved and what are the main obstacles that people may encounter in the realization of their own identity construction. Development is the result of the constant interaction between the characteristics of the person, of the process and of the relational context in a temporal dimension (chronosystem).

Conclusions

A rigorous analysis carried out on the *knowledge base* related to educational effectiveness,⁷ has highlighted the need to include students' school-training outcomes (success/ failure) within a complex process that involves a set of intertwined multilevel factors (single student, teaching/learning dynamics, relational group-class trend, ecology and school climate, national training system).

As we have been arguing for a long time,⁸ a global and inter-institutional approach is necessary when dealing with "fragile" subjects, in situations of psycho-social-educational risk. It is a question of globally changing the "look" at these students. In the beautiful words of Perticari, "*disadvantaged children are not only children destined to be marginalized at school; their absences, the difficulties that these children create, are nothing more than the reason for the essence of school. It's good to think of disadvantaged children as the vanguard of a school...*".⁹ A School yet to come!

In the following figure (Figure 4), from a dynamic and ecosystemic point of view, some positive actions to be developed to support minors in the so-called "Ecological School Transition" are identified.

The fundamental objective is to prepare a series of psycho-pedagogical and organisational measures capable of *preventing* the adaptive risks inherent in the so-called school transition. This is a targeted attempt to protect fragile subjects (SEC disadvantage, Special Educational Needs, etc.) from the massacre of school dropout.

An important socio-educational work that involves not only school operators but all those (teachers, managers, health and social services

personnel, political and administrative decision-makers, etc.) who - for various reasons - care about a healthy identity building of the children. To conclude, a series of questions posed by E. Morin that - in a time of *transitions* and *crisis* - challenge us and push us to assume an Ethics of Responsibility towards the more fragile Other, towards Humanity and towards the Planet.

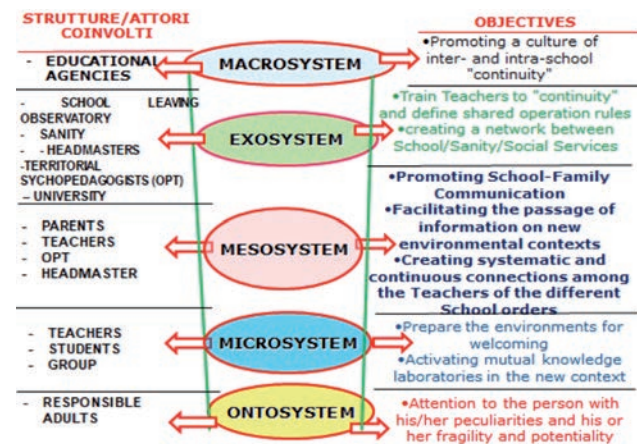


Figure 4. Structures/actors/targets.

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Transition times.
Supporting the child
and adolescent's
transitions
in pediatric condition



SHORT COMMUNICATIONS

Self-harm behavior in preadolescence: an integrated intervention model pediatric-psychologist

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During preadolescence, there are new dynamics related to physical growth, body identity, sexual definition and other development factors for the individual to deal with. It is a phase in which pre-teens don't always possess the psychological tools needed to deal effectively. Often, they find themselves experimenting preadolescence as a *jump* between their third childhood and adolescence, caused by an early and imposed adultization from their parents. Adults, in a conflict between their accelerated growth desire and the possibility of protracted hiperprotectivity, risk not to welcome the minor nor favour the passage that separates them from childhood. For pre-teens the coping and overcoming (with short time available) of the different phases of development can be differently suffered, accepted or rejected. In particular in the process of building one's identity and self-affirmation some signs of psychological suffering can be highlighted, including aggression towards oneself. Non-Suicidal Self-Injury (NSSI) can be the representation of this suffering and therefore the intentional and direct destruction of one's own body tissue without suicidal intent (International Society for the Study of Self-Injury, 2007). Adolescent NSSI can be associated with several worrying outcomes, including depression and anxiety,¹ eating disorders and drug use,² and suicidality.³ Self-harm is primarily an emotional regulation strategy to express distressing emotions, reduce dissociative symptoms, test interpersonal boundaries and prevent aggression towards others.⁴ In fact, in a relevant study,⁵ self-harming reported that adverse emotions (anger, depression, loneliness and frustration) were reduced during and after self-injury, while emotions considered positive (relief) and self-conscious (guilt, shame, disgust) have increased as a result of self-harm. Nock & Prinstein⁶ state that NSSI is intra-personal and reinforces itself automatically or socially. Therefore, understanding the social context of NSSI is important to conceptualize these behaviors in youth, given the susceptibility to the influence of peers during this period of development.⁷ Several studies⁸⁻¹⁰ confirm that social media are both a resource (empathetic and supportive comments) and a risk factor (normalization or encouragement of self-harm) for adoles-

cent cutting. For the latter hypothesis an important result is the correlation between the growing number of comments and the increase in the severity of the wounds that are published. The latest data (National Observatory of Adolescence, 2018) indicate the phenomenon as increasingly early and widespread: it can also start at 12 and it seems that two out of ten Italian teenagers are self-injurious. From a 2014 epidemiological survey 200,000 young people were affected in Italy, of which 90% between 13 and 16 years old and only 15% asked for help. 58% of cutters confided in a friend, 10% said or wrote to a teacher and only 11% managed to talk about it with their family, after being discovered by their parents, who contact a specialist (psychologist or doctor) (Ortophology Institute, 2016). Experience showed that pediatricians, more than other professionals, have more opportunities to identify some of the early signs of cutting. The American Academy of Pediatrics (AAP) and the American Academy of Child and Adolescent Psychiatry (AACAP) (2012) suggest that the presence of psychological disorders in childhood and adolescence can be detected early by the pediatrician, who should have the skills to identify them, to manage autonomously stress conditions and low profile disorders, to co-manage intermediate cases and direct complex ones to the most appropriate services. Among the issues there is the difficulty by pediatricians to welcome preadolescents in a functional and balanced way (if an empathic relationship has not been obtained previously) without risking their closure, and also in relating to parents avoiding reactions of refusal or excessive self-blame. An integrated institutional intervention is necessary, with a qualified collaboration between pediatrician and psychologist. The evaluation and development of innovative collaboration models for the identification and treatment of the three transition phases between childhood, preadolescence and adolescence is subsequent.

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Rock transitions in pre-adolescent chronic pathology: taking care between pediatric emergency room and pediatrics

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A single case study (Davide 13 years old, affected by ulcerative rectocolitis) is reported, describing the tools daily used in Pediatrics and Pediatric Emergency units, Villa Sofia-Cervello Hospital, Palermo: taking care of the evolutionary/developmental trajectory, between resources and critical issues, in conflict with developmental needs and the ones induced by pathology.

The symptoms/markers, to make a diagnosis of Ulcerative Rectocolitis on the basis of the combination of a detailed history, a scrupulous physical examination, laboratory tests, endoscopy and the corresponding histological assessment, were: (1) presence, duration and localization of abdominal pain ; (2) frequency and consistency of the alvo (3) presence of blood and/or mucus in the stool; (4) urgency to evacuate; (5) tenesmus and night awakening.¹

In Ulcerative rectocolitis, the inflammation is typically restricted to the colon with continuous extension starting initially from the rectum, with the affection tending to get restricted at the surface of the mucosa. In children, the disease can be characterized by pancolitis if the whole colon is affected. The most common symptom at the onset is rectorrhagia, often associated with muco-blood diarrhea characterized by pulpaceous or semi-liquid stools, tenesmus, evacuative urgency and often perievacuative abdominal pain, located in the lower abdominal quadrants. The onset can be subtle with a slow progression of symptoms, or acute outlining a severe attack pattern characterized by a high number of discharges of liquid stools with blood, dehydration, hypoalbuminaemia, weight loss, high fever, signs that could represent the prelude of a complication of the RCU, the toxic megacolon. The risk of neoplastic degeneration in the RCU has been confirmed with a cumulative incidence of colon cancer.²

At this point, from a typical developmental trajectory, crossed by surmountable regulatory crises, an atypical development trajectory and a non-normative crisis (feeling therapy as a conviction) is clearly defined.³

During access to the pediatric emergency room unit following an exacerbation of the disease, which would result in hospitalization in pediatrics and the pharmacologic and therapeutic treatment, the pediatric psychologist performs the following activities: facilitation of communication between family and health professionals; emotional containment during emergency/urgency management; promotion of a self-competence and self-regulation; instilling a sense of support, respecting loneliness, fear, referred to the emergency; support to

operators; accompaniment through relationships from emergency to pediatrics.

With hospitalization in pediatric unit, taking care of the pediatric condition is articulated in: working on disorientation and disbelief due to the transition from the safe environment of everyday life to a new place, different for more restricted spaces and times (the hospital) with strong stressful, painful sensory input; intervention on the mentalization of psychological and body experience; support for family relationships; elaboration of perceived trauma and experienced feelings of guilt; awareness of the psychological needs, difficulties and activation of existing resources; the re-signification of the disease event and the experience of hospitalization; the access of the emotional experience and acceptance to have a time and space for listening and sharing without judgment, fostering the possibility to experience the own personal power to the need of being accepted about his own personal without fear and embarrassment, feeling free to be again like anyone else, with elaboration and mentalization of emotions.⁴ The pediatric psychologist has thus facilitated the activation/reactivation of thought, so as to allow Davide to access and elaborate mental contents, experience, emotions, providing a different model to deal with stressful events, through contact with his own resources and system ("I am a part of the cure or I am a part of the disease").

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Drive the adolescent with cancer in the transition towards the adult age

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From the point of view of the pediatric oncologist, accompanying adolescents with oncological diseases during the transition to adulthood involves a precise understanding of patients' health needs and requirements, which strongly correlate to neoplastic diseases and the related intensity/duration of therapeutic strategy. There are varied experiences following the eradication of oncological disease, and it is also important to consider the typical psycho-physiological functions of adolescents in order to ensure the satisfaction of certain basic needs for their well-being.^{1,2}

Some studies have shown a lower quality of life and a higher level of psychological distress among individuals diagnosed with cancer during adolescence compared to community controls and those diagnosed in childhood.³ They often have greater difficulties with social integration, at work and in other projects of their lives. Literature has

highlighted the concepts of “resilience” and “post-traumatic growth” but also the possible discomfort suffered by those who have long-term difficulties starting from the conclusion of their treatment.⁴ Our practical work and experiences have led to propose intervention models and practices in order to meet the needs of our young patients. Psychological intervention offered to both patient and parents during the treatment phase gives both them the opportunity to address numerous factors that result in a better quality of life.

Our task is to facilitate the shift from a child care program to an adult care program, where necessary, after the completion of oncologic treatment. We should ensure clear information is given regarding surveillance and screening programs, the management of any complications secondary to the disease and treatment, along with adequate psychosocial support^{5,6}. The number of long-term survivors within Europe has been increasing by about 8000 per year. However, many are still at risk of developing secondary complications even after oncological therapy has ceased, especially those who have suffered a brain tumor or sarcoma. Long-term survivors may feel totally abandoned at the end of their clinical care as few resources have been invested in the off-therapy phase.

Family doctors do not always have the expertise to take charge of this step. In order to ensure that this expertise and know-how can evolve, it's important to involve family doctors in the care management of patients since the onset of the disease. In fact, family doctors could become crucial figures in the management of the post-care phase. Doctors and nurses are not always adequately aware of the long-term side effects of oncological treatment and some countries may struggle to provide answers to those who have overcome the ordeal of cancer. It is therefore essential that medical experts have the suitable recommendations and guidance for their patients. Owing to such questions, for our Pediatric Oncology Centre the transition is never complete. Long-term survivors often ask us for help concerning some problems related to the disease as well as difficulties associated with other family members; and accordingly, we are always available to offer any possible support.⁷ This availability also has a positive effect as it allows all long-term survivors to be guided, protected and provides them with a point of reference, even after the successful treatment of their diseases.⁸ The majority of the adolescents who have suffered a pediatric neoplasm, do not need to be referred to an adult oncologist, but instead should be accompanied by their family doctor; in particular cases this care should be supplemented by a specialist, with medium-to-long term care interventions, by for example, an endocrinologist, cardiologist, orthopedist, gynecologist, etc.

Another major concern, as pediatric oncologists, is certainly the initial care and management of adolescents (14 -19 years) with cancer. In reality, pediatric hospitals provide us with the ability to take charge of patients under the age of 14 years. When patients between 14 and 19 years or more (adolescents and young adults) fall ill, they can remain in a “no man's land” for an extended period of time; this uncertainty causes diagnostic and care delay issues, which are often connected with negative prognostic implications. Many diseases associated with young adults can have much more favorable outcomes if they are addressed with “pediatric-like” treatments. Therefore, another crucial battle should be in extending the pediatrician's age of competence to at least 18 years old, in addition to providing adequate space and resources for young adults to be taken care of contiguous with those dedicated to the care of children.

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Breastfeeding: privileged path in the evolutionary transition of preterm birth and parental couple

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Introduction

Worldwide, premature birth is a major cause of mortality and cognitive impairment of infants and elevated incidence (25 % or higher) of diagnosable mental disorders (post-partum depression, post-traumatic stress disorder) among preterm babies' parents.¹

Discussion

Long-term neurodevelopment impairment of preterm survivors has several causes: strong sensibility of cortical areas and brain volume to body weight size; exposure of immature brain to perinatal inflammation, starting from chorioamnionitis, which is the most common cause of preterm birth; intracranial hemorrhage of prematurity; and last but not least, painful procedures of Neonatal Intensive Care Unit (NICU) disturbing brain growth and functional connectivity.

In relation to the latter, NICU-related stress is associated with increase of serotonin transporter gene methylation (SLC6A4) and reduced anterior temporal lobe volume, which in turn is significantly correlated to less-than-optimal socio-emotional development (Personal-Social scale of GMD Scales) at 12 months of age.^{2,3} Emotional distress of NICU parents appears to be strictly related to early and prolonged physical separation, to influence the number of parental visits to the NICU and to interfere with neuro-behavioural trajectories of infants.

Rate of breastfed infants at discharge is a well-known indicator of NICU quality care. Compared to formula-fed preterm infants, very low birth weight newborns receiving their own mother's milk during the first days of life benefits of lower mortality and lower morbidity. Moreover, mental development index score of the Bayley Scales at 18 months of corrected age is 8-points higher than formula-fed babies and better values of developmental quotient persist far beyond the early childhood.^{4,5} In addition to that, brain volume, especially white matter, evaluated by magnetic resonance imaging,⁶ and brain connectivity have a positive correlation with the overall length of human milk feeding⁷ role of omega-3 long-chain polyunsaturated fatty acids (LC-PUFA), docosahexaenoic acid (DHA), and omega-6 fatty acid, arachidonic acid (AA), has been assumed, but inefficacy of LC-PUFA formula supplementation on Bayley developmental scores proves how human milk is a matchless and complicated mix of epigenetic inductors.

Breastfeeding plays a paramount role in the transitional process to motherhood. Physical and emotional closeness decreases the prevalence of depression in NICU mothers to levels reported in full-term infants' mothers.⁸ Family-centred individualized developmental care,⁹ interventions supporting parenting, skin-to-skin contact (Kangaroo Mother Care) are effective strategies to implement breastfeeding and early parents-preterm infant closeness and a safe way to improve maternal mental health as well. Proper design of NICUs, single-family room, that promotes alone time or skin-to-skin contact, is associated with higher rate of breastfed infants at discharge and shorter length stays in hospital.¹⁰

Conclusions

The American Academy of Pediatrics recommends own mother's milk or pasteurized donor human milk, if mother is unable to provide an adequate volume, rather than premature infant formula. Encouragement of human milk feeding for preterm infants is safe, effective, and an ethical responsibility for health care professionals as well.

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Psychosocial interventions for children and parents in pediatric oncology

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Background

A child's cancer diagnosis is one of the most stressful events that can happen to a family. Although the treatment has improved considerably and thus the chance of survival has increased, parents and child are confronted with a long intensive period of treatment that entails

major changes in the lives of the child and parents. Around 600 children in the Netherlands get cancer every year, and one in four children who are diagnosed with cancer dies from this illness. Ten years ago, a group of parents and healthcare professionals in the Netherlands started working towards one national children's cancer center that could accelerate advances in treatment. Those efforts led to the creation of the Princess Máxima Center for pediatric oncology: a unique center that brings together all the highly complex care and research for children with cancer in the Netherlands. This concentration and integration of specialized pediatric oncology reflects the following mission: to provide a cure and optimal quality of life for every child with cancer. Psycho-oncology care and research is an essential part of this mission.

Interventions

Over the years much research has been conducted into the quality of life and psychosocial consequences of cancer for both children and parents. Psychosocial consequences include emotional consequences such as anxiety and depression, reactions of stress to treatment, consequences for neurocognitive development, for behavior, for social contacts and relationships, and also for the quality of life. It is important to provide children and parents with psychosocial interventions to support them in coping with the consequences of childhood cancer and improve their quality of life and lessen the psychosocial consequences.

Our psycho-oncology department provides psychosocial support by psychologists, social work and child life. Interventions to reduce, prevent and identify problems in time are important. Two interventions have been developed to support children and parents in child oncology practice: Op Koers and KLIK, which are both implemented in our hospital next to the standard psychosocial care.

Op Koers program ('on course'): empowerment program: The Op Koers program consists of group courses (led by a psychologist) that aim to teach skills that children or other family member can use in difficult situations. With these skills, they can increase their resilience. The strength of the Op Koers program is that it uses evidence-based techniques from cognitive behavioral therapy. Participation in an Op Koers course in the hospital is not always easy given the distance and the time investment. In addition, adolescents have been found to participate in face-to-face course less often than younger children. Therefore, in addition to the face-to-face course in the hospital, an online version of Op Koers has also been developed: Op Koersonline (www.opkoersonline.nl). So children and family members, regardless of their place of residence or in which hospital they are treated, can participate on their own computer. Online courses for youth, siblings and parents are now available.

The Face-to-face courses consist of five to six 90-minute group sessions that take place in the hospital. Online sessions consist of six to eight 90-minute chat group sessions in a secured chat box on a set time and day of the week. In general, six months after the start of the intervention, a booster session takes place.

Every group consists of 3-6 participants and two course leaders, one of whom is always a specialized health care psychologist and the other can be an assistant: basic psychologist, social worker. In between the sessions, participants make homework assignments. In the modules for parents, additional in-depth information about the different topics is available in the online environment.

Coping skills are translated into five learning goals: (1) information seeking and information giving about the disease ('good to know better' principle), (2) use of relaxation during stressful situations (using exercises), (3) increase knowledge of self-management and compliance, (4) enhancement of social competence (group discussions, role playing), and (5) positive thinking (effective use of the Thinking-

Feeling-Doing model; replacement of inaccurate thoughts).

Over the years we conducted several studies which have shown the face-to-face program to be effective.¹ Currently two studies have been conducted in a RCT for the online course for adolescents and parents.² Preliminary results show positive outcomes for both courses.

KLIK: patient reported outcomes in clinical practice: Due to increased medical knowledge over the past decades, more and more children with chronic illnesses grow up into adulthood. Because of this, it is important to pay frequent attention to the quality of life of young chronically ill patients while they are growing up. It is also known that communicating about emotional problems having to do with a chronic or life threatening disease is important in adjusting to the disease, taking away insecurities and negative feelings. This is possible to accomplish if answers on questionnaires could be used in clinical practice. Therefore the KLIK PROM portal was developed.

KLIK is a Dutch abbreviation for "Quality of Life in the Picture". KLIK is a tool to make communication about quality of life easier during a consultation in pediatric care. The child fills in a questionnaire at home or in the hospital behind the computer. The doctor or nursing specialist can view the answers on the Patient reported Outcome (PRO) via the website (PROfile) and thus see at a glance where the child indicates that he or she suffers more or less often. Parents fill in questionnaires for younger children (< 8 years) or about themselves.

We know from research in pediatric oncology that significantly more psychosocial problems are identified and discussed when using the PROfile.³ It appears that doctors are more satisfied with their consultation with a PROfile and that the consultation does not take more time.⁴ With the KLIK method, systematic attention to development of the child with cancer is possible, one of the spearheads of the Princess Máxima Center. The KLIK PROM portal (www.hetklikt.nu) now contains many different questionnaires that can be used in care as well as in research. All data collected also become available for research after permission of children and parents.

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Intrafamily abuse and mental health in the evolutionary transition phases: the gestalt view on the complex trauma as a developmental disorder in disability conditions

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Intrafamily abuse is a traumatic event that always arises within a relationship that, even if it is an unique and occasional relationship, causes signs that affect the evolutionary state of the child compromising the development of its personality. The situation becomes more complicated when the victim is a child with intellectual weakness. The issue of sexual abuse and abuse in children with a limited

intellectual functioning is still underestimated, despite it represents a phenomenon that is far from negligible. A first attempt to bring out the issue of violence against disabled children from the vast literature about the child abuse, dates back to a systematic British study in 2006, further studies have been made and are still ongoing in Denmark, United States and in Northern Europe while, in Italy, studies and researches have focused more on the memory, the suggestibility of the minor and the operational recommendations for listening in the juridical field.¹ It is clear that intellectual weakness affects the life of a person in a decisive way, compromising not only the cognitive level but also the relational areas.

Researches show that the incidence of the abuse aimed at children with cognitive frailty is higher than that aimed at children without disabilities: the greater vulnerability, typical of the minor and peculiar characteristic of the child in condition of fragility, becomes fertile ground on which abusive behaviors take root. Physical and emotional dependence from caregivers, poor assertiveness towards people from whom they receive care, often unconditional trust towards others, compliance with requests from others, the tendency to seek approval, less knowledge and understanding of sexuality, the poor ability to discriminate between lawful and illegal conduct, inadequate interpersonal skills create in the abuser the perception that the child is an easy prey, ill-suited to reveal the abuse and therefore hardly credible and reliable. Characteristics of the abusive background, therefore, are easily exploited in order to access to the intimate sphere and violate, in an "undisturbed" way, the fragile cognitive, emotional and bodily boundary of the child who often cannot find words to give voice to that whirlwind of sensations in which fears, blackmail, excitement, helplessness and betrayal are mixed in a confused way. The abuse of power leaves the image of a deforming and devaluing body, because it attacks a weak and fragile self that has not found support and care within perverse and "sick" relationships. How can we help these fragile children to undergo the delicate phase of the adolescent transition? How can we support them in giving voice to what they have felt and experienced on their own skin? How can we help them get out of the relational fraud in which the grammar of sexuality has taken the place of affectivity?

During the adolescence, all subjects face particular and delicate evolutionary tasks, connected both to bodily transformations and to overcoming the infantile ways of relating to themselves, to parents and others. For frail children, these difficulties are greater than those encountered by their healthy peers. Although Gestalt therapy has historically privileged intervention with adults, it has characteristics that make it particularly effective in working with "fragile" adolescents. The centrality of the relationship, the importance given to the "here and now" of the experience, the attention placed on the body, the strong role of the action and therefore of the game, the driving force of creativity make Gestalt a ductile model not anchored to rigid patterns that privileges a more experiential and less language-based work. Adolescents with intellectual frailty are teenagers who have difficulty in giving voice to their feelings; their emotional vocabulary is scarce and the words they use often conceal a "naivety", which does not allow them to protect themselves.² Despite their inner earthquake, they struggle to narrate and narrate themselves. Gestalt therapy as an aesthetic model teaches us to look, with confident eyes at that beauty that belongs to the human being and to every contact that comes from a meeting.³ Gestalt therapy encourages to look at what the patient can do, and then co-create new relational possibilities that, often suffocated and unseen, have not had the opportunity to be born and emerge. For these kids, being seen in their resources is fundamental, since they have been surrounded by people who too often have seen and see "in figure" only what they lack. Often, being emotionally unregulated, they tend to exceed the window of tolerance, so

it is necessary to constantly calibrate their arousal and patiently bring them back to the here and now of the shared space. The therapeutic work is characterized by a tiring and patient work of stabilization, mirroring and connection; a dance made of small and courageous steps in which, through creative modalities, such as drawing, writing, playing, it becomes possible to retrace the steps of a heavy and serious story to finally make it thinkable and speakable. The goal is to be able to make possible the emergence of silenced feelings and emotions, and to be able to start, without forcing, that delicate and meticulous work of stitching between body, thoughts and emotions and finally, to be able to look at the "next" together, to that next step that breaks dysfunctional adaptive models and gives the possibility to experiment and live new stories and new relationships certainly, more adaptive and more functional.⁴

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Going through evolutionary transitions in promoting culture for organ donation: an integrated intervention in the Caltanissetta area schools

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Introduction

The reported contribution intends to propose a preventive work experience carried out by the Hospital Psychology and Humanization of Cures service of the ASP of Caltanissetta together with the Intensive Care Unit of S'Elia Hospital, in collaboration with some primary and secondary schools in the territory of Caltanissetta. These are specific activities to raise awareness and promote the culture of organ donation with children and pre-adolescents, pupils of the fifth grade and middle school classes, especially designed and planned with the purpose of promoting a cultural investment on the topic of organ donation with children and pre-adolescents, future adults of tomorrow. These activities also saw the involvement of the Regional and National Transplant Center (CRT and CNT) through the presentation of the actions related to the National Campaign on Organ Donation and Transplantation, promoted by the Ministry of Health aimed at young people.

This preventive intervention was born following the direct experience of integrated psychological support activated, over the years, within the Intensive Care Unit in cases of brain death and subsequent request for organ donation to family members, which occurs when a patient has not expressed a negative opinion during life (LAW 91/99; Ministerial Decree of the Health Ministry of April 8, 2000), especially in consideration of the numerous denials from the family, linked to the lack of knowledge and awareness of the path of organ donation.¹⁻⁵

Methods

About 400 children, a group of parents and teachers from some

schools in Caltanissetta have been involved during specific phases: *Narrative focus group on Donation* by proposing, in the different classes, metaphors and narrative stimuli, in order to encourage a common reflection in children and pre-adolescents through the construction of a shared model on the theme of donation and the results it brings; *Discussion-debate* with the medical team of the Intensive Care Unit, about the issue of organ donation and *Plenary return* of the results of the various Focus groups activated inside the classes, involving all students, parents and teachers of the schools.

It must be specified that in consideration of the different ages of the children and the different possibilities of understanding the concept of death linked to the evolution of their mental representation along cognitive development, different types of languages have been used: after the focus group, the video *Salvo e Gaia. A gift that is worth a life* (www.trapianti.salute.gov.it) has been used to present the topic of brain death and organ donation to the Primary school children. This video has also been commented by the medical team; a comparison/debate and plenary restitution has been planned with the the Middle School children by the presentation of materials and works prepared by the pupils (dances, poems, posters...), through the study of specific disciplinary contents related to the theme of brain death, subsequently addressed to the focus group with their reference teachers.

Results

The proposed activities have had a noteworthy positive response in children and pre-adolescents, as well as in the teachers of reference, who participated in a proactive, curious and open way, remaining fascinated by the delicate theme placed to their attention and openly manifesting a new mental representation of organ donation.

Conclusions

In conclusion, it seems that this initiative can make an important contribution to the creation of a culture of organ donation whose results will perhaps be more visible in the coming years. However, the confrontation with pupils, parents and teachers can help tackle a problem that seems distant and that instead could suddenly and dramatically invest anyone, calling for a choice of great civilization.

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The follow-up: supporting the premature infants and their families in the first years of life

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Prematurity (all birth that occurs before the 37th week of gestation, World Health Organization) represents an important perinatal health problem as it is one of the main causes of neonatal morbidity and death.

In the past decades, the gradual increase in survival of preterm births

led clinician to face preemies smaller for weight and gestational age (GA), at high risk for negative development sequences. Indeed, the immaturity of the biological systems, joined with the complications and the treatment needed for survival, have a relevant impact on infant, exposing him to the risk of developmental delays. They also more frequently present neuropsychological problems, such as language and attention deficits, disorders in perception, visual-motor integration and learning¹⁻³

Furthermore, the traumatic nature of preterm birth, the precarious conditions of endangered life for the infant and of his vulnerable appearance, unreactive and listlessness, causes in parents, particularly in the mother, painful emotions of fear, anxiety, depression, hostility, shame, failure and stress, that interfere with their sensitivity and availability.^{4,5} When interacting with parents, premature infants show less involvement, attention and positive emotions compared to term born babies.^{6,7} The mother's cognitive and emotional responses, her feeling of being unable to adequately cope with the demands of the situation express the acute reaction to the trauma of preterm birth. Within this context, moreover, the precocious separation from the infant and the need to delegate treatment to the medical staff constitute an obstacle for interactively co-building and for taking on the parental role and function. Therefore, for the mother it becomes difficult to relate and interact with the infant, particularly during the first period after birth, also because the traumatic interruption of the pregnancy underlines more acutely the discrepancy between the maternal representations that were created during the period of gestation and the post-birth reality. Literature in fact has documented significantly higher stress levels in mothers and fathers of preterm infants compared to those of parents of full term infants, from the moment of birth until the child's first years of life.^{5,8,9} The mother's emotional state influences the perception the woman has of the newborn, with harmful consequences on the elaboration of the trauma constituting a risk factor both for the persisting distress in subsequent phases, as well as for the development of a secure attachment system.

So, the care of preterm infants requires to extend support also their mothers and fathers during hospitalization but also during the first year of life through follow up programs.

Our experience of follow up began from the collaboration between the Neonatal Intensive Care Unit of Bufalini Hospital (Cesena, Italy) and the Department of Psychology (University of Bologna, Italy), ensuring an assessment by both pediatric and psychological perspective. The follow up is aimed to evaluate level of infant development from 3 months of c.a. to 24 months, with a special attention to the support to parenting. So the follow-up project assesses preterm infant development and the quality of the relationship with mothers and fathers, aside from parenting stress and symptoms of depression and anxiety, in a longitudinal perspective.

One of our studies¹⁰ evaluated the quality of preterm infant-mother interactions, considering severity of birth weight (extremely low, ELBW, and very low, VLBW) and maternal depression, compared to full term babies. Results showed adequate sensitivity in preterm infants' mothers and higher involvement with their infants, compared to full term mothers, despite ELBW ones exhibited an intrusive interactive pattern and a higher prevalence of depressive symptoms. More "active" patterns might be adaptive in these contexts, compensating for the weakness of interactive signals shown by preterm babies. The study nevertheless underlined the relevance of paying special attention to both ELBW infants and their mothers, in order to support the parenting role and the co-construction of early interactions.

Another study¹¹ deepened understanding of the role of parental gender on the quality of early parent-infant interactions with preterm babies. Moreover we aimed at evaluating the role of severity of prematurity (based on birth weight) on the quality of interactions. A first

interesting result is the lack of significant differences in the level of sensitivity between mothers and fathers. It should be noted, however, that in the case of non-sensitive behavior, parents in our study showed different interaction patterns with their preterm babies: mothers appeared mostly controlling while fathers were more unresponsive than mothers. Conversely, infant behavior did not differ during interaction with mothers or fathers. Finally, no differences emerged according to severity of prematurity.

Considering the effect of prematurity on infant development, another study¹² was aimed to evaluate the possible advantages of reading to preterm neonates during their stay in NICU on their later language development. A picture colored book in family's native language was given to 46 newborn's parents (Intervention Group-IG) on admission in NICU telling them to read to their neonate as often as possible. The book was left to the family on discharge home. At 12, 18 and 24 months of infant corrected age, we compared the level of infant hearing and language development, assessed by Griffiths Mental Development Scale, of IG babies with those of 54 infants (Control Group-CG) recruited before the beginning of the intervention. Reading intervention and Italian nationality were significantly associated to higher Hearing and Language quotients. Reading in NICU is a factor that positively influences the parents infants relationship and neonates' language development.

In Italy, one of the priorities of the Public Health is the protection of women during the perinatal period and of the unborn, for the positive effects it has on the quality of life of women and of their children and, consequently, on the health of the family and of the population as a whole. It should therefore be noted perinatal care requires both a network interaction of hospital and territorial and the collaboration with scientific societies. The hospital environment should encourage an optimal infant development, from conception, especially in case of prematurity and/or perinatal diseases, through the creation of highly specialized support structures; at the same time, the Family Consulting Service should represent an interface between the parental couple and perinatal professionals; finally, the University can represent an ideal point of reference and a link among research, training (carried out in an academic context) and intervention in the Territory. The collaboration among these three centers should be enhanced, in order to carry out primary and secondary prevention projects in order to promote the well-being of the child and his family.

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Efficacy of the support in medically-assisted procreation: an inter-institutional path

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Introduction

The present study refers to a research project related to PhD course in "Health Promotion and Cognitive Sciences", Department of Psychological, Educational Sciences and Human Movement of the University of Palermo. In particular, this research focuses on one specific supportive care treatment direct to parents who are facing pregnancy at risk also of preterm birth, in a longitudinal perspective (from prenatal to neonatal).

The study, which is currently in a start-up phase, will involve 100 couples recruited from a Medically Assisted Procreation Service which are at risk of preterm birth and/or which are living a diagnosis of foetal malformations or genetic syndromes. These conditions, once considered atypical conditions, are more common today, considering mother's advanced age, massive hormone therapies and environmental factors.^{1,2}

This research represents a discontinuity compared to the literature, because most studies analyze individual psychological variables such as anxiety, depression and infertility related-stress, but without any attention to the parental competence and repercussions on the child development.^{1,3-7}

Methods

The study moves to a longitudinal perspective from prenatal to neonatal phase; moreover a Control Group will be involved in the research recruited from another Hospital Service of Medically Assisted Procreation in Palermo.

The research is divided into three phases: T0 (at 20th to 24th gestational age); T1 (at one week from the delivery); T2 (at three months of the baby's corrected age).

The study for the Experimental Group considers the administration of one specific treatment entitled Prenatal and Neonatal Parental Experiential Observational Trial, which includes a well-structured procedural protocol that combines expressive with self-observation techniques:

- The technique "Creare con la sabbia"^{8,9} - Creating by sand- will be applied to each phase of the research. It's a validated laboratory method, for promote the narrative and redefining process of

the "pregnancy at risk", the labor and delivery and the prematurity and/or syndromic condition events.

- The "Intervista ai genitori in attesa"¹⁰ -This interview will be applied only at T0 of the research with expectant parents that includes the observation of the interaction between parents watching the video of the morphological ultrasound.
- The "Interviste sulle rappresentazioni materne e paterne dopo la nascita del bambino"^{11,12} - It's an interview about maternal and paternal representations after the baby's birth applied only at T1 and T2. These semi-structured interviews permit to couples to describe themselves relating to their relationship with the baby.
- The "Q-sort sulla competenza genitoriale"^{13,14} - it's a validate self-observation technique on parental competence about caregiving, scaffolding and coping - this technique will be applied in each phase of the research.

The outcomes expected in the Experimental Group are: the reduction of stress levels in mothers and fathers; the Strengthening and the Development of maternal and paternal self-representation as parents able to take care of special evolutionary needs during pregnancy; the Apgar scores, the birth-weight and the gestational age higher than the Control Group; the Adequate scores to development scales with regard to expected cut-offs at 3 months; high levels of satisfaction perceived by parents in relation to support and care treatments received.

Moreover both in the Experimental Group and in the Control Group will be applied some validated tools, listed below, to measure variables of the study: the Beck depression inventory for evaluate depression's symptoms; the Baby Care questionnaire to investigate parental cognitions related to baby care; the Prenatal Attachment Inventory, a self report questionnaire to examine maternal-foetal attachment; levels of Cortisol in Mothers and Fathers; a Human Satisfaction questionnaire; the Impact of event scale revised, a self-report questionnaire, which evaluate to specific traumatic stressor at one week from the traumatic event; the Parenting stress index: it's a questionnaire for evaluate parent's level of stress relating to their parenatal role; the Global rating scale of Mother-Infant Interaction (an observational procedure designed to evaluate the typology of interaction between mothers and infants); the Griffith Mental Scales Revised to evaluate infants development at 3 months of correct age.

Statistical Analysis

Data analysis provide for both descriptive and parametric and non parametric analysis. In particular there will be highlight:

- statistical differences between Experimental Group and Control Group.
- the evolutionary trend of outcomes respect to T0, T1, T2 through a parametric test as a T Student.
- Correlational analysis and predictive analysis between variables.

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Health care transition in patients with disability in the pediatric age

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There are several causes for disability in children (genetic in 5-10%, acquired pre and postnatal, perinatal in 45%, psychosocial factors in 15-20%). The genetic diseases in the pediatric age are often complex and rare. Rare diseases are frequently characterized by clinical pictures with multi-organ involvement and/or multiple functional deficits. They need integrated multi-specialistic and multidisciplinary assistance (both medical, psychological, social, and university and/or hospital structures of reference, territorial health and social structures).

Complex disabilities are often rare and heterogeneous pathologies, but linked by similar care problems, which require specific interventions due to the difficulties of diagnosis, the complexity of the clinical picture, the chronic and sometimes evolutionary course, the possible disabling outcomes and onerous treatment.

The main features of complex and rare disability reveal three factors:

- the rarity
- the chronicity
- the comorbidity

Intellectual disability (ID) is also present in 30% of patients with complex disabilities. People with ID represent 1-3% of the general population.

The data in the literature document the existence of health disparities for people with ID in terms of mortality, morbidity and quality of life¹. The "cascade of disparity" is the result of a series of determinants that plays different roles:

- GENETICS (30%): determine a greater risk of associated conditions and therefore of *sequelae* (e.g. thyroiditis and celiac disease in Down syndrome);

- SOCIAL (15%): they include low income, social isolation, vulnerability to abuse, etc.;
- ENVIRONMENTAL (5%): in terms of greater exposure to environmental pollutants and also inaccessibility to certain places in wheelchair;
- ACCESS TO MEDICAL CARE (10%): lack of attention to specific health needs (e.g. epileptic syndromes) and also to comorbidities (e.g. tumor risk);
- INDIVIDUAL (40%): poor knowledge of a correct lifestyle (e.g. oral hygiene, nutrition) and lack of access to prevention campaigns (e.g. vaccines, smoking, drugs).

In Sicily in the school year 2017-2018, 25,927 students with disabilities (3.49% of total students) were surveyed.

The health care transition is not a mere handover but rather a continuity of a path that involves the adolescent, the family, the world of pediatric care and the world of adult care, in a situation of fragility related to disability. It is not an event but a process that evolves and multiplies over time.

It is difficult to be able to give an exhaustive definition of the term "Transition", in the dictionary of the Italian language "Transition" (from the Latin *transire* "to pass") is defined as "Passage from one way of being or life to another, from one condition [...] or situation to a new and different".

In the medical field, the transition is defined as an intentional and planned transition of adolescents with chronic pathologies to care center for adults, with the aim of providing global care, through the provision of appropriate services and with a guarantee of continuity of cures.²⁻⁴

The evolution of medical knowledge has clearly improved the prognosis of many rare complex diseases, allowing an increasing number of affected children to reach adolescence and adulthood, thanks to the follow-up programs aimed at the early recognition of the various comorbidities. The significant increase in the number of adults requires an important expansion in the services dedicated to their care. To meet the needs of this increased number of adult patients, a proportional increase in the multidisciplinary team for adults is required. For patients with ID, the difficulties are certainly greater because the chronological age and mental age do not match, so it will be necessary to share paths in which the pediatric and adult team collaborate.

On September 15, 2015 in Italy, the "Agreement between the State, Regions and Autonomous Provinces of Trento and Bolzano" ratified the "National Plan of Chronicity"⁵ where it is confirmed that a structured transition must be organized, drawing up a personalized and appropriate path based on local reality, in compliance with the guidelines: "The transition of patients from pediatric to adult age should recognize a gradual transition from the pediatric network to that of adult medicine. The pediatric specialist structure and the treating Pediatrician should therefore integrate with the structures of adulthood and facilitate the care of the young adult suffering from complex chronic pathologies, especially if associated with disabilities[...]"⁵. The involvement of caregivers for patients with ID will be inevitable needed. The multidisciplinary team must put the person and his/her family at the center of each activity.

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Functional somatic complaints in pediatric age: alexithymia or anxiety and depression? An outstanding debate

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In daily pediatric clinical practice, recurrent somatic functional disorders, often medically unexplained, appear widespread among children and adolescents, resulting in frequent seeking to pediatric services and negatively impacting on the quality of life, school attendance and academic achievement.¹

Several studies have suggested a direct relationship between such somatic complaints and emotions.² Already at the end of the 19th century, James regarded emotional experience as directly resulting from the perception of somatic changes occurring in one's body under emotional conditions.³ In front of a bear, a sequence of sympathetic changes distresses the body. In the James' perspective, perception of these reactions would cause emotion. I am afraid because I have perceived changes in my body and I'm afraid because I realize I'm running away, and not I'm running away because I was afraid. More recently, Sifneos pointed out psychosomatic disorders as an expression of a poor ability to identify and manage one's own emotions.⁴ According to alexithymia construct, denoting any bodily signal in terms of somatic disease, along a difficulty in recognizing physical sensations as somatic expression of emotions appear as the core of alexithymia.⁵ Actually, somatic signals are not automatically symptoms of an alteration of physiological parameters. An increase in heart rate may be a symptom of a disease, but it may be also a somatic expression of an emotion or the result of a non-emotional event such as running. Recognizing one's emotions allows to clearly assess and differentiate somatic emotional responses and actual symptoms of disease. On these assumptions, somatic complaints in pediatric age should be referred to the difficulty in understanding bodily expression of emotions and in differentiating from the actual somatic disturbance.⁶ Moreover, poor emotion awareness may result in a difficulty to cope adequately with emotions,^{3,7} especially with internalizing ones. Unconscious or unsolved anxiety and depression may result both in increasing or extending physiological arousal and in somatic symptoms.⁸ Several studies have shown evidence for a relationship between anxiety and depression, alexithymia, and somatic complaints.^{9,10}

However, recent studies suggest that just focusing on the direct relationship between emotional awareness and somatic complaints may be a simplified perspective,^{8,11} as functional somatic complaints are often associated with anxiety and depression symptoms,⁹ increased levels of stress, stronger negative affect, supporting the hypothesis that poor emotion awareness might have an impact on anxiety and depression and secondarily on somatic complaints.¹¹ Therefore, the debate may be viewed as an outstanding issue and future research are required: whether and to what extent the impact of emotion awareness on somatic complaints in children and adolescents are mediated by anxiety and depression, or it must be thought as a direct association between alexithymia and somatic functional disorders. It seems, however, that much of this relationship can be mediated by experiencing internalizing emotions as anxiety and depression.¹¹

Answer to such debate may be crucial for a targeted therapeutic treatment primarily aimed at recovering anxiety and depression or improv-

ing emotional awareness in children with functional somatic complaints. Probably, increased emotional awareness may be for benefit of children with functional somatic disorders. However, such an intervention may improve anxious and depressive symptoms, reducing further exacerbations of recurrent somatic complaints.

Finally, a relationship between alexithymia, anxiety and executive functioning was found,¹² and emotional awareness and modulation was associated with stronger executive function, such as inhibition, impulse control, behaviour modulation, and flexibility.¹³ Therefore, an executive function training should be included in the context of treatment for alexithymia.

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Developmental transitions of children with congenital heart disease: from childhood to middle adulthood

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Introduction

In every transitional phase in their development, children born with a

congenital heart defect (ConHD) and their families are confronted with more developmental challenges than healthy peers. Hospitalizations and surgery are associated with painful sensory experiences, restricted movements, exhaustion, deprived nurturing, attachment problems. Parents experience overwhelming stress, grief and overprotection. Living with ConHD may result in physical (limited exercise capacity/exhaustion, painful invasive procedures, in hospital-deprived nurturing and attachment problems), emotional/behavioral problems (anxiety/depression, anger), cognitive (school en learning problems, neuropsychological deficits, absence from school) and social problems (being teased, adolescence: problems developing autonomy, fear of rejection as to intimate relations, bodily scars; adulthood: finding a job, a stable partner, having offspring, problems with mortgage, life/ health insurances). Finally, worldwide the transition in healthcare is complex, with many patients getting lost to follow-up in this process, which can have life threatening consequences. Before 1980, only 20% of the children born with a congenital heart defect survived whereas nowadays 90% of them survive into adulthood.

Methods

In 1990 practically nothing was known about long-term psychosocial outcomes. Therefore, we started our first cohort-study exploring a broad range of psychosocial outcomes, in which a cohort of ca. 500 consecutive patients, underwent an extensive psychological and cardiological examinations, every ten years (10, 20 and 30 years) after their first heart surgery during childhood. All patients were operated before 1980.

Results

At 10 year follow-up children with ConHD showed nearly 3 times as much psychopathology (e.g. anxiety/depressed, social and attention problems), compared to normative data.¹ Severity of the ConHD had no influence on psychopathology-outcomes. At 20 year follow-up, the marital status of adult patients, was comparable to the norm, but offspring rates were lower. Moreover, educational /occupation levels were lower: 27% had followed special education. Despite this, patients reported a good quality of life. Young females showed more psychopathology com-

pared to normative data.^{2,3} This was related to disease specific anxieties regarding relationships, pregnancy, and delivery. As in childhood, severity of cardiac defect had no influence. From 20 to 30 year follow-up levels of psychopathology decreased significantly and became even comparable to normative data. Predictors for long-term psychopathology were: the surgical scars and number of hospitalizations.⁴ Again, severity of the cardiac defect had no influence. At 30 year follow-up, sexual problems were found more often than in the norm. But overall quality of life of patients was even better than in the norm. Patients had learned to cope; they appeared to use other norms and values than healthy peers, worrying less about fertilities in life.

Conclusions

Over 30 years' time, the medical treatment of our patients has improved enormously. We compared the psychosocial results of this first cohort with a newer, more recently operated cohort. Unfortunately we found NO clear improvement was found on children's psychosocial outcomes. This can be explained by children's neurocognitive anomalies, impaired motor function and parental factors (overprotection, fear of sudden death). Therefore psychosocial care and early psychosocial intervention are crucial and should be implemented.

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