Transition times.
Supporting the child and adolescent's transitions in Pediatric condition
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Ordine degli Psicologi della Regione Siciliana

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

Accompagnare l'adolescente con patologia oncologica nella transizione verso l'età adulta

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Health care transition

- A reasonable definition of health care transition, adapted from the formulation by Blum et al, is the movement of older adolescents and young adults from a child-centered to an adult focused health care program.
- The key transitional care concerns and services that need to be provided for young adult survivors consist of:
- health related education
- health surveillance and screening
- management of cancer-related complications
- often psychosocial support.

A continuously growing population

- Today, almost 80% of children and adolescents with cancer survive their disease, so there are more than 300,000 childhood cancer survivors in Europe. A significant proportion is at high risk to develop adverse health-related outcomes that can appear several years after treatment completion.
- Many late effects depend on the type of cancer and its treatment. Patients with brain tumors and malignant sarcomas are very often affected by secondary diseases.
- Their journey from health through diagnosis and treatment to survivorship involves multiple transitions.
- Survivors require lifelong care that focuses not only on the medical risks arising from their cancer therapy, but also the psychosocial, educational, and vocational implications of surviving cancer.

The impact of the problem

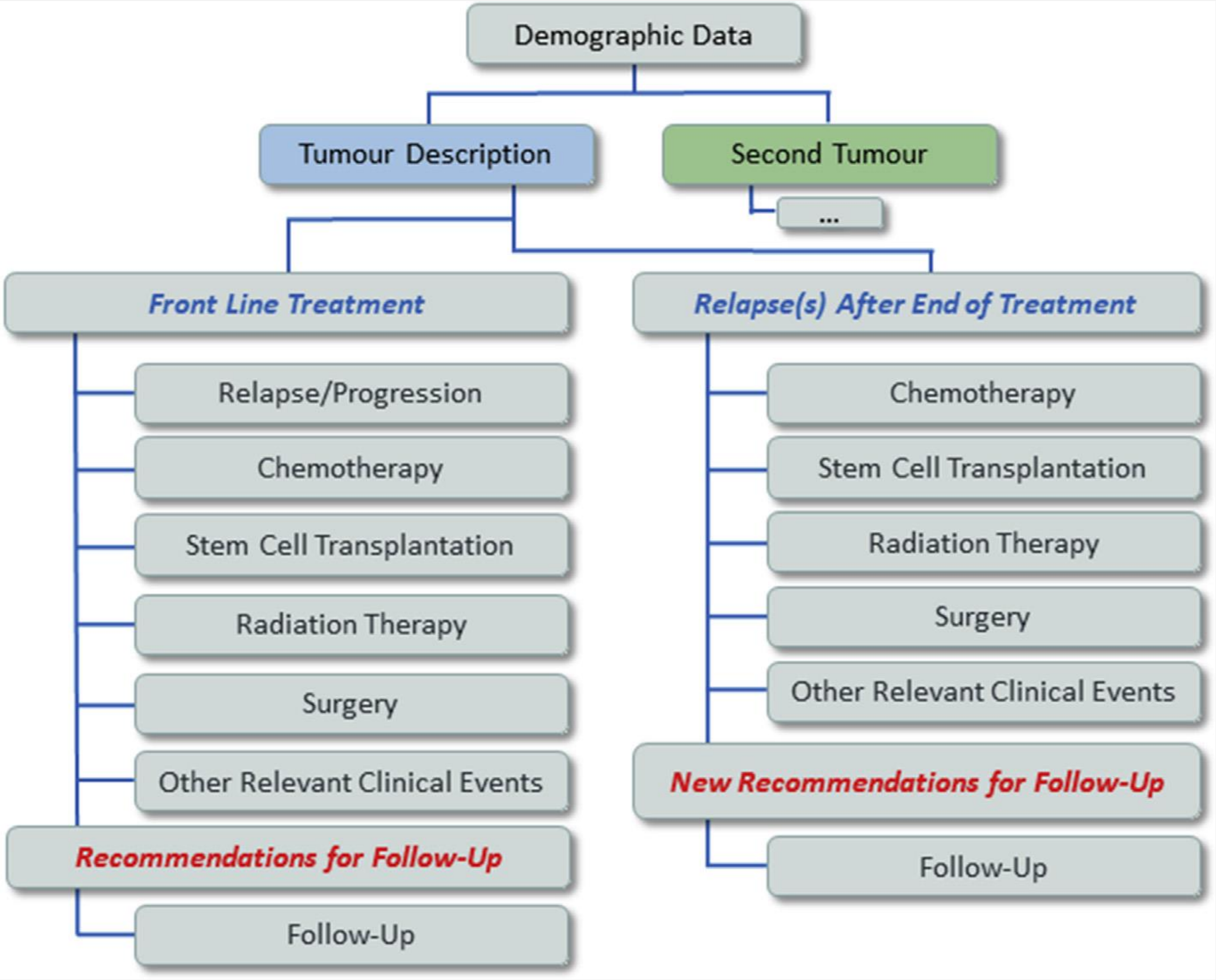
- The experience of long-term survivors in Europe is extremely variable, both within a country but especially between countries.
- One of the most important question is "who cares for patients after treatment is over?". In many countries, also in Europe and most of all in adolescent and young adult age, patients feel abandoned as their treatment ends, because lack adequate resources to assure the care they need.
- General Practitioner or Family Paediatrician usually lack confidence to deal with cancer related issues. It is mandatory that they must be involved as soon as possible in the management of their patients since the beginning of the disease and the definition of therapeutic program.
- They would take a crucial role in the management of the patient after the end of treatment.

What should we do?

- Not all survivors, mostly those treated many years ago, have adequate information of possible late effects and of their possible risks. There is not enough knowledge about screening investigations (what, when and why are they necessary), and survivors report fewer contacts with experts in the field, and the phrase “don’t know where to go” can summarize their common feeling.
- Physicians or nurses, who are in most cases the first points of contact, lack essential knowledge on likely side-effects of cancer drugs.
- Most young survivors experience long-term side-effects after chemotherapy or radiotherapy. In most countries, after a successful treatment, there is no long-term care plan for cancer survivors.
- We must give to our patients, after the end of treatment, a report of the clinical history, with detailed information about the disease and all treatments received, with personalized follow-up and screening recommendations.

The 'Survivorship Passport' for childhood cancer survivors

- It consists of electronic documents, which report the clinical history of the childhood or adolescent cancer survivor, developed by paediatric oncologists of SIOPE networks and experts of Cineca, together with parents, patients, and survivors' organizations within the European Network for Cancer research in Children and Adolescents.
- It consists of a template of a web-based, simply written document, translatable in all European languages, to be given to each cancer survivor.
- The SurPass provides detailed information about the original cancer and treatments received, together with personalised follow-up and screening recommendations.
- The SurPass is potentially an essential tool for improved and more harmonised follow-up of childhood or adolescent cancer survivor.

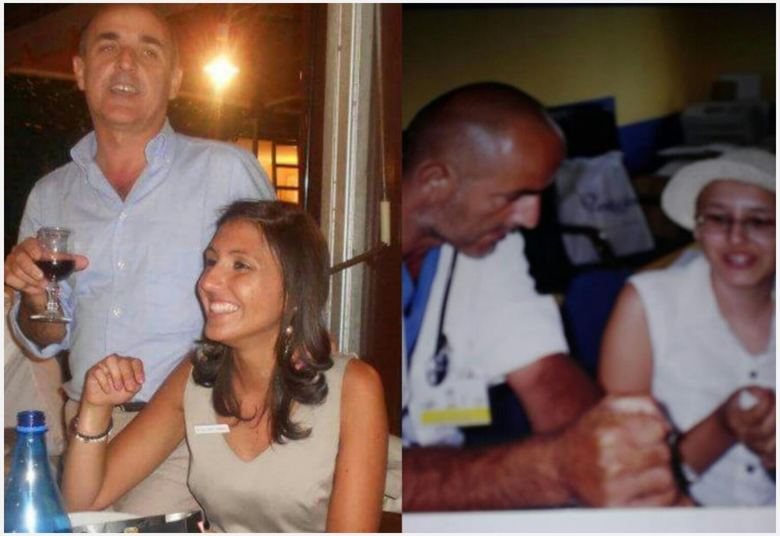


- Demographic Data
  - Tumour Description
    - *Front Line Treatment*
      - Relapse/Progression
      - Chemotherapy
      - Stem Cell Transplantation
      - Radiation Therapy
      - Surgery
      - Other Relevant Clinical Events
    - *Recommendations for Follow-Up*
      - Follow-Up
    - *Relapse(s) After End of Treatment*
      - Chemotherapy
      - Stem Cell Transplantation
      - Radiation Therapy
      - Surgery
      - Other Relevant Clinical Events
    - *New Recommendations for Follow-Up*
      - Follow-Up
  - Second Tumour
    - ...

They are also stigmatized as the society fails to fully integrate them in the workplace, and in some countries they find it hard to get home loans or insurances even 7-10 years after surviving the disease.

Generally, this is not true for the pediatric cancer center care, not only in our experience, but is generally seen in all the centers of our network, Italian Association of Pediatric Hematology and Oncology (AIEOP).

Our boys and girls remain linked to the staff of the pediatric care center for many years after the discontinuation of the treatment, for gratitude, emotional dependency, psychological support, and problem solving, and this last can include the whole enlarged family, "a tenacious umbilical cord".

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What could be the program?

- In the most of cases it is not necessary that the adolescent who suffered of cancer, diagnosed in pediatric age, should be referred to an adult oncology center.
- It can be enough a responsible and adequately informed taking the burden by the family doctor, that has been involved in the management since the beginning of the disease.
- In some particular cases it may be necessary an integrated management with one or more specialists, ie endocrinologist, orthopedic, cardiologist, gynecologist, dermatologist…. according to the characteristics of the original cancer diagnosis and potential long term side effects of the various treatments.

The challenge of treating adolescents and young adults with cancer

- No longer children and not yet adults. Adolescents and young adults (AYAs) with cancer represent a specific patient population posing outstanding challenges to oncologists all over the world.
- The true nodal point of the management of adolescents with cancer is the initial taking charge in the age group between 14 and 19 years.
- These patients, when they develop their disease, remain for a long time in "no-man's-land", the taking charge is delayed, and diagnosis is often done late.
- They present a dramatically extensive clinical picture and receive adequate treatment with considerable delay, with prognostic implications that impact on their chances of recovery.

What we can do to improve the results in adolescents group

- The real battle should be to extend the age of competence of the pediatrician to at least 18 years, and provide adequate space for their taking charge, in contiguity with those dedicated to the child.
- Cancers in AYAs are different from cancers in children and in older adults even when, at least by name, the disease is the same. Adolescence and young adulthood represent the period of transition from childhood to maturity.
- It was clearly demonstrated that AYAs with acute lymphoblastic leukemia can strongly benefit from 'pediatric type' treatments so that pediatric regimens are nowadays considered standard ALL-therapy even in adult oncology departments. This issue may be extended to other cancers and the related therapeutic program.

Adolescence towards adulthood

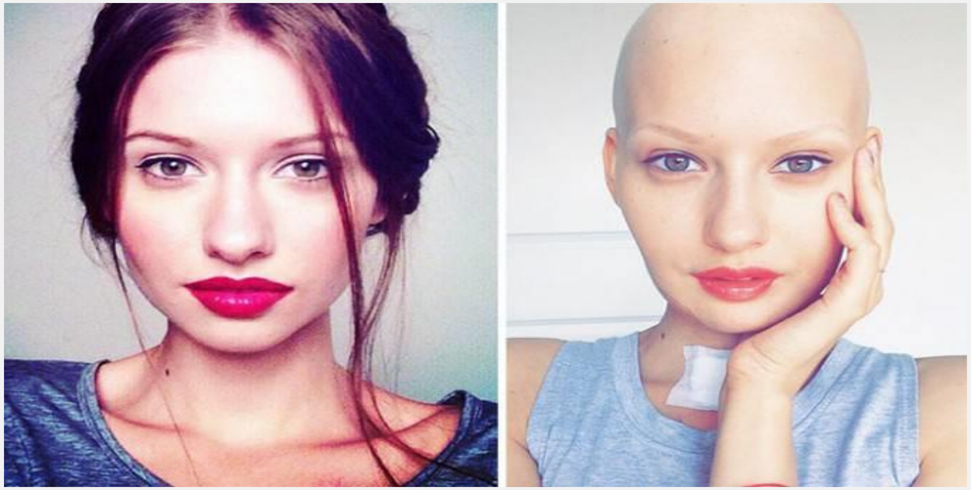
- it is without doubt a delicate and important moment in the formation of the individual’s personality

- The Basic Experiences must be “positive” not just during childhood but also during adolescence. These Experiences include being able to be contained and protected, letting themselves go, being loved, being seen, contact, movement, curiosity and knowledge and they must be given a lot of attention by the adult world.

- The experience of neoplastic disease during developmental age has very special characteristics both on the medical and psychological level.

The relationship with adolescents and parents

- Adolescents diagnosed with cancer are not only confronted with the cancer disease and associated stressors but also physical, social, emotional, and wider psychological changes related to the transition from childhood to adulthood



"The relationship with the parents is extremely important; supporting and guiding them is fundamental for the climate and the well-being of the whole family ».

PsycINFO® PubMed

In literature

«Trauma, traumatic modality, discomfort»

Vs

«Resilience, post-traumatic growth»

The fundamental work with parents

Which Trauma?

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Research on the psychological aspects related to the experience of cancer in pediatric age concerns mainly:

- QoL
- Family implications
- Cognitive, emotional, psychopathological outcomes
- Long-term QoL

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- "A greater alteration of QoL in cases where family stress becomes chronic and prevents any type of planning (Schultz et all, 2003)
- «Need to identify and intervene on families with greater psychosocial risk (Tarbell et all 1998)
- "Chronic stress on mothers; symptoms of anxiety, depression and impotence that alter the resources for the little patient (Rodrigue et al 1997)
- Families that openly express feelings and concerns, supporting each other favor the adaptation of the little patient to the stress during the procedures (Uzark et al, 1992)
- Correlation between prolonged levels of parental anxiety and perceptive and emotional confusion of small patients (Shemesh et al, 2005)

The Functions and the Basic Experiences

Being Held
Being Held, Being Contained (Being Stopped)
Protection
Being Taken Up
Being Taken Up
Being Carried (guidance)

Receiving Attention
Being Seen
Being Listened to
Being Understood
Being Helped
Being Encouraged)

Love
Being Loved (Belonging, Being Carried inside the other person)
Loving (Carrying the other person inside us)
Positive Continuity (Memories)

Strength
Original Strength (Detachment, Space)
Soft Strength
Calm Strength
Open Strength (Letting Out)
Changing Others (Moving)

Contact
Contact (Fusion)
Being Nourished (Absorbing)

The Functions and the Basic Experiences

Authority
Presence (Determination)
Authority (Standing, Confidence, Knowing Our Own Value)

Autonomy
Opposition
Separation

Control
Losing Control (Explosions)
Loosening Control (Head Bent, Collapses)
Soft Attention

Letting Go
Letting Go (Daydreaming)
Just Being
Abandoning ourselves to Calm

- Openness in emotions among family members, contact
- Ability to hold, understand one's child, guide the other through events and sensations (learning by absorption)
- Clarity in emotions and perceptions related to one's body
- Mobility in managing moments of stress. No chronicity
- Planning, support for autonomy

⬇

- Protection, positive expectation, strength, consistency in showing oneself.
- Greater psychological maturity, greater empathy and solidarity towards others, new values and priorities, better ability to face difficulties
- Greater possibility of returning to experience lightness, free movements, no tension, no continuous fears
- Authority and ability to plan life.

*Resilient subjects / resilient families

- Difficulty communicating emotions, lack of clarity, not said
- Difficulty recognizing physiological sensations related to stress and fear, magical thinking
- no calm in relationships, poor tendency to contact between family members
- Difficulty leaving tension, fear, and negative thoughts even temporarily.

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- Fear, perceptive confusion with respect to one's body and feelings, difficulty in showing oneself, high control
- Psychopathological disorders such as stress, depression, anxiety, social maladjustment

*Non-resilient subjects / Non-resilient families

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Gestione dell'ansia e della claustrofobia in Oncoematologia Pediatrica: un'esperienza durante un protocollo di Tomoterapia.

U.O. di Oncoematologia
Pediatrica di Palermo

S.I.F.
Società Italiana di
Psicoterapia Funziona

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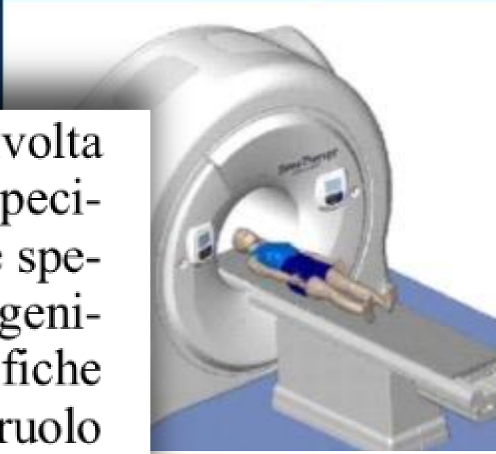

- **Introduzione**

L'Oncologia Pediatr
carico di tutto l'uni
famiglia. Talvolta le
del bagaglio famili
dello stato di bene
legato agli eventi.

zio di psicologia del reparto. L'attenzione è stata rivolta al paziente attraverso un intervento di psicoterapia specifico per la gestione dei sintomi utilizzando tecniche specifiche della Psicologia Funzionale Corporea; con i genitori sono stati svolti colloqui di supporto a specifiche competenze genitoriali. L'intervento ha giocato un ruolo importante per l'inizio e la buona prosecuzione del trattamento radioterapico, senza alcun ausilio di psicofarmaci; effetti positivi sono stati ottenuti anche sulla compliance e sulla qualità di vita del paziente.

- **12** **le)** a frequenza
gi erapia. Durante
og uire lo stato di
agitazione e di paura del ragazzo (tecniche: «respiro diaframmatico profondo; immaginazioni guidate, allentamento del controllo, allentamento tensioni muscolari, recupero di vagotonia, condivisione, comprensione e consapevolezza delle proprie percezioni»). Il ragazzo è stato accompagnato in radioterapia dallo stesso psicologo che ha svolto la seduta, accompagnandolo e guidandolo in ogni momento (in alcuni casi anche durante la seduta radioterapica tramite l'ausilio del microfono).

- **U.O. Di OncoEmatologia Pediatrica**

(Direttore Dr. Paolo D'Angelo)

Civico Di Cristina Benfratelli
Azienda di Rilievo Nazionale ad Alta Specializzazione

Genitori "SuperEroi"

Incontri tematici gruppi genitori

Da molti anni il nostro reparto raccoglie le esperienze dei genitori. Ogni volta che una nuova famiglia arriva nel nostro reparto comincia un lungo lavoro fatto di adattamento, ricerca di soluzioni ed emozioni uniche, ed intense; in questo percorso diventa importante conoscere quanto prima le migliori modalità che possono aiutare l'intera famiglia a vivere il momento di malattia in modo migliore, evitando di appesantire ulteriormente il clima familiare;

Gli incontri verranno condotti con lo scopo di incontrare i genitori, in assetto di piccolo gruppo, proponendo un confronto su temi importanti che riguardano la gestione del percorso di malattia, e temi più generali quali lo sviluppo e i bisogni del bambino e dell'adolescente, le "paure" dei bambini, il benessere psicofisico del singolo e della famiglia.

Dr. Rino Taormina

(Psicologo psicoterapeuta U.O di oncologia pediatrica)

Focus group genitori

Esperienze di base

Competenze genitoriali

ARNAS
CIVICO
DI CRISTINA

GRUPPO DI RIEQUILIBRIO

- incontri con cadenza quindicinale
- EBS:
  - Allentamento del Controllo
  - Forza
  - Contatto

Work in progress

rebalancing
stopping therapy
And
storytelling

“ Resilience“ and ”post-traumatic growth”

It is possible to understand both studies that underline long-term "discomfort" and those that record "post-traumatic growth".

Detecting "risk factors", and planning prevention interventions; in order to guarantee those Basic Experiences recognized as indispensable for the well-being

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