



**S.I.P.Ped. - Società Italiana di Psicologia Pediatrica**

**Le Unità di ricerca della S.I.P.Ped.**  
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**"Pediatric Oncoematology  
Research Unit"**

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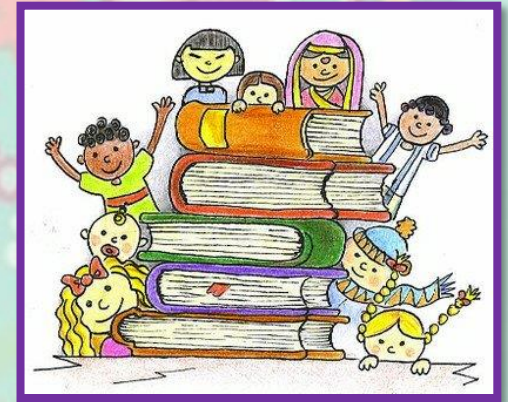
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# Within Pediatric Psychology....

Founded by Kagan (1965) and Wright (1967)

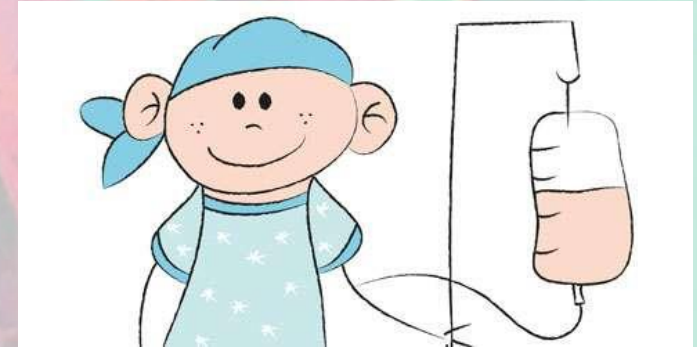
A field of studies that integrates the principles of developmental psychology with pediatric issues

Aims: to support developmental pathway and health of a child and to support his family, through the use of empirically validated techniques and methods, when there are pediatric problems



# ... Pediatric Psycho Onco-ematology

It comprises a diverse landscape of research that covers many psychological and social aspects, linked to the difficult experience of having a tumor during childhood or adolescence



An interdisciplinary field: focus on individuals and their relationships in managing trauma due to illness not only the pediatric patients, but also their families...a “family illness”

# The starting point

As a result of medical advances over the past 30 years, the survival of pediatric cancer patients has increased dramatically

Research indicates that psychosocial and neurocognitive consequences of cancer and its treatment can have adverse lifelong effects and that psychosocial care is critical to the care of a child with cancer and his family.



# Background

From 1993 to 2002, the **SIOP** Working Committee published guidelines to address specific clinical challenges faced by pediatric oncology patients, their families, and providers

They provided **recommendations for:**

- 1) the strategy for psychosocial intervention and structure of socio-economic policies
- 2) schooling and education during treatment
- 3) care of long-term survivors
- 4) communication of the diagnosis
- 5) maintaining an alliance between family members and the medical team
- 6) helping children with cancer transition from curative to palliative care
- 7) *involving siblings of children with cancer throughout their brothers' and sisters' treatment* (Spinetta, Jancovic et al., 1999)**
- 8) preventing and/or remediating provider burnout
- 9) refusal, non-compliance, and abandonment of treatment in children and adolescents with cancer

# ***Goals of the Pediatric Oncoematology Research Unit***

A multi-centric longitudinal project on  
***SIBLINGS***

*Their psychological wellbeing and needs*  
*Value of their relationship with the ill brother*

## ***Pediatric oncologic disease:***

A risk factor for developmental trajectories, not only for the ill child /adolscent, but also for her/his healthy sibling

## **SPIN-OFFS**

To contribute, from the multi-centric research data, to definition of care standards that will serve for taking care of siblings in U.O.C. of Pediatric Oncoematology

# THE RESEARCH PROJECT

## First step: Background review

The most current scientific evidence on the outcomes that a brother's disease may have on the sibling:

### NEGATIVE IMPACT

- **Emotional** (Lövgren, et al., 2016; Wallin, et al., 2016; McDonald, et al., 2015)
- **Social** (Rosenberg, et al., 2014)
- **family relationships** (Schulte, et al., 2004)
- **School** (Lövgren, Jalmsell, Wallin, Steineck, Kreicbergs, 2016)

### POSITIVE IMPACT

Increased **maturity** and **empathy**, self-design and meaning attributed to life (Nolbris, Nilsson, 2016).

## Weaknesses and methodological limits

- **Few** international studies and lack of Italian ones
- **Contradictory** outcomes
- Only qualitative data
- **Retrospective** studies
- Focus mostly on **impairments** (anxiety, depression, dysregulation)
- **Brotherhood not** as a **resource**
- **Age** range too ample (7-18 yrs)



## THE RESEARCH PROJECT

### Focus Areas

Siblings' representations about fundamental relationships, such as with a brother afflicted by an oncoemathologic disease and with their parents



- siblings' perceptions about the relationship with the sick brother during his illness
- siblings' representations about the relationships with their ill brother and their family
- Self-representations during brother's illness
- siblings' evolving resources / fragility in emotional and social developmental domains

## Second step: Research project

*Do siblings perceive the relationship with the ill brother, in the different stages of the illness, as a relational context in which you can support, share, and chose together? Is this perception different from that of children whose brother is healthy?*

*How do siblings perceive their relationships with parents during their brother's illness? Do they feel excluded, involved?*

*Which are their special needs?*

*How those representations and needs correlate with emotional, social and cognitive resources in siblings?*



# THE RESEARCH PROJECT

**Involving siblings and parents  
of oncoematologic pediatric  
patients**

## Focus Areas

- Oncoemathologic children's representations about relationship with their siblings at specific illness' time points
- Parental representations about siblings' evolving resources/fragilities during their brother's illness
- Parental couple functioning during their child illness, in terms of cohesion and adaptability

## THE RESEARCH PROJECT

**Research group:** Siblings, aged between 7 and 13, of children suffering from solid or liquid tumors, and their parents  
**exclusion criteria:** recurrences, transplants, brain tumors

**Recruiting:** within several centers of Pediatric Oncoematology in Italy  
Through collaboration with the AIEOP psychosocial work group

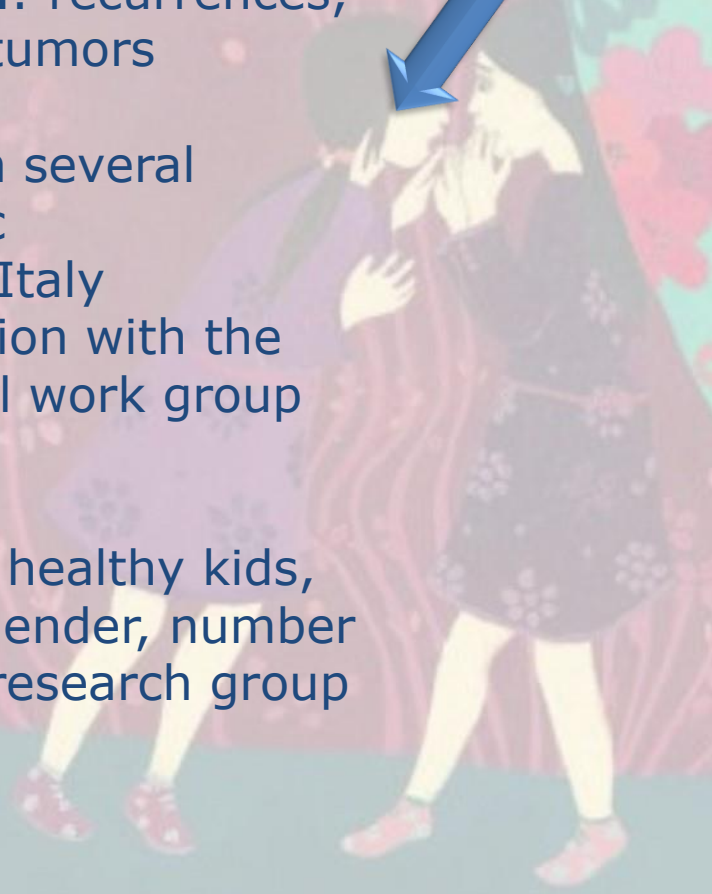
**Control group:** Brothers/sisters of healthy kids, matched for age, gender, number of brothers to the research group and their parents

## PARTICIPANTS



**Siblings**

**Parents**



# THE RESEARCH PROJECT

## RESEARCH DESIGN AND INSTRUMENTS



### Longitudinal design

**T1** = treatment induction  
(33rd – 78th days from  
diagnosis)

**T2** = beginning of  
maintenance therapies (1  
year post diagnosis)



### Siblings

- **BRQ** (Brother as a Resource Questionnaire)
- **SIB** (Siblings inventory of behaviour)
- **SDQ** (Strengths and Difficulties Questionnaire)
- **Narrative interview**

### Parents

- **SDQ** proxy-report
- **FACES – III**

# INSTRUMENTS

## BRQ

**BRQ** is an instrument designed and validated by the Research Unit of Paediatric Psychology of the Psychological, Pedagogical and Educational Sciences Department of the University of the Studies of Palermo.

It is aimed at investigating the individual child perception of the sibling relationship as a resource, by soliciting the reminiscence of the traumatic event experienced.

It consist of 21items grouped in the following factors:

**Sustaining the accomplishment of a task** (scaffolding);  
**Emotional sharing; Decision making during recreational activities**

Each item has to be scored on a **3-point scale** with 1='never', 2='sometimes', and 3='always'.

# INSTRUMENTS

## SIB

**SIB** was originally developed by Schaefer and Edgerton (1981) to assess sibling relationships in families with and without a disabled child.

Consists in 32 items grouped in the following factors:

***Companionship, Empathy, Teach/Manage, Rivalry, Aggression/Conflict, Avoidance***

### **How to interpret the results**

Because the subscales of the SIB are continuous measures, there is no clear cut-off point where one can say scores above this point are optimal and scores below this point are problematic.

What several researchers have done with sibling relationship scales is to use both the positivity and negativity scales and then make groups high and low on these dimensions using median splits. Thus, those scores above the median are considered "high" and those scores below are considered "low".

# INSTRUMENTS

## SDQ

**SDQ** (Goodman, 1999) consists of 25 items describing positive and negative attributes of children and adolescents that can be allocated to 5 subscales of 5 items each:

*emotional symptoms subscale, conduct problems, hyperactivity-inattention, peer problems, and prosocial behaviour*

Each item has to be scored on a 3-point scale with 0='not true', 1='somewhat true', and 2='certainly true'.

Higher scores on the prosocial behaviour subscale reflect strengths, whereas higher scores on the other four subscales reflect difficulties. A total difficulties score can also be calculated by summing the scores on the emotional symptoms, conduct problems, hyperactivity-inattention, and peer problems subscales (range 0–40).

Translated and adapted for the Italian population by Tobia et al. (2011)

# INSTRUMENTS

## Narrative Interview

**Ad hoc Narrative Interview** (Atkinson, 2002), **with 4 questions**  
(2 versions: 7-10 yrs; 11-13 yrs)

Responses (narratives) will be analyzed with respect to the representation of the Siblings' Self-narrative self in its twofold direction : Self-Narration and Self-Narrative Schemes

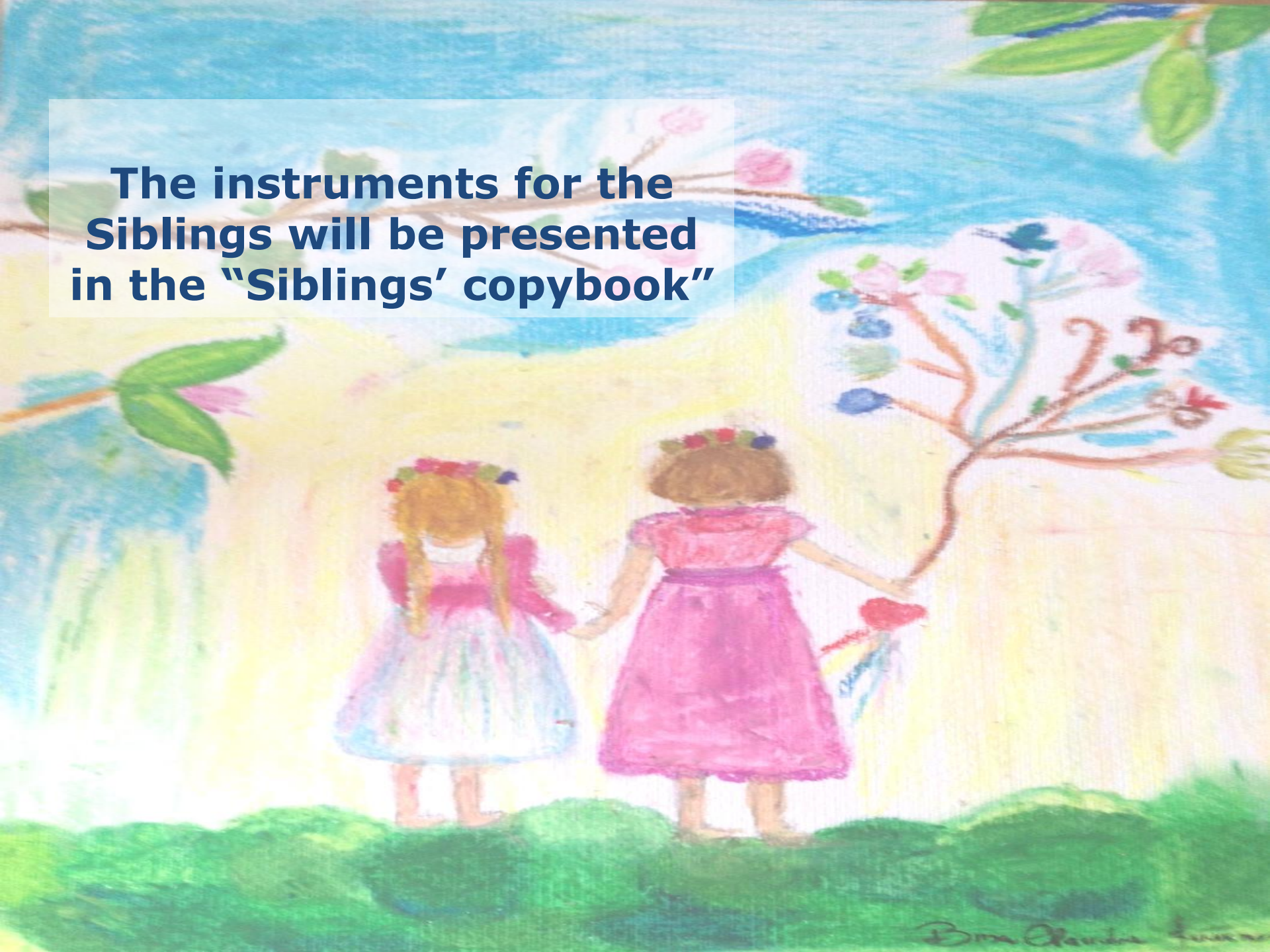
For **Self-Narration**, the structure of two story narrative texts will be analyzed:

- the plan of the **tale**, if and how the story of episodes related to brother's disease condition is presented as a fairy tale, according to a temporal order (sequentiality) with the presence of all narrative elements (characters, context, purpose) ,with unexpected variables that interrupt everyday life or routines (violation of canonicity)
- the plan of **intrigue** that refers to the meanings attributed to the lived experience, to the roles of characters, moods, relationships, critical elements, uncertainties, solutions in the narration.

For **Self-Narrative Schemes** , we will look for the nature and type of constructs on the relationship with the family members, highlighting type of problems that can characterize that relationship and possible problem solving.

In addition, we will analyze the constructs on the self and the possible perception of self in terms of effectiveness, strength and competence.

**The instruments for the Siblings will be presented in the "Siblings' copybook"**





# **FUTURE PERSPECTIVES**

We need to collaborate and to build shared guidelines

Starting from a documented clinical need, we have to organize a prompt response also for siblings

*“Help your brother's boat  
crossing over and even yours  
will reach the other shore”*

*(Hindu proverb)*



*Bonnie Clavin*