

2° Congresso Internazionale S.I.P.Ped.

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

FROM ILLNESS TO CURE
50 years experience in Pediatric Leukemia
Psychosocial Aspects

Giuseppe Masera

*Dept. of Pediatrics, University of
Milano (1965-1983) and Milano-Bicocca, Monza (1984-2015)*

Palermo, November 7, 2019

1) 60's

**From RESIGNATION, DESPAIR
To HOPE**

2) 1967

Donald Pinkel

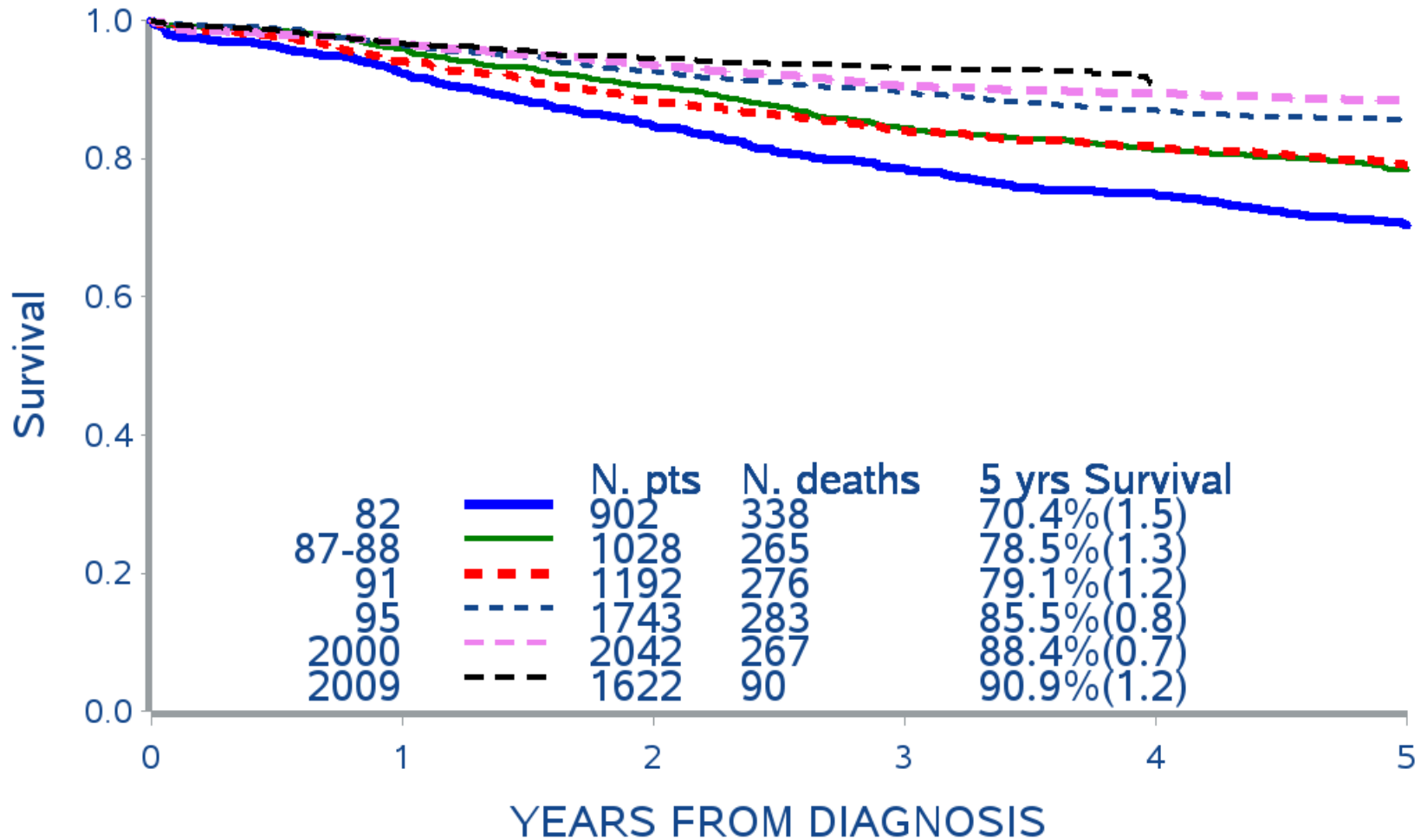
(St. Jude Children's Research Hospital in Memphis)

Acute Lymphoblastic Leukemia:

It is curable, it must be CURED

ALL AIEOP 1982 - 2009

8529 patients



3) 1969

COMMUNICATION

LISTENING

The word is a wing of silence
Pablo Neruda

4) 1969



**“Doctor you MUST tell me
what is Leukemia,
and if I can be CURED”.**

**Lorena
A.L.L., 10 years**

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G.M. - Palermo 07.11.2019

5) 1972

THERAPEUTIC ALLIANCE

6) 1975

CURE IS NOT ENOUGH

GIULIO J. D'ANGIO, MD*

CANCER *March* Supplement 1975



7) 1977

Jean van Eys

“The truly cured child”

van Eys J (Ed.) Baltimore, MD - Univ. Park Press

8) 1976

Global holistic approach Total cure and care



Momcilo Jankovic

- **Medical**
- **Educational**
- **Psychological**
- **Social**

9) END of 70's: SCHOOL

a) IN Hospital

b) AND Hospital

10) 1979: Maria Letizia



**Comitato Maria Letizia
Verga: 1979 - 2019 →**

11) 80's

COMMUNICATION - 2

To the Child (M.Jankovic)

a) With the parents

b) Without the parents

c) With the siblings also

12) 1988



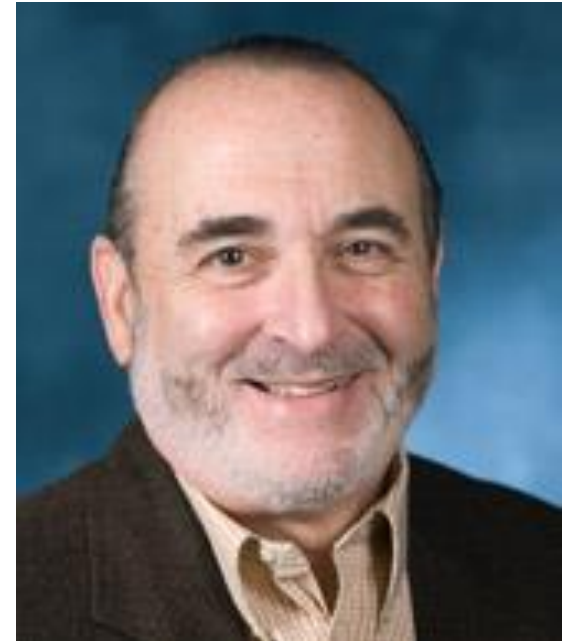
John Spinetta
Psychologist, San Diego State Univ.

13) 1992

QUALITATIVE HEALTH RESEARCH / October 2005

Thematic Evidence of Psychosocial Thriving in Childhood Cancer Survivors

Carla Parry
Mark A. Chesler



Mark Chesler
Sociologist, Michigan Univ.

Resilience – PTG – PTSD

14) 1991-2008

SIOP Psychosocial Committee

- *Chair:* Giuseppe Maserà
Co-chairs: Momcilo Jankovic, John Spinetta
- This Committee discussed various psychosocial issues and developed 13 documents on Guidelines, summarizing the experiences of major centers.



Prof. Tom Voûte
SIOP President, 1990-1992

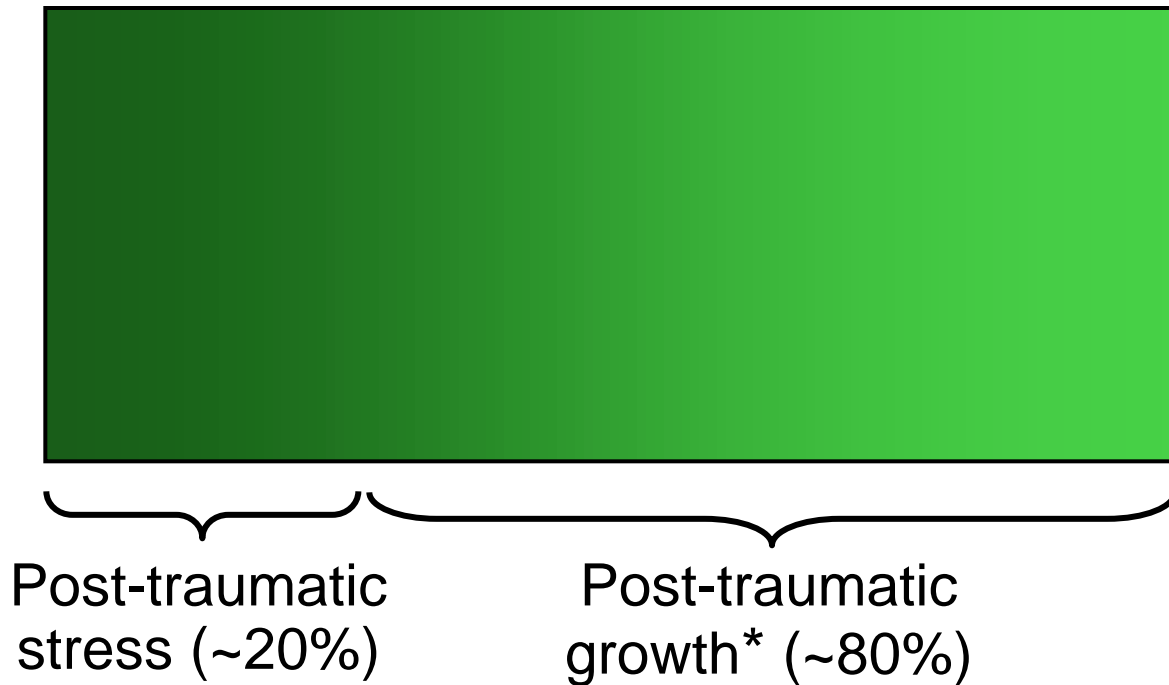
SIOP Psychosocial Committee

13 Psychosocial Guidelines in Pediatric Oncology

- 1. Critical commentary: Med Ped Oncol 21: 627-628 (1993)**
- 2. School/education: Med Ped Oncol 25: 429-430 (1995)**
- 3. Care of long-term survivors: Med Ped Oncol 27: 1-2 (1996)**
- 4. Communication of the diagnosis: Med Ped Oncol 28: 6 (1997)**
- 5. Therapeutic alliance: Med Ped Oncol 30: 183-186 (1998)**
- 6. The terminally ill children: Med Ped Oncol 32: 44-48 (1999)**
- 7. The siblings: Med Ped Oncol 33: 395-398 (1999)**
- 8. The burnout: Med Ped Oncol 35: 122-125 (2000)**
- 9. The refusal: Med Ped Oncol 38: 114-117 (2002)**
- 10. Informed consent: Med Ped Oncol 40: 244-246 (2003)**
- 11. Non-conventional therapies: Pediatr Blood Cancer 42:106-108 (2004)**
- 12. Communicating with the Dying Child: Pediatr Blood Cancer 50:1087-8 (2008)**
- 13. Optimal care for the Child with Cancer: Pediatr Blood Cancer, *Epub* 2009**

Psychological cure and care

Long-term survivors



*Resilience, thriving

Reference:

Marsland AL et al. In: Childhood Cancer and Sickle Cell Disease. A Biopsychosocial Approach. Ronald T. Brown, Oxford Univ. press, 2006, cap. 13: 237-61

Posttraumatic Stress and Psychological Growth in Children With Cancer: Has the Traumatic Impact of Cancer Been Overestimated?

Sean Phipps, James L. Klosky, Alanna Long, Melissa M. Hudson, Qinlei Huang, Hui Zhang, and Robert B. Noll

Conclusion

These findings suggest no evidence of increased PTSD or PTSS in youths with cancer. Although childhood cancer remains a significant and challenging event, these findings highlight the capacity of children to adjust, and even thrive, in the face of such challenge.



noi ragazzi guariti

Giuseppe Masera - Momcilo Jankovic



www.ancora.it

noi ragazzi guariti

Giuseppe Masera e Momcilo Jankovic
foto di Attilio Rossetti
prefazione di Giovanni Verga



ANCORA

15) The narratives

Our experience:

- 100 narratives collected from young adults (age 18-50) former leukemia patients, at least 5 years from diagnosis.

16) 2006



Erice, October 27-28, 2006

International workshop:
Cure and Care after childhood cancer

Organized by the Early and Late Toxicity
Educational Committee (ELTEC) of the I-BFM-SG

2° Congresso Internazionale S.I.P.Ped.

Current Perspective

Long term survivors of childhood cancer: Cure and care The Erice Statement

Riccardo Haupt^a, John J. Spinetta^b, Irina Ban^c, Ronald D. Barr^d, Joern D. Beck^e,
Julianne Byrne^f, Gabriele Calaminus^g, Eva Coenen^c, Mark Chesler^c, Giulio J. D'Angio^h,
Christine Eiserⁱ, Andreas Feldges^j, Faith Gibson^k, Herwig Lackner^l, Giuseppe Masera^m,
Luisa Massimoⁿ, Edina Magyarosy^o, Jacques Otten^p, Gregory Reaman^q,
Maria Grazia Valsecchi^r, Anjo J.P. Veerman^s, Anthony Penn^t, Anne Thorvildsen^u,
Cor van den Bos^v, Momcilo Jankovic^{m,*}, the International Berlin-Frankfurt-Münster Study
Group Early and Late Toxicity Educational Committee (I-BFM-SG ELTEC)

Eur J Cancer, 2007; 43: 1778-1780

Erice (Sicily, Italy)
October 27-29, 2006

Participation of

- 48 experts: Pediatric Oncologists (21)
 Psychologists (6)
 Sociologist (1)
 Nurses (6)
 Epidemiologists (5)
 Parents (5)
 Survivors (4)

from **15 European and North America Countries**

a) The goal

- The long-term goal of the cure and care of the child with cancer is that he/she become a **resilient, fully functioning, autonomous adult** with an optimal health-related quality of life, **accepted in the society at the same level of his/her age peers.**

Long term survivors of childhood cancer: Cure and care
The Erice Statement – *Eur J Cancer* 43 (2007) 1778–1780

b) Cure

- **Refers to the original cancer,** regardless of any potential for, or presence of, remaining disabilities or side effects of treatment.

Long term survivors of childhood cancer: Cure and care
The Erice Statement – *Eur J Cancer* 43 (2007) 1778–1780

- Children who have been treated for cancer can be **considered cured** when they have reached a time point at which the chance they will die is not greater than that of age-peers in the general population.

Long term survivors of childhood cancer: Cure and care
The Erice Statement – *Eur J Cancer* 43 (2007) 1778–1780



Long-term survivors of childhood cancer: cure and care—the Erice Statement (2006) revised after 10 years (2016)

Momcilo Jankovic¹ • Riccardo Haupt² • John J. Spinetta³ • Joern D. Beck^{4,5} • Julianne Byrne⁶ • Gabriele Calaminus⁷ • Herwig Lackner⁸ • Andrea Biondi¹ • Kevin Oeffinger⁹ • Melissa Hudson¹⁰ • Roderick Skinner¹¹ • Gregory Reaman¹² • Helena van der Pal¹³ • Leontien Kremer^{13,14} • Jaap den Hartogh¹⁵ • Gisela Michel¹⁶ • Eva Frey¹⁷ • Edit Bardi^{18,19} • Michael Hawkins²⁰ • Katie Rizvi²¹ • Monica Terenziani²² • Maria Grazia Valsecchi²³ • Gerlind Bode²⁴ • Meriel Jenney²⁵ • Florent de Vathaire²⁶ • Stanislaw Garwicz²⁷ • Gill A. Levitt²⁸ • Desiree Grabow²⁹ • Claudia E. Kuehni³⁰ • Martin Schrappe³¹ • Lars Hjorth²⁷ • participants in PanCare

**HERE IS OUR DEAR
LONG-TERM SURVIVOR!**



**YOU ARE A
LONG-TERM SURVIVOR,
OLD MATHUSALA!
I AM CURED!**



FRATO97

17) 2006

**To climb our Everest also
in Val Camonica**



18) Post-Therapy



Cancerworld

Mind the gap!

Who cares for patients after treatment is over?

Specialists feel responsible for their patients, but lack time to offer long-term care. Patients feel abandoned as their treatment ends, but lack resources to seek the care they need. GPs lack confidence to deal with cancer-related issues, and feel it is not their job. Simon Crompton asks how health systems can overcome these barriers to get cancer patients the long-term care they need to get their lives back.

No. 82, May 2018, pp 34-39

Post-Therapy



19) SOCIAL INTEGRATION

**MANY THANKS
FOR YOUR ATTENTION**