# The Youth Project at the Istituto Nazionale dei Tumori in Milan
# A clinical and organizational model to address the unique needs of AYAs

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24th August 2022

# What makes AYAs different?

ESMO GOOD SCIENCE BETTER MEDICINE BEST PRACTICE
ESMO OPEN CANCER HORIZONS

REVIEW

## Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE)

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It is well recognised that adolescents and young adults (AYA) with cancer have inequitable access to oncology services that provide expert cancer care and consider their unique needs. Subsequently, survival gains in this patient population have improved only modestly compared with older adults and children with cancer. In 2015, the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) established the joint Cancer in AYA Working Group in order to increase awareness among adult and paediatric oncology communities, enhance knowledge on specific issues in AYA and ultimately improve the standard of care for AYA with cancer across Europe. This manuscript reflects the position of this working group regarding current AYA cancer care, the challenges to be addressed and possible solutions. Key challenges include the lack of specific biological understanding of AYA cancers, the lack of access to specialised centres with age-appropriate multidisciplinary care and the lack of available clinical trials with novel therapeutics. Key recommendations include diversifying interprofessional cooperation in AYA care and specific measures to improve trial accrual, including centralising care where that is the best means to achieve trial accrual. This defines a common vision that can lead to improved outcomes for AYA with cancer in Europe.

**Key words:** adolescents and young adults, cancer, clinical trials, education, interdisciplinary

### INTRODUCTION

In recent years, the specific challenges related to the management of adolescents and young adults (AYA) with cancer are increasingly well recognised.[1] These challenges include inequitable access to oncology services which provide expert cancer care and consider their unique needs as AYA. In addition, the complex psychological, social and financial impact of a cancer diagnosis during a period of rapid physiological, personal and psychological growth affects well-being in significant ways.[2] Consequently, survival gains have improved only modestly compared with adult and childhood cancers.[3]

The challenges of appropriate models of care for AYA with cancer have been appreciated by the scientific community[4] and it is now well documented that traditional health care models do not meet the unique needs of AYA.[5,6]

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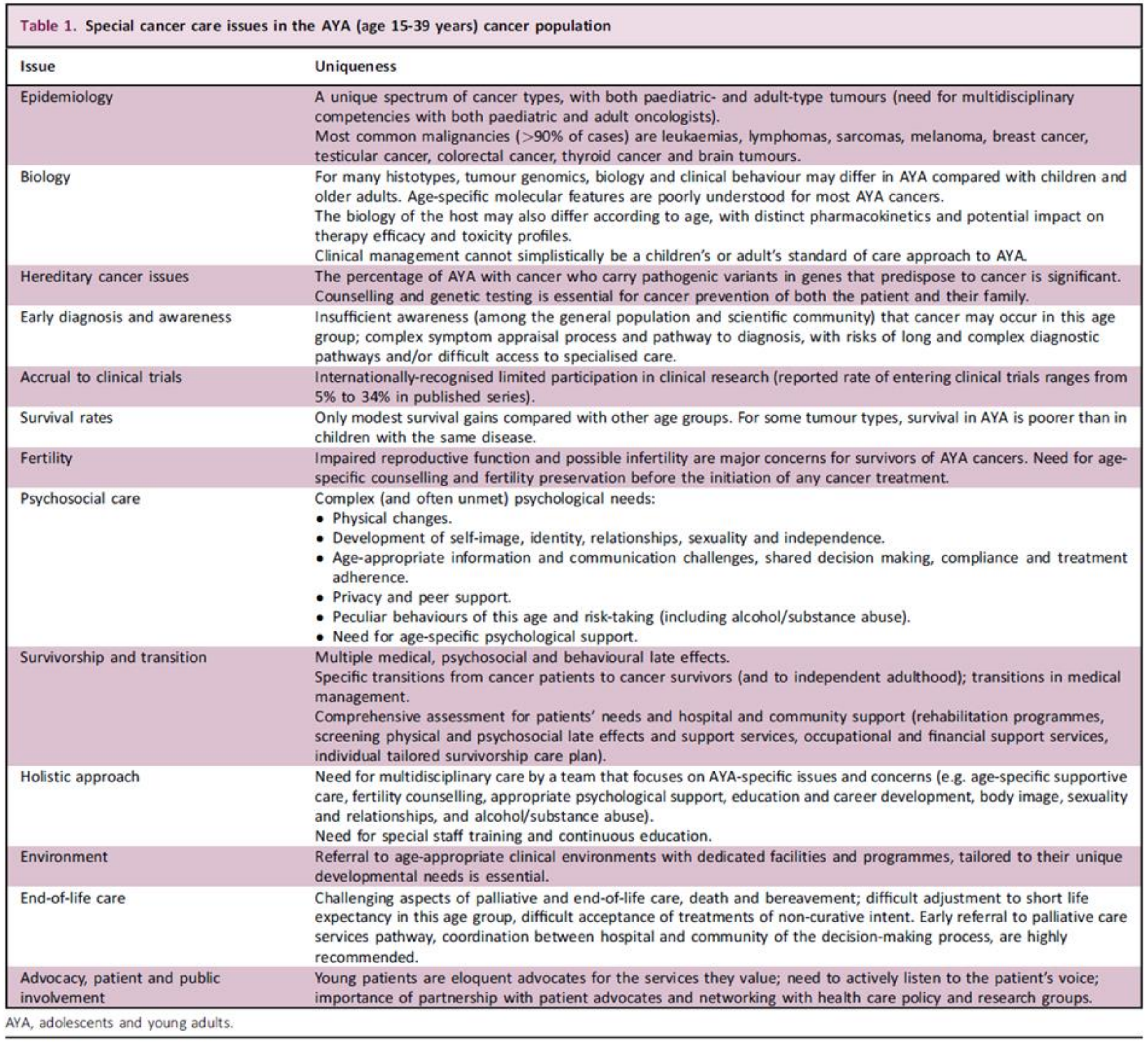
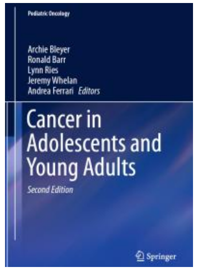


**Table 1.** Special cancer care issues in the AYA (age 15-39 years) cancer population

| Issue | Uniqueness |
|---|---|
| Epidemiology | A unique spectrum of cancer types, with both paediatric- and adult-type tumours (need for multidisciplinary competencies with both paediatric and adult oncologists).<br>Most common malignancies (>90% of cases) are leukaemias, lymphomas, sarcomas, melanoma, breast cancer, testicular cancer, colorectal cancer, thyroid cancer and brain tumours. |
| Biology | For many histotypes, tumour genomics, biology and clinical behaviour may differ in AYA compared with children and older adults. Age-specific molecular features are poorly understood for most AYA cancers.<br>The biology of the host may also differ according to age, with distinct pharmacokinetics and potential impact on therapy efficacy and toxicity profiles.<br>Clinical management cannot simplistically be a children's or adult's standard of care approach to AYA. |
| Hereditary cancer issues | The percentage of AYA with cancer who carry pathogenic variants in genes that predispose to cancer is significant. Counselling and genetic testing is essential for cancer prevention of both the patient and their family. |
| Early diagnosis and awareness | Insufficient awareness (among the general population and scientific community) that cancer may occur in this age group; complex symptom appraisal process and pathway to diagnosis, with risks of long and complex diagnostic pathways and/or difficult access to specialised care. |
| Accrual to clinical trials | Internationally-recognised limited participation in clinical research (reported rate of entering clinical trials ranges from 5% to 34% in published series). |
| Survival rates | Only modest survival gains compared with other age groups. For some tumour types, survival in AYA is poorer than in children with the same disease. |
| Fertility | Impaired reproductive function and possible infertility are major concerns for survivors of AYA cancers. Need for age-specific counselling and fertility preservation before the initiation of any cancer treatment. |
| Psychosocial care | Complex (and often unmet) psychological needs:<br>• Physical changes.<br>• Development of self-image, identity, relationships, sexuality and independence.<br>• Age-appropriate information and communication challenges, shared decision making, compliance and treatment adherence.<br>• Privacy and peer support.<br>• Peculiar behaviours of this age and risk-taking (including alcohol/substance abuse).<br>• Need for age-specific psychological support. |
| Survivorship and transition | Multiple medical, psychosocial and behavioural late effects.<br>Specific transitions from cancer patients to cancer survivors (and to independent adulthood); transitions in medical management.<br>Comprehensive assessment for patients' needs and hospital and community support (rehabilitation programmes, screening physical and psychosocial late effects and support services, occupational and financial support services, individual tailored survivorship care plan). |
| Holistic approach | Need for multidisciplinary care by a team that focuses on AYA-specific issues and concerns (e.g. age-specific supportive care, fertility counselling, appropriate psychological support, education and career development, body image, sexuality and relationships, and alcohol/substance abuse).<br>Need for special staff training and continuous education. |
| Environment | Referral to age-appropriate clinical environments with dedicated facilities and programmes, tailored to their unique developmental needs is essential. |
| End-of-life care | Challenging aspects of palliative and end-of-life care, death and bereavement; difficult adjustment to short life expectancy in this age group, difficult acceptance of treatments of non-curative intent. Early referral to palliative care services pathway, coordination between hospital and community of the decision-making process, are highly recommended. |
| Advocacy, patient and public involvement | Young patients are eloquent advocates for the services they value; need to actively listen to the patient's voice; importance of partnership with patient advocates and networking with health care policy and research groups. |

AYA, adolescents and young adults.



Pediatric Oncology

Archie Bleyer
Ronald Barr
Lynn Ries
Jeremy Whelan
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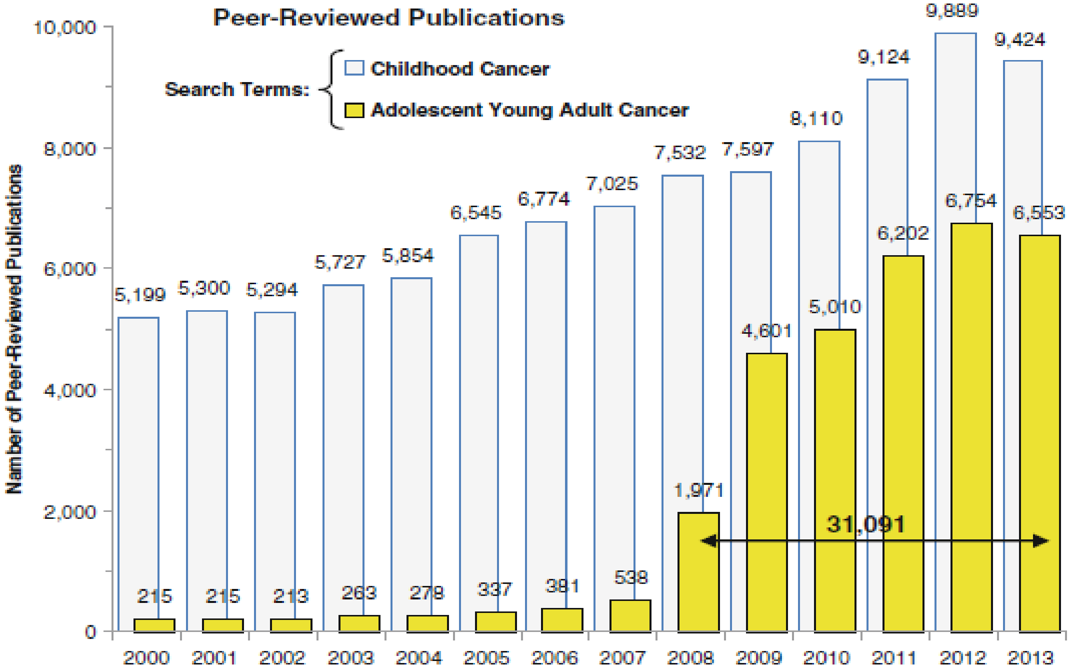

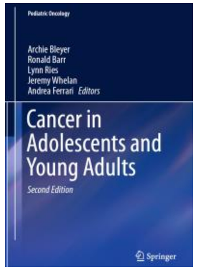

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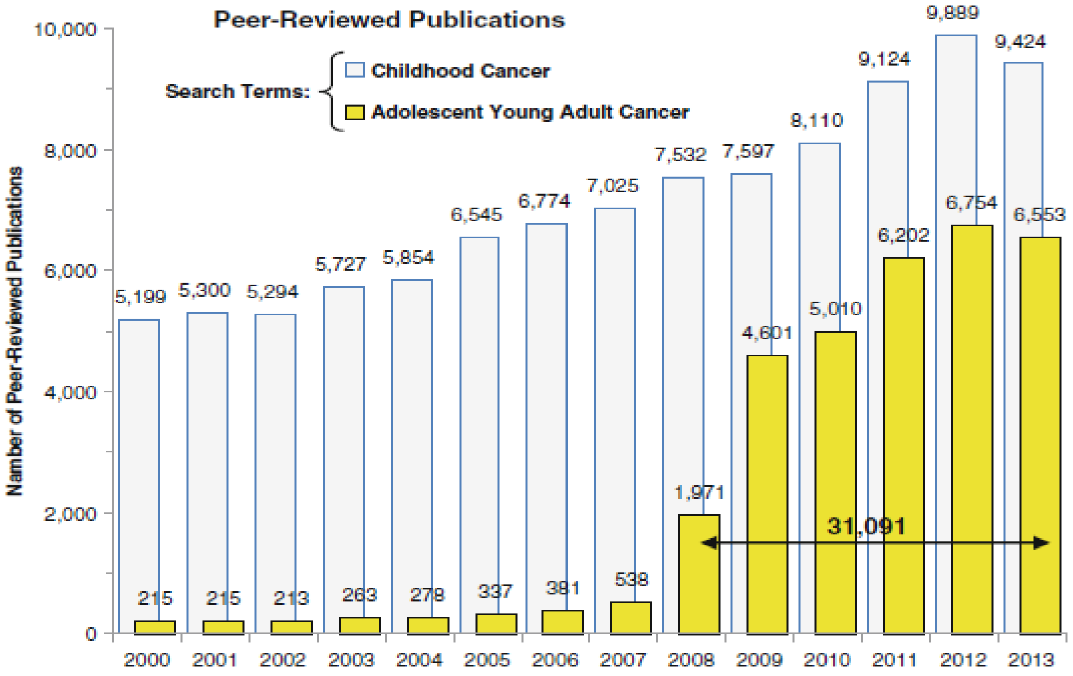

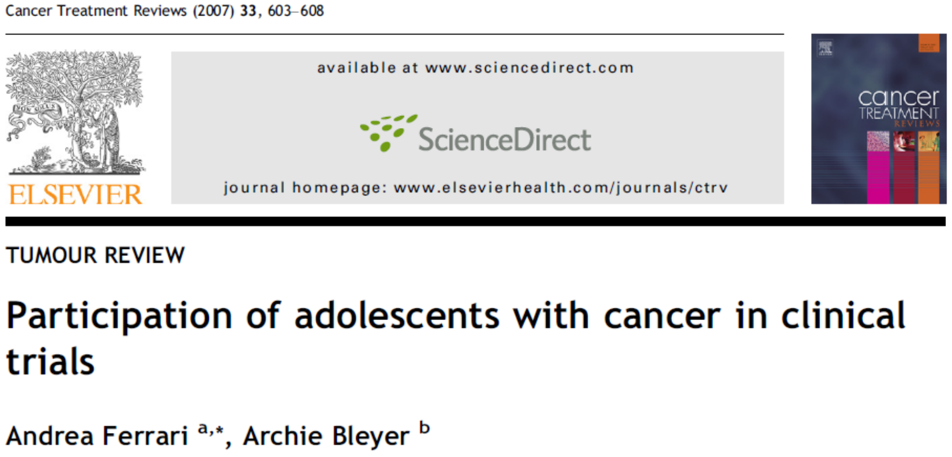

Cancer Treatment Reviews (2007) 33, 603–608

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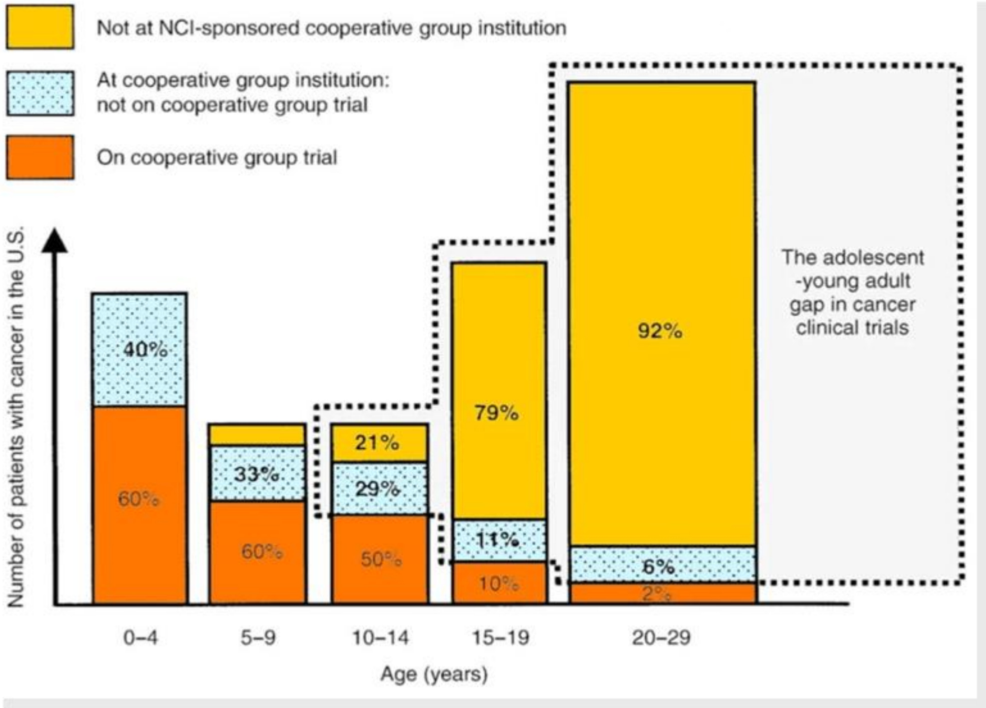
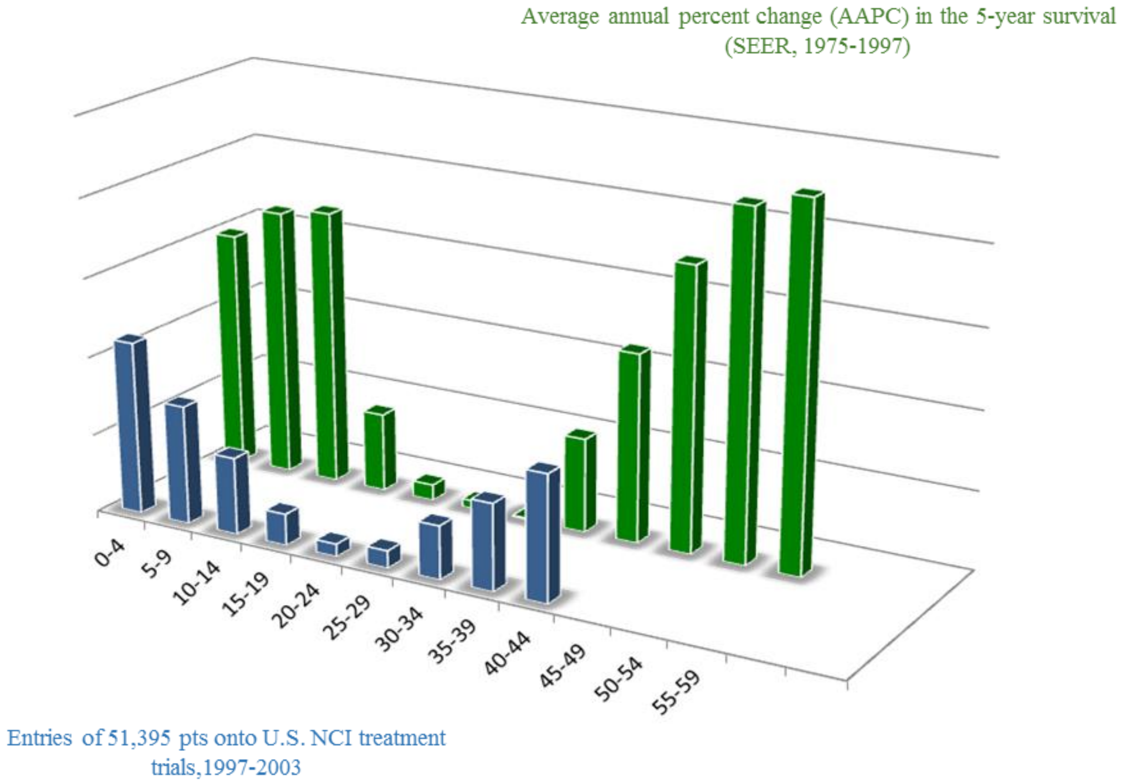
cancer TREATMENT REVIEWS

TUMOUR REVIEW

Participation of adolescents with cancer in clinical trials

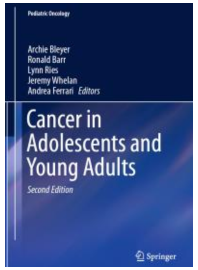
Andrea Ferrari [a,*], Archie Bleyer [b]





## Participation of adolescents with cancer in clinical trials

Andrea Ferrari [a,*], Archie Bleyer [b]



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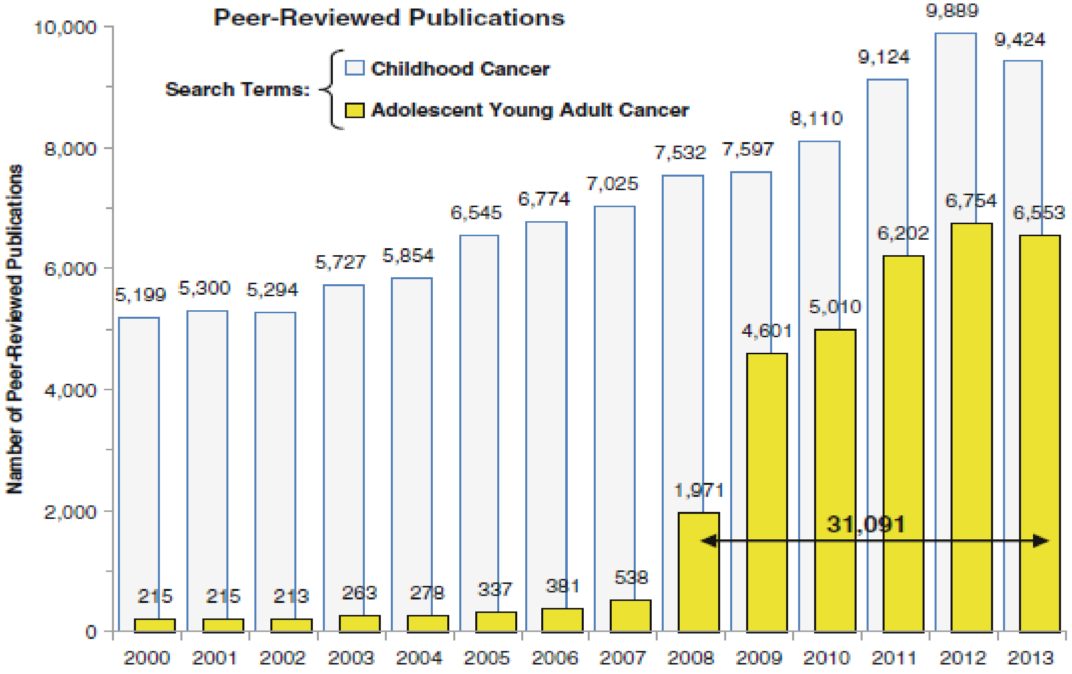


FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

con il patrocinio di

A.I.E.O.P.
Associazione Italiana Ematologia Oncologia Pediatrica

Aiom
Associazione Italiana di Oncologia Medica

## LA GESTIONE MULTIDISCIPLINARE DELL'ADOLESCENTE E DEL GIOVANE ADULTO CON TUMORE PEDIATRICO

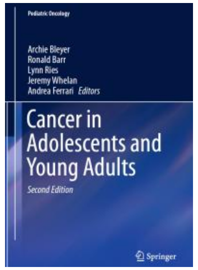
**Milano, lunedì 14 e martedì 15 maggio 2007**
**Aula A**
**Fondazione IRCCS Istituto Nazionale dei Tumori, Milano**

**INTERNATIONAL EXPERIENCES**
***Moderatore A.Ferrari - Milano***

**9.00** **AYA cancers: an overview** ***- A.Bleyer – Huston, United States***

**9.30** **The AYA International Working Group** ***- R.Barr – Hamilton, Canada***

**10.00** **Collaboration between pediatric and adult cooperative groups** ***– K.Albritton – Boston, United States***



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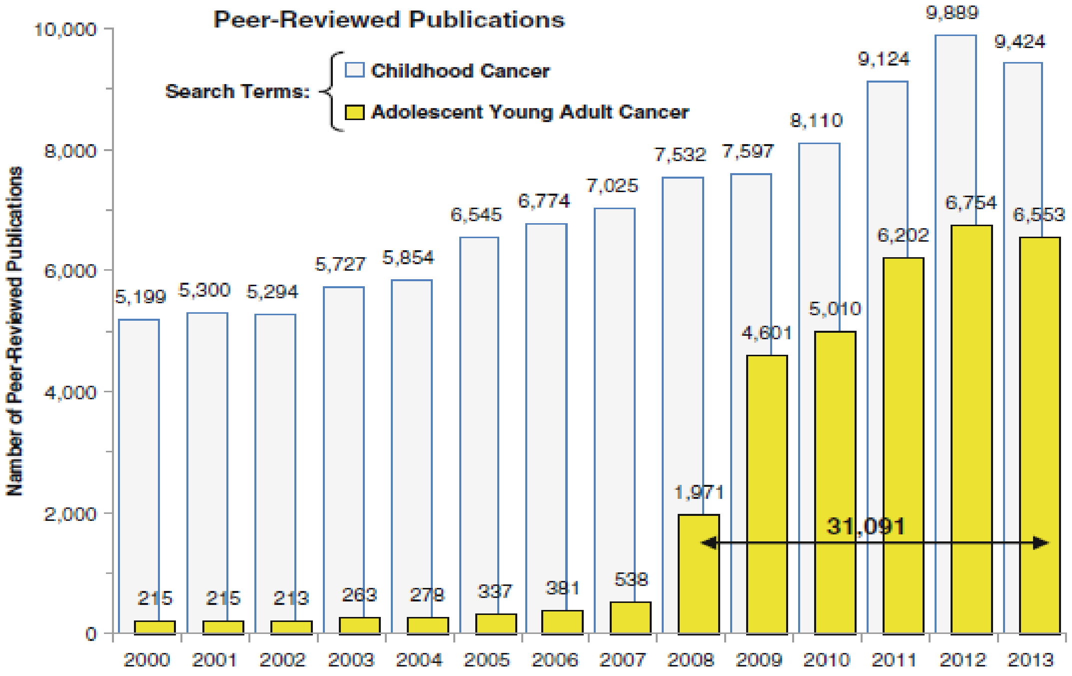


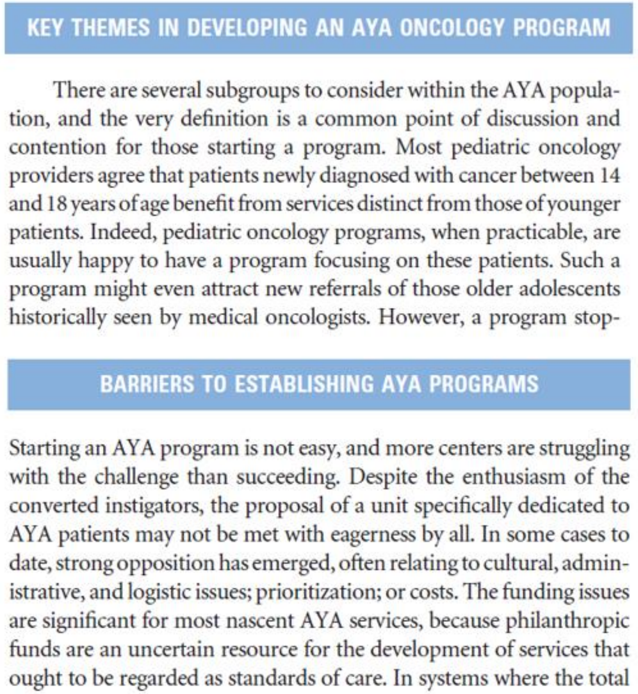
VOLUME 28 · NUMBER 32 · NOVEMBER 10 2010

JOURNAL OF CLINICAL ONCOLOGY

REVIEW ARTICLE

# Starting an Adolescent and Young Adult Program: Some Success Stories and Some Obstacles to Overcome

*Andrea Ferrari, David Thomas, Anna R.K. Franklin, Brandon M. Hayes-Lattin, Maurizio Mascarin, Winette van der Graaf, and Karen H. Albritton*



## KEY THEMES IN DEVELOPING AN AYA ONCOLOGY PROGRAM

There are several subgroups to consider within the AYA population, and the very definition is a common point of discussion and contention for those starting a program. Most pediatric oncology providers agree that patients newly diagnosed with cancer between 14 and 18 years of age benefit from services distinct from those of younger patients. Indeed, pediatric oncology programs, when practicable, are usually happy to have a program focusing on these patients. Such a program might even attract new referrals of those older adolescents historically seen by medical oncologists. However, a program stop-

## BARRIERS TO ESTABLISHING AYA PROGRAMS

Starting an AYA program is not easy, and more centers are struggling with the challenge than succeeding. Despite the enthusiasm of the converted instigators, the proposal of a unit specifically dedicated to AYA patients may not be met with eagerness by all. In some cases to date, strong opposition has emerged, often relating to cultural, administrative, and logistic issues; prioritization; or costs. The funding issues are significant for most nascent AYA services, because philanthropic funds are an uncertain resource for the development of services that ought to be regarded as standards of care. In systems where the total

# Key themes

1. multidisciplinary approach
2. pediatric and adult medical oncologists
3. patient-focused model
4. specific training
5. staffing
6. space
7. the availability of clinical trials
8. research
9. patient and family advocacy
10. definition of “who AYA are”
11. funding and metrics

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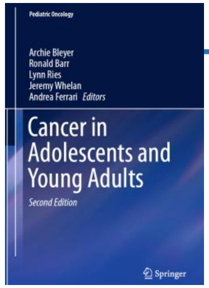

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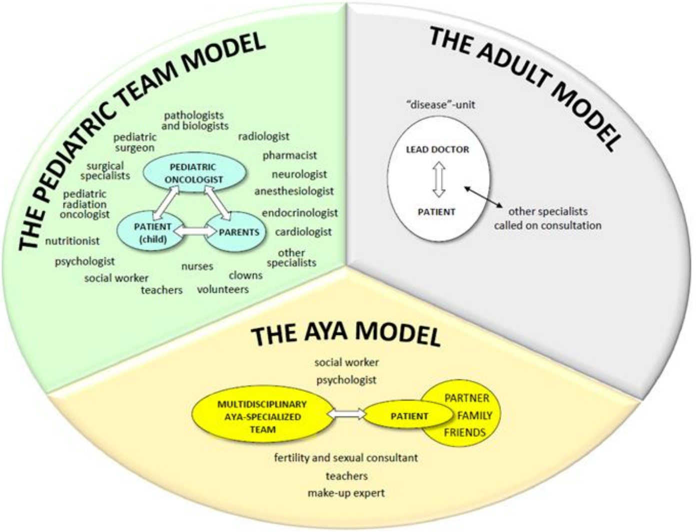
## Access and Models of Care 20

Andrea Ferrari, Karen Albritton, Michael Osborn,
Ronald Barr, Rebecca H. Johnson, Dan Stark,
and Jeremy Whelan

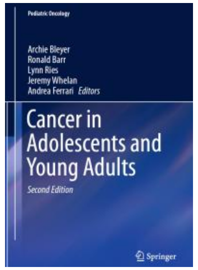


The identification of an ideal model of care is still a challenge.
It remains to be seen whether a single, ideal "new" model of delivery of care should exist, and its feasibility; or alternatively, what adjustments should be made to one or both systems"

Developing a dedicated program should reflect not only an ideal, but also acknowledge local issues, and variations in medical culture and resources

**model of care**: "an overarching design for the provision of a particular type of healthcare that is shaped by a theoretical basis, evidence-based practice and defined standards"

a **model of care** should have defined core elements and principles as well as a framework to provide the structure for implementation and subsequent evaluation



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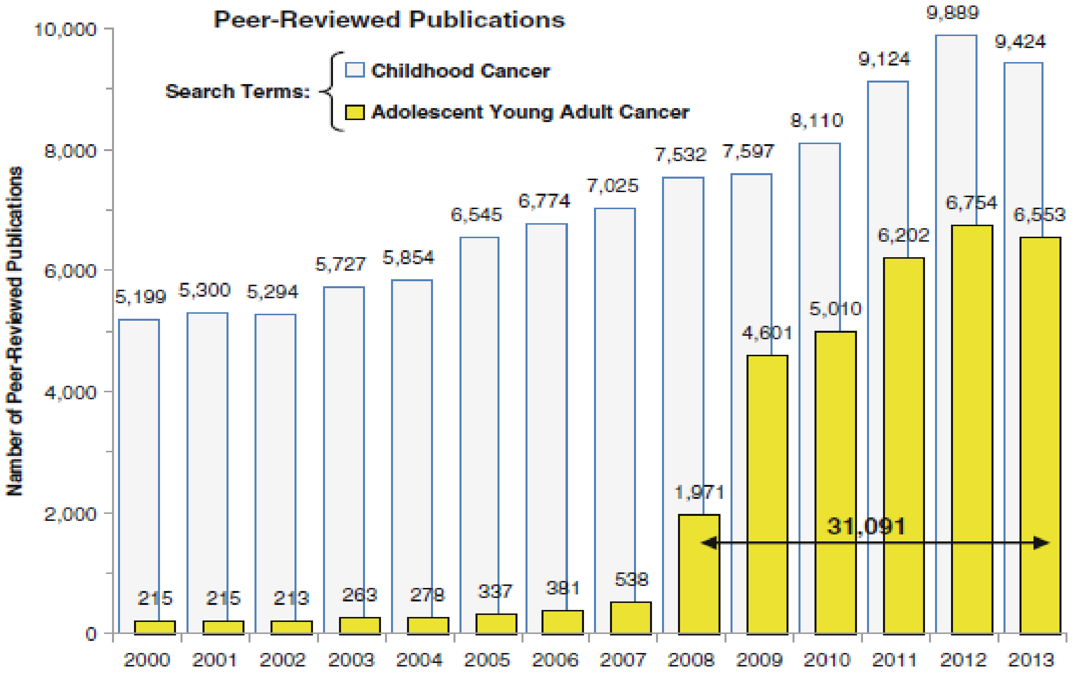

Tumori, 98: 399-407, 2012

# The Youth Project at the Istituto Nazionale Tumori in Milan

Andrea Ferrari[1], Carlo Alfredo Clerici[1,2], Michela Casanova[1], Roberto Luksch[1], Monica Terenziani[1], Filippo Spreafico[1], Daniela Polastri[1], Cristina Meazza[1], Laura Veneroni[1,2], Serena Catania[1], Elisabetta Schiavello[1], Veronica Biassoni[1], Marta Podda[1], and Maura Massimino[1]

frontiers in Pediatrics

August 2016 | Volume 4 | Article 88

# Model of Care for Adolescents and Young Adults with Cancer: The Youth Project in Milan

*Chiara Magni[1], Laura Veneroni[1], Matteo Silva[1], Michela Casanova[1], Stefano Chiaravalli[1], Maura Massimino[1], Carlo Alfredo Clerici[1,2] and Andrea Ferrari[1]**

*[1]Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy, [2]Department of Hemato-Oncology, University of Milan, Milan, Italy*

- launched in 2011 at the pediatric oncology unit of the Istituto Nazionale Tumori in Milan dedicated to adolescents (over 15 years old) and young adults (up to 25 years old) with solid tumors

ASSOCIAZIONE
BIANCA GARAVAGLIA
ONLUS

IL PROGETTO GIOVANI

DELLA PEDIATRIA ONCOLOGICA DELL'ISTITUTO NAZIONALE DEI TUMORI DI MILANO

The Youth Project at the Istituto Nazionale Tumori in Milan

…creare un nuovo modello di **organizzazione medica** e di **cultura specifica**, con la sfida di occuparsi non solo della malattia, ma della vita dei ragazzi, facendo entrare in ospedale la loro normalità, la loro creatività, la loro forza…

**Migliorare la qualità delle cure e la qualità della vita**

1. migliorare e standardizzare particolari aspetti clinici (l'accesso ai protocolli di cura, il supporto psicosociale, le misure di conservazione della fertilità, …)
2. creare spazi e progetti dedicati (attività basate sull'arte che offrono ai ragazzi strumenti nuovi per esprimersi e ai medici una finestra privilegiata sulla vita interiore dei ragazzi, complemento vitale alle forme più convenzionali di supporto psico-sociale)

**Staff dedicato**
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- Psicologo clinico referente (Carlo AClerici)
- Psicologi dedicati (Laura Veneroni, Elena Pagani)
- Educatore (Matteo Silva)
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- Responsabile Aula Musica (Stefano Signoroni)
- Assistente Spirituale (Don Tullio Proserpio)

"Sii entusiasta, sii creativo, sii il meglio che puoi"

Measuring the efficacy of a project for adolescents and young adults with cancer: A study from the Milan Youth Project

Youtube per informare gli adolescenti contro le diagnosi di tumore tardive

frontiers in Pediatrics August 2016 | Volume 4 | Article 88

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- Despite the appeal of an initial proposal to create a new unit specifically for AYA patients, it was soon clear that such a scheme was unfeasible for administrative, logistic and economic reasons. Hence the project was an offshoot of existing activities, making no major changes to the hospital's organization and posing no major demands on the institution's administration and board. Patients are managed by the pediatric oncology staff, but they have access to particular services.

- The Youth Project aims to create a new model of medical organization and specific culture, with **the challenge of dealing not only with the disease, but with the life of these patients**.

ASSOCIAZIONE BIANCA GARAVAGLIA ONLUS

IL PROGETTO GIOVANI

DELLA PEDIATRIA ONCOLOGICA DELL'ISTITUTO NAZIONALE DEI TUMORI DI MILANO

The Youth Project at the Istituto Nazionale Tumori in Milan

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"Sii entusiasta, sii creativo, sii il meglio che puoi"

YOUth PROGETTO GIOVANI

## The best thing you can feel is the awareness of having a future and being its master

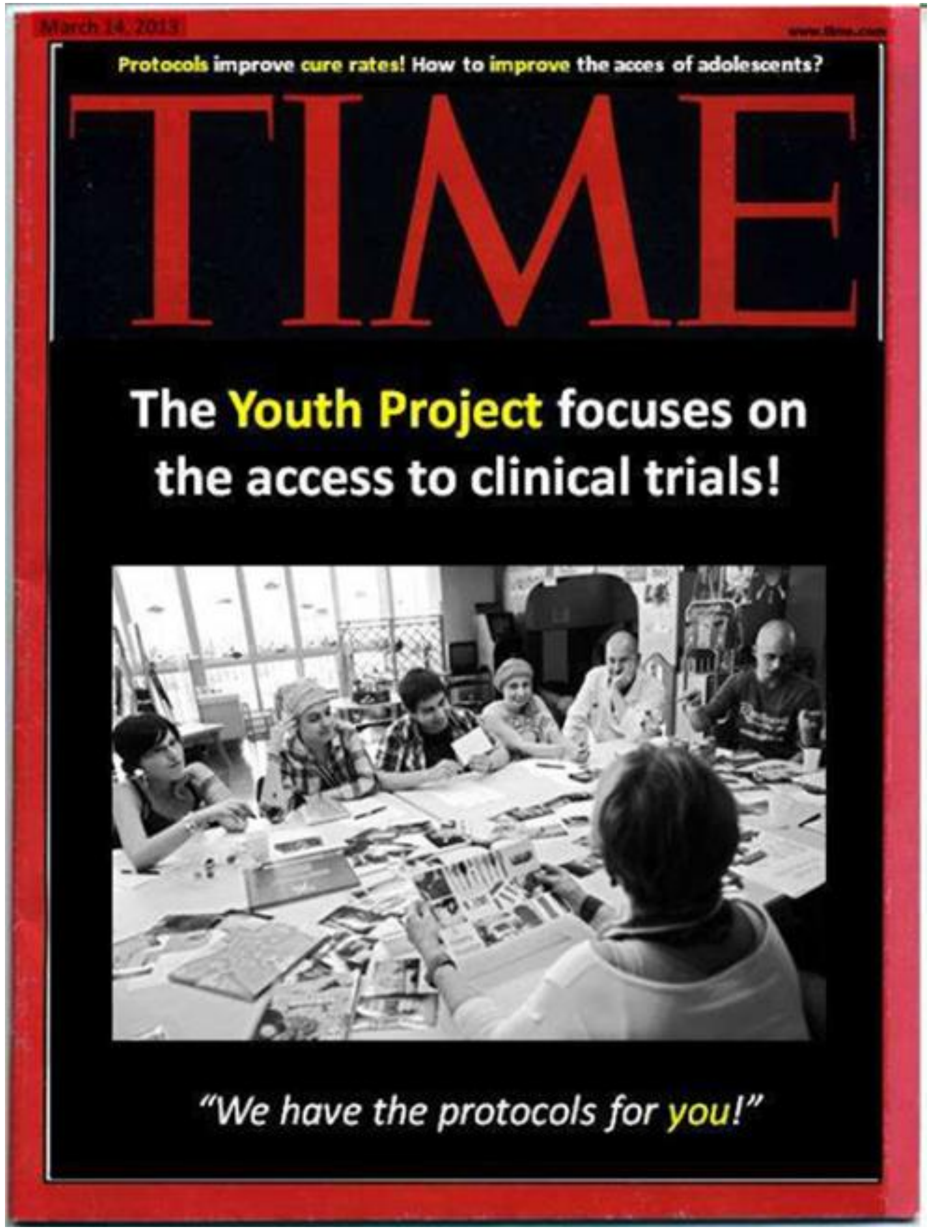
The **Youth Project** of Pediatric Oncology ward of the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan is dedicated to **adolescent patients and young adults with cancer**, with the aim of dealing not only with the disease, but with the lives of children.

The Youth Project has two aspects:

⇨ improve the **quality of care** of AYA patients: improving and standardizing particular clinical aspects, such as access to clinical trials, but also psychosocial support, fertility conservation measures, patient management after the conclusion of the therapy

⇨ to improve the **quality of life** of patients within this particular age group: creating dedicated spaces (a multifunctional room, a study room, a music room, a gym) and dedicated projects, in a department initially created to care for children, so to make the treatment place a little “special” for sick adolescents and young adults.

- **Clinical trials**



Protocols improve cure rates! How to improve the acces of adolescents?

The Youth Project focuses on the access to clinical trials!

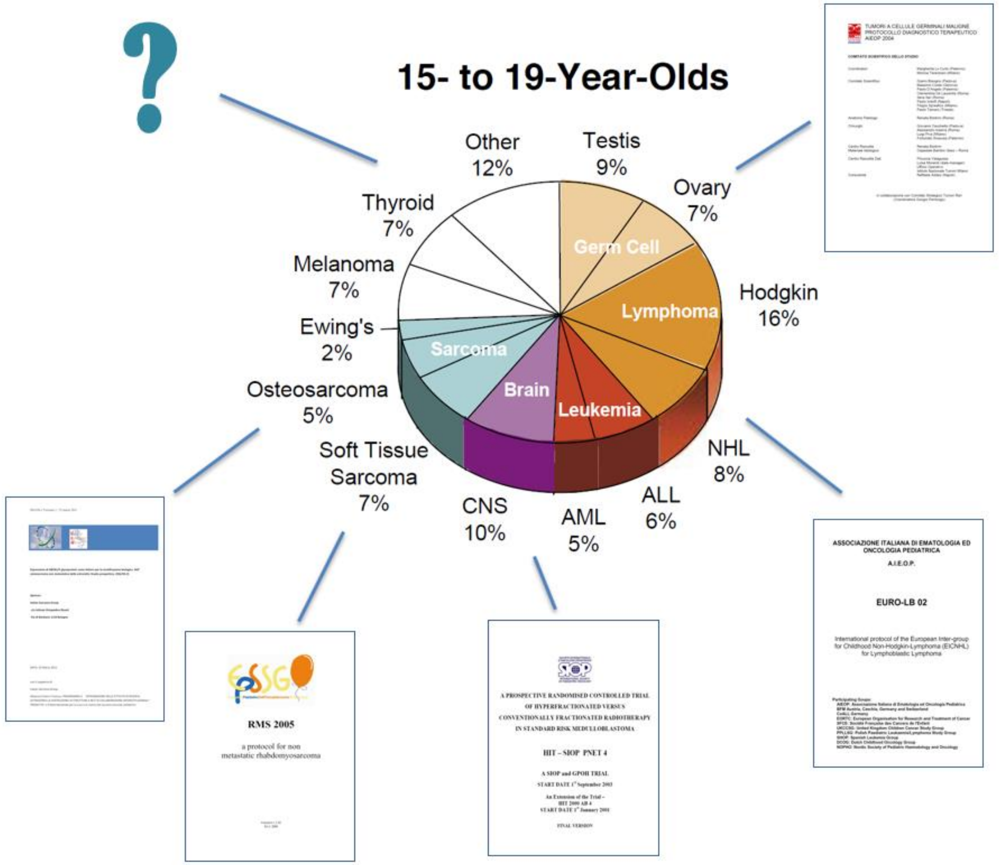
*"We have the protocols for you!"*

## ➢ Clinical trials

- national/international referral pediatric oncology unit
- 23 inpatient and 12 outpatient beds
- 260 newly diagnosed patients each year, with solid tumors

- unlike other Italian pediatric oncology centers at children’s hospitals or being part of pediatric departments in general hospitals, our unit is the only pediatric oncology unit in Italy within a large cancer hospital
- as well as attracting large numbers of patients over the years, this has facilitated close cooperation with the INT divisions dedicated to adult cancers

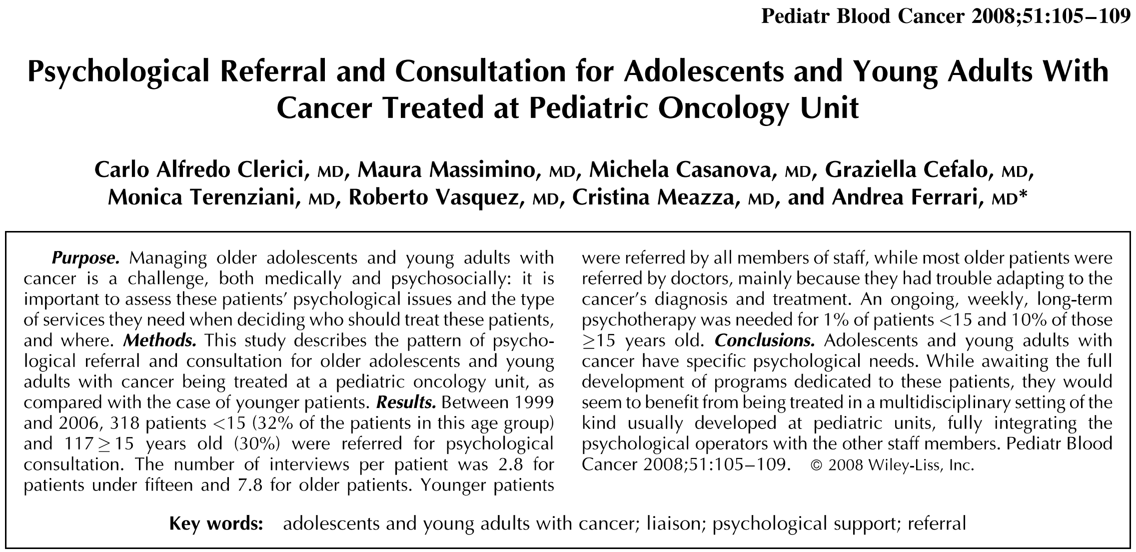
- (for many years now) there has been no upper age limit for admitting patients with pediatric cancers to our pediatric unit (up to 25 or even 30 years old)



- Clinical trials
- **Fertility conservation measures**

- Clinical trials
- Fertility conservation measures
- **Access to care after cancer therapy**

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- **Age-specific psychological, spiritual and social support**



Pediatr Blood Cancer 2008;51:105–109

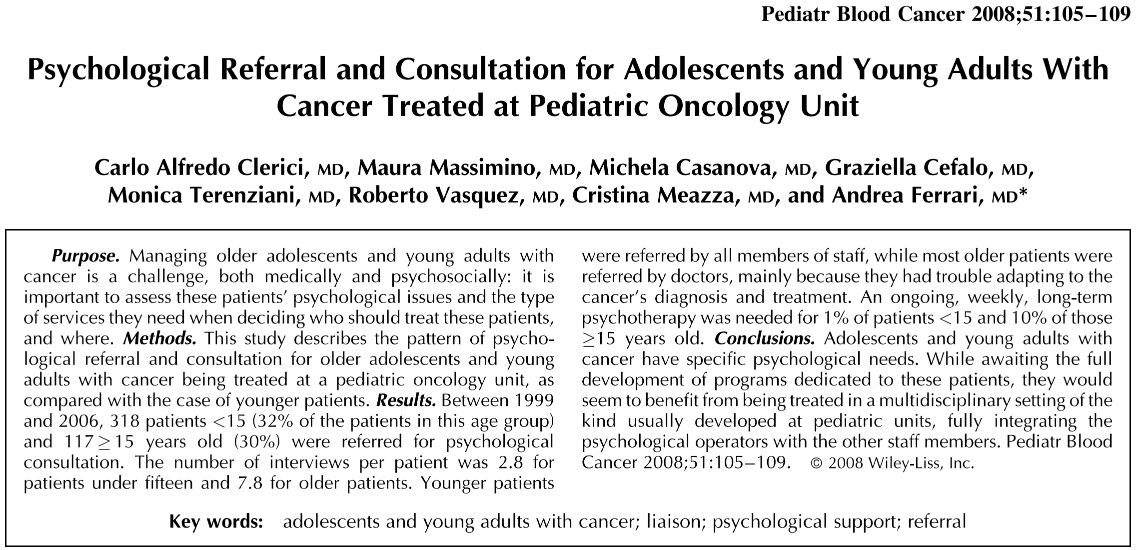
## Psychological Referral and Consultation for Adolescents and Young Adults With Cancer Treated at Pediatric Oncology Unit

Carlo Alfredo Clerici, MD, Maura Massimino, MD, Michela Casanova, MD, Graziella Cefalo, MD, Monica Terenziani, MD, Roberto Vasquez, MD, Cristina Meazza, MD, and Andrea Ferrari, MD*

***Purpose.*** Managing older adolescents and young adults with cancer is a challenge, both medically and psychosocially: it is important to assess these patients' psychological issues and the type of services they need when deciding who should treat these patients, and where. ***Methods.*** This study describes the pattern of psychological referral and consultation for older adolescents and young adults with cancer being treated at a pediatric oncology unit, as compared with the case of younger patients. ***Results.*** Between 1999 and 2006, 318 patients $<15$ (32% of the patients in this age group) and 117 $\geq 15$ years old (30%) were referred for psychological consultation. The number of interviews per patient was 2.8 for patients under fifteen and 7.8 for older patients. Younger patients were referred by all members of staff, while most older patients were referred by doctors, mainly because they had trouble adapting to the cancer's diagnosis and treatment. An ongoing, weekly, long-term psychotherapy was needed for 1% of patients $<15$ and 10% of those $\geq 15$ years old. ***Conclusions.*** Adolescents and young adults with cancer have specific psychological needs. While awaiting the full development of programs dedicated to these patients, they would seem to benefit from being treated in a multidisciplinary setting of the kind usually developed at pediatric units, fully integrating the psychological operators with the other staff members. Pediatr Blood Cancer 2008;51:105–109.

**Key words:** adolescents and young adults with cancer; liaison; psychological support; referral

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- **Age-specific psychological, spiritual and social support**



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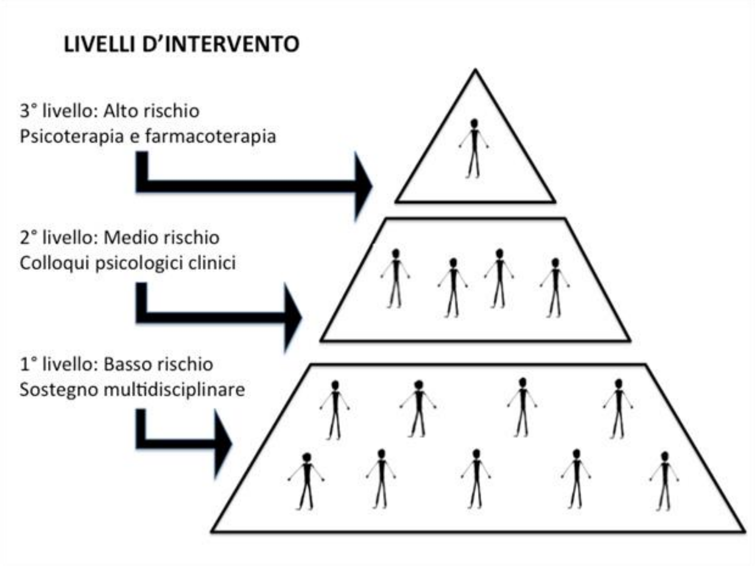


LIVELLI D'INTERVENTO

3° livello: Alto rischio
Psicoterapia e farmacoterapia

2° livello: Medio rischio
Colloqui psicologici clinici

1° livello: Basso rischio
Sostegno multidisciplinare

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- **Age-specific psychological, spiritual and social support**


Tumori, 100: e130-e135, 2014

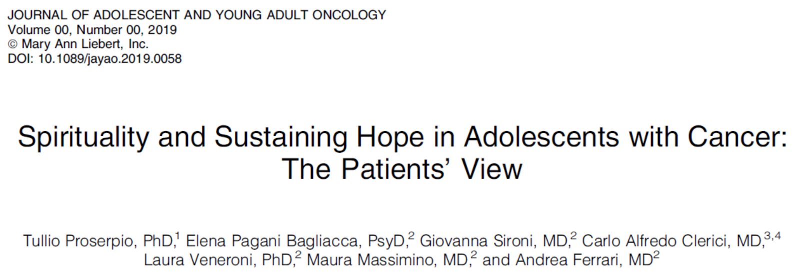
## Spiritual aspects of care for adolescents with cancer

Tullio Proserpio[1], Andrea Ferrari[2], Laura Veneroni[2], Barbara Giacon[2],
Maura Massimino[2], and Carlo Alfredo Clerici[3,4]

[1]*Pastoral Care Unit, Fondazione IRCCS Istituto Nazionale Tumori, Milan;* [2]*Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale Tumori, Milan;* [3]*Department of Pathophysiology and Transplantation, University of Milan, Milan;* [4]*Clinical Psychology, IRCCS Istituto Nazionale Tumori, Milan, Italy*


## Hope in cancer patients: the relational domain as a crucial factor

**Tullio Proserpio[1], Andrea Ferrari[2], Salvatore Lo Vullo[3], Maura Massimino[2], Carlo Alfredo Clerici[4,5], Laura Veneroni[2], Carlo Bresciani[6], Paolo G. Casali[7], Mauro Ferrari[8], Paolo Bossi[9], Gustavo Galmozzi[10], Andrea Pierantozzi[11], Lisa Licitra[9], Sara Marceglia[12], Luigi Mariani[3]**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## Spirituality and Sustaining Hope in Adolescents with Cancer: The Patients' View

Tullio Proserpio, PhD,[1] Elena Pagani Bagliacca, PsyD,[2] Giovanna Sironi, MD,[2] Carlo Alfredo Clerici, MD,[3,4]
Laura Veneroni, PhD,[2] Maura Massimino, MD,[2] and Andrea Ferrari, MD[2]

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- **Age-specific psychological, spiritual and social support**

Tumori, 100: e130-e135, 2014

### Spiritual aspects of care for adolescents with cancer

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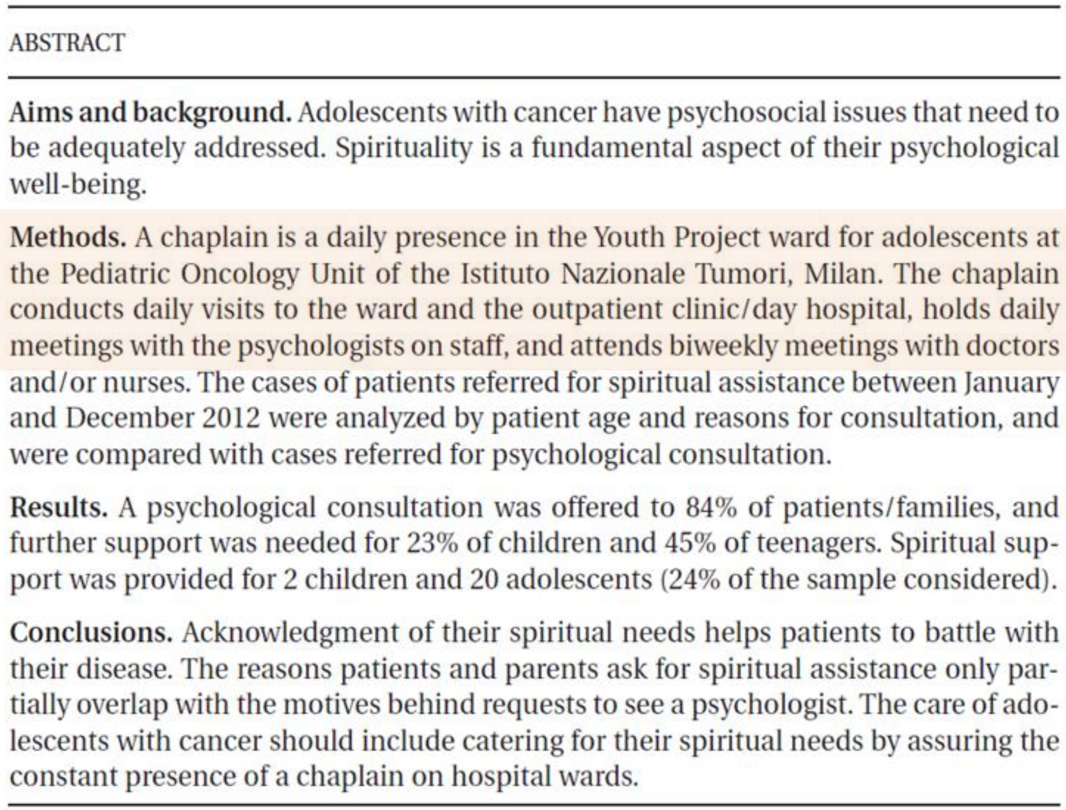
Assistenza spirituale

Video informativo sull'assistenza spirituale in oncologia pediatrica. Don Tullio Proserpio, cappellano presso l'Istituto Nazionale dei Tumori di Milano fornisce informazioni sull'assistenza pastorale ai pazienti e ai familiari.
Realizzazione di Alessandro Trapuzzano. Collaborazione di Carlo Alfredo Clerici e Laura Veneroni.



ABSTRACT

**Aims and background.** Adolescents with cancer have psychosocial issues that need to be adequately addressed. Spirituality is a fundamental aspect of their psychological well-being.

**Methods.** A chaplain is a daily presence in the Youth Project ward for adolescents at the Pediatric Oncology Unit of the Istituto Nazionale Tumori, Milan. The chaplain conducts daily visits to the ward and the outpatient clinic/day hospital, holds daily meetings with the psychologists on staff, and attends biweekly meetings with doctors and/or nurses. The cases of patients referred for spiritual assistance between January and December 2012 were analyzed by patient age and reasons for consultation, and were compared with cases referred for psychological consultation.

**Results.** A psychological consultation was offered to 84% of patients/families, and further support was needed for 23% of children and 45% of teenagers. Spiritual support was provided for 2 children and 20 adolescents (24% of the sample considered).

**Conclusions.** Acknowledgment of their spiritual needs helps patients to battle with their disease. The reasons patients and parents ask for spiritual assistance only partially overlap with the motives behind requests to see a psychologist. The care of adolescents with cancer should include catering for their spiritual needs by assuring the constant presence of a chaplain on hospital wards.

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- Age-specific psychological, spiritual and social support
- **Dedicated staff**

- Need for a specific comprehensive multi-disciplinary team focusing on all the specific aspects of AYA, involving professionals from various disciplines (e.g. psychologists, clinical nurses, social workers, youth workers, palliative care specialists, physiotherapists, occupational therapists, experts in nutrition, experts in fertility and sexuality)
- Involvement of both pediatric and adult medical oncologists/haematologists
- Need for special staff training and continuous professional education

REVIEW

## Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE)

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It is well recognised that adolescents and young adults (AYA) with cancer have inequitable access to oncology services that provide expert cancer care and consider their unique needs. Subsequently, survival gains in this patient population have improved only modestly compared with older adults and children with cancer. In 2015, the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) established the joint Cancer in AYA Working Group in order to increase awareness among adult and paediatric oncology communities, enhance knowledge on specific issues in AYA and ultimately improve the standard of care for AYA with cancer across Europe. This manuscript reflects the position of this working group regarding current AYA cancer care, the challenges to be addressed and possible solutions. Key challenges include the lack of specific biological understanding of AYA cancers, the lack of access to specialised centres with age-appropriate multidisciplinary care and the lack of available clinical trials with novel therapeutics. Key recommendations include diversifying interprofessional cooperation in AYA care and specific measures to improve trial accrual, including centralising care where that is the best means to achieve trial accrual. This defines a common vision that can lead to improved outcomes for AYA with cancer in Europe.

**Key words:** adolescents and young adults, cancer, clinical trials, education, interdisciplinary

### INTRODUCTION

In recent years, the specific challenges related to the management of adolescents and young adults (AYA) with cancer are increasingly well recognised.[1] These challenges include inequitable access to oncology services which provide expert cancer care and consider their unique needs as AYA. In addition, the complex psychological, social and financial impact of a cancer diagnosis during a period of rapid physiological, personal and psychological growth affects well-being in significant ways.[2] Consequently, survival gains have improved only modestly compared with adult and childhood cancers.[3]

The challenges of appropriate models of care for AYA with cancer have been appreciated by the scientific community[4] and it is now well documented that traditional health care models do not meet the unique needs of AYA.[5,6]

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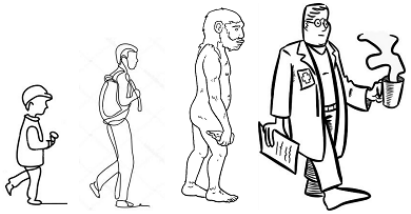
[†] Contributed equally.

[‡] Co-primary authors.

- ➢ Clinical trials
- ➢ Fertility conservation measures
- ➢ Access to care after cancer therapy
- ➢ Age-specific psychological, spiritual and social support
- ➢ **Dedicated staff**

il matteo silva



**l’anello mancante**

We have learned from our patients that there comes a time when clinical trials are not enough: there are other things – hidden smiles and laughs, eyes brimming with tears, eyes that make contact, silences, scribbled notes, a vibrating smartphone, the touch of a hand, little lies and tremendous truths – that we cannot leave to others (psychologists, social workers, youth workers, or nurses).

There comes a time when we doctors have to bring into play, along with our expertise, all our humanity, our strengths and weaknesses, as adults who have the enormous privilege of standing alongside (and being able to help) young people in the most difficult time of their lives.

We can discussed about possible models of care for AYA and possible key themes in developing a dedicated project. However, though rules and recommendations might be defined to improve the chances of success, the human element remains essential: no progress will be made without the fundamental influence of forward-thinking, charismatic heads willing to dedicate their professional lives to AYA patients.

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**Editorial**

## Our young cancer patients talk—we learn

**Andrea Ferrari and Maura Massimino**

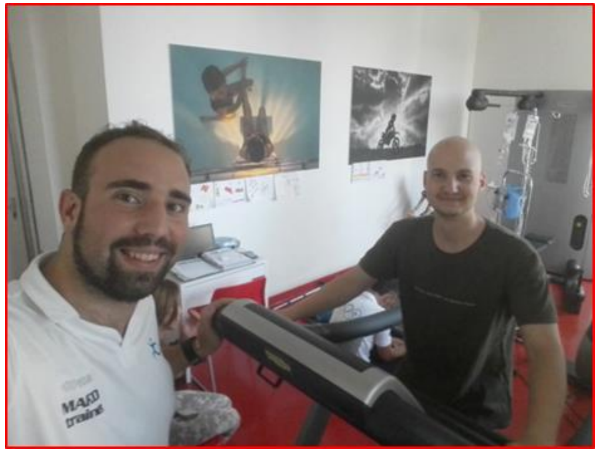
Adolescents and young adults (AYA) with cancer have attracted more attention in recent years, and the international scientific community has realized they are special patients who need dedicated programs [1]. Publications about the Youth Project run by the dell'Istituto Nazionale dei Tumori in Milan [2] describe activities based on the arts. Patients wrote and recorded a song, "Clouds of Oxygen", that voiced their fear of dying, but also of being left alone ("Take me with you, away from here"), but they also sang: "The best feeling of all is knowing you have a future and that it's in your hands" [3]. They expressed their need for beauty in a fashion collection ("We created beauty not just for us, but for others too. We discovered that our creativity can go beyond the limits imposed by our disease") [4]. They produced a carol about Christmas in hospital—Christmas Balls [5]—that unexpectedly went viral on social media [6]: they said: "The only present we want is a normal, even boring Christmas"; and explained that their caregivers could offer a hypothesis of normality, prepare the ground, but it was up to the young patients to make sense of their experience ("The real normal is the shape we give things"). They took photographs to illustrate their personal search for happiness (in their mum's Sunday dinner, or music with friends), or the suffering caused by their bodily changes (see Figure 1, Martina's self-portrait), or reactions like Sefora's defiant self-portrait published on the paper "In search for happiness" ([7]), taken in front of the mirror, without her wig, challenging her disease, regaining control of her appearance. These publications all discuss AYA with cancer from a novel perspective: the patients themselves take center stage, both in their projects and in our scientific publications. They tell their own story.

The aim of these few lines is to emphasize two lessons learned from working with AYA on the Youth Project. One concerns our model of global, multidisciplinary care that genuinely considers not only the clinical issues, but also the meaning of a patient's life. The starting point has to be a "protected" space in hospital. Our AYA with cancer voice their courage and awareness of their condition, but also reveal their fragility. Caregivers dealing with such patients often provide age-specific clinical facilities (clinical trials, fertility-preserving schemes), psychosocial support, dedicated spaces, opportunities for socializing and recreation, or means of expression like those described above. But these young people also need "protection". Adolescents make fragile patients. They need special psychological support because of the impact of their disease and treatment on their still-developing sense of identity and personality. They often remain fragile after completing their treatment too. Projects devised for them must be delicate (making room for lightheartedness, beauty, and hope), but also stable to help them weather the storm of their disease; and they must be professionally organized, and closely connected to the hospital. An example, to better explain: patients embark on such projects as a group; then at some point one of them may suddenly disappear. The others know why; this is their world, a real world where adolescents develop cancer, and may die. Such projects help bring these patients together and make friends (often forming very strong bonds because of the story they share), but they can also provide opportunities for further suffering. For these youngsters, the pain of losing a friend overlaps with the fear of suffering the same fate, or a sense of guilt about being one of the lucky survivors. Their anguish demands a protective network. Physicians and psychologists must be there for them, ready to provide support whenever necessary. There are no rules on how caregivers should handle such situations, but they must put their heart into it, and have the necessary professional expertise.

Another, more personal aspect worth emphasizing is that doctors need to learn how to engage with these patients. The relationship with our young patients should be based on professional trust, but it should make space for understanding, sharing. We have learned from our patients that there comes a time when clinical trials are not enough; there are other things—hidden smiles and laughs, eyes brimming with tears, eyes that make contact,

**Figure 1:** Martina's self-portrait in "Searching for happiness".

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- Age-specific psychological, spiritual and social support
- Dedicated staff
- **Spaces** and projects

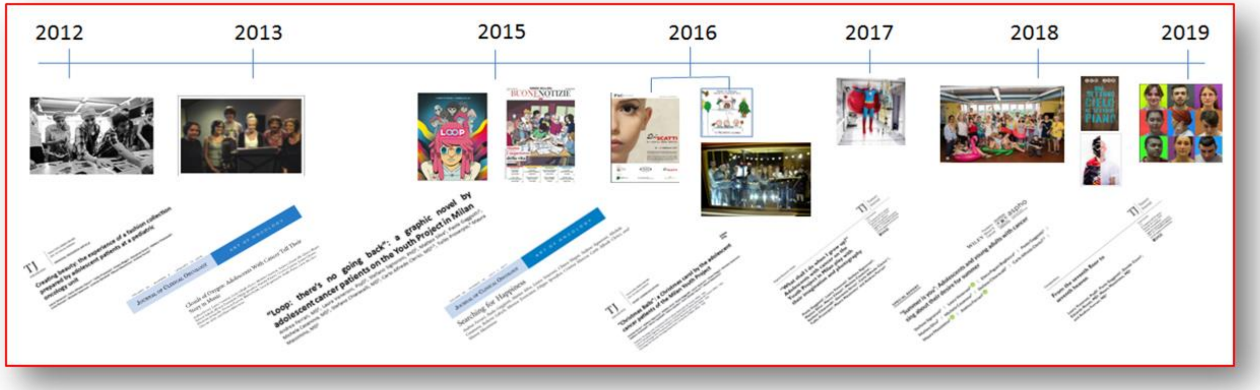


age-appropriate clinical environments with dedicated facilities and programmes, tailored to their unique developmental needs

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- Age-specific psychological, spiritual and social support
- Dedicated staff
- **Spaces** and projects

THE HIDEOUT

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- Age-specific psychological, spiritual and social support
- Dedicated staff
- Spaces and **projects**



- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- Age-specific psychological, spiritual and social support
- Dedicated staff
- Spaces and projects
- **Financial support**

- ✓ rearrangement of current resources
- ✓ new public investment
- ✓ peer-reviewed research grants
- ✓ **philanthropic support**

Philanthropic financial supports have been of great importance in developing many AYA programs, but it is clear that reliance on these may not be considered sufficient since a sustainable model of care needs institutional, community and government support.

Check for updates

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CORRESPONDENCE

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### From a story of pain, a tale of love (for patients and science)

Dear Editor,

With reference to articles published in *Tumori Journal* about the Youth Project at the Istituto Nazionale Tumori in Milan (1) and, in particular, those regarding artistic projects aiming to give adolescent patients with cancer innovative, creative tools to tell their stories (2-5), we would like to underline the role of Associazione Bianca Garavaglia (ABG) Onlus, Busto Arsizio (Varese), Italy (abianca.org), in the creation and development of the Youth Project.

In a global context of limited economical resources, a new initiative such as the Youth Project must be financed without encumbering the national health system (6). The economic support of private donors—charities and benefactors—is essential. Recalling the history of ABG is beneficial to show a model of fruitful collaboration between a public health institution, such as a hospital (and a project born within its context), and a private charity. For the last 30 years, ABG has supported the activities of the Pediatric Oncology Unit at the Istituto Nazionale Tumori in Milan, taking care of research projects and directly supporting care (with staff and assistance tools).

Recalling the history of ABG is significant for another reason: it is a tale of how a story of pain can be transformed into a story of love. Bianca Garavaglia was a 5-year-old girl with Ewing sarcoma. Bianca lost her battle to her disease. Despite the loss, for her mother Franca and her father Carlo, this end became a beginning. Franca and Carlo teach us that "with love you can keep on living"—a new life, a new strength, to fight for other sick children. They decided to create an organization capable of offering immediate and direct support to the facilities currently operating within the world of pediatric oncology: fundraising to promote scientific studies and medical cures, basic research, more effective medicines, equipment, and psychological support for patients and their families.

"We are proud of our Youth Project," says Franca Garavaglia. "Proud to be working with this wonderful group of experts and of young people, proud of being pioneers in creating a new model in which, together, we work to give access to adolescent patients to the most adequate treatments, therefore fighting to offer them greater probabilities of a cure. But we also commit to give them the possibility of studying, of doing sports and having fun together with friends and peers, telling their stories through artistic projects. This is the meaning of the Youth Project" (7).

Exclusively for the Youth Project, ABG has permitted the creation of multifunctional spaces dedicated to adolescent patients (a study room; a multifunctional room to meet, have fun, and engage; and a gym). It economically takes care of the Youth Project by financing the dedicated psychologist, the youth worker, and the trainers for the sport project, and supporting the costs of all music (2, 3), photography (5), and fashion (2) projects.

**Andrea Ferrari, Maura Massimino**

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ASSOCIAZIONE
BIANCA GARAVAGLIA ONLUS

per l'aiuto e il sostegno di iniziative
nel campo dei tumori infantili

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- Age-specific psychological, spiritual and social support
- Dedicated staff
- Spaces and projects
- Financial support
- **Metrics**

- The path to sustainability is a challenge because enthusiastic schemes may sometimes meet with obstacles in the form of ingrained cultures, physical space constraints, administrative and logistic issues, low prioritization, and costs (particularly in these times of shrinking health care resources).

- An important aspect of any AYA-dedicated program should concern the ability to demonstrate its value, and therefore how to define and measure the desired outcome.

- Need to identified a number of potentially reproducible, appropriate parameters for measuring the value of a program dedicated to AYA (difficult to demonstrate to the potential for improving survival rates for the patients involved)

RESEARCH ARTICLE

WILEY Pediatric Blood & Cancer SIOP aspho

**Measuring the efficacy of a project for adolescents and young adults with cancer: A study from the Milan Youth Project**

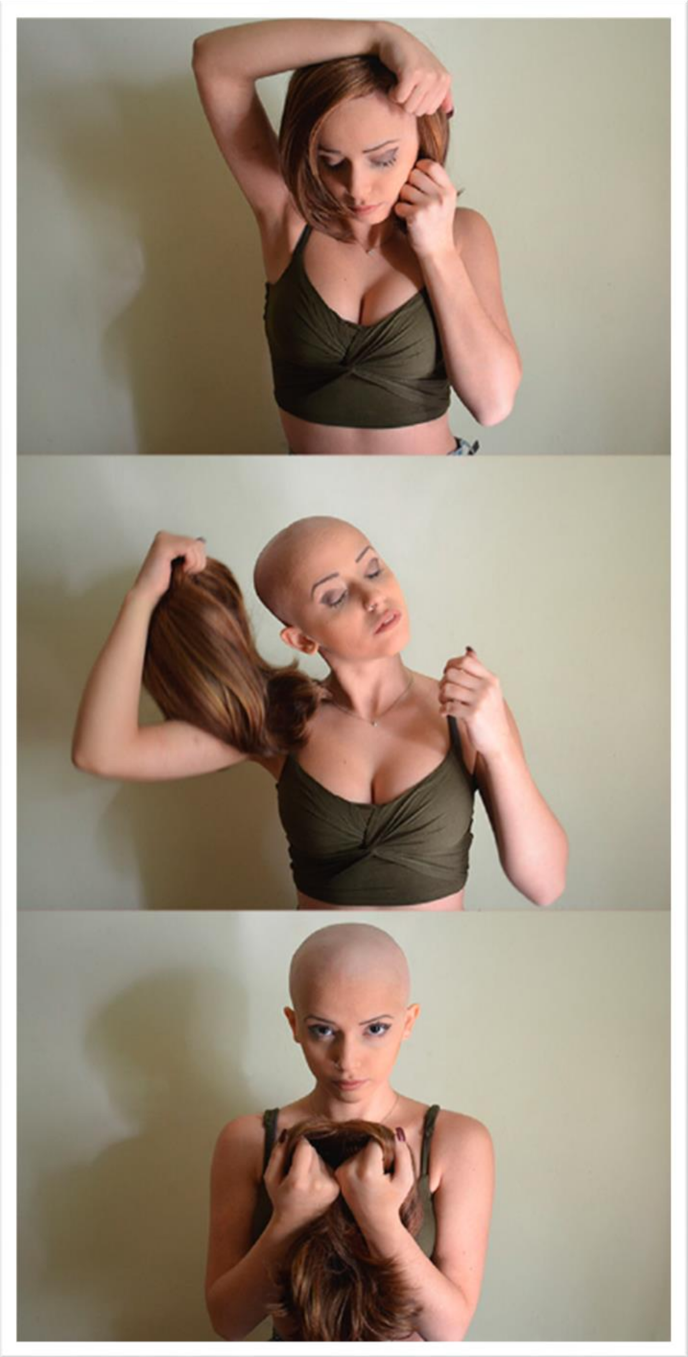
Andrea Ferrari[1] | Matteo Silva[1] | Laura Veneroni[1] | Chiara Magni[1] | Carlo Alfredo Clerici[2] | Cristina Meazza[1] | Monica Terenziani[1] | Filippo Spreafico[1] | Stefano Chiaravalli[1] | Michela Casanova[1] | Roberto Luksch[1] | Serena Catania[1] | Elisabetta Schiavello[1] | Veronica Biassoni[1] | Marta Podda[1] | Luca Bergamaschi[1] | Nadia Puma[1] | Alice Indini[1] | Tullio Proserpio[1] | Maura Massimino[1]

| Metrics utilized to measure the efficacy of the Youth Project |
|---|
| the growth of the number of AYA patients seen at the unit |
| the proportion of AYA patients enrolled in clinical trials |
| the fraction of AYA patients receiving fertility preservation |
| the proportion of patients receiving psychological support |
| the percentage of AYA patients participating in support projects/activities |
| patient satisfaction (specific survey) |
| AYA research and publications |
| community and media recognition |

- Clinical trials
- Fertility conservation measures
- Access to care after cancer therapy
- Age-specific psychological, spiritual and social support
- Dedicated staff
- Spaces and projects
- Financial support
- Metrics
- **Stakeholders**

- The sustainable development of AYA services will require acceptance as a standard of care at the community and government level

- Local programs ought to be complemented by a comprehensive approach, involving a national program

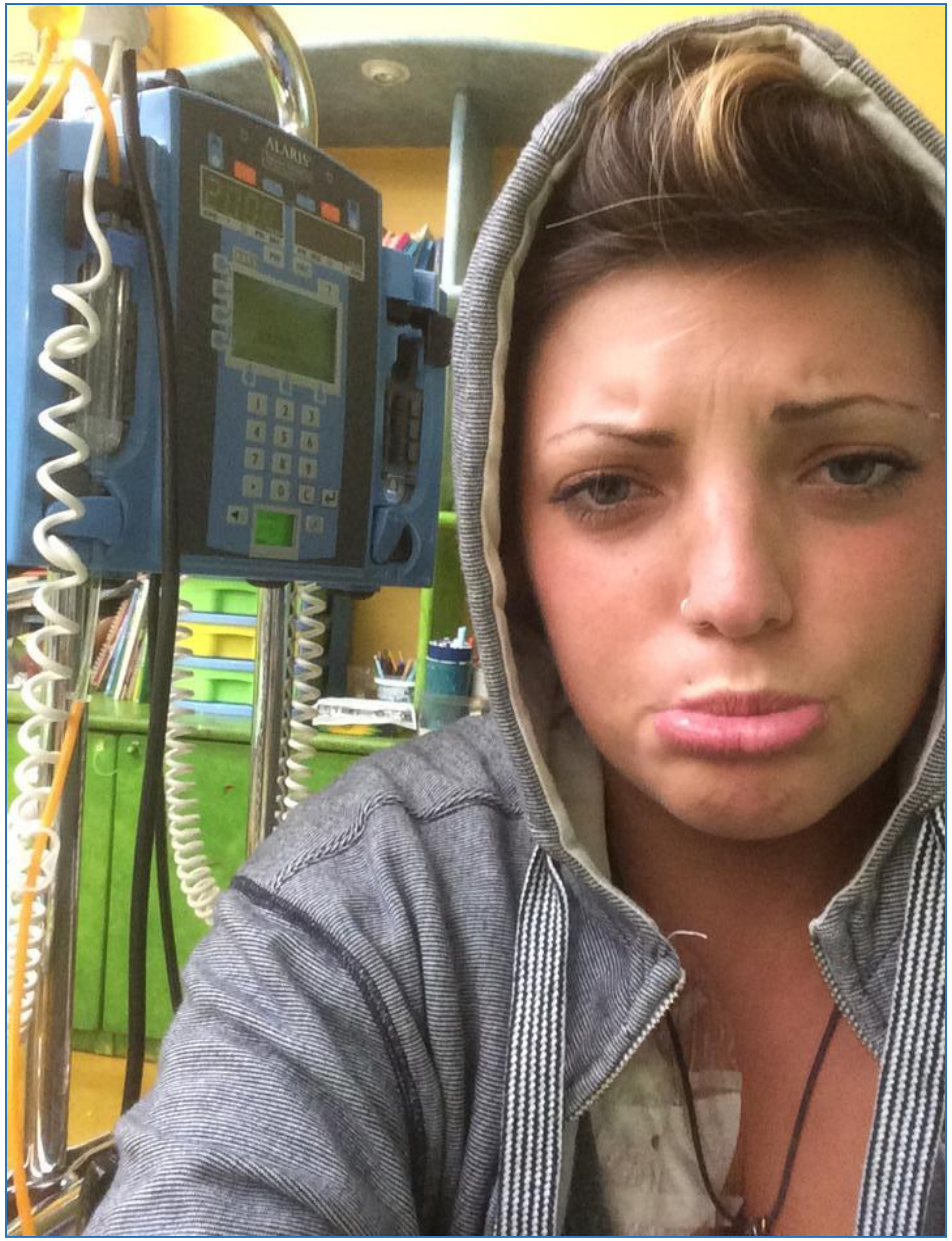


**“responding to the needs**
**of adolescents with cancer”**

do we know their needs?

let our patients be the ones who tell us their needs

let them to tell us their stories

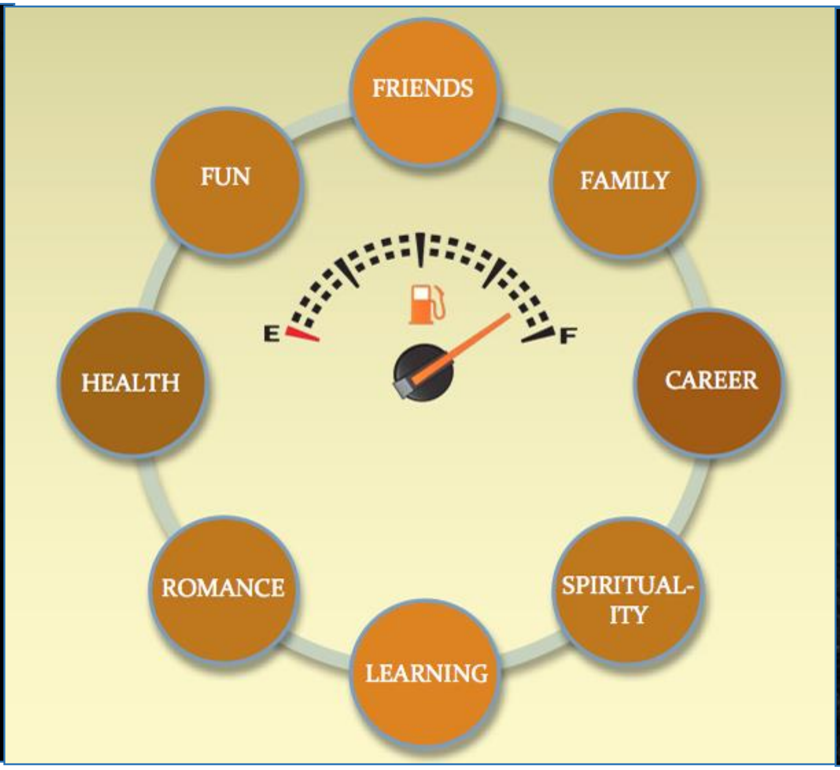


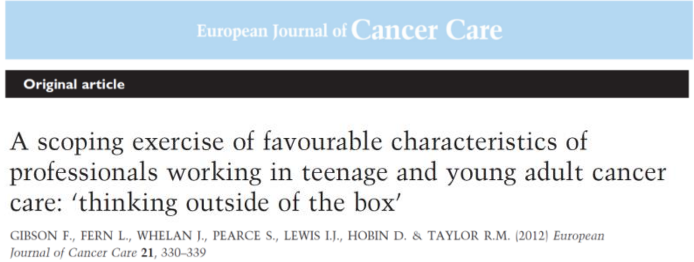
Cancer Treatment Reviews (2007) 33, 603–608

# Participation of adolescents with cancer in clinical trials

Andrea Ferrari [a,*], Archie Bleyer [b]

"treating adolescents with cancer"
is very different from
"treating cancer in adolescents"



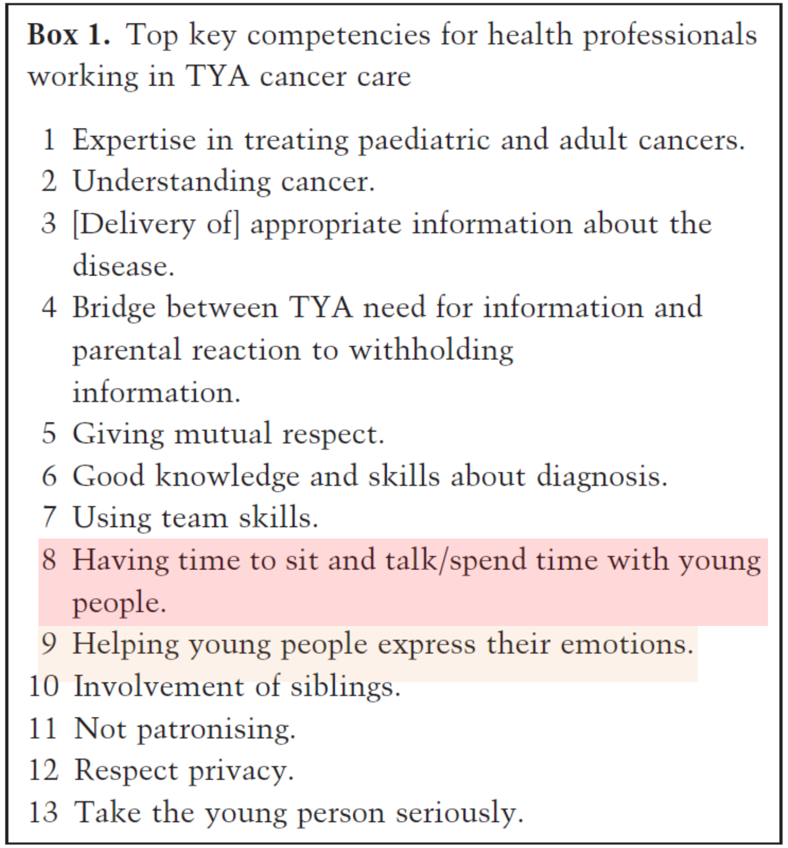


European Journal of Cancer Care

Original article

A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: 'thinking outside of the box'

GIBSON F., FERN L., WHELAN J., PEARCE S., LEWIS I.J., HOBIN D. & TAYLOR R.M. (2012) *European Journal of Cancer Care* **21**, 330–339



**Box 1.** Top key competencies for health professionals working in TYA cancer care

1 Expertise in treating paediatric and adult cancers.
2 Understanding cancer.
3 [Delivery of] appropriate information about the disease.
4 Bridge between TYA need for information and parental reaction to withholding information.
5 Giving mutual respect.
6 Good knowledge and skills about diagnosis.
7 Using team skills.
8 Having time to sit and talk/spend time with young people.
9 Helping young people express their emotions.
10 Involvement of siblings.
11 Not patronising.
12 Respect privacy.
13 Take the young person seriously.

ON CHILDREN, BLOOD, AND CANCER

WILEY Pediatric Blood & Cancer SIOP aspho The American Society of Pediatric Hematology/Oncology

# Shout in fury but smile at life: A portrait of an adolescent with cancer on the Youth Project in Milan

Andrea Ferrari[1] | Sefora Marino[1]* | Paola Gaggiotti[2] | Veronica Garavaglia[2] | Matteo Silva[1] | Laura Veneroni[1] | Maura Massimino[1]

ON CHILDREN, BLOOD, AND CANCER

WILEY Pediatric Blood & Cancer SIOP aspho

# Shout in fury but smile at life: A portrait of an adolescent with cancer on the Youth Project in Milan

Andrea Ferrari[1] | Sefora Marino[1*] | Paola Gaggiotti[2] | Veronica Garavaglia[2] | Matteo Silva[1] | Laura Veneroni[1] | Maura Massimino[1]

Correspondence

# From the seventh floor to seventh heaven

Laura Veneroni, PsyD[1], Paola Gaggiotti[1], Davide Ciceri[1],
Edoardo Rosati, MD[2], Maura Massimino, MD[1]
and Andrea Ferrari, MD[1]

TJ
ISSN 0300-8916

Tumori 2017; 00(00): 000-000
DOI: 10.5301/tj.5000655

SHORT COMMUNICATION

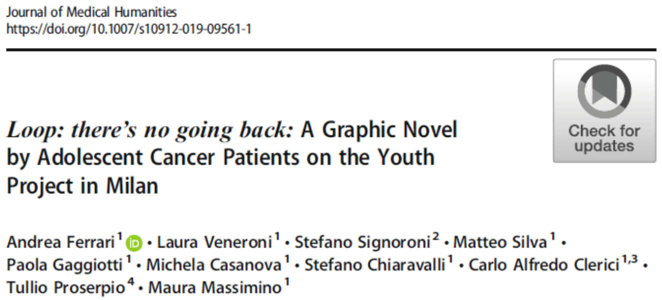
Online Only

# Winners' Cup: a national football tournament brings together adolescent patients with cancer from all over Italy

Matteo Silva[1], Marco Chisari[1], Stefano Signoroni[2], Alberto Bassani[3], Luca Tagliabue[4], Angelo Ricci[5], Mirco Daversa[5], Massimo Achini[4], Filippo Spreafico[1], Michele Murelli[1], Giuseppe Maria Milano[6], Gianni Bisogno[7], Luca Coccoli[8], Massimo Conte[9], Alberto Garaventa[9], Paolo Indolfi[10], Silverio Perrotta[10], Marco Spinelli[11], Federico Mercolini[7], Pietro Soloni[7], Marta Pierobon[7], Andrea Di Cataldo[12], Teresa Perillo[13], Maurizio Mascarin[14], Elisa Coassin[14], Laura Veneroni[1], Michela Casanova[1], Maura Massimino[1], Andrea Ferrari[1]


SLIDE AND ROLL
CERVEZA
ESCORPION


SLIDE AND ROLL
CERVEZA
ESCORPION



Journal of Medical Humanities
https://doi.org/10.1007/s10912-019-09561-1

*Loop: there's no going back:* A Graphic Novel by Adolescent Cancer Patients on the Youth Project in Milan

Andrea Ferrari[1] • Laura Veneroni[1] • Stefano Signoroni[2] • Matteo Silva[1] •
Paola Gaggiotti[1] • Michela Casanova[1] • Stefano Chiaravalli[1] • Carlo Alfredo Clerici[1,3] •
Tullio Proserpio[4] • Maura Massimino[1]

*Original Research Article*

TJ Tumori Journal

# “What shall I do when I grow up?” Adolescents with cancer on the Youth Project in Milan play with their imagination and photography

Tumori Journal
1–6

DOI: 10.1177/0300891618792466
journals.sagepub.com/home/tmj
SAGE

Paola Gaggiotti[1], Laura Veneroni[1], Stefano Signoroni[2],
Matteo Silva[1], Marco Chisari[1], Michela Casanova[1],
Stefano Chiaravalli[1], Giovanna Sironi[1], Carlo Alfredo Clerici[1,3],
Tullio Proserpio[4], Maura Massimino[1] and Andrea Ferrari[1]

TJ
ISSN 0300-8916
Tumori 2016; 00(00): 000-000
DOI: 10.5301/tj.5000597
SHORT COMMUNICATION

Online Only

## “Christmas Balls”: a Christmas carol by the adolescent cancer patients of the Milan Youth Project

Andrea Ferrari[1], Stefano Signoroni[2], Matteo Silva[1], Paola Gaggiotti[1], Laura Veneroni[1], Chiara Magni[1], Michela Casanova[1], Stefano Chiaravalli[1], Mirko Capelletti[1], Pietro Lapidari[1], Carlo Alfredo Clerici[3,4], Maura Massimino[1]

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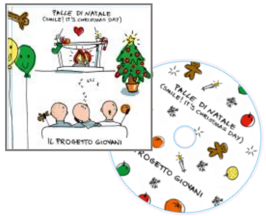

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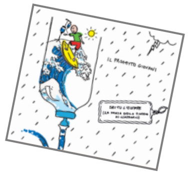


SPECIAL REPORT

WILEY Pediatric Blood & Cancer SIOP aspho The American Society of Pediatric Hematology/Oncology

## “Summer is you”: Adolescents and young adults with cancer sing about their desire for summer

Stefano Signoroni[1] | Laura Veneroni[2] | Elena Pagani Bagliacca[2] | Paola Gaggiotti[1] | Matteo Silva[2] | Michela Casanova[2] | Stefano Chiaravalli[2] | Carlo Alfredo Clerici[2,3] | Maura Massimino[2] | Andrea Ferrari[2]

“*Christmas together with those who’re left,*
*here at my side, in spirit,*
*our star lighting our way.*
*You’ll be my answer,*
*I’ll start again, become stronger*”

*Original Research Article*

TJ Tumori Journal

Tumori Journal
1–6

DOI: 10.1177/030089162098
journals.sagepub.com/home/tn
SAGE

# Adolescents with cancer on privacy: Fact-finding survey on the need for confidentiality and space

**Matteo Silva[1], Francesco Barretta[2], Roberto Luksch[1], Monica Terenziani[1], Michela Casanova[1], Filippo Spreafico[1], Cristina Meazza[1], Marta Podda[1], Veronica Biassoni[1], Elisabetta Schiavello[1], Stefano Chiaravalli[1], Nadia Puma[1], Luca Bergamaschi[1], Giovanna Gattuso[1], Giovanna Sironi[1], Annarita Adduci[1], Paolo Grampa[1], Maura Massimino[1] and Andrea Ferrari[1]**

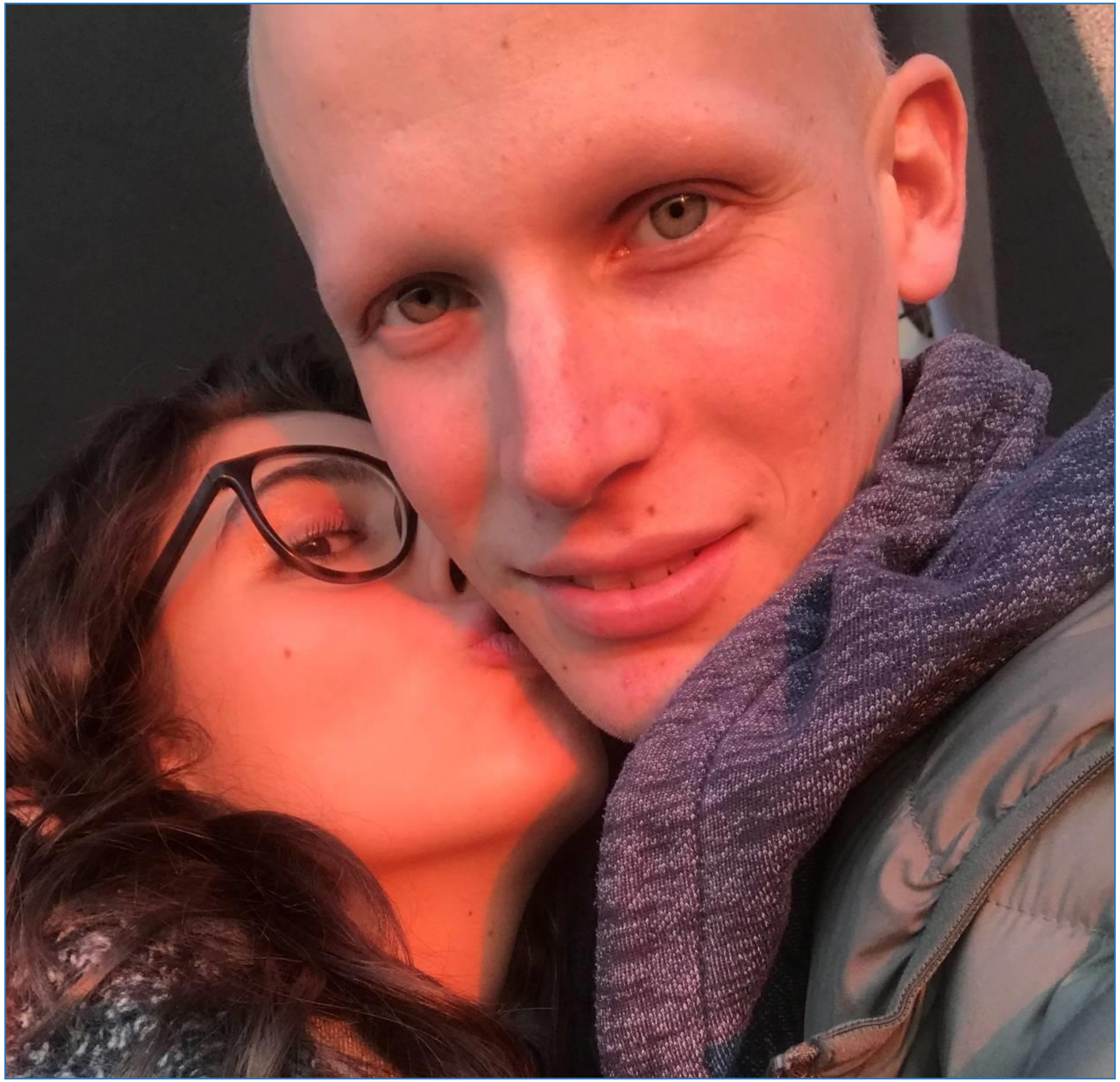
VOLUME 35 · NUMBER 19 · JULY 1, 2017

JOURNAL OF CLINICAL ONCOLOGY

ART OF ONCOLOGY

# Searching for Happiness

*Andrea Ferrari, Paola Gaggiotti, Matteo Silva, Laura Veneroni, Chiara Magni, Stefano Signoroni, Michela Casanova, Roberto Luksch, Monica Terenziani, Filippo Spreafico, Cristina Meazza, Carlo Alfredo Clerici, and Maura Massimino*

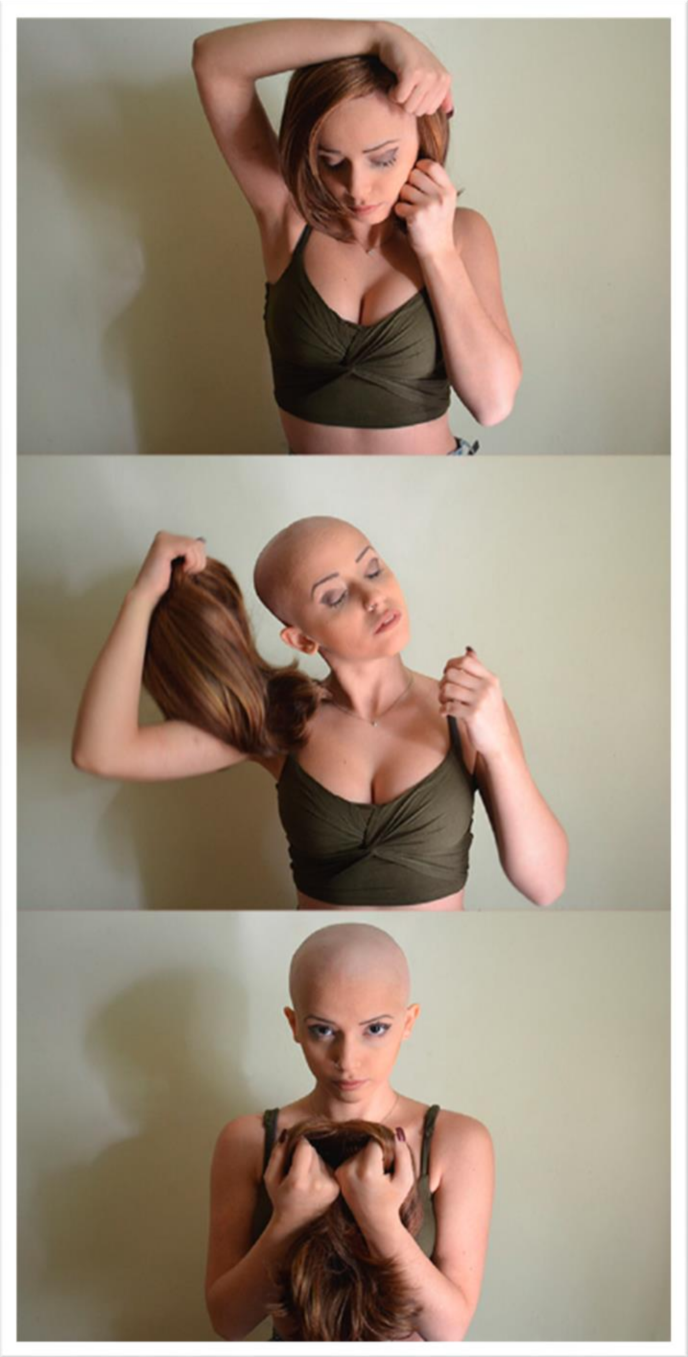


PEDIATRIC HEMATOLOGY AND ONCOLOGY
https://doi.org/10.1080/08880018.2020.1712502

Taylor & Francis
Taylor & Francis Group

# Investigating sexuality in adolescents with cancer: patients talk of their experiences

Laura Veneroni[a], Elena Pagani Bagliacca[a], Giovanna Sironi[a], Matteo Silva[a], Michela Casanova[a], Luca Bergamaschi[a], Monica Terenziani[a], Jessica Trombatore[a], Carlo Alfredo Clerici[b,c], Antonio Prunas[d], Marco Silvaggi[e], Maura Massimino[a], and Andrea Ferrari[a]



let our patients to tell us their stories, to tell us their needs

- a distinctive feature of the Youth Project is that it proposes **creative and artistic activities** (involving music, photography, fashion, novel writing, video productions), offering patients novel means of expression, and giving the medical staff easier access to their AYA patients' world.

## 1. get together

These projects gave our AYA patients an opportunity to **get together** and share the difficult time of their treatment with other young people going through the same experience.

An important feature of such projects is that patients can take part in the activities organised by the Youth Project regardless of whether they are receiving treatment at the time or have completed their course of therapy.

- valuable both for those receiving treatment, who see those who have finished their treatment as a positive example;
- and for those who have finished treatment and return to the hospital just to work on such projects: this helps them to carry on seeing the hospital as a reference, giving them a chance to experience the passage between their life during their treatment and their normal life elsewhere (a passage that may be delicate and difficult).

THE HIDEOUT

These projects gave our AYA patients an opportunity to live moments of **normality**, reminding them that before being a patient with cancer, they are teenagers, and finding a sense of **light-heartedness** even in the middle of their hospital stays and cures

VOLUME 28 · NUMBER 32 · NOVEMBER 10 2010

JOURNAL OF CLINICAL ONCOLOGY REVIEW ARTICLE

Sex, Drugs, and Rock 'n' Roll: Caring for Adolescents and Young Adults With Cancer

*Sue Morgan, Simon Davies, Susan Palmer, and Meg Plaster*

**Promoting normalcy**

One of the main challenges for young people with cancer is the possibility to continue to live as normal a life as possible, i.e. achieve developmental tasks, live their experiences and rites of passage, that cannot be postponed due to the event of a cancer diagnosis.

1. **get together**
2. **live moments of normality and light heartedness**

These projects gave our AYA patients an opportunity to **feel important**, working with professionals; this is not an easy achievement, given that it is a critical time of their lives, when their self-esteem might be deeply damaged.

1. **get together**
2. **live moments of normality and light heartedness**
3. **to feel important**

*The project involved 45 patients 15-26 years old (25 receiving treatment, and 20 being followed up). It was the patients who chose a music project and the topic of the song: they wanted to focus on their longing for summer, travelling, dreaming, dancing, and to bring that energy into the hospital.*
*The project was scheduled to take six months. For the first three, the group of patients worked with the Youth Project's multidisciplinary team (a dedicated physician, a youth worker, an artistic coordinator, and two dedicated psychologists) to pool their ideas, and write some lyrics about summer and travelling.*
*They worked partly in the multipurpose room reserved for AYA patients alongside the ward (every Wednesday afternoon), and partly from home, using the virtual room of a closed Facebook group.*
*Another two months were spent on preparing the final text and putting it to music with the help of three professional musicians, working in the 'music room' at the hospital.*
*During the final month, the song was recorded at a professional studio, where the patients sang and some also played their musical instruments. A video clip was recorded too, partly in hospital and partly in the recording studio.*
*The song was finally launched at a press conference held at the National Tumor Institute in June 2018, and attended by the patients too.*

These projects gave our AYA patients an opportunity to regain a **sense of future** and longer-term planning, working on a project expected to take several months

Their cancer obliges adolescent patients to abandon any plans and drastically change the way they think about the future. Their time horizon can shrink to the day they will be discharged from hospital, or the start of their next cycle of therapy.

1. **to get together**
2. **to live moments of normality and light heartedness**
3. **to feel important**
4. **to regain a sense of future**

These projects gave our AYA patients an opportunity to **express themselves** more freely .

They need to tell their story, to themselves and others.
Talking about their disease and how they feel is of great importance in the process of elaboration of the trauma of the cancer diagnosis, in order to find the inner resources to answer to the question “Why me?”.

Arts projects open a precious window on the inner world of adolescent cancer patients, enabling us to gain a better understanding of what they are really thinking and feeling, directly from their own words, as a complement of conventional methods for providing psychosocial support

1. **to get together**
2. **to live moments of normality and light heartedness**
3. **to feel important**
4. **to regain a sense of future**
5. **to express themselves**

These projects gave our AYA patients an opportunity to **talk about themselves to the community** and to mass-media, to improve the general population's awareness that even AYA can develop cancer, and that dedicated projects are needed.

With a sense of responsibility, young patients act as **testimonials** - working side-by-side with their physicians - in schemes designed to draw the attention to the clinical problems of AYA with cancer

1. to get together
2. to live moments of normality and light heartedness
3. to feel important
4. to regain a sense of future
5. to express themselves
6. to talk to the communty and act as testimonials

Visto alla riscossa Un gruppo di giovani malati oncologici lancia una canzone di speranza

Sfidare il cancro è musica per le nostre orecchie...

DREAM TEAM

UNITI DALLA SOFFERENZA

«ABBIAMO IMPARATO A NON DARCI PER VINTI»

EVENTI

I ragazzi del settimo piano

Gli adolescenti, la malattia, la musica, Faso e tante storie. Questa sera ai Frigoriferi Milanesi si festeggia il progetto con una anteprima live. Il backstage del brano "Nuvole di Ossigeno"

di Marina Malavasi - 10 dicembre 2013

Io Ascolto

Foto Matteo Volta

EVENTI

I ragazzi del settimo piano

Gli adolescenti, la malattia, la musica, Faso e tante storie. Questa sera ai Frigoriferi Milanesi si festeggia il progetto con una anteprima live. Il backstage del brano "Nuvole di Ossigeno"

di Marina Malavasi - 10 dicembre 2013

Io Ascolto

LA BUONA NOTIZIA DELLA SETTIMANA

NOI CANTIAMO PER GUARIRE!

UN GRUPPO DI GIOVANI PAZIENTI DELL'ISTITUTO DEI TUMORI DI MILANO HA INCISO IL SINGOLO «NUVOLE DI OSSIGENO», REALIZZATO CON FASO, IL BASSISTA DI ELIO E LE STORIE TESE

SETTE MESI DI APPASSIONANTE LAVORO

«IL BRANO LANCIA UN MESSAGGIO SULLA QUALITÀ DELLE CURE»

TRATTIAMO I RAGAZZI NEI CENTRI GIUSTI

UNA BAND DI ADOLESCENTI SCATENATI

CORRIERE DELLA SERA

BUONENOTIZIE

L'IMPRESA DEL BENE

Siamo i supereroi della vita

| Non siamo soli | Area di servizio | L'altra impresa | ControCorrente |
|---|---|---|---|
| Gli studenti archeologi 4 | Un premio ai «cittadini coraggiosi» 9 | «La povertà culturale» alle Case Bianche 21 | Le novità dell'housing sociale 24 |
| A New York c'è un'altra maratona 6 | Un Esodo lavorativo dopo il carcere 19 | Nell'ex Filangieri adesso si balla 22 | Servizio civile I numeri che mancano 27 |

**2012**

TJ
ISSN 0300-8916
Tumori 2015; 101(6): 626-630
DOI: 10.5301/tj.5000365
ORIGINAL RESEARCH ARTICLE

# Creating beauty: the experience of a fashion collection prepared by adolescent patients at a pediatric oncology unit

Laura Veneroni[1], Carlo Alfredo Clerici[2,3], Tullio Proserpio[4], Chiara Magni[1], Giovanna Sironi[1], Stefano Chiaravalli[1], Luisa Roncari[1], Michela Casanova[1], Lorenza Gandola[5], Maura Massimino[1], Andrea Ferrari[1]

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[4] Pastoral Care Unit, Fondazione IRCCS Istituto
[5] Radiotherapy Unit, Fondazione IRCCS Istituto

ABSTRACT
**Aims and background:** Adole
event of cancer diagnosis an
help young patients express
**Methods:** The Youth Project
creative spirit and express th
tion in all its various stages u
name (B.Live), and organized
**Results:** In all, 24 patients fr
mental resource in helping t
could take action, both on th
**Conclusions:** Facilitating the
This experience integrated t
support during the course of

**Keywords:** Adolescent, Art,

## Introduction

Adolescents who develop neoplastic d
selves having to deal not only with cancer
plies (from the treatment to the risk of dyi
traumatic disruption of their adolescence.

***Developing individuality: who am I, and w***

Adolescence is a time of transition whe
velops his or her own identity and relatio

**Accepted:** May 4, 2015

**Corresponding author:**
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Fig. 1 - Patients at work in the multifunctional room at the Pediatric Department, studying models and choosing colors, patterns, and fabrics (photograph by Laura Larmo).

Fig. 2 - Patients at work in the multifunctional room at the Pediatric Department, studying models and choosing colors, patterns, and fabrics (photograph by Laura Larmo).

Fig. 3 - Patients at work in the multifunctional room at the Pediatric Department, studying models and choosing colors, patterns, and fabrics (photograph by Laura Larmo).

Fig. 4 - Some of the patients pose at the end of the fashion show (photograph by Matteo Volta).

The project attracted the attention of the mass media and, owing to the space dedicated by the media to the artistic aspects of the project, enabled an important message to be circulated concerning the particular problems of adolescents with cancer. It gave doctors a chance to make the point that there are problems to solve concerning the early diagnosis of adolescent patients and their access to treatment protocols. That is why adolescents have a lower likelihood of survival than children with the same disease. The patients involved in the project appreciated the chance to be active partners, together with their doctors, not only in their personal battle against their own disease, but also as testimonials of an important message for themselves and for other patients like themselves. These teenagers spoke about how they had to battle not only against their disease, but also against everything that the disease could mean in terms of isolation, being unable to plan for the future, feelings of inadequacy and powerlessness, and of losing control.

## Results

### *What the patients had to say*

The fashion project proved a fundamental resource in helping the young patients involved to regain a positive self-image and the feeling that they could take action, both on themselves and in their relations with others. It enabled them to construct or reconstruct their own individuality: through fashion, they could find fulfillment and beauty.

Valeria (a 15-year-old girl with soft tissue sarcoma) explains: “This was a creative way to go beyond the limits that have been imposed on us by the doctors and our parents. We created something beautiful, and not only for ourselves, but for others too...” In their search for their own personal style of dress, the adolescents took action not only on themselves, but also on their relationships with other people, changing their approach to the world of their healthy peers. They were no longer on the sidelines of what was happening in the world; they became creators of new trends, an inspiration for others. While fashion represents inventing beauty (for

“We can create beautiful things based on our own senses: I create with purple, like the smell of lavender and the flavor of grapes, purple like cold, melancholy and envy” (Elisa, 16 years, Ewing sarcoma)

**2013**

VOLUME 33 · NUMBER 2 · JANUARY 10 2015
JOURNAL OF CLINICAL ONCOLOGY
ART OF ONCOLOGY

# Clouds of Oxygen: Adolescents With Cancer Tell Their Story in Music

*Andrea Ferrari, Laura Veneroni, Carlo Alfredo Clerici, Michela Casanova, Stefano Chiaravalli, Chiara Magni, Roberto Luksch, Monica Terenziani, Filippo Spreafico, Daniela Polastri, Cristina Meazza, Serena Catania, Elisabetta Schiavello, Veronica Biassoni, Marta Podda, Luca Bergamaschi, Nadia Puma, Carla Moscheo, Giacomo Gotti, and Maura Massimino*

being.[7] Music has an important place in every adolescent’s world. It helps teenagers acknowledge and feel emotions that would otherwise remain confused and indistinct. Through music, adolescents can communicate to others what they are unable to say in words: their search for their own identity; the sense of life, love, and sex; the urge to rebel; and their hopes for the future. Music has a cathartic effect: it can vent emotional overload and strain. Music also has a fundamental role in group experiences. When people play or sing together, they live together and contribute to a group effort, each in their own way, doing their best to overcome their own limits for the benefit of the group as a whole.

## MUSIC IN THE ISTITUTO NAZIONALE TUMORI YOUTH PROJECT

Music was chosen as a means of communication for the adolescents taking part in The Youth Project at the Istituto Nazionale Tumori in Milan, Italy.[8,9] The Youth Project aims to optimize clinical care (eg, adolescents’ inclusion in clinical trials, psychosocial support, fertility-preserving facilities) and develop a novel approach to the challenges of treating teenagers, paying attention to their quality of life, and making time and space inside the hospital for them to be together and to feel as normal as possible. A core objective is to give adolescent patients a chance to express themselves through different social activities. In a first project, the teenagers designed their own fashion collection and organized a fashion show. The second project, begun in 2013, focused on music, its purpose being to use music as a form of expression. (This is distinct from music therapy, which is the clinical and evidence-based use of music interventions as part of a therapeutic relationship with a credentialed therapist).[10]

With help from a famous Italian rock band (Elio e Le Storie Tese) and particularly from the group’s bass guitarist Faso and vocalist Paola Folli, our young patients wrote a song called “Clouds of

---

**Fig 1.** Patients at work with bass guitarist Faso in the multifunctional room at the Pediatric Department of the National Tumor Institute in Milan during the early stages of Clouds of Oxygen (photograph by Andrea Ferrari).

**Fig 3.** Some of the patients pose as a rock band for the photographer together with one of the musicians and one of the doctors (photograph by Matteo Volta).

Oxygen.” Twenty 15- to 25-year-old patients took part, half of them while receiving treatment for their cancer, the other half during their subsequent follow-up. The adolescent patients spent 3 to 4 hours with the musicians once every 2 weeks. These meetings were usually held in a dedicated room at the hospital (Fig 1), but some were held at the band’s recording studio (Fig 2). Patients at home who were unable to attend could join in by means of a dedicated, password-protected Facebook profile. The project took 8 months to complete. The song was launched at a special evening event, complete with media coverage (Fig 3). A video of our adolescents singing “Clouds of Oxygen” can be found on YouTube using as search criteria the words “Nuvole di ossigeno” (plus “English subtitles”),[11] and on the Youth Project Web site.[12] Words to the song are shown in Table 1.

## THE MESSAGE IN CLOUDS OF OXYGEN

Writing a good-quality, marketable song with a group of teenagers who were not musicians and had no experience in composition proved a real challenge, met with enthusiasm by patients and musicians alike. “It gave us a chance to have some fun, do something special, meet famous musicians, and see how a song is born and how a recording studio works,” said Elisabetta (being treated for soft tissue sarcoma). “It was an opportunity to do something together with people who had the same problems as me, to see that it wasn’t just my problem, to share anxieties and worries. Above all, it was a way for me to tell my story.” The role of the group was hugely important. One of the main challenges faced by adolescents with cancer is how to avoid being isolated from friends and schoolmates. Working to write a song helped them come together, identify with other young people with similar problems, establish a sense of solidarity, and feel less alone in coping with their uncertain future.

The song’s lyrics are a jumble of phrases, images, memories, hopes and fears, written by the teenagers—partly as a group, partly on their own—and then pieced together with the essential help of the professional musician. The music flowed in the same way; the teens were asked to bring brief sequences of notes: tunes they hummed to themselves on their mopeds, in the shower, or in the doctor’s waiting room. The musician blended all these contributions together to create a melody that the adolescents then helped to develop. With the addition of the right chords and musical arrangements, the song came to life. The music even contains snippets of hospital sounds, like the rhythmic hum of the chemotherapy pump and the nurses’ buzzer.

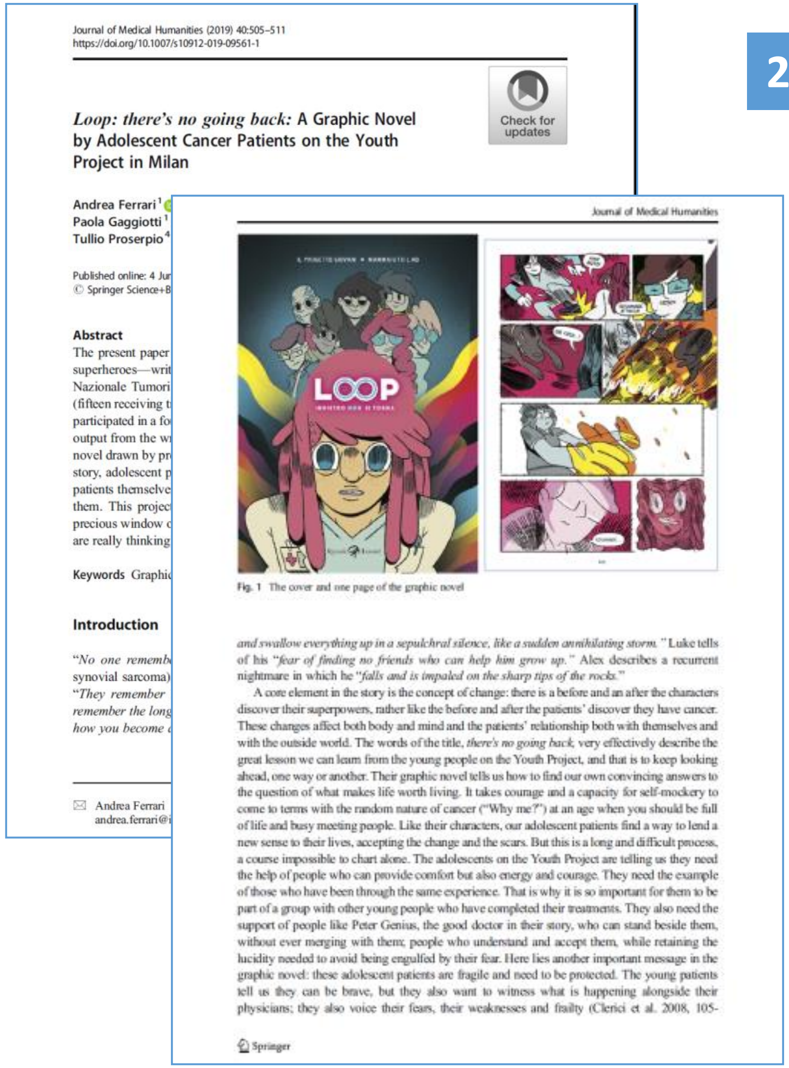
It was the adolescents who best explained the meaning of the lyrics. Elisabetta said, “One of the parts I wrote is ‘Let’s get away, swimming in a sea of blue.’ I love the sea. It has always given me a sense of escape from daily life, and especially now that daily life means chemotherapy. The idea of being immersed in a sea of blue can also mean sinking into a different world, away from the place where the body feels heavy and suffers. In the water, my body feels lighter.”

Sunsets were a recurring theme. (“Take me away, to see the sunsets of this world.”) Matteo (being treated for medulloblastoma) said, “Knowing that the sunsets of this world are repeated, day after day, helps us to remember that after sunset and the night comes a new dawn.” Matteo also wrote, “Clench your teeth if they tell you no, things aren’t right.” He goes on to explain, “I was never cross with the doctors, not even when they gave me bad news, or asked me to make sacrifices. They were doing it for my own good. That is why I also

**Fig 2.** Patients at the recording studio (photograph by Marco Uberti).

“The clear horizon that you see from a mountaintop, where you can look in every direction, feel the freedom, and see everything distinctly after a time of darkness and uncertainty” (Eleonora, 18 years, Ewing sarcoma)

**2014**



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https://doi.org/10.1007/s10912-019-09561-1

Check for updates

## *Loop: there's no going back:* A Graphic Novel by Adolescent Cancer Patients on the Youth Project in Milan

Andrea Ferrari[1]
Paola Gaggiotti[1]
Tullio Proserpio[4]

Published online: 4 Jun
© Springer Science+B

**Abstract**
The present paper
superheroes—writ
Nazionale Tumori
(fifteen receiving t
participated in a fo
output from the w
novel drawn by pr
story, adolescent p
patients themselve
them. This projec
precious window c
are really thinking

**Keywords** Graphic

**Introduction**

"*No one rememb*
synovial sarcoma)
"*They remember*
*remember the long*
*how you become*

Andrea Ferrari
andrea.ferrari@i

Journal of Medical Humanities

Fig. 1 The cover and one page of the graphic novel

*and swallow everything up in a sepulchral silence, like a sudden annihilating storm.*" Luke tells of his "*fear of finding no friends who can help him grow up.*" Alex describes a recurrent nightmare in which he "*falls and is impaled on the sharp tips of the rocks.*"

A core element in the story is the concept of change: there is a before and an after the characters discover their superpowers, rather like the before and after the patients' discover they have cancer. These changes affect both body and mind and the patients' relationship both with themselves and with the outside world. The words of the title, *there's no going back*, very effectively describe the great lesson we can learn from the young people on the Youth Project, and that is to keep looking ahead, one way or another. Their graphic novel tells us how to find our own convincing answers to the question of what makes life worth living. It takes courage and a capacity for self-mockery to come to terms with the random nature of cancer ("Why me?") at an age when you should be full of life and busy meeting people. Like their characters, our adolescent patients find a way to lend a new sense to their lives, accepting the change and the scars. But this is a long and difficult process, a course impossible to chart alone. The adolescents on the Youth Project are telling us they need the help of people who can provide comfort but also energy and courage. They need the example of those who have been through the same experience. That is why it is so important for them to be part of a group with other young people who have completed their treatments. They also need the support of people like Peter Genius, the good doctor in their story, who can stand beside them, without ever merging with them; people who understand and accept them, while retaining the lucidity needed to avoid being engulfed by their fear. Here lies another important message in the graphic novel: these adolescent patients are fragile and need to be protected. The young patients tell us they can be brave, but they also want to witness what is happening alongside their physicians; they also voice their fears, their weaknesses and frailty (Clerici et al. 2008, 105-

Springer

"I invented **Super Mike** to represent myself. Super Mike is incredibly strong and he recovers instantly whenever he's hurt. That's how I'd like to be" (Riccardo, 20 years, sarcoma of the meninges)

**2015**

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JOURNAL OF CLINICAL ONCOLOGY ART OF ONCOLOGY

## Searching for Happiness

*Andrea Ferrari, Paola Gaggiotti, Matteo Silva, Laura Veneroni, Chiara Magni, Stefano Signoroni, Michela Casanova, Roberto Luksch, Monica Terenziani, Filippo Spreafico, Cristina Meazza, Carlo Alfredo Clerici, and Maura Massimino*

Author affiliations and support information (if applicable) appear at the end of this article.

This is the story, told through their own photographs, of a group of adolescent patients with cancer in their search for happiness. Their images

particular gravity when considered from a room at the pediatric oncology unit of a cancer center. The patients each worked on their own personal
o explain through their images
eant to them at this particular
nd what gave them strength to
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ople's search for happiness took
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t thinking about their disease;
n the normalcy of daily life (a
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atment of their cancer). The
e disease as a starting point for
concept of happiness.
atients' photographs concerned
s, fast cars, the natural world,
grandparents. In the notes ac-
photographs some patients as-
with "winter sunshine," "hot
ing," "mum's lasagna on Sun-
f chocolate," and "lying on the
usic." Other comments offered
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nd "managing not to waste even
of our patients wrote that "to
s you have to lose it first."
patient whose photography at
to reflect an attempt to escape,
eference to his or her medical
ave a hidden, more profound
ple, the photographs taken by
medulloblastoma) are almost
ils become detached from the
ound to signify absolute beauty,
ense of drama (in his marked
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aning) that communicates,
ly, a sort of anguish, a sense
1). Viola (treated for acute
kemia) took photographs of

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Ferrari et al

Fig 1. One of the photos taken by Matteo (treated for medulloblastoma) for his individual project on the search for happiness.

people smiling, but the background from which they emerge is always dark and dismal.

Lorenzo (treated for ependymoma) took pictures from unusual perspectives (Fig 2). He explained: "My photographs are the metaphor of how I try to deal with the obstacles that life places before me, and how I seek happiness. I have learned how to try and overcome the obstacles from my worst limitation, the visual impairment caused by my disease. I literally had to learn to look at reality from different perspectives. Then I realized that I could transform this difficulty of mine into an opportunity. I look at reality from different angles, finding particular details that make it special and fascinating. Maybe the important thing is not to see the whole picture, but to look (and live) from as many alternative and original viewpoints as possible. This enables you to give a different interpretation to what you see, it lets you find something unique in every view, with the awareness that you can find happiness in it."

Two girls, Sefora and Martina, chose to photograph themselves and tell us explicitly about their disease, in rather

Fig 2. One of the photos taken by Lorenzo (treated for ependymoma). Lorenzo takes photographs from unusual perspectives because, as he himself explained, his disease has left him with a visual impairment that makes him look at reality from different angles.

Fig 3. A self-portrait by Sefora (treated for synovial sarcoma) without her wig.

startling images. Sefora (treated for synovial sarcoma) removed her wig in front of the camera, showing her bald head. She wanted to not only produce an iconographic image of cancer but also show how she met the challenge of the disease, looking it straight in the face. Sefora wanted to find happiness by regaining possession of her beautiful appearance, but her gesture also reveals a sense of anger and fatigue (Fig 3).

Martina (treated for Ewing sarcoma) took melancholy pictures. "I wanted my photographs to illustrate what my search for happiness has been like in this period of my life. On the one

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"I literally had to learn to look at reality from **different angles**, finding particular details that make it special and fascinating; you find something unique in every view, with the awareness that you can find happiness in it" (Lorenzo, 18 years, ependymoma,)

**2016**

TJ
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SHORT COMMUNICATION

Online
Only

## "Christmas Balls": a Christmas carol by the adolescent cancer patients of the Milan Youth Project

Andrea Ferrari[1], Stefano Signoroni[2], Matteo Silva[1], Paola Gaggiotti[1], Laura Veneroni[1], Chiara Magni[1], Michela Casanova[1], Stefano Chiaravalli[1], Mirko Capelletti[2], Pietro Lapidari[2], Carlo Alfredo Clerici[3,4], Maura Massimino[1]

[1] Pediatric Oncology Unit, Fon
[2] Unit of Hereditary Digestive
[3] Clinical Psychology Unit, Fon
[4] Oncology and Hemato-Onco

ABSTRACT
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Introduction

For young people, wha
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This is the story of a Ch
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The Youth Project

Singing is one of several
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Accepted: December 6, 2016
Published online: December

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Ferrari et al 3

Fig. 2 - The making of the video: a Christmas party for the young people of the Youth Project (photograph by Veronica Garavaglia).

Fig. 3 - Some of the patients pose for the photographer together with the musician/researcher (in the middle) and some caregivers (photograph by Veronica Garavaglia).

a normal Christmas, something completely ordinary, with his mum preparing Christmas dinner. The box he envisages holding isn't a box of things he wishes for, but a box of 'people who are wishing,' of all the young people who are in his same situation, and who just want to be back to normal." When dealing with adolescent patients, it is common to see that what they want most is to be treated like normal young people. They do not want to be pitied; they do not appreciate special attention. They want to be like their healthy peers, ordinary young people like everyone else, even though they have had the misfortune of developing a severe disease (the room number 13 in the lyrics of their Christmas carol also symbolizes their bad luck). Despite their cancer, they want the same things in life as other people. They want to fall in love with a classmate, study for a difficult examination, and argue with their parents over how long they can stay out in the evenings; they want to dress up, to get drunk on Saturday nights (8).

Lorenzo (receiving treatment for a brain tumor) told us, "For me, the Youth Project is about entering this room and not needing anything," and Cristian (being treated for an

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"**The real normal is the shape we give things**" (sings Samuele, 19 years, rhabdomyosarcoma) "It is up to us, the patients, to decide what Christmas means to us, and how we want to experience it."

**2017**

Check for updates

*Original Research Article*

TJ Tumori Journal

## "What shall I do when I grow up?" Adolescents with cancer on the Youth Project in Milan play with their imagination and photography

Tumori Journal
1–6
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Paola Gaggiotti[1], Laura Veneroni[1], Stefano Signoroni[2],
Matteo Silva[1], Marco Chisari[1], Michela Casanova[1]

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4 *Tumori Journal 00(0)*

Figure 1. Camilla dressed as a genie in a lamp.

Figure 2. Jari would like to be a superhero for children and adolescents who are ill.

Figure 3. Rebecca dreams to become a scientist and "discover something in the medical field that can make even the most awful treatments, like chemotherapy, more tolerable."

Figure 4. Davide dressed as a motocross rider.

I'm not sure what I want to be, I know for certain that I want to contribute to helping other people the way those around me now are helping me to stay on the right path. I'd like to become a youth worker perhaps, which ultimately means being a superhero for children and adolescents who are ill" (Figure 2).

Rebecca, 19 years old: "It's really difficult to decide what I'd like to be when I grow up. I still haven't worked it out (too many different dreams, which one will be best for me?). But one of my favorites is to become a scientist or researcher and discover something in the medical field that can make even the most awful treatments, like chemotherapy, more tolerable. And if we want to really exaggerate, I want to win a Nobel prize for my studies. I'm allowed to dream big, right?" (Figure 3).

Matteo, 22 years old: "My ambition is to become a good designer who, in his small way, can have the inventiveness and creative spirit to design products, objects that can be useful and helpful to society. Without being the inventor of the century, but trying to contribute in my own way to making the world a better place. But actually my secret dream for when I grow up is to stay a child."

Davide, 17 years old: "I've never allowed myself to be discouraged by anything or anybody, and especially not by those who told me it would be impossible to get back to doing everything I did before. But that's my dream and I want it to come true. 'Impossible' is a word that doesn't exist in the vocabulary of a dreamer. I decided to take this photo dressed like a motocross rider" (Figure 4).

Marco, 22 years old: "I've never been a dreamer. People who know me know that I almost never dream. At night I sleep, and I sometimes snore. People who dream can wake up and find that reality very often isn't up to their expectations. I've always preferred practical things, facts, things I can see and touch, problems I can look at, analyze and solve, if I can. But I've increasingly realized that, rather than 'doing great things,' it's important to 'be great people,' whatever you do. When I'm a grownup I'd like people to think of me and say, 'I have good memories of Marco.' I'd like to be good at reading situations in life, capable of adding a positive note and a good smell to other

"***'Impossible'*** is a word that doesn't exist in the vocabulary of a dreamer" (Davide, 17 years, osteosarcoma)

## 2018

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DOI: 10.1002/pbc.27630

**SPECIAL REPORT**

### “Summer is you”: Adolescents and young adults with cancer sing about their desire for summer

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Matteo Silva[2] | N
Maura Massimino[2]

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Email: andrea.ferrari@istitutotum

1 | INTRODUCTIO

The care of adolescents and y
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Various dedicated projec
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Abbreviation: AYA, adolescents and yo

Pediatr Blood Cancer. 2019;66:e27
https://doi.org/10.1002/pbc.2763

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**FIGURE 1** Group photo of the young patients in hospital after recording the video clip (picture by Veronica Garavaglia)

some also playing their musical instruments. A video clip was recorded too, partly in hospital and partly in the recording studio. The song was ultimately launched at a press conference held at the National Tumor Institute in June 2018, with the AYA participants in attendance.

### 1.2 | Music to tell a story: the words of our AYA cancer patients

The major objective of the project was to give our young patients a novel way to voice their hopes and fears. In the first months of the laboratory, the patients produced an abundance of lyrics about summer, evenings spent gazing at the stars, making new friends, romantic encounters, and the urge to travel. Some wrote simple sentences, in prose and rhyming verse, and some wrote longer passages. The content was often cheerful and poetic, but sometimes melancholy:

> *"I go to the station, catch a train, a rucksack on my back, and a dear friend beside me. A night at the campsite, and one at the hostel, we draw the world with a pen and a crayon."*
>
> *"You've hidden your happiness under the sand, in that spot on the beach that you whispered to me."*
>
> *"All your life is a summer season, a holiday to recall; don't sail in the hold, the North star is waiting for you on shore."*

There were more or less explicit references to the hospital ("The Youth Project's like a pirate ship") and to the patients' difficulty coping with their disease and their treatments ("First of all, we need to feel the sun shining inside us"). Some mentioned traveling companions no longer with us ("Like a shell, plucked from the sand, this summer you're not here, and you've no idea how angry it makes me. Here, I swear, I so miss your company, but I want you to know you'll always be in my thoughts").

A collection of the patients' work won a literary prize organized by the Italian Association of Medical Oncology, an important acknowledgment of all their efforts, since the final lyrics of the song contained only a small part of their material.

The song words and video clip draw a parallel between longed-for summer travels and journeying for treatments, the journey of disease. The video shows the patients preparing their bags and taking the elevator, they are not sure where. They emerge on floor 7¾ (the Pediatric Oncology ward is on the seventh floor), reminiscent of Harry Potter's secret railway platform 9¾. This is a special place where they find friends and fun, love and music, where a summer party is in full swing (Figure 1). "I'll smile despite the rain, because summer is you, if you dance with me, dance, and don't worry any more"—they sing, and again "We'll travel at night so that, when you ask me where we're going, I can promise there'll be sunshine" (Supporting Information Table S1).

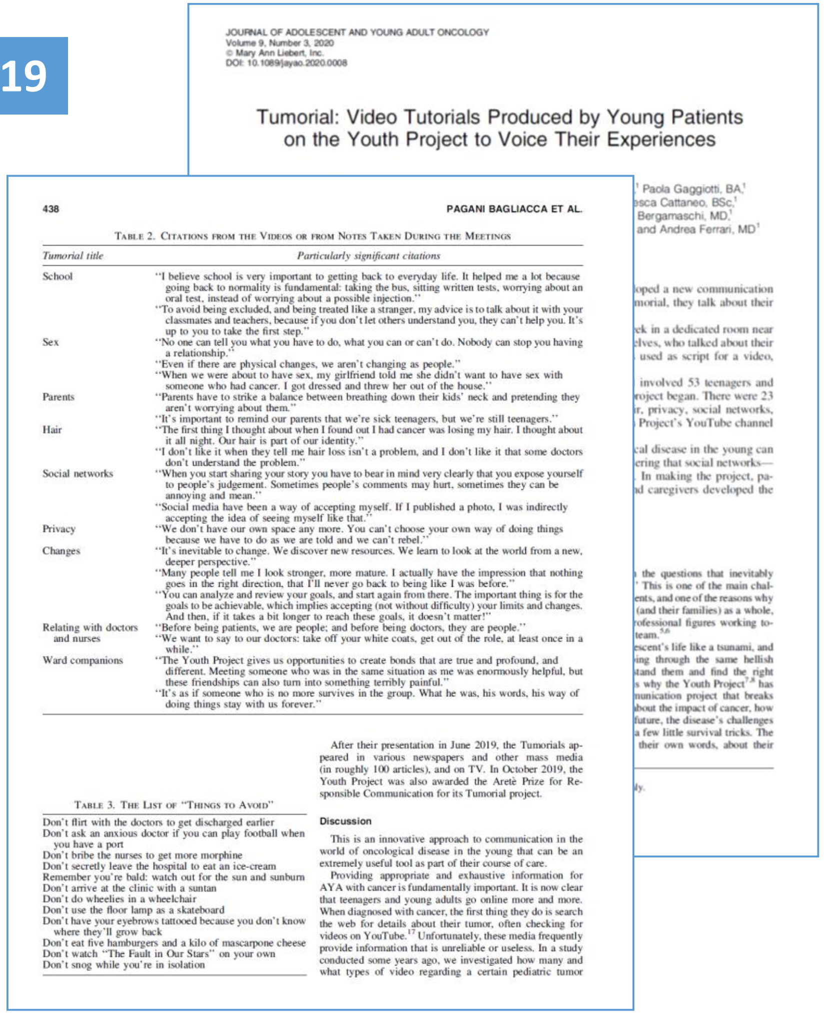
In the subtitle "Rain dance in reverse", the patients wanted to express the sense of magic they experienced: "rain washing away the pain in your soul"—they said. Or again: "Here the magic is in a rain dance in reverse, because we want to make the sun shine on our life again"; "We find so many friends and smiling faces, and such an urge to dance, inside an oncology department—a place we thought would be sad and horrible: it really seemed like magic" (Figure 2).

### 2 | DISCUSSION

Our experience with the "Summer is you" song underscores the value of the Youth Project model and the use of creative laboratories as a novel form of psychosocial support for AYA cancer patients—through group acceptance and shared emotions in a long-term project—as a complement to the more traditional approaches based on interviews. The challenge of such projects is to let our patients know that it is safe and often therapeutic to talk about themselves, especially to

“We'll travel at night so that, when you ask me where we're going, I can promise there'll be **sunshine**” (Martina, 17 years, lymphoma)

## 2019



JOURNAL OF ADOLESCENT AND YOUNG ADULT ONCOLOGY
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DOI: 10.1089/jayao.2020.0008

### Tumorial: Video Tutorials Produced by Young Patients on the Youth Project to Voice Their Experiences

,[1] Paola Gaggiotti, BA,[1]
esca Cattaneo, BSc,[1]
Bergamaschi, MD,[1]
and Andrea Ferrari, MD[1]

loped a new communication
morial, they talk about their

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escent's life like a tsunami, and
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s why the Youth Project[7,8] has
munication project that breaks
bout the impact of cancer, how
future, the disease's challenges
a few little survival tricks. The
their own words, about their

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Table 2. Citations from the Videos or from Notes Taken During the Meetings

| *Tumorial title* | *Particularly significant citations* |
|---|---|
| School | “I believe school is very important to getting back to everyday life. It helped me a lot because going back to normality is fundamental: taking the bus, sitting written tests, worrying about an oral test, instead of worrying about a possible injection.”<br>“To avoid being excluded, and being treated like a stranger, my advice is to talk about it with your classmates and teachers, because if you don't let others understand you, they can't help you. It's up to you to take the first step.” |
| Sex | “No one can tell you what you have to do, what you can or can't do. Nobody can stop you having a relationship.”<br>“Even if there are physical changes, we aren't changing as people.”<br>“When we were about to have sex, my girlfriend told me she didn't want to have sex with someone who had cancer. I got dressed and threw her out of the house.” |
| Parents | “Parents have to strike a balance between breathing down their kids' neck and pretending they aren't worrying about them.”<br>“It's important to remind our parents that we're sick teenagers, but we're still teenagers.” |
| Hair | “The first thing I thought about when I found out I had cancer was losing my hair. I thought about it all night. Our hair is part of our identity.”<br>“I don't like it when they tell me hair loss isn't a problem, and I don't like it that some doctors don't understand the problem.” |
| Social networks | “When you start sharing your story you have to bear in mind very clearly that you expose yourself to people's judgement. Sometimes people's comments may hurt, sometimes they can be annoying and mean.”<br>“Social media have been a way of accepting myself. If I published a photo, I was indirectly accepting the idea of seeing myself like that.” |
| Privacy | “We don't have our own space any more. You can't choose your own way of doing things because we have to do as we are told and we can't rebel.” |
| Changes | “It's inevitable to change. We discover new resources. We learn to look at the world from a new, deeper perspective.”<br>“Many people tell me I look stronger, more mature. I actually have the impression that nothing goes in the right direction, that I'll never go back to being like I was before.”<br>“You can analyze and review your goals, and start again from there. The important thing is for the goals to be achievable, which implies accepting (not without difficulty) your limits and changes. And then, if it takes a bit longer to reach these goals, it doesn't matter!” |
| Relating with doctors and nurses | “Before being patients, we are people; and before being doctors, they are people.”<br>“We want to say to our doctors: take off your white coats, get out of the role, at least once in a while.” |
| Ward companions | “The Youth Project gives us opportunities to create bonds that are true and profound, and different. Meeting someone who was in the same situation as me was enormously helpful, but these friendships can also turn into something terribly painful.”<br>“It's as if someone who is no more survives in the group. What he was, his words, his way of doing things stay with us forever.” |

Table 3. The List of “Things to Avoid”

Don't flirt with the doctors to get discharged earlier
Don't ask an anxious doctor if you can play football when you have a port
Don't bribe the nurses to get more morphine
Don't secretly leave the hospital to eat an ice-cream
Remember you're bald: watch out for the sun and sunburn
Don't arrive at the clinic with a suntan
Don't do wheelies in a wheelchair
Don't use the floor lamp as a skateboard
Don't have your eyebrows tattooed because you don't know where they'll grow back
Don't eat five hamburgers and a kilo of mascarpone cheese
Don't watch “The Fault in Our Stars” on your own
Don't snog while you're in isolation

After their presentation in June 2019, the Tumorials appeared in various newspapers and other mass media (in roughly 100 articles), and on TV. In October 2019, the Youth Project was also awarded the Aretè Prize for Responsible Communication for its Tumorial project.

#### Discussion

This is an innovative approach to communication in the world of oncological disease in the young that can be an extremely useful tool as part of their course of care.

Providing appropriate and exhaustive information for AYA with cancer is fundamentally important. It is now clear that teenagers and young adults go online more and more. When diagnosed with cancer, the first thing they do is search the web for details about their tumor, often checking for videos on YouTube.[17] Unfortunately, these media frequently provide information that is unreliable or useless. In a study conducted some years ago, we investigated how many and what types of video regarding a certain pediatric tumor

“Before being patients, **we are people**; and before being doctors, **they are people**: we want to say to our doctors: take off your white coats, get out of the role, at least once in a while” (Matteo Davide, 24 years, medulloblastoma)

2019

## The Arts

### YOU$^{TH}$: the sweatshirt collection created by adolescents with cancer

Being diagnosed with and treated for cancer is traumatic at any age, but the situation is even more difficult when it occurs during adolescence. Young patients with cancer are suddenly faced with a new condition that severely interferes with various aspects of their everyday life. The emotional responses to this new diagnosis have an important impact on psychological wellbeing, with an overall negative effect on body image, school attendance, relationships with friends and family, sense of freedom and independence, and, most importantly, about future prospects. Adolescent patients have a special need to search for ways to ensure their life is not dominated by their disease and at the same time they must maintain a sense of normality in their lives. Professionals who care for adolescents with cancer must be aware that these patients are particularly demanding, with many unmet needs to consider (eg, the delicate symptom appraisal process and the complex pathway to diagnosis, which is often delayed; access to optimal care including accrual to clinical trials; the need for age-specific psychosocial support; the challenges of communication and adherence to treatment; the necessity for an age-appropriate environment; the specific issues regarding fertility and the impact of disease and treatment on sexuality, body image, and relationships with peers), and with a challenging clinical management.

In the past 15 years, several projects (eg, the Teenage Cancer Trust activites and the BRIGHT-LIGHT project in the UK; the LiveStrong and Progress Review Group programme in the USA; and the European Network for Teenagers and Young Adults with Cancer) designed for this particular age group of patients have been developed, but a standardised model of care has yet to be established. An ideal programme should limit the devastating impact that this disease might have, by attempting to reduce isolation through connection with other adolescents (ward companions or peers outside the hospital), by educating and training staff on how to manage the emotional and developmental needs of this age group, and by modifying the hospital environment (eg, dedicated space with simple attendance rules, to respect the need for privacy but also to facilitate interaction with peers and prevent isolation; and specific multifunctional areas with appropriate technology) to make it more comfortable for them.

Various papers have been published in the past 5 years on how adolescents with cancer included in the Youth Project at the Istituto Nazionale dei Tumori in Milan (Italy) have expressed their hopes and fears, their anger, and their determination to keep smiling in creative projects involving music, photography, novel writing, and video productions. In this project, the boys and girls participating in the Youth Project have designed a fashion collection (a range of sweatshirts) and a logo: YOU$^{TH}$. The project involved 32
15–24 years (20 of whom were receiving t
12 who had completed their course of t
worked with the fashion designer Gentu
patients shared their ideas, studied grap
and chose models, materials and colours
top-quality end-product intended for the
adolescents also created a trademark to ide

**Pediatric Oncology Unit** (E P Bagliacca, M Silva, L Veneroni, M Casanova, M Massimino, A Ferrari), **Tumor Genomics Unit** (P Gasparini), **and Hereditary Digestive Tract Tumors Unit** (S Signoroni),

Figure 1: The patient in the photo, Jari, is wearing a sweats
of himself taken a few months earlier, during his cancer tr

Figure 2: Several youngsters on the Youth Project showing off their sweatshirts

their fashion collection, but also the whole Youth Project. The logo aims to convey the idea of a youth that is strong, its superscript meaning to the n$^{th}$ power. But the word is slashed by a horizontal line that, for the young designers, originally represented the scar left by their Port-a-Cath (the catheter used for their chemotherapy infusions), which all young cancer patients have. The scar represents an opening in their bodies not only for cancer treatments to go in, but also for emotions, change, projects, colours, and dreams to come out. This slash has been stylised, but remains, as described by the young patients, "like something that cuts your adolescence in two, a wound, but also something that duplicates it, like an opportunity for rebirth". The YOU™ logo is boldly stated on the front of all the sweatshirts, reflecting a sense of empowerment. Three of the models have the word "fuck" on the back, to voice the rebellious spirit of adolescence, and also the patients' frustration with their condition. One of the sweatshirts shows a patient's face, partly concealed by the same slash that cuts through the YOU™ logo (figure 1). The young designers produced eleven different models, which went on sale at a dedicated stand in the famous Rinascente megastore in Milan's Piazza Duomo in December, 2019 (figure 2). All proceeds will go to the non-profit Associazione Bianca Garavaglia Onlus, which supports the Youth Project.

This project gave the adolescent patients an opportunity to get together and share difficult experiences with other young people going through similar treatment. An important feature of such projects is that patients can take part in the activities organised by the Youth Project regardless of whether they are receiving treatment at the time or have completed their course of therapy. This approach is valuable both for patients receiving treatment, who see those who have finished treatment as a positive example, and for those who have finished treatment and return to the hospital to work on such projects. This helps them to carry on seeing the hospital as a reference, giving the adolescents a chance to experience the passage between their life during their treatment and their normal life elsewhere—a passage these young patients describe as one of the most difficult in the whole course of their cancer experience. For them, the sweatshirts designed in hospital are emblematic of their hard journey, a physical reminder that they can share outside and wear in their daily lives. As Anna, one of the adolescents with cancer, describes it, "I shall wear my sweatshirt the first day I go back to school".

Working on a project expected to take several months to complete also enables patients to regain a sense of planning for the future. Their cancer obliges adolescent patients to abandon any plans and drastically change the way they think about the future. Their time scales can shrink to the day they will be discharged from hospital, or the start of their next cycle of therapy. When our young people started working in May and June, 2019, towards the launch of a fashion collection in December, it gave them a chance to think more positively about the future.

While being treated for their cancer, our young patients could use their fashion ideas to express themselves. Their choices of colours and logo revealed their tastes, values, and emotions, and brought colour and beauty inside the hospital. Spending time together during these projects allowed the patients to experience moments of normality, reminding them that before becoming a patient with cancer, they were teenagers, and finding a sense of light-hearted relief even in the middle of their hospital stays and treatment. At the same time, participating in significant projects together with professionals, made them feel important: this is not an easy achievement, considering that adolescence is a crucial time in an individual's life, when self-esteem can be deeply affected by negative experiences. The idea behind the sweatshirts designed by our young patients in hospital is that they will be worn by others, healthy young people too, promoting meaningful exchanges. Such forms of communication might result in the development of mechanisms that drive people outside the world of oncology to talk about cancer, including the more strictly medical aspects, such as the difficulty of accessing appropriate treatments and clinical trials, and the need for age-specific spaces in hospitals and dedicated projects.

*Elena Pagani Bagliacca, Matteo Silva, Laura Veneroni, Michela Casanova, Patrizia Gasparini, Stefano Signoroni, Maura Massimino, *Andrea Ferrari*

We thank the designer Gentucca Bini and the Associazione Bianca Garavaglia Onlus for supporting the Youth Project and the fashion collection YOUTH; without the Associazione Bianca Garavaglia Onlus, the Youth Project would not exist. The authors also thank the Associazione Dudù for You Onlus for supporting the fashion collection YOUTH, the photographer Veronica Garavaglia, the Rinascente store in Milan Piazza Duomo, Colzani Camici, Stamperia Airily, Cristiano Urban, the Agenzia Grafica VitamineD, Pietro Ferrari, Gigio Damia, and Luca Cocco.

"Like something that cuts your adolescence in two, a wound, but also something that duplicates it, like an opportunity for **rebirth**"
(Jari, 16 years, lymphoma)

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2019

JOURNAL OF ADOLESCENT AND YOUNG ADULT ONCOLOGY
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## Experiencing Social Isolation (Even in the Era of COVID-19 Pandemic Lockdown): Teachings Through Arts from Adolescents with Cancer

Andrea Ferrari, MD,[1] Elena Pagani Bagliacca, PsyD,[1] Laura Veneroni, PsyD,[1] Matteo Silva, BA,[1]
Patrizia Gasparini, PhD,[2] Stefano Signoroni, PhD,[3] Roberto Luksch, MD,[1] Monica Terenziani, MD,[1]
leazza, MD,[1] Marta Podda, MD,[1]
Stefano Chiaravalli, MD,[1]
lassimino, MD[1]

tic approach to discuss about their social
sionals, 17 young patients closed in their
ntasy place) producing texts and images,
forced to social isolation by the lockdown
h us meaningful life lessons: how social
hat is really important in life.

-19

ncer patients, regardless of hospitalization, find
ving an experience of social distancing for the
being sick: often an invisible barrier rises be-
s (who lose their hair and are waiting for the
chemotherapy treatments) and classmates (who
r a test at school, a kiss from the dream girl/boy,
l at the beach with friends). Being left out—
as different, as sick—is the great fear of ado-
cancer.[4–6]
Youth Project—dedicated to adolescents
old) and young adults (defined as up to 25 years
optimize clinical aspects of patient care (as the
clinical trials, e.g.) and to promote a life as
sible for the patients in care, by providing them
ific spaces and organizing specific activities.[7,8]
ears, the Youth Project develops projects that
patients tools to express their experiences
ivity and art.[9–19] On various occasions, ado-
nts have told professionals how the aspect of
particularly experienced by them and how they
ate a project on it.
describes how a project called "Condominy"
"condominum" or "apartment building"),

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n, Italy.
Italy.
umori, Milan, Italy.

an, Italy.

dedicated to isolation, was created, with a view to tell all the lessons that these adolescent patients recurrently deal with during social isolation, in such a peculiar period related to COVID-19 pandemic in which we all find ourselves living in a somewhat similar situation, isolation, confinement, fear, and uncertainty of the future.

### Methods

This project was realized between April 2018 and March 2019. Participating patients were adolescents and young adults (15–24 years) who were receiving treatment at the Pediatric Oncology Unit of the Istituto Nazionale dei Tumori of Milan, or patients who had completed their treatments no more than 1 year previously. No further specific inclusion/exclusion criteria were used. Patients were invited to join this initiative by the Youth Project team (that includes dedicated doctors, psychologists, youth worker, and art project director) and were totally free to join or not the project.

All patients (or their parents/legal guardians for underage patients) gave their written informed consent to their involvement in the project (the Youth Project program is approved by the Research Ethics Committee at the Istituto Nazionale dei Tumori).

As for other artistic projects,[9–16] additional specific professionals were involved, that is, artists, architects, modelers, graphic designers, and photographers. These professionals were selected by the Youth Project staff, for their specific technical expertise, but also for their ability in comprehending the need of establishing a challenging relationship with young people with cancer. Professionals were explained the aims of such projects, which used arts to offer patients a novel way to voice their emotions and tell their stories, and to provide a particular form of psychosocial support, complementing the more classical approaches based on interviews.

Closed in the isolation room, young patients described their ideal room, a bit real but a bit of a fantasy place that represents their personality and their dreams. To this end, they produced texts, images, drawings, and music. All these materials were shared with the professionals taking part in the project: the aim was to build architectural models, one for each "room" (Fig. 1). To do this, architects and other professionals tried to identify the features that better represented the description made by the patients, and prepared some sketches. These sketches were shared with each patient, to obtain the final three-dimensional model more consistent with patients' original ideas.

All the work was carried out during group meetings (organized in the dedicated multipurpose room alongside the pediatric unit), but was also developed "at home" using the virtual room of a closed Facebook group that was created for this purpose.

The Youth Project team (and, in particular, the dedicated psychologists) constantly participated to all the discussions and meetings with patients, to guarantee the complete respect of all their psychological aspects.

Subsequently, the different rooms were ideally put together in an apartment building, which become a common space, assembling different feelings, different music, different cities, and different lives. The photographs of the models and the texts were then grouped into a book, including also

FIG. 1. Two architectural models created with the help of professional architects and modelers on the basis of patients' description.

"Feeling lonely, while being surrounded by people who want to give you affection; feeling alone without friends, because your friends cannot relate to what you are going through. To feel good about yourself, you need to accept the **sense of loneliness**" (Mary, 18 years, Ewing sarcoma)

## 2020

Check for updates

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DOI: 10.1002/pbc.28948

Pediatric Blood & Cancer aspho WILEY

ON CHILDREN BLOOD, AND CANCER

### Looking out to see within: A photography project developed by adolescents with cancer during the COVID pandemic

**Andrea Ferrari**[1]
**Stefano Signoroni**

[1] Pediatric Oncology Unit, Fond
[2] Hereditary Digestive Tract Tu

**Correspondence**
Andrea Ferrari, Pediatric Oncol
Email: andrea.ferrari@istitutotu

This photo essay is the story
people with cancer in the m
gram, the Youth Project at
dedicated to young patients
dual aim of optimizing medi
clinical trials, and promotin
these young patients novel
photography, creative writir
The photography projec
sessions to comply with th
COVID-19 pandemic. It wa
Youth Project staff to laun
photographer (Alice Patric
After illustrating examples
invited the young participa
way, combining the languag
thought fit. Since the start o
of lockdown—of being unal
the case for our patients o
the photographer proposed
look out on the world (Figur
pital, when you can't enjoy
dreaming are the clouds in t
stuck in bed, and I fly with
the photographic journey
onto the outside world of pe
dows as openings that let i
(Figures 4–6).

*Pediatr Blood Cancer.* 2021;68:e2
https://doi.org/10.1002/pbc.28

2 of 4 | WILEY — FERRARI ET AL.

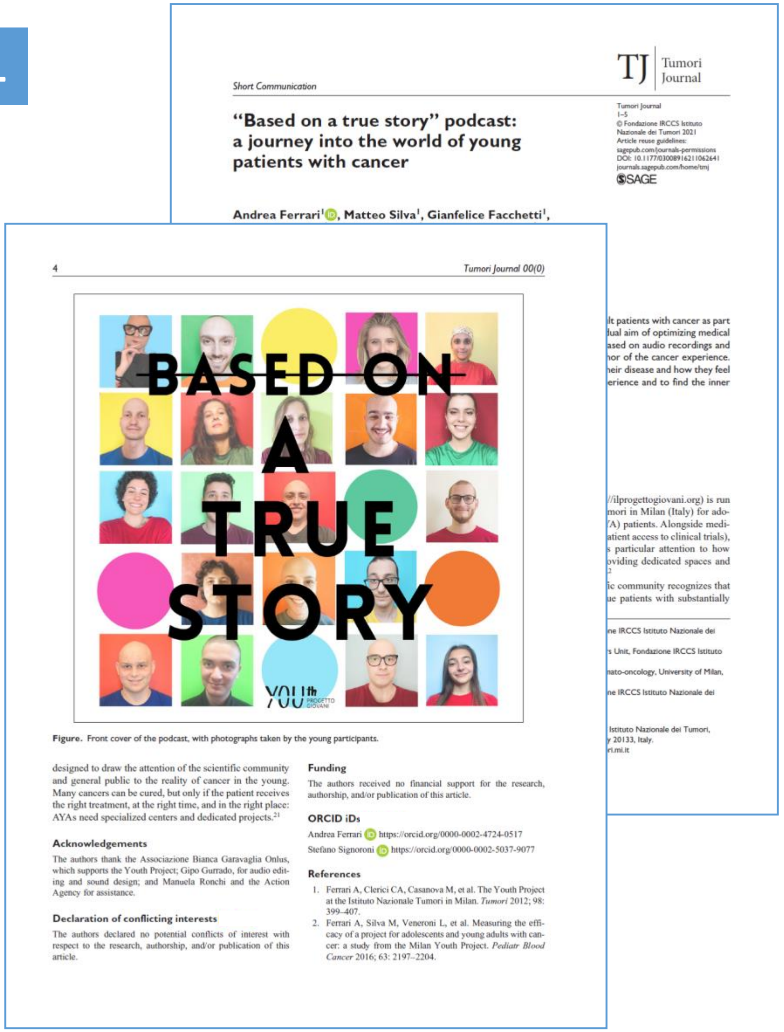
**FIGURE 1** The first topic of the project focused on the window through which we can look out on the world. While many patients took photographs of the view from the window of their bedroom, Matteo Davide took a photograph of the window itself, with the shutters closed. "Windows can be open or closed: imagine a boy who finds himself shut in, having to cope with a disease that has disrupted the life he knew. He has spent a lot of time shut in a room, and had time to turn his gaze inwards to try and make sense of things. There are many things he has yet to understand, but one thing is clear to him: the only person who can decide if and when to open or close my window is me"

**FIGURE 2** "Like autumn leaves, my hair falls in front of the mirror, and winter arrives in an instant. It doesn't take much, just a bit of sunshine, a guitar and an innocent smile on the face of spring, and we can breathe the summer air again" (Daniele)

In conclusion, we believe that this experience emphasizes the importance of giving young patients with cancer a chance to freely "voice" their emotions, and helping them process what is happening to them. Using art as a filter can make it a little easier to give vent to strong emotions, while also enabling them to be more genuine and less restrained in expressing their feelings. This ultimately helps our young patients find the resources and the venues they need to cope with the life-changing experience of being diagnosed and treated for cancer in as positive a manner as possible.

**FIGURE 3** "Looking at a photo of how you were before the cancer can hurt, but it's easier if you do it with your best friend, who has shaved her head like you in a gesture of affection that only a real friend can make" (Lucia)

## 2021



*Short Communication*

TJ Tumori Journal

### "Based on a true story" podcast: a journey into the world of young patients with cancer

Tumori Journal
1–5
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SAGE

**Andrea Ferrari**[1], **Matteo Silva**[1], **Gianfelice Facchetti**[1],

lt patients with cancer as part
lual aim of optimizing medical
ased on audio recordings and
nor of the cancer experience.
heir disease and how they feel
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//ilprogettogiovani.org) is run
mori in Milan (Italy) for ado-
A) patients. Alongside medi-
atient access to clinical trials),
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4 — *Tumori Journal 00(0)*

**Figure.** Front cover of the podcast, with photographs taken by the young participants.

designed to draw the attention of the scientific community and general public to the reality of cancer in the young. Many cancers can be cured, but only if the patient receives the right treatment, at the right time, and in the right place: AYAs need specialized centers and dedicated projects.[21]

**Acknowledgements**

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"Like autumn leaves, my hair falls in front of the mirror, and winter arrives in an instant. It doesn't take much, just a bit of sunshine, a guitar and an innocent smile on the face of spring, and we can **breathe the summer air again**" (Daniele, 21 years, rhabdomyosarcoma)

"So I emptied the suitcase. I took out all the clothes for going out dancing and I filled it instead with strength, hope, saintly patience, courage and determination - and lots of pajamas, of course. I looked in the mirror and said to myself, '**Now it's up to you**'" .
(Giorgia, 18 years, sarcoma of the kidney)

**2022**


*Correspondence*

TJ | Tumori Journal

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2022, Vol. 108(2) 189–190

DOI: 10.1177/03008916221080189
journals.sagepub.com/home/tmj
SAGE

## Playing cards designed by young cancer patients with the Youth Project in Milan

Andrea Ferrari[1], Matteo Silva[1], Alice Patriccioli[1],
Marco Chisari[2], Carlo Alfredo Clerici[1,3]
and Maura Massimino[1]

**Abstract**
This short piece briefly describes a creative project undertaken by a group of adolescent and young adult cancer patients as part of our Youth Project (a scheme dedicated to young cancer patients with the dual aim of optimizing medical aspects of their care and promoting a holistic approach to their needs, including the organization of artistic activities). In this project, young cancer patients designed their personalized playing cards, with kings receiving chemo, queens wearing bandanas, jacks dressed as nurses, and jokers as doctors. The playing cards, with the patients' own words, contain a little bit of these young cancer patients' stories in them.

"Talking about **magic** when we're undergoing chemotherapy helps us to see beauty even where there is none. These cards depict us, and our magicians, our doctors and nurses. Magic is something inexplicable, something you don't expect, like a laugh and a hug on a pediatric oncology ward"
(Edoardo, 17 years, osteosarcoma)


IL PROGETTO GIOVANI PRESENTA

**Come per magia**

Intervengono:
I ragazzi del Progetto Giovani
Mago Tittix
Dott.Andrea Ferrari - responsabile Progetto Giovani
Dott.ssa Maura Massimino - Direttore Struttura Complessa Pediatria Oncologica INT
Dott. Marco Luigi Votta - Presidente INT
Dott. Carlo Nicora - Direttore generale INT

Modera: Edoardo Rosati - giornalista scientifico

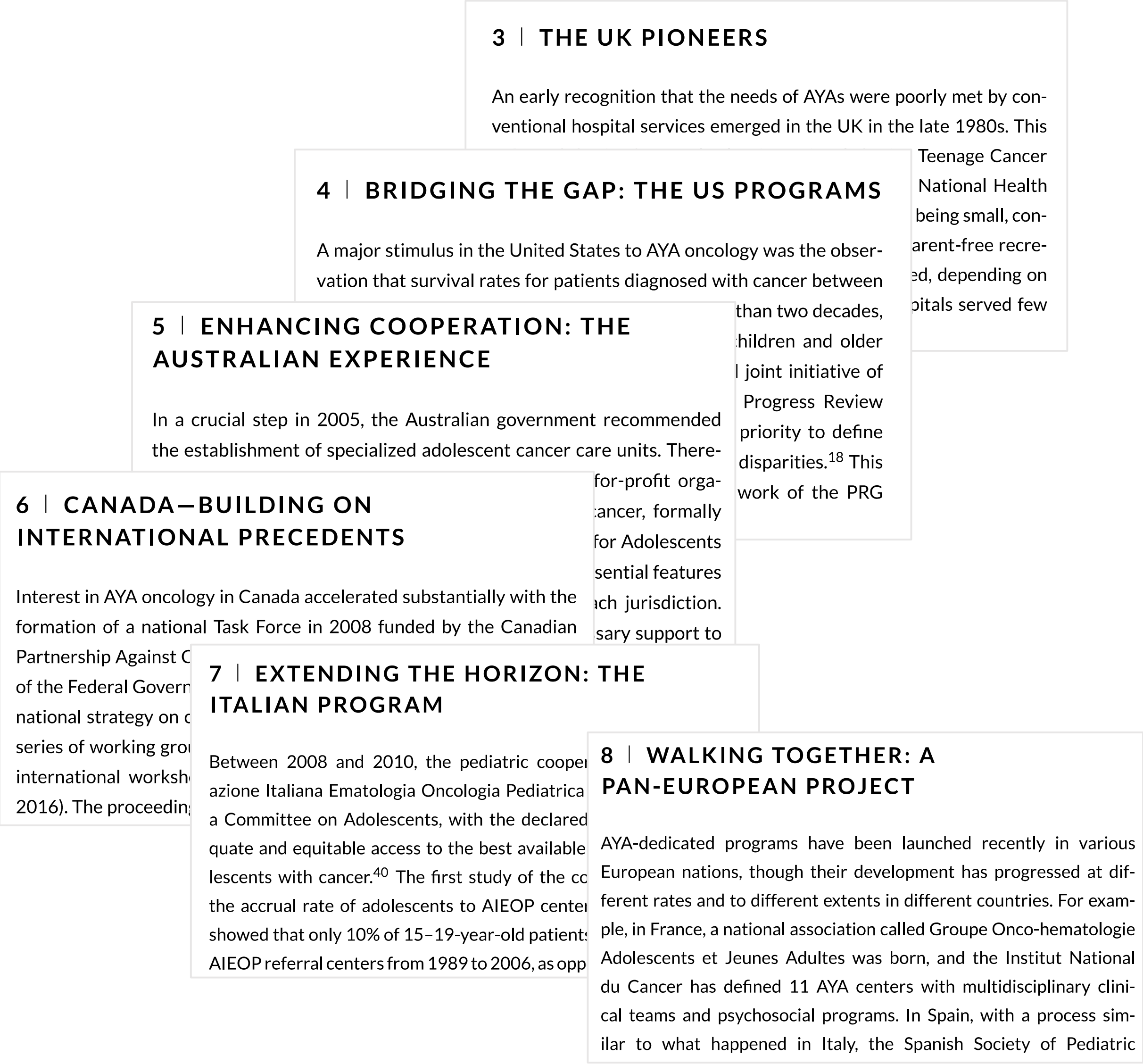
**7 GIUGNO – ORE 11 – AULA MAGNA DELL' INT**

“The Youth Project gave me the opportunity to make a friend of my fears…

and we’ve even had a lot of fun…

…but you need to understand that this is ***Science***, it is ***Science of the Suol***”

(Camilla, 22 years, osteosarcoma)



## 3 | THE UK PIONEERS

An early recognition that the needs of AYAs were poorly met by conventional hospital services emerged in the UK in the late 1980s. This
Teenage Cancer
National Health
being small, con-
arent-free recre-
ed, depending on
pitals served few

## 4 | BRIDGING THE GAP: THE US PROGRAMS

A major stimulus in the United States to AYA oncology was the observation that survival rates for patients diagnosed with cancer between
than two decades,
hildren and older
l joint initiative of
Progress Review
priority to define
disparities.[18] This
work of the PRG

## 5 | ENHANCING COOPERATION: THE AUSTRALIAN EXPERIENCE

In a crucial step in 2005, the Australian government recommended the establishment of specialized adolescent cancer care units. There-
for-profit orga-
ancer, formally
for Adolescents
sential features
ach jurisdiction.
sary support to

## 6 | CANADA—BUILDING ON INTERNATIONAL PRECEDENTS

Interest in AYA oncology in Canada accelerated substantially with the formation of a national Task Force in 2008 funded by the Canadian
Partnership Against C
of the Federal Govern
national strategy on c
series of working grou
international worksh
2016). The proceedin

## 7 | EXTENDING THE HORIZON: THE ITALIAN PROGRAM

Between 2008 and 2010, the pediatric cooper
azione Italiana Ematologia Oncologia Pediatrica
a Committee on Adolescents, with the declared
quate and equitable access to the best available
lescents with cancer.[40] The first study of the co
the accrual rate of adolescents to AIEOP center
showed that only 10% of 15–19-year-old patients
AIEOP referral centers from 1989 to 2006, as opp

## 8 | WALKING TOGETHER: A PAN-EUROPEAN PROJECT

AYA-dedicated programs have been launched recently in various European nations, though their development has progressed at different rates and to different extents in different countries. For example, in France, a national association called Groupe Onco-hematologie Adolescents et Jeunes Adultes was born, and the Institut National du Cancer has defined 11 AYA centers with multidisciplinary clinical teams and psychosocial programs. In Spain, with a process similar to what happened in Italy, the Spanish Society of Pediatric

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DOI: 10.1002/pbc.26528

**REVIEW**

WILEY Pediatric Blood & Cancer SIOP aspho The American Society of Pediatric Hematology/Oncology

# International evolution in AYA oncology: Current status and future expectations

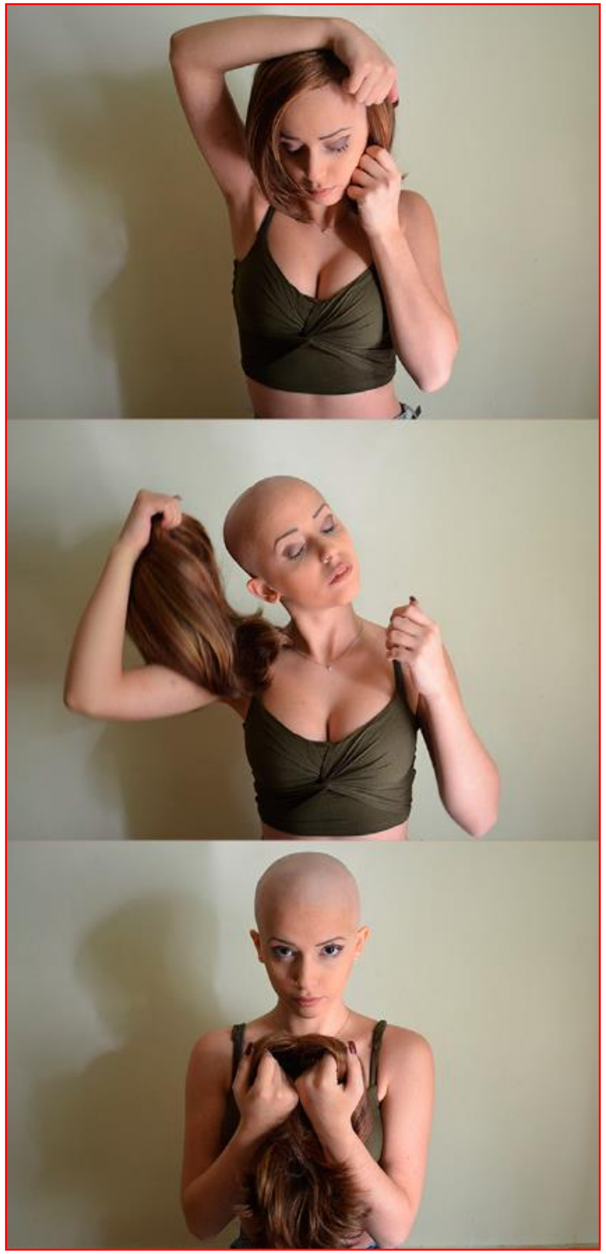
Andrea Ferrari[1] | Ronald D. Barr[2]

2007

# “first” AIEOP Committee on Adolescents

Italy has tried to deal with the increasing demand for AYA-specific care and a first nationwide project began in 2007, promoted by the Italian Association for Pediatric Hematology-Oncology (Associazione Italiana Ematologia Oncologia Pediatrica [AIEOP])

The AIEOP Adolescents Committee launched various initiatives, in particular, various projects aimed to induce the scientific community to pay more attention to these patients, and to organize educational projects designed for teenagers and their families.



A few examples worth mentioning are:

- a campaign called “**There’s no reason why**” (to improve awareness that cancer can develop in adolescence)

- the **#fattivedere** campaign (an Italian term with the dual meaning of “Don’t hide!” and “Get a check-up”) aimed at helping young people to interpret any symptoms they experience, seek medical advice, and arrive at an earlier diagnosis;

TJ
ISSN 0300-8916
Tumori 2016; 102(3): 270-275
DOI: 10.5301/tj.5000493
ORIGINAL RESEARCH ARTICLE

“There’s no reason why”: a campaign to raise cancer awareness among adolescents

Chiara Magni[1], Francesca Maggioni[2,3], Angelo Ricci[3], Elena Barisone[4], Momcilo Jankovic[5], Emma Sarlo Postiglione[3], Enrica Cargnel[6], Barbara Rita Barricelli[7], Stefano Valtolina[7], Laura Veneroni[1], Stefano Chiaravalli[1], Pietro Lapidari[1], Mirko Capelletti[1], Carlo A. Clerici[1,8], Andrea Biondi[5], Andrea Ferrari[1]

Early diagnosis is important. It comes from you.

- If you feel a **pain** that doesn’t have any other medical reason and that always comes back
- If you have a **swelling** you don’t know where it comes from and that doesn’t heal in many weeks
- If you have been feeling **tired** for a long time, with no clear reason
- If you often have **bleedings**
- If you have been losing a lot of **weight** in the past weeks
- If you have a **mole** that changed its form, color or dimension
- If you experience any long lasting **symptom** that you don’t understand,

Don’t panic: consider there may be lots of explanations for it but just to be sure, we suggest you see your doctor

A few examples worth mentioning are:

- a campaign called “**There’s no reason why**” (to improve awareness that cancer can develop in adolescence)
- the **#fattivedere** campaign (an Italian term with the dual meaning of “Don’t hide!” and “Get a check-up”) aimed at helping young people to interpret any symptoms they experience, seek medical advice, and arrive at an earlier diagnosis;
- The congress “**The hospital that I, as an adolescent, would like**”, organized by SIAMO and FIAGOP with the support of the Italian Health Ministry

Among the speakers at the convention, alongside medical and psychological professionals, there were also several adolescent cancer patients involved in the Youth Project.

Our patients told us what they expected from the medical and nursing staff taking care of them, and what kind of facilities made life easier when they had to spend a lot of time in the pediatric oncology ward.

A few examples worth mentioning are:

- a campaign called “**There’s no reason why**” (to improve awareness that cancer can develop in adolescence)
- the **#fattivedere** campaign (an Italian term with the dual meaning of “Don’t hide!” and “Get a check-up”) aimed at helping young people to interpret any symptoms they experience, seek medical advice, and arrive at an earlier diagnosis;
- The congress “**The hospital that I, as an adolescent, would like**”, organized by SIAMO and FIAGOP with the support of the Italian Health Ministry
- the “**Winners’ Cup**” (a football tournament for adolescents with cancer or a history of cancer that, in its third edition in 2019, involved young people from eight different European countries.

TJ
ISSN 0300-8916

Tumori 2017; 103(4): e25-e29
DOI: 10.5301/tj.5000655

SHORT COMMUNICATION

Online
Only

## Winners’ Cup: a national football tournament brings together adolescent patients with cancer from all over Italy

Matteo Silva[1], Marco Chisari[1], Stefano Signoroni[2], Alberto Bassani[3], Luca Tagliabue[4], Angelo Ricci[5], Mirco Daversa[5], Massimo Achini[4], Filippo Spreafico[1], Michele Murelli[1], Giuseppe Maria Milano[6], Gianni Bisogno[7], Luca Coccoli[8], Massimo Conte[9], Alberto Garaventa[9], Paolo Indolfi[10], Silverio Perrotta[10], Marco Spinelli[11], Federico Mercolini[7], Pietro Soloni[7], Marta Pierobon[7], Andrea Di Cataldo[12], Teresa Perillo[13], Maurizio Mascarin[14], Elisa Coassin[14], Laura Veneroni[1], Michela Casanova[1], Maura Massimino[1], Andrea Ferrari[1]

such as the FIAGOP parents’ associations, the FC Internazionale Milano professional football club and its sponsor Pirelli, and the Milan committee of the Centro Sportivo Italiano (CSI) (a national body for sports and social promotion), under the auspices of the Comitato Olimpico Nazionale Italiano (The National Olympic Sports Committee). The basic idea of SIAMO was to induce its various pediatric cancer treatment centers to form a group of adolescents, starting with a football team. This could then prompt the development of other local projects dedicated to these adolescents with cancer being treated at the various Italian oncology units. The football tournament was held on April 22, 2017, in Milan, at the Centro Sportivo di Formazione Suning in Memoria di Giacinto Facchetti, owned by the FC Internazionale. There were 12 teams involved, representing a total of 16 different pediatric oncology centers from all over Italy (some teams were formed in cooperation by several centers): Milan, Monza, Genova, Padova, Rome, Bologna, Modena, Napoli, Bari, Pisa/Firenze, Aviano/Udine/Trieste, and Palermo/Catania. The tournament was held from 8 AM until late in the evening, with 3 rounds of 4 teams each, semifinals, and finals, for a total of 22 matches (Figs. 1 and 2). Each team consisted of 12 players from 15 to 24 years old (mainly male, but also female), all patients who were being treated for cancer or had already completed their therapies. The teams were accompanied by 4 adults (generally physicians or nurses, or members of parents’ associations). The Winners’ Cup thus involved 144 adolescent patients who met in Milan to play football together and share their stories (Fig. 3). The teams stayed 2 nights in hotels near the football field and this made it easier for participants to socialize. The players were also followed by numerous supporters from all over Italy, in many cases other patients who could not play themselves for various reasons. About 600 people watched the matches.

An event of this kind had never been attempted before in Italy. Bringing together such a large group of patients from all over the country for such a festive occasion, to play sports and swap their experiences of cancer, proved an extraordinary success, also arousing the interest of the mass media, including the national television channels. This gave SIAMO a chance to bring these young people into the spotlight, telling the stories of their courage and of their ability to carry on normally. It was also an opportunity to speak about the special needs of these patients, who live in a no man’s land between the worlds of pediatric and adult oncology, and who are entitled to their own spaces and to dedicated projects.

The attention of the media was facilitated partly by the popularity of football as a sport in Italy, but also by the Winners’ Cup anthem, which was circulated on the web. The song—“Uniti per vincere” (United to win) —was written by the adolescents on the Youth Project in Milan and the musician Stefano Signoroni (the same team produced a successful Christmas carol called “Palle di Natale”) (15, 16). The video of the song (https://www.youtube.com/watch?v=OuwQckowZxw) also features contributions from patients in Bari, Genova, and Padova. The lyrics (Tab. II) repeatedly say “we are,” which in Italian reads exactly the same as the acronym SIAMO.

### *Sport as a medicine to help combat disease*

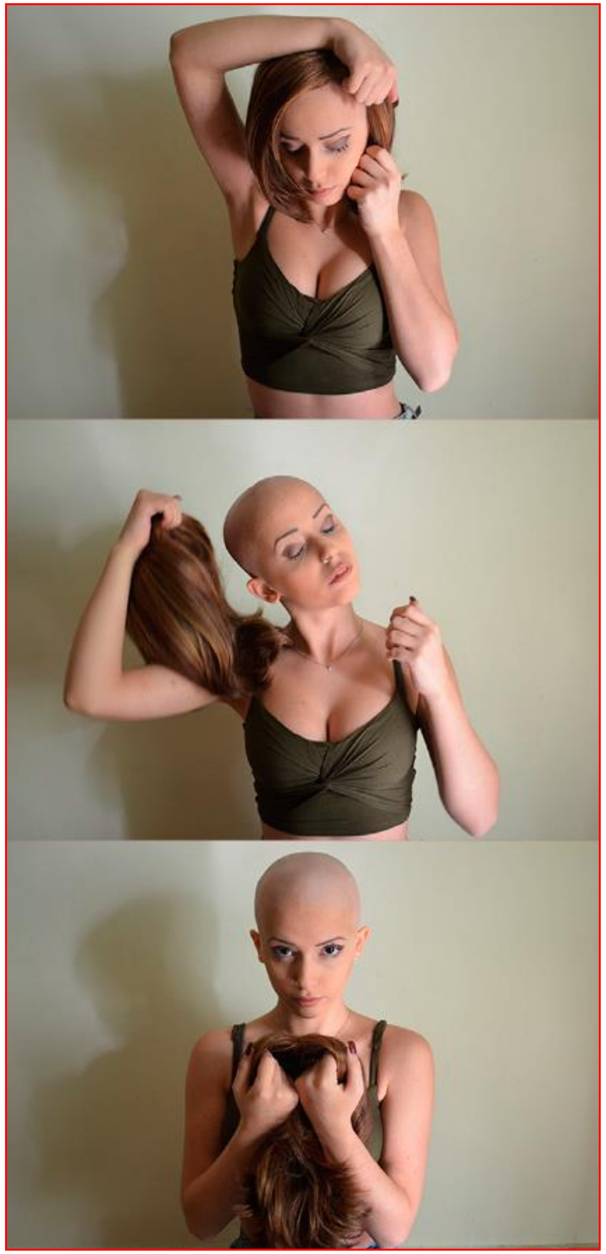
The adolescents want to “change reality.” They are “united to win.” By coming together, and playing sports together, they want to combat the reality of their disease. For young cancer

Fig. 1 - Players in one of the teams taking part in the Winners’ Cup egg each other on before the match. Picture by Pietro Ferrari.

Fig. 2 - An action during one of the Winners’ Cup matches. Picture by Pietro Ferrari.

Fig. 3 - After the prize-giving, the adolescents and the adults accompanying them gather in the field for a group photograph. Picture by Pietro Ferrari.

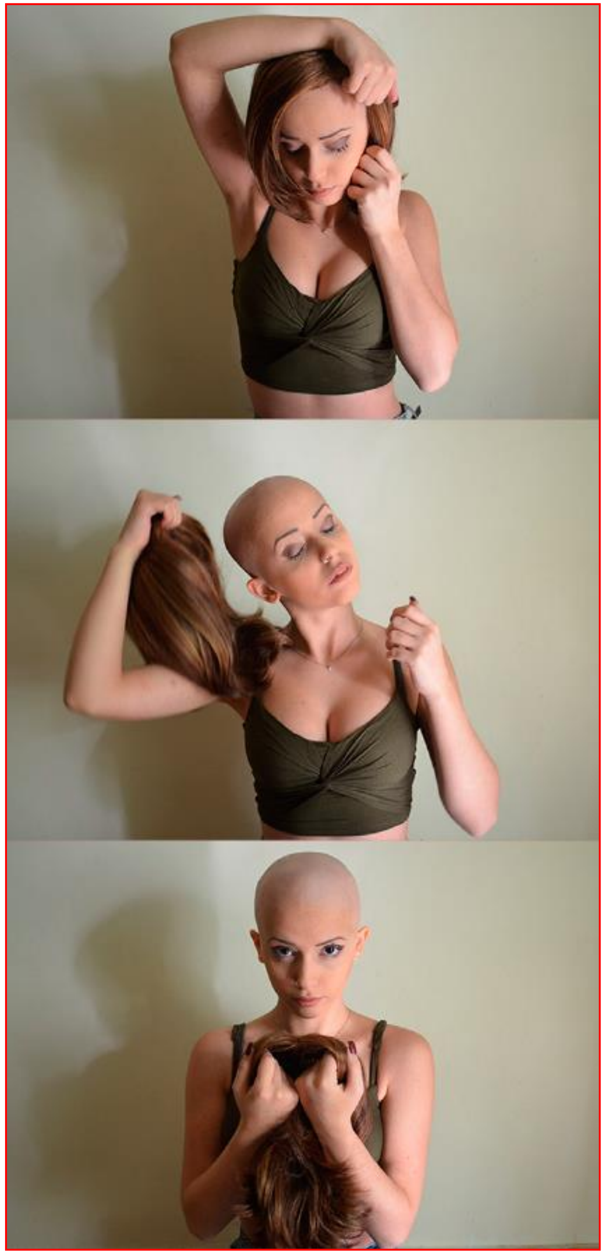
2007 “first” AIEOP Committee on Adolescents



2007 “first” AIEOP Committee on Adolescents

2014

A national project called SIAMO (Società Italiana Adolescenti con Malattie Onco-ematologiche [Italian Society for Adolescents with Onco-hematological Diseases]) was launched in 2014 as an extension of the AIEOP Committee on Adolescents.
The aim was to create a broad-based, comprehensive national platform together with scientific societies focusing on adult oncology (and other stakeholders, such as parents’ associations).
Unfortunately, efforts to develop a genuinely effective collaboration between pediatric and adult oncologists failed, and, given the lack of support from the Italian national health service and government, the SIAMO project was abandoned in June 2018



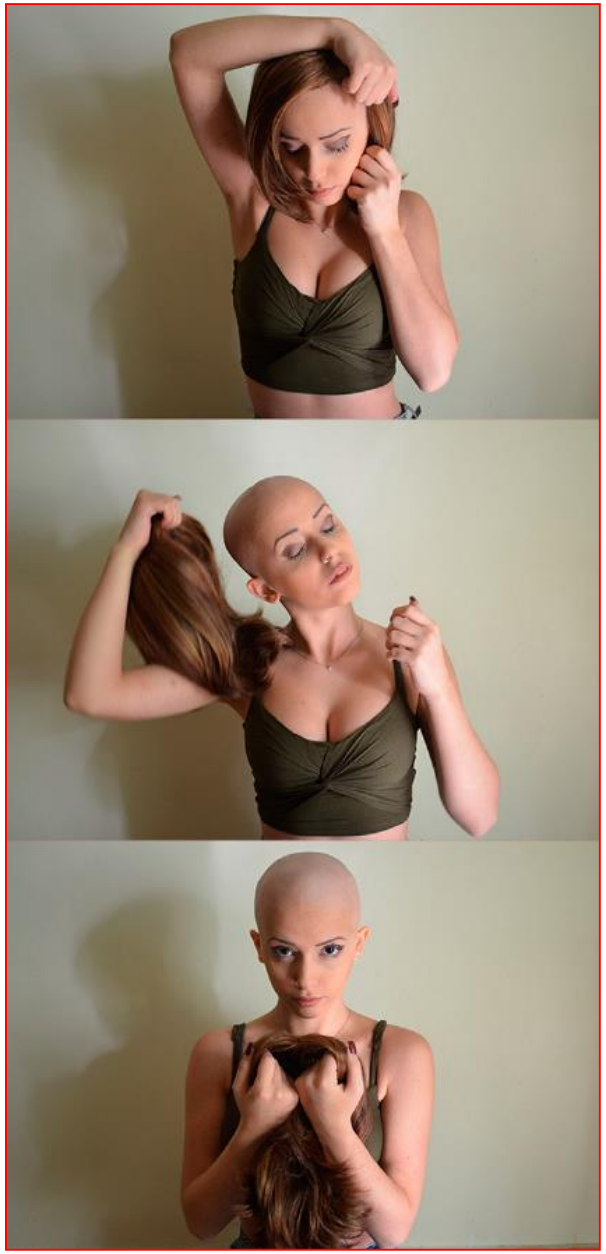
2007 “first” AIEOP Committee on Adolescents

2014 SIAMO

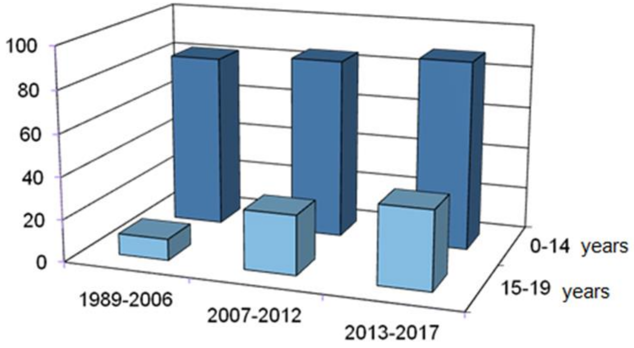
2018 “second” AIEOP Committee on Adolescents

2020 AIEOP Adolescent Working Group

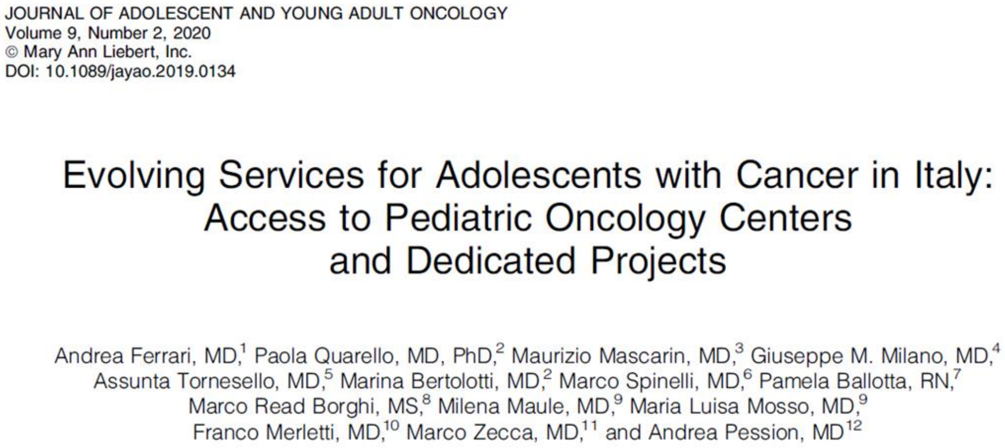
The effort of AIEOP to improve adolescents’ access to AIEOP centers, raising awareness that adolescents can suffer from cancer, and promoting cooperation with the world of adult medical oncology however continued.



- The percentage of adolescents treated at AIEOP centers has increased over the years, with the O/E ratio rising from 10% in 1989–2006 to 28% in 2007–2012, to **37%** in 2013–2017



- Nowadays only a minority (**20%**) of AIEOP centers still set age limits for patient admission <18 years (and they are units with low patient volumes).
- This should be seen as an important improvement vis-a`-vis the situation described 10 years ago, when 44% of AIEOP centers imposed age limits at 16, 15, or even 14 years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Evolving Services for Adolescents with Cancer in Italy:
Access to Pediatric Oncology Centers
and Dedicated Projects

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Franco Merletti, MD,[10] Marco Zecca, MD,[11] and Andrea Pession, MD[12]

- A survey also showed that 19 AIEOP centers now have specific projects in place for adolescents.
- Ten years ago, only two Italian centers had attempted to organize tai-lored projects for them)

2007 “first” AIEOP Committee on Adolescents

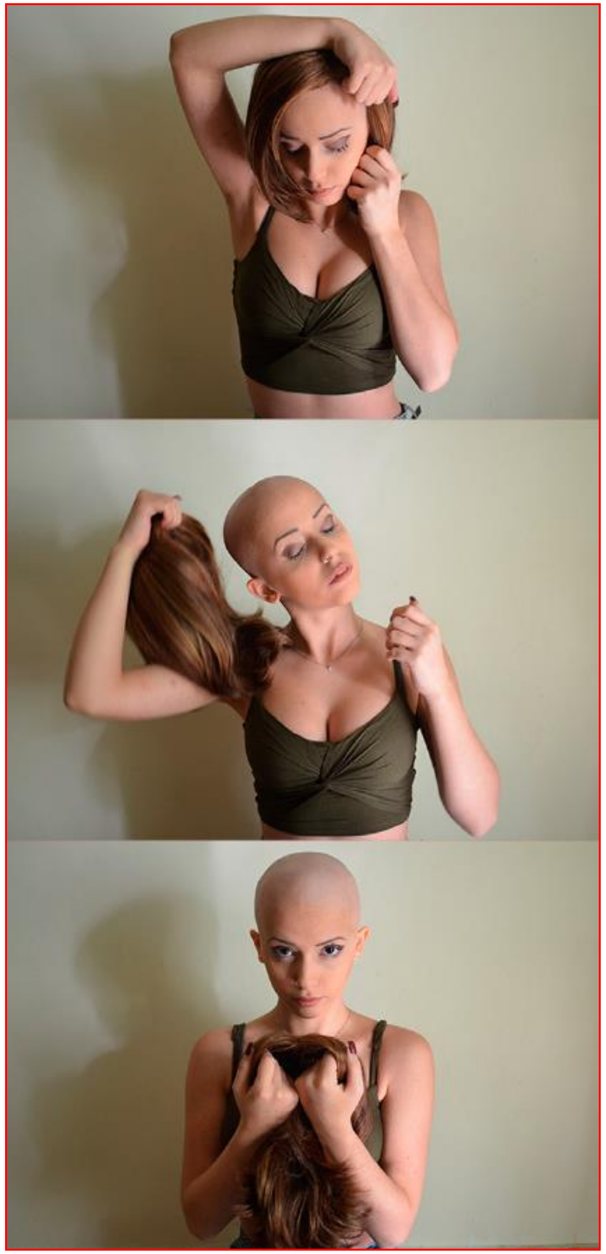
2014 SIAMO

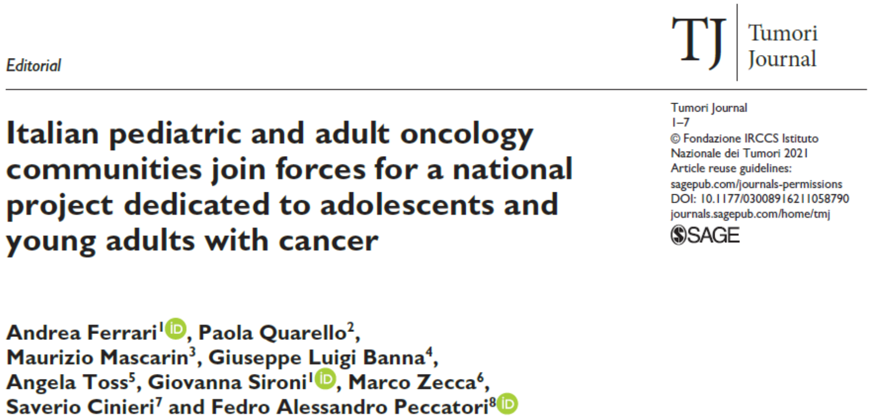
2018 “second” AIEOP Committee on Adolescents

2020 AIEOP Adolescent Working Group

2021 **AIEOP-AIOM Working Group dedicated to AYAs**

Efforts to achieve a closer collaboration between pediatric and adult oncologists on the topic of AYAs have continued to be made, and - in April 2021 - the Italy’s adult medical oncology society (AIOM - Associazione Italiana di Oncologia Medica) joined forces with the AIEOP to set up a formal AIEOP-AIOM Working Group dedicated to AYAs.





*Editorial*

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**Italian pediatric and adult oncology communities join forces for a national project dedicated to adolescents and young adults with cancer**

**Andrea Ferrari[1], Paola Quarello[2], Maurizio Mascarin[3], Giuseppe Luigi Banna[4], Angela Toss[5], Giovanna Sironi[1], Marco Zecca[6], Saverio Cinieri[7] and Fedro Alessandro Peccatori[8]**

2014

2018

2020

2021 **AIEOP-AIOM Working Group dedicated to AYAs**

- to formalize the **collaboration between pediatric and adult oncologists**;
- to **raise awareness** regarding cancer in AYA age by producing **educational projects** and making them available via e-learning platforms;
- to promote **clinical and biological research** on cancer in AYAs
- to draw up **clinical recommendations** or guidelines on various topics common to both societies;
- to promote cooperation with potential **stakeholders**;
- to establish (in an institutionally-shared document) the **essential structural and functional characteristics** for a center to be considered suitable for the clinical management of adolescent patients, with the aim of identifying a network of specifically dedicated onco-hematological centers - be they medical oncology or pediatric oncology units - distributed all over the country;
- to earn **institutional recognition** in order to make the program sustainable, make local programs part of a comprehensive national approach, and adopt a standard of care, the final goal being to establish a comprehensive national approach supported by the central government and the Italian national health system;
- to decide on the best approach to treating adolescent patients with onco-hematological diseases, starting from the patients' needs, from "**what is best for them**", and always bearing in mind the importance of involving the patients themselves.

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19 – 20 September 2022

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Milan (Italy)

CO-PRESIDENTS OF THE CONGRESS
Fedro Alessandro Peccatori e Andrea Ferrari

Thank you very much for your attention