



Sex, love and rock 'n roll

Fedro Alessandro Peccatori

Istituto Europeo di Oncologia, Milano

Bologna, 4/10/2023

XLVIII

CONGRESSO NAZIONALE

AIEOP

Bologna

2-4 Ottobre 2023

Il sottoscritto Fedro A Peccatori

*ai sensi dell'art. 3.3 sul Conflitto di Interessi, pag. 17 del Reg.
Applicativo dell'Accordo Stato-Regione del 5 novembre 2009,
dichiara*

*che negli ultimi due anni **NON** ha avuto rapporti diretti di
finanziamento con soggetti portatori di interessi commerciali in
campo sanitario*

- ✓ Più che bambini -> **adolescenti e giovani adulti (AYA)**
- ✓ Trattare un adolescente/giovane adulto con tumore necessita di una **equipe multidisciplinare** che comprenda medici, infermieri, psicologi, etc con competenze di **pediatria oncologica**, ma anche di **oncologia dell'adulto**



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Search

ESMO > About ESMO > Organisational Structure > Educational Committee > Adolescents and Young Adults Working Group

ESMO/SIOPE ADOLESCENTS AND YOUNG ADULTS WORKING GROUP: MAJOR ACHIEVEMENTS

2022

- Contribution to the [Handbook of Cancer in Adolescents and Young Adults](#)

2021

- [Adolescents and young adults \(AYA\) with cancer: a position paper from the ESMO/SIOPE AYA Working Group published in the ESMO Open](#)
- [ePoster at ESMO Congress 2021](#)

2020

- [Special Session at the ESMO Virtual Congress 2020: Research in AYA with cancer: Age-specific challenges and ways forward](#)

Related Links

[Adolescents and Young Adults Working Group](#)

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)

A. Ferrari^{1,2}, D. Stark^{3,4}, F. A. Peccatori⁵, L. Fern⁶, V. Laurence⁷, N. Gaspar⁸, I. Bozovic-Spasovic⁹, O. Smith¹⁰, J. De Munter¹¹, K. Derwich¹², L. Hjorth¹³, W. T. A. van der Graaf¹⁴, L. Soanes¹⁵, S. Jezdic¹⁶, A. Blondeel¹⁷, S. Bielsack¹⁸, J.-Y. Douillard¹⁹, G. Mountzios²⁰ & E. Saloustros²¹

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Available online 23 March 2021

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 key 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 community⁴ and it is now well documented that traditional health care models do not meet the unique needs of AYA.^{5,6}

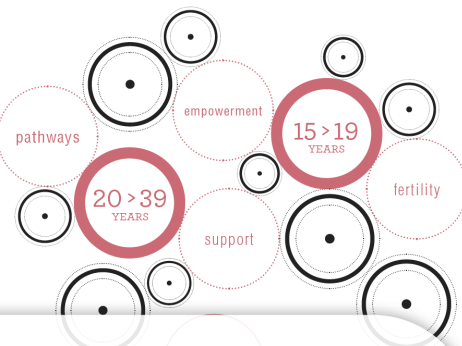
¹Correspondence to: Prof. Andrea Ferrari and Prof. Daniel Stark, ESMO Head Office, Via Giuseppe 4, CH-6900 Lugano, Switzerland. Tel.: +41 91 973 1999; SIOPe Head Office, Clos Chêvreuil-avenue Champ 30, 1200 Brussels, Belgium. Tel.: +32 2 880 62 82.

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ESMO HANDBOOK OF CANCER IN ADOLESCENTS AND YOUNG ADULTS

Edited by Giannini Mountzios, Stefan S. Bielsack, Niven Mehra

ORIGINAL RESEARCH

Cancer burden in adolescents and young adults in Europe

A. Trama^{1*}, D. Stark², I. Bozovic-Spasojevic³, N. Gaspar⁴, F. Peccatori⁵, A. Toss⁶, A. Bernasconi¹, P. Quarello^{7,8},
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Available online 6 February 2023

Background: Cancer epidemiology is unique in adolescents and young adults (AYAs; aged 15-39 years). The European Society for Medical Oncology/European Society for Paediatric Oncology (ESMO/SIOPE) AYA Working Group aims to describe the burden of cancers in AYAs in Europe and across European Union (EU) countries.

Patients and methods: We used data available on the Global Cancer Observatory. We retrieved crude and age-standardised (World Standard Population) incidence and mortality rates. We reported about AYA cancer burden in Europe and between 28 EU member states. We described incidence and mortality for all cancers and for the 13 cancers most relevant to the AYA population.

Results: Incidence and mortality varied widely between countries with the highest mortality observed in Eastern EU countries. Cancers of the female breast, thyroid and male testis were the most common cancers across countries followed by melanoma of skin and cancers of the cervix. Variations in cancer incidence rates across different populations may reflect different distribution of risk factors, variations in the implementation or uptake of screening as well as overdiagnosis. AYA cancer mortality disparities may be due to variation in early-stage diagnoses, different public education and awareness of cancer symptoms, different degrees of access or availability of treatment.

Conclusions: Our results highlight the future health care needs and requirements for AYA-specialised services to ensure a homogeneous treatment across different countries as well as the urgency for preventive initiatives that can mitigate the increasing burden.

Key words: adolescents and young adults, cancer, incidence, mortality, population-based cancer registry

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<https://doi.org/10.1016/j.esmoop.2022.100744>

Lettera di intenti

Creazione di un gruppo di lavoro intersocietario AIOM-AIEOP dedicato ai pazienti adolescenti e giovani adulti con tumore

Gli adolescenti e i giovani adulti rappresentano un sottogruppo di pazienti particolari che necessitano di approcci clinici dedicati. Agli aspetti psico-sociali relativi a questa fascia di età, si aggiungono elementi clinici come il problema di accesso alle cure e di arruolamento nei protocolli clinici, la particolare epidemiologia e la mancanza di studi biologici dedicati, il problema della preservazione della fertilità, il bisogno di un approccio multidisciplinare che richieda la collaborazione diretta di esperti di varie discipline e la partecipazione congiunta dell'oncologo medico e dell'oncologo pediatrico. Di fatto questi pazienti corrono spesso il rischio di trovarsi in una terra di mezzo tra il mondo dell'oncologia pediatrica e quello dell'oncologia medica dell'adulto.

Negli ultimi anni lo sforzo congiunto delle comunità scientifiche dell'oncologia pediatrica e di quella dell'adulto ha portato alla costituzione di un gruppo europeo dedicato – ESMO-SIOPE AYA Working Group* - nato con obiettivi educazionali e con l'idea di promuovere azioni comuni. Il gruppo ha recentemente pubblicato un position paper che sintetizza gli aspetti clinici principali dei pazienti in questa fascia di età.**

Sul modello della cooperazione ESMO-SIOPE sviluppatasi in ambito europeo, AIOM e AIEOP intendono costituire anche in Italia un gruppo di lavoro intersocietario dedicato ai pazienti adolescenti e giovani adulti con tumore (in AIEOP già esiste un gruppo di lavoro dedicato agli adolescenti).

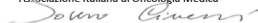
Scopo primario del gruppo è quello di promuovere attività volte ad aumentare la consapevolezza sulle problematiche relative a questi pazienti (sia tra la comunità scientifica che tra la popolazione generale) e pianificare quindi eventuali progetti comuni. Successivamente, il gruppo coinvolgerà anche esperti di altre discipline come ematologi, infermieri e psicologi e gruppi di pazienti e rappresentanti di pazienti.

Con questa lettera di intenti, il Presidente eletto di AIOM ed il Presidente di AIEOP approvano formalmente la costituzione del gruppo di lavoro intersocietario costituito, almeno inizialmente, dai dottori: Andrea Ferrari, Maurizio Mascarin, Paola Quarello (oncologi pediatri) e Fedro Peccatori, Angela Toss, Giuseppe Banna (oncologi medici).

Il gruppo riporterà direttamente ai Professori Cinieri e Zecca.


Prof. Saverio Cinieri
Presidente eletto AIOM

Associazione Italiana di Oncologia Medica



Prof. Marco Zecca
Presidente AIEOP

Associazione Italiana Ematologia Oncologia Pediatrica



GRUPPO INTERSOCIETARIO AIOM-AIEOP

Core members AIEOP:

Andrea Ferrari (Milano)
Paola Quarello (Torino)
Maurizio Mascarin (Aviano)

Core members AIOM:

Fedro Peccatori (Milano)
Angela Toss (Modena)
Giuseppe Banna (UK)




Members AIEOP:

Marta Canesi (Monza)
Giuseppe Milano (Roma)

Members AIOM:

Lorena Incorvaia (Palermo)
Matteo Lambertini (Genova)

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

Andrea Ferrari¹ , Paola Quarello²,
Maurizio Mascarin³, Giuseppe Luigi Banna⁴,
Angela Toss⁵, Giovanna Sironi¹ , Marco Zecca⁶,
Saverio Cinieri⁷ and Fedro Alessandro Peccatori⁸ 

Abstract

Adolescents and young adults with cancer have substantially different clinical and psychological needs compared to those of pediatric patients and of older adult patients. We describe the development of an Italian national project dedicated to adolescents and young adults with cancer.

Keywords

Adolescents, young adults, AYA, Italy, AIEOP, AIOM

APPUNTAMENTI AIOM I MERCOLEDÌ DELL'ONCOLOGIA

"Né adulti, né bambini"

Intergruppo AIOM/AIEOP adolescenti e giovani adulti con cancro

In accordo con la più recente definizione internazionale, si considerano adolescenti e giovani adulti (AYA) i pazienti di età compresa tra i 15 e i 39 anni. Al di là della definizione arbitraria, questi pazienti corrono il rischio di trovarsi in una terra di mezzo tra il mondo dell'oncologia pediatrica e quello dell'oncologia medica dell'adulto. Gli AYA rappresentano un sottogruppo di pazienti particolari che necessitano di approcci clinici dedicati. Agli aspetti psico-sociali relativi a questa fascia di età, si aggiungono elementi clinici come la particolare epidemiologia, il problema di accesso alle cure e all'arruolamento nei protocolli clinici, la peculiarità degli aspetti genetici, il bisogno di un approccio multidisciplinare che richieda la collaborazione diretta di esperti di varie discipline e la partecipazione congiunta dell'oncologo medico e dell'oncologo pediatrico.

AIOM e AIEOP hanno creato un gruppo di lavoro intersocietario dedicato ai pazienti AYA che si propone di promuovere attività volte ad aumentare la consapevolezza sulla problematica relativa a questi pazienti sia tra la comunità scientifica che tra la popolazione generale e pianificare progetti comuni.


- Il gruppo si propone di:
- ▶ promuovere attività di comunicazione, educazione e formazione finalizzate ad aumentare la consapevolezza sulle problematiche cliniche e psico-sociali dei pazienti AYA con tumore
 - ▶ promuovere progetti di ricerca comuni sui pazienti AYA con tumore
 - ▶ favorire lo sviluppo di raccomandazioni cliniche su patologie o argomenti trasversali clinici e psico-sociali dei pazienti AYA
 - ▶ promuovere la collaborazione con potenziali stakeholders
 - ▶ definire le caratteristiche strutturali e funzionali che un centro deve avere per occuparsi di pazienti AYA

PROGRAMMA

- 17.00 - 17.05
| **Presentazione del webinar**
Saverio Cinieri, Francesco Perrone
- Moderano: **Andrea Ferrari, Fedro Peccatori**
- 17.05 - 17.20
| **Overview generale su adolescenti e giovani adulti con cancro**
Maurizio Mascarin
- 17.20 - 17.35
| **L'accesso alle cure e ai protocolli clinici**
Paola Quarello
- 17.35 - 17.50
| **Gli aspetti psicosociali**
Carlo A. Clerici
- 17.50 - 18.05
| **La genetica**
Angela Toss
- 18.05 - 18.15
| **Q&A**
Andrea Ferrari, Fedro Peccatori



Cancer Predisposition Genes in Adolescents and Young Adults (AYAs): a Review Paper from the Italian AYA Working Group

Angela Toss^{1,2} · Paola Quarello^{3,4} · Maurizio Mascarin⁵ · Giuseppe Luigi Banna⁶  · Marco Zecca⁷ · Saverio Cinieri⁸ · Fedro Alessandro Peccatori⁹ · Andrea Ferrari¹⁰

Accepted: 18 November 2021 / Published online: 23 March 2022
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Abstract

Purpose of Review The present narrative systematic review summarizes current knowledge on germline gene mutations predisposing to solid tumors in adolescents and young adults (AYAs).

Recent Findings AYAs with cancer represent a particular group of patients with specific challenging characteristics and yet unmet needs. A significant percentage of AYA patients carry pathogenic or likely pathogenic variants (PV/LPVs) in cancer predisposition genes. Nevertheless, knowledge on spectrum, frequency, and clinical implications of germline variants in AYAs with solid tumors is limited.

Summary The identification of PV/LPV in AYA is especially critical given the need for appropriate communicative strategies, risk of second primary cancers, need for personalized long-term surveillance, potential reproductive implications, and cascade testing of at-risk family members. Moreover, these gene alterations may potentially provide novel biomarkers and therapeutic targets that are lacking in AYA patients. Among young adults with early-onset phenotypes of malignancies typically presenting at later ages, the increased prevalence of germline PV/LPVs supports a role for genetic counseling and testing irrespective of tumor type.

Keywords Adolescents · Young adults · Cancer · Predisposition genes

Editorial

Get up, stand up: Alongside adolescents and young adults with cancer for their right to be forgotten

Paola Quarello^{1,2} , Angela Toss³, Maurizio Mascarin⁴,
Giuseppe Luigi Banna⁵, Marta Canesi⁶ , Giuseppe Maria Milano⁷,
Lorena Incorvaia⁸, Matteo Lambertini^{9,10}, Monica Terenziani¹¹,
Carlo Alfredo Clerici^{11,12}, Giulio Enea Vigevani¹³,
Giordano Domenico Beretta¹⁴, Arcangelo Prete¹⁵,
Saverio Cinieri¹⁶, Fedro Alessandro Peccatori¹⁷ 
and Andrea Ferrari¹¹ 

Abstract

Adolescent and young adult cancer survivors may experience various forms of social difficulties years or even decades after completing their cancer treatments. This article will hopefully help the Italian national project dedicated to adolescents and young adults with cancer promoting political and legal solutions to stop discrimination and supporting the right to be forgotten.

Keywords

Adolescents, young adults, AYA, Italy, right to be forgotten, survivors

Date received: 12 April 2022; accepted: 29 April 2022

Healthcare Professional Communication on Sexual Health: A Report from the Italian Working Group on Adolescents and Young Adults with Cancer

Paola Quarello^{1,2,†}, Angela Toss^{3,4,†}, Paola Berchialla⁵, Maurizio Mascarin⁶,
Matteo Lambertini^{7,8}, Marta Canesi⁹, Giuseppe Maria Milano¹⁰, Lorena Incorvaia¹¹,
Giuseppe Luigi Banna¹², Fedro Peccatori^{*,13,†}, Andrea Ferrari^{14,†}

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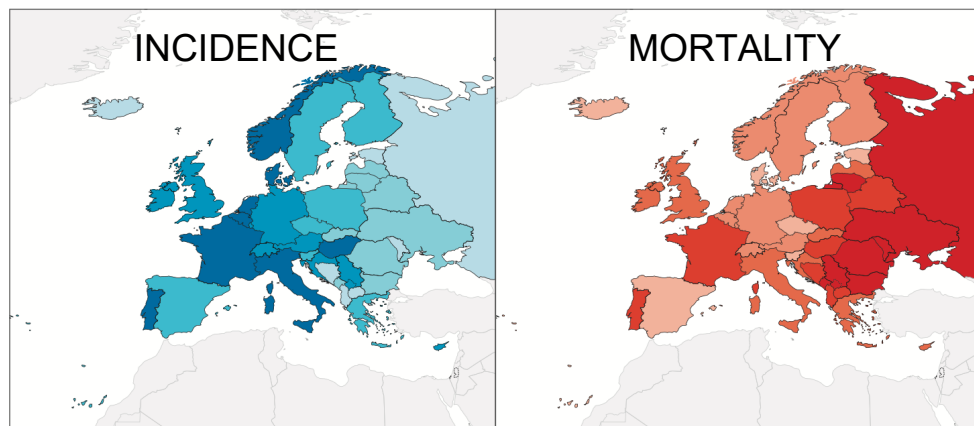
¹³Gynecologic Oncology Department, European Institute of Oncology IRCCS, Milano, Italy

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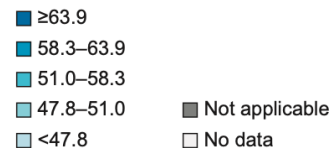
*Corresponding author: Fedro Peccatori, European Institute of Oncology IRCCS, Via Ripamonti 435, 20141 Milano. Email: fedro.peccatori@ieo.it

†Contributed equally.

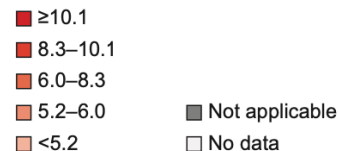
- ✓ AYA with cancer: persone con tumore tra i 15 e i 39 anni
- ✓ 112.000 nuovi casi ogni anno in Europa
- ✓ 12.700 morti



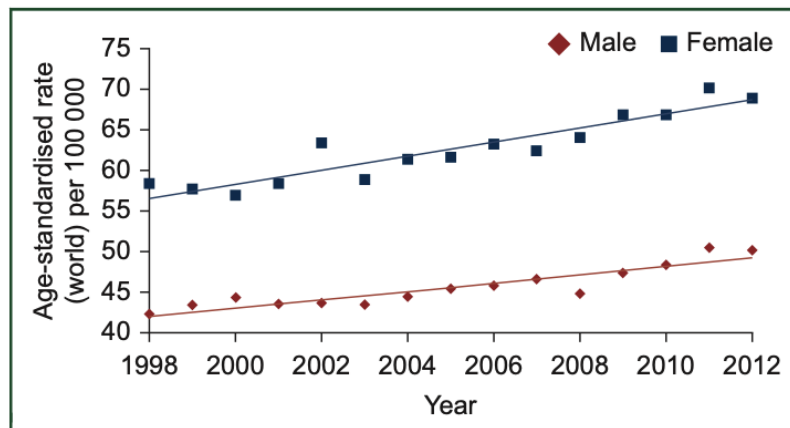
ASR (World) per 100 000



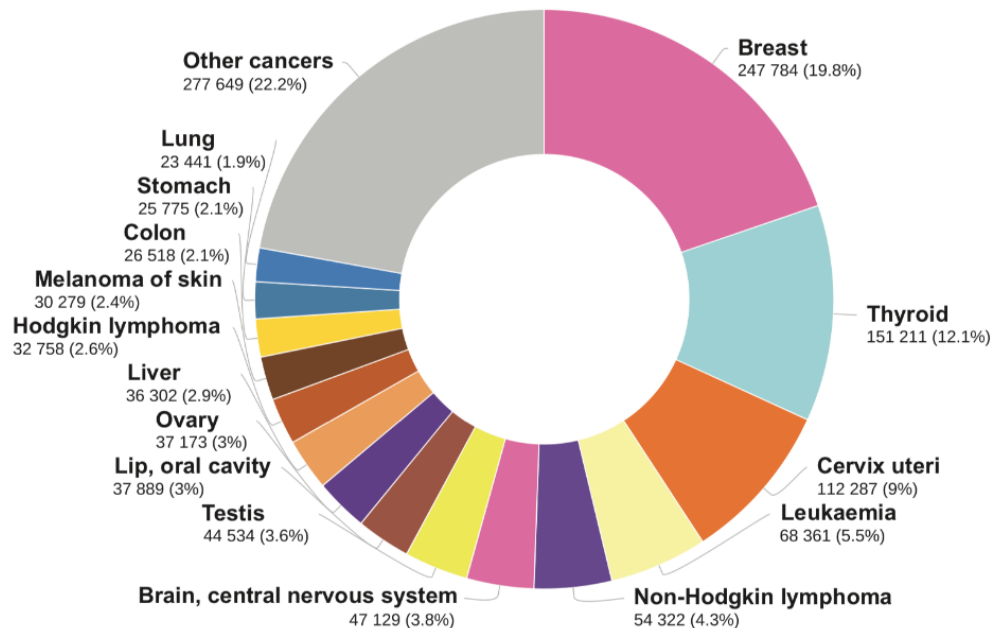
ASR (World) per 100 000



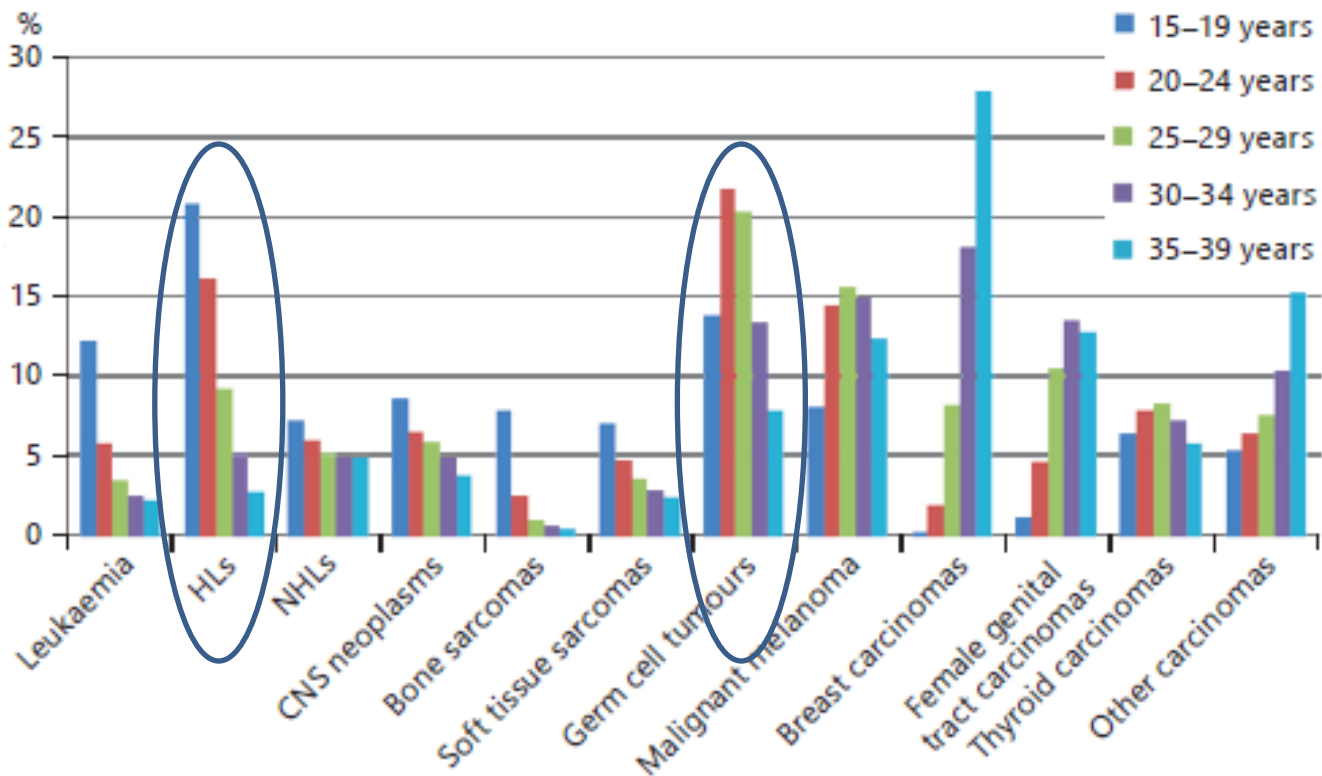
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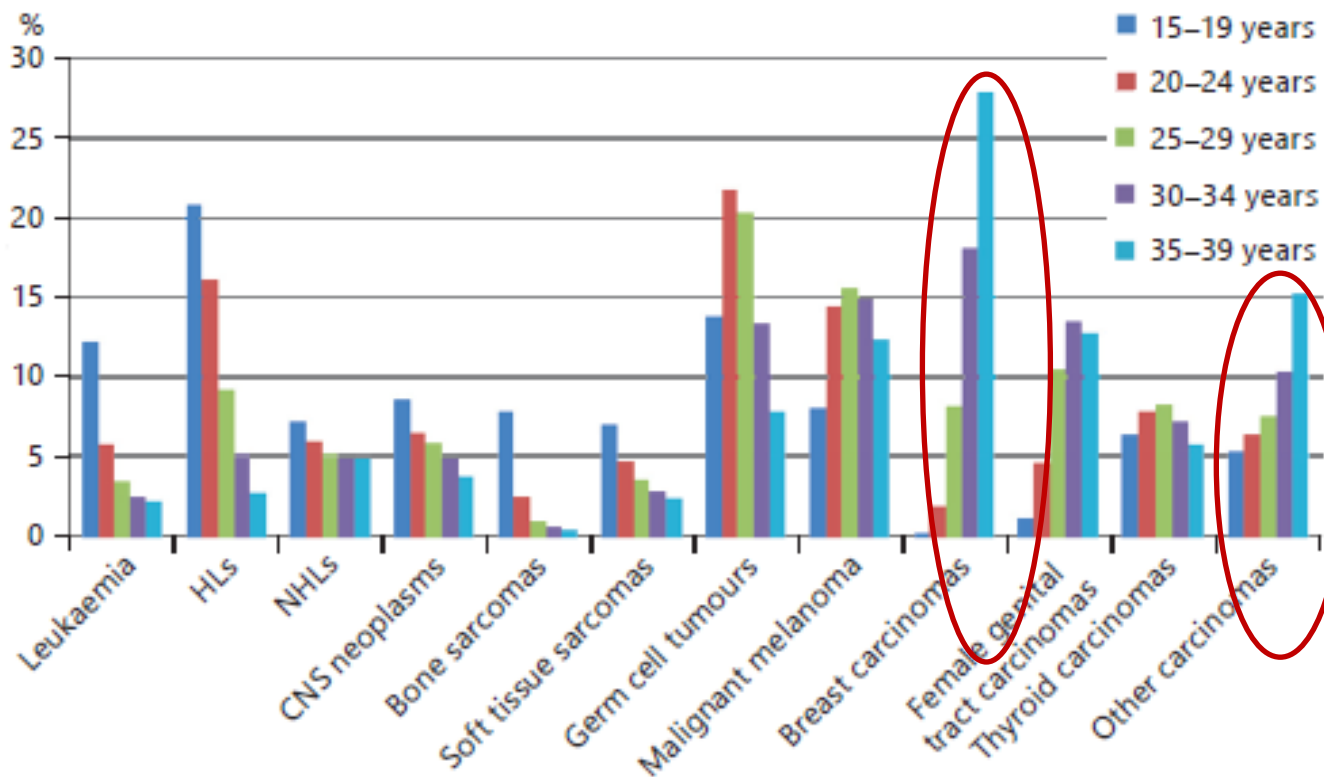


Both sexes



Most frequent cancers in AYAs:
leukaemia, lymphoma, CNS
tumours, bone tumours, STS, GCTs,
melanoma, breast, colorectal and
thyroid.





Special care issues

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). 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. The biology of the host may also differ according to age, with distinct pharmacokinetics and potential impact on therapy efficacy and toxicity profiles. 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: <ul style="list-style-type: none"> • Physical changes. • Development of self-image, identity, relationships, sexuality and independence. • Age-appropriate information and communication challenges, shared decision making, compliance and treatment adherence. • Privacy and peer support. • Peculiar behaviours of this age and risk-taking (including alcohol/substance abuse). • Need for age-specific psychological support.

Special care issues

Issue	Uniqueness
Survivorship and transition	Multiple medical, psychosocial and behavioural late effects. Specific transitions from cancer patients to cancer survivors (and to independent adulthood); transitions in medical management. 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). 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.



Love

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

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

From the St James's University Hospital, London; Leeds Teaching Hospitals Trust, Leeds, United Kingdom; and Western Australian Cancer & Palliative Care Network, Perth, Australia.

Submitted February 21, 2009; accepted March 12, 2010; published online ahead of print at www.jco.org on May 24, 2010.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

A B S T R A C T

Adolescents and young adults (AYAs) with cancer are a distinct group whose needs have been poorly addressed within health care systems. This imbalance is being addressed in some countries, and this growing specialty is now receiving the recognition it requires in order to develop further. This article discusses some of the psychosocial issues of AYAs and, with reference to the phrase of sex, drugs, and rock and roll, highlights the various rites of passage that young people experience. It also discusses how services and professionals can work alongside AYAs, enabling them to feel a part of the process by providing age-appropriate environment and expertise.

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- ✓ Amore: Francesca Bomben
- ✓ Rock 'n' roll: Daniela Greco



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ENJOY & GRAZIE!