

AGORA Therapeutic Patient Education Program for adolescent and young adults (AYA) with cancer: A review of 10 years' experience at Gustave Roussy Cancer Centre

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BACKGROUND

Therapeutic patient education (TPE) is particularly relevant for adolescent and young adult (AYA) cancer patients, providing the resources and skills required to become proactive and to maintain and improve their quality of life during and after cancer care. Gustave Roussy developed a dedicated TPE AYA program "Agora" in 2012. The program is delivered at the hospital, during a visit for treatment, clinic review or other examination. The offer is open to patients. Some workshops are also open to family/friends/partners. Workshops are delivered by two trained experts according to the theme.

RESULTS

Vision for integration of TPE within the patient pathway...

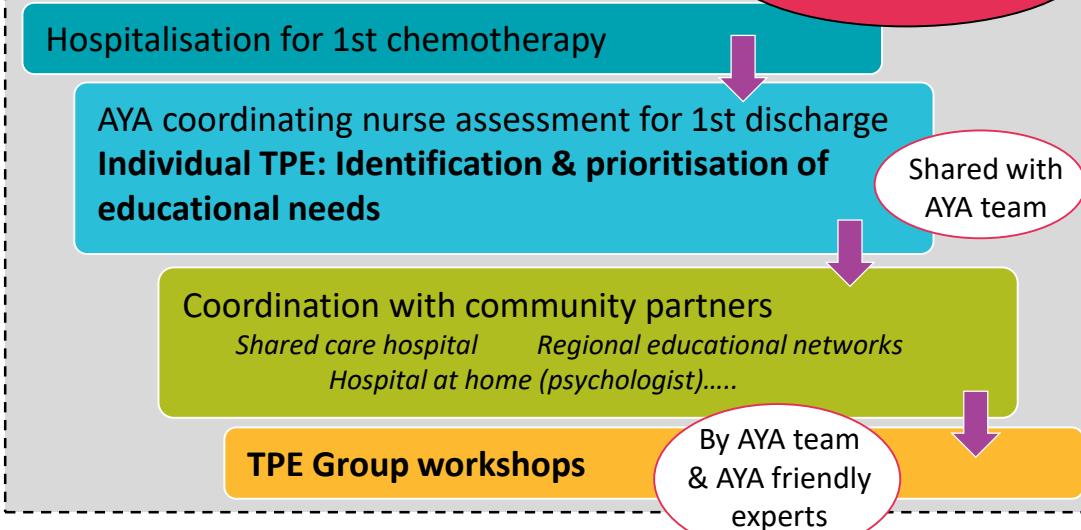
Evaluation of educational needs
 By whom? AYA coordinating nurse (CN) with the patient
 When? After diagnosis, near the start of treatment

Therapeutic alliance
 Priorities agreed conjointly & personalised

Implementation: Therapeutic education workshops
 8 workshops available
 Choice according to patient need / request
 Prioritised according to stage of treatment pathway

Assessment

... and within the care pathway



OBJECTIVE

A review of the development of the program over the last ten years and an analysis of the current offer.

METHODS

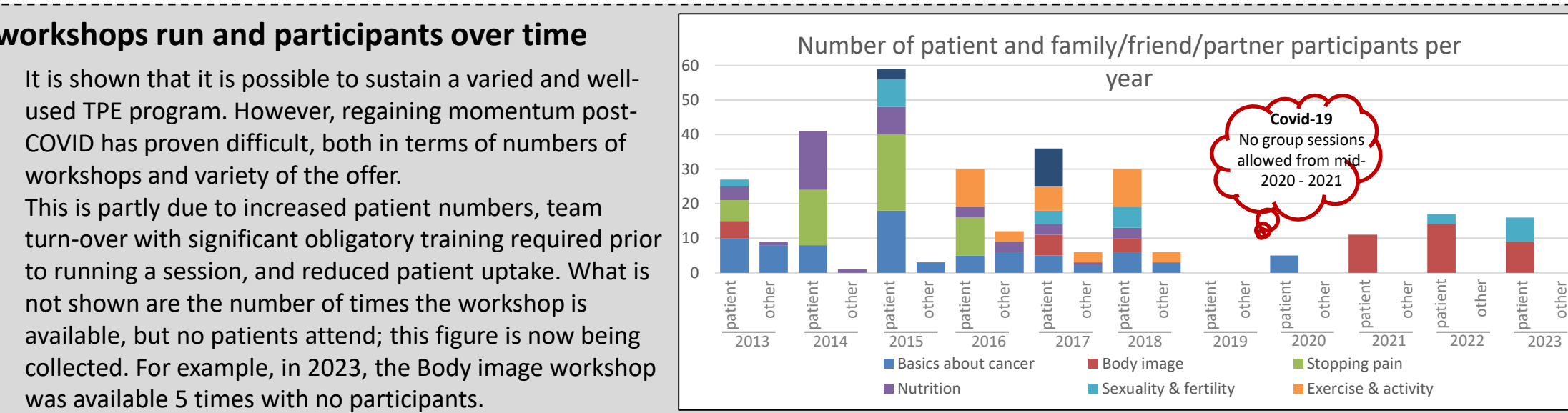
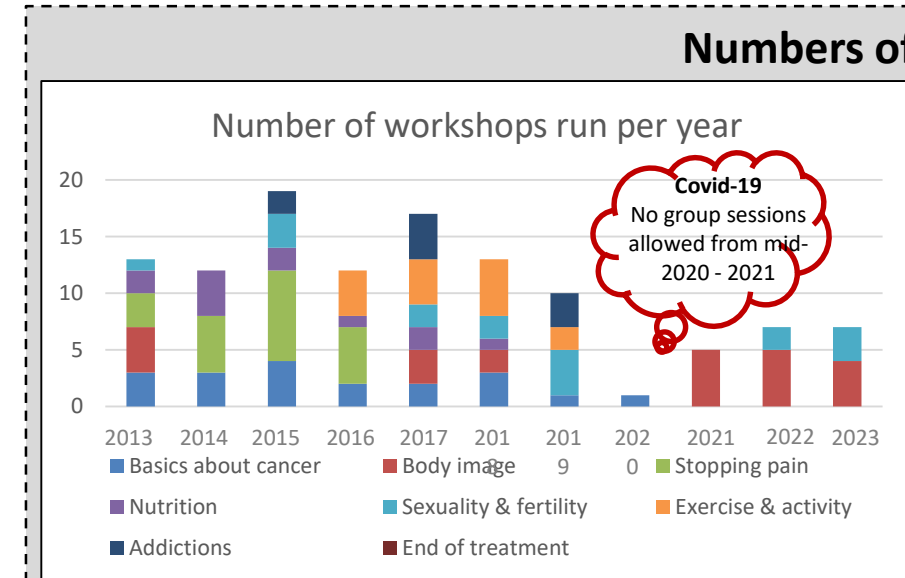
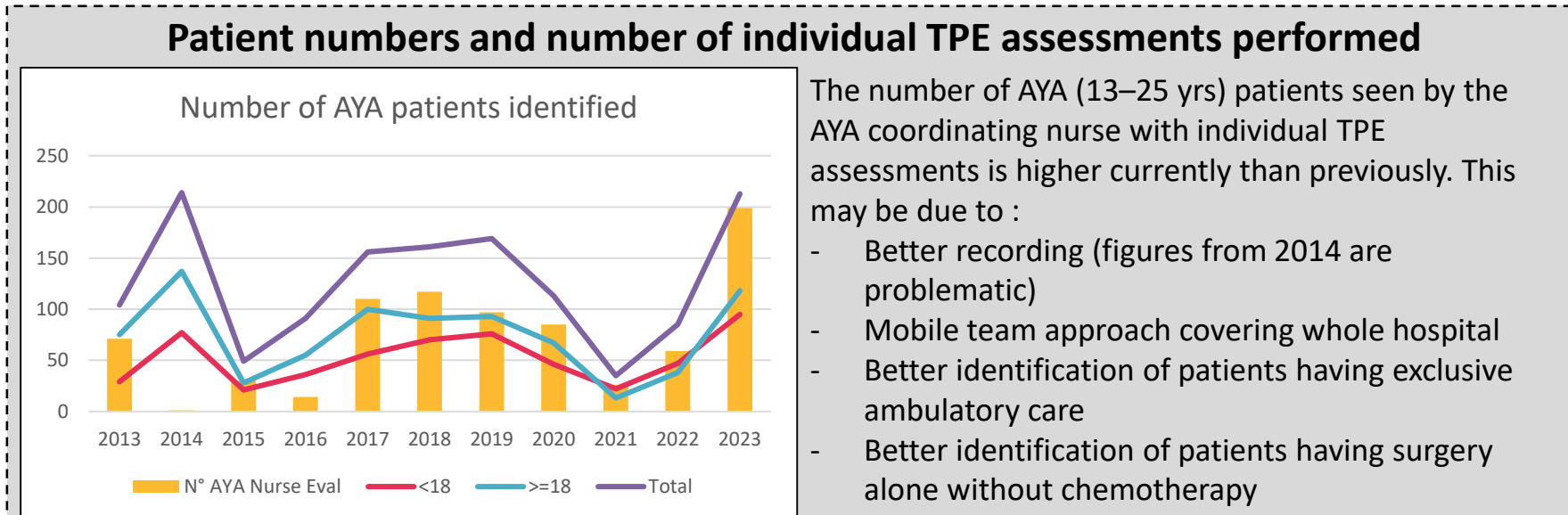
Qualitative overview of the evolution of the program since 2012. Since its inception, an excel record of the patients and others who participate for which workshops has been kept. Participants are invited to review the workshops and this feedback is also recorded in excel. Analysis of the number of workshops and the contemporaneous patient evaluations from 2012 – 2024.

Origins of the AGORA TPE program

AYA unit established in Gustave Roussy in 2002
 Governmental Cancer Plan in 2009 formalising the specific needs of AYA cancer patients and indication to develop appropriate structures
 Therapeutic education program developed in 2012 with :

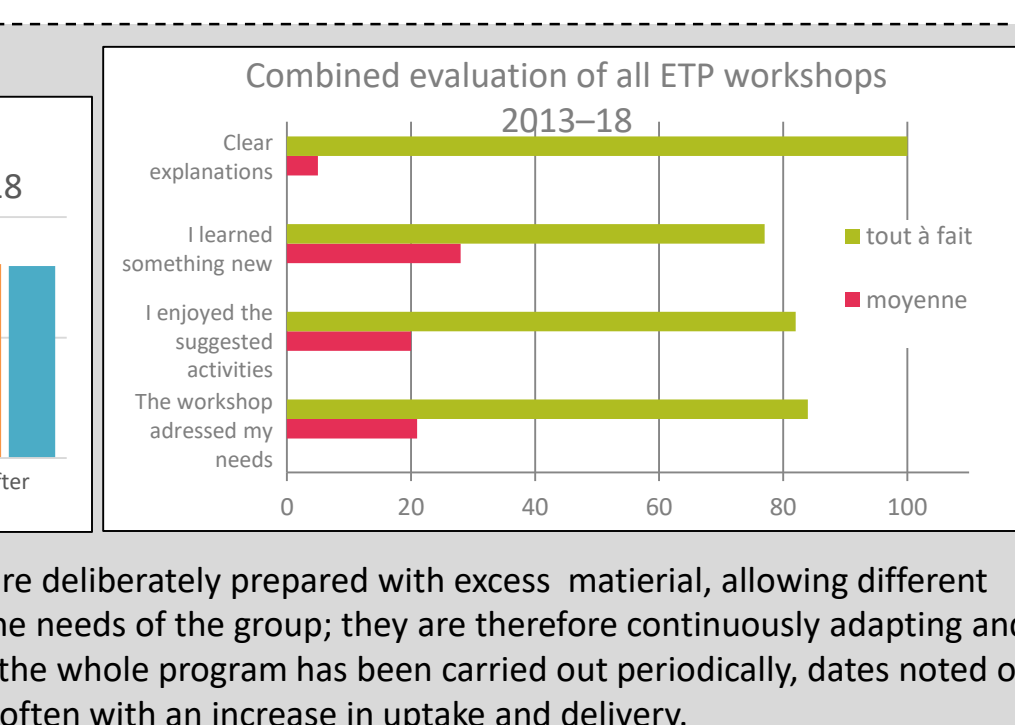
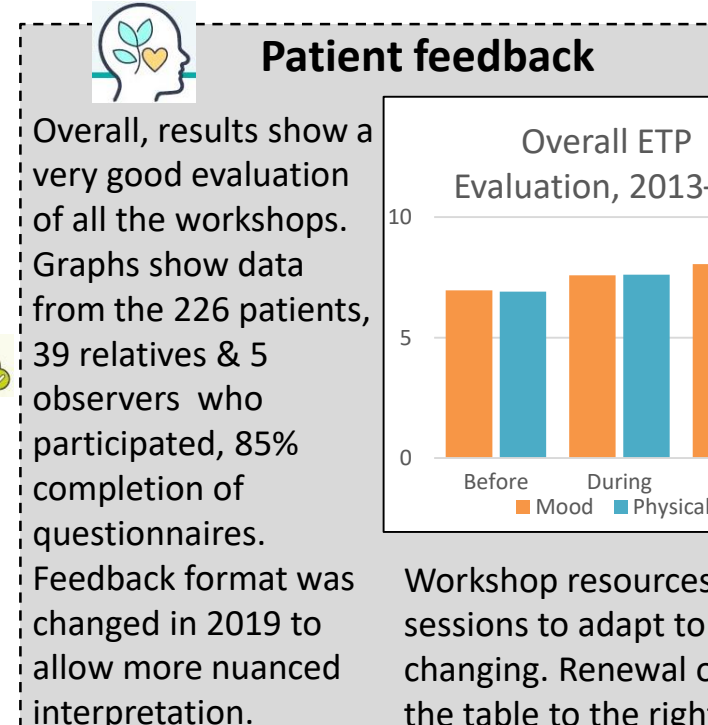
- Transversal specialist multidisciplinary team**
 Paediatric and adult oncologists
 AYA coordinating nurse
 AYA psychologist, social worker and educator
- Jeunes Solidarité cancer**
 Co-construction with JSC, a charity organised by and for AYA patients with cancer
- Financial support**
 Plan cancer 2009-2013, Institut National du Cancer, La Ligue
- Authorisation**
 Formal recognition by health authority in 2012

First patients included in 2013



Workshops in 2013 vs 2024

Theme	2013	2024
What is cancer? revised 2019 & 2024	✓	✓
SELFIE NO FILTER, Body image, revised 2016	✓	✓
STOP PAIN, revised in 2018 & 2023	✓	✓
STILL LOVING FOOD, Nutrition, revised 2019, '24	✓	✓
When my heart goes BOOM! Sexuality & fertility, revised 2016, '21, prix unicancer 2016	✓	✓
AJACTIV' Exercise & activity, started in 2016	✓	✓
Addictions, started in 2015	✓	✓
End of treatment, created in 2019 not started (COVID), due to restart in septembre 2024	✓	✓



Verbatim feedback, 2022-23

What did you appreciate?
 Discussion & exchange
 Being able to raise issues and get answers about subjects doctors don't discuss and learn more
 I liked being able to express myself concerning my individual situation but also to understand the experience of other patients

One word to describe TPE
 Interesting, Rich/enriching, Deep understanding, opening, Appropriate

What did you not appreciate?
 Nothing/RAS (x10)
 Suggest more interactive games (we discussed topics that can be difficult in a group)

AGORA program shared & adapted across France

Resources have been shared with the support of French paediatric oncohaematology and AYA organisations (SFCE and Go-AJA). Each centre is free to use the resources and adapt them as required. New TPE workshops have been created by centres according to local need.



INFO: French reglementary requirements

- 40 hours obligatory training for anyone running a TPE session
- 80 hours obligatory training for the person with a coordination role
- Detailed 4-yearly evaluation to maintain accreditation
- Annual activity reports

Challenges

AYA Population continuously evolving !
 This is the delight of working with this population, but often means that what one patient cohort needs and requests is no longer relevant once it has been developed. Being able to adapt quickly and building flexibility into the system is essential!

Staffing issues
 Hospitals are facing significant workforce issues for multiple reasons, aggravated by COVID-19. In order to run this complex program, a stable team is essential.

Coordination and attendance
 Even when we have expert professionals available & the workshop dates have been shared & patients are interested, actually having the right patient in the hospital on the right day, and in a clinical/mental state to participate is a constant time-consuming difficulty

Future

Reinforcing the team to allow 1 person to focus exclusively on TPE
 Improve communication with community teams (initial evaluation, workshops attended & agreed actions)
 Relaunch of post-treatment TPE, revision of nutrition & cancer information workshops
 Apps currently under development for AYA to enable TPE participation from home & for autonomous learning

CONCLUSIONS

TPE is essential for AYA undergoing treatment for cancer. Developing a program is complex in terms of administrative requirements, staff training and ongoing coordination and updating. But, when delivered well is an effective means to improve AYA wellbeing and understanding of their disease, its treatments and consequences. Future assessment could evaluate long-term perceived benefit of TPE for those patients who benefited from it during their treatment. The next steps will require ongoing program evolution in partnership with AYA patients to address their needs. This could include the development of e-ETP appropriate for group participation and interaction, enabling patients to participate when they are outside their main hospital or are treated in a centre not offering the TPE they need.