

Lifestyle changes and integrative care

Not only medical-technical aspects of AYA oncology care, but also sport, work and complementary care may reduce symptoms and improve quality of life in cancer patients. During SPACE 4 AYA 2018, an expert panel discussed the ways in which AYAs can deal with cancer and the consequences of their disease. In addition, an app was launched to help AYAs with cancer to communicate with their loved ones.

For cancer patients, including AYAs with cancer, there are several ways – apart from regular oncology care – to improve their quality of life. Take sport and exercise, for instance. “Sport and exercise can help cancer patients to better deal with their disease and treatment and recover more quickly due to limited loss of condition and muscle strength. In addition, exercise boosts confidence, reduces fatigue and improves the ability to concentrate”, **Ms Rosemarie Jansen** says. She is AYA nurse specialist at the AYA expertise centre at Radboudumc in Nijmegen as well as member of the AYA ‘Sport and Exercise’ Dream Team in the central-eastern part of the Netherlands. This Dream Team was set up recently by Radboudumc in close collaboration with *Stichting Tegenkracht* and *Enjoy the Ride* Nijmegen. The aim of the team is to inform AYAs and care professionals of and improve access to sport and exercise in cancer.

Work: an AYA-specific theme

It is difficult for AYAs to find a job. They have little work experience due to their young age, and are unintentionally perceived as a risk group by employers due to their disease. In addition, it is not easy to follow treatments while also working for various reasons, such as (severe) fatigue, psychosocial problems or communication problems. There are several ways to help cancer patients to keep working or return to work. Take the tailored programme Stay at work, for instance. This programme enables AYAs to adjust their work (and/or training) to the their treatment schedule. In this way, patients are often able to keep on working during and/or following treatment. However, close collaboration between all parties involved is necessary to make this programme a success”, says **drs. Desiree Dona**, clinical oncology occupational health physician at Radboudumc. Apart from Stay at work, there are several other programmes

offering cancer patients personalised support in following treatment while also doing (voluntary) work or a training course. The clinical occupational health physician’s task is to link care to work as much as possible.

Match app for understanding and contact

A particularly festive moment during the SPACE 4 AYA symposium was the launching of the AYA Match app by **Ms Sophia Steeman** and **Mr Marvin de Vos**. During the interactive sessions, they discussed with the audience the theme ‘Contact and understanding during the cancer process’. The speakers talked about the development and finalisation of the app. The aim of the app is to help AYAs with cancer to communicate with their loved ones and the other way around. The results of a needs assessment had shown that this AYA group requires support to share their feelings and needs during their disease and treatment and to make delicate subjects discussible. The launching of the app was accompanied by the start of a research project on the effect of the AYA Match app. The scope of the project is: “Does this digital intervention improve quality of life and psychosocial functioning?” The results of a study into the use and potential added value of the app

will be presented in 2 years’ time. It will then be shown whether Match lives up to expectations.

Integrative medicine

The aim of integrative medicine is to link regular oncology care with evidence-based complementary care. “Although cancer cannot be cured by complementary care, including mindfulness, massage and acupuncture, this type of care can often reduce side effects of regular oncology care and contribute to the improvement of quality of life”, says **drs. Ines von Rosenstiel**, paediatrician and expert in Integrative Medicine at the Haga Teaching Hospital in the Hague and Ziekenhuis Rijnstate in Arnhem.

As not all information about safety and efficacy of complementary care substances is accurate and reliable, hospitals can acquire special datasets, such as the Natural Medicines Comprehensive Database. Von Rosenstiel says: “There are also many high-quality textbooks and peer-reviewed articles about the added value of complementary care in oncology. I think it would also be a good idea if more Dutch centres employ an integrative medicine consultant and build a regional network of carefully selected complementary care providers.” ●

Physical and mental health effects

Cancer and cancer treatment are associated with various adverse physical and mental health effects. The impact on AYAs shows not only similarities with but also differences from the impact on older patients. During the 2018 SPACE 4 AYA symposium, several care professionals discussed three health-related effects that may occur in AYAs with cancer: cognitive abnormalities, thrombosis and fatigue.

Patients with brain tumours often suffer from cognitive abnormalities. “However, we know that approximately one-third of patients with a tumour located outside the nervous system may also experience cognitive problems. These problems may be associated with fatigue, anxiety, depression and comorbidities, but also with the treatment. Research has shown that chemotherapy can cause cognitive changes in a number of patients. Far less clear is the association between hormonal and targeted therapy and cognitive changes. At present, there are no interventions available to prevent or stop these changes. Cognitive rehabilitation, and cognitive strategy training in particular, can help reduce the impact of cognitive changes on daily life and work. Providing information and making a correct diagnosis are helpful in choosing the right intervention”, says **prof. dr. Sanne Schagen** says, clinical neuropsychologist at the Antoni van Leeuwenhoek hospital in Amsterdam.

Thrombosis

Although deep venous thrombosis and pulmonary embolism mainly occur at older age, AYAs with cancer may also get thrombosis. “In an American study, 16% of 122 AYAs with sarcoma were diagnosed with thrombosis. In half of them, thrombosis was asymptomatic and found by chance on a CT scan made to assess the cancer process. We know that certain factors determine the risk of thrombosis, such as the extent of cancer, chemotherapy, prolonged bed rest and dehydration. Fortunately, we are often able to prevent thrombosis. Thrombosis in cancer patients can be treated with low-molecular-weight heparin (LMWH) or vitamin K antagonists. Future treatment may include direct oral anticoagulants (DOACs). Currently, it is not sufficiently clear whether cancer patients benefit more from DOACs compared to regular medicines. In addition, specific antidotes are not yet available for all DOACs”, says **prof. dr. Menno Huisman**, vascular medicine internist at Leiden University Medical Center.

Fatigue

During treatment, the majority of cancer patients get tired. After completing treatment, 25 to 33% of patients continue to report fatigue. This type of fatigue tends to be more serious and persistent than ‘regular’ fatigue. Taking rest does not or only partially alleviate fatigue, and there is no clear relationship between activity and extent of tiredness. “As a result, patients with cancer perceive this type of fatigue differently and feel frustrated, discouraged and exhausted. Research has shown that fatigue in cancer patients is associated with reduced quality of life and impaired or altered physical, mental, emotional and social functioning. For AYAs in particular, who are in their prime, fatigue can be a very limiting symptom”, says **prof. dr. Hans Knoop**, clinical psychologist at the Academic Medical Center in Amsterdam.

Why does fatigue in cancer patients often persist? Knoop says: “Behavioural factors seem to play an important role in this. Fatigue may persist due to sleeping disorders, anxiety, depression and reduced physical activity. At the same time, these behavioural aspects offer opportunities for treatment of fatigue, for instance by means of physical exercise and cognitive behavioural therapy. There are

also indications that mind-body interventions such as mindfulness and yoga may have positive effects.” ●

Reference

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The fifth anniversary of SPACE 4 AYA

SPACE 4 AYA, a leading symposium for care professionals and young adults with cancer about age-specific AYA care, was organised for the fifth time on 8 March 2018. AYA stands for Adolescent & Young Adult, i.e. young adults aged 18-35 who are diagnosed with cancer. This time, the symposium was held at Stadion Galgenwaard in Utrecht. Because of the fifth anniversary, it was time to party and say a big ‘thank you’ to all AYAs and care professionals involved. Naturally, powerful presentations were being held as well. By means of epidemiology and presentations about AYA-related themes, the symposium demonstrated that age-specific care must be offered as soon as the diagnosis has been made to empower the AYA and his/her loved ones. Age-specific care improves the AYA’s quality of life, reduces health care consumption and emphasises the tasks of care professionals, namely showing compassion and work as a team, using all different kinds of expertise. The overall aim is to do whatever is possible and desirable – together with the AYA and his/her loved ones – to enable the AYA to lead a dignified life during and after cancer diagnosis and treatment.



Working shoulder to shoulder on age-specific AYA care

More than 350 AYAs and their loved ones, nurses, nurse and medical specialists, medical social workers, psychologists, physiotherapists and other (future) professionals with a special interest in age-specific AYA care attended the symposium on 8 March 2018. This heterogeneous group of participants makes SPACE 4 AYA a unique and extraordinary event in terms of form and content. The participants received a wide range of information about age-specific AYA care by means of presentations, an information market and scientific abstracts. They discussed the most recent developments in healthcare, scientific research and training programmes with regard to cancer at the AYA age.



Mr Tom van ‘t Hek, chairman of the symposium, introduced the contributing speakers. He also introduced several other people: **Mr Julian Noij**, who discussed ‘Food for care’, the innovative concept for hospital food and drink developed by the ‘AYA & Food’ Dream Team; **dr. Henk Elsevier**, who set up the ‘Intimacy and Sexuality’ Dream Team together with AYAs and professionals in order to make this subject discussible; **dr. Ina Beerendonk** (Radboudumc), who started the campaign ‘Exercise for Cancer and the Desire to have Children’ (*Beweeg voor Kanker en Kinderwens*) together with **drs. Michelle van den Berg** in order to raise money for the research project ‘Every young woman with cancer should be offered a consultation about fertility’ (*Iedere jonge vrouw met kanker heeft recht op een gesprek over vruchtbaarheid*); and **Ms Rebecca ter Mors** of the Foundation Young People & Cancer (*Stichting Jongeren & Kanker*) and member of the AYA activity committee. She proudly presented the splendid

JK jubilee magazine, which included impressive stories from AYAs and care providers.

A novelty at this jubilee symposium was the on-stage presentation of three scientific abstracts. **Dr. Floortje Mols** (Tilburg University) discussed ‘Age-related differences in health-related quality of life among thyroid cancer survivors compared to a normative sample: results from the PROFILES Registry’; **drs. Rhodé Bijlsma** (UMC Utrecht) discussed ‘Age-specific care for adolescents and young adults with cancer (AYAs); an e-module for medical students and care professionals’ (*Leeftijdsspecifieke zorg voor adolescenten en jongvolwassenen met kanker (AYAs): een e-module voor Medisch studenten en zorgprofessionals*), and **Mr Johan de Munter** (Ghent University Hospital, Belgium) discussed the abstract ‘Improving fertility outcomes for AYAs with Hodgkin disease: the importance of a multidisciplinary care path for young people’. ●

The programme committee consisting of AYAs and professionals had organised a varied programme based on feedback received from participants of the previous SPACE 4 AYA symposium. The symposium was opened by **theatre group Plezant** with a surprising act and link to the festive evening programme. Throughout the programme, inspiring stories were being told that were relevant to AYA care in the Netherlands. **Prof. dr. ir. Koos van der Hoeven**, chairman of the National AYA ‘Young & Cancer’ Platform board, referred to the fact that AYA care was celebrating its fifth anniversary. Without the joint, dedicated effort from AYAs and professionals, AYA care would not have existed. However, the National AYA ‘Young & Cancer’ Platform has not yet been receiving

structural financial support. For this reason, there is a need for sponsors. The – partially temporary – support from Roche Netherlands, Netherlands Comprehensive Cancer Organisation (*Integraal Kankercentrum Nederland, IKNL*) and Radboudumc Nijmegen enables the AYA platform to work and implement nationwide policies. It also boosts age-specific care, research and training programmes. All these factors contribute to the improvement of the AYA’s quality of life as soon as the diagnosis has been made. Other external parties and sponsors, including the hyacinth growers, Janssen-Cilag, *Innovatiefonds Zorgverzekeraars* and *VIOZ (Veelzijdig in Ondersteunende Zorg)* contribute to the areas of Education & Awareness, Training and Research.

hAYAcint action

As usual, the SPACE 4 AYA symposium was concluded with the announcement of the results of the annual hAYAcint campaign. Chairman **Mr Tom van ‘t Hek** invited the hyacinth growers, **dr. Evelien Manten** and **Ms Sophia Steeman** on stage. Before the proceeds were announced, it was emphasised how great it is that so many donations were made to this campaign. Take the hyacinth growers who each offered hundreds of bunches of hyacinths, the free transport to fifteen hospitals, and the auction at Royal FloraHolland in Rijnsburg. “I still remember the first time we were standing here four years ago, receiving 9,000.00 euros. We were already so happy with that result! This campaign also unites AYAs, care professionals, doctors and sponsors. They all work together to achieve comprehensive AYA care.”

The cheque was handed to Eveliëne and Sophia by the hyacinth growers. The record-high proceedings were announced amidst loud applause: 25,838.30 euros. We are very grateful for this result, and would like to say a big ‘thank you’ on behalf of all AYAs and professionals! ●



Epidemiology of tumours in adolescents and young adults

Dr. Olga Husson, staff scientist at the Institute of Cancer Research, London.

Cancer in adolescents and young adults (AYAs) is a unique process. AYAs are still developing when they get cancer. Both the AYA and the doctor do not expect cancer at such an early age. As a result, symptoms are not always recognised and diagnosis may be delayed. AYAs may present with a wide range of tumour types that often show biological differences from tumour types in other age groups. Therefore, it may be unclear how and where to treat AYAs. In addition, supportive care is not always tailored to the age-specific needs, such as being able to answer age-specific questions.

Based on data from the Netherlands Cancer Registry, the incidence of tumours and survival rates among AYAs was evaluated. Between 1989 and 2015, 93,607 AYAs aged 15 to 39 were diagnosed with cancer, i.e. 3,500 AYAs a year (41% male; 59% female; 6% diagnosed at age 15-19; 9% at age 20-24 and 85% at age 25-39). Together, they make up 5% of the total population annually diagnosed with cancer. The annual incidence of cancer among AYAs shows a slight increase (1.6% in men and 1.1% in women). Various types of cancer may occur at the AYA age. They include not only

tumours mainly found in children (leukaemia and childhood brain tumours) or adults (colon cancer, breast cancer and lung cancer), but also types of tumours that mainly occur at the AYA age (Hodgkin disease, melanoma, thyroid cancer and germ cell tumours). There are also differences between the types of tumours found in women and men. Five-year relative survival rates increased from 68 to 85% in men and 75 to 86% in women between 1989 and 2015. However, some types of tumours, such as leukaemia, brain tumours, rhabdomyosarcomas, lung cancer, ovarian can-



Olga Husson

disease or higher disease stage at the time of presentation, and uncertainty about treatment.

Based on the results, the following is recommended:

- raising awareness among young people as well as care professionals of the occurrence of cancer in young adults remains necessary; improved prevention and reduction in delayed diagnosis;
- AYAs show differences in tumour biology, which may require different treatment strategies; more laboratory and translational research is needed to substantiate this;
- so far, only few AYA-specific clinical trials have been set up, and the participation rate among AYAs is low. This issue needs to be addressed;
- the collaboration between the paediatric and adult oncology departments must be improved, allowing a smoother transition from paediatric to adult care;
- training programmes for care professionals should focus more on age-specific aspects;
- the majority of AYAs have a good chance of survival. Therefore, attention must be paid as soon as the diagnosis has been made to long-term treatment effects and prevention of overtreatment as a result of overdiagnosis;
- there is a need for multidisciplinary, age-specific AYA care provided by the national AYA platform. ●

AYA care in practice: “Oh, I thought that was quite normal!”



Suzanne Franssen

AYA Ms Suzanne Franssen opened the plenary session on AYA care in practice by an impressive account of her experiences. In a moving, matter-of-fact presentation she described the rollercoaster she and her loved ones had been on after she was diagnosed with sarcoma. At Radboudumc Nijmegen, she received AYA care that was fully tailored to her needs. Franssen was under the impression that this integrated, personalised approach to care for young adults was quite normal in the Netherlands. She then learned from the AYA outpatient team of the AYA expertise centre at Radboudumc that AYA care was set up in the

Netherlands in 2013 for this very reason. Next, drs. Suzanne Kaal, project leader of the regional AYA expertise centre at Radboudumc and internist-oncologist, gave an update on AYA care in 2018. Each year, approximately 2,700 people aged 18-35 (the AYA age) are diagnosed with cancer. Although 75% of them will survive, cancer threatens their future. The AYAs' search for the right treatment usually takes a while, which may have a negative impact on their prognosis and survival rates. They were not able to ask age-specific questions, as they were too old for the paediatric oncology department but too young for the adult oncology department. In addition, the AYAs could not get in touch with each other, and the various specialists and professionals had only limited, dispersed knowledge of cancer at the AYA age due to the wide range of tumours. As a result, AYAs did not receive the recognition they deserved. Both AYAs and professionals thought it was time for change! Working closely together, they gradually changed the care path by thinking out of the box. The 'founding mothers' prof. dr. Winette van der Graaf and prof. dr. Judith Prins set up the first AYA care team (AYA outpatient clinic) at Radboudumc in 2009 as an experimental field and by adopting a bottom-up approach. This was an interdisciplinary team

with one or more nurse specialists in the lead, working together one on one with the treating doctor. A team that can make regular, age-specific questions from AYAs discussible after the diagnosis has been made, no matter if these questions can be answered. The subjects may include fertility, food and drink, work, study and emotions. Such intervention empowers the AYA and helps him or her to deal with cancer and its consequences. In addition, intervention following diagnosis has a rehabilitating effect and prevents care consumption later on in the process. Due to the success of this approach, with dr. Eveliene Manten-Horst as quartermaster, the National AYA 'Young & Cancer' Platform was set up in 2013. Together with AYAs, this network of care professionals shaped age-specific, integrated AYA care in the Netherlands. The structure of the network was based on 'echeloning', i.e. general hospitals providing basic AYA care and AYA expertise centres at university medical centres providing complex AYA care, depending on the AYAs' needs. The platform consists of six regional networks, allowing AYA care to be offered close by the AYA. As from 2017, the platform has had an AYA scientific committee. Training programmes have also been focusing on AYA care. For instance, the e-module 'AYA care for medical students' (AYA-zorg voor

geneeskundestudenten) at University Medical Center Utrecht has been set up. This module is also made suitable for instruction of care professionals. At present, the AYA platform has a foundation board and an active online AYA community with more than 500 AYAs from all over the country. The platform also tries to change the perception of cancer being a risk when it comes to work, mortgages and insurances, for instance. ●

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Suzanne Kaal

Improvements in age-specific AYA care and the AYA's quality of life

Dr. Floortje Mols, senior lecturer at Tilburg University, and dr. Olga Husson, staff scientist at the Institute of Cancer Research, London.

In Europe, there are 10 million cancer survivors, 20% of whom are in good health. In the group aged 15-29, the ten-year prevalence has increased by 33%. Since 2004, the Netherlands Comprehensive Cancer Organisation (IKNL) and Tilburg University have been conducting joint research into the quality of life of people with cancer. Research topics include the impact of specific medical treatments on the lives of patients. The quality of life of thousands of (former) cancer patients is being longitudinally evaluated based on the PROFILES Registry (Patient Reported Outcomes Following Initial Treatment and Long term Evaluation of Sur-

vivorship).¹ Linking these data with detailed cancer registry information results in a unique, dynamic monitoring system for patient-centred outcomes research. Because in this study AYAs are monitored as well, we gain more insight into the impact of getting cancer and following treatments on their lives. For instance, a study among patients at the AYA age with lymph node cancer conducted by Husson et al. showed that AYAs with lymph node cancer report lower quality of life than AYAs without cancer.² The impact of the disease and treatment is bigger in AYAs than in older patients with lymph node cancer.³ Of the group of AYAs with lymph node cancer, 62% is afraid that the disease will come back. Forty-eight per cent report chronic fatigue compared to 20% of AYAs without cancer. However, the provision of personalised AYA

care requires an adequate analysis of which problems will develop in whom following diagnosis, and why. Increasing knowledge of the underlying mechanisms allow the development of interventions that may contribute to the desirable level of quality of life, prevention of (late) health problems and joint decision-making as to which treatments are preferred. The study performed by dr. Olga Husson based on her KWF (Dutch Cancer Society) research fellowship is a first step in evaluating sociodemographic factors, lifestyle, biological markers and molecular and genetic factors that can influence – together with treatments – the AYAs' quality of life during and after cancer diagnosis and treatment. By linking cancer registry data with data from the PROFILES Registry, a so-called risk stratification model can be developed which allows

an insight into which patient is at low, average or high risk of getting (late) symptoms as a result of cancer and/or treatments, and why.⁴ As a result, it is possible to:

1. take informed and joint decisions;
2. monitor the AYA in a specific manner and timely anticipate deterioration in health;
3. develop interventions aimed at improving AYA care;
4. empower the AYA and – by doing so – empower patient organisations relevant to AYAs as well as the Dutch Federation of Patient Organisations. ●

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Optimal communication between care professionals, patients and their loved ones

Communication is an essential, but also complex part of the relationship between care professionals, patients and their loved ones. That is the reason why this topic was discussed at length at SPACE 4 AYA 2018. Several skills and tools were discussed that could improve patient-care professional communication. In addition, the website hoestie.nu was launched, enabling AYAs to inform their loved ones of their disease and treatment.



Marij Hillen

Establishing a relationship based on mutual trust, transferring information and taking decisions are three important goals of doctor-patient communication. Trust is considered to be a basic ingredient of optimal communication. "Trust depends on features of both doctors and patients, and on circumstances such as pressure of time. Older patients have a blind faith in their doctor more often compared to young patients. Usually, AYAs do not automatically trust the care professional. Instead, they like to see how the contact evolves. Unfortunately, cancer does not allow them to ponder on questions like: "do I think my doctor

is trustworthy?" However, doctors can help build trust by verbal and non-verbal communication skills such as maintaining eye contact", according to dr. Marij Hillen, KWF research fellow at the Department of Medical Psychology of the Academic Medical Center (AMC) in Amsterdam.

Information transfer

In addition to establishing a relationship based on mutual trust, it goes without saying that information transfer is another important component of doctor-patient communication. Hillen says: "Younger patients would like to receive more information than older patients. Adequate information transfer has been achieved if information has been heard, understood, memorised and used by patients in a correct manner. It should be considered that increasing age, for instance, is associated with memory loss. In contrast, considering emotions evoked by information and tailoring communication to individual abilities and needs may facilitate remembering. Tools such as question prompt sheets may empower patients to ask questions about their disease or treatment."

Making decisions together

Decision-making is an important part of

the care process. "It is important for parties involved to realise that patients may have different preferences, which may also differ from those of doctors. It has been shown that doctors are not very good at predicting their patients' preferences. For instance, they tend to underestimate the preference for less invasive treatments and the wish to be actively involved in the decision-making process. But what exactly does joint decision-making mean? It means that the patient is aware that a decision is to be made, and a choice can be made between several options. It also means that the patient knows the pros and cons of these options, and communicates about and considers them. The patient then decides together with the care professional which option suits him or her best, or leaves that decision to the care professional", says dr. Anne Stiggelbout, professor of Medical Decision Making at the Leiden University Medical Center.



Anne Stiggelbout



Bram Verhees

Hoestie.nu

Not only communication between the patient and care professionals, but also between the patient and his or her loved ones can be complex, time-consuming and tricky. AYA Ms Anna-Eva Tulkens (1981-2017) developed the hoestie.nu internet platform to help AYAs with cancer to communicate with their loved ones. "It was shown that sharing information about the disease and treatment was quite a challenge despite the opportunities offered by social media. On hoestie.nu, AYAs can share their health stories with their loved ones on a private webpage. As a result, they can spend more time on subjects not related to their disease when meeting their loved ones face to face", says dr. Bram Verhees, who was Tulkens' partner and manages the Hoestie Foundation. Last year, they started a collaboration with the Maastricht Oncology Centre at the Maastricht University Medical Centre (MUMC+). The website won the prestigious 2017 Roche Oncology Award. During the 2018 SPACE 4 AYA symposium, the public version of hoestie.nu was officially launched. ●