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Poster Abstracts

P28 Building an AYA Oncology Program from the Ground Up: Of Towers and Bridges

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INTRODUCTION AND AIMS: Adolescent and young adult (AYA) oncology patients require a multifaceted approach to reach better outcomes. One strategy is to establish a dedicated AYA program so our aim was to build one at John's Hopkins All Children's Hospital (JHACH) that best fit our unique medical landscape.

METHODS: Our team assessed patient needs, our strengths and weaknesses and proceeded to build our program. As a COG member, our patients were offered many national clinical trials, but our age limit is 21 and we are not members of adult cooperative groups, limiting access to some trials. We also lacked expertise in some AYA-specific diagnoses like melanoma. We created disease-specific groups and have tasked their leaders to establish partnerships with AYA champions at the state's only NCI-designated cancer center in nearby Tampa. Regarding fertility preservation, we established a partnership with the nearby academic reproductive endocrinology program. Increasing access further, foundation funds cover consultations, services and gamete storage. JHACH hired an embedded psychologist, full-time teachers, more care coordinators and more social workers. Philanthropy created AYA-focused nurse practitioner positions to coordinate fertility consults and overall clinical care. We recruited a physician to expand our survivorship program.

RESULTS: We built a hospital-based team of focused professionals (a tower) and are partnering with adult oncology and fertility programs (bridges) to create a comprehensive AYA oncology program.

DISCUSSION AND CONCLUSIONS: We are creating the ideal AYA program to fit the needs of our patients while overcoming the limitations of our hospital. Our success will be measured by patient volume, clinical trial enrollment, patient satisfaction, well-being assessment tools, but ultimately improved survivorship and quality of life in our patients. In the future our goal is to build partnerships with community oncology programs where most of the older AYA patients are receiving care.

P29 The Dutch Adolescent and Young Adult (AYA) approach: building a national AYA network in collaboration with AYAs and healthcare professionals

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Yearly 2,700 AYA patients aged 18-35 years are diagnosed with cancer in the Netherlands. AYAs expressed a huge need for age-specific integrated care. Based on the experience of the AYA Expertise center Radboudumc, a national AYA 'Young & Cancer' Platform in the Netherlands was started in 2013. This nation-wide platform functions as a care network where AYAs and healthcare professionals of the academic medical centers and several regional hospitals participate. This care network provides an optimal environment for implementation and innovation of age specific integrated care starting at diagnosis, knowledge exchange, scientific research on 'cancer at the AYA age' and education. Age specific care is stepwise structured with the general practitioner who is aimed to recognize the AYA, the general

hospitals for basic AYA care and the AYA expertise centers in the university medical centers for complex age specific care. Today 7 out of 8 university hospitals function as AYA expertise centers and more and more general hospitals join the national platform. Since 2014 the AYA4 online community is open to all Dutch AYAs. On the secure community separate modules exist for patients and informal caregivers; also since 2014 annual national conferences, called 'SPACE 4 AYA' both for healthcare professionals as well as AYAs and caregivers takes place. Members of the national AYA platform developed an AYA interdisciplinary education program guaranteeing the quality and unambiguous AYA care among health care professionals. Research examines effects of the Dutch AYA approach as well as age specific integrated needs. The Dutch AYA 'Young & Cancer' Platform illustrates nicely what can be achieved by close collaboration and co-creation between AYAs and healthcare professionals.

P30 Student learning from an international AYA cancer site visit

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CASE DESCRIPTION: A student on the Postgraduate Certificate in Teenage and Young Adult Cancer Care, United Kingdom (UK), who works for a cancer charity in Ireland availed of a travel scholarship from Coventry University/ Teenage Cancer Trust to extend learning beyond the online platform. A dual site visit to two specialist Adolescent and Young Adult (AYA) cancer services, in Birmingham and London, was arranged so that AYA specialist cancer care could be observed in practice. The recipient set objectives and organised travel with the support of academic mentors and Teenage Cancer Trust funded staff. **DISCUSSION:** Three days travel were sponsored, which involved visiting 2 clinical sites responsible for the provision of specialist tailored care to AYA patients with cancer. The trip included visiting Teenage Cancer Trust specialist inpatient units and experiencing services in both the inpatient and outpatient setting. The author attended multidisciplinary team (MDT) meetings focused on AYA cancer care and was accommodated by meeting with specialist staff from a variety of professional backgrounds that are vital to the provision of comprehensive, tailored care of these patients

KEY LEARNING: The experience proved to be inspirational and informative. The author was afforded the invaluable opportunity to meet and connect with AYA specialist professionals and experts. Valuable application from academic studies to clinical practice was achieved. The significant contribution of charitable organisations to the provision of AYA specific care in the UK was observed. The uniqueness of the psychosocial AYA MDT meeting and teamwork was a significant learning point and demonstrated how the AYA cancer experience is shaped by expert care. The passion and determination of the staff involved was evident. This experience was extremely valuable further motivated the student to influence AYA cancer care in Ireland by sharing what was learned.

immediate aggressive chemotherapy, brings challenges associated with treatment and during survivorship.

METHODS: We utilized the haematology department specific AML database to identify AYA patients (age 19 =< 35 years) diagnosed with AML. The medical data set included 20 patients and no AYA patients were excluded from analysis. No Quality of Life (QoL) data was recorded. Kaplan-Meier survival statistics were computed and plotted to present overall survival data.

RESULTS: Among 162 adult AML patients treated from September 2013 to March 2017, 20 patients (12,3%) were AYAs with median age of 28.5 yrs. At diagnosis, 4 (20%) patients were included in a clinical trial whereof 1 (5%) patient in control arm and 3 (15%) patients in the experimental arm. Nineteen patients (95%) were treated with intensive chemotherapy and 1 patient received supportive care. Six patients (30%) are still alive. Overall survival (OS) from data entry was 39,4% for the total cohort. **DISCUSSION AND CONCLUSIONS:** Despite good access to medical care, there is still room for improvement in survivorship outcomes. Our analysis shows limited overall survival numbers among AYAs treated for AML. More effective strategies are needed to improve access and inclusion of AYA patients in clinical trials, as they are currently under-represented. Awareness for age-specific needs is crucial in AYA cancer care. Therefore psychosocial age-specific aspects are important and should be included in the specific AML database for the use in future QoL improvements.

P16 Co Creation methods to develop the best future for Dutch AYA

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INTRODUCTION: Compared to children and older adults with cancer, adolescents and young adults with cancer aged 15-39 (AYA) struggle to find care that is adjusted to their age (Zebrack, 2012). Involving them in co-creation (Sanders, 2012), using collective creativity, to improve the design of care (Sanders, 2010) can be very useful (Elsbernd, 2018). However, it remains unclear what co-creation methods are best used to develop healthcare services and products for AYA and how the use of co-creation results to improve services and products.

AIM: To get a better understanding of co-creation methods in AYA care and research projects of the Dutch 'Young and Cancer' Platform by examining the experience of the organisers and the participants of Dream Team projects. Dream Teams have been created to work on various unmet care needs for AYA with cancer, in order to improve age-specific care. See 'Me and my' AYA themes (see Figure 1). A Dream Team consists of AYAs and (care) professionals who have expertise on a specific theme. The team works equally together and integrates all experiential expertise and professional expertise on a project basis. The Dutch AYA platform uses co-creation in these projects.

METHODS: The use of co-creation is analysed with the CIMO framework. This framework looks at the context (C), intervention (I), mechanism (M) and outcomes (O) of the method (Denyer, 2008). Qualitative interviews with participants of co-creation design practices of the Dutch 'Young and Cancer' Platform as AYA cancer patients, informal caregivers and health care professionals will be conducted.

RESULTS: Co-creation methods used in Dream Team projects will be mapped upon the CIMO framework to understand what mechanisms of co-creation were successful. Preliminary results will be presented at the conference.

P17 CBT-Based Group Therapy Implementation for AYAs

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INTRODUCTION AND AIMS: Previous research has demonstrated that AYAs report higher levels of psychological distress compared to same-aged controls (Kaul et al., 2017) and (older) adult cancer survivors (Lang, David, & Giese-Davis, J., 2015; Stava & Lopez, Vassilopoulou-Sellin, 2006). Furthermore, AYAs frequently report feelings of isolation and alienation (Newby et al., 2000) and poor social functioning compared to population norms (Husson et al., 2017). Prior studies have demonstrated positive effects of AYA peer support groups (Adler, 2008). The current study outlines and evaluates implementation of a group therapy protocol.

METHODS: An outpatient psychotherapy clinic housed in an outpatient cancer center offered a 6-week closed psychotherapy group, specifically designed for and advertised to young adults, and facilitated by a psychologist.

RESULTS: The identified cognitive behavioral therapy group protocol was informed by research and the unique challenges faced by AYAs. The group utilized a 6-week cognitive behavioral therapy format outlined below. Session 1: Group guidelines, personal cancer stories, new CBT skill (CBT Model), introduce homework (Emotion & Behavior Tracking) Session 2: Homework Review, new CBT skills (Behavioral Activation; Progressive Muscle Relaxation), introduce homework (Daily Activity Diary) Session 3: Homework Review, new CBT skill (Identifying Cognitive Distortions), introduce homework (Simple Thought Record) Session 4: Homework Review, new CBT skill (Cognitive Restructuring), introduce homework (7-column Thought Record) Session 5: Expert AYA medical panel Q&A Session 6: Homework Review, new CBT skill (Healthy Sleep Habits), introduce homework (Sleep Diary)

DISCUSSION AND CONCLUSIONS: Barriers to implementation included consistent attendance, variability of patients' psychological needs, and logistics (i.e. time and frequency of groups). Unexpected positive outcomes were the willingness of patients to personally engage in group therapy and the desire for ongoing group follow-up. Future studies should focus on identifying the effective components of CBT group therapy and additional models of service delivery.

P18 The AYA DAY: An All-in-One Psychology, Exercise, and Dietitian Service Delivery Program

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INTRODUCTION AND AIMS: AYAs demonstrate unique psychosocial needs. For example, AYAs report higher levels of psychological distress compared to adults (Lang, David, & Giese-Davis, J., 2015; Stava & Lopez, Vassilopoulou-Sellin, 2006) and exhibit poorer observance of healthy

administrative model has been created to implement the program. Additionally, obtaining the resources to provide these AYA services has been a patchwork of external and internal funding by complementing internal resources with targeted grant and philanthropy funds.

DISCUSSION: It isn't enough to have a vision for a comprehensive and collaborative AYA program. As well, internal and external resources must be identified in order to pull together the necessary money, personnel and infrastructure to fit into a complex organizational structure. While there is no "one size fits all" approach to building and AYA program, the need for collaboration and thinking outside the organizational "box" is necessary. We have created a novel, hybrid administrative and funding model to build a comprehensive and sustainable program.

KEY LEARNINGS: Identifying novel ways to gather AYA resources and infrastructure.

P22 Helping Adolescents and Young Adults with cancer to "normalize" their social contacts: Study into the effects of the AYA Match App

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INTRODUCTION AND AIMS: Adolescents and young adults (AYA) with cancer experience a significant shift in social relationships during and after treatment. AYA cancer patients are at serious risk of poor social functioning up to at least 2 years after diagnosis. Qualitative research shows that over half of AYAs are interested in social support through an online intervention. In response to this, the Dutch National AYA 'Young & Cancer' Platform co-created mobile application 'AYA Match app' with potential users (patients, peers). The Match app focuses on open and mutual communication, connection and compassion between AYAs and peers, through different features of the application (e.g. Rules to Play, Activities). The aim of the study is to evaluate the app in terms of perceived helpfulness and to examine the effect of the app on social functioning in both patients and their peers.

METHODS: Users of the application are invited to participate in a longitudinal questionnaire study with 3 assessments: before use, 12 weeks and 6 months after first use of AYA Match. Main outcomes are social support, social functioning and usefulness of the application.

RESULTS: Up till 2 July 2018, 62 AYA-patients (88% female; 17-38 years) were enrolled in the study. Preliminary results show that 75% of the AYA cancer patients indicate to struggle with the fact their peers avoid getting in contact with them, and 58% felt uncomfortable taking part in social activities: "I feel alone at times because peers don't get me. Awkwardness is key in most conversations. People don't know what to say to me, which is very unpleasant since I notice it either way."

DISCUSSION AND CONCLUSION: At the AYA conference in December, we will be able to show the baseline results of the study, as well as promotion- and demonstration videos of the application.

P23 Beyond Protocols: A Psychosocial Program for Hematopoietic Stem Cell Transplant Patients and Families

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INTRODUCTION AND AIMS: Pediatric Hematopoietic Stem Cell Transplant (HSCT) can be an isolating experience. Post-transplant patients are unable to attend school or public