

of radiotherapy. However, in the modern era of high precision radiotherapy techniques including particle beam therapy, it is important to re-visit the therapeutic efficacy of radiotherapy in the primary and salvage treatment of patients with extracranial GCTs.

**Methods:** Systematic review of radiotherapy in the primary and salvage treatment of extracranial GCT patients.

**Results:** Curative radiotherapy is currently reserved only for focal residual, refractory or recurrent disease which cannot be salvaged with surgery or chemotherapy. Radiotherapy is also effective in obtaining an effective palliation in metastatic relapses. Utility of radiotherapy should be carefully evaluated in the management of patients with extracranial GCTs in the low- and middle-income countries where availability of chemotherapy resources are limited.

#### GCT-79 Status and recommendations for radiotherapy within interdisciplinary treatment concepts of paediatric extracranial germ cell tumours

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**Background:** Radiotherapy (RT) has no standardized role in treatment concepts for paediatric extracranial/extragenital germ cell tumours. We would like to further elaborate the role of external beam RT.

**Methods:** Literature and current protocols were reviewed. RT data and outcome of the MAKEI 96 study together with institutional experiences were retrospectively evaluated.

**Results:** According to recent protocols like MAKEI 96, RT is only considered for recurrent or residual disease after intensive multimodal therapy and particularly for mediastinal and sacrococcygeal localizations. However, data supports that RT ( $\geq 45$  Gy) seems to be beneficial for local control (LC) [1]. The majority of patients are irradiated on an individual basis according to heterogeneous dose concepts. Within the analysis of the MAKEI study, 36 patients (median age 12 y, 0.1–18 y, RT in 1987–2017) with different histological findings (predominantly dysgerminoma and yolk-sac tumour) in several localizations (particularly sacrococcygeal and ovarian tumours) could be reviewed for RT strategies. So far, RT concepts varied widely (total dose 20–60 Gy, single dose 1.5–4 Gy). More recently, highly conformal techniques were increasingly used ( $n = 7$ ). RT is effective to achieve and support LC. Due to possible sequelae, RT needs to be used with caution and every case should be discussed in interdisciplinary boards. However, recommendations for a standardized RT-concept are needed and should be implemented in a prospective treatment protocol for further prospective evaluation and quality assurance of RT. Furthermore, highly conformal techniques e.g. proton therapy should be considered to limit the dose burden to normal tissue in paediatric patients.

#### Reference

- [1] Schneider *et al.*, 2001 Treatment of recurrent malignant sacrococcygeal germ cell tumors: analysis of 22 patients registered in the German protocols MAKEI 83/86, 89, and 96. *JCO*.

## Late Effects and Quality of Survival

### GCT-80 Late effects and quality of survival

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**Background:** The 5-year survival for children, adolescents and young adults (CAYA) treated for cancer has increased from 30% in the 1970s to more than 80% at present. There are up to 300,000 childhood cancer survivors in Europe and this number is increasing. Years after treatment, CAYA cancer survivors are at high risk for developing health and psychosocial late effects, resulting in excess morbidity and mortality compared the general population. The impact on the quality of life (QoL) of survivors and their families are significant. CAYA cancer survivors, especially germ cell tumour survivors, are at increased risk for fertility impairment if cancer treatment adversely impacts reproductive organ function. Survivors and their families highly desire having biological children. Treatment that involves reproductive organs can cause impaired spermatogenesis, testosterone deficiency, and physical sexual dysfunction in male CAYA cancer survivors. Female CAYA cancer survivors are at increased risk of primary ovarian insufficiency associated with infertility but also with other sequelae secondary to estrogen deficiency, such as osteoporosis, cardiovascular disorders, impaired psycho-social well-being, and compromised sexual health.

**Methods:** Literature and guideline review.

**Results:** Clinical practice guidelines (GPG) can facilitate these survivors' access to optimal surveillance and management of potential adverse effects that could improve cancer survivors' health and quality of life. PanCare ([www.pancare.eu](http://www.pancare.eu)) and the International Late Effects of Childhood Cancer Guideline Harmonization Group ([www.ighg.org](http://www.ighg.org)), developed evidence-based harmonized surveillance recommendations for gonadotoxicity in male and female CAYA cancer survivors, and CPG for fertility preservation in both male and female CAYA cancer patients.

### GCT-81 Survivorship and the True North (TrueNTH) Testicular Cancer Tool

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**Background:** Testicular cancer survivors (TCS) suffer from various short-term and long-term physical, psychological, and social consequences of diagnosis and treatment. Some TCS experience high levels of clinical anxiety and distress. Psychological distress immediately after diagnosis can be a significant problem; over 50% of men reported a 'crisis reaction' soon after diagnosis. Since existing supports focus on long-term survivors, the provision of information and peer-support immediately post diagnosis may significantly reduce distress and fulfil this unmet need.

**Methods:** TrueNTH Testicular Cancer (TC) is a web-based resource, optimised for mobile devices that is funded and operated by the Movember Foundation. TrueNTH TC provides personalised information and peer support to newly diagnosed TC patients, and comprises of Testicular cancer and treatment related information, 'Ask an Expert' functionality providing direct access to the knowledge base of TC experts and men with a lived experience and 'Connect with a man' functionality that provides peer-support from a matched TCS. Our

study examines if TrueNTH TC reduces short-term distress in newly diagnosed patients. Our study will recruit 86 newly diagnosed patients and randomise them to immediate access versus delayed access to TrueNTH TC. The impact on distress (distress thermometer) and anxiety (Hospital Anxiety and Depression Scale) will be assessed. Results will be correlated with stage at diagnosis, treatments received and outcomes, captured within iTestis, Australia's national testicular cancer registry. Semi-structured qualitative interviews in a subset will also be conducted.

**Results:** Our study opened in April 2019, and has recruited 11 patients within 1 month.

### GCT-82 A retrospective review of weight status and dietetic intervention in children with germ cell tumours

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**Background:** There is limited evidence investigating role of nutrition and weight status during and post treatment in paediatric tumours, particularly germ cell tumours (GCT).

**Methods:** A retrospective chart review (2014–2019) of cases presenting to Great Ormond Street Hospital, London with a GCT, including yolk-sac tumour (YST), as a primary diagnosis who had dietetic input at some stage during their treatment. Hospital records were reviewed for data including weight and height, and dietetic intervention during and post treatment.

**Results:** Since 2017, 19 children were diagnosed with GCT; of these dietetics was involved with 5 cases (26%). In this audit, dietetics have been involved with ten cases since 2014 (YST n = 5; other GCT = 5); of whom 8 were seen at diagnosis. At diagnosis, 4 (GCT) cases were classified as overweight (BMI > 91st centile); all others (n = 6) were within a healthy weight range (BMI 25–75th centile). At 6-month follow-up (n = 5), 2 remained on the same weight centile, one reduced a centile, and two cases (YST) increased three centiles – each moving them into overweight/obese category. All cases needed nutrition support (NS); five had an ongoing need for oral NS. Seven cases had nasogastric tube feed at one point during their treatment. Four cases received parenteral-nutrition (PN); 3 during high-dose-chemotherapy. One case had percutaneous endoscopic gastrostomy (PEG) for a prior condition. In summary, nutrition support is essential to the management of GCT. More work is needed to develop a screening tool to ensure nutritionally compromised children are not missed.

### GCT-83 Testicular Cancer Support Groups: Is there a need?

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**Background:** Urology patients have the highest suicide rates. We felt that survivorship was lacking for testicular patients. Working at the germ-cell cancer tertiary referral service covering a population of 7 million patients, we felt a duty to establishing a survivorship group. Our Trust offers psychological services to all patients within a year of treatment, due to funding constraints. Some of our patients had reported relationship breakdowns leading to anxiety and depression. This included needing to tell a new sexual partner about the loss of a testicle, resulting in patients reliving their cancer diagnosis.

**Methods:** We audited clinics over two-months. The men stated they wanted a patient-only group. Challenges included securing a venue and e.g. dealing with parents attending without their affected teenage son. The first monthly meeting drew an attendance of 8 men. We are now a year on and regularly drawing 9–15 members. We expanded access with a closed Facebook page and email reminders hitting 52 and 289 patients, respectively. Our ongoing challenge is to boost attendance further, thus improving survivorship and patient experience. Our group is a monthly open-door access group. Men are free to drop in and out, we are very proud to have transgender and LGBT members.

**Results:** Men want support groups following a testicular cancer diagnosis. We have developed and maintained the support group. This will assist in aiding recovery, wellbeing, decreasing isolation and improving cancer/aftercare journey. This will increase therapeutic alliance/relationship between clinical-nurse-specialists (CNS), treating physicians and patients in an informal setting.

### GCT-84 The impact of a supranetwork-multidisciplinary team (SMDT) on decision making in testicular cancers: A ten-year overview of the Anglian Germ Cell Cancer Collaborative Group (AGCCCG)

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**Background:** The germ-cell-tumour (GCT) supra-regional MDT for the Anglian Network (SMDT) covers a population of 7.5 million. We reviewed 10-years of discussion and split them into 5 domains [overall outcomes, chemotherapy regimens (untreated disease/salvage therapy), radiology, pathology and specialized cases) to assess the impact of the MDT on decision making.

**Methods:** Initially, adult testicular cancer cases only were discussed; over time teenage and young adult and ovarian GCT cases were also included. It was agreed all centres could treat IGCCCG good- and selected intermediate-prognosis patients, whilst all poor-prognosis and relapse patients had their care centralized at one of 3 high-volume centres.

**Results:** A total of 2,892 cases were reviewed over this period. During the first 5 years, patients with good-prognosis disease had poorer survival in small-volume vs. high-volume centres (87.8% vs. 95.3% p = 0.02); not significant in the last 5 y (93.8% vs. 97.2%; p = 0.31). Radiology review of 3,206 scans lead to rejection of a diagnosis of progression in 26 cases, in a further 10 cases patients initially considered metastatic were down-staged to stage 1. 790 pathology reviews by 2 specialized uro-pathologists lead to changes in 75 cases. PET-CTs were undertaken during this period but did not help to predict those with viable cancer. Management of 26 patients with significant mental health issues unable to give informed consent were determined. MDT-working has led to improved outcomes for patients with GCTs. Some patients have clearly been spared chemotherapy following discussion. Further interrogation of this data may allow further recommendations for changes in therapy.