

the role of radiotherapy and the importance of high-volume centres to improve outcomes, and a review of the evidence is presented.

Conclusions: Complete macroscopic excision should be the goal of surgical resection. The ability to achieve a complete resection combined with tumour grade are the most important predictors of local recurrence and overall survival. A systematic extended resection of involved adjacent organs to achieve negative margins is safe and may improve local control and is best performed in high-volume centres by a multidisciplinary sarcoma team. The role of radiotherapy needs to be investigated in a prospectively randomised fashion to establish the appropriate place in the management of retroperitoneal sarcoma.

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The Role of Radiotherapy in Retroperitoneal Sarcoma

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A retroperitoneal sarcoma (RPS) is a rare malignancy. It comprises about 15% of all soft tissue sarcomas. Although RPS is diagnosed at a median size of 15–18 cm, they remain asymptomatic for a relatively long period. The majority (70%) of RPS is either a liposarcoma or a leiomyosarcoma and 60% of them are of high grade histology.

The chance to obtain negative margins in these large tumours is small. In 40–50% of cases the surgeon has to leave macroscopic tumour behind (R2 resections). This accumulates into a local failure rate of 52–60% at 5 years. Predictive factors for local recurrence are grade, margin status, the fact whether patients have been operated upon in reference centers and whether or not radiotherapy (XRT) has been applied.

The cause of death in patients with extremity sarcomas (ESTS) is most often metastatic disease. In contrast, most RPS patients die due to local failures. In order to obtain the highest probability of abdominal control complete resection with gross negative margins and aggressive en bloc resection of the primary disease is now considered standard of surgical care.

What is the role of XRT in RPS and are aspects from XRT in ESTS applicable to RPS? In contrast to ESTS it is almost impossible to perform postoperative XRT due to the high complication rates of the small intestines, kidneys and liver. Possibly the best timing of XRT is preoperative. In the presentation XRT trials and studies focused on RPS are discussed.

Special Session (Mon, 26 Sep, 13:15–14:15) Optimal Care in Rare Cancers

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Palliative Care Issues in Patients With Brain Tumours

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Primary brain tumours belong to the rarer neoplasms with less than 2% of the newly diagnosed cancers. One fourth to one third of these are highly malignant gliomas with an overall dismal prognosis. Due to the lack of curative treatment options for many patients with primary brain tumours and their reduced life expectancy, good palliative care is essential. Brain tumours often lead to serious deterioration of neurological and cognitive functions. Besides the existential distress, patients and their families suffer from fears that this condition may lead to a change or loss of individual control, cognition or consciousness, as well as the patients' personality.

Despite undisputable proceedings in therapy the options to limit the progression of the disease for the majority of patients with malignant brain tumours are limited. Therefore the management has to focus on the best possible palliation. To meet the specific palliative care needs of these patients appropriately, a more detailed evaluation of this specific group is required. Recent data shows that patients with incurable primary brain tumours have disease specific palliative care issues that diverge clearly from a general palliative care population. Patients with primary brain tumours had evidence of more advanced disease such as poorer performance status and higher levels of nursing support. The predominance of disorientation and confusion in patients with primary brain tumours often leads to serious overburden in families and raise the need for social support. This is a major issue in families who care for patients with brain tumours, far more than in the care for the general palliative care population. Confusion impacts significantly on the social structures, as it aggravates high levels of distress in family members.

Specific palliative care problems in patients with brain tumours reveal the need for an appropriate provision of interdisciplinary and multiprofessional care in this patient population, with a particular view on the needs of the family caregivers and an early integration of social and psychological support.

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Kidney Cancer systematic Symptom Assessment and Evidence Based Care for Patients With Renal Cell Carcinoma That Undertake Treatment With Tyrosine Kinase Inhibitors, TKI

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An important question in clinical cancer care is how to develop powerful and effective strategies to provide up to date evidence based care along with the fast development of new antitumoral drugs.

Historically, renal cell carcinoma, RCC, has been viewed as a therapy-resistant cancer. The recent development of targeted agents, such as tyrosine kinase inhibitor (TKI), has dramatically improved the outcomes in renal cell cancer treatment. The development of TKI has led to new challenges in cancer care related to the specific side effects that occur with treatment. The most common side effects are related to the skin especially hand and feet and symptoms from the oral mucosa. Even if the side effects are not life threatening, the problems can affect the patients physical, psychological and social wellbeing. Further more the side effects can lead to dose reduction and cause disruption in the treatment which can have negative effect on survival for the patient. Adequate assessment of symptoms is important so that treatment of side effects can be adequate and effective. At the oncology department of the Karolinska University Hospital approximately 50 new patients with RCC are seen every year and an increasing number are treated with TKI.

The aim of this project is to evaluate the effect of interventions that nurses provide to treat TKI related side effects and to develop a systematic subjective symptom assessment using the Memorial Symptom Assessment Scale, MSAS, and to compare it with the assessment done with the CTCAE v 3.0. The aim is further on to develop evidence based interventions for the symptoms and side effects related to treatment with TKI.

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Addressing the Needs of Head and Neck Cancer Patients and Survivors

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Background: Optimal care for patients treated for rare cancers like malignancies of the head and neck presents a dual challenge imparted by rarity. Rarity imposes the difficulty of generating sufficient evidence to guide care. It also generates obstacles in creating expertise among treating clinicians. Wide variability in head and neck cancer incidence globally along with diversity among this anatomically grouped set of diseases creates an additional layer of intricacy, furthering the challenge of optimal care.

Materials and Methods: This paper relies on composite evidence to outline optimal care for people with head and neck cancer. An integrative review of current advances in biomedical and surgical care as well as symptom management and supportive care anchors the analysis. The author's qualitative research in head and neck cancer treatment and survivorship experience and clinical practice augment the review.

Results: The landscape of head and neck cancer treatment is rapidly evolving. The dominant surgically focused paradigm in which function and quality were commonly sacrificed for survival advantages is being replaced with a multimodality paradigm in which chemo-radiotherapy as well as minimally invasive surgical options offer options that preserve function and quality in daily life. Advances in understanding viral and other mechanisms enhance the precision and effectiveness for some head and neck cancers. Concomitant advances in symptom management, supportive and palliative care as well as psycho-oncology lag behind biological, biomedical and surgical gains.

Conclusions: The gaps in evidence burdens clinicians and patients alike, generating individual needs, best practice solutions, and pressing need for research in symptom management, supportive and palliative care as well as psycho-oncology. Strengths in evidence-based practice are highlighted to derive a research agenda to promote optimal care.