

decisions increasingly get side-tracked by discussions about money. The current situation is uncomfortable for all and untenable in the future. In the UK the Department of Health commissioned a report by Michael Richards on recommendations as to how novel, unapproved but licensed drugs can be paid for within a National Health Service. In this talk some of those recommendations will be discussed together with illustrative DVD clips of an oncologists talking to patients about co-payments or top-up fees

23 INVITED

Getting your share of good care – an Eastern European perspective

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Good care for myeloma patients should start with access to information. Yet, the acknowledged best practice in the Western European countries is not necessarily implemented by the emerging European countries such as Romania where cancer patients struggle sometimes to have friends and/or relatives translate foreign leaflets and brochures. When it comes to rare diseases such as multiple myeloma, with an incidence of about 3,000 in 22 million people, the situation is even worse.

In the Romanian hospitals for haematological diseases there are neither brochures nor leaflets on display. The Ministry of Health seems not to be concerned with this issue (invoking lack of resources) and what is even more difficult to understand, unlike in many other Western European countries, the Pharmaceutical industry has not done anything to overcome this situation.

Patients' empowerment, patients' rights do not exist as concepts.

24 INVITED

Silent no more: cancer patients as advocates

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Perspective of life changes after the diagnosis of cancer patients being diagnosed with the deadly disease seek the most effective therapy and surgery as well as personalised aftercare. Without sufficient information patients have to rely on their doctor's decision to share the decision of the best cancer treatment and care with their doctors. Patients need easy to understand information and good communication skills.

Patient support organisations can empower cancer patients to take an active role in the decision making process regarding the right treatment option for them. Patient initiatives and support groups have come a long way. In the 1980ies they started getting involved with the patients rights and information supply of quality cancer care. Primary aim of cancer patients as advocates is to enable other patients to communicate with their doctors on one level and take part in the decision making of their therapy.

It is a paradigm change for doctors, health services and politicians. They have to accept that patients today are starting to change their behaviour in terms of dealing with their disease. Adequately informed patients reach a better compliance of their medication and quality of life. Patient groups support their members in taking responsibility for their disease free and overall survival.

It is essential that patients as advocates in order to receive better treatment and care raise their voices to fight inequalities in best quality cancer treatment in Europe. All cancer patients must have access to non-discriminating, multidisciplinary and innovative cancer therapies.

Special Session (Mon, 21 Sep, 14:00–15:00)

Bladder cancer in the elderly – issues on operation and choice of chemotherapy

25 INVITED

Surgery for bladder cancer in elderly patients: risk, benefit and selection of technique

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Purpose: To outline the indications for minimal-invasive (transurethral) tumour resection with or without additional radio- and chemotherapy and for more radical surgery with the necessary of a subsequent urinary diversion.

Source of data: Literature from sources such as Medline from the last seven years, recent guidelines (EAU, WHO) where the author actively contributed and personal data

Results: Recent data have shown that women are older than men at primary diagnosis of BC. Approximately 1/3 of patients present with muscle-invasive tumours out of which approximately 1/3 are already metastatic. No

clear definition of an "elderly" patient exists for pelvic surgery. An age of ≥ 75 years (Karnofsky performance score 90–100%) or ≥ 70 years (KPS 80% or less) is proposed. Of those patients that succumb BC, 64 and 74% die within the first 2 and 4 years, resp. Regardless of quality of life patients who do not need an intestinal interposition for the urinary diversion after cystectomy but are required a narrow wet stoma for the rest of their life. According to an international survey the majority of elderly patients receive an ileal (abdominal) conduit, but in centres of excellence an orthotopic neobladder is offered in up to 1/3 of these patients.

Conclusions: The indications for a cystectomy in elderly patients (as defined above) are muscle invasive and symptomatic BC and a life expectancy of at least 5 years. Type of urinary diversion is dependent on tumour location and extent performance status and motivation. All patients who do not fall into the category outlined above, need extensive TURB with or without laser or other forms of interventional methods.

26 INVITED

Chemotherapy options in cisplatin-unfit patients with advanced urothelial cell cancer

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Findings of single-arm phase II and prospective randomized clinical trials involving patients with advanced urothelial cancers led to the conclusion that urothelial tumors are chemosensitive and that the treatment regimen should be a platinum- based combination. Through the 1990s, the combination of methotrexate, vinblastine, doxorubicin and cisplatin (MVAC) was the widely accepted treatment standard and proved to be superior in terms of prolonging life. Toxicities associated with this treatment, including diminished renal function, neutropenia and sepsis and mucositis tempered the use in the considerable group of patients who are comprised functionally (performance score (PS) < 2) and have compromised renal function and other comorbid conditions. The gemcitabine/cisplatin (GC) regimen has been shown a valuable alternative chemotherapy option, providing identical response rates and survival, with the benefit of fewer side effects. Even in elderly patients (> 75 years) GC is a feasible option, provided that patients are still basically healthy and have good renal function.

For individuals with a compromised renal function (creat clear 30–60 ml/min) a carboplatin-based combination (in lieu of cisplatin) is recommended, with dosing based on the estimated renal function of the individual patient. The single agent activity of carboplatin is 12%, which seems slightly inferior to that of cisplatin which was associated with an overall response rate of 17%. Carboplatin combination chemotherapy studies have produced median survival durations of 8–10 months, which again suggests a slightly inferiority against the 14–15 months obtained with MVAC and GC. Unfortunately carboplatin and cisplatin have never been directly compared in randomised trials that were sufficiently powered to test for superiority or non-inferiority. A confounding factor in interpreting the data from non-randomized studies is the proportion of patients with adverse prognostic factors for survival in phase II trials. The 2 predominant factors for survival following MVAC therapy are the presence of visceral disease in liver or bone and low PS (Bajorin risk groups 0, 1, or 2 factors present, corresponding with 0%, 11% and 33% 5-year survival rates). Patients with no risk factors have a median survival of 18 months versus 4.4 months for those with the least favorable combination of adverse features present. Decreasing the proportion of patients with adverse prognostic factors in phase II trials will thus impact outcome and provide flattering results. In this light it is also difficult to interpret the non-randomized phase II data more recently obtained with platinum-free combination chemotherapy, particularly taxanes with gemcitabine. Apart from myelotoxic effects these regimens seems to be well tolerated, but the true merit of these combinations can only be answered in randomized trials. The EORTC and Spanish Oncology Genitourinary Group have recently finished their randomized phase II/III trial of gemcitabine/carboplatin (G/carbo) vs carboplatin/methotrexate/vinblastine (M-CAVI), in patients deemed unfit for cisplatin due to PS 2 and/or or impaired renal function (creat clear < 60 ml/min). The randomized phase II part trial results have recently been presented (in press J Clin Oncol). Overall response rates were 42% for G/carbo and 30% for M-CAVI and severe acute toxicity (SAT) was manageable. Patients however, with both stratification parameters present (poor PS plus poor renal function), or poor PS plus visceral disease (Bajorin risk group 2) had a response rate of only 26% and 20% and a SAT rate of 26 and 25%, respectively. Carboplatin combinations are active in this group of cisplatin-unfit patients. However patients with multiple adverse prognostic factors are not likely to benefit from combination chemotherapy. Alternative treatment modalities should be sought for this subgroup of very poor risk patients.