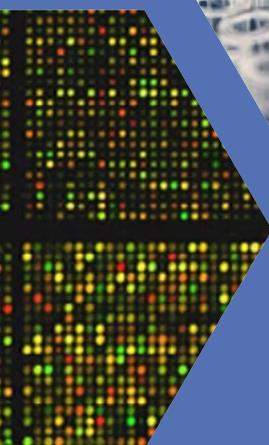
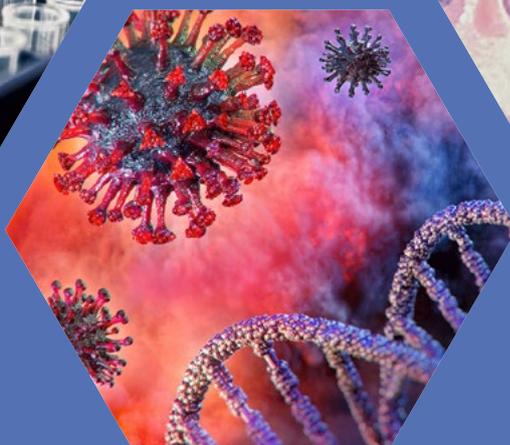
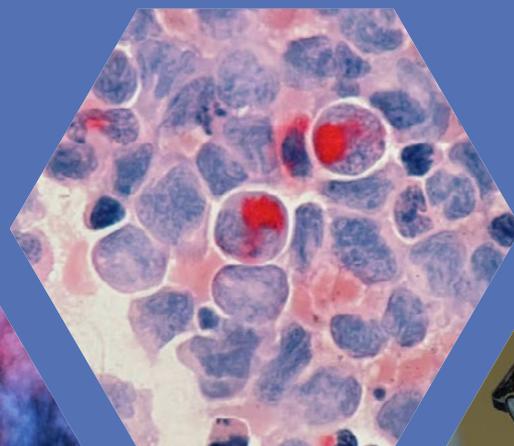


A global destination in sight for paediatrics:

Doing it right to bring Oncogenomic into healthcare systems for children across all regions globally



December 2021



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Section 1: Impact of COVID 19

The impact of Covid has been massive around the world, affecting economic and social life as well as its huge toll in mortality and morbidity. Healthcare generally has been put under unprecedented strain, and the treatment of cancer in particular has suffered from interruption of treatment, delays in diagnosis, and lower levels of presentation of patients with symptoms. Paediatric oncology has been so severely affected that in some cases - and especially in the developing world - gains made in recent years in diagnosis and treatment are under threat of being reversed.

COVID-19 pandemic threatens global life-saving gains in childhood cancer Prof Kathy Pritchard-Jones

University College London, London, UK

The treatment of children and young people with cancer has been particularly disrupted by the COVID-19 pandemic, compounding the divergences in survival rates between the 85% achieved in high income countries and the 30% in resource-limited setting, according to Prof Kathy Pritchard-Jones. She saw the Covid-19 pandemic as a threat that could reverse global life-saving gains in the survival of childhood cancer, posing particular problems for implementing the World Health Organization's global initiative on childhood cancer, with its aim of achieving survival worldwide to at least 60%, and saving a million lives of children from cancer by 2030. She outlined how to support the WHO's call to governments and health service planners to include the needs of patients with cancer in national recovery planning and mitigation strategies to ensure sustainability in everything from accessing diagnostics to accessing uninterrupted treatment. She also stressed the importance of maintaining public awareness of the signs and symptoms of cancer in children and young people, and knowledge of pathways to access diagnosis and treatment. "Late diagnosis of childhood cancer continues to be a problem around the world," she said. The biggest threat right now is the reduction in the number of new cases being diagnosed, which implies that children with cancer are not coming forward for medical attention in some countries and will presumably never be diagnosed or maybe diagnosed later with more advanced disease that's more difficult to treat. Her recommendations included better health service planning and data collection and tracking of children with cancer, maintenance of adequate stocks of essential medicines, and consideration of the economic implications of Covid disruption for parents and carers. (The threat of the COVID-19 pandemic on reversing global life-saving gains in the survival of childhood cancer: a call for collaborative action from SIOP, IPSO, PROS, WCC, CCI, St Jude Global, UICC and WHPCA)

(<https://ecancer.org/en/video/9495-covid-19-pandemic-threatens-global-life-saving-gains-in-childhood-cancer>)

COVID-19: Managing paediatric patients under the COVID pandemic **Carmen Ballestas**

Memorial Healthcare System, Florida, Miami

COVID-19's negative impact on paediatric oncology care was discussed by Dr Carmen Ballestas in a review of how her hospital had managed the challenges for cancer patients and their families. The concerns extended over possible complications, as well as over inadvertent admission of asymptomatic patients to cancer units, with the attendant risk of infecting immuno-compromised patients. To minimise the risks of transmission inside the hospital, schedules were adjusted in the outpatient department and for procedures, while ensuring that patients on active treatment were not delayed. A consortium of children's oncology treatment centres produced some general information for patients and their families to guide and – as far as possible – provide reassurance. The advice covered the need to avoid interruptions of treatment, and explained and described symptoms, suggesting what to do and who to call in case of questions. Since most paediatric oncology patients and families are aware that fever is a significant symptom they are accustomed to calling in such circumstances, and the upfront teaching and counselling the hospital provides about symptoms of concern when children are first diagnosed also helped. Most of the younger patients made some changes to their lifestyle on top of those that tend to follow a cancer diagnosis, becoming still more vigilant. Oncology families are generally prudent about going out but are now still more stressed, with disturbed sleep patterns and other disruptions, and hospital staff therefore take every opportunity to talk to them at every visit to the clinics. The hospital also has family support groups, for children and adolescents, and teenagers display frequent anxieties over the future, necessitating further support.

(<https://ecancer.org/en/video/8956-covid-19-managing-paediatric-patients-under-the-covid-pandemic>)

Section 2 Inequalities:

Vulnerable populations around the world suffer from higher incidence of disease generally, but also from a combination of other factors that often leave them disadvantaged in terms of cancer treatment and outcomes. These factors range from susceptibility in certain sectors of the population to lower levels of prosperity or displacement in the face of conflict or climate change. Redressing these inequalities can be seen as a macro-economic as well as a moral or humanitarian win.

Disparities in myeloma: Closing the gap Prof Joseph Mikhael

Translational Genomics Research Institute, Phoenix, USA

Has stressed the need to raise awareness around disparities in myeloma diagnosis and treatment in more vulnerable populations, focusing on the African-American population in the USA. In this group, myeloma is twice as common and yet has an inferior survival outcome - around half - than that of Caucasian-American patients, as a result of lack of access to treatment options. He urges colleagues to help close the gap and offers suggestions on how this can be achieved. He also notes that this issue is not specific to the USA but is a global problem.

<https://ecancer.org/en/video/9943-disparities-in-myeloma-closing-the-gap>

Inequalities, affordability and central importance of primary prevention Professor Richard Sullivan

King's College London and Chair of Trustees ecancer, UK

Has explored issues of inequalities, affordability and prevention in the post pandemic world. He points out that the Covid pandemic shares many characteristics with the numerous pandemics in recorded history, and has highlighted enormous inequality across the globe. But prevention requires attention to the whole ecosystem - and in terms of cancer that must include the political economy aspect, which is not so much the risk factors of obesity and tobacco and diet, but is an issue of inequality, and the influence of local factors and history. The 1973 oil crisis and the resulting structural adjustment programs damaged public health across continental Africa and damaged the progress of prevention, and since 2010 a succession of global crises, wars and conflicts have impacted the development agenda worldwide. Prevention also suffers in the face of very weak public health systems, and those who are illiterate or poor are the principal victims. On top of the generalised rural and urban split, there are big differences between prosperous Europe and Central Asia, and again to the even poorer regions of South Asia or sub saharan Africa. Solutions depend on shifting away from a focus on new technology and concentrating instead on patient pathways based on prevention and public, and on making the economic case for prevention. Account should be taken of productivity losses from avoidable morbidity and premature mortality in calculating the value of investments in

early diagnosis and screening, and the growing costs of care in a population with poor health can be mitigated by investments in prevention. A key may be to put prevention on the development agenda, he suggests, warning against what he sees as an error of focusing only on infectious diseases in pandemic preparations.

<https://ecancer.org/en/video/9832-inequalities-affordability-and-central-importance-of-primary-prevention>

Section 3: Early Diagnosis and Screening

Because childhood cancer is still relatively rare, its identification is all the harder, making it vital to maximise the use of screening and early diagnosis. One of the most effective measures now available for tackling cancer at source is the widespread use of HPV vaccination, but differences in access – and in national policy – mean that such public health campaigns are at present more successful in some countries, and predominantly those with greater healthcare resources.

Childhood cancer: Early cancer detection through screening Dr. Carlos Rodriguez

National Children's Hospital Dr. Carlos Saéñz Herrera, in Costa Rica

He highlighted how childhood cancer often occurs in a non-specific way, simulating other frequent and benign processes. This, associated with its low incidence, makes suspicion and diagnosis difficult. Since pediatric cancer is so rare, the doctor may not suspect it at first. However, early diagnosis and rapid referral of the patient to a specialist centre can reduce morbidity and mortality, he said.

<https://ecancer.org/en/video/9870-childhood-cancer-early-cancer-detection-through-screening>

HPV Vaccination in LMIC - barriers to uptake Dr Partha Basu

International Agency for Research on Cancer (IARC)/ WHO, France

According to Dr Partha Basu, for cervical cancer there are two worlds - countries like the United Kingdom which are going to eliminate this cancer in a few years, and on the other hand sub-saharan African countries with the highest burden of cervical cancer, where girls have no access to HPV vaccine and women no access to effective cervical cancer screening. Or India and China, sharing 35% of the cervical cancer burden of the world, still hesitating on introduction of the HPV vaccine. Recent international attempts to boost take-up of preventive measures were starting to advance when Covid struck and disrupted the process with attention to other vaccination programmes. Unilateral action on HPV vaccination by some smaller states in India has had good results, but requires new partnerships and the adoption of a longer-term view of health spending, as well as adaptation of programmes to cope with widespread shortages of vaccine.

<https://ecancer.org/en/video/10027-hpv-vaccination-in-lmic-barriers-to-uptake>

Section 4: Data and Clinical Trials

The data revolution is accompanying the therapeutic revolution that is increasingly being realised by better understanding of the biology of disease. Exploitation of data – both from clinical practice and clinical trials – is helping earlier identification of specific manifestations of disease, and leading to new therapies, advice on better targeted treatment, and better prognosis and outcomes. But enrolment in clinical trials is still low, often owing to a lack of adequate communication between the medical community and the public. And national policy, particularly in LMICs, can play a more influential role in ensuring that clinical trials conducted in a country are relevant.

Practical applications on new data of genetic ALL subtypes

Prof Robin Foà

Sapienza University of Rome, Rome, Italy

Commented on the wide learnings about the genetic landscape of ALL in both children and adults, pointing to how better understanding of the biology of diseases often translates as better prognostic certification and management. He outlines how it is helping earlier identification of Philadelphia chromosome-positive ALL, with its currently unfavourable prognosis, and explains how advances should soon translate into better targeted treatment. His conclusion is that changes in prognoses are currently predominantly benefiting children in developed countries, where long term survivorship is around 80%, with other types of ALL far behind, but further improvements can be expected from improved understanding of the genetic biology of the disease.

<https://ecancer.org/en/video/10095-practical-applications-on-new-data-of-genetic-all-subtypes>

Clinical trials participation is directly influenced by the information received by cancer patients and caregivers

Dr Daniel Vorobiof

Belong,Life, New York, USA

Only an estimated 3% of cancer patients worldwide enrol in clinical trials, but trial participation is in fact an important treatment option, he says – at times the only one, for oncology patients. His study of the use of real-world evidence with a specialised digital health platform is demonstrating that clinical trials participation is directly influenced by the information received by cancer patients and caregivers. Digital health platforms are an important source for patients clinical trial awareness, he insists.

<https://ecancer.org/en/video/9742-clinical-trials-participation-is-directly-influenced-by-the-information-received-by-cancer-patients-and-caregivers>

Choosing Trials Wisely: What type of clinical trials should be a priority for LMICs?

Dr Bishal Gyawali

Queen's University, Kingston, Canada and Department of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, USA

Dr Bishal defines avoiding wisely as making a conscious decision to avoid things that are not in the best interest of the patient. In this context, he goes on, avoiding clinical trials wisely means focusing on the essentials for LMICs, and not merely following models based on the evidence from high income countries. It is important to avoid a mismatch of conducting trials without visible impact on the cancer burden in a country. But the conduct of appropriate trials in LMICs, offering equity in access to novel drugs, capacity building and staff training opportunities, can be an advantage for the local health system. The need is to be very selective in what type of clinical trials to prioritise – since obviously participating in big industry sponsored multinational clinical trials that are not relevant to the local populations should not be a priority.

<https://ecancer.org/en/video/10015-choosing-trials-wisely-what-type-of-clinical-trials-should-be-a-priority-for-lmics>

Section 5: Capacity

Over and above cancer incidence in any population, the key factors governing outcome are the abilities of the health system to identify, diagnose and treat patients. This capacity depends above all on trained healthcare professionals, but is also reliant on adequate infrastructure, access to relevant data, and access to relevant technology. Constant improvements in management of disease also depend on the widened understanding of the underlying biology of cancer, and on the optimal deployment of emerging therapies.

Managing immune-related adverse effects in Africa Dr Mohammed Ezzi

University of Nairobi, Kenya

He recalls how immune checkpoint inhibitors for immunotherapy have, since their discovery in the mid 2000s, been approved for the treatment of 19 cancers, including two agnostic indications. A patient with the right biomarker can now benefit from this therapy, although due to the mechanism of action, the immune system tends to target healthy cells, creating adverse effects that are not commonly seen with conventional chemotherapy. His goal is to raise awareness of immune-related adverse effects and how they can be treated among oncologists and non-oncologist physicians. This is particularly important for patients who travel to an urban centre for treatment but then return to a rural area, where any side-effects may not be recognised because this is still a relatively novel therapy. Africa needs more research to be carried out on immunotherapy and on immune-related adverse effects, so that the findings can be passed on to fellow physicians, residents and other medical colleagues.

<https://ecancer.org/en/video/10092-managing-immune-related-adverse-effects-in-africa>

Section 6: Role of Biomarkers & Treatment

The emergence of targeted therapies over recent years has offered new hope to patients and their families after a diagnosis of cancer. New treatments in precision medicine are making possible improved survival and quality of life, and in many cases complete cure for conditions until recently considered desperate. But success in development and deployment of these therapies is dependent on the sophisticated screening that genomics is making possible, and on precision in the understanding of the underlying disease and its staging – and biomarker testing has assumed a key role in this.

ESMO 2021: PARPi data and their role in mono/combination therapies

A discussion of using PARP inhibitors in metastatic castration-resistant prostate cancer explored combinations and sequencing, and the prospects for moving beyond monotherapy. According to **Dr Neal Shore** (*Carolina Urologic Research Center, Myrtle Beach, USA*), **Prof Eleni Efstathiou** (*Houston Methodist Cancer Center, Houston, USA*), **Prof Fred Saad** (*University of Montreal Hospital Center, Montreal, Canada*) and **Prof Andrew Armstrong** (*Duke University, Durham, USA*), there are hopes that a combination will show synergy molecularly and clinically where the PARP inhibitor may leverage the biology of the other inhibitor to generate more clinical benefit than possible in sequential administration. Prolonging survival is important, but not at all costs, and in elderly patients the concerns are as much about quality of life, so therapy choice should be conditioned also by the capacity to control and mitigate side-effects. The discussion underlined the merits of taking the time to check patient history and to adopt a system-wide approach in therapy planning. The contribution of biomarkers is essential, it was stressed. The discussion also ventilated serious cautions against premature judgements of the efficacy of some of these new therapies by accepting unquestionably early trial results reported as press releases. The participants emphasised the need for fuller data on the potential for added toxicity, potential economic issues, and accessibility. The challenges of interpreting single arm studies without control group limit the scope for commentary, because of the difficulty of speculating without comparing the novel therapy with other approaches.

<https://ecancer.org/en/video/10002-esmo-2021-parpi-data-and-their-role-in-mono-combination-therapies>

Rare inherited pathogenic germline variants observed in sporadic paediatric neuroblastoma cases

A study by **Dr Emily Blauel** of the *Children's Hospital of Philadelphia, USA*, in *rare pathogenic inherited germline variants in sporadic paediatric neuroblastoma* reported that approximately 2% of all cases have a positive family history of disease, and are classified as familial neuroblastoma. In these cases, patients are likely to have an underlying pathogenic germline

mutation in the ALK or PHOX2B gene. The remaining cases, the vast majority, are thought to arise spontaneously. Based on large volumes of germline data from whole genome germline sequencing on the parents and on the patients, the study better defined the genomic landscape and susceptibility of neuroblastoma and provided better understanding of what is happening at the genomic level and its influence on the development of new blastomas. Key findings were that 16% of the cohorts had a germline pathogenic or likely pathogenic mutation and cancer gene present, in line with expectations from other large genomic sequencing efforts. The study established that the vast majority of these germline variants were inherited, with an equal proportion between maternal and paternal inheritance. Patients that harbour these pathogenic variants fared worse than other in terms of event-free survival and overall survival. The conclusion was that paediatric patients with sporadic neuroblastoma harboured rare pathogenic variants in cancer predisposition genes that were inherited and associated with worse disease outcomes. The data from this study can impact the future treatment of neuroblastoma in terms of escalation in the treatment plan or different type of treatment plan, and also how to counsel families.

<https://ecancer.org/en/video/9722-rare-inherited-pathogenic-germline-variants-observed-in-sporadic-paediatric-neuroblastoma-cases>

Prof Andrea Biondi

University of Milano-Bicocca, Milan, Italy

Prof Andrea Biondi of the University of Milano-Bicocca in Italy commented on the transformation of prospects for young patients with Ph+ ALL (Philadelphia chromosome-positive ALL) - the relatively rare sub-group of ALL among paediatric patients up to the age of 18. The prognosis was poor, with a survival rate of less than 40%, at the time the only approach was to get the disease into remission and then perform a stem cell transplantation as soon as possible. But the advent of tyrosine kinase inhibitors has improved the prognosis, boosting overall survival to 70%, and reducing the long term side effects that bone marrow transplantation had generated. There was, however, a significant increase in toxicity from intensive chemotherapy + TKI, even including death. The aim now is to reduce toxicity and to improve treatment effectiveness for this sub-group, whose prognosis is still significantly lower than other pediatric cancers. He looked forward to improving the landscape further with alternative approaches, including immunotherapy, on which he is running trials in Europe.

<https://ecancer.org/en/video/10102-paediatric-all-perspective>

Conclusions:

The efforts around the world to maintain and improve public health and to tackle cancer are usually well-intentioned and often well-targeted. But not always - and it is important to maintain a strategic vision of health policy within a broader economic, social and political context. If the many external factors that impact on health and on cancer care are ignored, they may nullify the most heroic efforts on the ground.

“Looking beyond technology in cancer care”:

Prof Richard Sullivan

King's College London / Chair of Trustees ecancer, UK

In a talk entitled “Looking beyond technology in cancer care”, Richard Sullivan contested the notion that cancer can be satisfactorily addressed only in purely biomedical terms or in relation to the technologies to treat patients. Addressing the challenges of cancer at world level, he advocated a switch to the way of thinking about systems, and a readiness to reject dogma, as the way to achieve what he termed ‘progressive universalism’ in care. Merely national approaches to cancer control are no longer appropriate, in light of the more frequent movement of cancer patients across borders, and the intrinsic complexity of cancer. The prevailing paradigm of cancer care, dominated by a western and almost colonial view of the world, is insufficient, he argued, advocating a vision of cancer in the broader social, political and economic context, taking account of the historical context, and the way that political forces have shaped - and can negatively influence - choice.

Therapeutic geographies matter, he said, pointing to Iraq, to Palestine, to Afghanistan, to Lebanon and to Mexico, where external factors condition cancer control and access to services. System considerations should also govern choice of treatment and technologies, he argued, urging the adoption of pathways that can speed treatment as well as refine treatment. Pathways and systems that can diagnose and treat in a timely manner can deliver benefits that may be preferable to the acquisition of new technologies.

<https://ecancer.org/en/video/10020-gordon-mcvie-lecture-looking-beyond-technology-in-cancer-care>

Courses:

Paediatric Cancer Staging: Bone and Soft Tissue Sarcoma

The ecancer module Paediatric Cancer Staging: Bone and Soft Tissue

Sarcoma has been developed for oncologists interested in learning about the core principles of cancer staging for paediatric tumours. It provides an acquaintance with the general principles of the paediatric cancer stage and its Tiered classification, and enhances understanding of the paediatric cancer stage and its applications for bone and soft tissue sarcoma. It also applies the Toronto paediatric staging guidelines to real cancer cases.

https://ecancer.org/en/elearning/module/441-paediatric-cancer-staging-solid-tumours?category_parent=0&category_child=0&keyword=&language=&profession=

Paediatric Cancer Staging: Solid Tumours

The ecancer module Paediatric Cancer Staging: Solid Tumours is aimed at

oncologists interested in learning about the core principles of cancer staging for paediatric tumours - an accepted classification of malignant tumours in paediatric cancer. Its modules develop understanding of the general principles of the paediatric cancer stage and its tiered classification, as well as its applications for solid tumours. It also explains how to apply the Toronto paediatric staging guidelines to real cancer cases. The teaching materials highlight the heterogeneous nature of paediatric cancers that makes NM inapplicable for most, and the consequent resort to disease-specific staging systems instead. But it spells out the challenges in the use of different systems for the same disease, and the differences between countries, and urges the need for consistency in paediatric cancer stage collection, not least to facilitate international comparisons and studies.

In the tiered staging system for 18 major childhood malignancies, Tier 1 is for registries with limited resources, Tier 2 for well-resourced cancer registries, and Tier 3 for optional additional prognostic factors. The materials focus on staging systems for 5 tumour types: neuroblastoma/Wilms Tumour, ovarian tumours, testicular tumours, hepatoblastoma and retinoblastoma, and specify that the guidelines are intended for population-based cancer registries, not to replace the staging systems of clinical trials or to reflect or guide clinical decision making.

https://ecancer.org/en/elearning/module/441-paediatric-cancer-staging-solid-tumours?category_parent=0&category_child=0&keyword=&language=&profession=

Dr Ching-Hon Pui

St Jude's Children's Research Hospital, Memphis, USA

Dr Ching-Hon Pui has explored the differences in treating adults and children with acute lymphoblastic leukaemia, and highlighted the importance of the inherited cancer susceptibility gene for the pathogenesis and treatment of the disease, and for the patient's family. Earlier uncertainty over the factors that led to most children with leukaemia being diagnosed between two to five years of age, with theories that included infectious disease, is being displaced by study of the germline cancer susceptibility gene. Studying germline polymorphisms also helps elucidate racial and ethnic differences in the type of leukaemia and in explaining why patients develop either B-cell or T-cell ALL. His studies have identified the cancer susceptibility gene in an increasing proportion of child cases, important for how the patient responds to treatment and what treatments to avoid. This information also allows screening of siblings and other family members, to permit monitoring for early detection of cancer.

(<https://ecancer.org/en/video/8605-identifying-cancer-susceptibility-genes-in-paediatric-all>)

Dr Janine Stutterheim

Princess Máxima Center, Utrecht, Netherlands

Dr Janine Stutterheim's study explored the clinical implications of minimal residual disease detection in infants with KMT2A-rearranged acute lymphoblastic leukaemia treated on the Interfant-06 protocol – an area where few studies have been reported, and where outcomes are generally poor. Investigation suggested prognosis and best treatment pathways for these patients. The findings were that negative MRD levels at the end of induction predicted a higher proportion of outcomes with 6-year disease-free survival (60.2%) than intermediate levels (45%) and high levels (33%). End-of-consolidation level MRD results were also predictive of outcome with slightly stronger correlations. Infants treated with lymphoid-style consolidation had a stronger correlation with 6-year DFS with negative levels than the EOI measurement, similar for intermediate levels, and conspicuously lower for high MRD levels, while for myeloid-style-treated infants, the corresponding figures were 45.0%, 41.3%, and 45.9%. The study concluded that induction therapy is a useful mechanism for selecting patients for subsequent therapy; infants with high EOI MRD may benefit from AML-like consolidation, whereas patients with low EOI MRD may benefit from ALL-like consolidation. Patients with positive EOC MRD had dismal outcomes. The findings will be used for treatment interventions in the next Interfant protocol.

(<https://ecancer.org/en/video/9369-clinical-implications-of-mrd-detection-in-infants-with-kmt2a-rearranged-all-treated-on-the-interfant-06-protocol>)

Peter Bader

Goethe-Universität, Frankfurt am Main, Germany

Prof Peter Bader stressed that debate is urgent over questions as to the use of novel and specific treatment options for children, where there is still no final position on the best therapy. He took as an example CAR-T cell therapy in the treatment of young patients with relapsed or refractory acute lymphoblastic leukaemia compared to the use of blinatumomab and HSCT, where evidence is, he said, increasingly available supporting the effectiveness of these alternatives in different populations. His work with CAR-T cells has shown the options and the possibilities using them to treat high risk children and young adults. However, over 40 years there are several tens of thousands of children who have been treated by stem cell transplantation and there are clearly identified risk factors making it possible to know how to use this type of treatment to cure certain patients for a long time, while there is less data on long-term effects of CAR-T therapy. His view was that both treatment options are valuable and it is important that they are used so it becomes increasingly clear in which patient groups each is the most effective. The hope is that long term toxicity will come to be demonstrated as less than with HSCT.

([https://ecancer.org/en/video/8619-cart-t-cell-therapy-in-young-patients-with-relapsed-refractory-all the treatment of young patients with relapsed or refractory acute lymphoblastic leukaemia](https://ecancer.org/en/video/8619-cart-t-cell-therapy-in-young-patients-with-relapsed-refractory-all-the-treatment-of-young-patients-with-relapsed-or-refractory-acute-lymphoblastic-leukaemia))

Prof Laila Hessissen

Mohammed V University of Rabat, Rabat, Morocco

Prof Laila Hessissen highlighted the gap between low- and middle-income countries and high-income countries in the care and outcomes of paediatric patients – largely as a consequence of inadequate paediatric facilities to accurately diagnose and treat. In a talk entitled “Outcomes in paediatric oncology: Are we closing the gap between LMICs and high-income countries?”, her recommendations emphasised the need for government involvement. She pointed out that while survival rates in high income countries are 80-90%, they are only 20% for children around the world, because 80% of children around the world are living in LMICs, leaving a survival gap of about 50%. In Africa there are particular shortages of paediatric oncology facilities, and paediatric facilities frequently lack the resources for accurate diagnosis and treatment of cancer. Even those that can offer treatment reach only half of the probable need, since about 50% of childhood cancer in Africa is undiagnosed. The general population and even many health care providers are not aware of the symptoms of childhood cancer; many are simply unaware that children can have cancer. Many individuals and groups are working in Africa on initiatives to improve the situation but real progress depends on engagement at government level too. Collaboration with governments is necessary so as to have a

comprehensive cancer plan for children, and to ensure access to the drugs for adequate treatment. Another issue is maintain treatment, since as many as half the children in treatment abandon their therapy. This requires the establishment of local teams trained to work with children who are referred for cancer with appropriate protocols for the local context.

[https://ecancer.org/en/video/8619-cart-t-cell-therapy-in-young-patients-with-relapsed-refractory-all the treatment of young patients with relapsed or refractory acute lymphoblastic leukaemia](https://ecancer.org/en/video/8619-cart-t-cell-therapy-in-young-patients-with-relapsed-refractory-all-the-treatment-of-young-patients-with-relapsed-or-refractory-acute-lymphoblastic-leukaemia)

Implementation of a molecular tumour board in LATAM: the impact on treatment decisions for patients evaluated at Instituto Alexander Fleming, Argentina

A study led by **Martino Osvaldo Angel** of the *Instituto Alexander Fleming, Buenos Aires, Argentina*, reported the first-year experience of the institute's Molecular Tumour Board. It concluded that in most of the cases evaluated, the MTB was able to provide treatment recommendations based on targetable genetic alterations. Molecular-guided extended personalised patient care is effective for a small but clinically significant proportion of patients in challenging clinical situations. The authors take the view that the implementation of a MTB is feasible in the Latin America region.

The MTB fulfilled its role of recommending personalised therapy for patients with cancer beyond standard-of-care treatment, based on a comprehensive molecular analysis of the tumour in a molecular pathology laboratory that is important for all targeted therapies approaches. At each of its monthly meetings, five cases referred by the treating oncologists were presented and discussed. The MTB recommendations were discussed with the patients/families by the treating oncologist, with the final decision to choose therapy left to the treating physicians. Of the 32 patients presented at MTB, 28 (87.5%) had potentially actionable alterations and only 4 (12.5%) had no actionable mutation. Six (19%) patients received a local regulatory agency approved drug recommendation, nine (28%) patients received an off-label approval treatment recommendation and three (9%) patients did not receive the treatment due to access and reimbursement of the drug.

<https://ecancer.org/en/journal/article/1312-implementation-of-a-molecular-tumour-board-in-latam-the-impact-on-treatment-decisions-for-patients-evaluated-at-instituto-alexander-fleming-argentina>

Survivor and parent engagement in childhood cancer treatment in Iran

Improved patterns of doctor-patient relationships and communication, more effective psychosocial support, and greater use of peer support groups for survivors and parents were the chief recommendations from a study of childhood cancer treatment in Iran conducted by a team led by **Shirin Ahmadnia** of *Allameh Tabataba'i University, Tehran*. The study documented

childhood cancer survivors' and parents' experiences and quality of engagement, including perceptions and expectations, during their cancer treatment journey as part of an International Society of Paediatric Oncology review of patient, family and stakeholder engagement in ten low- and middle-income countries in 2019, on the premise that patient and parent engagement is a critical part of childhood cancer care and must be prioritised and respected. Participants' expectations included improved communication and information flow among doctors, nurses, psychologists and social workers, parents and patients. The dominance of a medical-only rather than a multidisciplinary approach in care and the lack of integrated information provision and of assistance in navigation of the childhood cancer care systems were among obstacles identified. Training in communication skills during diagnosis, investigations and treatment and implementation of a multidisciplinary approach should be undertaken, it was recommended, with simple revisions in healthcare policies through Ministry of Health guidelines and protocols or action by hospital directors. Continued exploration of patient and parent engagement during childhood cancer treatment across Iran is , the study concluded - permitting an evaluation of the effectiveness of the changes in practice.

<https://ecancer.org/en/journal/article/1220-survivor-and-parent-engagement-in-childhood-cancer-treatment-in-iran>

Education and training of clinical oncologists—experience from a low-resource setting in Zimbabwe

The growing worldwide burden of cancer presents particular challenges in low- and middle-income countries, where human resource capacity development is at its most acute. In the African continent, lack of sufficient numbers of qualified staff has been one of the obstacles in developing a dequate and modern cancer treatment centres, alongside socio-economic demographics and disparities in overall care. In Zimbabwe clinical oncology was established in 1990 in a collaboration between the Government of Zimbabwe and the WHO. Training through the University of Zimbabwe's Master of Medicine in Radiotherapy and Oncology postgraduate programme has yielded more than 20 clinical oncologists who have initiated cancer treatment facilities in Africa and beyond as a regional resource, training others in transfer of skills in sub-Saharan Africa. Collaborations with external partners address deficiencies in training, and support nationals working abroad to return to teach newer technologies and techniques. This programme has trained professionals who have remained in the continent and have significantly contributed to the expansion of services in their respective countries of practices. The curriculum continues to evolve from knowledge-based training to competency-based training. However, there is a need to expand the current infrastructure to keep up with changing technology and new therapies, with an emphasis on

subspecialisation. Aligning the programmes to cater for the dynamic nature of oncology - and for local specificities - is another continuing need.

<https://ecancer.org/en/journal/article/1208-education-and-training-of-clinical-oncologists-experience-from-a-low-resource-setting-in-zimbabwe>

Oncology training and education initiatives in low and middle income countries: a scoping review

Safir Karim of the Department of Medical Oncology at the University of Calgary, Canada, led a scoping review of published training and education initiatives for oncology health professionals in LMICs- a critical component of building the workforce. The lack of an adequately trained oncology workforce is a significant barrier to adequate cancer control in low and middle-income countries, where the global cancer burden already falls disproportionately, it found, while helping to elucidate the strategies used. Analysis of eligible articles revealed that the majority of initiatives were targeted towards physicians and focused on continuing medical education, and almost all were done in partnership with a collaborating organisation from a high-income country. Fewer than half of the initiatives involved e-learning. And there was limited data on the impact of the initiative on patient outcomes. The conclusions were that there are few oncology training and education initiatives in LMICs published in English. The recommendations from the study were that initiatives should be encouraged for non-physicians, along with efforts to foster collaboration within and between LMICs, and to undertake knowledge-sharing initiatives and studies that measure the impact of these initiatives on developing an effective workforce.

<https://ecancer.org/en/journal/article/1313-determinants-of-completion-of-cancer-directed-treatment-an-experience-from-a-rural-cancer-centre-sangrur-punjab-state-india>

Determinants of completion of cancer directed treatment: an experience from a rural cancer centre, Sangrur, Punjab state, India

Access to cancer diagnosis and treatment is suboptimal in low and middle-income countries, and compliance with treatment is uneven, for reasons that include financial barriers, lack of family support and fear of treatment. **Atul M Budukh** of Tata Memorial Centre in Mumbai, India, led a study of determinants of treatment completion in cancer patients in a government-run hospital, in a rural part of Punjab. Of 2,528 cases analysed, 1,362 (54%) completed treatment and 1,166 (46%) did not. The results of the analysis indicate that patients with an age of greater than 60, distance from hospital and lack of access to government health schemes have direct negative correlation with treatment completion. Educated patients and patients who received curative treatment have showed higher compliance. Other variables - clinical extent of disease, religion, gender and income

– did not appear to have any significant effect on the treatment completion. The study concluded that cancer hospitals, health departments and policymakers planning for cancer care or control in India should take into consideration the impact of age, education, distance from the hospital, curative treatment and availability of government health schemes for financial support.

<https://ecancer.org/en/journal/article/1313-determinants-of-completion-of-cancer-directed-treatment-an-experience-from-a-rural-cancer-centre-sangrur-punjab-state-india>)

Impact of stigma and stigma-focused interventions on screening and treatment outcomes in cancer patients

A study by **Elizabeth O Akin-Odanye** of , *Ibadan University College Hospital in Nigeria* and **Anisah J Husman** of the *College of Health Professions and Sciences at the University of Central Florida,USA*, systematically reviewed the current data on cancer-related stigma across different populations to identify effective interventions used to address it, since stigma is known to negatively influence cancer patients' psychosocial behaviour and treatment outcomes. Assessment of the eligible articles revealed varying levels of methodological quality, but the conclusions drawn were that cancer stigma is expressed across different segments of society that include elites and healthcare providers, with developing countries reporting higher rates of stigma. The experience of stigma varied by cancer type, but cancer was consistently associated with imminent death in all studies reviewed. Cancer patients experiencing stigma were more inclined to conceal their diagnosis and to seek medical help later. Whilst cancer stigma principally resulted in negative psychosocial outcomes in patients, there were also instances of post-traumatic growth emanating from the stigma experienced. Literature on cancer-related stigma interventions was scant, despite the fact that it remains high in both clinical settings and amongst the general public. There is need for more interventions to combat cancer stigma and its effect in both patient and non-patient population. Anti-cancer public enlightenment campaigns should be sensitively designed to avoid further fuelling stigma against patients with certain types of cancers.

<https://ecancer.org/en/journal/article/1308-impact-of-stigma-and-stigma-focused-interventions-on-screening-and-treatment-outcomes-in-cancer-patients/abstract>

For more information

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The European Alliance for Personalised Medicine brings together Europe's leading healthcare experts and patient advocates to improve patient care by accelerating the development, delivery and uptake of personalised medicine and diagnostics.

