2nd EORTC Symposium:
Quality of Life, Symptom Research and Patient-Reported Outcomes in Cancer Clinical Trials

The 2011 EORTC Symposium held in the European Parliament in Brussels last 7-9 September confirmed the international attention paid to Quality of Life for cancer patients. The event enhanced the previous Symposium by introducing innovations on health related quality of life, symptom research and cancer clinical trials, including their design, implementation and analysis. Thanks to an extraordinary collaboration with the Portuguese Member of the European Parliament Marisa Matias, it was possible to give an institutional framework to the scientific gathering and engage a constructive debate with the European legislators and policy makers.

During the three-day event 31 Faculty, international leaders in their fields, presented diverse perspectives on HRQOL. All the different stakeholders in clinical research were involved including European patient groups. Patricia Garcia-Prieto and Earnene Nadwane from the ECPC (European Cancer Patient Coalition), Jan Geissler from CML Advocates network and Louis Denis from Europa Uomo gave an insight into the patient experience, addressing difficulties such as access to international clinical trials, survivorship issues etc.

The figures fully confirmed the success of the event, with 240 attendees from 44 different countries and the positive feedback from the participants wishing to repeat the experience. Andrew Bezzomby, Head of the QOL Department and Symposium Chair, announced a 2012 Conference (17-19 October) co-funded by a European Commission grant with the aim to give continuity to the initiative.

In order to facilitate the participation of young investigators and those from developing countries the EORTC created a Travel Fellowship program. Hundreds of applications were submitted, and the QOL Scientific Committee selected with a capricious care the 50 awarded from many worldwide candidates with promising CVs. The awarded Fellows represented 25 countries, bringing a particular and fresh view. We asked the Fellows to talk about their Symposium experience and here are accounts of young investigators from Poland, Portugal, Malaysia, Egypt and China describing not only the scientific value but also the networking opportunities the Symposium represented for them.

Arantza Gastar Pallares

I am a 28-year old medical doctor from Poland. I am currently in my internship year and working at the 2. Chair Specialistic Hospital in Krakow, Poland. As for next years' plans I am going to start my PhD studies at the Jagiellonian University in Krakow and continue my work as a physician.

My scientific interests focus mainly on health-related quality of life and overall physical and mental well-being of patients. As a medical doctor I am trying to popularize the concept that though fighting to cure patients is of great importance, doctors cannot forget that for some patients good quality of life is more important than prolonging the "no matter the cost".

Currently I am involved in a series of projects focused on translating and validating the EORTC's tools for health-related quality of life questionnaires in cancer patients. Even though most of EORTC's tools have been translated into Polish, not all of them have been psychometrically validated. So there is still lot of work ahead.

Quality of life concepts are quite popular in my country and many researchers work in that field. Quality of life starts to be seen as a possible outcome measure in clinical trials in Poland, thus the need for appropriate instruments. That is why we are currently working on translating and validating the EORTC tools.

Taking part in the 2nd EORTC Symposium on Quality of Life, Symptom Research and Patient Reported Outcomes in Cancer Clinical Trials was a great experience for me. It gave me the chance to meet people from all over the world and exchange ideas about working on and with patients reported outcome measures. It has inspired should proven to me that the quality of life concept is popular all over the world. I hope that I have learned at the Symposium will certainly contribute to my future work, especially the Translation Workshop and the talk by Prof. Cor Grootenhuis about designing quality of life questionnaires.

Once again I would like to say that attending the Symposium was a fantastic experience. It was great to meet the EORTC staff in person.

Krzysztof Tomaszewski
Jagiellonian University Kraków, Poland

I work as an attending physician and lecturer at the Department of Clinical Oncology, Tanta Faculty of Medicine, Egypt. I also spend 3-year fellowship at the Department of Oncology, Massachusetts General Hospital, Harvard Medical School, Boston USA. I have shared in many peer-reviewed articles and I also edited two chapters in the book entitled "Breast Cancer: A Multidisciplinary Approach to Diagnosis and Management".

The quality of life in patients undergoing treatment for cancer is greatly underestimated in Egypt and I think this is one of the major defects in our practice. I learned about the EORTC organization from the website and I was so happy to know about the travel awards. I applied and I was lucky enough to have the fellowship.

Attending this meeting was a unique experience to me since the topics were so much different from any other meetings I used to attend. This has been a very powerful life experience for me. The different people I met from diverse countries and cultures has made my learning experience more meaningful and real. I've seen how diversity can result in immense synergies, fruitful learning, and strong friendships. Also, meeting the experts in this field was an excellent chance to exchange thoughts with the potential for future collaboration.

The EORTC quality of life symposium opens me to new perspectives in my career. I really enjoyed it very much and I look forward to attending future EORTC meetings concerning with quality of life in cancer patients as far as future fellowships would be granted.

Mohamed Abd El - Hamid Aim El- Din
Department of Clinical Oncology
Tanta Faculty of Medicine, Egypt

I'm a 30-year old Portuguese Medical Oncology resident, at the verge of becoming a specialist. I health-related Quality of Life (HRQOL) was the motto for the clinical research I undertook during my Master in Oncology. Presently, I await the public defense of the dissertation entitled "Assessing the information given to cancer patients attending Day Hospital in a comprehensive cancer center", where I used EORTC QLQ-C30 and the information module EORTC QLQ-INFO25 as measurement instruments.

Attending the EORTC QOL Symposium, while writing my dissertation, was fundamental to contact directly with major experts in QOL worldwide, learning valuable tips and advice from them, and also for the opportunity to make contacts with other young researchers working in the field, which I believe will be most useful to me in the future, as I plan to continue working on this subject, namely developing a clinical trial where QOL will be an important endpoint.

Ana Catarina Pinto
Resident in Medical Oncology
Portuguese Institute of Oncology
Coimbra, Portugal

Hi, I am China from China. The 2nd EORTC symposium was truly rewarding and educational. I learned a lot from diverse topics of designing, translating and analysis of HRQOL in clinical trials, also gained a lot useful information in my own research area of gynecological cancer. Those topics in panelist and HRQOL were very informative and encouraging. The unique nature of this symposium included hearing the voice from patient perspective. That's truly meaningful. I love this symposium, I met many top researchers and scientists from all over the world, the Gala dinner was well organized as well.

Ying Chun Zang
The Hong Kong Polytechnic University,
School of Nursing, China

When I was at the preliminary stage of planning my current research on the outcome of tumour-related hemiplegic bony, a colleague suggested including Quality of Life (QOL) assessment into it. It was something new to me, but from there on, I came across with the EORTC QOL-30 Questionnaire, and was invited to attend the symposium in Brussels. It was an amazing experience! The lectures were inspiring, some of the sessions made the whole idea on QOL research sound very interesting and meaningful.

I can still remember my short discussion with Conrad Cleeve during one of the breaks. I would like to specially thank him for his willingness to spend time to discuss and giving his sincere and motivating suggestions on my research. Back in Malaysia, the last decade had seen a boom in health related quality of life (HRQOL) research. This may be related to researchers' readiness to use the generic HRQOL by World Health Organization (WHO). With the increasing improvement in the management of incurable or chronic illnesses, HRQOL is gradually incorporated to assess the quality of service, cost utility analyses, effectiveness of interventions, and the need for health care. I am a trainee lecturer and a registrar in Orthopaedics, and will be completing my Masters by the end of 2012.

Capitalizing on my special interest in orthopaedic oncology and reconstruction, I am seeking as many opportunities as possible to gain experience and knowledge to improve my services and management to orthopaedic cancer patients. I would like to thank the EORTC for awarding me the Travelling Fellowship and looking forward to share the result of my research once completed.

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