

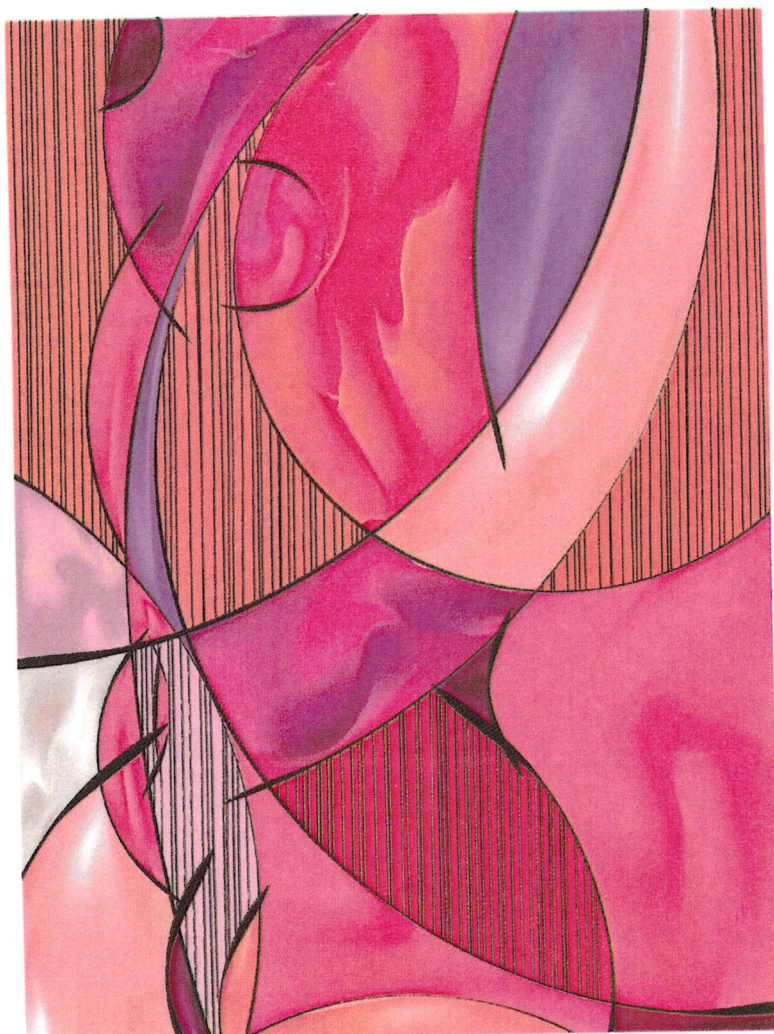


IN THIS SUPPLEMENT
ADVANCED BREAST CANCER
THIRD INTERNATIONAL CONSENSUS CONFERENCE (ABC3)



THE BREAST

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participated. 146 patients, 34 caregivers, 18 spiritual/community leaders participated. Relief of distressing symptoms reported in 80%. Responses on palliative care analyzed using questionnaires while community/spiritual leaders participated through focus group discussions. 90% participants expressed need for model that incorporates palliative services into the mainstream of medical therapy should be emphasized as standard care approach.

Results/findings: Poor wellbeing, appetite, pain and fatigue were most prevalent symptoms reported by the patients. 50% of the patients reported severe pain and 9% reported no pain. Spiritual pain control had highest correlation to QOL in comparison to functional, emotional, physical and social wellbeing. 90% of patients and caregivers reported free communication about illness. We also need to modify attitudes of caregivers towards psychosocial needs of breast cancer patients and their families. Breast cancer care hospitals must have separate departments for handling these issues.

Conclusions/recommendation: This study gives demographic picture of terminal cancer patients and family caregivers in public healthcare system and some aspects of palliative care. Resource-poor-nations need NGO to develop such programs in absence of government-run-healthcare-setup. We NGO activists need conference to discuss our project ideas/concerns/difficulties with senior researchers from USA/EUROPE. ESO must take initiative in propagating such efforts in developing-nations. Development of comprehensive breast cancer service program is distant dream in resource poor nations. We NGO patient advocates need international funding support for palliative care programs.

PO48

TERMINOLOGY USED IN ADVANCED BREAST CANCER AND THE NEED FOR CONSISTENCY

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Terminology used in oncology is frequently derived from ancient Greek, E.g. the term 'metastatic' meaning to 'change place'. The past decade has seen many advances in both identification of sub types of breast cancer and its treatments. Consequently terminology to describe breast cancer has evolved; both patients and health professionals use a range of terms to describe the disease, in addition to the traditional TNM classification of malignant tumours. There is a need for terminology to clearly explain the stage of breast cancer and individual assessment, to appreciate the complex prognostic factors involved and an awareness of potential difficulties, which can arise when terms are misinterpreted. A survey of breast care nurses found wide variations in terminology used and the need for consistency and clarity when talking with patients and professionals. The term 'metastatic' was widely used by international organisations attending a global advocacy working group in New York (MBCAWG 2009). In the UK the National Institute for Health and Clinical Excellence (NICE 2009) published guidance on advanced breast cancer and the European School of Oncology Advanced Breast Cancer(ABC) guidelines (2012) clarifies the term ABC includes locally advanced, inoperable breast cancer. In the UK, cancer charities frequently use the term 'secondary' which can be ambiguous, with patients reporting confusion about what is relevant for them when accessing information. A survey of 46 breast care nurses was undertaken, the findings demonstrated 77% used more than one term when talking to colleagues, terms ranged from metastatic 41%, secondary 35%, advanced breast cancer 19% and stage 4 5%. Other terms used when talking with colleagues included recurrence 1%, distant spread 1% and aggressive 1%. When talking with patients 54% of nurses used the term secondary with advanced breast cancer used by 14% and other terms used were recurrence or distant spread. 15% of nurses reported the term secondary had other meanings which included; a second primary cancer or secondary care. Advanced breast cancer describes a complex, disease

and individual assessment of the patients understanding of their illness is essential. Arguably defining the precise terminology may not be as important in the treatment setting where each person's treatment is individually planned, based on their specific diagnosis. However, there can be difficulty in translating clinical trial findings to the patient populations and from the perspective of patient information it is important correct terminology is used to ensure the patient is receiving appropriate information, which is one of the recommendations for clinical practice.

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GETTING BACK INTO LIFE

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I am a two-time breast cancer survivor, Dutch, living in Cologne, Germany. In 2000 I was diagnosed with a collision tumor, triple-negative and a third tumor, which was benign. All three cosily nested in one breast. Exactly 5 years later I had a second cancer. After my first surgery with immediate partial reconstruction, I went through chemotherapy and radiation. THIS TRACK WAS A MARATHON AND NOT A SPRINT. Breast cancer changed my life completely. One of my new challenges was painting; I had never painted before. Images were created in my subconscious. I decided to make a story out of it, just for myself. 22 Paintings with the title "Message of Hope"... my healing journey. Then my friends told me: "you have to do something with it". So I began to contact international cancer organisations, they were interested and invited me to present my Slideshow. Since 2010 ECCO//ESMO//ASCO//ECPC//EUROPA DONNA//REACH TO RECOVERY INTERNATIONAL//VITAL OPTIONS INTERNATIONAL+++ have been supporting and inviting me to speak about "Getting back into Life", as well as to present and exhibit my survivorship story "Message of Hope". My mission is to encourage breast cancer patients and motivate them to unlock their creative potential, which could heal both soul and body. My project is to reinforce the connection between Art, Cancer and Patients Supportive Care. My goal is to make a difference in the Breast Cancer Community through creative expression. I believe ART IS LIFE and LIFE IS ART. Just recently I decided to commit myself in a unique project "Global License in Oncoplastic Surgery". Initiated by 2 Doctors. They will present this issue for the first time in a special session at the Barcelona Breast Meeting BBM in March. My painted poster "The Expert Eye" will be incorporated: Using my Artwork to Speak Out. There is no official Oncoplastic Surgery Specialty Training. This need to be created as an integral part of Breast Surgical Training worldwide and be a concept of WHO to be established. We patients need the availability of a reliable Global Register of Specialists. Oncoplastic Surgery can be involved in any stage of Breast Cancer. OPS was originally conceived to help patients with large tumors, locally ADVANCED BREAST CANCER.WHAT IS MY PASSION? To inspire breast cancer patients how to express their feelings thru Art. To advise breast cancer patients finding Specialists in Oncoplastic Breast surgery so that they can be confident to receive top health care. There are Too Many Mastectomies, Too Many Mutilations and Too Many Breast Centres WITHOUT Licensed Specialists in Oncoplastic Breast Surgery. THIS breaks my heart!

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PSYCHOLOGICAL SUPPORT TO CANCER PATIENT THROUGH VOLUNTEERS AND SURVIVORS

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Introduction: The diagnosis of cancer is like a bolt from the blue to the patients and relatives. It causes tremendous mental stress and panic. Taking the patient and the family members out of such mental and familial stress is a very difficult job.