

**REPORT ON THE SECOND SCIENTIFIC MEETING
OF THE EUROPEAN SOCIETY FOR PSYCHOSOCIAL ONCOLOGY (ESPO)
AMSTERDAM, OCTOBER 24th, 25th 1988.**

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The European Society for Psychosocial Oncology (ESPO) was formed in August 1986. ESPO's principal aim is to provide and to promote a greater understanding of the psychological, social and ethical aspects of cancer and its treatment. It seeks to respond both seriously and sensitively to the need for psychological and social support for cancer patients at all stages of their illness, for their families and also for health care providers. Awareness of and interest in the psychosocial sequelae of a malignant illness has grown enormously over the past decade. Passive (and at times in the past) sterile pre-occupation with concepts such as "quality of life" is increasingly being overtaken by cooperative studies which are diverse to the point of encompassing methodological and procedural issues of measurement, theories of coping and of support, the feasibility and effect of psychosocial intervention, the study and application of ethics and information reception and transmission. ESPO aims to facilitate and to promote inter-disciplinary research of high quality. Caring for patients - whether it is in the home or the hospice or in hospital - is the central theme of psychosocial oncology. The necessary search for and drive toward excellence in academic awareness, objective research and clinical input, is now beginning - albeit slowly - to yield rich dividends. Membership of ESPO is open to all health care professionals and scientists who live and work in Europe and who are actively engaged in clinical work or scientific research into psychosocial aspects of cancer. Its first and present holder of the office of President is Professor Robert Zittoun of Paris and its Secretary is Dr J de Haes of Leiden.

Clearly, scientific meetings provide a necessary and an appropriate locus for the dissemination and exchange of information and of ideas and since the time of its inception, ESPO has held two such annual meetings. The first took place in Madrid in November 1987, whilst the second was held in the Netherlands Cancer Institute, Amsterdam, in October 1988. ESPO's third annual meeting is currently being planned to coincide with the ECCO-5 Meetings,

which are to be staged in London in September of this year. Arrangements are currently in hand to make this a joint conference with The British Psychosocial Oncology Group (BPOG). It is scheduled to take place in the Royal College of Physicians, London, on September 1 and 2 1989. The purpose of this publication is to summarize the proceedings of the Amsterdam Conference, (October 1988) and to publish abstracts of short papers presented orally at that meeting.

There were four sessions in all, under the topic headings of, "PSYCHOSOCIAL INTERVENTIONS (Chair, J de Haes), "THEORIES OF COPING AND SUPPORT" (Chair, S Bindemann), "QUALITY OF LIFE MEASUREMENT" (Chair, N Aaronson) and "ETHICS AND INFORMATION GIVING" (Chair, R Zittoun) A parallel "Round Table" session on "PSYCHOTHERAPEUTIC INTERVENTION" (Chair, C Bolund) was also held.

The invited Speaker at the First Session was Professor Jerome Cohen, School of Social Welfare, UCLA Los Angeles, U.S.A. In his lecture, Professor Cohen provided a detailed review of the process of development and institutional commitment to psychosocial research in the American Cancer Society (ACS), commencing within the Californian Division and expanding to becoming an acknowledged national commitment. Professor Cohen referred to the special contribution of the "Psychosocial Task Force" of the Californian Division, with their special remit, namely to explore and to 'open up' psychosocial issues, from prevention through detection, diagnosis, treatment support, rehabilitation and continuing care. National workshops were staged, bringing researchers and practitioners together on a national level. These activities have become a regular and an essential feature of communication- and skill-transmission in psychosocial activity in the USA. Professor Cohen spoke of the need for continuity in creating and developing organizational structures which can support research activities and ensure a continuous flow of highly-skilled research workers in the following key areas; cooperative longitudinal

studies, which will monitor crisis response and adaptation over time, in patients with all types and at all stages of disease. 2. well-designed clinical trials designed to study the influence of psychosocial interventions and 3 studies of an evaluative type which can simultaneously assess effects of treatment of physical disease on quality of life and longevity.

"Do we have a good theory of coping? This was the question raised by Dr David Nerenz, our second invited speaker as the title of his paper during the session on, "Theories of Coping and Support". Dr David Nerenz is Director of the the Center for Applied Research, Henry Ford Hospital, Detroit, MI, USA. Dr Nerenz began by referring to the importance of the concepts of coping and social support for all research workers in psychosocial oncology. Whilst there is a large body of empirical work relating these concepts to stress, adaptation, survival and other outcome measures, there is a surprisingly weak theoretical foundation for the substantial amount of it. Dr Nerenz went on to review theories of coping and social support, focusing upon similarities and differences which are amenable to empirical testing. He referred to weaknesses in current theory, including the difficulty of clearly defining, "coping" and "social support" in non-circular ways. Dr Nerenz also commented upon what he regarded as the strengths of 'coping and social support theory' and ended by reviewing its future needs and possibilities.

The "Quality of Life Measurement" session was introduced by our third guest speaker, Dr John Ware Jr, former head of the Health Sciences Program, The Rand Corporation, Santa Monica, California and currently, Director of Institute Advancement for Health and Medical Centre, Boston, Mass. USA. Dr Ware began by reviewing quality of life measures, paying particular attention to the concept of standardization in health status measurement and the development and evaluation of short measures. He emphasized the need which currently exists - both in health policy and in clinical research activities

(clinical trials) - for practical tools in the area of health status or quality of life assessment. Dr Ware referred to the influence which the WHO's broader definition of "health", i.e., as a multi-dimensional concept of well-being, is having upon the need for and the development of functional measures; e.g., physical, mental and social states. This altogether larger perception is in turn leading to a requirement to translate, to express and to evaluate it by means of standardized generic measures, possessing proven reliability and validity. Dr Ware illustrated the importance of the range of measurements in a well-population, as being exemplified by scales which had been developed by the RAND Health Insurance Experiment. He cited the RAND experience as a good example of a precision problem, e.g., illness-related measures could not show the benefits of free medical care because of distributional problems. When the RAND trials began, 78% of the sample scored perfectly the "impact of sickness". More precise scales were therefore constructed, enumerating many health status levels on a continuum. The problem is now being overcome by better and more appropriate methods of measurement, e.g., multiple questions replacing the one global rating, use of a more sensitive scaling method etc. Dr Ware illustrated the development of short measures, in the "Medical Outcomes Study" (MOS) comprising 20 items. This instrument attempts to measure physical functioning, role functioning, mental health, health perceptions and pain. It has been shown to be reliable and cost-effective on time. Its validity is presently being tested. Dr Ware ended with a plea for more standardization in health status or quality of life measurements, i.e., health care costs or benefits across conditions and treatments, cannot be analysed without a standard.

The Fourth Session on "Ethics and Information Giving" was addressed by Dr C Schaake-Koning, of The Netherlands Institute, in a lecture entitled, "Historical Background and Dilemmas in the Informed Consent Procedure". Dr Schaake-Koning began by referring to the more explicit nature of ethical

aspects of medical decisions, since the Neurenberg Law Suits and especially since the Declaration of Helsinki, with the modifications of Tokyo and Venice. In spite of the general ideas as they are laid down, cultural and social interpretations differ widely from country to country and even from hospital to hospital. Dr Schaake-Koning referred to the work of The Medical Ethical Committee, which began in 1980. At that time, written informed consent was required only for Phase 1 studies. A re-statement was issued in 1986, when written information according to several checkpoints for all studies was proposed. Dr Schaake-Koning referred to the pattern which has emerged in the Netherlands, where difficulty is being experienced, not with the acceptance of proposals by medical staff, but rather with precise elucidation of the essential points of protocols for patients. She further referred to a 1988 Bill which is especially concerned with ethical aspects of research with human beings and which stipulates a requirement for written informed consent. Work is currently being carried out within the Netherlands Cancer Institute, in an attempt to study problems related to the informed consent procedures and in order to improve and refine the process for all concerned. In the absence of data which is still being collated from this study, Dr Schaake-Koning commented on her own observations concerning problems for members of hospitals' staff and for patients.

The "Round Table" session on "Psychotherapeutic Intervention" took place over both days and its thirty two participants revealed a wide distribution in professional training and working conditions. Opportunity and facilities available, together with prevailing attitudes toward psychosocial needs of patients among senior clinical staff, appeared to be a crucial factor in determining actual practice. Relevant factors influencing patients' decisions and choice were, stage of and attitude toward malignant illness, individual and personality differences and perceived awareness of the need to strengthen existing coping skills and defence mechanisms against uncertainty, intense

fear, anxiety and depression. The point was strongly made and generally agreed that intervention should always reflect adequate assessment, based upon the functional status and needs of the individual patient and information available concerning his/her temperament and personality. This in turn, led to detailed consideration of the hypothesized relevance of personality structure as a major determinant to accurate diagnosis of psychosocial needs, treatment modality(ies) being proposed and therapeutic goals. This demands a flexible approach which where sensitively adopted, can facilitate a sound theoretical explanation for vulnerability as a function of individual differences, e.g, ego-strength, defence organization, reality adjustment, basic trust etc. It was agreed that psychosocial intervention with cancer patients requires a highly skilled and an appropriately experienced approach. Empathy on the part of other members of health-care staff although necessary, is frequently insufficient. These considerations led on to discussion concerning the crucial role of hospitals' nurses and doctors, especially where specialist intervention is not readily available on a daily basis. Here, an indirect approach on the part of the psychotherapist was considered, in which skilled support and counsel may be made available to members of hospitals' staff to enable them to provide the necessary vital support. The two day session ended with suggestions of topics for future sessions of this kind, e.g, diagnostic issues, need for standardization of psychotherapeutic approaches, possible negative effects, necessary intervention, teaching and training needs, the need for staff support and supervision.

The following abstracts were presented orally at appropriate sessions. (A further thirty studies were presented in poster sessions which in subject matter, adequately represented the sessions' topics referred to above.