

treatment should seek to avoid doctor and patient bias and both may be compromised when assessing AM! Physical methods of AM can be assessed by prospective randomised controlled trials, ideally testing one method versus placebo but given the self-selecting patient population more realistically comparing one method of AM with another. Psychological methods are best assessed by established quality of life instruments but careful study design is essential to try and control addition (non-declared) supportive therapies, and of course the effect of concomitant CT may adversely affect quality of life but increase survival. Patients motivation for using AM is usually a hope that survival will be increased and therefore the ultimate end-points in assessing AM should include quality of life studies and overall effects on survival.

1005

The role of the nurse in palliative care

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The role of the nurse in health care can be described based on their professional domain: the consequences of disease and treatment. It doesn't give us a very specific description of tasks, qualifications and responsibilities, but it is directive to come up to the different requirements for nurses.

Patients in palliative care are confronted very much with the consequences of disease and treatment, so is their family and the professional support team.

The role of the nurse in palliative care is not easy to describe because of the variety in organisational models dealing with palliative care problems. Nevertheless, there are similarities in the different settings in all our countries. In this presentation the similarities will be discussed in order to come to a common understanding.

The roles that will be discussed are:

- (a) the nurse as the analyst of (nursing) problems
- (b) the nurse as the co-ordinator of holistic care
- (c) the nurse as the advocate of the patient and the family
- (d) the nurse as the teacher for patient, family and the health care professionals
- (e) the nurse as the team-leader of the palliative support team.

Specific attention will be paid on the necessary use of measuring-instruments, communication skills and ways and means to obtain expert knowledge.

Central themes guiding the discussion about the nurses role in the interdisciplinary support team in palliative care are the 5 C's of:

- (a) Co-ordination
- (b) Communication
- (c) Complementation
- (d) Creativity
- (e) Continuity.

1006

How far should we go in treating cancer patients?

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At least 50% of the patients with cancer will not be cured by our current therapeutic efforts. It does not mean however that, in those incurable patients, there is not a place for palliative chemotherapy and radiotherapy. As a matter of facts, with the use of supportive care techniques, relatively aggressive palliative therapy of neoplasia, and even experimental therapy, can be given to patients with advanced tumors.

However, such a therapy may not be reasonable beyond certain limits; this is the case when the performance status is low, the life expectancy is short or when treatment is declined by the patient. Under these circumstances, it is often appropriate to decide that cardio-pulmonary resuscitation will not be performed. However, this does not necessarily imply that all supportive care interventions should be automatically withdrawn and that these "not to be resuscitated" patients should only receive treatments which make them comfortable. Many of these patients can benefit from adjusted palliative therapies in combination with supportive care techniques.

Nevertheless, to avoid overtreatment which can occasionally lead to a significant reduction of the quality of life in these patients, a try and evaluate approach is proposed; this implies that interventions will be discontinued as soon as their inconvenience outweighs the benefit, rather than to palliate these adverse symptoms with new interventions.

It is clear that this comprehensive approach needs to take into account

the patient's will and the medical possibilities. It would be unacceptable to treat an unwilling patient or to administer futile therapies.

1007

Patient needs as analysed through national "helplines"

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Purpose: In order to improve patients-physicians relationship, ECL (European Cancer Leagues) has asked for a survey on this theme.

Methods: A questionnaire was handed out at the Helpline Conference in Granada, Spain, 2-4 May 96 to receive information on the types of problems the conference-delegates, who answer the helplines, have been running into regarding this special matter while speaking with patients or family members.

Results: 33 helpline-delegates from 23 European countries answered the twelve questions. I will present the results of this questionnaire. Other problems, not mentioned in the questionnaire, will be added.

Conclusion: There is a problem identified: Lack of good communication: it has to be taken seriously.

1008

Nordic cancer union: Programs in communication a way to increase patients satisfaction

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Purpose: How to increase doctors skill in communication?

Method: A standard teaching program has been tested in 5 Scandinavian countries. One teacher and 6 doctors in each courses has been fulfilled.

Result: All course attending doctors has been evaluated. There is a high score (increase) in the ability to communicate. 20 items are tested and the results will be revised.

Conclusion: The result is inspiring The Norwegian Cancer Society (one member of NCU) has put the program on their main agenda for the coming years.

1009

What's up doc? - A patient's perspective on Doctor/patient communication

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The presenter is a former patient, treated successfully for testicular teratoma. He is a lawyer by occupation.

Arising from my personal experience as a patient, the following issues seem to be the most important:

- (1) Prior consideration of the personality, background, intelligence, social circumstances and state of knowledge of the patient.
- (2) The need for training and self-knowledge in the Doctor as to his ability to communicate effectively.
- (3) The need to listen and really hear the patient's response - the importance of body language, tone, the undercurrents of questions and "the questions not asked".
- (4) Often, patients do not hear or interpret properly what is said to them. There is likely to be a need for continuous reinforcement.
- (5) The need to have the whole caring team will briefed on the patient's understanding of his condition, his attitude to it and his concerns.
- (6) The need for appropriate optimism, reassurance, warmth, humour and "small talk."
- (7) The only golden rule is that there is no golden rules.

1010

Informed consent & cancer clinical trials

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All agree that the randomised controlled trial is the gold standard for evidence based medicine. All agree on the ethical imperative for informed consent prior to recruiting patients into such trials. Most agree that the informed consent charade is the major rate limiting factor in improving statistical power of these clinical trials yet few are prepared to confront head on this dilemma. It is my view that the time for individuals to be informed