

Plenary Lecture

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Quality care: Fantasy or reality?

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Quality assurance and control has been developed in the frame work of clinical trials and regards all aspects the process. Protocol development, relevance of the scientific question, statistics, realistic in terms of numbers and time. Control of forms and procedures and actual on site data verification. The main lessons of quality assurance in clinical research has been that there are many flaws at each level compromising the final outcome, unless rigorously controlled. Next to procedures and data checks the actual quality of care given to the patients has been evaluated. In radiotherapy an internationally recognized program has been developed and implemented to control field size, dose calibration etc. For chemotherapy a so called chemotherapy symptom checklist has been developed, implemented and reviewed. For surgery this is less standardized but it is generally accepted that quality of the initial surgery is next to stage a very important prognostic factor. For example the relevance of the number of nodes removed in case of an axillary node dissection in breast cancer and in colonic cancer is an independent prognostic factor for outcome. Furthermore experience of the surgeon and the multi disciplinary team is related to outcome.

If these factors are relevant for clinical research, why should it not be relevant for patient care outside the frame work of clinical trials? We are advocating evidence based medicine and we presume that we can translate the result of clinical trials to daily practice. This requires the same prerequisites as we have identified for clinical research. Do we have the optimal infra structure? Do we have the appropriate training? Do we have a multi disciplinary team to treat certain cancers? Do we see the appropriate numbers to maintain experience? Do we deliver surgery, radiotherapy and chemotherapy according to recognized standards. And last but not least do we have the skills to implement new insights into our practice? The answer on many of these questions is no or at least uncertain. This means there is room for improvement.

It is obvious that the doctor is not the single dominant factor in this process. The support and knowledge provided by the nurses are essential in this process. Recognition of the relevance of quality on all levels of care is the first step for improvement. It is important to select the relevant items for outcome in the process before embarking on program to improve quality of care. In conclusion quality of care is relevant and reality but not sufficiently recognized implemented.

Proffered Papers

Supporting patients and families

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ORAL

Informal carers in cancer contexts: their activities and needs

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Purpose: To report a study of the care-giving activities, experiences and needs of informal carers (mainly spouses) of cancer patients, part of a 3 year NHS funded research project on the psychosocial needs of cancer patients and carers.

Methods: Data collection involved a descriptive cross-sectional survey of carers (an achieved sample of 262 respondents, with similar numbers of male and female carers) followed by in-depth guided interviews with a sub-sample of surveyed carers (n=32).

Results: Care work findings:- additional care work demands were an important feature of informal carers' experiences, although this varied with the stage of the patient's disease and the presence of either co-morbidity in patients or morbidity in carers. Specific groups of carers expressed the need for help with particular practical tasks and with the personal effects of the burden of care work.

Emotion work findings:- carers of either gender worked hard to manage the emotions of the patients as well as their own feeling states; these aspects of emotion work were intimately connected. Carers felt they had

to be strong and positive and to try to maximise the sense of life carrying on as normal. Spousal carers often symbolically shared in the illness and presented the struggle with cancer as a joint one.

Conclusion: The roles of informal carers are very significant in the cancer journey, and give rise to carer psychosocial needs. Male carers are less likely than female carers to express these needs. By understanding the roles of informal carers, health professionals can be sensitive to, and supportive of, carers expressed or latent needs.

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ORAL

Children as relatives, - a challenge for nurses

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Purpose: Little empirical evidence exists concerning the impact of a parent's cancer diagnosis on his/her children. The main purpose of this study is to gain knowledge of the situation of children who have a parent suffering from cancer in order to develop adequate strategies for a nursing approach. The specific aims are:

- * to describe the reactions of children and parents when a parent is suffering from cancer

- * to describe the children's and the parents need for help and assistance when a parent is suffering from cancer

- * to develop an intervention program that can meet the recorded/reported needs in order to promote the children's quality of life and help them to cope with serious illness in the family