persons is not attractive because of immediate risk, cost, lack of doctors and inconvenience to the patients; nevertheless, colonoscopy has been suggested with intervals of 10 years.

Colonography has not been evaluated for screening purpose yet, but may be used when colonoscopy is incomplete.

Among other markers those of DNA are most promising, but multiple DNA alterations must be targeted.

At the present time, guidelines should be developed at national level for FOBT programs in average risk populations, based on feasibility studies in limited parts of the country, like it has been done in UK. It should be foreseen, that endoscopical, histopathological as well as radiologic services must expand.

Initial colonoscopy should be reserved for high risk groups.

1072

How to cope with cancer?

E. Rasmussen. *Mandag Morgen, Copenhagen, Denmark*

Coping with cancer demands a new partnership between doctors and patients and a new understanding of the social and psychological consequences of cancer. So far we have focused too much on the decease itself and too little on the patient. Cancer is not only a decease, but the biggest and toughest challenge that can hit a human being on all dimensions at one time. Therefore cancer should not alone be treated as a decease. In consequence of this doctors must either expand their own competencies or accept and cooperate with at much broader field of complementary treatments.

My presentation goes through the different stages of challenges the cancer patient has to cope with and suggests what kind of partnerships is needed at each stage to ensure the best possible outcome for every single patient.

1073

Optimizing the time between breast cancer diagnosis and treatment through Collaborative Care.

M. Mendelsohn, J. Belkora, L. Esserman. *UCSF, Carol Franc Buck Breast Care CenterUCSF Comprehen, San Francisco, USA*

When a woman receives a breast cancer diagnosis, she is flooded with emotions, information and questions. She is overwhelmed with the task of quickly learning the language of cancer terminology and the subsequent availability and choices of therapy. The Collaborative Care Program was developed to support women through the time period from diagnosis through treatment. This is a method that enhances medical provider to patient communication by taking them through a systematic and defined process that delineates questions, answers and options in a manner that is understandable to both participants in the decision process. The interventions may be both qualitative (Consultation Planning) and quantitative (Treatment Selection).

Medical providers are highly trained in the areas of diagnostic and therapeutic intervention but there is a lack of skill building within medical training that enables them to help patients in the science and art of decision making. The typical health care consumer lacks training in this same area. The gap between patient-provider aspirations and capabilities may be termed the Decision Gap. At the UCSF Carol Franc Buck Breast Care Center, providers are focused on tailoring treatment to biology and, very importantly, patient preference. The potential poor outcomes that can result from not employing these methods may include treatment related complications, poor resource utilization and patient as well as provider dissatisfaction.

There are many variables in patient preference regarding decision making. Often, patients feel intimidated by the medical environment, are worried about taking too much of the provider's time, and/or have difficulty synthesizing their concerns. The questions that patients seek answers to that will ultimately drive their decisions are sometimes not things that a provider would have any way to predict.

The Collaborative Care process is demonstrated through examples of particular cases that illustrate the outcomes that have demonstrated positive impact on patient and provider satisfaction, decision quality and communication while taking into account the decision quality conditions of frame, values, alternatives, information, reasoning and commitment.

1074

Continuity and quality from the time of the cancer diagnosis until the treatment is completed

A. Gregor. *Western General Hospital, Clinical Oncology, Edinburgh, United Kingdom*

Continuity of care and access to information are quoted as the two most pressing priorities for patients and clinicians. Modern management of cancer increasingly requires care delivered by teams of professionals working in different specialities and in diverse geographical settings. What are the characteristics necessary for effectiveness of multidisciplinary teams? 1 Are there specific roles which one or another professional group should lead in?2 Or is it the process of care that must be specified and supported by administrative actions and information management? Is the holy grail of continuity an outdated proxy for consistency of management and information or expression of medical dependency and paternalism?3

The task of this presentation is the initial part of "cancer journey" from the diagnostic interview, post diagnostic evaluation/ staging, multidisciplinary decision conference and formulation of a management plan, treatment delivery and evaluation and immediate post treatment aftercare. The formulation of a plan for follow up and rehabilitation is taken as the end of this process although most patients will need and have an ongoing clinical relationship beyond this rather arbitrary point.

The core relationships are between the patient his family, carers, various members of the hospital multidisciplinary team and the primary care team but may include employers, social services and external support staff from voluntary sector. The care process at this stage needs to be fast and decisions about prognosis and details of therapy which are of critical importance will depend on scenario which changes with the progress and outcome of the investigations and assessment.

Individual members of the clinical team have rarely access to the totality of the information and/or the expertise to come to a summated and accurate decision. At this stressful time patients and their family search for reassurance and certainety through multiple contacts with various members of the team and risk receiving conflicting information which further enhances their distress.

Variety of approaches to integrated care have been tested in clinical settings. Their summary could be expressed in a simple framework addressing *the four P's: pathways, personnel, protocols and "paper".*

- *Pathways* of care need to be defined so that patients and their clinical team know the plan including dates and places of key events.
- Each and every *member of the team* must know their own role and responsibility- agreement on communication strategy and content is a part of this process and patients need to know who and where to contact if they need to or get lost. Specialist nurses provide this case manager role most frequently, but other health acre professionals or even administrative staff may be just as useful providing they are trained and supported.
- *Protocols* provide guidance on what to do and how to do it with the explicit agreement and realisation that exceptions will happen.
- Under the heading of *paper* is the documentation and information needed. If this process is to be safe and efficient than the traditional forms of uni-professional assessment and letter writing between team members is not adequate- it must be supported by modern technology. A combination of an open web based information resource describing the process of care and a closed system of an EPR available under strict QA control and need to know basis to the clinical team provides the best compromise between open access to information and security of clinical data and has the additional benefit of being able to capture and report selected performance indicators as a by product.

Fundamental review of roles and responsibilities of all clinicians within the team are essential to redefine the new paradigm of doctor patient relationship. Clarity will improve the quality of the encounter and the experience for all parties involved. It needs to be done in a positive, flexible and systematic way with the patients at the centre of all considerations and recognise the cultural and professional barriers that will need to be crossed if such change is adopted and implemented in practice.

1075

Advocacy for cancer patients

A. Vinkel. *Danish Cancer Society, Department for Patient Support, Copenhagen, Denmark*

Through her 12 local counselling centres, national cancer helpline and rehabilitation centre Dallund, the Danish Cancer Society offers information and support to cancer patients and their relatives. In 2002 more than 26.000 counselling interviews were performed. Further a great number of activities invite patients to share their insights to help others find their way to cope with cancer.

Thus cancer patients and their relatives share their experiences and put forward their wishes for treatment, knowledge, care and support. And apart from empowering the patients to help them cope in the best possible way, the Danish Cancer Society uses the knowledge gained through the many contacts in its work to change conditions for all cancer patients by setting the political agenda in the cancer field.

If you look at cancer as a kind of journey from the point of suspicion of cancer through diagnose, treatment and rehabilitation or palliation it is clear that there is a lack of knowledge. E.g. how do people new to the cancer experience make treatment decisions, how do they cope with the physical and emotional side effects of cancer and what happens after treatment? It is important not only to treat the cancer but also to take care of the patient from the time of the diagnosis until the journey is over.

The presentation will highlight initiatives taken by the Danish Cancer Society to secure optimal information and support to cancer patients.

The initiatives focus on

- securing patients access to good quality, tailored and timely information
- securing cancer patients treatment within a recommended time limit. Danish patients are legally guaranteed this right but it does not work due to lack of equipment and health professionals.
- ensuring access to as many relevant treatment offers as possible. If no proven treatment is available cancer patients should be able to participate in clinical trials of new treatments.
- securing cancer patients the right to a second opinion
- seeing to it that the recommendations of The National Cancer Control Plan are implemented
- supporting the great number of cancer patients that research shows use alternative treatment by cooperating with The Knowledge & Research Centre for Alternative Medicine in Denmark and by supporting research in this field
- establishing information, advice and support network on the www.cancer.dk