Methods: 240 patients with diagnosed malignancy and pain >3 days and average pain >3/10 will participate in a cluster randomized trial on 18 wards in 2 German university hospitals. According to modified "Precede Model of health behavior" from Green (Yates, Edwards et al. 2004), patients self management skills are affected by the patients' knowledge, activities and attitude to pain management. Therefore patients from the intervention wards received additionally to standard pain treatment, the SCION-PAIN program consisting of 3 modules: pharmacologic pain management, non-pharmacologic pain management and discharge management. The intervention will be conducted by specially trained oncology nurses and will include the components of knowledge, skills training, and coaching to improve self care regarding pain management beginning with admission followed by booster session every 3rd day and one follow up telephone counseling within 3 to 4 days after discharge. Patients from the control wards received standard pain treatment and standard care.

Primary endpoint will be the group difference in patient-related barriers to management of cancer pain – BQII (Gunnarsdottir 2002) 7 days after discharge. Secondary endpoints are: Average pain intensity, HRQoL, Adherence to pain medication and coping with pain.

Expected Results: The study will determine if the self management skills of the patients continue to be used when the intervention stops, e.g. after discharge from hospital.

It is hypothesized that patients who receive the multi-modular structured intervention will have less patient-related barriers to the management of cancer pain.

4165 ORAL

An evaluation of the association between age and health related quality of life and symptoms in cancer patients – a pooled analysis of closed EORTC Randomized Controlled Trials

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Background: Previous studies have demonstrated the prognostic value of age in cancer survival, with older cancer patients reporting a poorer survival than younger patients. However, for health care professionals it is important to understand the relation of association between age and age-related factors, such as Health Related Quality of Life (HRQOL) of cancer patients. The objective of this study was therefore to investigate the influence of age on the HRQOL of cancer patients.

Methods: Patients from 30 closed European Organisation for Research and Treatment of Cancer (EORTC) Randomized Controlled Trials, covering 11 cancer sites, were included in this retrospective pooled analysis. HRQOL was recorded at baseline using the EORTC QLQ-C30. The variable age was dichotomized at 70 years; representative for younger and older cancer patients. A multivariate analysis, modelling the binary variable age, and corrected for gender, cancer site, disease severity (metastases vs. non metastases), World Health Organization (WHO) performance status, on 15 HRQOL scales was used.

Results: Baseline HRQOL data were available for 5,388 patients younger than or equal to 70 and 718 patients older than 70. HRQOL impairment between the two age groups was reported at baseline for global health status (<0.001), physical functioning (<0.001), role functioning (0.009), cognitive functioning (<0.001), financial difficulties (<0.001) and for the symptoms fatigue, nausea & vomiting, pain, dyspnea, appetite loss, constipation (all <0.001). Thus, for the functioning and symptom scales, older people reported a poorer HRQOL compared to younger people. However, interestingly, older cancer patients reported a lower financial burden compared to younger people.

Conclusions: Our pooled analysis indicates that the HRQOL of older cancer patients is affected differently by cancer compared to younger patients. Older people reported a poorer score in different HRQOL domains. Health care professionals should be aware that the most vulnerable cancer patients are older people and hence our results could provide insights to help provide suitable clinical awareness and care for more senior patients. However, older patients in general reported that the financial burden of this disease was of a limited impact compared to younger patients. This could be important for supportive care services when treating younger patients.

4166 ORAL

Gastro-intestinal cancer patients: how they perceive and cope with disease and treatment-related symptoms over a 12-month period

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Background: Symptom prevalence within cancer is well documented. Despite this, little is known about the patients' experience of these symptoms, over an extended period. The importance patients place on the physical impact of their symptoms is often inextricably bound with both their psychosocial impact and a range of social, emotional and financial experiences. Providing clear information about symptoms, particularly the physical impact of treatment and toxicity, is well recognised, but less attention has been given to understanding the wider context of the patient experience of living with cancer. This knowledge is of particular importance in current patient-centred health care systems.

Materials and Methods: We recruited 19 patients with gastro-intestinal (GI) cancers from a large cancer centre in the UK who were interviewed at 4 time points in their illness trajectory: immediately after diagnosis (T1), and at 3 (T2), 6 (T3) and 12 (T4) months thereafter. The number of completed interview data sets was 56. The data were analysed using thematic analysis.

Results: During the acute treatment phase, T1−2, patients were focused on the impact on quality of life and daily function of disease and treatment-specific symptoms. Key concerns included pain, neuropathy, nausea, taste changes, altered bowel function and fatigue. Patients also emphasised the emotional impact of diagnosis and treatment, concerns about the lack of clear and timely information and the communication skills of their health professionals, and discussed fears vs. hopes for the future. At later time points, T3−4, the focus shifted to more existential issues, such as regaining control and independence, ways of coping, the lack of clarity from health professionals in relation to longer term care, anxiety about recurrence, financial concerns and hopes of surviving until newer treatments could be developed.

Conclusions: This longitudinal study provides important insights into the experiences and feelings of GI cancer patients which in turn should prompt an improvement in care. Alongside familiar themes such as the need for consistent, clear and timely information throughout patients' treatment trajectory (highlighted by the UK Cancer Reform Strategy, 2007), greater insight is required into patients' concerns and how their needs and priorities change over time. More attention needs to be given to supportive care from the patient's perspective which includes their existential, social and financial survivorship issues alongside their multiple physical symptoms.

Oral presentations (Tue, 22 Sep, 09:00−11:00)

Experiences of care

4170 ORAL

The experiences of young people from first symptoms to the diagnosis of cancer: a narrative study

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The difficulties in prompt diagnosis, referral and treatment of cancer in young people are thought to be a contributing factor for poor outcomes in this age group compared to people who are younger or older. There is very little research concerning the period leading to diagnosis for both teenagers and young adults. This study aimed to understand the pre-diagnostic and diagnostic phase of cancer in young people, reported as near as possible to the time of diagnosis by young people themselves.

Twenty four young people between the ages of 16 and 24, who were between two to four months from diagnosis with a solid tumour, were recruited to the study from four principal treatment centres in England. Narrative interviews were undertaken as well as a documentary analysis of the medical notes. Data were analysed to examine how these narratives were structured and connected to broader contextual issues concerning both cancer and this age group and the broader negotiation of entry into the health care system.

Shared themes within these narratives shaped a group narrative and an emerging conceptual framework. This included the individual's perception of, and meaning given to, their symptoms; the impact of others in determining the identification of a threat from the symptoms; the negotiation of generalist health care and then entrance into specialist care. A narrative of diagnostic delay was evident in some of these stories. Alongside this process is the influence of symptoms, diagnosis and in some cases delay in diagnosis which all impacted on the identity and the biography of these young people.

The experience of the time from first symptoms to diagnosis was revealed to be complex and multidimensional with many factors contributing to the process of attaining a diagnosis. This paper will present both the method and findings of this study with the aim of sharing the young people's accounts of their pre diagnostic and diagnostic period. This study offers new insights into the experiences of young people from first symptoms to a diagnosis of cancer. These have implications for developments in practice, policy and research; where the ultimate aim must be to improve the experiences of diagnostic delay for this patient group.

4171 ORAL

Educational film – a new opportunity to reach teenagers and young adults with cancer

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When a young person is diagnosed with cancer, their life alters completely. The natural process of disengagement from their parents is instantly replaced by mutual dependency.

What most young people take for granted – school, parties, friends, sports and sweethearts – are put on hold. Instead the daily life of a young person suffering from a life threatening illness becomes overwhelmingly one of hospital admissions, treatments and side-effects, separation and sacrifice. These specific needs and preferences that young people with cancer have are difficult to meet on a traditional adult or children's oncology ward. A group of pioneering nurses from Aarhus University Hospital, in Denmark found a solution to this dilemma. They created an oncology Youth Ward caring for cancer patients between the ages of 15−22.

What began as a trial project has now become an established and respected routine. The patients, their families and the medical staff value the new environment and benefit from the innovative ideas and caring work practices on the Youth Ward.

The core aspect of our care: When we look back at the 8 years which has passed since the project "Teenagers between 15−22 years with cancer" ended we found that there were five elements that were important in today's youth care.

These 5 elements are:

1. Contact nurses
2. Contact consultant
3. Network meetings
4. "Parentfree time"
5. Outpatient consultations with the patient and family, after the treatment is completed.

Nursing in the future: It represents a great professional challenge to care for and support the young patient and their family through this difficult time. They can be full of despondency and have very few victories.

The young people of today use a variety of different media sources. In order to reach the young people, we have produced an educational film to show and inform them and their parents what to expect in the nearest future, during and after treatment.

Caring for young people with cancer is an ever ongoing process. We strive to attend conferences in order to get new ideas, benefit from other departments by sharing our experiences and knowledge, hopefully leading to optimize the care for young people.

We have made our educational film in English and got our book on youth nursing translated into English so our methods and experiences can be known the world over.

Today's society focuses greatly on young people as trendsetters, consumers and target groups. Young people are considered to be a unique group – a status we believe should also apply when they are patients in our hospitals.

You are welcome to download a free draft of the book:
www.youthwards.oncology.dk

4172 ORAL

Creating a space – Teenagers and young adults with cancer and network-focused nursing

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Background: In transition between dependant childhood and independent young adulthood, teenagers and young adults (TYAs) are extremely vulnerable when diagnosed with cancer and while undergoing treatment. Social support and contact with their social network is of major importance. However, there is little empirical knowledge of how nurses can assist them in obtaining this.

Study purpose: To generate a substantive theory that explains what happens when oncology nurses interact with TYAs with cancer and their significant others in order to support them in preserving, establishing, and strengthening family relationships and social network during the treatment period.

Material and Methods: *Method*: Grounded Theory (Glaser and Strauss 1967, Charmaz 2006). *Data collection*: In-depth interviews, participant observation, informal conversations and documents. *Setting*: A Danish oncology youth unit for patients aged 15−22 where a network-focused nursing program has been implemented. *Participants*: 7 nurses, 12 TYAs with cancer and 19 parents or partners.

Findings: C*reating a space* for teenagers' and young adults' normal growth and development was identified as the mutual basic social process. Nurses, TYAS and significant others tried through actions and interaction to resolve problems related to TYAs' developmental needs and risk of isolation due to the cancer trajectory.

Two parallel but interacting patterns of behaviour pushed this process forward:

1. Nurses engaged in various ***Bridging*** processes by strategies of '*Tuning in*', '*Framing the situation*', '*Navigating towards the goal*' and '*Connecting people'*.
2. TYAs and significant others activated resources that aimed at ***Keeping their world together*** by '*Embracing the program*' and '*Building strength*'.

Nurses worked at reaching into the private sphere, extending beyond family centred care and including the wider social network.

Conclusions: The study offers new insight into a previously unexplored area of nursing practice. It contributes to knowledge by providing a theoretical framework for clinical practice. Meeting the needs of TYAs with cancer is a complex and highly demanding practice that needs to be addressed by nurses, educators, researchers and health policy makers. As oncology nurses are in unique position to use their knowledge in mobilising resources in the patients' social network, implementation of a network-focused nursing program is recommended. The findings of this study can be used by nurses to assist them in this endeavour.

4173 ORAL

Cancer beliefs in disadvantaged populations

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Background: Cancer incidence is greater and the outcome of cancer poorer for people living in socio-economically disadvantaged areas. Such inequalities are strongly linked to health behaviours such as smoking, diet, exercise and alcohol consumption. Healthy lifestyles are therefore key to closing the gap, yet promoting them frequently increase inequalities as advantaged populations respond more to the message. Exploring disadvantaged populations' understandings of lifestyles and cancer aetiology is thus important. This would accord with the World Cancer Research Fund's (2009) recommendation that we understand the underlying factors that lead to risky behavioural choices; "*the causes of the causes*" of cancer. This study explores lay understandings of healthy lifestyle messages and cancer risk amongst 179 people living in three disadvantaged Scottish communities characterised by higher cancer morbidity and mortality. In assessing the processes involved in the reception and interpretation of healthy lifestyle information in relation to cancer beliefs, the findings can help inform and improve practice for health care professionals working with disadvantaged populations.

Methods: A qualitative rapid appraisal approach, including semi-structured interviews and focus groups with 179 community members and 19 public health and health care professionals, was used in three disadvantaged communities in Glasgow, United Kingdom.

Results: Findings show that participants do not receive healthy lifestyle messages passively but actively construct cancer related health beliefs including both scientific knowledge and elements of personal, social and area histories. Scientific knowledge was often seen as provisional,