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POSTER

# Resilience scores in a cohort of cancer patients in chemotherapy treatment on ambulatory basis

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**Background:** Resilience is defined as the ability to successfully cope with change or misfortune, allowing a person or group to regain balance and keep going despite adversity and also to find meaning amidst confusion and tumult. It is a positive personality characteristic that enhances individual and group adaptation. Few data exists regarding its systematic evaluation in cancer patients. The objective of this study is to evaluate and describe resilience scores in a population of ambulatory solid tumors cancer patients receiving chemotherapy treatment.

**Methods:** Individual Resilience scores were measured by the Wagnild and Young Scale, validated for portuguese language from Brazil. It is a 25-item questionnaire, scored on a 7-point scale from 1=disagree, to 7=agree, with all items worded positively. Scores range from 25 to 175, higher scores reflecting higher resilience. This scale was applied to 48 ambulatory solid tumor cancer patients (24 of them with breast cancer), in chemotherapy treatment at Oncosinos/Hospital Regina in Novo Hamburgo, Brazil. The study was approved by the Ethics committee and all patients signed the informed consent form.

**Results:** The mean age of all patients was 52 years (19–76) and 34 (70%) were women. The most common cancer types were: breast (48%) and colorectal (21%). The majority of patients had stage IV disease (47%) receiving chemotherapy on a palliative basis. The mean score of resilience was 141±12 (101–174). The scores showed a normal statistical distribution. No statistical differences in the mean resilience scores were detected between groups of patients as defined by: sex ( $P=0.11$ ), age  $\geq$  or  $<50$  years ( $P=0.9$ ), cancer type ( $P=0.78$ ), cancer staging ( $P=0.9$ ), or the chemotherapy treatment intention (palliative or curative,  $P=0.91$ ). Within the subgroup of 24 patients with breast cancer, the mean age was 49 years and the overall results are very similar to the whole cohort of patients, with a mean resilience score of 141, also displaying a normal statistical distribution of resilience scores and showing no statistical difference between different stages.

**Conclusions:** The resilience scores in this cohort of patients display a statistically normal distribution. Our results suggest that the total resilience score represents an intrinsic individual characteristic that is independent of cancer stage, cancer type, age and sex of the patients. Its relation to quality of life, and even prognosis of patients needs further studies.

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# Extravasation mentor – train the trainer programme in the United Kingdom

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**Background:** The first author was a member of the task force who produced the European Oncology Nursing Society (EONS) extravasation toolkit including management guidelines and both authors were involved with the development of the United Kingdom Oncology Nursing Society (UKONS) bridged documents. Following these documents they were both members of the multiprofessional group who provided a train the trainer extravasation program throughout the United Kingdom for key professional groups who provide a chemotherapy service within a variety of settings, including nurses, pharmacists and academics.

**Materials and Method:** This interactive program was delivered to key clinical staff working within chemotherapy delivery services and provided an overview of extravasations in terms of pathophysiology, prevention and ways of minimising the risk, detection, treatment options and possible consequences, discussed patient case studies and published EONS guidelines, along with time for discussion and sharing experiences from clinical practice.

**Results:** Evaluation by attendees was very positive, the attendees felt the program was very good/excellent and fully met their expectations and importantly they all agree to disseminate the information by delivering the sessions locally to their colleagues, which would raise their awareness and ultimately benefit patient care. Following the evaluation of the initial program a further program is currently being delivered.

**Conclusion:** Based on our experience in the United Kingdom this method of delivering education and presenting evidence based guidelines could be

utilised in other countries to benefit both professionals providing the care and patients receiving the care.

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# Education – as a new concept of support to cancer patient's on chemotherapeutical treatment

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**Introduction:** Cancer has always been a synonym for suffering and death, especially for uneducated people. The WHO Declaration for human rights includes, among others, the fundamental human right to inform about the disease and therapy. Because of that, education of cancer patients should be incorporated as an integral part of chemotherapeutical treatment.

The aim of cancer patient's education is to demystify facts about cancer, chemotherapy and side effects of chemotherapy. Educated patients are skilled to reduce unpleasant symptoms of disease and to achieve the best possible quality of life.

Nurse is escort cancer patients education through individual work, small groups and organized popular healthy lectures.

The goals of our investigation were:

1. To assess needs of cancer patients for education and
2. To assess a frequency of appearance a nurse diagnosis (needs of cancer patients for specific knowledge about side effects of chemotherapy, proper nutrition during chemotherapy and diagnostic procedures) according to the others health problems.

**Methodology:** The research was conducted during 2007. at the Institute for Oncology and Radiology of Serbia in Belgrade. A hundred and fifteen cancer patients were enrolled in the study. Confirmed diagnosis of cancer and the patient's informed consent about participation in the study were required. All patients's answered a questionnaire specifically designed to assess the needs for education.

**Results:** Results showed us the needs of cancer patients for education especially their interest to getting information about side effects of chemotherapy and proper nutrition.

**Conclusion:** Education of cancer patients has to be systematic and planned according to patient's wishes and needs. It seems to be powerful weapon against the disease.

Nurse, as a member of medical team, must be very educated, skillful and good expert to respond to these challenges.

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# Final results of a multi-centred research study: the feasibility using workload measurement tools to assess data management workload for a cooperative group study in Australia

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**Background:** The workload associated with conducting cancer trials at investigative sites in Australia is not well documented, currently no workload benchmark exists. Workload assessments are routinely determined by perceived trial difficulty and estimated clinical trial accrual, methods that do not realistically account for trial workload. Consequently these methods cannot be used to assess the true workload of site study coordination. This study was instigated to determine if selected data collection tools are suitable instruments for capturing data required to assess clinical trial workloads. Secondary objectives of the study are to determine actual time spent performing data management tasks, based on the predetermined identified parameters and to establish estimates for study coordination time and costs.

**Methods:** Australian Sites participating in a cooperative group colorectal study recorded time spent completing trial specific tasks according to defined parameters. Data from all aspects of trial activity (enrolment, treatment, follow-up, ethics, administration, communication and monitoring) was recorded over a 12 month period. The treatment and follow up data was then tabulated by visits and cycles to facilitate a cost analysis model. In addition information pertaining to the organisational structure and infrastructure of the study sites, staff education, experience and responsibilities was also gathered.

**Results:** The data collection sheets were satisfactory instruments to capture trial related workload data. From the data gathered it was possible to determine and establish mean task times for a number of trial activities. These parameters also provided a platform for identifying factors that should be taken into account when developing a clinical trial budget for an investigative site. Data of professional training, tertiary education and professional experience of trial staff has been reported for the participating sites.

**Conclusions:** This study provides insight into the time requirements involved in undertaking recognized clinical trial tasks for a specific colorectal study in Australia. It also identifies some less recognized workload issues which should be taken into account when assessing workload and budgets for clinical trials. Undertaking a study of this nature has been challenging and highlights the need for a more research into the issues of clinical trial workload to be undertaken in order to establish industry benchmarks.

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**Determining the minimal clinically important difference for health related quality of life scores from the EORTC QLQ-C30 in lung cancer patients: an analysis of pooled data**

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**Background:** Patient assessment of Health Related Quality of Life (HRQOL) in cancer clinical trials has increased over the years. However, understanding the clinical meaning of HRQOL scores requires further investigation. The objective is to determine changes in HRQOL scores on the EORTC QLQ-C30 scales (with range 0–100) which correspond to the minimal clinically important difference (MCID).

**Materials and Methods:** Two closed European Organization for Research and Treatment of Cancer (EORTC) randomized controlled trials enrolling in total 812 advanced NSCLC cancer patients were jointly analyzed. WHO performance status (PS) was chosen as a clinical anchor for 6 HRQOL scales of the QLQ-C30 questionnaire; physical (PF), social (SF) and role (RF) functioning, global health status (GH), fatigue (FA) and pain (PA). Estimates of the MCID for the scales were calculated using a combination of an anchor and distribution-based approach. Changes in clinical anchor were categorized into 3 groups; improvement, no change and deterioration. Analysis of variance was used to compare HRQOL scores across groups. The differences in the mean of HRQOL score changes between adjacent groups and effect size (difference divided by standard deviation at baseline) were calculated. Adjacent group differences corresponding to an effect size of at least 0.20 were used to estimate the MCID.

**Results:** 485 patients who had both HRQOL and PS scores on at least 2 time points (baseline and on/after treatment) were included, and the 2 available most separated time points were chosen for analysis. Significant differences ( $p < 0.05$ ) in HRQOL across groups were noted for all 6 scales. The ranges of adjacent group differences and effect sizes ( $>0.20$ ) were; PF (6.1–9.9; 0.25–0.41), SF (7.7; 0.27), RF (10.9–12.3; 0.31–0.35), GH (10.2; 0.46), FA (5.9–15.7; 0.22–0.60) and PA (14.8; 0.47). The results suggest the following estimates (mean) of the MCID; PF: 6, SF: 8, RF: 11, GH: 10, FA: 6 and PA: 15.

**Conclusions:** Our results suggest that in patients with advanced NSCLC undergoing treatment, the functioning, global health status and fatigue scales can be interpreted using a change in score of 6 to 11 as the MCID (on scales with range 0–100). For pain, a relatively higher MCID estimate of 15 was found. These MCID estimates can be used to classify patients by changes in HRQOL and symptoms over time as well as to aid sample size determination for future studies. Further validation in cancer patients with other diagnoses is planned.

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**Information needs of patients with cancer considering participation phase I trials**

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**Background:** Improvement of cancer treatment is achieved by clinical trials. Patients with solid tumours with no standard treatment options may consider participation in phase I trials. Hope on a miracle is in many cases the reason for participation. Lack of knowledge about the purpose of a phase I trial can be a major obstacle for ethical informed consent.

A study was performed to investigate the information that can motivate patients in the first three stages of the model of Prochaska and DiClemente considering participation of a phase I trial at the ErasmusMC Daniel, Rotterdam.

**Materials and Methods:** A qualitative study was performed with semi-structured interviews using a topic list. The topic list was based on literature research concerning cancer patients' information needs. The Delphi method was used to define the list. Twelve interviews were taken from eight patients, four men and four women at the age of 36 to 71 years old. The verbatim interviews were evaluated using a qualitative database program Kwalitan.

**Results:** During the first three stages of the model of Prochaska and DiClemente, precontemplation, contemplation and preparation, the patients' information needs change. At precontemplation, the patient is informed about the lack of treatment options and needs information concerning the possibilities to participate in clinical trials. The attitude and the oral information given by the physician and/or nurses add to the decision making during contemplation. All patients found the written information too long and half of them did not understand this information. During preparation, control over informed consent is important for patients.

**Conclusions:** In the first three stages of the model of Prochaska en DiClemente patients with solid tumours with no standard treatment options need open, honest, understandable information. This information should be provided in an emphatic way, with an eye for the patients' needs, problems and backgrounds. Thus patients are better prepared to make a well-advised decision whether or not to participate in a phase I trial.

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**Teenager and young adult cancer care – A grounded theory study of network-focused nursing**

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**Background:** Several research findings identify social network and support systems as important aspects in the rehabilitation and coping processes of teenagers and young adults (TYAs) with cancer and their parents. However, there is little empirical knowledge of how nurses can support TYAs and their social network. Research in this area has not been done nationally, and is limited internationally.

At an oncological youth unit in Denmark nurses have developed a systematic intervention programme in caring for TYAs with cancer and their significant others (parents and on rare occasions a partner). Nursing activities are directed towards interactions intending to help the TYAs and their significant others in maintaining contact with a supportive social network.

**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:** The qualitative research method Grounded Theory guided the study (Glaser and Strauss 1967, Charmaz 2006).

Sources of data:

1. 7 nurses working in the Youth Unit, Department of Oncology, Aarhus University Hospital,
2. 12 TYAs with cancer aged 15–22 who had been or were being treated in the unit, and
3. 19 parents or partners were included in the study.

Data were collected through in-depth interviews, participant observation, informal conversations and documents.

**Findings:** A basic social process of *Creating a space* for teenagers' and young adults' normal growth and development was the nurses' main challenge.

*Bridging* was defined as the core concept in nurses' strategies. By strategies of: 'Tuning in', 'Framing the situation', 'Navigating towards the goal', 'Connecting people', the nurses worked at reaching into the private sphere, extending beyond family centred care and including the wider social network. The nurses had to earn their way into this private world.

**Conclusions:** Nurses worked proactively to preserve social integration of the patient and the significant others and to provide conditions for including the wider social network. Establishing a trustful and respectful partnership with an emerging independent young adult and his or her family requires a highly sensitive approach, careful assessment and cooperation. Findings of this study show how this can be accomplished and can inspire nurses to improve care of TYAs with cancer – an area of nursing that needs to develop internationally.