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Improving Breast and Lung Cancer Services in Hospital Using Experience Based Co-design (EBCD)

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Background and Aims: This project sought to design better experiences for patients and health care staff from the breast and lung cancer services within two large teaching hospitals in England. Experience based co-design (EBCD) was the chosen action research approach (Bate and Robert 2007). EBCD is a new and innovative methodology combining (1) a user-centred orientation (by adopting a narrative storytelling approach) and (2) a participatory, collaborative change process, allowing staff to 'see the person in the patient' and placing patient and staff experience at the centre of service development.
Methods and Results: The project involved an in-depth qualitative study of how care was delivered by staff and received by patients, focusing on patients' emotional 'journey'. It included 36 filmed patient narratives, capturing the key emotional 'touch points', 60 staff interviews about their experience of providing services, and ethnographic observation of clinical areas. Patient and staff interviews were analysed to identify themes and issues for which were fedback to patients and staff at various group events. For example, a composite 30 minute film of breast and lung cancer patients' experiences, was created and used to feedback patient narratives to staff. Through a facilitated three-stage change process which will be described, patients and staff agreed on joint priorities for improvement and then worked together in co-design groups that focused on identified priority areas (for example information provision, day surgery, continuity of care, diagnosis and outpatient care).
Discussion and Conclusions: The paper reflects on lessons learned for improving patient/staff experiences through the use of EBCD. It explores the value of the EBCD approach, the use of narratives, observation and film (excerpts will be shown) as a way of humanising health care and engaging staff and patients in a change process to facilitate meaningful and lasting improvements in service provision.

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Developing and Testing a Novel, Evidence-based and User-tested Toolkit for Assessing and Improving Teamworking in Multidisciplinary Cancer Teams

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Background: Cancer multidisciplinary teams (MDTs) are well established as a core element of cancer care worldwide. A UK national survey completed by over 2000 MDT members led to the publication of '*The characteristics of an effective MDT',* providing a benchmark for assessment. We report the development and preliminary testing of a toolkit: MDT-FIT (Feedback for Improving Teamworking).
Material and Methods: Development: a prototype toolkit was based on literature review, focus groups, surveys and interviews with over 350 MDT members from over 60 teams. There was consensus that this should include: rules of engagement; on-line survey; independent observational team assessment; feedback report; and facilitated discussion to agree actions. The relative merits of different types of observer and facilitator were debated.
Preliminary testing: Five MDTs (106 team members) tested MDT-FIT, involving: (i) an on-line survey completed by team members individually, containing: a 42-item MDT questionnaire and a questionnaire on leadership, based on UK national recommendations (ii) independent assessment of a filmed MDT meeting by an in-Trust clinician/manager, a non-clinical researcher, and a teamwork expert; (iii) a team feedback report (iv) team discussion of findings, facilitated by either an in-Trust clinician/manager, the MDT lead, or a teamwork expert. Team-members commented on MDT-FIT via an online survey. Moreover, telephone interviews were held with 28 purposively selected team-members, observers and facilitators. Short-term outcomes were assessed 3−6 weeks post-meeting.
Results: In general, team-members agreed that the online survey had content validity but needs shortening; independent observation adds value (especially by in-Trust and teamwork experts); the feedback report was relevant and useful (but needs shortening); and the facilitated discussions were useful regardless of who facilitated. Short-term outcomes included changes to scheduling and membership of meetings, method of case discussion, and involvement of team members.
The MDT questionnaire showed good internal consistency (Cronbach alpha >0.70) in relation to key domains of team functioning: leadership; teamworking/culture; patient-centred care; and clinical decision-making. Responses to the MDT questionnaire correlated strongly with responses to the leadership questionnaire ($r = 0.79$, $p < 0.01$), thus indicating concurrent validity.
Conclusions: Preliminary testing shows that MDT-FIT is acceptable and can result in immediate team improvement. Further testing of the MDT questionnaire and of the feasibility and effectiveness of Trust-based team observers and facilitators is currently underway.

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Patients' Perceptions of Caring When Receiving Home or Hospital Care During the Acute Posttransplant Phase After Allogeneic Hematopoietic Stem Cell Transplantation (ASCT)

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Background: At the Centre for allogeneic stem cell transplantation unit (CAST) Karolinska University Hospital, patients can choose between home or hospital care during the acute posttransplant phase. Specific requirements must be fullfilled before patients in homecare can be treated at home. Studies from CAST (Svahn et al., 2002, 2006) have reported that homecare during ASCT reduced incidence of infections, acute graft versus host disease (aGVHD) and improved treatment-related survival. To further investigate these two caring contexts the present study aim to evaluate and compare patients satisfaction and support from the healthcare staff when receiving care in home or hospital during the acute posttransplant phase.
Material and Methods: Data were collected during October 2006 to December 2009 with The Sympathy- Acceptance-Understanding-Competence-questionnaire (SAUC) when patients were discharge and a total of 41 patients (20 female, 21 male) participated. Median age was 54 (32−67) years. 19 patients received home care and 22 hospital care. 32 patients were married/cohabitant. AML ($n = 17$) was the most common diagnose and 36 patients received perhial stemcell as graft source. The SAUC- questionnaire contains 45 questions divided into 3 general domains; person-support, self-support, self-perspective. Self-perspective contain 4 areas; life plan, repertoire, internal and external environment. A mean score (ranging from 0−7) were calculated for each domain/area − high score indicated better patient satisfaction. Data analysis are ongoing regarding the open ended questions.
Results: Patients reported high satisfaction, regardless of caring context, in 5 of 6 domains/areas; self-support [md 6 (4−7)], self-perspective; life plan [md 6 (3−7)], repertoire [md 6 (4−7)], internal [md 6 (3−7)] and external environment [md 7 (5−7)]. Patients reported a lower satisfaction [md 5 (4−7)] in the domain person-support. No significant differences were found between the homecare and hospital care group in the 6 dimensions/areas.
Conclusions: This study shows that patients are highly satisfied with the care and the support regardless of caring context. The clinical experience is that patients cared for at home are more satisfied than patients treated at hospital however the measurement used in this study do not support this. Other factors need to be studied to explain the differences in clinical experience and patient reported satisfaction.

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How Can We Measure Nursing Sensitive Outcomes in an Oncology Nursing Minimum Data Set (ONMDS)?

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Background: Nurses are responsible for promoting and supporting standards of care and being able to track the results of their assistance to achieve quality outcomes. The main outcomes of cancer patients include control of the symptoms of disease or treatment, functional status or performance status. Each one of them has different measurement instruments and this could represent a limitation in the use of an ONMDS that includes 49 nursing sensitive outcomes (NSOs). In clinical trials

adverse events are evaluated with just one instrument, the Common Terminology Criteria Adverse Events (CTCAE) designed by the National Cancer Institute. This scale uses severity grades from 1 to 5: where Grade 1 is mild adverse event (AE); Grade 2 is moderate AE; Grade 3 is severe AE; Grade 4 is Life-threatening or disabling AE; Grade 5 is Death related to AE. Can nurses use this instrument to evaluate nursing sensitive outcomes?
Material and Methods: At the European Institute of Oncology 20 experienced oncology nurses representing surgical, medical and critical areas participated in a nursing record working group. This group created the ONMDS composed of 49 nursing sensitive outcomes recognized as most common and often oncological outcomes regardless of the treatment that the patient undergoes. In the pre-test study the group used a checklist to analyze 50 nursing records of cancer medical patients to evaluate which instruments were used to measure nursing outcomes. The group explored the CTCAE and discovered that all NSOs chosen were also adverse events. Then using case studies the group tested the feasibility of this scale for nursing care and the coherence of nursing-sensitive outcomes evaluation among nurses. The CTCAE was translated into Italian and translated back again into English to validate it.
Results: In the nursing records' analysis no validated scales were found except the numeric rating scale for pain and the Conley's scale for falls. CTC enables a coherent, standardised and consistent evaluation scale among nurses, a common language between other members of the team, continuity of care among different areas, and the possibility to quantify complexity of care, facilitate the case-method and the clinical trajectory.
Conclusions: We commenced a CTC assessment study in the nursing care environmnent and we had preliminary results on its validity in the post-test study with the analysis of other 50 nursing records. The next 6 months monitoring will be able to confirm definitely the feasibility of CTCAE in nursing care.

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The Development of a Dignity Care Pathway (DCP) for Use by Community Nurses With People Receiving End of Life Care at Home

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Background: People experiencing end-of-life care fear loss of dignity and a central tenet of palliative care is to help people die with dignity. Palliative care should be based on holistic assessments, with the patient and carers, of their physical, social, emotional, cultural, and spiritual care needs and comprise a broad range of care activities addressing distress that might influence on their sense of dignity. This study has developed, implemented and tested an intervention, the Dignity Care Pathway (DCP), providing evidence to conserve the dignity of dying patients/ families receiving end-of-life care at home.
Materials and Methods: This 2 year intervention study is underpinned by the UK Medical Research Council (MRC) complex intervention framework. The DCP is based on the theoretical model developed by Chochinov et al (2002). It has 4 sections; a manual; Patient Dignity Inventory (Chochinov 2008); reflective questions and care actions. Reflective questions and care actions in the DCP were evidenced from a systematic literature review and focus group interviews with patients, carers, and HCPs. Use of the DCP was preceded by an education day. Feasibility and acceptability of the DCP tested in a mixed method qualitative evaluation with a purposive sample of community nurses using diaries; longitudinal in-depth interviews and case studies.
Results: The evaluation shows that the DCP is acceptable to community nurses, helps them identify when patients are at the end of life helped identify key concerns from the patients' viewpoint and aids them providing holistic end of life care. The tool requires the nurse to have excellent communication skills and some nurses found it hard to initiate a conversation on dignity and care. All nurses wish to continue to use the DCP and would recommend it to others.
Conclusion: Community nurses use of the DCP will help patients receive individualized care, which will directly relate to the issues they have identified as most distressing and/or important and their preferred measures to address these issues, and carers to receive information and support relating to the patient's care and their request for support.

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Developing and Feasibility Testing of Nurse Sensitive Outcome Measures for Ambulatory Cancer Chemotherapy

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There is increasing interest in Nurse Sensitive Outcomes Indicators (NSOI) that can be used to examine and demonstrate the impact of high quality nursing care. As a consequence the UK National Cancer Action Team commissioned us to develop of a set of outcome-based measures that would be sensitive to the work of nurses in ambulatory cancer chemotherapy settings. The initial phase of this work consisted of a systematic literature review that identified three broad areas where evidence for sensitivity to nursing was strongest. Subsequently we evaluated the feasibility, acceptability and preliminary efficacy of our outcome-based measure in clinical practice.
Methods: We developed indicators on those areas identified as most likely to be nurse sensitive in the systematic review − symptom management, safe medication administration and patient experience of the process of symptom management and care provision. Guidance on the selection of the indicators was provided by three reference groups: users, clinicians and experts in the field of outcomes development. Following preliminary piloting, our outcome measures were distributed as patients arrived to receive ambulatory chemotherapy at 10 cancer centres across the UK between December 2010 and March 2011. Data were analysed descriptively and regression-based models were used to adjust for casemix.
Results: The NSOI developed primarily relied on patient self report via a specially designed measure which was completed on 2466 occasions during the study period. Analysis revealed variability both in terms of patient's experience of subjective symptoms and the support nurses provide to patients. For the whole sample moderate to severe nausea was reported by approximately 25% 0% of the sample. For the whole sample the rate for moderate or severe nausea 25%, however examination of scores by centre revealed differences between sites. Thus 75% at Centre P reported moderate to severe nausea as compared to 25% at Centre J. This variability remained even after casemix adjustment. Similar results emerged for other symptoms and these will be discussed in more detail in the presentation. When asked about their perceptions of the process of symptom management, the majority of respondents (80%) reported that chemotherapy nurses ask about their symptoms, are aware of symptom severity and provide useful information and practical advice for symptom management. However, once again, there was substantial variability between centres.
Conclusions: Monitoring outcomes provides a stimulus to develop services to improve the experience and health of patients. Validated nurse sensitive measures open the possibility of demonstrating the 'added value' of specialist nursing services and of using registered nurses in settings where they might be replaced by less qualified staff.

Oral Presentations (Mon, 26 Sep, 09:00−11:00)
Nursing Oncology − Supportive Care

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The Meaning of Living With an Exulcerated Breast Carcinoma

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Background: Living with an exulcerated breast carcinoma may have a big impact on the lives of women and their families. The aim of this study is to understand the lived experiences of women with a malignant fungating breast.
Material and Methods: The methodological framework of interpretative phenomenological approach according to Heidegger was used. Semi-structured interviews were conducted with nine women. Van Manen's hermeneutic analysis was used to analyse the data.
Results: The results demonstrate how the women had to learn how to live with an unbounded body as the wound became the centre of their life. The women report on the unpredictability, and uncontrollability of the wound due to symptoms such as malodour, bleeding, exudate, pain and itching. Therefore the women developed strategies to bring the wound symptoms under control. Various methods were adopted often using inadequate products of the medicine chest or alternative medicine products. There were also psychosocial consequences to deal with such as embarrassment due to odour and exudate as well as the visibility of the wound, which