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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 feedback 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 fulfilled 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 perihel 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