CREATE' Collaborative Rehabilitation Environments in Acute STrokE – An Experience-Based Co-Design Approach (EBCD) to improving activity experiences of stroke patients in four hospitals in England.

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Important

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Scientific summary

Background

Stroke is the most common form of neurological disability in the UK. Depending on the severity of their stroke, survivors will spend anything from a few days to many months as an inpatient. Rehabilitation is an essential component of multi-disciplinary stroke care. The 2016 National Clinical Guideline for Stroke (England, Wales and Northern Ireland) – recommends that '*Patients with stroke should accumulate at least 45 minutes of each appropriate therapy every day'*. Yet a focus on 'delivery of therapy' - which is usually provided only Mondays to Fridays - fails to recognise the need to make rehabilitation the basis of the patient's day, as opposed to an infrequent part of it . Any independent or supervised activity - whether physical, social or cognitive - helps recovery but observational studies show that stroke patients can be inactive and alone more than 60% of waking hours. These figures have remained unchanged since the 1980's despite many organisational changes, guidelines and national targets. Boredom and apathy are commonplace; both can negatively impact on patient outcomes. Innovative approaches to addressing the longstanding problem of inactivity are now justified.

Experienced-based Co-design (EBCD) has successfully initiated improvements for patients, staff and visitors in other acute settings. EBCD draws on observational fieldwork and filmed narratives with patients to help trigger different conversations and interactions between patients and staff with the goal of improving health care services. The approach entails equal roles for staff, patients and families to co-design the changes they care most about.

Our aim was to evaluate the feasibility and impact of patients, carers and staff collaborating to develop and implement changes to increase supervised and independent therapeutic patient activity in acute stroke units. We focused on supervised or independent social, cognitive and physical activity and used an umbrella term of 'activity' for anything that patients do with or without help, however small, outside of individual one-to-one scheduled therapy sessions. We also aimed to understand both the experience of taking part in EBCD and whether the interventions developed and implemented in an initial two units could be transferred to two further units using an accelerated EBCD (AEBCD) improvement cycle.

The feasibility of an accelerated form of EBCD was demonstrated in an earlier HS&DR study in Intensive Care Units and lung cancer services but without a focus on the transferability of co-designed solutions and there was no evidence of use of AEBCD in stroke services.

Objectives

Our first objective was to complete a rapid evidence synthesis of the evidence on the efficacy and effectiveness of co-production as an approach to quality improvement in acute healthcare settings.

We then used full and accelerated cycles of EBCD in four stroke units and studied the impact of the changes made on the quality and amount of activity.

Our evaluation focused on the following questions:

1. How do patients and carers experience the use of a co-production approach and what impact does it have on quality and supervised and independent therapeutic activity on a stroke unit?

2. How do staff from acute stroke units experience the use of a co-production approach and what improvements in supervised and independent therapeutic activities does the approach stimulate?

3. How feasible is it to adopt Experience-based Co-design (EBCD) as a form of co-production for improving the quality and intensity of rehabilitation in acute stroke units?

4. What role can patients and carers have in improving implementation of National Clinical Guidelines recommendations on quality and intensity of rehabilitation in acute stroke units?

5. What are the factors and organisational processes which act either as barriers or facilitators to successfully implementing, embedding and sustaining co-produced quality improvements in acute care settings, and how can these be addressed and enhanced?

Methods

Design: The intervention was EBCD used in four stroke units. Stroke units in sites 1 and 2 undertook all six components of EBCD to co-design improvements to impact on stroke patients' physical, social and cognitive activity. In sites 3 and 4 we used an accelerated EBCD cycle starting from a joint staff,

patient and family member event to initiate co-design work prompted by trigger films previously developed in sites 1 and 2.

We employed a mixed-methods case comparison approach to our evaluation using interviews, observations, behavioural mapping, and self-report surveys (PROM/PREM) pre- and post-implementation of EBCD cycles. A thematic analysis of qualitative data was carried out and findings pre and post implementation of improvements within and between sites were compared We generated descriptive statistics from behavioural mapping and PROM/PREM data An embedded process evaluation drawing on Normalization Process Theory (NPT) integrated qualitative data and researcher reflections, analysing barriers and facilitators to implementation of improvements across settings

Setting: Two stroke units in London and two in Yorkshire (acute and rehabilitation settings). The 2016 National Acute Organisational Audit report showed that all 4 units performed within the mid-range across key quality indicators and were subject to staffing pressures and increasing caseload complexity reported nationally.

Participants: 76 staff, 53 stroke patients and 26 family members (carers) were recruited for the evaluation. Participants and additional staff, patients and family members took part in various stages of the EBCD cycle. There were 43 co-design meetings held across all sites involving 23 stroke patients, 21 family carers and 54 staff from across all professions and including rehabilitation and support workers and volunteers.

Results: Our rapid evidence synthesis revealed three main outcomes: (a) the value of patient and staff involvement in co-design; (b) generation of ideas for changes to processes, practices and clinical environments; and (c) tangible service changes and impacts on patient experiences. Overall there was a lack of rigorous evaluation of co-production studies in acute healthcare. Future studies should consider clinical and service outcomes and cost-effectiveness of co-production relative to other forms of quality improvement.

These findings informed our own approach to implementing EBCD, including recognising the importance of local facilitators, recruiting a broad number of patient and carer co-design group members and maintaining an emphasis on the relational aspects of the work.

Qualitative findings (interviews and observations) across all units showed it was feasible to co-produce changes to increase social, cognitive and physical activity through joint work in three priority areas: 'Space' (environment), 'Activity' and 'Communication'. EBCD led to improvements both in its full and accelerated forms. Sites 1 and 2 together co-produced and implemented more than 40 improvements across the three priority areas over nine months. Filmed patient narratives from these sites proved powerful triggers for action and were utilised in sites 3 and 4 where a similar number and range of improvements were implemented over an accelerated time period of six months.

Changes across sites were broadly similar and included: environmental and (unit) organisational changes to enable greater social interaction between staff, patients and families; engagement with community groups and the voluntary sector for singing, art and exercise groups; therapy dogs; and personalising bed spaces to encourage 'home into hospital' using 'something about me boards' for every patient, introducing photograph hangers and familiar home items to facilitate greater social interaction between patients and staff.

Post-implementation interviews indicated patients, family members and staff had engaged well with EBCD and reported that substantive changes had occurred. Patients and families perceived positive benefits from participating in the co-design groups, felt they were equal and valued members and gained satisfaction from seeing the improvements being implemented. Staff reported CREATE had been a positive experience, in contrast to their usual work with little time for creative thought and relational activities. Staff across all units saw co-design as a way to make positive changes to their working environment which provided more activity opportunities for patients. Staff who had not taken part in EBCD expressed similar perceptions.

Ethnographic observations confirmed the use of new social spaces where patients and families could meet and interact, and more activity opportunities provided by groups and community volunteers. However, we found minimal change in the priority area of 'Communication'; staff interactions remained fundamentally task-focused with minimal interaction with patients beyond that required for routine care tasks.

Activity levels measured by behavioural mapping were largely inconsistent showing a mixed pattern of activity and inactivity (social, cognitive and physical) in those observed pre or post implementation of co-designed changes. Taking the broad measure of 'any activity' there was

improvement across all sites but less changes in sites 3 and 4 (accelerated EBCD) than in sites 1 and 2 (full EBCD).

PROM/PREM data were inconsistent across sites, response rates were low varying from 12-38% but cohorts who returned questionnaires had impairment levels, dependency, emotional and social limitations congruent with national stroke statistics. PREM data suggested an improvement in patients' reporting 'enough things to do their free time' post implementation of EBCD.

Using NPT to interpret factors influencing engagement with EBCD and implementation of co-produced improvements, we found the structured time limited process of EBCD in both the full and accelerated forms legitimised and supported participatory co-production activity. All participants recognised that increased activity needed to be embedded in everyday routines and work in stroke units. Communication between staff and patients which supported activity was most challenging to initiate and sustain.

Conclusions

It has proved feasible to implement EBCD in four stroke units. Doing so resulted in qualitatively positive changes in the unit environments and increased activity opportunities for patients. There was no discernible difference in experience or outcome between the full and accelerated forms of EBCD. Staff, patients and families in all sites engaged in similar ways with co-design and developed changes in the domains of Space, Activity and Communication. Improvement ideas were successfully transferred and contextualised from sites 1 and 2 to sites 3 and 4. Staff participating in EBCD reported a positive impact on their working environment and patients and families perceived the process to be positive and constructive. Staff not taking part were able to describe distinct changes to their working environment and more activity opportunities.

Implementation of EBCD and the co-designed changes were influenced by several factors and organisational processes; these included long established ward routines which prioritise care tasks, the need to deliver on national audit targets and staff pressures compounded by high turnover and shortages.

Our findings mirror other research to increase activity levels on stroke units which show mixed results. However compared to previous studies, new activities and changes were driven by the perspectives of staff, patients and carers, using a recognised quality improvement method.

Implications for healthcare

The benefit of using co-design to initiate change

We believe the strength of EBCD in both full and accelerated form is the facilitated, structured, participatory and time limited process. The nature of the 'work' was fundamentally different to usual staff-led - or externally driven - quality improvement initiatives in stroke. The approach prioritised participation of stroke patients and their families in more creative and relational interactions and outputs to improve opportunities for independent and supervised activity. The involvement of patients and carers increased the accountability of staff participants and made it less likely that planned changes would not proceed. Co-design facilitated carers' and volunteers' continued involvement in activities and directly contributed to changes made to the day-to-day working of these stroke units. Co-design also initiated new and ongoing engagement with local people and/or organisations for whom the hospital is a key part of local communities.

The ongoing challenge of (in) activity in stroke units

Culture change within any organisation is challenging and our project was no different. Whilst the tangible improvements in space and activity opportunities were visible many interactions between staff and patients remained largely task-driven. Interactions facilitating social exchange, cognitive activity, or practicing a physical activity remained relatively uncommon.

Across all sites we found concern that 'something must be done' and a willingness for staff, patients and families to work together to make improvements. For this approach to be applied across stroke units, local facilitation provided by a member of staff with protected time and allocated is required. The stakeholder mapping exercise at the start of EBCD was critical. Change requires buy-in and commitment from multiple stakeholders, including senior management to validate the shift from focusing on achieving national audit targets to a cultural change in the therapeutic value of stroke unit care. This will take time but trigger films and the experiences of the participants in the four units in our study could help encourage changes, many of which can be initiated quickly and relatively cheaply.

Early consideration of community/voluntary sector engagement is also important; a key learning from sites 1 and 2 using the full EBCD cycle. This enabled awareness raising and interest from a range of local community groups who subsequently added to activity opportunities through art, exercise groups, reading and music activities.

Implications for research

The cost effectiveness of the methods used are unknown. Quality improvement methods - such as accelerated EBCD used in sites 3 and 4 - could be highly cost-effective if improvements can reduce inactivity of inpatient stroke patients, contribute to an increase in independence in activities of daily living and reduce length of stay. Equally, the participatory approaches used in EBCD can have a positive impact on the morale, meaning and purpose of staff in the face of increasing staff shortages and caseload pressures.

Our rapid evidence synthesis highlighted common barriers encountered in co-production approaches. However, we found little difficulty in recruiting patients and carers and retaining their involvement. This was largely due to the dedicated efforts of our local researchers and the willingness of staff in co-design groups to both engage with and support stroke patients and their families to participate in the process.

Several research questions have emerged from our study:

- Can the CREATE AEBCD approach using stroke specific trigger films be used in other acute stroke units and what would be the contextual adaptations required to enable an increase in activity opportunities for patients through changing the environment (space), communication (enabling activity) and activity opportunities (more access to voluntary and community groups, activity boxes etc.)
- What additionally needs to be done to change the culture of activity on a stroke unit? How can 'enabling activity' become part of the routine work of all staff, including nursing staff?
- What degree of cultural and environmental change is required in order to bring about a significant improvement in activity and what are the alternatives to quantitative evaluation approaches such as behavioural mapping?
- How can patients/families and local communities support sustained activity outside of scheduled therapy provision?

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