



Using Experience-based Co-design with older patients, their families and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process and outcomes



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ABSTRACT

Background: Increasing use of emergency departments among older patients with palliative needs has led to the development of several service-level interventions intended to improve care quality. There is little evidence of patient and family involvement in developmental processes, and little is known about the experiences of – and preferences for – palliative care delivery in this setting. Participatory action research seeking to enable collaborative working between patients and staff should enhance the impact of local quality improvement work but has not been widely implemented in such a complex setting.

Objectives: To critique the feasibility of this methodology as a quality improvement intervention in complex healthcare settings, laying a foundation for future work.

Setting: an Emergency Department in a large teaching hospital in the United Kingdom.

Methods: Experience-based Co-design incorporating: 150 h of nonparticipant observation; semi-structured interviews with 15 staff members about their experiences of palliative care delivery; 5 focus groups with 64 staff members to explore challenges in delivering palliative care; 10 filmed semi-structured interviews with palliative care patients or their family members; a co-design event involving staff, patients and family members.

Findings: the study successfully identified quality improvement priorities leading to changes in Emergency Department-palliative care processes. Further outputs were the creation of a patient-family-staff experience training DVD to encourage reflective discussion and the identification and application of generic design principles for improving palliative care in the Emergency Department. There were benefits and challenges associated with using Experience-based Co-design in this setting. Benefits included the flexibility of the approach, the high levels of engagement and responsiveness of patients, families and staff, and the impact of using filmed narrative interviews to enhance the 'voice' of seldom heard patients and families. Challenges included high levels of staff turnover during the 19 month project, significant time constraints in the Emergency Department and the ability of older patients and their families to fully participate in the co-design process.

Conclusion: Experience-based Co-design is a useful approach for encouraging collaborative working between vulnerable patients, family and staff in complex healthcare environments. The flexibility of the approach allows the specific needs of participants to be accounted for, enabling fuller engagement with those who typically may not be invited to contribute to quality improvement work. Recommendations for future studies in this and similar settings include testing the 'accelerated' form of the approach and experimenting with alternative ways of increasing involvement of patients/families in the co-design phase.

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Contribution of the Paper

What is already known about the topic?

- Internationally in developed countries there are increasing numbers of older people with palliative care needs who are attending emergency departments (ED).
- A small number of ED-based palliative care approaches have been developed but these have seldom simultaneously involved the patients, families or ED clinicians in their design and implementation.
- Experience-based Co-design is a proven approach for enabling collaborative working between patients, families and staff in healthcare quality improvement projects but has not previously been applied in the complex setting of improving the care of older palliative patients in the ED.

What this paper adds

- Experience-based Co-design can be an effective approach for enabling collaborative quality improvement 'work' between older, palliative patients, their families and ED staff; the approach can be adapted to cater to the needs of vulnerable older people in order to include them in a participatory action research process.
- A wide range of practical changes in the provision of ED-based palliative care for older people can be stimulated through the use of a structured approach to involving patients, families and ED staff
- The paper highlights the need for further research to explore ways of ensuring patients and their families can contribute to ongoing improvement work and the evaluation of the impact of that work on the quality of care.

1. Background

Internationally, developed countries are seeing an increase in their older populations (75+) living for longer with co-morbidities and palliative care needs (Hall et al., 2011). One consequence of this is growing use of Emergency Departments (ED) by older palliative patients towards the end of their lives (Albert et al., 2013; Blackwell and Grudzen, 2014; Lowery and Quest, 2015). The nature of the ED makes visits challenging for such patients, family members and staff alike. This is due to a variety of factors including: patient and family emotional distress (Gordon et al., 2010); lack of staff access to relevant patient information (Kelley et al., 2011); challenging conversations about goals of care (Grudzen et al., 2012a; Nobar and Lisk, 2014); and environmental factors such as noise, time limitations, demands of other patients and lack of privacy (Bailey et al., 2011a; Beckstrand et al., 2008).

Different approaches to improving the quality of palliative care delivered in a non-traditional palliative care environment include: initiation of palliative care consultations in the ED (Lamba et al., 2014); creating older person-only units (Hwang and Morrison, 2007); and closer collaboration between EDs and palliative care teams (Quest et al., 2009). An approach not previously implemented is that of enabling collaborative working between patients, family caregivers and healthcare staff in designing ED-based palliative care services. This is despite evidence that patient involvement and collaboration is more likely to meet the specific needs of patients, be more reliable and more likely to be implemented in practice (NICE, 2015; Staley et al., 2014). There is limited exploration of the needs and experiences of patients and families as well as ED staff to guide and inform such quality improvement (QI) efforts (Beckstrand et al., 2008; Grudzen et al., 2012a, 2011; Smith et al., 2010a), particularly in the UK (Bailey et al., 2011a, 2011b). In this specific setting, careful consideration is

needed to identify, understand and explore the experiences of participants, facilitate joint (patient, family and staff) ownership of the change process and implement a QI intervention.

2. The intervention: Experience-based Co-design

One partnership-based approach is Experience-based Co-design (EBCD) (Bate and Robert, 2007; Robert et al., 2015). EBCD is a form of Participatory Action Research (PAR) that is described as '... an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership ...' (The King's Fund, 2011). EBCD has previously been used in the separate redesign of services in (a) several EDs (Iedema et al., 2010; Piper et al., 2010b), (b) cancer care services (Adams et al., 2013; Tsianakas et al., 2012), and (c) an older persons service (Bowen et al., 2011) suggesting that the approach may lend itself to the challenge of responding to palliative care needs for older people and their families in an ED.

EBCD is a practical and rigorous process for exploring and improving upon experiences with the full involvement of those both providing and using a healthcare service. Use of EBCD in QI efforts is growing (Donetto et al., 2014) with projects in at least fifty-nine health services across six countries and in a variety of clinical settings. These include cancer, emergency services, and gerontology (Bowen et al., 2013; Donetto et al., 2014; Piper et al., 2010b; The King's Fund, 2011; Tsianakas et al., 2012). In the UK a practical, free to access online toolkit has been developed to support EBCD studies in the National Health Service (NHS) (The King's Fund, 2011).

EBCD is one form of co-design increasingly adopted by healthcare QI practitioners because its underlying mechanisms can be applied and lead to improving experiences in a wide variety of settings. Specific strengths cited for the approach include:

- increased patient and staff engagement in change activities (Donetto et al., 2014);
- a sense of ownership and community where staff and patients' attitudes towards one another have been challenged positively (Tsianakas et al., 2012);
- organisations valuing the input of patients and family caregivers more and moving away from the medical paternalistic paradigm (Iedema et al., 2010); and
- patients and staff reports of finding the process empowering, cathartic and enabling them to be 'heard' (Donetto et al., 2014; Robert et al., 2015).

The epistemological and ontological roots of EBCD stem from PAR. Where EBCD stands as a QI methodology in its own right is both in its replicable processes and toolkit (that help provide a framework to guide co-design of services), based upon three bodies of knowledge: narrative-based approaches to change, learning theory and user-centred design (Robert, 2013). The ethos of the approach is an applied anthropological one, aiming to capture, understand and improve patient experiences of health care (Robert, 2013).

The user-centred design focus of EBCD ensures the patient's, family caregiver's and staff member's lived experiences, expertise and knowledge of what needs improvement underpins and propels local QI work. The EBCD process outlined in (Robert et al., 2015) explores experiences by equipping participants with the means to draw understanding from their personal story in order to recognize 'touch points'; the definitive moments that shape an overall experience (Bate and Robert, 2007). Through sharing of, and reflecting together on, these 'touch points' and their individual experiences, participants develop a shared narrative of what it is like to be cared for, and work within, a particular service.

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