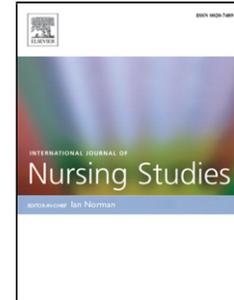


## Accepted Manuscript

Title: 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

Authors: Rebecca Wright née Blackwell, Karen Lowton, Glenn Robert, Corita Grudzen, Patricia Grocott



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**Title:** 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

**Author Names and Affiliations:**

(Corresponding author)

Dr. Rebecca Wright née Blackwell<sup>1</sup>

Florence Nightingale Faculty of Nursing and Midwifery, King's College London, JCMB, 57 Waterloo Road, London, SE1 8WA, UK

Professor Karen Lowton

Department of Sociology, University of Sussex, Freeman Building, Falmer, Brighton, BN1 9RH, UK

Professor Glenn Robert

Florence Nightingale Faculty of Nursing and Midwifery, King's College London, JCMB, 57 Waterloo Road, London, SE1 8WA, UK

Dr. Corita Grudzen

Ronald O. Perelman Department of Emergency Medicine, Associate Professor of Emergency Medicine and Population Health, NYU School of Medicine, USA

Professor Patricia Grocott

Florence Nightingale Faculty of Nursing and Midwifery, King's College London, JCMB, 57 Waterloo Road, London, SE1 8WA, UK

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<sup>1</sup> Permanent address:

Post-Doctoral Fellow| Research Division  
Ronald O. Perelman Department of Emergency Medicine  
NYU School of Medicine  
462 First Ave. | New York, NY 10016 | A-866  
[Rebecca.Blackwell@nyumc.org](mailto:Rebecca.Blackwell@nyumc.org)

**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 hours 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.

Keywords: Emergency department

Experience-based Co-design

Families

Older people

Palliative care

Participatory action research

Patient experience

Staff experience

## **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, Grudzen et al., 2011, Smith et al., 2010a), particularly in the UK (Bailey et al., 2011a, Bailey et al., 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.

### ***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-centered 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. The shared narratives become a foundation for patients, family caregivers and staff to work as 'user designers', undertaking co-design (improvement) activities as equals (Bate and Robert, 2007). Together, participants develop priorities and implement strategies to improve the experiences of future patients, families and staff. Whilst the foundations of this methodology are not in themselves innovative, their combination and application in the healthcare QI context has generated a practical and inclusive change

intervention which can be a valuable way of improving the quality of services (Robert et al., 2015).

Reports of the impact of using EBCD are mixed but process evaluations predominantly relate to the same issues, all of which have implications for exploring and improving palliative care in the ED. These issues are typically: engagement and expectations of patients and staff; ownership and project management; building trusting relationships; time management; evaluating impact; and the potential complexity of the approach (Donetto et al., 2014). In deciding to use EBCD within this study, the key feature that was important to consider was the vulnerability of the older palliative patients, family caregivers and staff population involved.

Our intention for this paper was not to report on the methods used in our study which are detailed elsewhere (Blackwell, 2015), nor to replicate literature describing the use of EBCD (Bowen et al., 2013, Hampson et al., 2013, Tsianakas et al., 2012, Wiseman et al., 2011). Rather, our intention is to move the debate forward, reflecting on the use of a co-design approach within a challenging setting and with a vulnerable population. Thus, this paper has two aims. Firstly, to critique the use of EBCD in the particular setting of EDs, adding to the growing literature on the application of co-design approaches to QI work and thereby laying a foundation for future applied work in this area. Secondly, to present evidence specifically about palliative care needs in the ED from older patients, their families and staff.

## **Methods**

The study reported here was undertaken at a UK-based teaching hospital catering to a diverse demographic with approximately 171,500 ED visits annually, of which an estimated 16,435 are aged 65 or older. The hospital has two sites with the ED based at the larger site, containing a triage and waiting area, paediatric ED and two treatment areas for minor and major health injuries respectively, and a resuscitation room.

Semi-structured 35-50-minute audio-recorded interviews supported by a topic guide (see appendix) were conducted by [author] with a convenience sample of 15 ED staff members about their experiences of palliative care delivery in the ED (see Figure 1 for participant numbers throughout the EBCD process).

Interviews were transcribed and then analysed using thematic framework analysis. Specific words and phrases about individual experiences were coded, and then categorized into broad themes that spanned all experiences, highlighting aspects of the ED most likely to negatively or positively influence perceptions of the experience (Lacey and Luff, 2007, Ward et al., 2013). The research team agreed final themes. In addition, approximately 150 hours of informal non-participant observation was conducted (supported by field notes) at the ED during research activities such as recruitment or focus groups. These data were used to provide practical examples of themes in focus groups and at the co-design event (see below). Findings were presented at five hour-long focus groups with 64 ED staff member who provided validation that the analysis represented a broader, shared experience (Figure 2).

Ten patients and their family caregivers were recruited during their ED visit who agreed to a follow up telephone conversation to discuss the study and set a date for a filmed, 45-minute narrative interview. Narrative interviews allowed the participants to share what led to their ED visit, and to discuss their perceptions of the subsequent ED experience, with occasional questions asked by [author] to clarify information or explore an issue in more depth (Bate and Robert, 2007). The same analytical approach was applied to these data including ten individual follow up meetings to gain validation of the analytical processes and subsequent findings (Figure 3).

The study concluded with the co-design event. This was a 4-hour session in which ED, palliative care and ED operations staff met, viewed an edited version of the patient film and collaborated with patients and family caregivers to share their experiences and design potential new strategies to improve the delivery of ED-based palliative care.

The study was further informed by a month long international fieldtrip to an older person-only ED at the Mount Sinai Hospital in New York City (Hartocollis, 2012). The fieldtrip was initiated as a means of translating learning from an innovative approach to care, both to enhance the EBCD process and provide ideas and suggestions for possible QI activities at the case study site.

After a 4-month interval from the conclusion of the co-design event, a follow-up email was sent to seven ED and palliative staff participants from the co-design event (nurses N=4; doctors N=3) asking for their perspectives on the study and what, if any subsequent actions they had taken. Six responded, citing changes at the study site, in their personal practice, as well as on-going multidisciplinary collaborations. As all responses were of a similarly positive nature in regards to

the impact of the project, we have provided extracts from the most illustrative (below). This final activity was a fact-finding exercise rather than a formal evaluation. The email responses were not treated as research data but rather as informative updates providing a foundation for future use and expansion of the methodology with vulnerable populations in busy and unpredictable environments.

Diagram 1 illustrates from where the different data were derived; full details of the methods can be found elsewhere (Blackwell, 2015).

## **Findings**

### **Quality improvement**

Here we reflect upon the impact of the EBCD intervention as we informally traced it up to 4-months after the co-design event. A summary of the main challenges for delivery of ED-based palliative care identified by ED staff, patients and families is provided in Figures 2 and 3.

We grouped and now present our critical assessment of ‘impact’ in terms of:

- a series of local improvement priorities as selected and approved by the staff, patient and family participants which led to changes in the conduct and delivery of ED-based palliative care;
- the production and dissemination of a second version of the patient and family film now including staff voices; and
- the identification of generic design principles for improving palliative care in EDs based on the learning from Mount Sinai Hospital.

Improvement Priorities: The shared narrative that emerged from the staff, patient and family interviews and across staff and patient feedback sessions highlighted common experiences needing improvement at different points during the patient journey in the ED. The barriers to ED-based palliative care (Figures 2 and 3) were discussed at the co-design event, leading to potential strategies to address them (Figure 4).

As these shared improvement priorities emerged it became evident that whilst the ED needed greater support in the delivery of ED-based palliative care, the stories from the patients and family members revealed surprisingly simple needs, given the complexity of conditions and terminal stage for many of them. The data gathered from patients and family members were used by the ED clinical lead to encourage staff to start considering the small but significant things that make a difference to patients and families and can easily and gently be provided in the chaotic ED environment; for example eye contact, smiling or supportive comments like ‘hang in there’. While not expecting staff to know full details of their prognosis or future treatment, patients, and particularly family members valued being seen and acknowledged. This was evidenced by one of the 4-month follow-up e-mails from an ED nurse who had attended the study co-design event:

*‘...As Palliative Care link nurse at the time, I wasn’t quite sure how to improve palliative care in the ED. After going to the presentation of the study and specifically watching the video of palliative care patients’ and families’ experiences of being in the ED, I suddenly saw what impact small changes could have on improving their basic care. I also realised how much could be done to improve their overall experience during their time in the ED. Things such as touching the person, acknowledging their presence while walking past, offering something to drink or to eat while they wait or offering them a phone call are all basic nursing skills which ED nurses can easily forget as they rush around doing what may seem as more important clinical activities in the acute setting...’*

[Email communication: ED Nurse: co-design event participant (CDE ID 6)]

From the first stage of their involvement in this study through to the end, the staff in the ED drove forward changes and improvements in care delivery. A significant change that emerged and had direct consequences for the ED staff was the collation and dissemination of palliative care services and support information. This fed into the agreement between the nursing leadership and researcher that feedback focus groups would also include some teaching in palliative care. The interview findings had shown that staff seemed to have little knowledge about the wealth of palliative care services and support available to them at the study site. Therefore, the palliative care team were consulted as part of the preparation for the focus group and a short document was developed containing an outline of the services, contact numbers, hours of operation and list of useful resources. This document was well received and put into use

in the main department and on the shared computer desktop. Further discussion at the co-design event led to additional document updates by staff, including moving it to a central folder on the desktop, which contained similar information for different services. The following extract is from another 4-month follow up email from a palliative care doctor reflecting on the changes at the study site during the research processes:

*'...Your involvement has certainly facilitated more of a dialogue. The workshop in particular put us in contact with two very able, enthusiastic members of the team who were keen to work with us and make access to palliative care easier to understand for the emergency department staff. With their help we revised the information on palliative care services and put it on the desktop which they use. The walk-throughs which started in May 2014 have meant that I know some of the staff and their faces and hopefully have improved access. The teaching sessions in which we jointly participated in March/April 2014 gave us an opportunity to speak to the team about what palliative care does in a way that was easier for them to assimilate and also meant that they know our faces and gave us some useful ideas about how to work more easily with them. My sense is that there are more referrals directly to us from the ED... There are issues which still remain - principally the issue of how to flag palliative care patients when they attend ED. The complexity of IT systems has made this difficult to solve - but we will keep working on this...'*

[Email communication: palliative care doctor, provided information for focus groups and co-design event participant (CDE ID 3)]

A second significant change was the redesigning of the Electronic Patient Records (EPR) referral form. During interviews staff expressed a lack of awareness of palliative care support within the hospital. This included little to no knowledge of a direct EPR form for patients with palliative medical or social needs. The EPR form had been available for a year prior to the start of the study in 2011 but never used. The staff response was fed back, surprising the palliative care team who had thought lack of use reflected lack of need. The form was rewritten and restructured collaboratively by staff from the ED and palliative care team and reissued into practice with subsequent uptake.

The third change was initiated during the feedback sessions when a number of ED staff raised concerns about accessing the palliative care team; many were unaware that the palliative care team had offices at both hospital sites. ED staff suggest that the palliative care team could carry out ED ‘walk-throughs’ in which the team visit the ED and give ED staff the opportunity to ask questions or raise concerns about patients who needed palliative care input. This process was conducted in other specialties, reducing ED isolation from the rest of the hospital and improving interdisciplinary relationships. Again, when fed back to the palliative care team this was received with interest. The palliative care team initiated weekly ED walk-throughs by one of the palliative care doctors. An email communication during the 4-month follow up suggested that these changes were positively received with further developments planned:

*‘...Walk-throughs are developing. Beginning to see the same faces again and had some interesting conversations as well as two referrals via Hospital Outpatient Treatment (HOT) clinic referral...Often just missing people because of the time we attend but I can see the value of going at that time, and reminding them of what we do for the day ahead. Am keeping a log of contacts made. Our presence has coincided with the hospital at home team raising their profile, so there is some natural linkage. Also the COPD team work is developing so that will probably also overlap...’*

[Email communication: palliative care doctor, provided information for focus groups and co-design event participant (CDE ID 3)]

As the study progressed the palliative care team became more involved in the ED. Following the co-design event, a palliative care doctor began meeting with an ED nurse and doctor to work on improving palliative care processes and information sharing between the palliative care team and ED. The outcomes of this collaboration are still emerging but that there is commitment from both sides to improve the palliative care delivery in the ED. There seems to be a growing recognition in the ED of what the ED clinical lead calls ‘soft skills’; the small but significant interactions that are so greatly valued by patients and families as expressed in their film and at the co-design event.

As a final example of the impact of the study (in quality improvement terms), an ED nurse and doctor present at the co-design event volunteered to collaboratively explore and improve the pathway through the ED experienced by palliative care patients and their families. The ED nurse

was keen to implement the patient-family film into staff training and the ED doctor volunteered to focus on raising awareness of the palliative care services available at the hospital site amongst ED staff as well as exploring ways to improve IT systems affecting the transfer of patient information. In addition to the practical changes listed by these ED practitioners, the extract below demonstrates their ownership of the research data and findings. As neither of these members of staff had been involved in this study prior to the co-design event, it is interesting to see how effective the stories shared through the patient-family film and subsequent discussion were in engaging people who were new to the study at this latter stage:

*'...This knowledge prompted us to consider placing the sick palliative care patient away from other patient groups, especially the noisy or disruptive patients and educating ED staff on what really matters to this patient group and their family members. It prompted us to create an easily available flowchart of all resources available and in what circumstances they should/could be contacted. We are also starting a trial in triage where sicker or special needs patients are streamed past triage and directly into the department and palliative care patients will be specifically included in this group in order to reduce time spent in the waiting area and therefore the ED as a whole. We also had a meeting with the palliative care consultant in order to try to connect the information on her department's patients with information that could also be accessed on the ED database. We also discussed the idea of creating files for palliative care patients to bring with them to the ED so that their care plans and details are immediately available to staff on arrival in the ED. The research has also encouraged discussion and an awareness of the special needs of palliative care patients and their family members and what training should be offered to ED staff and has clearly had a great impact on me and the department as a whole!'*

[Follow up email extract from ED nurse: co-design event participant (CDE ID 6)]

Trigger film: The co-design event highlighted the influence of the patient-family film.

Participants observed that despite the higher ratio of staff to patients or family members at the event, the film powerfully presented the patient-family voice. It was able to highlight patient and family anxieties from being too scared to ask for a drink, not knowing how to find the toilets, and being exhausted repeating one's story to each new clinician. A recommendation by several staff at the co-design event was to make a second version of the film incorporating the staff

experience. This was done after the event using actors to repeat the relevant staff quotes and inserting the sound bites, with subtitles, into the film. The final film now serves as an ED training tool, to trigger reflection and discussion. Its purpose is to encourage the viewer to ask of themselves ‘How can these things happen? Is this my experience too?’ This questioning maintains the ethos of inquiry and improvement that has underpinned this research and the data collection. With agreement and permission from the study participants the DVD has been made available for wider dissemination as a discussion trigger film for ED-based palliative care teaching and QI activities, following signed consent for the use, storage and management of the film. To date, the film has been requested and sent to palliative care and emergency clinicians and researchers in the UK, US, Australia and Sweden to support and inform various research studies, quality improvement work and teaching activities.

Design Principles: The term ‘design principles’ (Romme and Damen, 2007) was used to define a series of quality improvement suggestions elicited from observations of care of older and palliative care patients at the older person-only ED at Mount Sinai Hospital in New York (Hartocollis, 2012). Three design principles and a series of practical implementation suggestions were the outcome of translating the tacit knowledge of organisational change agents (in this case the Geriatric ED staff and research team) into coherent and relevant principles (Plsek et al., 2007) that could be applied in the study site in the UK. Figure 5 contains an example of one of these three principles, a suggested route to applying it in practice and details of the observation that informed the development of this principle (for the full list of design principles see Appendix).

The principles were shared with the UK research site at various points in the EBCD process (such as the staff feedback session and co-design event) as prompts for discussion and reflection (Plsek et al., 2007, Romme and Damen, 2007), that also influenced care delivery systems. The UK study site began a rebuild project during the conduct of the study. As ED leadership staff reviewed and redesigned the ED, the findings of the fieldtrip were fed in. One opportunity for this input was the co-design event. The innovative US work was discussed as a trigger for co-design event participants to think laterally about potential changes that could be made. A senior ED nurse was given a copy of the report and design principles document, sharing later during the

4-month follow up emails how they influenced plans for sharing information in the new department. The information ‘slices’ he mentions refers to long banners that will line the walls of the new bed spaces in the rebuilt ED. They contain factual information about the department, waiting times and processes:

*‘...As discussed your work [the design principles] certainly inputted into the wording on these slices with an emphasis of giving patients and relatives information regarding what they are waiting for, who to speak to about any concerns, what to do about food and drink. We also are working on a 'fast track system' where patients such as palliative care patients who walk-in are fast tracked to majors for further assessment. We are also developing 24-hour streaming so those patients will be identified as soon as they come into A&E...’*

[Follow up email communication from senior ED nurse: co-design event participant (CDE ID 4)]

The inclusion of this information speaks directly to the patient and family concerns and those small but significant interactions that were so important to their ED experiences. The design principles, which were developed in parallel to the main EBCD study, are included here to demonstrate the flexibility of EBCD and the ways in other work can be incorporated to enhance wider change efforts.

### **A reflexive critique of the practical challenges**

We found that in order to involve older palliative patients, their family caregivers and ED staff in an EBCD project there were seven important considerations, some of which entailed adaptations to the usual process. In proposing EBCD as a viable approach for improving the quality of palliative care delivery for older patients and their families in an ED it is important to bear each of these in mind.

#### **1. Limited knowledge base requiring the development of a conceptual framework**

The lack of existing knowledge about palliative patient and family caregivers and staff ED experiences meant that a clear framework was required to first help understand - before then learning from - such experiences. To critically apply the principles and processes of EBCD to this study, [author] developed a conceptual framework as a way of identifying, labelling and classifying key information about the experiences under investigation (Diagram 2) (Huckabay,

1991). The justification for the development of the framework was that an individual's 'experienced reality' (Bate, 2007) had to be valued and acknowledged if the defining moments (touch points) of the experience were to be understood (Dewar, 2009).

The conceptual framework distinguished between the impact of (a) understanding and (b) expectations on experience (Carr et al., 2001), on the premise that experiences do not stand alone as solitary encounters in a person's life (Carr et al., 2001). The framework was used as a visual tool throughout the study to demonstrate the mechanisms of EBCD to ED staff or other stakeholders, why experiences were being focused on, and how these data would ultimately inform practical change.

## **2. Limited time and resource constraints altering the expected timeline of an EBCD project**

Typical EBCD projects are completed within a year. However, we faced time and resource constraints that slowed down the change process including: the intervention being led by a sole researcher; the undertaking of the international fieldtrip; and the decision not to gather patient experiences alongside data collection relating to staff experience (see point 4 below). As a result of adaptations to the approach the study followed the timetable shown in Figure 6.

A 'resource' challenge included the high ED staff turnover at the research site, meaning different staff members were involved at the start and conclusion of the study. Whilst not a problem unique to this EBCD project, or indeed any PAR approach, staff turnover made evaluation of the experience of being involved in the study in terms of the personal impact on staff problematic. For this reason, we limited our 4-month follow-up to focus on specific changes made at the study site and spoke only to staff who had attended the co-design event. However, as outlined below, ongoing engagement activities mean that staff turnover did not negatively impact the study. Rather, new staff engaged with the processes and discussions to such a degree that they provided validation of the findings from the initial staff data collection.

## **3. Initiating the research and engaging the research site in ownership and collaborative working as an external facilitator**

EBCD projects are often initiated internally to address a perceived need for local QI work, whereas this study was designed and facilitated by an external researcher. This meant that

engagement with the research and setting up of the project (Stage 1) occurred incrementally with the progression of each EBCD stage, and with the agreement of the study site. Regular contact and updates with the ED clinical managers via email and in-person visits to provide ongoing feedback to the staff during handover meetings, development days and all-staff meetings were found to be useful mechanisms for maintaining engagement, despite significant periods of time where the researcher was unable to be present in the ED. These visits and informal conversations with staff during data collection activities helped develop and cement relationships, encouraging continuity despite high staff turnover. Conversely, a benefit of an external position was the fresh perspective such a role brought, providing new insights and an objective stance. For example, during the analytical phase and at the co-design event the external role of the researcher enhanced discussions between staff and patients-family caregivers, being seen as an unbiased perspective. In contrast, where the EBCD lead is a staff member at a study site there can be imbalances of power explaining why some EBCD projects have purposefully used external facilitators who are skilled in bringing about organizational and behavioral change in relevant settings (Donetto et al., 2014, Piper et al., 2010a).

#### **4. Lack of knowledge and evidence about ED-based palliative care preventing parallel collection of staff, patient and family data**

The previously mentioned lack of foundational knowledge and evidence about older palliative care patients in the ED meant it was not clear that it would be possible to recruit palliative patients to undertake collaborative QI activities. Thus, our early work was undertaken as a preliminary exploratory study. The consequences of this alternative timeline were mixed. As stated, many of the staff who took part had left the study site by the time the co-design event was held, potentially jeopardizing the validity of findings. However, an extended timeframe also enabled an institutional fieldtrip the findings from which enriched co-design event activities (see below).

#### **5. Extending the study to incorporate international learning**

Between Stages 2 and 3 the study was extended to incorporate an international fieldtrip in the form of a one-month visit to an innovative model of care: a geriatric-only ED based at Mount Sinai Hospital in New York. The subsequent five months were spent translating the learning from this fieldtrip into a series of design principles and lessons for introducing services for older

and palliative care patients in the UK ED research site (see appendix) (Blackwell, 2013). As with the example shown in Figure 5, each design principle emerged from observations and informal interviews with staff, patients and families conducted during the fieldtrip. The final report and design principles were submitted for approval to the leadership team at the US ED (GEDI WISE: Geriatric Emergency Department Innovations in care through Workforce Informatics and Structural Enhancements) who supported the translational learning and principles drawn from their work (Blackwell, 2013). Although unorthodox, this extension had considerable benefits for the study. These included, for example, raising staff interest and engagement by presenting new models for providing care, and identifying strategies for the recruitment of older palliative patients and their families in the ED study site.

## **6. Adaptations to patient involvement due to limited capacity and life expectancy**

A prominent concern at the beginning of the study was that patients might not survive the full process of the project or be able to participate fully in co-design activities. However, rolling recruitment throughout the study is an alternative strategy that could potentially engage a larger group of patient-family participants. Inherent difficulties were found in engaging and maintaining input and collaboration with older palliative care patients and their families, most prominently because of the changing and unpredictable nature of their conditions. This led to interviews and follow up meetings being cancelled or rearranged at short notice. To avoid overwhelming participants, engagement activities were staggered. At each interaction participants were thanked for their input and reminded that their involvement was voluntary and they could withdraw or ‘pause’ their input if they needed to. Several took this option, giving verbal feedback after the study that made them feel supported and valued. The flexibility of EBCD meant that research activities could take place in different locations, and it was noted that willingness to participate increased when people were told that interviews could take place in their home. The physical deterioration of several patients and some family caregivers meant it was necessary to cancel the planned shared patients and family member event and conduct one-to-one feedback sessions. Although necessary, this was a major adaptation that significantly limited the building of collaborative relationships between the patient and family participants. However, being flexible and realistic about their capacity to engage in the research process meant that the patients and families remained engaged in the study and were able to provide their perspective and input prior to the co-design event with staff.

In many EBCD studies, routine meetings draw together participants who build collaborative working relationships. However, given the degree of unknown factors participants were facing about their health, (or that of their loved one) this was not possible. To foster engagement and emphasize the value patient and family involvement brought, [author] clarified with participants how often she would be in touch and at which stages of the study, keeping a record to track how participants were responding. In this way [author] became the main conduit for the study, building relationships with participants who ultimately encouraged greater communication. In a larger research team this role could be shared, but it is the one-to-one relationships that were most useful in maintaining engagement and interest, even when participants' conditions deteriorated.

### **7. Ethical considerations in filming palliative patients and family caregivers**

In applying EBCD to an older palliative care population in the ED ethical principles of particular relevance were: anonymity and consent; risk; and recruitment and withdrawal. Specifically, the terminal nature of the patients' conditions meant that sensitivity in recruitment was required; filming interviews prevented full anonymity for patients and family interviews; and there was potential for emotional distress as participants recalled their experiences, particularly in the case of bereaved family members (Addington-Hall, 2002, Goodman et al., 2012). To guide ethical decision making and project management, Dewing's five principles of process consent that cater for more vulnerable people in research - particularly those who may have changing capacity in the degree to which they can participate - were followed: 1) background and preparation; 2) establishing a basis for capacity and other abilities; 3) initial consent; 4) on-going consent and monitoring; and 5) feedback and support (Dewing, 2008).

These five principles were combined with learning from the international fieldtrip. This led to the development of a phased recruitment process. Firstly, permission to make contact after discharge from hospital was gained from patients in the ED, followed by a telephone call a week after discharge from hospital with postal delivery of the information form. If agreeable, the filmed interview was then conducted in the weeks following discharge. This allowed people time to provide fully informed consent, as well as ensuring they were well enough to participate. Participants could withdraw at any stage without providing a reason. Further, given the potential for patient demise during the study, a protocol was developed giving the surviving next-of-kin

the option to withdraw or maintain the patient's data within the study. To maintain some anonymity, identifiable data, such as full name and condition, were kept confidential and only participant approved segments of interviews were used for the final patient film with written consent.

## **Discussion**

In this paper, we sought to 1) critique the use of EBCD in an ED setting, and 2) present evidence specifically about palliative care needs in the ED from older patients and staff. In regards to our first purpose, although adaptations were required to counter the various challenges described above, the core elements of EBCD were present in this study

The undertaking of this research exerted an influence that led to changes in different aspects of palliative care delivery at the ED suggesting a 'research effect' hypothesis, whereby reactionary changes occur organically in the clinical research setting in response to the research process.

Unlike the more negative connotations of the Hawthorne effect (McCambridge et al., 2014), or researcher bias, the changes that took place at the ED were observed to be initiated by ED staff participants arising from internal discussions where they reflected on their own practice. We also acknowledge the role of wider-ED changes, such as the rebuild project, that likely influenced the willingness of staff and management to engage in a research project that fed specifically into broader departmental goals. As other studies reflecting on barriers to PAR cite managerial reluctance or opposing priorities within transformation efforts, this positive climate of change was fortuitous (Coughlan et al., 2007, Smith et al., 2010b).

In EBCD the 'co' is pivotal, referring to the collaborative work of patients and staff, family members and those facilitating the process, rather than to a single group and a researcher. Consequently, the adaptations to the study time line described above and the conduct of the different stages were crucial if the individual voices, particularly of the patients, were to be heard and impactful, particularly when the fast-pace of the ED was juxtaposed with the complex needs of older, palliative patients. This was particularly pertinent in light of reports of palliative patients and families being excluded from discussions and decisions about their care (Leadership Alliance for the Care of Dying People, 2014, Williams, 2013). Nonetheless, the lack of patient and family representation at the co-design event was a limitation to the collaborative work.

Despite the success of the co-design event in QI terms it would undoubtedly have been richer with more patients and families in attendance. One potential route to overcoming this challenge in future work would be the use of a ‘rolling recruitment’ process whereby patients and family members are routinely recruited from the ED and invited into the study. This might also have led to additional collaborations in the latter stages of the EBCD process. This reflection is partly based on the ease with which ED staff new to the study were able to relate to the stories of their colleagues and join the study at different stages throughout its undertaking.

In presenting evidence about palliative care needs in the ED for the participants, the flexibility of EBCD was its greatest strength. It ensured patients and families were given a voice to say what palliative care meant for them in the ED, shedding light on how ED staff needed to be trained and the ways in which the ED could adapt its model of care. The patient-family film was particularly valuable in aiding this flexibility, as well as providing a record of experiences. Films presenting this type of personal narrative have been well received and are an effective QI tool (Robert et al., 2015). Consequently, a recommendation to support future iterations of this type of study is the development of a tailored film library of patient and staff narratives of their ED-based palliative care experience. This would allow an ‘accelerated’ EBCD (AEBCD) approach to occur which would quickly help collaborators identify key areas in practice in need of improvement. In addition, pre-existing films would reduce the research burden on palliative patients and potentially lead to greater involvement in co-design activities.

In claiming the DVD is a contribution to practice it is important to address possible criticisms that the information may lose its relevance as practice evolves and develops, or have a limited ‘shelf-life’ when staff have viewed it. In response, a study of the accelerated EBCD approach provides useful insight (Locock et al., 2014) and would suggest that even as practice in the ED develops, the perspectives of the participants contained on the DVD can still serve as triggers for debate and review on how the service has evolved. A second response to the long-term usefulness of the DVD is based on an observation made by one of the ED staff interviewees. The ED has a very high turnover of staff requiring which means that training and education need to be routine. It also means that there will be an ever-changing staff body new to the information on the film that will arrive with their own experiences and perspectives. This factor also speaks to the longer-term implications for maintaining behaviour and practice changes and improvements following EBCD projects.

In reference to our second purpose, we would argue that it was the flexibility of EBCD that enabled considerable depth and richness to emerge regarding the ED-based palliative care needs of patients, families and ED staff. To date the majority of ED-based palliative care research has focused on broad staff experiences rather than with older people specifically (Beckstrand et al., 2012, Grudzen et al., 2012a, Grudzen et al., 2012b, Smith et al., 2009). Figures 2 and 4 in particular highlighted the challenges facing ED when confronted with a patient group whose needs sit beyond the traditional ED group. Our findings that a lack of training, constricting time pressures and processes more suited to ‘spectacular’ emergent patient needs (Bailey et al., 2011a) are found elsewhere in the literature (Bailey et al., 2011b, Beckstrand et al., 2008, Grudzen et al., 2012b, Lamba et al., 2013, Smith et al., 2009). Less work has been conducted with patients and families (Grudzen et al., 2011), and none has been identified that draws them beyond exploratory interviews into actively contributing to change efforts. Indeed, this paper demonstrates that it is far easier to draw out staff needs than patient needs, due to the relative ease of engagement. However, our findings summarized in Figures 3 and 4 suggest that for some palliative care patients and their family members, addressing basic care needs, such as hydration and communication are just as important as clinical competence, and may be of greater immediate relevance to their feelings of safety and trust and the memory of their experience.

We have critiqued the conduct and adaptations of EBCD throughout this article, particularly highlighting the need for flexibility and a staged approach. One final point for discussion is the lack of a formal evaluation and in-depth analysis of the longer-term impact of the quality improvements. The limitations previously highlighted meant that a rigorous evaluation was not possible so we adopted an informal fact-finding exercise via email correspondence with staff who attended the co-design event. We acknowledge that this approach prevented probing questions and deep exploration with ‘less’ engaged staff or patients and their families, though we assert that remaining flexible in our approach and limiting the research burden generated rich data that met our stated aims. However, looking to future research and having demonstrated the feasibility of this research approach in the ED setting with palliative care patients and families, we would recommend embedding a formal evaluation into the protocol. Such formal evaluations of the impact of co-design approaches in other healthcare settings are present in ongoing studies (Jones et al., 2016, Palmer et al., 2015).

## **Conclusion**

This paper critically reviews the use and adaptation of EBCD in a study that aimed to enable high levels of participation to draw out evidence about ED-based palliative care needs in a QI intervention involving older palliative care patients, their family members and ED staff. EBCD is a useful approach for encouraging collaborative working between vulnerable patients, family and staff in complex healthcare environment. There are a number of challenges to be considered but the flexibility of the approach allows the specific needs of the participants to be accounted for, ensuring fuller participation for those who may usually not be able to provide input into local QI work. Recommendations for future research in ED-based palliative care include the use of the ‘accelerated’ EBCD, rolling recruitment, the creation of a film library of patient and family narratives and a formal impact evaluation.

## **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.

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Copies of the trigger film are available via request from the main author or by emailing eping.

### **References**

- Adams, M., Maben, J. & Robert, G. 2013. Improving Patient-Centred Care through Experience-based Co-design (EBCD): an Evaluation of the Sustainability and Spread of EBCD in a Cancer Centre. London: King's College London.
- Addington-Hall, J. 2002. Research sensitivities to palliative care patients. *European Journal of Cancer Care*, 11, 220–224.
- Albert, M., McCaig, L. & Ashman, J. 2013. Emergency department visits by persons aged 65 and over: United States, 2009-2010. Hyattsville: National Center for Health Statistics.
- Bailey, C., Murphy, R. & Porock, D. 2011a. Trajectories of End-of-Life Care in the Emergency Department. *Annals of Emergency Medicine*, 57, 362-369.
- Bailey, C. J., Murphy, R. & Porock, D. 2011b. Dying cases in emergency places: Caring for the dying in emergency departments. *Social Science & Medicine*, 73, 1371-1377.
- Bate, P. 2007. Bringing the Design Sciences to Organization Development and Change Management: Introduction to the Special Issue. *The Journal of Applied Behavioral Science*, 43, 8-11.
- Bate, P. & Robert, G. 2007. *Bringing User Experience to Healthcare Improvement: The Concepts, Methods and Practices of Experience-Based Design*, London, Radcliffe Publishing.
- Beckstrand, R. L., Smith, M. D., Heaston, S. & Bond, A. E. 2008. Emergency Nurses' Perceptions of Size, Frequency, and Magnitude of Obstacles and Supportive Behaviors in End-of-Life Care. *Journal of Emergency Nursing*, 34, 290-300.
- Beckstrand, R. L., Wood, R. D., Callister, L. C., Luthy, K. E. & Heaston, S. 2012. Emergency nurses' suggestions for improving end-of-life care obstacles. *Journal of Emergency Nursing*, 38, e7-14.

- Blackwell, R. 2013. Fieldwork at the Mount Sinai Geriatric Emergency Room, New York: Improving experiences of care for older people, their carers and staff in the Emergency Department. London: Florence Nightingale Foundation.
- Blackwell, R. 2015. *Improving the experiences of palliative care for older people, their carers and staff in the Emergency Department using Experience-based Co-design*. PhD, King's College London.
- Blackwell, R. & Grudzen, C. 2014. End of life care in emergency settings. *Emergency Nurse*, 21, 13.
- Bowen, S., Dearden, A., Wolstenholme, D. & Cobb, M. 2011. Different views : including others in participatory health service innovation. In: BUUR, J. (ed.) *PINC 2011 : Participatory innovation conference 2011*. Sonderborg, Denmark. Sonderborg, University of Southern Denmark.
- Bowen, S., McSevenya, K., Lockley, E., Wolstenholme, D., Cobb, M. & Dearden, A. 2013. How was it for you? Experiences of participatory design in the UK health service. *CoDesign: International Journal of CoCreation in Design and the Arts*.
- Carr, A., Gibson, B. & Robinson, P. G. 2001. Is quality of life determined by expectations or experience? *BMJ*, 322, 1240-1243.
- Coughlan, P., Suri, J. F. & Canales, K. 2007. Prototypes as (Design) Tools for Behavioral and Organizational Change: A Design-Based Approach to Help Organizations Change Work Behaviors. *The Journal of Applied Behavioral Science*, 43, 122-134.
- Dewar, B. M., R. Smith, S. Pulling, S. Tocher, R 2009. Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting. *Journal of Research In Nursing*, 15, 29-41.
- Donetto, S., Tsianakas, V. & Robert, G. 2014. Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions. London: King's College London.
- Goodman, C., Froggatt, K. & Mathie, E. 2012. NIHR School for Social Care Research Methods Review: End of life care. London: National Institute for Health Research.
- Gordon, J., Sheppard, L. & Anaf, S. 2010. The patient experience in the emergency department: A systematic synthesis of qualitative research. *International Emergency Nursing*, 18, 80-88.
- Grudzen, C. R., Richardson, L. D., Hopper, S. S., Ortiz, J. M., Whang, C. & Morrison, R. S. 2012a. Does Palliative Care Have a Future in the Emergency Department? Discussions with Attending Emergency Physicians. *Journal of Pain and Symptom Management*, 43, 1-9.
- Grudzen, C. R., Richardson, L. D., Major-Monfried, H., Kandarian, B., Ortiz, J. M. & Morrison, R. S. 2012b. Hospital Administrators' Views on Barriers and Opportunities to Delivering Palliative Care in the Emergency Department. *Annals of Emergency Medicine*, 5.
- Grudzen, C. R., Stone, S. C., Mohanty, S. A., Asch, S. M., Lorenz, K. A., Torres, J. M., Morrison, M., Ortiz, J. M. & Timmermans, S. 2011. "I want to be taking my own last breath": Patients' reflections on illness when presenting to the emergency department at the end of life. *Journal of Palliative Medicine*, 14, 293-296.
- Hall, S., Petkova, H., Tsouros, A. D., Costantini, M. & Higginson, I. 2011. Palliative care for older people: better practices. Copenhagen: World Health Organisation.
- Hampson, M., Baeck, P. & Langford, K. 2013. By Us, For Us: The power of Co-Design and Co-Delivery. In: TEMPERLEY, J. (ed.) *People Powered Health*. London: Nesta.
- Hartocollis, A. 2012. For the Elderly, Emergency Rooms of Their Own. *The New York Times*, 9th April 2012.
- Huckabay, L. 1991. The role of conceptual frameworks in nursing practice, administration, education, and research. *Nursing Administration Quarterly*, 15, 17-27.
- Hwang, U. & Morrison, S. 2007. The Geriatric Emergency Department. *Journal of American Geriatrics Society*, 55, 1873-1876.
- Iedema, R., Merrick, E., Piper, D., Britton, K., Gray, J., Verma, R. & Manning, N. 2010. Co-design as discursive practice in emergency health services: The architecture of deliberation. *Journal of Applied Behavioural Science*, 46, 73-91.

- Jones, F., Clarke, D., Robert, G., Harris, R., McKeivitt, C., Macdonald, A. & Cloud, G. 2016. Using co-production to improve patient carer and staff experiences in health care organizations: a multi-centre, mixed methods evaluation in inpatient stroke units. 'CREATE' Collaborative Rehabilitation Environments in Acute sTroKE'.
- Kelley, M., Parke, B. & Jokinen, N. 2011. Senior-friendly emergency department care: an environmental assessment. *J Health Services Research & Policy*, 16, 6-12.
- Lacey, A. & Luff, D. 2007. Qualitative Data Analysis.: The NIHR RDS for the East Midlands/ Yorkshire & the Humber.
- Lamba, S., DeSandre, P. L., Todd, K. H., Bryant, E. N., Chan, G. K., Grudzen, C. R., Weissman, D. E. & Quest, T. E. 2014. Integration of palliative care into emergency medicine: the Improving Palliative Care in Emergency Medicine (IPAL-EM) collaboration. *J Emerg Med*, 46, 264-70.
- Lamba, S., Nagurka, R., Zielinski, A. & Scott, S. 2013. Palliative Care Provision in the Emergency Department: Barriers Reported by Emergency Physicians. *Journal of Palliative Medicine*, 16, 143-147.
- Leadership Alliance for the Care of Dying People 2014. One chance to get it right. Improving people's experience of care in the last few days and hours of life. .
- Lowery, D. S. & Quest, T. E. 2015. Emergency Medicine and Palliative Care. *Clinics in Geriatric Medicine*, 31, 295-303.
- McCambridge, J., Witton, J. & D.R., E. 2014. Systematic review of the Hawthorne effect: New concepts are needed to study research participation effects. *Journal of Clinical Epidemiology*, 67, 267-277.
- NICE. 2015. *Patient Carer & Public Involvement & Engagement* [Online]. London: National Institute for Health Research (NICE),. Available: <https://www.crn.nihr.ac.uk/wessex/about/patient-care-public-involvement-engagement/> [Accessed 09/10 2015].
- Nobar, N. C. & Lisk, C. 2014. Attitudes to end of life care in emergency and general internal medicine doctors. *European Geriatric Medicine*, 5, S109-S110.
- Palmer, J. V., Chondros, P., Piper, D., Callander, R., Weavell, W., Godbee, K., Potiriadis, M., Richard, L., Densely, K., Herrman, H., Furler, J., Pierce, D., Schuster, T., Iedema, R. & Gunn, J. 2015. The CORE study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness in the community mental health setting. *BMJ Open*, 5 e006688.
- Piper, D., Iedema, R. & Merrick, E. 2010a. Emergency Department Co-Design Program 1 Stage 2 Evaluation Report - Final Report to Health Services Performance Improvement Branch. Sydney: NSW Health. Sydney: Centre for Health Communication, University of Technology.
- Piper, D., Iedema, R., Merrick, E. & Perrott, B. 2010b. Experience-based Co-Design Program 2 Stage 1 Evaluation Report - Final Report to Health Services Performance Improvement Branch, NSW Health. In: IMPROVEMENT, H. S. P. (ed.). Sydney: Centre for Health Communication, University of Technology Sydney.
- Plsek, P., Bibby, J. & Whitby, E. 2007. Practical Methods for Extracting Explicit Design Rules Grounded in the Experience of Organizational Managers. *The Journal of Applied Behavioral Science*, 43, 153-170.
- Quest, T. E., Marco, C. A. & Derse, A. R. 2009. Hospice and Palliative Medicine: New Subspecialty, New Opportunities. *Annals of Emergency Medicine*, 54, 94-102.
- Robert, G. 2013. Participatory action research: using Experience-based Co-design to improve the quality of health care services. In: ZIEBLAND, S., COULTER, A., CALABRASE, J. & LOCOCK, L. (eds.) *Understanding and Using Health Experiences Improving patient care*. Oxford: Oxford University Press.
- Robert, G., Locock, L., Purushotham, A., Sturmey, G. & Gager, M. 2015. Patients and staff as co-designers of healthcare services. *BMJ*, 350.
- Romme, A. G. L. & Damen, I. C. M. 2007. Toward Science-Based Design in Organization Development: Codifying the Process. *The Journal of Applied Behavioral Science*, 43, 108-121.

- Smith, A., Fisher, J., Schonberg, M., Pallin, D., Block, S., Forrow, L., Philips, R. & McCarthy, E. 2009. Am I Doing the Right Thing? Provider Perspectives on Improving Palliative Care in the Emergency Department. *Annals of Emergency Medicine*, 54, 86-93.e1.
- Smith, A. K., Schonberg, M. A., Fisher, J., Pallin, D. J., Block, S. D., Forrow, L. & McCarthy, E. P. 2010a. Emergency Department Experiences of Acutely Symptomatic Patients With Terminal Illness and Their Family Caregivers. *Journal of Pain and Symptom Management*, 39, 972-981.
- Smith, L., Bratini, L., Chambers, D.-A., Jenson, R. V. & Romero, L. 2010b. Between idealism and reality: Meeting the challenges of participatory action. *Action Research*, 8, 407-425.
- Staley, K., Buckland, S. A., Hayes, H. & Tarpey, M. 2014. 'The missing links': understanding how context and mechanism influence the impact of public involvement in research. *Health Expectations*, 17, 755-764.
- The King's Fund. 2011. *Experience-based co-design. Working with patients to improve health care* [Online]. Available: <http://www.kingsfund.org.uk/projects/ebcd> [Accessed 15/10/ 2013].
- Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., Griffin, M. & Wiseman, T. 2012. Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Support Care Cancer*, 20, 2639-47.
- Ward, D. J., Furber, C., Tierney, S. & Swallow, V. 2013. Using Framework Analysis in nursing research: a worked example. *Journal of advanced nursing*, 69, 2423-2431.
- Williams, L. e. 2013. *More Care, Less Pathway. A review of the Liverpool Care Pathway*. London.
- Wiseman, T., Tsianakas, V., Maben, J., Robert, G. & Richardson, A. 2011. Improving breast and lung cancer services in hospital using Experience Based Co-design (EBCD). *European Multidisciplinary Cancer Congress*. Stockholm, Sweden: European Journal of Cancer. Conference: 2011 European Multidisciplinary Cancer Congress Stockholm Sweden. Conference Start: 20110923 Conference End: 20110927. Conference Publication: (var.pagings). 47 (pp S295), 2011. Date of Publication: September 2011.

**Figure 1: Participant Numbers throughout the Study**

Staff Interviews		Staff Focus Groups	Patient/Family Interviews		Co-design Event
Nurses N=9	*M: N=2 **F: N=7	Nurses N=56 Doctors N=8	Patient N= 6	M: N=3 F: N=3	Patient N=1 Family caregiver N=1 ED staff N=6 Palliative care team N=1 Facilitators N=3 Researchers N=2
Doctors N=6	M: N=2 F: N=4	<b>Total N=64</b>	Family caregiver N=4	M: N=1 F: = 3	<b>Total N=14</b>
<b>Total N=15</b>			<b>Total N=10</b>		
*M = Male; ** F=Female					

**Figure 2: Barriers to ED-based Palliative Care Identified by ED Staff**

<p><b>1. Patient age:</b> Refers to specific issues in providing care for older people including those with palliative care needs in the ED, such as variations in attitudes towards older people that influence the likelihood of involving them in decisions about their own care.</p>
<p><b>2. Access to Information:</b> Refers to issues related to a lack of access to information about patients on admission to the ED and the ways in which different services were or were not working together, for example what is the ceiling of care or resuscitation orders?</p>
<p><b>3. Communication with patients, family members and other staff:</b> Refers to issues relating to communication of information that impacted on care delivery for older palliative patients, such as communication between services inside and outside of the ED.</p>
<p><b>4. Understanding of palliative care:</b> Refers to lack of understanding about what palliative care is, who should provide it, and when and how it should be given.</p>
<p><b>5. Role uncertainty:</b> Refers to issues around roles in palliative care provision in the ED and wider healthcare system, such as differences in understanding of the roles of specialists and generalists.</p>
<p><b>6. Complex systems and processes:</b> Refers to issues relating to existing systems or lack of processes, such as accessing different services through challenging referral processes; I.T. systems within the hospital using different platforms that do not link together preventing access to patient information.</p>
<p><b>7. Time constraints:</b> Refers to challenges staff face in providing the level and quality of care they wish to due to time constraints.</p>
<p><b>8. Limited training and education:</b> Refers to a lack of palliative care training and education at pre- and post-registration levels.</p>

**Figure 3: Barriers to ED-based Palliative Care Identified by Patients and Family Caregivers**

<p><b>1. Systems and Processes:</b> Refers to patient and family caregivers struggles with the overall structure and processes of the ED, for example waiting times, knowing how to ask for help, where the toilets are, being left waiting and discomfort in the physical environment.</p>
<p><b>2. Communication and Information:</b> Refers to challenges patients and families had with staff encounters, including how personal information was shared between services and between staff and patients for example, if family members were listened to when they voiced their concerns, or being asked what they were hoping for from the visit.</p>
<p><b>3. Acknowledgement and Validation:</b> Refers to how well patients and families felt that their personal experience was understood or supported by staff, for example being offered a drink or a phone call, including family members in conversations or patients in decision-making</p>
<p><b>4. Recommendations:</b> Refers to suggestions put forward by patients and family caregivers for improvements to care delivery, such as a space for older patients, or palliative care clinicians present in the ED</p>
<p><b>5: Changing Expectations:</b> Refers to the myriad of factors facing older people with palliative care needs as their health and lifestyle changes, for example their own mobility, and the manner in which their needs can be addressed by healthcare providers begins to change.</p>

**Figure 4: Staff and patient-family improvement priorities and subsequent change**

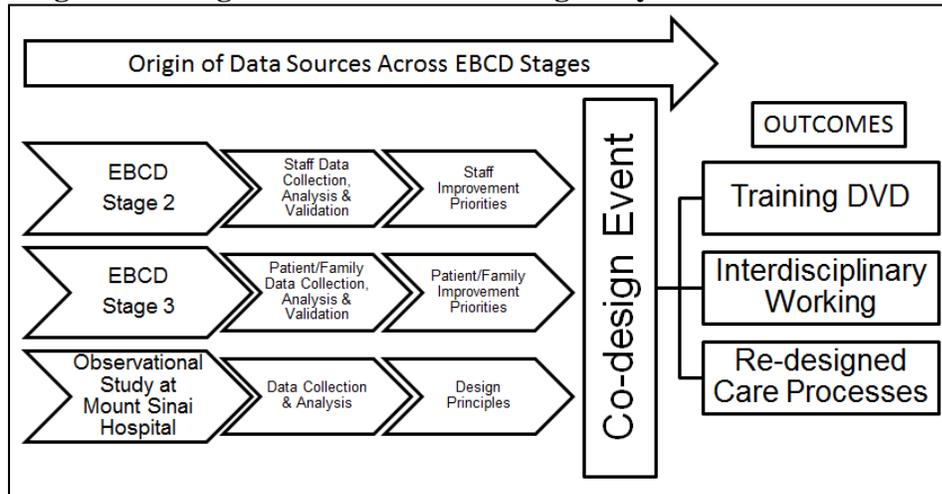
Staff priorities	Patient and family priorities	Planned or implemented changes in practice following co-design event
<b>Helping patients and families find their way:</b> <i>degree of information available about the patient and their ceiling of treatment on admission to the ED</i>	<b>Finding our way:</b> <i>feelings of panic and uncertainty, why we come to the ED, where do we go on admission to the ED.</i>	Re-designing triage systems and pathways through the ED for older, frail and palliative care patients.
<b>Being informed and informing patients and families:</b> <i>accessing key personal and information to provide the appropriate care in a timely manner.</i>	<b>Knowing what's happening:</b> <i>waiting to be treated, waiting for results, understanding how the ED system and processes work.</i>	Greater provision of ED structures and protocols now routinely available to patients and families within each cubicle.
<b>Seeing the person in the patient:</b> <i>knowing what to say, and if and how to raise end of life or goals of care conversations; remembering the family member; including the patient and/or family in decisions about their treatment and ceilings of care.</i>	<b>Seeing the person in the patient:</b> <i>fear of the family to leave the patient alone in case they die; fears of the patient if they are alone; how they are acknowledged and validated impacts of interactions on the patient and family following the ED visit.</i>	Reports of individual ED staff members changing their practice and how they personally interact with patients and family members.
<b>Expectations of the care we can give:</b> <i>training and experience in palliative care or lack thereof influences staff confidence and the palliative care that will be delivered. Identifying patient needs takes skill and confidence.</i>	<b>Expectations of care:</b> <i>the reason for the visit influences the patient and family expectations of staff and outcomes. For some the ED is a port of safety, for others it is the result of deterioration, lack of support or catastrophic event.</i>	Routine palliative care training provided to ED staff with support from the palliative care team.

**Figure 5: Example of Design Principle**

Design Principle	Application	Observation from practice
<p><b>COMMUNICATION</b></p> <p><b>Establish effective ways, firstly, of communicating with staff at all levels that helps them to understand their respective roles in providing high quality care to these patients and how they relate to each other, and secondly to disseminate information to the department and across the organisation.</b></p>	<p><b>1. Include all staff as change agents by:</b></p> <p>a. <i>Regularly scheduled meetings or forums for staff groups to communicate changes and new roles, review problems and share successes.</i></p> <p>b. <i>Feedback of outcomes of meetings by staff representative to the leadership team</i></p> <p>c. <i>Allowing staff to share challenges and concerns and responding via the feedback cycle</i></p>	<p>Interactions with staff suggest they are willing and keen to change practice and improve patient care. However, there is some resistance from staff regarding the older person ED, many of which stem from concerns over patient safety and lack of awareness of available resources. Night staff in particular appeared to feel left out of communication and provision of support systems. If there was a forum to feedback concerns, I was not aware of it. Therefore it would appear advantageous to provide a system that allows staff to safely share their concerns and be fully briefed regarding departmental changes.</p>

**Figure 6: Timetable of EBCD in the ‘Improving palliative care in the ED’ study**

Months 1 - 4: Setting-up
Months 5-9: Gathering staff experiences Analysis and validation
Months 10-14: International fieldtrip, Analysis and presentation of findings
Months 15-17 Gathering patient experiences Analysis, validation and creation of patient film
Month 17: Staff & patient co-design meeting
Months 18-19: Co-design work

**Diagram 1: Origin of data sources during study****Diagram 2: Conceptual framework showing the application of EBCD in the study setting**