

Views of Care at End of Life: An action research study exploring the best ways of eliciting patient and family views of end of life care and giving real time feedback in acute hospitals

Professor Bridget Johnston¹

¹ School of Medicine, Dentistry & Nursing, College of Medical, Veterinary & Life Sciences, University of Glasgow

² NHS Greater Glasgow & Clyde

Abbreviated abstract: This participatory action research study guided by the principles of the 'Appreciative Inquiry' sought to explore views of care at end of life in partnership with patients, relatives and healthcare staff and co-create, and evaluate a real-time feedback tool to improve quality of care in acute hospitals in NHS Greater Glasgow and Clyde.

Previous work, challenge, and approach

- In the United Kingdom (UK), over 600,000 people are dying each year and one in four are not accessing the end of life care they need (Hospice UK, 2019).
- In Scotland, with a population of 5.4 million, there are approximately 58,000 deaths annually of which 48% occur in the acute hospital setting and dying patients are treated in almost all hospital settings (The Scottish Government, 2018). Delivering high quality end-of-life (EOL) care must therefore be an important goal for acute hospitals.
- To improve care for the dying, it is imperative to measure the quality of care. However, there is no consensus on the optimal tool or timing post-bereavement to assess end of life care in hospitals (Heckel et al. 2020).

Techniques and Methods

- This is a participatory action research study guided by the principles of 'Appreciative Inquiry' that sought to explore views of care at end of life in partnership with patients, relatives, and healthcare staff and co-create, and evaluate a real-time feedback tool to improve quality of care in acute hospitals in NHS Greater Glasgow and Clyde.
- In the exploratory phase of the study, in accordance with 'diagnosing' and 'action planning' of the action research cycle, we conducted a rapid review, analysed people stories on Care Opinion, and spoke to key stakeholders (patients with life-limiting conditions bereaved clinical and non-clinical staff about their views of care at the end of life and how we can improve communication with people who are at the end of life.
- In the 'Action' and 'Evaluation' phases, we recruited seven wards with highest mortality rate across NHS Greater Glasgow and Clyde (four medical and two older people services and one specialist cancer care) to test the most favoured feedback tools chosen by the participants in the first phase of the study for a duration of 6 weeks.

Results and Conclusions

- Findings from the exploratory phase showed that the majority of the study participants had a positive insight to staff professionalism in providing compassionate and dignified care and family support, and areas needing improvement included staffing pressure and poor and ineffective communication affected by multiple factors including COVID-19. However, such problems should be fed back to hospitals in order to identify causes and prompt improvement.
- In terms of finding out the best ways of getting feedback from patients and their family members, the majority appreciated a phone call from the area where the person who mattered to them died or filling in the 'Care Of the Dying Evaluation' (CODE) questionnaire.
- Good quality of end-of-life care improves the quality of dying in terminally ill patients. Findings from this study will guide the implementation of a patient and family feedback tool into routine practice across NHS Greater Glasgow and Clyde aimed at achieving a good quality of dying for patients with life-limiting condition and post-bereavement support for bereaved relatives.

