

# Views of Care at End of Life: Using Care Opinion to explore end of life experiences

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**Abbreviated abstract:** This study sought to understand the experiences of end of life care provided in hospitals in the West of Scotland by exploring the main themes within the content of stories posted on a nationally endorsed nonprofit feedback online platform, Care Opinion. Novel perspective of patients' experiences of end-of-life care were the appreciation of quality of care, staff professionalism, and importance of trust and effective communication.

## Related publications:

Khonsari S, O'Neill C, Mayland CR, et al. Views of Care at End of Life: A Secondary Analysis of Online Feedback Using Care Opinion. *Journal of Patient Experience*. 2022;9.

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# Previous work, challenge, and approach

- With the rapid growth of digital innovations, new ways of gathering online feedback have been promoted alongside the traditional use of paper survey questionnaires (Locock et al 2020).
- In the UK, three-in-four users of the Internet read comments prior to buying a product or service and two-in-five post online reviews (Ofcom 2021).
- There is an increasing focus in Scotland on patient experience as an aspect of patient safety and quality improvement. A survey conducted as part of a major UK review of online feedback, Improving National Health Service (NHS) Quality Using Internet Ratings and Experience (INQUIRE), found that online feedback is seen by those posting online reviews or comments as more positive than expected (van Velthoven et al. 2018).
- Although there are studies on the use of social media and palliative and end-of-life care (PEOLC), there are no studies specifically investigating the content of online public feedback about PEOLC services.
- This study sought to understand experiences of end-of-life care provided in hospitals in the West of Scotland by exploring the main themes within the content of stories posted on a nationally endorsed nonprofit feedback online platform, Care Opinion, within a 2-year period.



# Techniques and Methods

- An “Appreciative Inquiry” (AI) lens (Cooperrider et al. 2008) was chosen to guide this study to gain an understanding of care that went well, while identifying and learning from negative aspects of care.
- We gathered and analysed public feedback stories, and their associated staff responses, posted on Care Opinion Scotland over a 24-month period (March 2019 to 2021) relevant to end-of-life care provided in acute hospitals across NHS GGC.
- Feedback was included in the study if they discussed the treatment or diagnosis of a life-limiting condition, end-of-life care experience, or service in hospital settings within NHS GGC. Stories that related to primary care, or non hospital services were excluded.
- To understand the content of people stories/ feedback, Braun and Clarke's six-phase reflexive thematic analysis was used in conjunction with using NVivo by QSR International to organise the qualitative data.
- Existing staff responses were quality-appraised using the best-practice response for evaluating the quality of staff responses.

# Results and Conclusions

- Of the 1428 stories published on “Care Opinion” from March 2019 to 2021 regarding hospitals in the West of Scotland, 48 (3.36%) were related to end-of-life care, of which all were included in data analysis.
- We found that people tended to post positive feedback about their experiences with end-of-life care. People reported positively about staff professionalism in providing compassionate and person-centered care to meet their loved ones needs at end of life. Nevertheless, other experiences of care related to challenges facing healthcare services, particularly during the COVID-19 pandemic.
- Quality appraisal of staff responses highlighted areas for improving feedback. Despite research suggesting conversational responses are more desirable by service users, they were the least popular type of responses in our sample and were mostly from negative stories. In contrast, appreciative responses were commonly from families reporting positively about their experiences of end-of-life care.
- This study has provided a novel perspective of patients’ experiences of end-of-life care in hospitals in the West of Scotland. Novel insights were importance of trust and meeting patient’s needs at end-of-life particularly by nursing staff.