





Views of Care at End of Life: A Secondary Analysis of Online Feedback Using Care Opinion

Journal of Patient Experience
Volume 9: 1-10
© The Author(s) 2022
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735221103029
journals.sagepub.com/home/jpx


Sahar Khonsari, PhD¹ , Claire O'Neill, MSc²,
Catriona R Mayland, MD³, Fraser Gilmour, BA(Hons)⁴,
Marc Aitken, MBChB⁵, Alistair Mckeown, MBChB² ,
Sian Russell, BSc(Hons)², Angela Mcalees, RN²,
Morag Gardner, MSc², and Bridget Johnston, PhD⁵ 

Abstract

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. We used “Appreciative Inquiry” as a theoretical framework for this study to determine what works well in end-of-life care, while also identifying areas for further improvement. 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. Using the software package NVivo and thematic analysis, we identified 4 key themes. We found that people overwhelmingly posted 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. 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. This study can add to the aim of improving staff response to people’s concerns about 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 the appreciation of quality of care, staff professionalism, effective communication, and meeting patient’s needs at end-of-life particularly by nursing staff.

Keywords

end-of-life care, communication, health information technology, clinician–patient relationship, care opinion, COVID-19, online feedback

Introduction

With the rapid growth of digital innovations over the last decade, new ways of gathering online feedback have been promoted alongside the traditional use of paper survey questionnaires.¹ According to a report on online consumer behavior in the United Kingdom (UK),² three-in-four users of the Internet read comments prior to buying a product or service and two-in-five post online reviews.

There is an increasing focus in Scotland on patient experience as an aspect of patient safety and quality improvement. Care Opinion is a nationally endorsed nonprofit public feedback platform for health and social care services that was set up in the UK in 2005.³

- ¹ School of Medicine, Dentistry & Nursing, College of Medical, Veterinary & Life Sciences, University of Glasgow, Glasgow, UK
- ² NHS Greater Glasgow and Clyde, Glasgow, UK
- ³ University of Sheffield; Honorary Clinical Fellow, University of Liverpool, Sheffield, UK
- ⁴ Executive Director and Head of Care Opinion, Stirling, Scotland, UK
- ⁵ Clinical Professor of Nursing and Palliative Care, School of Medicine, Dentistry & Nursing, University of Glasgow and NHS Greater and Clyde, College of Medical, Veterinary & Life Sciences, University of Glasgow, Glasgow, UK

Corresponding Author:

Bridget Johnston, Clinical Professor of Nursing and Palliative Care, School of Medicine, Dentistry & Nursing, University of Glasgow and NHS Greater and Clyde, College of Medical, Veterinary & Life Sciences, University of Glasgow, 57-61 Oakfield Avenue, Glasgow G12 8LL, UK.
Email: Bridget.Johnston@glasgow.ac.uk



There is little analysis of why people post on Care Opinion, how staff respond, and how people feel about the responses they receive. 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.⁴ Providing information for other service users (39%), expressing admiration for a service (36%), and contributing to the quality of care within the NHS (15%) were the top reasons for providing feedback. Complaining about a service, treatment, or professional was less common compared to providing praise.

In palliative and end-of-life care (PEOLC) feedback can identify areas where changes can be made, or services improved. There is little published research on the content of “Care Opinion” posts in the context of PEOLC. The collation and analysis of people stories is a useful exercise, facilitating understanding of the wide-ranging experiences of service users when receiving end-of-life care in acute hospitals within NHS Greater Glasgow and Clyde (NHSGGC).

Aim

This study was part of the first phase of a larger multi-method participatory action research in which we aimed to identify the main themes within the content of online feedback/stories on the “Care Opinion” platform provided by people regarding their experiences of end-of-life care in hospitals within NHSGGC. The focus of this study was on the “Discovery” phase of the 4D cycle to map best practices and gain insights particularly—though not exclusively—of what service users appreciate in their stories on “Care Opinion” about end of life care at hospitals within the NHSGGC.

Table 1. Search Strategy.

Search Terms	Results
“dying” OR “death” OR “died” OR “Passed away” OR “bereaved” OR “bereavement” OR “grief” OR “grieving” OR “end of life” OR “palliative” OR “palliative care” OR “life-limiting disorder” OR “terminal” OR “terminal care” OR “terminal illness”	17,950
“NHS Greater Glasgow and Clyde”	4350
1 AND 2	153
After applying date limit: on or after March 1, 2019 to on or before March 31, 2021	61
After reviewing for inclusion/exclusion criteria:	48
• Irrelevant (Maternity care, n = 3; Orthopaedic Disorder, n = 2; Child and COVID-19 shielding issues, n = 1; paperwork and mortuary, n = 1; stroke n = 1)	
• Nonhospital, GP (n = 2)	
• Nonhospital, NHS24 (n = 1)	
• Nonhospital, home care (n = 1)	
• Nonhospital, hospice (n = 1)	

Abbreviation: NHS, National Health Service.

Methods

To approach this study, we sought a framework that allows generating a sense of optimism, creativity, and motivation for change through using available resources and current strengths in place. Therefore, an “Appreciative Inquiry” (AI) lens was chosen to guide this study to gain an understanding of care that went well, while identifying and learning from negative aspects of care.⁵

AI is a strength-based approach focusing on the assets of an organization and its stakeholders’ values that includes building effective partnerships and collaborations between researchers, practitioners, and service users through encouraging less hierarchical structures and more equalized power to identify and build upon positive mechanisms and outcomes across the system.⁶ AI comprises 4 iterative phases (discovery, dream, design, and destiny) known as the 4D cycle that are flexible and can be adapted to different settings and populations.

The AI approach was used to develop a framework based on service users’ vision of change to service from a “bottom-up” perspective. As AI values wholeness and humanity, it complements values of holistic care and compassion thereby supporting the specific context of end-of-life care.

We conducted a thematic analysis of public feedback stories about end-of-life care posted on Care Opinion Scotland during a 2-year period as well as quality appraisal of stories’ associated with professional responses.

A subscription was granted by Care Opinion for full access to the platform for ease of data extraction and additional functions (eg, data access, report generation, and visualization). The two analyzing authors attended training sessions on the platform and its features.

Data Collection

We gathered and analyzed public feedback stories, and their associated staff responses, posted on Care Opinion Scotland over a 24-month period (March 2019–2021) relevant to end-of-life care provided in acute hospitals across NHSGGC. As pressures on health services have been greatest since the onset of the COVID-19 pandemic, we included 2019 to review more heterogeneous comment/feedback pool.

Search filters were designed in conjunction with our patient and public involvement (PPI) group, the patient experience team at NHSGGC, and the director of Care Opinion Scotland to maximize sensitivity and specificity (Table 1).

Two authors ran the search and screened stories for inclusion independently using an inclusion criteria form (see Appendix 1). Ambiguous results were resolved by discussion within the research team.

Inclusion/ Exclusion Criteria

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 NHSGGC. Stories that related to primary care, nonhospital

Table 2. Summary of Themes and Subthemes and Representative Quotes.

Themes/subthemes		Total (n = 48), n (%) ^a
Theme 1: Feelings about the experience of end-of-life care		39 (81.25)
Subtheme	Appreciation of staff	29 (60.41)
Quotes	<p>1. We are heartbroken Mum isn't with us any more, but will be forever thankful and grateful to you all, for taking such good care of her in her final days (Margaretsdaughter).</p> <p>2. We are extremely grateful for all the loving attentions given to Mum and ourselves during this difficult time (EchoPapa).</p> <p>3. I want to thank all staff involved looking after my mum from admission to the end of life... I would like to say all NHS staff are heroes but these people will hold a place in heart forever (Bigaal).</p> <p>4. The senior Charge Nurse was a great support for us all and I can see how her leadership, empathy and compassionate skills is relayed throughout the team. All the medics and staff were outstanding and there at every point we needed them, we can't thank you all enough (aquariuscw67).</p> <p>5. The nurses who were on duty that day were kind, compassionate and respectful...I would like to thank everyone involved in my mums care and for the time spent with our family at the worst time of our lives (Thanksforeverything).</p>	
Subtheme	Compassion	13 (27.08)
Quotes	<p>6. All the staff were kind, attentive and professional to Mum and to us as a family - I felt they were wrapping us in a blanket of care and support ... (CMH).</p> <p>7. They made a difference to a shocked and grieving man and we can't thank them enough for looking after our family when we weren't there ourselves (Bradyfamily).</p> <p>8. They looked after us making sure we were as comfortable as was possible (fluteqe63).</p>	
Subtheme	Trust	8 (16.66)
Quotes	<p>9. Having no family in the UK and being elderly myself made it difficult to visit every day but I felt at ease that my loved one was in good hands (Anonymous family member).</p> <p>10. Due to COVID we were unable to visit her...I have no doubt that everything that could be done (Thanksforeverything).</p> <p>11. The approach and relationship they built with mum made her feel at ease, reassured and she trusted them which gave her such a positive outlook...Although we don't have our mum now, the care shown throughout her journey has given us and my dad great comfort (JTA).</p>	
Subtheme	Being ignored	8 (16.66)
Quotes	<p>12. We arrived in her room to discover she had been sat on a chair without her buzzer and was in the process of getting up and I actually caught her as she has delirium at present and does not know what she is doing which again I find unacceptable (LP2103).</p> <p>13. I made it clear to the nursing staff that my mother's mobility had been poor due to the onset of the sepsis and my concerns were that she would fall...Subsequently my mother had two falls the second fall which broke her shoulder after which my mother was bed-bound. It saddens me to explain that her fall was her attempt in making her way to the bathroom as she had soiled herself due to the lack of response to her aid buzzer (39SWO).</p> <p>14. My father was covered in bruises and his toenails were going into his skin where was his care!!! (Flowerpots)</p>	
Subtheme	Disappointment	5 (10.41)
Quotes	<p>15. My husband was very ill and could not manage a shower, he was left in a bed damp with sweat, unwashed, and not shaved. He was very distressed about that (bootattack)</p> <p>16. I was extremely unhappy with the care and compassion given by staff...Everyone could see him unwell and in pain - he deserved a bit of dignity. My husband passed away several days later. He was shown no compassion in his last days. Shameful treatment that will never leave me (Summer21).</p> <p>17. We feel that she never received end of life care and as a family we have been left devastated. We were never told this and feel guilty because we could have cared for her differently and been more prepared for her passing. We also feel let down (Assessor1).</p>	
Theme 2: Meeting needs at end of life		34 (70.83)
Subtheme	Family involvement and shared decision making	29 (60.41)
Quotes	<p>18. We were made to feel at the centre of any decisions regarding his treatments and ongoing care. At every single stage of his journey, we were briefed and contacted, we were never 'told' which gave me such confidence what to do (aquariuscw67).</p> <p>19. The consultant on duty in A&E that day who had compassionate communication skills and involved the family in decision making (Ekresident).</p> <p>20. The ward were led by our wishes for Dads end of life care and we were able to be with him (aquariuscw67).</p> <p>21. We were allowed to be with her together when she died which was a huge comfort to us as a family and something we will be eternally grateful for (Thanksforeverything).</p>	

(continued)

Table 2. (continued)

Themes/subthemes	Total (n = 48), n (%) ^a
Subtheme Quotes	24 (50)
	Person-centered care
	22. <i>The auxiliaries at 2am, wheeling in big chairs to mum's room with blankets and pillows so we could all stay closer to her...the offer of additional food 'to make sure we were taking care of ourselves', the endless pots of tea, the hugs and the hankies when we needed them (Margaretsdaughter).</i>
	23. <i>we were also given a knitted heart each & my mum was also given one which was lovely and unexpected. The nurse looking after us gave us a little teddy bear for each of my mums grandchildren and they are now one of their most treasured possessions - something totally unexpected which made a huge difference (Thanksforeverything).</i>
	24. <i>They done everything they could for my sister to make her final days count, from organising a local celebrity to visit her to making Christmas happen (Lucy77).</i>
Subtheme Quotes	7 (14.58)
	Teamwork
	25. <i>The oncology team and staff on Ward 10 worked closely together to manage Mum's pain and to put in place a palliative radiotherapy programme (KellieMac).</i>
	26. <i>I've never met a palliative care nurse before - what a great job she did in taking time to chat and explain things to me (CMH).</i>
	27. <i>How diligently, respectfully, cohesively, and effectively your team worked together, to deliver a truly exemplary standard of care - not just to our mum - but with each staff / patient interaction we saw on your ward (Margaretsdaughter).</i>
Subtheme Quotes	6 (12.5)
	Controlling symptoms at end of life
	28. <i>... Mum had been in an incredible amount of pain and the staff in Ward 10 tried everything possible to reduce this (KellieMac).</i>
	29. <i>she was turned regularly and kept pain free and we were able to spend the precious last days by her side knowing she was getting the best care (CMH).</i>
	30. <i>The palliative care CNS who in the end made sure there was no pain or suffering. This has given me and my family great comfort (Bigaal).</i>
Theme 3: Communication and information	31 (64.58)
Subtheme Quotes	21 (43.75)
	Effective clinician–patient /relative communication
	31. <i>spending time taking us through mum's scans,.. And repeating it all again slowly as needed until we understood (Margaretsdaughter).</i>
	32. <i>The nursing staff and anaesthetist took the time to listen to our concerns and I appreciate this (Sarah-Loum).</i>
	33. <i>The Dr who had been looking after my mum came to speak to us and was very kind. We were also spoken to by the anaesthetist who had looked after her and she was great at giving us time to ask questions and answered clearly and honestly (Thanksforeverything).</i>
	34. <i>We phoned every day for an update They told him we were thinking of him every day!.. Dr phoned me with regular updates he was a great support to me through an awful time (Kpar3).</i>
	35. <i>Dad was elderly and admitted with underlying health conditions and screened positive for COVID. I was updated daily by his consultant...At every single stage of his journey we were briefed and contacted (aquariuscw67).</i>
Subtheme Quotes	9 (18.75)
	Difficult conversations when approaching end of life care
	36. <i>I received a call explaining she was unlikely to recover from the infection she had. From that moment I felt she was in very caring hands (CMH).</i>
	37. <i>The ARU consultant, who told us the truth but still managed to give hope (hoc majorum virtus).</i>
	38. <i>Unfortunately, his diagnosis was an advanced malignancy. While this has been incredibly difficult to hear, I cannot emphasise enough the high level of competence and compassion with which he has been communicated with and cared for (Gratified Daughter).</i>
	39. <i>....delivering the worst news possible with such empathy, care and compassion... (Margaretsdaughter).</i>
Subtheme Quotes	9 (18.75)
	When communication breaks down
	40. <i>Our mum's death certificate states respiratory failure II and undiagnosed progressive neurological condition. We feel that she never received end of life care and as a family we have been left devastated. We were never told this and feel guilty because we could have cared for her differently and been more prepared for her passing. We also feel let down (Assessor I).</i>
	41. <i>All I can say is she only had a problem with her leg, she had a diabetic bullae - but then how did she get sent to the coronary care unit in bute and pass away. I believe their actions led her to have pneumonia (Butt89).</i>
	42. <i>We felt communication was poor. We were never given the name of her consultant. We also felt Senior review was lacking - she had low blood pressure and a poor urine output but wasn't reviewed by anyone senior (JB57).</i>

(continued)

Table 2. (continued)

Themes/subthemes	Total (n = 48), n (%) ^a
Theme 4: Health care challenges	20 (41.66)
Subtheme	Staffing pressure
Quotes	7 (14.58) 43. <i>The nursing staff on 6B seemed extremely overrun and I feel they did not have much time for my mother... (39SWO).</i> 44. <i>She had been sat on a chair without her buzzer and was in the process of getting up... I know the demand on the services, but this is a vulnerable patient and just should not happen (LP2103).</i> 45. <i>My husband acknowledges in his document that staff also suffered from varying degrees of stress (bootattack).</i>
Subtheme	Staff behavior and negative attitudes
Quotes	6 (12.5) 46. <i>I came across bad attitudes, rude manners, and lack of basic nursing in some of the staff we came into contact with!... On arrival to the ward this night the staff became very defensive and rude - one nurse in particular stating "these things happen". (39SWO)</i> 47. <i>We experienced outright unprovoked aggression from several members of staff (bootattack).</i> 48. <i>The member of staff there (who had no identification on) I felt was extremely rude barked at my Aunts son what was her date of birth which he provided... we originally started to come across the same member of staff once again and again the attitude we received from them and the way they spoke to us has actually made me write this post I felt they were rude beyond belief and as an organisation if you think it is acceptable for staff to speak to members of the public in this manner you will receive a lot more bad publicity. (LP2103).</i> 49. <i>When the call was finally answered, the staff member instantly came across argumentative. Even though they knew I was calling about my dad that passed of Covid. Spoke to me in a rude voice and said that they can't give me details when dad was admitted, even to family. There was no need for the coldness and attitude. This person made me feel so upset and I was crying. They really did not have to be so cold-hearted (pyxisnc98).</i>
Subtheme	Prolonged waiting
Quotes	6 (12.5) 50. <i>My dad has always made it clear, that he wanted to die at home. But he became acutely unwell, over last weekend, with two bad falls. Doctor came on Monday and said best to be in hospital. Took 7.5 h for ambulance. Despite living next door to RAH, he was eventually taken to IRH, which is a good half hr away (Poppy333).</i> 51. <i>She arrived there at 5 pm and didn't get into a proper bed until 11 pm. She was fasted for theatre, and cancelled 4 days running, before finally going for her operation on the 5th day. She died in recovery after her operation (JB57).</i> 52. <i>I called to get information about my dad that passed of Covid. Took over 2 h to get through to records (pyxisnc98).</i> 53. <i>He waited in hospital corridor for hours with lack of empathy or dignity, he was in extreme pain. He didn't see a doctor for five hours, all that time in pain (Summer21).</i>
Subtheme	Lack of equipment and supplies
Quotes	2 (4.16) 54. <i>My husband was starved all day then only thing available was toast and jam... He was shivering but there were no blankets... The air conditioning did not work so patients used wet towels on their heads to keep cool... When my daughter summoned the doctor on call on a Sunday they asked what we wanted them to do about it. My daughter said care for my Dad. We started to take our own pillows (bootattack).</i> 55. <i>Staff on the ward encouraged my mother's mobility and due to the lack of equipment agreed that her walking stick was adequate. my mother could not stand for more than 10 s without needing to be seated again. Subsequently my mother had two fall... My mother's falls mat had been folded up and put under her beside cabinet as it was "broken" (39SWO).</i>
Subtheme	Lost personal property
Quotes	1 (2.08) 56. <i>It's been horrible as every time I have asked the hospital about the belongings, I was getting told different things as to where these belongings were at one point we got told the belongings were lost and its only a wallet, they don't see what the problem is. THEY ARE MY FATHERS BELONGINGS (Flowerpots).</i>
Subtheme	COVID-19 pandemic visitor restrictions
Quotes	7 (14.58) 57. <i>We couldn't visit for 10 days but the staff were great!... When dad became poorly I was allowed to visit just for an hr each day (Kpar3).</i> 58. <i>Only one of us can go into visit my mother with all the covid restrictions. (MaryWeeScot).</i> 59. <i>From caring for him intensely, for several months, we have now not seen him all of this week. I know we are still in pandemic, but if in full PPE, we would surely be fine. Because of caring for our dad, we have followed every rule for the year, please, please someone help us (Poppy333).</i> 60. <i>Dad was elderly and admitted with underlying health conditions and screened positive for COVID. We were terrified as a family that we wouldn't be able to be with Dad and he could end up alone and distressed (aquariuscw67).</i>

^aAs people stories contained multiple subthemes their numbers do not add up to the total number of stories within a theme.

services were excluded. Any disagreement was resolved by discussion with the research team.

Data Analysis

To understand the content of people stories/ feedback, Braun and Clarke's six-phase reflexive thematic analysis⁷ was used in conjunction with using NVivo by QSR International⁸ to organize the qualitative data.

The extracted data was read by two members of the research team (SK, SR) to gain familiarity with feedback content and achieve data immersion for the development of codes. A provisional coding framework for the analysis was then refined through multiple iterations to produce a final coding framework. The final codes were categorized into themes/subthemes and reviewed by two clinical experts in palliative care to discuss differences in opinion and reach a consensus. Stories were read and classified as positive, negative, or mixed in relation to the end-of-life care content and tone.

Existing staff responses were quality-appraised using the Plymouth Listen, Learn and Respond Framework (PLRRF). Baines et al.⁹ co-designed and tested the PLRRF framework as a best-practice response for evaluating the quality of staff responses to Care Opinion posts by identifying different factors considered influential in effective organizational responses from a patient perspective. The framework has been also successfully applied to staff responses to Care Opinion in various fields, beyond its original use in mental health services.^{1,6} Where there was more than one staff response to a story, the most detailed response was chosen for the quality appraisal.

Results

Of the 1428 stories published on "Care Opinion" from March 2019 to 2021 regarding NHS GGC, 48 (3.36%) related to end-of-life care in acute hospitals. Four core themes were identified from qualitative analysis:

1. Feelings about the experience of end-of-life care.
2. Meeting needs at end of life.
3. Information and communication.
4. Healthcare challenges.

The majority of stories were coded more than once and grouped into 2-or-more themes or subthemes. Based on the research team's interpretations of stories content and tone, three quarters were classified as positive ($n = 36/75\%$), less than one-fifth of stories were negative ($9/48, 18.8\%$); the remaining were mixed ($n = 3/6.3\%$). "Feelings about the experience of end-of-life care" was the prevalent theme with the most expressing their appreciation toward staff ($39/48, 81.25\%$). Table 2 provides a summary of themes/subthemes contained in people stories with a selection of representative quotes illustrating each theme.

Feelings About the Experience of end-of-Life Care

Feedback relating to feelings about end-of-life care experiences was mixed. The majority of stories praised staff and conveyed gratitude. "Compassionate", "supportive", "kind", "respectful", "professional", and "competent" were common terms used to describe staff (Table 2, quotes 1-5). "Compassion" was mentioned in several stories and was fundamental to positive relatives' experiences during end-of-life care (Table 2, quotes 6-8).

'Trust' was very important when family members were not able to visit their loved ones in hospital (Table 2, quotes 9, 10). Effective patient-clinician relationships were perceived as a key element in building trust and reassurance - comforting both patients and relatives during end-of-life care (Table 2, quote 11).

Some responders included negative care experiences in their posts. Staff disregarding family concerns about their loved one's condition (Table 2, quotes 12, 13), unsafe environments/surrounding for vulnerable patients (Table 2, quotes 12), inadequate care, lack of dignity, and compassion (Table 2, quotes 14, 16), particularly in the absence of family members (Table 2, quotes 13) were evident in people stories. These were associated with strong feelings of being ignored and disappointment toward staff and quality of end-of-life care. When family members were uncertain about the reasoning for their family members sudden deterioration before death, experiences of end-of-life care could become unpleasant and disappointing (Table 2, quote 17).

Meeting Needs at end of Life

People commonly described positive experiences of how staff were supportive of meeting their loved ones needs at the end of life.

Family involvement and shared decision making during end-of-life care were reflected in several of the posts and appeared to be highly important to meeting needs at the end of life. The perception of "being at the center of any decisions regarding treatment and care" was often detailed through the use of effective phrasing. For example, as evidenced in one of the stories, they were never "told" but rather shared the decision making. This highlights the importance of two-way patient-provider relationship and the transition of patients and family members from passive recipients of care and treatment to active participants (Table 2, quotes 18, 19). Facilitating family presence at the time of death was a key concern in feedback with end-of-life care which was consistent with their wishes (Table 2, quote 20). This also helped them accept the situation, feel comfort, and give meaning to the trajectory of life-limiting illness and death as well as to their own experience (Table 2, quote 21).

The provision of person-centered care was regularly highlighted and indicative of high-quality care from the relatives' perspective. Providing welcoming spaces and comfortable

amenities to allow overnight visiting were highlighted as an important resource for relatives (Table 2, quotes 22, 23). While the experience of a family member's death could have significant impacts on bereaved relatives, they reported that receiving "something totally unexpected" such as a knitted heart or teddy bear from nursing staff is important in memory-making in their bereavement (Table 2, quote 24). They noted the efforts of staff in "making final days of their loved one count" through organizing family gatherings (Table 2, quote 25). Stories noted this made a "huge difference".

Multidisciplinary teamwork was repeatedly described as "positive" and "core" to good end-of-life care (Table 2, quotes 25-27). Praise for the wide range of health professionals involved in end-of-life care was evident (Table 2, quote 27).

Controlling symptoms was associated with good care at end of life, giving a sense of comfort in family experiences. Pain was the most frequent symptom highlighted in stories. People perceived that staff helped to reduce pain in dying patients (Table 2, quotes 28-30).

Communication and Information

Feedback reported positively the skills and professionalism of team members in communicating in an honest and empathic manner during end-of-life care. The competency of nurses and doctors was highlighted, as was making time to talk, actively listening to concerns, and ensured the information provided was sufficient and comprehensible (Table 2, quotes 31-33). Despite visitor restrictions due to the COVID-19 pandemic, communication by telephone/video call was perceived as optimal and families were kept appropriately informed (Table 2, quotes 34, 35).

One key feature of positive reviews was that clinicians were skilled and competent enough in breaking sad news with empathy (Table 2, quotes 36, 37). The acts of kindness and compassion shown when approaching end-of-life care had a positive impact on the relationship between the health care provider and family (Table 2, quotes 38, 39).

Table 3. Spread of Responders by job Title.

Responder role/title	Response contribution, Total (n = 58), n (%)
Nursing Team	25 (43.1)
Chief Nurse	15 (25.86)
Lead Nurse	8 (13.79)
Senior Charge Nurse	1 (1.72)
Clinical Nurse Specialist	1 (1.72)
Patient Experience and Public Involvement Team	13 (22.41)
General Manager	6 (10.34)
Business Manager, Emergency Care, and Medical Services	3 (5.17)
Clinical Services Manager	2 (3.44)
Corporate Affairs and Engagement	2 (3.44)
Deputy Regional Director	1 (1.72)
Chief Allied Health Professional	1 (1.72)
Unspecified	5 (8.62)

In other cases, relatives experienced a lack of proactive regular communication with the health care team. This was often associated with a breakdown in the trust between relatives-clinicians (Table 2, quote 40-42).

Health Care Challenges

Difficult working conditions, low staff numbers, high work volume, and lack of time spent caring have been noted by some relatives as a marker of poor care (Table 2, quotes 43-45).

Perceived lack of dignity and respect was a factor in reporting a negative care experience in some stories (Table 2, quotes 46, 47). This included both clinical and nonclinical staff (Table 2, quote 48). On reflection, relatives noted sensitivity

Table 4. Staff Responses and Quality Appraisal of Existing Responses.

PLLR Scope ^a	Questions, % (n)
Introductions	Have you provided a picture of yourself? 47.9% (n = 23/48) ^b
	Have you provided your name in the title of your response? 100% (n = 48/48)
	Have you addressed the story provider? 83.33% (n = 40/48)
Explanations	Have you identified your role? 95.83% (n = 46/48)
	Have you explained your role? What you're responsible for etc.? 10.4% (n = 5/48)
	Have you explained why you in particular are responding? 10.41% (n = 5/48)
Speed of response	Are you responding within 7 days? 100% (n = 48/48)
Thanks and apologies	Have you thanked the story provider for taking the time to provide their feedback? 81.25% (n = 39/48)
	If positive, have you offered to pass the feedback on? 100% (n = 36/36)
	If negative, have you apologised and reassured the provider that you are there to help and listen? 83.33% (n = 10/12)
Content	Have you uniquely tailored your response? 100% (n = 48/48)
	Have you offered to make contact with the story provider at a later date? 100% (n = 13/13)
Signposting	Have you directed the story provider to other relevant services and explained that services purpose? 83.33% (n = 10/12)
	Have you provided: contact details, opening times, and a named person? 81.81% (n = 9/11)
Sign-off	Have you provided more than one contact option? 27.27% (n = 3/11)
	Have you signed off your response in a polite manner? 95.83% (n = 46/48)

^a"Plymouth Listen, Learn and Respond framework" (PLLR).

^b"Traffic light" colour coding system (green ≥ 60% good practice; orange = 50% to 60% acceptable; and red ≤ 50% areas for possible improvement).

*Only applicable to positive or mixed stories.

**Only applicable to negative or mixed stories

to the quality of verbal communication. Families expected that the choice of word, tone, and pitch of voice be adapted to their emotions particularly during the difficult time of the COVID-19 pandemic (Table 2, quote 49).

Prolonged waits for ambulances, hospital beds, planned care, and treatment were highlighted as having the potential to adversely impact relatives' experience. This was seen to be associated with lack of coordination/consistency across services (Table 2, quote 50-52). It was frustrating and worrying for family members when they witnessed their loved ones in pain for several hours, waiting in the hospital to be visited by a health care professional (Table 2, quote 53).

When basic essential equipment was in short supply there were negative experiences of end-of-life care (Table 2, quotes 54, 55).

The negative experience of missing cash or valuables belonging to the deceased loved ones was in the minority in the analyzed stories (Table 2, quote 56). However, it does highlight the importance of collecting and managing patients' personal property.

Total ban on visits and end of life only visiting policies during the COVID-19 pandemic were felt to be insufficient and had a negative impact on family members' experiences (Table 2, quotes 57-60). Families felt that if visits had been permitted, they would be able to play their role in supporting and caring for their loved ones (Table 2, quote 59). Visitor restriction was associated with a very strong feeling of powerlessness and distress. Visits were perceived by relatives as essential for not letting the patient die alone (Table 2, quote 60).

Analysis of Staff Responses

All stories received a response within 7 days with only one "changes made" reported. There were 58 responses in total, from 28 staff members. The majority of responses came from the nursing team ($n = 25/43.1\%$) or from the Patient Experience and Public Involvement Team ($n = 13/22.41\%$). The response by job title is presented in Table 3.

We used thematic analysis to summarize how responses performed against the "PLLR" criteria.⁶ As illustrated in Table 4, boxes marked in green show good practice while red boxes suggest areas for possible.

In terms of response type, negative stories commonly received offline responses with responders keener and more comfortable in addressing these concerns in other forums. This may reflect either discomfort with addressing challenging issues in a public forum, or an effort to respond in a comprehensive and considered manner. Positive stories mainly received appreciative responses in which it was commonly highlighted that relevant staff members would be identified and feedback would be passed on. However, it was rarely clear if the appropriate team or individual had successfully received the feedback.

Both positive/negative stories often received thanks/apologies. Thanks were commonly offered regarding specific elements of the feedback, particularly, the beneficial impact positive feedback could have on staff performance and their confidence. Respondents also offered thanks, regardless

of the feedback content, for the time and effort people had spent describing their experiences of end-of-life care. Where people had reported negative experiences, apologies were made by responders, prompting the story author to continue the conversation via various methods from providing their contact details to sign posting to patient experience teams or other relevant services. However, it was unclear to what extent staff was able to learn from the story and improve the delivery of subsequent end-of-life care.

Discussion

Our findings of feedback sentiment support the notion that online feedback is generally positive, as sentiment leaned toward positive stories. There is also evidence that respondents to questionnaires/satisfaction scores tend to come from the extremes such as those very satisfied and those very unsatisfied.² Using AI's "Discovery" phase helped bring to light the service's positive capacity in regard to end-of-life care, in order to discover and make explicit "what works" or "what is already going well". Relatives commonly reported positively about staff professionalism, particularly in providing person-centered care and family support. Experiences of communication with healthcare providers also were described positively, highlighting the importance of building rapport, allocating adequate time to provide information and updates to patients and their families in every stage of end-of-life care. Despite this, when people felt one-or-more aspects of their loved ones care was missing, they were more likely to report negative experiences.

Although AI is a "strength-based" approach, we have highlighted negative care experiences to prevent data neglect associated with problems or concerns.

Disappointment was also expressed in relation to staffing pressure, prolonged waiting, lack of equipment, lost personal property, and visiting restrictions. These often resulted from multiple factors, for example, the COVID-19 pandemic. However, such problems should be fed back to hospitals in order to identify causes and prompt improvement.

A further finding was that despite research suggesting transparent, conversational responses are more desirable by service users,^{6,10} 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 suggests that positive stories are less likely to be utilized to improve experiences of healthcare, and that negative feedback is more likely to be used to impact the way that subsequent care is delivered.

Limitations

Similar to all research exploring the impact of technology on improving health care, users of such services are not necessarily representative of the overall population, with low-literacy, disabled and older adults, and those who have limited access to the Internet being less likely to provide online feedback.^{11,12}

Furthermore, due to the anonymity of data on Care Opinion, sociodemographic characteristics of the story authors are not known.

There are a higher number of positive posts compared to negative ones on Care Opinion^{11,12} and this was evident in our study. Therefore, there is limited data on how service users perceive suboptimal care or articulate negative experiences.

This study offers a starting place for exploration of end-of-life care experienced by families but future research with dying patients and hospital staff would enable greater understanding and potential improvements to services or care.

Conclusion

This study has provided a novel perspective of patients' experiences of end-of-life care in hospitals within NHS GGC. Novel insights were the appreciation of quality of care, staff professionalism, effective communication, and meeting patient's needs at end of life particularly by nursing staff.

Acknowledgments

The authors would like to thank the patient experience team NHS GGC, Care Opinion Scotland, and all the anonymous family members and friends who posted on Care Opinion.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Scottish Government.

Author's Contribution

All authors provided substantial contributions to the conception or design of the work, or the acquisition, analysis, or interpretation of data for the work, drafted the work or revised it critically for important intellectual content, provided final approval of the version to be published, and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Ethical Approval

Ethical approval is not applicable for this article.




Statement of Human and Animal Rights

This article does not contain any studies with human or animal subjects.

Statement of Informed Consent

There are no human subjects in this article and informed consent is not applicable.

ORCID iDs

Sahar Khonsari  <https://orcid.org/0000-0003-3342-7572>
Alistair Mckeown  <https://orcid.org/0000-0002-2198-9474>
Bridget Johnston  <https://orcid.org/0000-0003-4051-3436>

Supplemental Material

Supplemental material for this article is available online.

References

1. Locock L, Skea Z, Alexander G, Hiscox, C Laidlaw, L, Shepherd J. Anonymity, veracity and power in online patient feedback: a quantitative and qualitative analysis of staff responses to patient comments on the 'care opinion' platform in Scotland. *Digit Health*. 2020;6:2055207619899520.
2. Ofcom. Adults' Media Use and Attitudes report https://www.ofcom.org.uk/__data/assets/pdf_file/0025/217834/adults-media-use-and-attitudes-report-2020-21.pdf (2021, accessed September 18, 2021).
3. Care Opinion. Care Opinion in Scotland <https://www.careopinion.org.uk/info/care-opinion-scotland> (2021, accessed August 13, 2021).
4. van Velthoven MH, Atherton H, Powell J. A cross sectional survey of the UK public to understand use of online ratings and reviews of health services. *Patient Educ Couns*. 2018;101:9; 1690-6.
5. Cooperrider DL, Whitney D, Stavros JM. Appreciative inquiry handbook: For leaders of change. 2nd ed. Brunswick, OH: Crown Custom, 2008.
6. Trajkovski S, Schmied V, Vickers M, Jackson D. Using appreciative inquiry to transform health care. *Contemp Nurse*. 2013;45(1):95-100.
7. Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. London: Sage, 2022.
8. QSR International Pty Ltd. NVivo qualitative data analysis software, version 12. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software> (2018, accessed September 18 2021).
9. Baines R, Donovan J, de Bere S R, Archer J, Jones R. Responding effectively to adult mental health patient feedback in an online environment: a coproduced framework. *Health Expect*. 2018;21: 5 887-98.
10. Mazanderani F, Kirkpatrick SF, Ziebland S, Locock L, Powell J. Caring for care: online feedback in the context of public healthcare services. *Soc Sci Med*. 2021: September114280.
11. Ramsey LP, Sheard L, Lawton R, O'Hara, J. How do health-care staff respond to patient experience feedback online? A typology of responses published on care opinion. *Patient Experience Journal*. 2019;6:2; 42-50.
12. Hanna E, Robert G. Understanding amputation care in England and Scotland: a qualitative exploration of patient stories posted on an online patient feedback site. *Disabil Rehabil*. 2021:1-9.
13. Care Opinion. Patient-centred quality improvement in palliative and end of life care: learning from online feedback using Care Opinion, <https://www.careopinion.org.uk/blogposts/598/care-opinion-in-palliative-and-end-of-life-ca> (2017, accessed November 5, 2021).
14. Sheard L, Peacock R, Marsh C, Lawton R. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study. *Health Expect*. 2019;22:46-53.

Appendix
Appendix I. Inclusion/Exclusion Criteria
Form

meets all inclusion criteria and does NOT meet the exclusion criterion.

Instructions: Answer each question by checking the box on the right marked “Yes” or “No”. A story/post is eligible if it

No.	Inclusion Criteria	Check one	Comment	Initials and Date
1	Story posted on Care Opinion Scotland between March 2019 and March 2020 and April 2020 and March 2021.	<input type="radio"/> Yes <input type="radio"/> No		
2	Story discusses the treatment or diagnosis of a life-limiting condition and/ or end-of-life care experience.	<input type="radio"/> Yes <input type="radio"/> No		
3	Story is relevant to end-of-life care provided in acute hospitals across NHS Greater Glasgow and Clyde.	<input type="radio"/> Yes <input type="radio"/> No		
4	The content is relevant and useful and not only related to GP surgery or nonhospital services.	<input type="radio"/> Yes <input type="radio"/> No		