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A case-controlled study of relatives' complaints

concerning patients who died in hospital: the role of treatment

escalation / limitation planning

ABSTRACT

BACKGROUND   Patient complaints are an important resource for informing quality improvement strategies. Complaints about quality of care at end-of-life have not been independently assessed in a controlled study.

Treatment Escalation and Limitation Plans (TELPs) have previously been shown to reduce non-beneficial interventions and harms. Their role in influencing patient complaints is unknown.

OBJECTIVES   To independently assess quality of care among patients who died in hospital and whose next-of-kin submitted a letter of complaint, and make comparisons with matched controls. To identify whether use of a TELP affected the principal outcomes.

DESIGN   The study was an investigator-blinded retrospective case-note review of 42 complaints cases and 72 controls matched for age, sex, ward location and time of death.

OUTCOME MEASURES   Quality of care: Clinical 'problems', non-beneficial interventions (NBIs) and harms using the Structured Judgment Review Method. Complaints were categorised using the Healthcare Complaints Analysis Tool.

RESULTS   The event frequencies and rate ratios for clinical 'problems', NBIs, and harms were consistently higher in complaints cases compared to controls. The difference was only significant for NBIs (p=0.05). TELPs were used less frequently in complaints cases (23.8% versus 47.2%, p=0.013). The relationship between TELP use and the three key clinical outcomes was non-significant.

CONCLUSIONS Care delivered to patients at end-of-life whose next-of-kin submitted a complaint was poorer than among control patients when assessed independently by blinded

reviewers. Regular use of a TELP in acute clinical settings has the potential to influence complaints relating to end-of-life care but this requires further prospective study.

KEY WORDS   patient complaints, quality of care, end-of-life care, treatment escalation and limitation plan

RUNNING HEAD   Complaints about end-of-life care

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INTRODUCTION

Providing services that meet standards for quality and safety is a daily necessity for all healthcare professionals. It involves monitoring and assessment, accountability, and strategies for improvement. This approach focuses largely on technical and management aspects of service provision. However, to complement this, patients' experiences of the healthcare system provide information that may be used as a platform for quality improvement [1]. Unsolicited complaints are an important source of feedback [2,3]. Most institutions have established mechanisms for responding to individual complaints but are less equipped to translate the lessons learned into changes in practice [4].

For patients who are at the end of life, quality of care assumes a significance that is probably greater than at any other time, not just for the patient but also for immediate family members. For professionals involved in the care of dying patients, there is "one chance to get it right" [5]. Patients at the end of life are more vulnerable to the impact of errors and harms. Family members are also understandably sensitised to their dying relative's interests at a time when they are likely to be in the first stages of bereavement and for that reason emotionally vulnerable. This may alter both the threshold as well as the motivation for complaints submitted after a patient's death in hospital. These factors confer particular importance on the response that is made to receiving and processing complaints [6,7], even though only a small minority of relatives are dissatisfied with the care of a patient who has died [8].

One of the challenges is that, allegedly, there is poor correlation between issues deemed to be unsatisfactory by family members and lapses or errors in treatment and care identified by clinical staff and risk managers [9,10]. Clinicians tend to focus on adverse incidents

whereas patients and carers tend to report problems in the sequence of care and in communication. Sadly, this may mean that improvement strategies address technical deficiencies but without improving quality from a patient's perspective. Further, despite complaints, clinicians in particular can remain insensitive to those aspects of care that were of greatest significance to the next-of-kin of a dying patient - often characterised by personal attitudes that include disrespect [11-13].

When *simultaneous* comparisons are made, patient-reported service deficiencies may coincide with those that are identified by professional staff. In one study, poor co-ordination of care reported by patients was associated with a significantly increased frequency of adverse events and medical errors [9]. However, as far as we are aware, no systematic comparisons have been reported between the nature of families' complaints and independently assessed quality of care provided to patients who have died in the acute hospital setting. One of the principal aims of our study was to investigate this relationship and to explore whether or not there is discordance between the substance of next-of-kin complaints and the standards of care that patients actually receive.

In 2015 we introduced the use of a Treatment Escalation Limitation Plan (TELP) to the three district general hospitals in our region. The use of a TELP has previously been shown to reduce non-beneficial treatment and harms [14,15]. Against a background of increasing complexity in medical treatment and its delivery, using a TELP may facilitate improved communication about treatment decisions and reduce discontinuity of care. These are significant contributors to errors in treatment as well as patient dissatisfaction [16,17]. Thus, the use of a TELP may be particularly relevant to the experience of dying patients and their next-of-kin.

HYPOTHESES

The study hypotheses were: first, that there would be a significantly greater frequency of independently measured clinical 'problems', non-beneficial interventions (NBIs) and harms among patients who died in hospital and whose next-of-kin subsequently submitted a letter of complaint, compared to controls; second, that any difference would be influenced by having a TELP.

AIMS

The aims of this study were:

1. To categorise the complaints received by our Patient Affairs Department from the next-of-kin of recently deceased patients.

2. To quantify the clinical 'problems', NBIs and harms during patients' last hospital admission before death and for whom a complaint was submitted, and to compare the frequency of these outcomes with those in matched controls.

3. To assess whether there was any relationship between clinical 'problems', NBIs and harms and the nature of the complaints made by patients' next of kin.

4. To identify whether the use of a TELP during a patient's final illness was associated with the frequency of subsequent complaints.

METHODS

The study was a retrospective, blinded, matched case-control study. It involved a structured review of clinical treatment and harms in patients who died in hospital, and comparisons were made between these outcomes in patients whose next-of-kin submitted a letter of

complaint concerning their in-hospital care, and among patients for whom no complaint was received.

Index cases

Cases were consecutive patients who died in the three district general hospitals in NHS Lanarkshire (University Hospital Hairmyres, University Hospital Monklands and University Hospital Wishaw) between January 2015 and December 2017, and whose next-of-kin submitted a letter of complaint to the NHS Lanarkshire Patient Affairs Department after their death.

Controls

For each index case, two controls were selected by the Data Management service. These were patients who had also died in hospital, matched for age (to within 10 years), sex, hospital ward location and time of death (within one month of cases) but for whom there was no complaint.

Assessment of whether a death was 'expected'

The principal investigator first assessed whether each patient's death was 'expected' or 'unexpected' using a modification of the Gold Standard Framework (GSF) Pro-active Identification Guidance (PIG) [18]. The PIG is based on the General Medical Council (UK) 2010 definition of patients "likely to die within the next 12 months" [19]. GSF criteria were used to identify an 'expected' death (see Table 1). However, only two of the three recommended triggers were used: the "Surprise Question" was considered inappropriate in a retrospective mortality case-note review.

Treatment Escalation / Limitation Plans and DNACPR

Whether each case / control had a TELP [14] and/or a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order was recorded.

An example of the TELP used in NHS Lanarkshire hospitals (known locally as the Hospital Anticipatory Care Plan) is provided in Appendix 1. The TELP was introduced incrementally in the acute medical, surgical, Intensive Care and Care of the Elderly units in NHS Lanarkshire hospitals in 2015. Training and education included a training video and one-to-one coaching sessions to all relevant consultants on the topics of futility, medical harms and prognostic conversations as well as how to use the TELP. Each TELP *pro forma* includes comprehensive guidance regarding ethical and medico-legal obligations for its use.

Assessment of clinical 'problems', non-beneficial treatments (NBIs) and harms.

For each index case and control, hospital notes were reviewed by the investigators (DRT and CJL) using the Structured Judgment Review Method (SJRM) [20,21]. This methodology provides a template of 8 domains for which clinical 'problems' i.e. issues regarding standards of care, non-beneficial treatments (domains 1 to 3 only) and harms are identified. The case notes were provided by the NHS Lanarkshire Data Management service. The investigators were not permitted by the Data Management service to know whether the notes were obtained from a complaint case or a control subject.

In the reviews, a clinical 'problem' was defined as any aspect of the patient's care where there was the potential to have an adverse effect on patient safety. 'Non-beneficial intervention' was defined as a treatment undertaken or continued with the intention of stabilising or reversing the patient's clinical status but failing to do so. This did not include comfort measures. A 'harm' was defined as an identifiable event resulting from treatment

overuse or underuse, or where the potential benefits of an intervention were significantly outweighed by detriment.

The principal investigator (DRT) undertook reviews for all cases and controls. Independently, a second investigator (CJL) undertook duplicate reviews for 20% of all cases. These were randomly selected. Kappa scores for inter-rater agreement were calculated. Both clinicians had previous experience with mortality case-note reviews [14].

Complaint letter evaluation

After completion of all case-note reviews and only after the database had been sealed, copies of the original complaints letters were made available to the investigators. These were evaluated using the Healthcare Complaints Analysis Tool [22,23]. Using this instrument, each complaint was coded as to its principal category (clinical, management, relationships) and two subcategories (see Table 3).

Statistical analysis

The study outcomes were clinical 'problems', NBIs and harms as defined using the SJRM. Analyses were undertaken to determine whether there was a statistically significant difference at a 95% confidence level in the rates for these three outcome measures between the study group and the control group. Chi-squared tests were used to test differences in proportions. Models were fitted using Poisson regression to test the difference in rates. The output of this model was the Incidence Rate Ratio (IRR) between the cases and controls. The models were fitted both with and without adjustment for age at death. Time (days) between admission and death was used as an offset in both adjusted and unadjusted models.

Ethics

The study comprised a retrospective case note review and based on Health Research Authority criteria, formal Ethics Committee approval was not required. However, all institutional requirements for personal data protection were observed. All patient records were anonymised. No information regarding the processing or investigation of any of the complaints or their outcomes was made available to the investigators, and there was no contact between the investigators and the complainant or the hospital staff / ward concerning whom complaints may have been directed.

RESULTS

From 2015 to 2017 inclusive, 59 complaints (23, 21 and 15 in each successive year) were received by the NHS Lanarkshire Patient Affairs Department. The overall rate of complaints was 0.7% i.e. 59 from 8385 patients. Of these, 17 were excluded from the analysis: 1 because the original complaint letter was missing; 9 because hospital notes were not available; 6 because it was not possible to obtain adequately matched controls; and 1 because hospital notes were not available for both of the matched controls. For 12 of the index cases, only 1 matched control could be obtained. Thus, data from 42 cases and 72 controls were analysed.

The demographic details are shown in Table 2. The length of stay was shorter among cases compared to controls (11.8 versus 15.5 days) but this was not statistically significant (p=0.25).

Complaints classification

The nature of complaints using the Healthcare Complaints Analysis tool [21,22] is shown in

Table 3. Although there were 42 index cases, complaint letters often included more than one relevant issue. Thus, the total number of items in each category and sub-category (total = 69) exceeded the total number of index cases. The number of complaint letters which cited 1, 2, and 3 or more different categories of complaint was 21, 14 and 7 respectively.

Fifty five percent (55.1%) of complaint items were related to quality and safety issues, 40.6% to relationship issues categorised as lack of humane-ness and caring, and only 4.3% to management issues.

Clinical 'problems', non-beneficial interventions and harms

The frequencies and rates of clinical 'problems', NBIs and harms are shown in Table 4. In each instance, the event rates (expressed as "per 100 admissions" and as "per 1000 bed days" to take account of the length of stay of each patient and hence exposure to possible adverse events) were numerically higher among cases than controls. However, between-group differences were only statistically significant at the 95% level for the number of patients who had at least one harm (greater in cases compared to controls, p=0.04) and for the rate ratio for NBIs (p=0.05, adjusted for age and 'expected death').

The event rates for clinical 'problems', NBIs and harms expressed per 1000 bed days for the eight individual domains of the SJRM template are shown in Table 5. It was not considered appropriate to analyse these data statistically given the small number of events. There was no evidence of correlation between the events rates and the frequency of complaints per index case.

The kappa score for inter-rater agreement concerning SJRM outcome measures was 0.74 (95% confidence interval: 0.67 – 0.81).

Use of DNACPR and TELPs

DNACPR orders were used in 73.8% of cases compared to 87.5% of controls (p=0.06). Similarly, TELPs were used significantly less frequently in cases (23.8%) compared to controls (47.2%, p=0.013). The incident rate ratios were not significantly different between complaints cases who did or did not have a TELP.

DISCUSSION

As far as we are aware, this is the first study to compare the clinical care received by patients whose immediate next-of-kin submitted a complaint following their death, with the care received by matched controls. This was assessed by independent case-note review using the Structure Judgment Review Method [20,21]. Importantly, the investigators were blinded as to whether the hospital notes were obtained from cases or controls. This enabled independent systematic assessment to be carried out and this showed that the overall quality of care was poorer in complaints cases compared to controls. Even although statistical significance was not reached for some of the outcome measures, the pattern for rates of clinical 'problems', NBIs and harms was a consistent one: the rates were higher among cases than controls.

Our findings help to dispel the view that complaints submitted in the context of bereavement might be motivated by emotionally-charged perspectives on the part of next-of-kin that lack objectivity [10,24]. Although this may be the case in a few instances, our results indicate that in general, complaints arose against a background of clinical care that was objectively less satisfactory than for other carefully matched patients. This contrasts with other reports [13,25].

In our study there was no consistent picture as to the nature of the background issues. The event rates for individual SJRM domains (Table 5) did not identify any dominant theme except for 'clinical monitoring' for which reviewers found that events occurred only among complaints cases. This may point to the possibility that lack of staff-patient contact - for whatever reason - was an underlying contributor to dissatisfaction among cases' family members.

The secondary hypothesis for our study was that the frequency of complaints in relation to a patient's last illness would be associated with differences in use of a TELP. The NHS Lanarkshire TELP (see Appendix 1) was introduced in 2015 and training and education regarding its use continued across all three NHSL hospitals during 2015-7, corresponding to the period during which complaints were submitted. In an earlier study we have reported that using the TELP is associated with a 2-3 fold reduction in 'problems', NBIs and most importantly, harms [14]. The mechanisms whereby a TELP programme results in reduced adverse outcomes are unclear. The TELP is a communication tool. However, it was anchored in substantial training and education that was designed to encourage prognostic conversations and shared decision-making with patients and families, as well as improved communication and reduced discontinuity of care among staff, especially out-of-hours [26]. In the present study we found that the TELP was used significantly less frequently among complaints cases compared to controls (23.8% versus 47.2%, p=0.013). However, there was no significant effect on the rates of 'problems', NBIs, or harms: study numbers were insufficient to test this hypothesis adequately. Whether use of a TELP mitigates dissatisfaction and formal complaints on the part of patients or their next-of-kin requires further study.

Contrary to our expectations, the complaints were not dominated by those categorised under the heading 'relationships problems' i.e. pertaining to communication and humaneness, staff attitudes and behaviours (Table 3). This is in contrast to what has been reported elsewhere [27]. Rather, issues related to quality and safety, including errors in diagnosis and treatment occurred as frequently. This pattern may possibly reflect the inadequacies of a structured methodology for classification of complaints [28]. However, it also highlights the importance of undertaking formal assessment because more robust information may then be used to direct how complaints are handled not just individually, but in terms of institutional processes. Depending on the emphasis, there is obviously a difference between giving priority to communication skills training and addressing systemic deficiencies in care delivery.

It may be that the number of complaints about treatment that we observed reflects another underlying issue. In the context of providing treatment for dying patients, on the one hand rigid adherence to treatment protocols by on-call hospital staff may be inappropriate [29], and on the other, family members' expectations about the potential for treatment to achieve recovery may be just as inappropriate. Separately or together the "fix it or fail" approach by either party has the potential to generate disagreement and dissatisfaction. This emphasises the importance of having appropriate and mutually agreed goals of care when managing patients at the end of life [29].

Our study has important strengths, notably the study design. Each case had at least one matched control. In addition, case-note evaluation was undertaken by investigators who were blinded to group allocation and this task was completed before the letters of

complaint were made available and categorised by the investigators. This enabled an unbiased assessment of both cases and controls. The chief weaknesses of the study were firstly, that the number of cases was smaller than we would have liked, in part due to the rigour with which selection criteria for controls were applied. In addition, the majority of case note reviews were undertaken by only one investigator, although the kappa score for inter-rater reliability for those that were reviewed by two investigators was satisfactory, and similar to what we obtained in a previous study with four reviewers using the same assessment tool. Ideally the study would have been better resourced with multiple reviewers for each case [30,31].

In conclusion, our study identified a meaningful relationship between complaints about care delivered to patients at the end of life and deficiencies identified by independent assessment of that care. Our findings suggest that in addition to addressing complaint items individually as is currently widely practised [32], the institutional response to complaints might benefit if complaints cases were routinely assessed by an independent reviewer who is blinded to the nature of the complaint and whose review employs a validated tool (in this case the SJRM). This would permit obtaining objective data more systematically. In turn, this would potentially mean that systemic quality improvement issues are more likely to be identified and addressed [23,24,32-34]. Finally, as part of a complaints reduction strategy, the regular use of a TELP in acute medical and surgical settings may provide positive benefits, but this needs further prospective study.

REFERENCES

1. Entwhistle V., Firnigl D., Ryan M., Francis J., Kinghorn P. Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map. J. Health Service Res. and Policy. 2012; 17: 70-78.

   doi.org/10.1258/jhsrp.2011.011029

2. Pichert J., Hickson G., Moore I. Using patient complaints to promote patient safety. In: Advances in Patient Safety: New Directions and Alternative Approaches. Eds: Henriksen K., Battles J.B., Keyes M.A., Grady M.L. Rockville, MD. Agency for Healthcare Research and Quality (US). 2008.

3. Gillespie A., Reader T. Patient-centred insights: using health care complaints to reveal hot spots and blind spots in quality and safety. Millbank Quarterly. 2018; 96: 530-567. doi: 10.1111/1468-0009.12338

4. Gallagher T.H., Mazor K.M. Taking complaints seriously: using the patient safety lens BMJ Qual. Saf. 2015; 24: 352–355. doi: 10.1136/bmjqs-2015-004337.

5. Sykes N. One Chance to Get it Right: understanding the new guidance for care of the dying person. British Medical Bulletin, 2015, 115: 143–150 doi: 10.1093/bmb/ldv030

6. Mayland C.R., Mulholland H., Gambles M., Ellershaw J., Stewart K. How well do we currently care for our dying patients in acute hospitals: the views of the bereaved relatives? BMJ Support Palliat Care. 2017; 7: 316-325. doi: 10.1136/bmjspcare-2014-000810.

7. Liu J.J., Rotteau L., Bell C.M., Shojania K.G. Putting out fires: a qualitative study exploring the use of patient complaints to drive improvement at three academic hospitals. BMJ Qual Saf. 2019 May 23. doi: 10.1136/bmjqs-2018-008801

8. Nolen-Hoeksema S., Larson J., Bishop M. Predictors of family members' satisfaction with hospice. Hospice Journal - Physical, Psychosocial, & Pastoral Care of the Dying. 2000; 15: 29-48.

9. Christiaans-Dingelhoff I., Smits M., Zwaan L., Lubberding S., van der Wal G., Wagner C. To what extent are adverse events found in patient records reported by patients and healthcare professionals via complaints, claims and incident reports? BMC Health Serv. Res. 2011; 11: 49. doi: 10.1186/1472-6963-11-49.

10. Taylor B.B., Marcantonio E.R., Pagovich O., Carbo A., Bergmann M., Davis R.B., Bates D.W., Phillips R.S., Weingart S.N. Do medical inpatients who report poor service quality experience more adverse events and medical errors? Med Care. 2008; 46: 224-8. doi: 10.1097/MLR.0b013e3181589ba4.

11. Wofford M.M., Wofford J.L., Bothra J., Kendrick B., Smith A., Lichstein P.R. Patient complaints about physician behaviors: a qualitative study. Acad. Med. 2004; 79: 134-8.

12. Sokkol-Hessner L., Folcalelli P.H., Sands K.E.F. Emotional harm from disrespect: the neglected preventable harm. BMJ Qual. Saf. 2015; 24: 550-553. doi: 10.1136/bmjqs-2015-004034.

13. van Mook W.N., Gorter S.L., Kieboom W., Castermans M.G., de Feijter J., de Grave W.S., Zwaveling J.H., Schuwirth L.W., van der Vleuten C.P. Poor professionalism identified through investigation of unsolicited healthcare complaints. Postgrad Med J. 2012; 88: 443-50. doi: 10.1136/postgradmedj-2011-130083.

14. Lightbody CJ, Campbell JN, Herbison GP, et al. Impact of a treatment escalation/limitation plan on non-beneficial interventions and harms in patients

during their last admission before in-hospital death, using the Structured Judgment Review Method. BMJ Open 2018; 8: e024264. doi: 10.1136/bmjopen-2018-024264.

15. Fritz Z, Fuld JP. Development of the Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a cross-disciplinary approach. J. Eval. Clin. Pract. 2015; 21: 109-117. doi:10.1111/jep.12256 pmid:25393809.

16. Haggerty J.L., Reid R.J., Freeman G.K., Starfield B.H., Adair C.E., McKendry R. Continuity of care: a multidisciplinary review. BMJ 2003; 327:1219-21.

17. Cook R.I., Render M., Woods D.D. Gaps in the continuity of care and progress on patient safety. BMJ 2000; 320: 791-794.

18. Thomas K., Wilson J.A. Gold Standards Framework: Prognostic Indicator Guidance for clinicians to support earlier recognition of patients nearing the end of life. 2016. https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf Accessed October 2019.

19. General Medical Council. Treatment and care towards the end of life: good practice in decision making. 2010. www.gmc-uk.org/guidance. Accessed October 2019.

20. National Mortality Case Record Review Programme (resources). The Structured Judgement Review Method from the Royal College of Physicians, London. 2016. https://www.rcplondon.ac.uk/projects/outputs/national-mortality-case-record-review-nmcrr-programme-resources.

Downloads/SJR_science%20background_2018%20(1).pdf. Accessed October 2019.

21. Hutchinson A., Coster J.E., Cooper K.L., Pearson M., McIntosh A., Bath P.A. A structured judgement method to enhance mortality case note review: development and evaluation. BMJ Quality and Safety 2013. doi:10.1136/bmjqs-2013-001839.

22. Reader T.W., Gillespie A., Roberts J., Patient complaints in healthcare systems: a systematic review and coding taxonomy. BMJ Quality & Safety 2014; 23: 678-689. doi:10.1136/bmjqs-2013-002437

23. Harrison R., Walton M., Healy J., Smith-Merry J., Hobbs C. Patient complaints about hospital services: applying a complaint taxonomy to analyse and respond to complaints. Int. J. Qual. Health Care 2016; 28: 240–245. doi.org/10.1093/intqhc/mzw003.

24. Fisher K.A., Mazor K.M. Patient and family complaints in cancer care: what can we learn from the tip of iceberg? Jt. Comm. J. Qual. Patient Saf. 2017; 43: 495-7. doi.org/10.1016/j.jcjq.2017.07.003

25. Greaves F., Laverty A., Millett C. Friends and family test results only moderately associated wit conventional measures of hospital quality. BMJ 2013; 347: f4986. doi: 10.1136/bmj.f4986

26. Haggerty J.L., Reid R.J., Freeman G.K., Starfield B.H., Adair E., McKendry R. Continuity of care: a multidisciplinary review. BMJ 2003; 327: 1219-1221.

27. Hogg R; Hanley J; Smith P. Learning lessons from the analysis of patient complaints relating to staff attitudes, behaviour and communication using the concept of emotional labour. J. Clin. Nursing. 2018; 27: e1004-e1012. doi: 10.1111/jocn.14121

28. De Vos, M.S., Hamming J.F., Marang-van de Mheen P.J. The problem with using patient complaints for improvement. BMJ Qual. Saf. 2018; 27: 758–762. doi:10.1136/ bmjqs-2017-007463

29. Taylor D.R., Lightbody C.J. Futility and appropriateness: challenging words, important concepts. Postgrad Med J. 2018; 94: 238-243. doi: 10.1136/postgradmedj-2018-135581

30. Localio R.A., Weaver S.L., Landis R., Lawthers A.G., Brenhan T.A., Hebert L., Sharp T.J. Identifying adverse events caused by medical care: degree of physician agreement in a retrospective chart review. Ann Intern Med 1996; 125: 457 e64. 11.

31. Hutchinson A., Coster J.E., Cooper K.L.,McIntosh A., Walters S.J., Bath P.A., Pearson M., Young T.A., Rantell K., Campbell M.J, Ratcliffe J. Comparison of case note review methods for evaluating quality and safety in health care. Health Technology Assessment (Winchester, England). 14(10): iii-iv, ix-x, 1-144, 2010.

32. Anderson K., Allan D., Finucane P. Complaints concerning the hospital care of elderly patients: a 12-month study of one hospital's experience. Age and Ageing 2000; 29: 409-412. doi.org/10.1093/ageing/29.5.409

33. Mack J.W., Jacobson J., Frank D., Cronin A.M., Horvath K., Allen V., Wind J., Schrag D. Evaluation of patient and family outpatient complaints as a strategy to prioritize effort to improve cancer care delivery Jt. Comm. J. Qual. Patient Saf. 2017; 43: 498-507. doi: 10.1016/j.jcjq.2017.04.008

34. Flott K.M., Graham C., Darzi A., Mayer E. Can we use patient-reported feedback to drive change? BMJ Qual. Saf. 2017; 26: 502-7. doi: 10.1136/bmjqs-2016-005223

TABLE 1 Gold Standards Framework Pro-active Identification Guidance [see ref 18].

Gold Standards Framework prognostic indicators for an 'expected' death	- acute life-threatening conditions presenting as sudden catastrophic events (death likely within a few hours or days). - advanced, progressive, incurable conditions that suggest a life-expectancy of 12 months or less. - general frailty with or without declining performance status that suggest a life-expectancy of 12 months or less. - existing conditions that confer an increased risk of dying from acute deterioration in their health.
Triggers	- The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'? (This trigger was not used in the context of a retrospective review). - General indicators of decline – deterioration, increasing need or choice for no further active care. - Specific indicators related to principal medical diagnoses (outlined in the Guidance document).

TABLE 2. Demographic data for cases and controls

	Cases (n=42)	Controls (n=72)
Age in years (mean, range)	75.4 (56-92)	77.0 (51-95)
Sex (male/female)	26/16 (62% male)	44/28 (61% male)
Gold Standards Framework: "expected death"	Yes = 76%	Yes = 75%
Length of stay in days (mean, median, (range))	11.8 6 (1-78)	15.5 10 (1-88)
Location		
Medical wards	36 (86%)	66 (92%)
Surgical wards	5 (12%)	5 (7%)
Other	1 (2%)	1 (1%)
Advance Plans		
DNACPR	31 (73.8%)	63 (87.5%)
Treatment Escalation / Limitation Plan	10 (23.8%)	34 (47.2%)

TABLE 3. Categorisation of complaints submitted by next of kin to NHS Lanarkshire Patient Affairs Department for 42 patients who died between January 2015 and December 2017 using the Healthcare Complaints Analysis Tool [22,23]. The total numbers in Sub-categories 1 and 2 are greater than for the Principal Category, and the total number in Principal Category adds up to more than 42 because more than one item of complaint was submitted per Principal Category.

Principal category	n	Sub-category 1	n	Sub-category 2	n
Clinical problems	33	Quality	26	Examination	1
				Patient journey	10
				Quality of care	7
				Treatment	9
		Safety	11	Errors in diagnosis	4
				Medication errors	2
				Safety	3
				Skills and conduct	2
Management problems	3	Institutional issues	0	Bureaucracy	0
				Environment	0
				Finance and billing	0
				Service issues	0
				Staffing and resources	0
		Timing and access	3	Access and admission	0
				Delays in investigation / treatment	3
Relationships Problems	21	Communication	10	Communication breakdown	4
				Incorrect or conflicting information	2
				Patient staff dialogue	5
		Humane-ness / caring	14	Respect, dignity and caring	6
				Staff attitudes	9
		Patient rights	2	Abuse	1
				Confidentiality	0
				Consent	1
				Discrimination	0

TABLE 4. Frequency of clinical 'problems', NBIs and harms in cases and controls using an adaptation of the Structured Judgment Review Method [19,20]. CI = 95% confidence intervals. IRR = incidence rate ratio for each outcome where controls have a reference value of 1.00. *unadjusted for sex, age, and "expected" death based on Gold Standards Framework criteria, [18]. Whereas clinical 'problems' were identified in each of the 8 domains outlined in the SJRM, NBIs were obtained from domains 1 to 3 (Assessment, investigation or diagnosis; Medication / IV fluids / electrolytes / oxygen; Treatment and management plan).

	Clinical 'problems'		NBIs		Harms	
	Cases	Controls	Cases	Controls	Cases	Controls
Patients (n)	42	72	42	72	42	72
Number of patients with at least one event (n)	36	51	20	27	27	32
Proportion of patients with at least one event	0.86	0.71	0.48	0.38	0.64	0.44
	p=0.07		p=0.29		p=0.04	
Events (n)	67	99	23	34	38	44
Rate per 100 admissions	160	138	55	47	90	61
	IRR 1.2 (95% CI: 0.85-1.59, p=0.35)		IRR 1.2 (95% CI: 0.70-2.00, p=0.59)		IRR 1.5 (95% CI: 0.96-2.30, p=0.07)	
Rate per 1,000 bed days	345	192	139	56	185	98
	IRR 5.3 (95% CI: 0.6-46.6, p=0.13) *IRR 3.4 (95% CI 0.5-21.7, p=0.20)		IRR 30.0 (95% CI: 0.9-957.8, p=0.05) *IRR 9.5 (95% CI 0.7-135.9, p=0.1)		IRR 5.0 (95% CI: 0.4-71.2, p=0.23) *IRR 3.2 (95% CI 0.3-32.6, p=0.32)	

TABLE 5. The rates of clinical 'problems', non-beneficial interventions (NBIs) sand harms expressed per 1000 bed days for individual domains in the Structured Judgment Review Method template [20,21]. The data were not statistically analysed.

Structured Judgment Review Method domains		Rate per 1,000 bed days					
		Clinical 'problems'		NBIs		Harms	
		Cases	Controls	Cases	Controls	Cases	Controls
1	Assessment, investigation or diagnosis	29	42	2	4	12	1
2	Medication, intravenous fluids, electrolytes, oxygen	70	49	61	38	11	27
3	Treatment and management plan	83	40	76	15	35	23
4	Palliative of end of life care	55	35	-	-	10	26
5	Operation, invasive procedure	16	11	-	-	2	7
6	Clinical monitoring	21	0	-	-	1	0
7	Resuscitation following a cardiac or respiratory arrest	49	13	-	-	43	13
8	Other	21	1	-	-	19	0