Unexpected deaths in cardiology outpatients – what can we learn from case review?

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Summary

Objectives: A proportion of cardiac patients managed at a cardiology outpatient clinic will die between clinic visits. This study aimed to identify the cause of death, to determine if case review occurred and if a formal review of such cases might be useful.

Design: Single-centre retrospective cohort study.

Setting: A remote regional centre in the North of Scotland.

Participants: All patients who had been removed from the cardiology outpatient clinic due to death in the community.

Main outcome measures: Cause of death, comorbidities and treatments were collected from hospital records and the national register of deaths. Chi-squared test and Student’s t-test were used with significance taken at the 5% level.

Results: Of 10,606 patients who attended the cardiology outpatient clinic, 75 (0.7%) patients died in the community. The majority (57.0%) died from a non-cardiac cause. Eleven patients (14.9%) died due to an unexpected cardiac death. A detailed case note review was undertaken. In only two (18.2%) cases was any note made as to the cause of death in the hospital records and in only one was there details of post mortem discussion between primary and secondary care.

Conclusions: A small proportion of patients attending a cardiology outpatient clinic died in the community. Documentation of the death in the hospital notes was very poor and evidence of post mortem communication between primary and secondary care was absent in all but one case. Better documentation and communication between primary and secondary care would seem desirable.

Keywords

Death, outpatients, cardiology, primary care, secondary care, communication

Introduction

Cardiovascular disease remains a leading cause of mortality worldwide. Despite recent improvements in outcomes, coronary heart disease remains the most common cause of death in the UK with Scotland and Northern Ireland having the highest mortality rates from coronary heart disease with 200/100,000 in men and 100/100,000 in women.\(^1\)

Coronary heart disease is also the leading cause of premature death (death under 75 years) with rates of 16% in males and 10% in females.\(^1\)

While several cardiac treatments confer mortality benefits,\(^2\)–\(^5\) optimisation of treatments is not always achieved.\(^6\) In the UK, cardiac patients may be managed solely in primary care or shared care between general practitioners and cardiologists with interval review in hospital outpatient clinic. Once a patient’s condition is treated, or if care is deemed terminal, then usual practice would be for patients to be discharged back to the sole care of the general practitioner. Therefore, while cardiac disease is a leading cause of death it would not be expected that a high proportion of those under active review within the cardiology outpatient setting would die. However, the frequency and cause of death in the cardiology outpatient population is unknown.

Furthermore, while primary care will routinely be informed of a patient’s death in hospital, the converse is not always true. Thus, cardiologists are often unaware of the death of their (out) patients and it is unknown if review of such cases would be useful. Many studies have reported the suboptimal communication between primary care and secondary care.\(^7\)

For patients who frequently transit the primary–
secondary care interface, such as those with chronic conditions, communication and coordination between the different disciplines are essential for the delivery of quality care. Effective communication across the interface is important not only in this regard but also to minimise risk to patient safety. Communication problems at the interface have elsewhere been noted to cause fragmentation of patient care.

Presently, in the UK, there is no system in place for general practitioners to easily update secondary care on changes in a patient’s condition including death. Consultants are often only notified of their patient’s death when they stop attending clinic appointments, or not at all. This would seem to be an obvious area where improved communication between primary and secondary care might be advantageous.

Therefore, the aim of this study was to identify the cause of death in patients under ongoing review in a cardiology outpatient clinic. Secondary aims were to determine if discussion occurred between primary and secondary care about these cases and if systematic formal review of such cases might be useful.

Methods

Study design and setting

This was a single-centre retrospective case review of patients who had attended a general cardiology outpatient clinic at a rural regional centre in the north of Scotland. This clinic provides outpatient cardiac services for a dispersed population of over 250,000.

Patient identification

The study included all patients who had been removed by administrative staff from the cardiology outpatient clinic list due to death between 22 November 2010 and 15 November 2012.

Data collection

Information regarding clinic attendance was gained from the hospital administration system including the names of patients removed from the list due to death. Further data collected from hospital records included date of birth, diagnosis, list of medications, co-morbidities and if available, the cause, date and place of death. The official cause and location of death were sourced from the Scotland’s People database accessed at the Highland Archives Centre. This public access database provides various types of information about people’s heritage; date of births, deaths and marriage.

Data handling

The cause of death was ascertained for each patient. Patients were then divided into those that died from a cardiac event and those that died from a non-cardiac event. The patients within the cardiac group were further separated into those with existing life-limiting conditions (defined by the clinical team, e.g. such as severe heart failure due to left ventricular systolic impairment or moderate–severe valvular disease) and non-life-limiting conditions in an attempt to define ‘expected’ versus ‘unexpected’ deaths. The hospital notes were reviewed to see if the cause of death was documented or if any communication between care settings had taken place.

Data processing and analysis

Categorical and numerical data were both collected in Excel (Microsoft v13). Means, standard deviation and percentages were calculated as appropriate. Categorical data were assessed by Chi-square test and continuous data using Student’s t-test where appropriate using an online statistical package. Significance was taken at the 5% level.

Ethical approval

As this was a case-based review of a clinical service and due to the nature and design of the study, there was no contact with patients nor randomisation and thus formal ethical review was not necessary according to the National Patient Safety Agency National Research Ethics Guidelines for defining research. The permission of the local Caldecott guardian was obtained prior to handling the data.

Results

Outpatient death rates and causes of death

During the study period, 10,606 outpatients (6294 male and 4312 female) attended the cardiology outpatient clinic. During this time, 75 patients (0.7%) died while waiting for review. There was a non-significant trend towards a greater proportion of men who died than women (54/6294 (0.9%) men vs. 21/4312 (0.5%) women; \( p = 0.51 \)).

The mean age of the outpatients who died was 74.9 ± 8.7 years. There was no difference in the age of male or female patients (74.7 ± 8.9 vs. 75.4 ± 8.3 years; \( p = 0.37 \)). The number of deaths and proportion of those who died based on gender and age are shown in Figure 1. As expected, older patients were more likely to die compared with younger patients by a factor of 10.
One patient was excluded from further analysis as the clinical notes were missing. Of the 74 remaining outpatient deaths, 32 (43.0%) died from a cardiac cause and 42 (57.0%) died from a non-cardiac cause. The cause of death reported on the death certificate is shown in Table 1. As expected, there were differences in the mode of death between those deemed to have a life-limiting versus non-life-limiting cardiac condition (Table 2).

### Table 1. Cause of death as reported on death certificate.

| Cause of death (n = 74)     | n (%) |
|-----------------------------|-------|
| Myocardial infarction       | 18 (24.0) |
| Cancer                      | 15 (20.0) |
| Heart failure               | 11 (14.7) |
| Respiratory causes\(^a\)    | 9 (12.0) |
| Stroke                      | 5 (6.7) |
| Sepsis                      | 4 (5.3) |
| Other\(^b\)                 | 12 (16.2) |

\(^a\)Respiratory causes included chronic obstructive pulmonary disease and pulmonary emboli.
\(^b\)Other group included gastrointestinal disease, accidental injury, suicide and renal failure.

Case file review of unexpected cardiac deaths

For the purposes of this study, the patient group of most interest were those with a non-life-limiting cardiac condition who died from a cardiac cause, i.e. an unexpected cardiac death. Of the 74 deaths, 11 (14.9%) were unexpected cardiac deaths. The mean age of this group was 72.8 ± 11.5 years. Of these, 10 (90.1%) were male. A detailed case note review was undertaken (Table 3). In two cases (18.2%), a Do Not Attempt Cardiopulmonary Resuscitation order was in place and in two (18.2%) cases, brief documentation regarding the patients' deaths were found, stating that the consultant had been informed of the patients' deaths in the community; however, details on how this information was communicated was not documented.

In the detailed case review, antiplatelet prescription was generally good, although one patient with ischaemic heart disease was not prescribed an antiplatelet due to a severe gastrointestinal bleed and another patient was a new patient referral and was on no medication. However, in the three patients with left ventricular impairment, an angiotensin converting enzyme inhibitor was prescribed in only one patient and a beta-blocker in two patients. It was not clear from the notes why treatment was not optimal, although one patient did have chronic kidney disease which may have precluded use of an
angiotensin converting enzyme inhibitor. In the four patients with atrial fibrillation, only one was anticoagulated; again it was not clear from the medical notes why the others were not (Table 3).

Table 2. Cause of death as reported on the death certificate based on presence or absence of a life-limiting cardiac condition.

| Cause of death           | Total, n (%) | Life-limiting cardiac condition \(^a\) (expected) n (%) | Non–life-limiting cardiac condition \(^b\) (unexpected) n (%) |
|-------------------------|--------------|---------------------------------------------------------|-----------------------------------------------------------|
| Total (n)               | 74 (100)     | 21 (100)                                                | 53 (100)                                                  |
| Myocardial infarction   | 18 (24.0)    | 8 (38.1)                                                | 10 (18.9)                                                 |
| Cancer                  | 15 (20.0)    | 0 (0)                                                   | 15 (28.3)                                                 |
| Heart failure           | 11 (14.7)    | 11 (52.4)                                               | 0 (0.0)                                                   |
| Respiratory causes \(^a\) | 9 (12.0)    | 0 (0)                                                   | 9 (16.9)                                                  |
| Stroke                  | 5 (6.7)      | 0 (0)                                                   | 5 (9.4)                                                   |
| Sepsis                  | 4 (5.3)      | 0 (0)                                                   | 4 (7.5)                                                   |
| Other \(^b\)            | 12 (16.2)    | 2 (9.5)                                                 | 10 (18.8)                                                 |

\(^a\)Life-limiting condition defined as severe and untreatable coronary disease, severe end stage valvular heart disease or severe heart failure.

\(^b\)Other group included gastrointestinal disease, accidental injury, suicide and renal failure.

Discussion

Summary

This study has for the first time described the mode of death in patients under active follow-up at a cardiac clinic. The most frequent cause of death was myocardial infarction followed by cancer and heart failure. Following detailed review of the case files of those who died from unexpected cardiac deaths, there were few opportunities to have altered the outcomes for these patients. Nevertheless, medical therapy may not have been optimal and routine review of such cases should be considered. Furthermore, there may have been an opportunity to address other care issues to ensure that a death or post-death family care was optimal. The poor documentation and communication between primary and secondary care would currently make routine case review challenging.

Strengths and limitations

This was a single-centre study and therefore there is a risk that the findings are not generalisable. Nevertheless, the cardiac unit at Raigmore Hospital sees all cardiology patients in the region and, apart from complex electrophysiology and cardiac surgery, the unit provides all other cardiology care so very few patients are seen in other centres. It is therefore unlikely that there is a selection bias and this cohort is likely to represent the average Scottish population. Furthermore, while there were a relatively small number of deaths, the study did run over a 48-month period with over 10,000 clinic attendances. Therefore, it is likely that the results are generalisable to other cardiology outpatient populations.
Table 3. Detailed case review of unexpected deaths.

| Demographics | Drugs | Cause of death | Miscellaneous |
|--------------|-------|----------------|---------------|
|              |       |                | Place of death* | Other conditions | Do not attempt cardiopulmonary resuscitation |
| Age | Gender | Existing cardiology diagnosis | Left ventricular systolic function | Angiotensin converting enzyme inhibitor/angiotensin receptor blocker | Beta-blocker | Anti-platelet | Other cardiac drugs | Non-cardiac drugs | AI | BI | CI | | 2 | |
| 81 M | Chronic heart failure | mod | Y | N | – | Furosemide | Iron/proton pump inhibitor/Insulin | Myocardial infarction | Ischaemic heart disease | Valvular disease | – | Hospital | Gastrointestinal bleed | N |
| 65 M | None | NA | No medication as unseen new patient | Myocardial infarction | Ischaemic heart disease | – | Community | N |
| 55 M | Acute coronary syndrome | Mod | N | Y | Aspirin | Statin | Diabetic medication | Myocardial infarction | Hypertension | Type II diabetes mellitus | – | Community | Type II diabetes mellitus | N |
| 67 M | Angina | None | Y | Y | Aspirin | Statin/Glycerol trinitrate | Myocardial infarction | – | – | – | Hospital | – | N |
| 78 M | Atrial fibrillation | None | N | N | Aspirin | Isosorbide mononitrate | Asthma inhalers | Myocardial infarction | – | – | Chronic obstructive pulmonary disease | Community | Emphysema | N |
| 52 M | Angina | None | meds stopped as palliative | Hypertension | HD | – | – | Community | pancreatic cancer | Y |
| 74 M | Atrial fibrillation | None | N | Y | Aspirin | Furosemide | Gabapentin/Mirtazapine | Myocardial infarction | – | – | Type II diabetes mellitus | Metastatic prostate cancer | Community | N |
| 83 M | ST-elevation myocardial infarction | None | N | Y | Aspirin | Clopidogrel | Statin | Myocardial infarction | – | – | Type II diabetes mellitus | Chronic kidney disease 3 | Hospital | Type II diabetes mellitus/chronic kidney disease 3 | N |
| 85 M | NonSTEMI/Atrial fibrillation/chronic heart failure | Mod | N | Y | – | Furosemide | Isosorbide mononitrate | Proton pump inhibitor | Ischaemic heart disease | – | – | Chronic heart failure | Chronic kidney disease 3 | Hospital | – | N |
| 79 F | Myocardial infarction | None | Y | N | Aspirin | Amiodarone | Statin | – | Myocardial infarction | Ischaemic heart disease | Hypertension | Chronic heart failure | Community | rectus sheath haematoma | Y |
| 82 M | Atrial fibrillation/mitral regurgitation | None | Y | N | Warfarin | Furosemide | Statin | – | Myocardial infarction | Ischaemic heart disease | – | Atrial fibrillation/severe mitral regurgitation | Community | Hypertension | N |

*Death occurred in community hospital.
contraindications) between primary and secondary care, might provide a focus for improving future care. None of the ‘unexpected’ deaths were due to heart failure.

Many patients died of non-cardiac causes, and these represented the common causes of death in the general population with cancer being the most common non-cardiac mode of death. This is not surprising given that many cancers share the same risk factors as those for cardiac disease, namely older age, smoking, obesity and a sedentary lifestyle.

In the smaller cohort with unexpected deaths, the vast majority, 10/11, were reported to have had a myocardial infarction/ischemic heart disease as the cause of death. However, the accuracy of this diagnosis is difficult to ascertain as none had a post-mortem examination. Sudden death in patients with known ischemic heart disease may be caused by myocardial infarction although arrhythmia and stroke may be difficult to exclude. The case notes review demonstrated that while prescription of antiplatelet drugs was high, in general, anticoagulation was underutilised. Also, one patient with chronic heart failure and one patient with prior myocardial infarction were not prescribed a beta-blocker with no relevant contraindication found.

Communication. The most striking finding from this study was the lack of documentation of a patient’s death in the hospital medical notes and evidence of clinical review. Given these patients were undergoing shared care between primary and secondary care, at first glance, this would appear odd. Furthermore, the lack of such communication suggests a lost opportunity for case review and discussion. It is possible that such communication was done by email or phone but it is unlikely that this would represent a significant number of cases as the bulk of communication with the hospital from primary care is by conventional letter. Furthermore, if there was email communication, it may be assumed that this would also be filed in the patient’s notes. However, there is acknowledgement that email communications cannot easily be integrated into patients’ medical records. Waldren and Kibbe called for such communication to be ‘seamlessly interfaced’ with electronic health record software systems, but given the absence of a common electronic health record between primary and secondary care, this would seem some way off.

The most likely explanation is that the death of the patient was notified to the hospital administration but that generally neither primary nor secondary care clinicians perceive a need for further case review. The detailed case review in this small number of patients would suggest that this is a missed opportunity to optimise patients’ care in a small number of cases. Meeting with interface colleagues on an equal footing compared with the more traditional didactic approach of the specialist teaching the general practitioner may have benefits not only for improving patient care, but in also developing trust between clinicians, increasing the organisation’s (National Health Service) social capital, i.e. interface clinicians’ willingness and ability to come together for the benefit of patient care. Joint learning events might help clinicians to develop networks and share learning as a means of establishing ‘Communities of Practice’.

Finding data and identifying the cause of death

One of the unexpected observations during this study was how challenging it was to ascertain the cause of death from medical records. Documentation of the cause of death was missing from the vast majority of the hospital notes, and in primary care the electronic records are centralised soon after the patient’s death making review more difficult. The cause of death in this study was obtained from the public access register although this has a six-month delay in releasing this information into the public domain and required physical presence in the building of the registrar to undertake the search. The above facts compound the existing communication barriers between primary and secondary care and it is little wonder that more routine comprehensive review of patient deaths in the community does not happen. Furthermore, post-mortems are uncommon and, therefore, it is not possible to say whether all interpreted cause of deaths were accurate.

Recommendations for practice change

The authors believe that current communication systems between primary and secondary care are suboptimal. We recommend that an interface ‘significant event analysis’ be initiated by primary care following a patient death in the community. This would allow a standard and formal review of a patient’s care and result in shared learning that could be beneficial, promoting improved relationships and communication with the potential for improved patient care.

Conclusions

This study has shown that in cardiac patients under active outpatient review, myocardial infarction was the most common cause of unexpected death.
While a detailed retrospective case review uncovered seemingly limited opportunity to improve medical treatment, it would seem appropriate that dialogue between primary and secondary care routinely occurred in these cases, and may lead to discovery of learning not initially apparent. The potential benefits of such a discussion may lead to improvements to patient care at the interface and be helpful in developing working relationships between clinicians. Documentation in the hospital record of the details of the patient’s death was very poor and gaining information on the cause of death was difficult; these barriers to communication between primary and secondary care could be improved. Although firm evidence is lacking in this area, it is our opinion that routine review of unexpected deaths with input from primary and secondary care should occur to ensure that patient care was optimised in the individual and that organisational care is as good as possible.

Declarations

Competing Interests: None declared.

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Guarantor: SJL

Contribution: TMK – undertook data collection and analysis and wrote the first draft; NB – co-wrote the paper; AO – co-wrote the paper; IGR – had input to original study concept and co-wrote the paper; RS – co-wrote the paper; GFR – had input to original study concept and co-wrote the paper; SJL – had original study concept and co-wrote the paper and the guarantor.

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References

1. Bhatnagar P, Wickramasinghe K, Williams J, Rayner M and Townsend N. The epidemiology of cardiovascular disease in the UK 2014. Heart 2015; 101: 1182–1189.
2. The Consensus Trial Study Group. Effects of enalapril on mortality in severe congestive heart failure. N Engl J Med 1987; 316: 1429–1435.
3. Domanski MJ, Krause-Steinrauf H, Massie BM, et al. A comparative analysis of the results from 4 trials of beta blocker therapy for heart failure: BEST, CIBIS-II, MERIT-HF, and COPERNICUS. J Cardiac Fail 2003; 9: 354–363.
4. Pitt B, Zannad F, Remme WJ, et al. The effect of spironolactone on morbidity and mortality in patients with severe heart failure. Randomised Aldactone Evaluation Study Investigators. N Engl J Med 1999; 341: 709–717.
5. Cohn JN and Tognoni G; Valsartan Heart Failure Trial Investigators. A randomised trial of the angiotensin-receptor blocker valsartan in chronic heart failure. N Engl J Med 2001; 345: 1667–1675.
6. Cleland JG, Cohen-Solal A, Aguilar JC, et al.; IMPROVEMENT of Heart Failure Programme Committees and Investigators. Improvement programme in evaluation and management; Study Group on Diagnosis of the Working Group on Heart Failure of The European Society of Cardiology. Management of heart failure in primary care (the IMPROVEMENT of Heart Failure Programme): an international survey. Lancet 2002; 360: 1631–1639.
7. Marshall MN and Phillips DR. A qualitative study of the professional relationship between family physicians and hospital specialists. Profession Geogr 1999; 51: 274–282.
8. Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE and McKendry R. Continuity of care: a multidisciplinary review. BMJ 2003; 327: 1219–1221.
9. Farquhar MC, Barclay S, Earl H, Grande G, Emery J and Crawford R. Barriers to effective communication across the primary/secondary interface: examples from the ovarian cancer patient journey (a qualitative study). Eur J Cancer Care 2005; 14: 359–366.
10. Pollard LC, Graves H, Scott DL, Kingsley GH and Lempp H. Perceived barriers to integrated care in rheumatoid arthritis: views of recipients and providers of care in an inner-city setting. BMC Musculoskeletal Disord 2011; 12: 19.
11. Chew-Graham C, Slade M, Montána C, Stewart M and Gask L. Loss of doctor-to-doctor communication: lessons from the reconfiguration of mental health services in England. J Health Serv Res Policy 2008; 13: 6–12.
12. http://www.rcgp.org.uk/policy/rcgp-policy-areas/~media/Files/Policy/A-Z-policy/2015/RCGP-Patient-safety-implications-of-general-practice-workload-July-2015.aspx (accessed 3 October 2015).
13. McGrath MJ. Differing attitudes between psychiatrists and primary care providers at the interface. Hawaii Med J 2000; 59: 447–450.
14. Genealogy Scottish Family Birth Records Census Ancestry Scotland UK, www.Scotlandspeople.gov.uk (accessed 3 October 2015).
15. https://www.nice.org.uk/guidance/cg172/chapter/introduction (accessed 3 October 2015).
16. Goodyear-Smith F, Wearn A, Everts H, Huggard P and Halliwell J. Pandora’s electronic box: GPs reflect upon email communication with their patients. Inform Prim Care 2005; 13: 195–202.
17. Waldren SE and Kibbe DC. Email in clinical care. BMJ 2004; 329: E325.
19. Marshall MN. Qualitative study of education interactions between general practitioners and specialists. *BMJ* 1998; 316: 442–445.
20. Williams LL. The fair factor in matters of trust. *Nurs Admin Q* 2006; 30: 30–37.
21. Fukuyama F. *Trust: the social virtues and the creation of prosperity*. New York: Free Press, 1995.
22. Coleman J. Social capital in the creation of human capital. *Am J Social* 1988; 94: 95–120.
23. Beech R, Henderson C, Ashby S, et al. Does integrated governance lead to integrated patient care? Findings from the innovation forum. *Health Soc Care Commun* 2013; 21: 598–605.