original article

Is it possible and worth keeping track of deaths within general practice? Results of a 15 year observational study

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See editorial commentary, pp 325–6

Objective

The aim of this study was to assess the value of maintaining a death register in a general practice with particular reference to monitoring quality of care.

Method

A general practice in an inner London setting was chosen for the study. The practice had a list size of 2545 patients and was notified of patient deaths by the local health authority. A manual death register was maintained by the practice. The data collected included place of death, cause of death, and timing of death notification to the practice.

Results

During the study period, 578 patients died. Of these, 360 (64.1%) died in hospital, 139 (24.8%) at home, and 38 (6.8%) in a hospice. Death certification was completed in 33.6% of cases, and the cause of death was obtained from patients' records in 33.6% of cases. The practice maintained a manual death register, and this was used to monitor the quality of care provided to its patients.

Conclusion

A death register can examine trends in practice deaths by age and place of death, and comparisons can be made with nationally published mortality data. The practice should continue to maintain a death register, and the data collected can be used to improve the quality of care provided to its patients.

Methods

The study was carried out between August 1985 and July 2000 in an inner London practice with an initial list size of 2545, rising to 4900 during the study period. With an age/sex structure comparable to that of the population of England and Wales, the practice's patient population resides in one of the more deprived areas of the country. The study was carried out using a random sample of patients, and the data were collected using a computerized database.

Box 1 Definitions

UK Primary Care Trusts: primary care organisations established in the National Health Service in 1997, responsible for provision of primary care services and for commissioning health services from other community and hospital trusts.

Clinical governance: a framework through which National Health Service organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment which will promote excellence in clinical care.
Very few UK doctors have been found guilty of murdering their patients, but the Shipman case has highlighted the possibility of systemic failure in UK civil procedures when death certificate information could not be obtained by the practice or from the family of the deceased. The Shipman case has also highlighted the importance of charting the demography of patient deaths over time and observing and comparing practice death rates with national mortality rates, as well as discerning possible trends in place of patient death.

A register of deaths could allow a practice to:

- Chart the demography of patient deaths over time.
- Observe and compare practice death rates with national mortality rates.
- Discern possible trends in place of patient death.
- Track accurately the causes of death.
- Become aware in a timely way of who has been bereaved.

### Box 3 How could a register of deaths contribute to GP clinical governance?

#### Box 4 Characteristics of study practice

- **August 1985**
  - 1 whole time equivalent GP
  - No nursing assistance
  - 1 part time receptionist
  - 2545 patients
  - Urban deprived area
  - Above average morbidity

- **July 2000**
  - 2.75 whole time equivalent GPs
  - 1 whole time equivalent practice nurse
  - 6 administrative and reception staff
  - 4900 patients
  - Urban deprived area
  - Above average morbidity

### Box 5 Information fields in paper death entry forms

- Name, address, date of birth.
- Details of closest surviving relatives (including those not registered with the practice if contact details known).
- Date and place of death.
- Whether there had been any domiciliary involvement by the terminal care team prior to death.
- Whether the death was investigated by the coroner and whether a coroner’s report was requested by the practice and/or received.
- Whether there had been any domiciliary involvement by the terminal care team prior to death.
- Cause of death as advised by informant.
- Cause of death as stated on death certificate if available.
- Whether the death was investigated by the coroner and whether a coroner’s report was requested by the practice and/or received.
- Whether there had been any domiciliary involvement by the terminal care team prior to death.

When we learned about a patient’s death, a paper death entry form was completed with the information shown in box 5. At the end of the 15 year period a computer database was compiled, supplemented by reference to patients’ notes. An additional field—date of last contact with the practice— was added, defined as consultation in the surgery, at home, a telephone call from a patient, or a community nurse contact.

Where there was no information about cause of death as recorded on the death certificate, the deceased patient’s health authority of residence was asked to supply this information. Where death certificate information could not be obtained by these means, the underlying cause of death was inferred from information supplied when death was notified to the practice, coded according to the International Classification of Diseases (ICD) 9th edition.

An attempt was made to estimate how many deaths may have occurred without our knowledge by undertaking a computer search to ascertain patients aged 65 and over who had not contacted the practice since February 1999 (when computer recording of consultations began). We wrote to 82 patients...
who lacked computer evidence of practice contact over the
preceding 18 months and received no response from 39. The
relevant health authorities of residence were asked to search
their databases for recorded deaths of these 39 people.
Permission for this work was obtained from the two local
research ethics committees covering our practice area.

RESULTS

Demography of deaths

Five hundred and seventy eight patients were identified as
having died during the study period, 296 (51%) of whom were
female. No additional deaths were identified from the health
authority search of selected patients (n=39). Only five of the
578 patients’ medical records were missing and for these
deaths the manual register was our only source of informa-
tion. 438 patients (76.6%) who died were aged 65 or over at
time of death, 88 (15.4%) were aged 45–64, 32 (5.6%) 25–44,
and 14 (2.4%) were under 25 years. The exact date of death
was unknown for seven patients but in one case age at death
was not known. No additional deaths were identified from the
health authorities of residence were asked to search
their databases for recorded deaths of these 39 people.

Practice mortality and formal notification of deaths

Three year age standardised practice death rates fell signif-
ificantly from 35.59/1000 in 1985/8 to 27.12/1000 in 1997/2000
(χ² test for trend = 18.54, p=0.00002; table 1), a fall suggestive
of a steeper decline in practice than the national mortality rate
over this period (fig 1). Informal notification of death (from
relative, neighbour or newspaper report) was received for 238
patients (41.2%), and in 80 cases (13.8%) this was the only
information received about the death. Formal notification of
death was received for 498 patients (86.2%) from the follow-
ing sources: hospitals (n=280, 56.2%), coroners (n=71,
14.3%), other health service staff (n=40, 8.0%), hospice
(n=38, 7.6%), GP (n=36, 7.2%), health authority (n=23,
4.6%) the police (n=8, 1.6%), and unknown (n=2, 0.5%).
The percentage of patients for whom formal notification of
death was received increased non-significantly from 84.8% in
1985/8 to 90.7% by 1997/2000 (χ² = 1.78, p=0.18). Analysis of
formal notification by place of death showed variation
between local hospitals (highest hospital notification rate
94.5%, lowest 77.6%, χ² =14.52, p=0.006), while the notifica-
tion rate from hospices was 100%, significantly higher than
that of hospitals combined (χ²=14.58, p=0.002) (data not sh-
own).

The interval between death and date of formal notification
could be calculated for 491 patients and was within 7 days of
death for 392 patients (79.8%), within 8–14 days for 60
(12.2%), and within 15–28 days for 30 (6.1%). For nine
patients the time interval between death and notification
ranged from 29 to 1606 days.

Place of death

The place of death and time trends in place of death are shown
in table 2. During the study period 360 patients (64.1%) died
in hospital, 139 (24.8%) at home, and 38 (6.8%) in a hospice.

<table>
<thead>
<tr>
<th>Place of death</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>360</td>
</tr>
<tr>
<td>Home</td>
<td>139</td>
</tr>
<tr>
<td>Hospice</td>
<td>38</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>561</td>
</tr>
</tbody>
</table>

Table 1 Three year age standardised practice death rates*

<table>
<thead>
<tr>
<th>3 year period</th>
<th>No of practice deaths</th>
<th>Practice list size at mid point</th>
<th>3 year crude practice death rate/1000</th>
<th>Standardised 3 year practice death rate/1000 (95% CI)**</th>
<th>3 year death rate/1000 in England &amp; Wales***</th>
</tr>
</thead>
<tbody>
<tr>
<td>August 1985–8</td>
<td>105</td>
<td>3012</td>
<td>33.86</td>
<td>35.59 (28.66 to 42.51)</td>
<td>34.73</td>
</tr>
<tr>
<td>August 1988–91</td>
<td>131</td>
<td>3989</td>
<td>32.84</td>
<td>36.81 (30.43 to 43.19)</td>
<td>33.81</td>
</tr>
<tr>
<td>August 1991–4</td>
<td>121</td>
<td>3923</td>
<td>30.84</td>
<td>32.79 (27.33 to 39.19)</td>
<td>33.28</td>
</tr>
<tr>
<td>August 1994–7</td>
<td>106</td>
<td>4605</td>
<td>23.01</td>
<td>27.04 (21.87 to 32.22)</td>
<td>32.48</td>
</tr>
<tr>
<td>August 1997–2000</td>
<td>108</td>
<td>4864</td>
<td>22.20</td>
<td>27.12 (21.99 to 32.27)</td>
<td>31.78</td>
</tr>
</tbody>
</table>

* Date of death not known for 7 patients.
** Standardised (direct method) to England and Wales mid 1999 estimated population.
*** Calculated from Office for National Statistics figures.

χ² test for trend = 18.54, p=0.00002.

Table 2 Time trends in place of death (%) *

<table>
<thead>
<tr>
<th>Date of death</th>
<th>Hospital</th>
<th>Home</th>
<th>Hospice</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>August 1985–8</td>
<td>67 (64.5)</td>
<td>23 (22.1)</td>
<td>6 (5.8)</td>
<td>8 (7.7)</td>
<td>104</td>
</tr>
<tr>
<td>August 1988–91</td>
<td>89 (69.0)</td>
<td>31 (24.0)</td>
<td>3 (2.4)</td>
<td>4 (3.1)</td>
<td>129</td>
</tr>
<tr>
<td>August 1991–4</td>
<td>68 (58.6)</td>
<td>32 (27.4)</td>
<td>8 (6.9)</td>
<td>8 (6.9)</td>
<td>116</td>
</tr>
<tr>
<td>August 1994–7</td>
<td>70 (66.7)</td>
<td>27 (25.7)</td>
<td>5 (4.8)</td>
<td>3 (2.9)</td>
<td>105</td>
</tr>
<tr>
<td>August 1997–2000</td>
<td>66 (61.8)</td>
<td>26 (24.3)</td>
<td>14 (13.1)</td>
<td>1 (0.9)</td>
<td>107</td>
</tr>
<tr>
<td>Total</td>
<td>360 (64.1)</td>
<td>139 (24.8)</td>
<td>38 (6.8)</td>
<td>24 (4.3)</td>
<td>561</td>
</tr>
</tbody>
</table>

* Information on 17 deaths insufficient to allow classification.
Death in hospital v elsewhere: χ² test for trend=0.36, p=0.549.
Death at home v elsewhere: χ² test for trend=0.21, p=0.649.
GP had been present at the time of a patient's death or within 30 minutes or so of death in only four cases (0.69%). Information was available about last contact with the surgery before death for 566 patients (97.6%); 45% (n=255) had had contact within a month of death and a further 19% (n=108) within 2 months of death. Five patients had never been seen at the surgery and five babies died in hospital around the time of birth.

Over the 15 year period 143 deaths (24.7%) were reported to the coroner, and this percentage remained similar throughout the study period (table 3). Despite a practice policy of writing to coroners to request reports, coroners' reports were received personally known to us and received care of varying intensity and thereby to be more closely accountable to their population. It is 15 years since Julian Tudor Hart urged conscientious GPs to be their own coroners, to take on a local public health role and thereby to be more closely accountable to their population.

### Causes of death

Table 4 shows how information about the cause of death was obtained for this study. Cause of death information from death certificates could be obtained from medical records in only 194 cases (33.6%) but was obtainable from health authority sources for a further 289 (50%). No death certificate information was obtainable for 95 deaths (16.4%), and no information of any sort could be found about cause of death for 31 patients (5.4%).

The commonest causes of death are shown in table 5. The frequency of death from different causes is similar to that for England & Wales ($\chi^2=9.86, p=0.079$ (data not shown)). Twenty seven deaths were in the ICD category injury and poisoning, of which 15 (56%) were men; six were murdered, nine were killed in road traffic accidents (seven pedestrians, two pedal cyclists). Three deaths occurred from drug overdose, two in established drug users and the third in a naive user. Three patients committed suicide, two of whom had a schizophrenic illness. Half of the deaths from injury and poisoning occurred in patients aged under 45, but these causes contributed to only one third of the total deaths in that age group. Other important causes of deaths in this age group were HIV (n=7, all between 1990 and 1994), malignancy (n=7), and complications of intravenous drug misuse (n=4).

### Bereavement

Twice as many men who died over this period widowed a wife than women who widowed a husband, although the mean age at death of both groups was the same (table 6). Twenty three patients (4%) who died left grieving parents. For 64 patients (11%) we could discern no surviving relatives at the time of their death.

### DISCUSSION

It is 15 years since Julian Tudor Hart urged conscientious GPs to be their own coroners, to take on a local public health role and thereby to be more closely accountable to their population. Over a 15 year period our practice register provided data about sufficient numbers of deaths to enable us to look at trends over time and to make simple comparisons with national data; a larger practice could expect to do so over a shorter period. But meaningful interpretation of our findings is difficult as death rates are influenced by many factors beyond health care delivered by a general practice. Nevertheless, cause of death findings highlight the large impact of circulatory disease and neoplasms upon mortality in an average sized UK general practice. Because deaths from common diseases are overshadowed in our memories by more dramatic and tragic deaths in younger patients, these findings serve as a powerful reminder to us of the importance of implementing preventive care in general practice, an approach that needs to go hand-in-hand with public health initiatives to control these conditions.

The majority of people represented by these data were personally known to us and received care of varying intensity and involvement within the practice and from hospital colleagues.
Four hundred and sixty left behind bereaved relatives and friends, many of whom were (and remain) registered with us. This reinforces the difficulty of documenting the movement in GP records and of making contact to offer support to relatives after a death. We were formally notified of death within 7 days in only 392 cases (68%); 87 (15%) were never formally notified to us.

UK general practice offers exceptional opportunities to observe, record, classify, and analyse clinical phenomena, but the extent to which this can be undertaken as part of service provision is limited. Our study shows that assembling a reasonably complete register of deaths is feasible—97.8% of ascertainable deaths were recorded by our register—but this could only be achieved with additional time and resources available from research funding. Practice computerisation now makes it administratively straightforward to establish templates to collect selected data on deaths, although such additional monitoring carries some resource implications. Our experience strongly suggests, however, that there are serious problems with the timeliness, accuracy, and completeness of information that can routinely be collected in this way.

The most important difficulty to be overcome by within-practice monitoring of deaths based on information usually supplied to GPs is in building up an accurate picture of causes of death. Sufficient death certificate information to allow us to assign the underlying cause of death was routinely made available to us from NHS and other sources in less than one third of cases, and this information was not based on the automated cause coding used by the Office for National Statistics to standardise assignment of the underlying cause of death. Further problems were created by difficulties in obtaining cause of death information from certificates issued by coroners. After contacting coroners specifically to request this information, no report was provided on 68.5% of occasions, an experience similar to that reported from Manchester.

A report from Newcastle, where the health authority introduced a system to provide GPs with automated cause coded information on deaths, suggested it was useful to practices with regard to administration, bereavement care, and medical audit. The value of such a system would be enhanced if it enabled practices to compare trends in their practice with those in other practices within the PCT and nationally. However, to introduce such a system nationally in the first instance would require death certificates to be modified to include identification of the GP (GMC number, name or address) with whom the patient was registered at death.

Routine monitoring of mortality at practice level may be of limited value in detecting high death rates associated with poor practice because the expected number of deaths per year per GP is both small and variable. However, this does not exclude a role for practice level mortality monitoring in detection of seriously divergent (criminal) practices. A simple way to alert monitoring agencies to the possibility of significantly divergent practice as perpetrated by Shipman (box 2) would be to monitor place of death from mandatory precoded place categories. As collected by US and Japanese death certificates, an unusually high number of deaths at home compared with the norm of a locality or any death on a surgery’s premises should probably trigger some further investigation.

Another variable worth tracking might be the percentage of a practice’s total death certificates issued by GPs—over 15 years we issued only 52 of 578 (9.0%). In the USA and Japan information on time of death is routinely collected which, if added to the UK certification process, could alert authorities to unusual patterns of mortality. It is not yet clear in the UK, however, whether aberrant behaviour and high normal variation can be monitored by one and the same system. The risk of creating “a statistical cacophony of false positive suspicion” may already have occurred; since the Shipman conviction two GPs have been suspended pending investigation of a possible association between deaths and opiate prescribing, but no unlawful activity has been proved.

In our practice, establishing and maintaining a death register has been a useful learning exercise which clearly satisfied the first three purposes outlined in box 3. However, comprehensive maintenance of a register based on data routinely accessible to a general practice cannot meet the fourth purpose—to track cause of death. Varied sources of information, mixed reliability of cause of death information, and no cause of death data for 16.4% of deaths severely curtailed the monitoring value of a death register. In our experience, the fifth purpose—to become aware in a timely way of who has been bereaved—cannot be met either as notification of deaths to the practice was both too slow and incomplete. Accordingly, we now record only basic information: date and cause of death (if known) and the identities of bereaved relatives whom we contact soon after a death and again the following Christmas. In addition, patients who have died in the previous 6 months are discussed at a multidisciplinary practice meeting, a limited exercise which would significantly benefit from GPs routinely receiving standardised death certificate information about their deceased patients.

**CONCLUSION**

Monitoring of deaths within UK general practice is currently too complex a task to be undertaken by individual practices as part of their service responsibilities. National Statistics should consider providing GPs with death certificate information and with analyses of comparisons of PCTs and national populations. Simple changes to information recorded on death certificates—such as the inclusion of precoded place of death and a GP identifier—would facilitate making valid comparisons.

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**Box 6 Key messages**

This study shows that a register of practice deaths can allow GPs to:

- chart the demography of patient deaths over time;
- observe and compare practice death rates with national mortality rates;
- discern possible trends in place of death.

However, if a death register relies only on routinely provided data, notification of death may be too delayed to support appropriate care for bereaved relatives. Information on cause of death will be incomplete and inaccurate, which limits its clinical governance value for GPs wishing to use this information to identify preventable deaths and improve services.

- National Statistics should consider providing GPs with death certificate information and with analyses which make comparisons with PCT and national populations. This would require the addition of a GP identifier to the death certificate.
- Practice level mortality information could play a role in detecting divergent clinical practice if time and place of death and the percentage of certificates issued by the GP were routinely monitored to identify unusual characteristics. This would require further changes to information recorded on death certificates, in line with practices in the USA and Japan.
REFERENCES


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