J R Coll Physicians Edinb 2018; 48: 299–303 | doi: 10.4997/JRCPE.2018.403 **ORIGINAL RESEARCH PAPER**

Hospital doctors' experiences of caring for dying patients

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Abstract

Background The aim of this study was to examine, by means of a postal questionnaire, the experience of all grades of doctors caring for patients dying in an acute hospital in Scotland.

Method A postal questionnaire was sent to 306 doctors working in inpatient medical and surgical specialties, emergency medicine, anaesthetics and intensive care medicine in an acute hospital.

Results There was an overall 41% response rate (127/306). Of responding doctors 55% had cared for 10 or more patients in the previous year. A quarter of respondents had personal experience of bereavement outside of clinical practice within the previous year. A total of 65% of responding doctors agreed that their most memorable patient death had had a strong emotional impact upon them. Responding doctors reported benefit from peer support. There was no association between length of time as a doctor and difficulty rating for talking to patients about death (p-value: 0.203). There was no association between difficulty rating and length of time working as a doctor when talking to relatives about death and dying (p-value: 0.205). We considered the questionnaire responses in relation to Scottish Government policy and initiatives associated with the care of the dying, and the future training and support of doctors caring for this group of patients and their relatives.

Conclusion Doctors describe similar experiences in terms of communication difficulties and emotional effects of caring for dying patients irrespective of their length of time working as a doctor.

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Introduction

More than 50% of all deaths in the UK occur in acute hospitals.[1] Caring for dying patients is an integral part of the clinical experience for doctors. The Scottish Government recognises the importance of Palliative and End of Life Care and has produced a Strategic Framework for Action[2] containing several commitments that will support 'a sense among staff of feeling adequately trained and supported to provide palliative and end of life care' and the objective of developing 'A greater openness about death and dying and bereavement in Scotland'.

Doctors can play a pivotal role in encouraging openness in discussing issues around death and dying but they need to be comfortable in doing so. Previous studies have shown that doctors can experience strong and lasting emotional reactions relating to some patient deaths and some doctors may benefit from emotional support in relation to this.[3,4] A previous study carried out amongst foundation year doctors identified training and support interventions relating to communication, ethics and the impact of one's own emotions and stress, which could improve the ability to practice effectively when caring for dying patients.[5] This study examines experiences of both non-Consultant- and Consultant-grade doctors caring for patients dying in an acute hospital and considers how these experiences may relate to the delivery of the Government's framework.

Method

Data were collected via an anonymised single-shot postal questionnaire sent to all doctors working in inpatient medical and surgical specialties, emergency medicine, anaesthetics and intensive care medicine at the Royal Alexandra Hospital in Paisley, a large district general hospital in the West of Scotland. Doctors in training and those with a substantive post were eligible for the study.

The questionnaire was based on a previous study[5] and was informed by literature review.

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Consent was implied by completing and returning the questionnaire.

Those participating in the questionnaire study were signposted to currently available support mechanisms and offered additional support from the Royal Alexandra Hospital palliative care team or counselling service at ACCORD Hospice in Paisley if required.

Research and development approval for this work was granted by Greater Glasgow and Clyde Health Board.

Questionnaires were analysed by two specialists in palliative medicine supported by a training-grade doctor and a medical student. Chi-squared association tests were conducted to assess the association between the doctors' level of experience and potential difficulties associated with caring for dying patients.

Results

Of the 306 postal questionnaires delivered, 128 were returned, of which 127 could be analysed giving a 41% response rate. In the rejected questionnaire, the respondent had only answered questions on the first page of the questionnaire. All other questionnaires analysed had responses on all pages and were considered for the analysis, although some individual questions had data missing.

Respondents

The age range of respondents (Table 1), length of time working as a doctor (Table 2) and response from different specialties (Table 3) are shown. Of the questionnaires that could be analysed, one responder did not confirm their age and one did not confirm the length of time they had been working as a doctor. Of those that confirmed their age, the majority (75/126, 60%) were aged 35 years or above. Just over two-fifths (56/126, 44%) had worked as a doctor for more than 15 years. Clinicians from a wide range of hospital specialties responded.

Experience of death and dying

Almost one-quarter of respondents (30/126, 24%) had personal experience of bereavement of a close family member or friend in the previous year.

Respondents were asked how many patients within the last year of life they had been involved with at, or around, the time of death. Of the 126 respondents, eight (6%) had no involvement with dying patients. One respondent was involved with one death (0.8%). Twenty-five (20%) were involved with between two and five deaths. Twenty-two (17%) were involved with between five and ten deaths and 70 (55%) were involved with more than 10 deaths. Of those that responded to being involved with more than 10 deaths in the previous year, the three highest responding specialties were general medicine (24/126, 19%), emergency medicine (15/126, 12%), and anaesthetics and intensive care medicine (13/126, 10%). One respondent did not answer this question.

When questioned how long the respondents had known their most memorable patient before their death, the number of completed responses was 118. Nine (8%) had known the patient for less than 1 hour, 34 (29%) for up to 24 hours and 23 (19%) had known the patients for months.

A total of 119 respondents answered the question as to whether the most memorable patient's death was expected. Eighty-two (69%) felt the death was expected, 27 (23%) felt it was unexpected and 10 (8%) did not know.

When questioned as to whether these patients had unrelieved suffering, most (93/119, 78%) disagreed or strongly disagreed with this statement.

Table 1 Age of respondents

Age range of respondents (years old)	Number of respondents
20–24	10 (7.9%)
25–29	27 (21.4%)
30–34	14 (11.1%)
35–40	20 (15.9%)
40–50	27 (21.4%)
Above 50	28 (22.2%)

One respondent did not confirm their age

Table 2 Length of time respondents had worked as a doctor

Length of time working as a doctor	Number of respondents
Less than 1 year	10 (7.9%)
Less than 2 years	16 (12.7%)
2–4 years	9 (7.1%)
4–7 years	12 (9.5%)
7–10 years	5 (4.0%)
10–15 years	18 (14.3%)
More than 15 years	56 (44.4%)

One respondent did not confirm length of time working

Table 3 Specialty response

Specialty response	Number of respondents
Anaesthetics	11 (8.7%)
Anaesthetics/intensive care medicine	13 (10.3%)
Emergency medicine	26 (20.5%)
General medicine	32 (25.2%)
General surgery	18 (14.2%)
Obstetrics and gynaecology	10 (7.9%)
Orthopaedics	15 (11.8%)
Urology	2 (1.6%)

Table 4 Sources of support

Source of support after death	Number of responses
Consultant	50
Educational Supervisor	4
Family (of doctor)	46
Foundation Grade Doctor	24
Friends	41
Nurses	40
Other training grade doctors	21
Pets (dog)	1

In relation as to whether the most memorable patient's death had had a strong emotional impact on them, over three-fifths of respondents (77/119, 65%) agreed or strongly agreed with this statement.

When considering the support available after these memorable deaths, almost half of the respondents (53/113, 47%) felt they disagreed or disagreed strongly that they had received adequate support. Of these 43% (23/53) were doctors who had been working for 15 years or more.

When questioned on the level of difficulty in talking to patients about death, two-fifths of respondents (53/126, 42%) scored it at a difficulty of 7 or more out of 10. On matching this question to length of time as a doctor, 39% of those practising for over 15 years (22/56) scored 7 or more out of 10. Of those practising for 4–15 years 54% (19/35) scored 7 or more out of 10 and 12/35 (34%) of those practising up to 4 years scored 7 or more out of 10. There was no association between length of time as a doctor and difficulty rating for talking to patients about death (p-value: 0.203).

When questioned on the level of difficulty in talking to patient's relatives about death, a third of respondents (40/126, 32%) scored it at a difficulty of 7 or more out of 10. On matching this question to length of time as doctor this represented 35% (14/40) of those practising for over 15 years, 27% (11/40) of those practising for 4–15 years and 37% (15/40) of those practising up to 4 years. There was no association between difficulty score and length of time working as a doctor (p-value: 0.205).

In relation to certifying death most respondents found this much less difficult with 87% (110/126) scoring this between 0–3 out of 10.

Speaking with bereaved relatives was challenging for a substantial number of respondents with 35% (44/126) scoring this at a difficulty of 7 or more out of 10. On matching this to length of time as a doctor this represented 29% of those practising for over 15 years (13/44), 32% (14/44) of those practising for 4–15 years and 39% (17/44) of those practising for up to 4 years. There did appear to be a significant association between length of time as a doctor and difficulty talking to bereaved relatives (p-value: 0.036). Observation from our sample suggests that less experienced doctors find it more difficult to talk to bereaved relatives than doctors with more experience.

The challenges that respondents face when making decisions with nutrition and hydration in patients who are at risk of dying were reflected in questions regarding starting and stopping medical feeding and fluids. A total of 44% (55/126) replied yes when questioned if they had ever felt uncomfortable with a decision to stop medical feeding and fluids, while 57% (72/126) responded that they had felt uncomfortable with decisions to start medical feeding or fluids.

Difficulty in discussing the withholding of cardiopulmonary resuscitation (DNACPR) was felt by 52% (65/124) of respondents.

Sources of support are reported in Table 4. Within free-text responses to sources of support, other sources mentioned included the hospital chaplain and the hospital palliative care team. One response related to the benefit of the peer support of the critical care multidisciplinary team in providing reassurance when withdrawal of care was being discussed as the most appropriate decision.

Themes from free-text responses

Free-text boxes enabled respondents to provide further information in relation to their own experiences of various issues related to death and dying. The free-text responses were reviewed by the authors of this paper and were grouped into themes. The main themes related to issues surrounding DNACPR decision-making, withdrawal of treatment, personal emotions, dealing with uncertainty, symptom control issues and discussing futility. Specific difficult situations centred on the deaths of children and young people, as well as the deaths of those with young children and those that died as a result of trauma and violence. A more comprehensive description of free-text responses will be reported in the future.

Discussion

This study provides insight into the experiences of doctors working across a wide range of specialties within a district general hospital setting. The responding doctors represented the whole medical workforce in terms of age and length of service, providing an overview of the entire demographics' experience. Almost one-quarter of respondents had personal experience of death outside of clinical practice within the previous year. Within clinical work only 6% of respondents had not been involved with a death in the previous year compared to 55% who had been involved with 10 or more deaths. This should not be surprising as it is recognised that at least 50% of deaths in Scotland will occur in hospital.

When questioned about their most memorable experience of a patient's death there was a wide variation amongst respondents in how long they had known the patients. For some this was a relatively short time, a matter of hours to a short number of days, whereas others had known the patient for months. Although many of the shorter time scales were reported by those working within emergency medicine, intensive care medicine and surgery, there were still some from these departments that reported on a patient they had known for much longer. Most respondents felt that the patients that they remembered the most had not had unrelieved suffering and the death had been expected. Free-text comments, however, did reveal that some respondents felt that symptom control for patients could be better and further training in this and communication skills would be helpful. When asked if the death had had a strong emotional impact upon them 65% agreed it had. However, only 11% of respondents strongly agreed with this statement. A previous study of hospital doctors reported 10% of respondents experience physical or emotional responses described as moderate-to-severe in nature.[6] In dealing with this emotional response, 47% of doctors reported a feeling of inadequate support after the memorable death. A total of 43% of this cohort of doctors had been practising for over 15 years. This finding concurs with previous studies where researchers found, contrary to expectations, that junior medical staff did not differ from their more senior colleagues in their emotional reactions to patients' deaths.[6,7] More than half of doctors did feel that they had received enough support. When questioned on sources of support it was clear that support from peers, and family and friends was very important to those that responded. Nursing staff also provided many doctors with support at the time of death. Those that received peer support in this study were more likely to have received support from within their own specialty and from someone at a similar level of seniority. This reflects previous studies that found doctors are seen as an acceptable source of support by clinicians dealing with emotionally stressful situations.[8,9]

Despite many clinicians having to deal with dying patients and their relatives on a regular basis, a substantial number of clinicians (42%) describe discussing death with patients as difficult, scoring it at 7 or more out of 10. When comparing cohorts in terms of how long the respondents had been working as a doctor 39% of those working for over 15 years, 54% of those working for 4–15 years and 34% of those working for less than 4 years scored 7 or more out of 10. When discussing death and dying with relatives respondents appeared to find this less difficult than discussing with patients; however, 32% still described their perception of difficulty with a score of 7 or more out of 10. For many clinicians having to discuss death and dying regularly and their level of seniority did not reduce the perception of difficulty, except for speaking to bereaved relatives where less experienced doctors appeared to find this more difficult. Difficulty, of course, does not necessarily equate with poor or inadequate communication with patients and their relatives, but may show the stress and challenges in carrying out this work. However, many fellow clinicians did not find this aspect of clinical work as challenging as their peers and further research would be helpful to determine why some doctors find this aspect of clinical practice more challenging than others.

The free-text comments in relation to the discussions that take place around the time of death illustrate reasons for the levels of difficulty. Respondents commented on the challenges of dealing with deaths as a result of trauma or violence, as well as the deaths of children and young people. Respondents described having to deal with their personal emotions in accepting the fallibility of treatments and feelings of helplessness. Comment was made on the difficulty in trying to find words of comfort in situations that they themselves find difficult to accept. Specific challenges were recorded when dealing with uncertainty, especially in relation to the withdrawing or commencing of food and fluids. There exists a range of guidance in this area including that from the General Medical Council,[10] but despite this the realities of clinical practice make this a challenging area.

There was a fairly equal split in terms of expressing difficulty in discussing the subject of DNACPR with patients. A total of 52% reported difficulty while 48% reported no difficulty. The main difficulties expressed in free-text responses surrounded the initiation of discussion about cardiopulmonary resuscitation where those responding felt a pressure to have these conversations in a time pressured and inappropriate environment. The challenge of dealing with unrealistic expectations of a futile intervention were also expressed and a worry that this later affected the clinicians therapeutic relationship. However, other comments within free-text responses noted that not having clarified decisions regarding cardiopulmonary resuscitation resulted in difficulties in providing appropriate levels of care. The Scottish Government has produced both an integrated adult policy[11] and a children's and young people's acute deterioration management policy[12] to guide both clinicians, patients and their relatives. Again despite the provision of good guidance there is a challenge for many in how this is delivered in practice. There would be merit in considering further training and support with regards to policy application and use in practice.

There are a number of limitations to this study. More than half of the potential population did not complete a questionnaire and return it. Those that did respond may have exhibited recall bias as we asked them to recall a memorable patient death that may not reflect their normal response to a clinical death. We cannot claim that the responses recalled are the same as those doctors that did not respond. We adapted a previously used questionnaire for the purposes of this study and cannot be sure that this has reduced the validity of this questionnaire.

This study shows that the doctors responding describe similar experiences in terms of communication difficulties and emotional effects of caring for dying patients irrespective of their level of seniority. Further thought and discourse may be required to determine how to ensure that doctors feel 'adequately trained and supported to provide palliative and end-of-life care'.[2] Such discourse would benefit from the support of both NHS Education for Scotland and Health Improvement Scotland. Current formal communication training in end-of-life care is mostly delivered in the early years of a doctor's career, but these findings suggest that such opportunities would be beneficial to a wider range of career grade doctors. Communication training may not be the only way to improve a doctor's experience of difficult conversations around death and dying. It may also be beneficial in thinking how doctors can use patient-centred programmes, such as NHS Scotland's 'What matters to you?', when initiating discussions concerning death and dying.[13] If the public engages with the Chief Medical Officer for Scotland's concept of realistic medicine[14] this may also make dialogues regarding the issues of initiating or withdrawing treatments and cardiopulmonary resuscitation easier for patients, their families and doctors. Many doctors agreed they experienced a strong emotional response to a memorable death and a significant minority of respondents felt they did not receive enough support. Peer support was considered acceptable and individual specialties may benefit from considering developing further specific peer support following distressing deaths, such as those from trauma or violence, or for those departments exposed to a larger volume of deaths. J

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