How can training in care of the dying be improved?

Gajebasia, S., Pearce, J., Redman, M., Johnson, M. & Finn, G

**Introduction**

In the UK, following medical school graduation, foundation year doctors (FYs) undertake a two-year training programme within a foundation school which oversees their training. FYs are expected to care for dying patients and the General Medical Council mandates that UK graduates will be able to do this1. However, undergraduate education has been criticised for failing to prepare doctors for this2. FYs feel unprepared3 and have unfulfilled learning needs4.

UK guidance on care of the dying was published in ‘Priorities for Care of the Dying Person’5. Five areas of care are recommended: ‘recognise’5,‘communicate’5, ‘involve’5,‘support’5 and ‘plan and do’5.The aim of this study was to explore FYs’ experiences in care of the dying. Three research questions were asked, table 1. We have shown that FYs’ experiences are variable and within the five priorities5 good practice and areas for improvement exist6. In this paper we present the primary data analysis related to question three.

[Table 1]

|  |
| --- |
| **Research Questions** |
| 1) What are the experiences of FYs?2) How do these relate to the five ‘Priorities for Care of the Dying Person’5?3) How can any findings inform under- and post-graduate medical education curricula? |

**Methods**

A qualitative study was conducted using semi-structured face-to-face, telephone and videoconferencing interviews to allow for exploration of experiences and to maximise participation. All FYs in the North Yorkshire and East Coast foundation school were invited through email, social media, posters and word-of-mouth to form a convenience sample. Participants provided informed consent and completed a demographic questionnaire.

‘Priorities for Care of the Dying Person’5 was used as the conceptual framework because it outlines nationally recognised areas for care. The conceptual framework was used to derive the standardised interview question stems alongside other published literature. Following a pilot interview, which was formed of one videoconferencing group interview with three participants, the questions stems (table 2) were agreed.

 [Table 2]

|  |
| --- |
| **Question Stems** |
| What training have you had and how well has it prepared you? Any training in the 5 priorities (as outlined in the Priorities for Care of the Dying Person5) and how could this be improved? Are there any specific areas you would like training on? What would be the best way to provide this? What else could be done to better prepare you?  |

Between January and March 2016, eight group interviews (two to five participants each) and twenty-one individual interviews were held, each conducted by one researcher (JP/MR/SG/GF). Interviews were recorded and transcribed verbatim. Due to the use of a conceptual framework, data were analysed in accordance with framework analysis7, with familiarisation of the interview transcripts, line by line coding, formation of a coding framework, charting of the data and interpretation. There were some pre-determined codes as a result of the conceptual framework and interview questions but the authors were open to other codes as the data was inductively analysed. Coding was primarily conducted by MR but reviewed by others. The themes and sub-themes were formed from the pre-determined codes and codes found on analysis. Data analysis software was used to organise the data. Thematic saturation was reached as no new themes emerged from the data. Ethical approval was granted by Hull York Medical School; institutional approvals were granted from involved NHS Trusts.

**Results**

Forty-seven (14%) out of 335 FYs participated and none withdrew. Forty-four participants attended UK medical schools.

***Themes***

Three main themes emerged; 1) learning opportunities, 2) varied methods for learning and 3) self-identified training needs (table 3).

[Table 3]

|  |  |
| --- | --- |
| **Themes** **(and subthemes where relevant)** | 1. Learning opportunities
2. Varied methods for learning

A. Learning from experienceB. Learning from observationC. SimulationD. Written guidanceE. Supervision1. Self-identified training needs

A. PrescribingB. CommunicationC. Recognising dyingD. DocumentationE. Societal perspectiveF. Emotional resilience |

For anonymity, the data are identified by interview type (group (G), individual (I)), interview number and, where relevant, participant number (P).

*1. Learning opportunities*

The teaching received varied.

*“I found my Medical School was really good at teaching end of life care.”(G8P4)*

*“I haven't had any end of life care training…”*(I4)

Timeliness of teaching was important.

*“…we had like breaking bad news communicating skill sessions but I know that they're quite early on, like the first clinical year [of medical school], when you maybe don't have enough actual medical knowledge to really appreciate them properly.”(G7P4)*

1. *Varied methods for learning*

*A. Learning from experience.* Participants valued experience, particularly with practical skills.

 *“I think it's very much…experienced based, like the more time to talk about and the more people and family talk to, you're a bit more prepared each time…”(G4P1)*

*B. Learning from observation.* Learning from observation was recognised as beneficial.

*“...we actually had one week of placement in fourth year and final year in a palliative hospice, which I found was very useful again because you see the day-to-day management, erm, of a palliative patient…in real time, it's not something you're going to read in, in a book or something you're going to learn…on a theoretical basis...”(G3P2)*

*C. Simulation.* The value of simulation was noted.

*“…it's a good way to kind of practice that for real life.”(G8P1)*

*D. Written guidance.* Written guidance was a helpful resource.

*“This is the [end of life care] booklet with the drugs, fantastic, and it's a really useful guide…”(G8P4)*

*E. Supervision.* Supervision from senior colleagues, nursing staff and palliative care specialists was useful.

*“…he [palliative care consultant] would always take the time to explain to me, you know, why are we doing this?”(G3P2)*

 *3. Self-identified training needs*

*A. Prescribing.* A lack of confidence with a desire for guidance was highlighted.

*“I felt very unprepared when I had to prescribe it [anticipatory medications] for the first time….”(G1P3)*

*“I think a lot more guidance on palliative [care] and what kind of medications you can give…would be really useful.”(G2P1)*

*B. Communication.* Communication skills were identified as a learning need.

*“I’ve had situations where relatives have asked, ‘Well, by giving my Mum this medication, are you not erm, bringing her death closer…actually that’s one of the kind of questions that we need training on how to answer.”(G1P3)*

*C. Recognising dying.* Participants would value training on recognising dying.

 *“Yes, training…would have been helpful, it's sort of recognising a patient who is dying…”(I6)*

*D. Documentation.* Training needs on how to document in the clinical record, complete death certificates and cremation forms arose.

*“…it's not something we're, we're really taught either, like I never remember having tutorials on like how to document like end of life care.”(I9)*

*E. Societal perspective.* Participants commented on their lack of knowledge about the legal and ethical factors involved and their understanding of different cultural beliefs with regards to dying.

*“…I don't know where the…legal or ethical boundaries come…with regards to end of life.”(G3P2)*

*“…people coming in with different religions and from different countries…they see death in different ways and they want things done in certain ways…”(I1)*

*F. Emotional resilience.* Death presented emotional challenges and that preparation for this was lacking.

*“…a really important aspect is, erm, how to emotionally deal with…the patient dying, but it's something that…was never taught or discussed in medical school.”(I13)*

**Discussion**

Given FYs are expected to care for dying patients, it is important to understand their training experiences and needs. The variation in training, despite curriculum specification, was notable and training needs ranging from biomedical aspects of clinical practice through to psychosocial issues and personal resilience were identified. The clinical and psychosocial training needs map to the foundation programme curriculum item of ‘manages palliative and end of life care’8(p.71). Addressing these learning needs will also enable FYs to be able to achieve the ‘Priorities for Care of the Dying Person’5 recommendations.

There is a need to improve training and ensure learning opportunities are maximised for undergraduates and postgraduates, for example, the use of hospices as training sites9. Consistent with previous findings2,3,10 our participants described learning about care of the dying through experience, observation, simulation and written and verbal guidance, therefore these methods should be further utilised to meet FYs’ needs. It was noted that the timing of this learning had significant impact on its value and that it should occur when it was most clinically relevant. Our data showed that exposure to care of the dying was welcomed as a medical student, particularly during more senior years, and that simulation exercises in a safe environment had a valuable role. In practice, spiral curriculum approaches would seem appropriate, where earlier “safer” practice could be built on when the topic was revisited later in the course after more clinical exposure. This could be further supported by training early in the foundation programme. Within this spiral curriculum, emotional resilience could be built with each learning event. Table 4 outlines recommendations for training.

[TABLE 4]

|  |
| --- |
| **Recommendations for training** |
| **Undergraduate level** | **Early postgraduate level (foundation level)** |
| - Undergraduate training must meet the General Medical Council requirements of ‘management of symptoms, practical issues of law and certification, and effective communication and teamworking’1(p.5).Following this study, the authors also recommend:-Training in care of the dying should be integrated into the spiral curriculum, to allow students to build their knowledge, skills and experience over time.-All medical students should receive basic teaching about the meaning and principles of care of the dying, how to recognise dying, the pharmacology of medications used in care of the dying, how to verify death and complete death certification paperwork. -All students should be provided with training and some practical experience via simulated scenarios of breaking bad news.-All medical students should be provided with some practical experience of care of the dying, with time in a hospice and/or working with inpatient or outpatient palliative care services if possible, particularly in the later years of their course to prepare them for starting work and to gain an understanding of the teamwork involved.-All medical students should be introduced to the concept of emotional resilience and how to prepare for this.  | -Foundation training must meet the curriculum items as outlined by the foundation programme8.Following this study, the authors also recommend:-To continue training within a spiral curriculum by building upon knowledge, skills and experience acquired at medical school, with more focus on real-life care events but to use classroom-based study days and hospice placements as appropriate.-For care events encountered at work to be a trigger for learning, with support from the senior members of the clinical team via clinical debrief/supervision.-To observe senior members of staff break bad news or have conversations on the topic of care for the dying with patients and/or families. Depending on the FYs competence and senior support available, there may be opportunity for the FY to lead this conversation. Simulated scenarios would offer a safe environment for FYs to learn and practice their communication skills further.-All FYs should receive training on prescribing, recognising the dying patient and the ethical/legal/cultural aspects of care for the dying.-All FYs should be provided with support on how to document care in the medical record appropriately. All FYs should be supported in completing death certificates and cremation forms by senior members of the healthcare team.-All FYs should be made aware of where NHS Trust guidance on care of the dying can be accessed and how to contact the palliative care team. -All learning events or care of the dying experiences should be an opportunity for building emotional resilience, with support from more senior members of the healthcare team. |

Strengths of this work include reaching thematic saturation and using a convenience sample which may have resulted in recruiting participants with strong views at either extreme. Limitations included relying on participants’ memory of events, over months/years, and participants having a variable post duration at the time of the interviews (between five and 19 months) which may have resulted in different opportunities.

MR, JP and SG, were FYs at the time of conducting the interviews, which may have helped participants express their opinions, or it may have been a barrier to discussions due to fear of peer judgement. To ensure fair data interpretation GF and MJ, both experienced researchers and not FYs, were involved in data analysis.

**Conclusions**

Training experiences vary and training needs exist around prescribing, communication, recognising dying, documentation, societal perspective and emotional resilience. Many of these training needs reflect the foundation programme syllabus and when addressed will help FYs achieve the ‘Priorities for Care of the Dying Person’5 recommendations. It is important to acknowledge the FYs’ expressed training needs and use them to improve training. Teaching this topic at clinically relevant times in a spiral curriculum is suggested as a way to deliver this teaching across undergraduate and early postgraduate training using existing learning methods.

**References**

1. General Medical Council. Outcomes for graduates (Tomorrow’s Doctors). General Medical Council [Internet]. 2015 [cited 2018 September 3]. Available from https://www.gmc-uk.org/-/media/documents/outcomes-for-graduates-jul-15-1216\_pdf-61408029.pdf
2. Gibbins J, McCoubrie R, Forbes K. Why are newly qualified doctors unprepared to care for patients at the end of life? Med Educ. 2011;45(4):389-399.
3. Bowden J, Dempsey K, Boyd K, Fallon M, Murray SA. Are newly qualified doctors prepared to provide supportive and end-of-life care? A survey of foundation year 1 doctors and consultants. J R Coll Physicians Edinb. 2013;43(1):24-28.
4. Linklater GT. Educational needs of foundation doctors caring for dying patients. J R Coll Physicians Edinb. 2010;40(1):13-18.
5. Leadership Alliance for the Care of Dying People. Priorities for care for the dying person: duties and responsibilities of health and care staff. Leadership Alliance for the Care of Dying People. 2014 [cited 2017 October 22]. Available from http://webarchive.nationalarchives.gov.uk/20160506190405/http://www.nhsiq.nhs.uk/media/2485900/duties\_and\_responsibilities\_of\_health\_and\_care\_staff\_-\_with\_prompts\_for\_practice.pdf.
6. Redman M, Pearce J, Gajebasia S, Johnson M, Finn G. Care of the dying: a qualitative exploration of foundation year doctors’ experiences. Med Educ. 2017;51(10):1025-1036.
7. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117.
8. UK foundation programme office. Syllabus. UK foundation programme office [Internet]. 2016 [cited 2017 October 22]. Available from: <http://www.foundationprogramme.nhs.uk/curriculum/Syllabus>.
9. Arolker M, Barnes J, Gadoud A, Jones L, Barnes L, Johnson MJ. “They’ve got to learn” – a qualitative study exploring the views of patients and staff regarding medical student teaching in a hospice. Palliat Med. 2010; 24(4):419-426.
10. Parikh PP, Brown R, White M, Markert RJ, Eustace R, Tchorz K. Simulation-based end-of-life care training during surgical clerkship: assessment of skills and perceptions. J Surg Res. 2015;196(2):258-263.

Dr. Sareena Gajebasia (SG), Dr. Jessica Pearce (JP) and Dr. Melody Redman (MR), with supervision from Dr. Gabrielle Finn (GF) and Professor Miriam Johnson (MJ), undertook this work in partial fulfilment of the academic foundation programme training in the North Yorkshire and East Coast foundation school.

SG: developed the concept and contributed to the study’s protocol. Involved in data collection and data interpretation. Prepared the first draft of the manuscript and contributed to revisions of the intellectual content.

JP: developed the concept and contributed to the study’s protocol. Involved in data collection and data interpretation. Contributed to the intellectual content of the paper.

MR: developed the concept and contributed to the study’s protocol. Involved in data collection and data interpretation. Contributed to the intellectual content of the paper.

GF: Contributed to the study’s protocol. Involved in data collection and data interpretation. Contributed to the intellectual content of the paper.

MJ: Contributed to the study’s protocol. Involved in data interpretation. Contributed to the intellectual content of the paper.