Title

Care of the dying: A qualitative exploration of Foundation Year doctors’ experiences.

Authors

Dr Melody Redman, Dr Jessica Pearce, Dr Sareena Gajebasia, Prof Miriam Johnson, Dr Gabrielle M. Finn

Institution

Hull York Medical School, John Hughlings Jackson Building, University of York, Heslington, York, North Yorkshire YO10 5DD

Corresponding author

Dr Melody Redman, hy8mgr@hyms.ac.uk

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Ethical approval
Ethical approval was granted by the Hull York Medical School (HYMS) Ethics Committee.
Abstract

Context

Foundation Year doctors (FYs), who are newly qualified, are expected to provide care for dying patients. Experiences at this early mandatory stage of training may form the foundation for future encounters, but little is documented about what these experiences involve. The aim of this research was to explore the experiences of FYs in caring for the dying, using the recently published ‘Priorities for Care of the Dying Person’ as a conceptual framework, to identify areas for improvement in education and clinical practice.

Methods

Semi-structured group and individual interviews were conducted to explore the experiences of FYs and how these relate to the five aspects of the ‘Priorities for Care of the Dying Person’: ‘recognise,’ ‘communicate,’ ‘involve,’ ‘support,’ and ‘plan and do’. All FYs in North Yorkshire and East Coast Foundation School (n = 335) were invited to participate and 47 FYs were recruited from five sites through convenience sampling and snowballing. Recordings were transcribed verbatim and a framework analysis approach was used with the published ‘Priorities for Care of the Dying Person’ guidelines as a conceptual framework.

Results

Five main themes and 13 subthemes emerged from the data. The five main themes, which mapped to the conceptual framework, were: recognition that the patient is dying; communication with the patient, family and other staff; involvement of the patient and family in their care; support for the dying person and their family; planning and carrying out good care of the dying. Examples of when things are done poorly or done well were shared as context to experience.

Conclusions

Areas for improvement were identified around all five main themes. These will be useful to inform undergraduate and foundation training to improve the experiences of Foundation Year doctors, and thereby improve patient care.

Reference


Abstract word count = 286 (excluding reference)
Introduction

Care of the dying patient is an integral responsibility of Foundation Year doctors (FYs). In their first year as a doctor, FYs will look after around 40 patients who pass away, and approximately 120 patients nearing the end of their life.1 (page 232) The General Medical Council (GMC) recognises care of the dying as an integral part of medical practice, and their guidance is set out in their 2010 publication, ‘Treatment and care towards the end of life: good practice in decision making.’2 Recently, the Leadership Alliance for the Care of Dying People (LACDP) published a pivotal document ‘Priorities for Care of the Dying Person’3 which outlines five key priority areas to be addressed by the healthcare team. These five areas are ‘recognise,’ ‘communicate,’ ‘involve,’ ‘support,’ and ‘plan and do.’3 LACDP contains 21 national organisations, including many major stakeholders such as the Department of Health and Health Education England.4 A national care of the dying audit occurs regularly5 but the experience or performance of FYs is not addressed.

The Foundation Programme is a two-year broad training programme for newly-qualified medical graduates working in the UK. Doctors on this programme are known as Foundation Year 1 (FY1) or Foundation Year 2 (FY2) doctors, and their duties consist of both service provision and clinical training. In 2015, 15,355 of 59,250 doctors in training posts in the UK were FYs.6 The Foundation Programme curriculum includes competencies relating to care of the dying.7 Following on from this, the majority of training and career pathways for doctors -will involve some aspects of care of the dying. Therefore, this common stage of training is a key opportunity to instil principles of good practice of care of the dying. Whilst there is much literature considering these issues for medical student education and broader stages of training5,8-12, it is important to understand the experiences of FYs specifically.

Studies focusing specifically on FYs’ experiences of caring for the dying are limited.13-15 One Scottish study showed that FYs felt inadequately prepared to care for a dying patient, a thought echoed by senior medical staff.13 Another study concluded that ‘undergraduate medical education is currently failing to prepare junior doctors for their role in caring for dying patients.’14 Similarly, Linklater identified that there are areas within caring for the dying that FY1s found difficult, such as communication, lack of support from senior medical staff, and providing inappropriate medical treatment when futile.15 There may be emotional distress and responsibility felt by all staff in these situations, alongside uncertainty and ethical dilemmas.2 (page 10) A pathway intended to aid in care of the dying, which was in widespread use across England, was recently withdrawn, and a review undertaken16 following alarming media reports and criticism of poor care. A 2016 Cochrane review found limited evidence of the effectiveness of pathways to assist with providing this care.17 Care of the dying is emotive, important, and closely scrutinised, and has potential to be a particularly challenging area for FYs.

In view of the significance of care of the dying and the literature which suggests that doctors are underprepared for this role13-15, the aim of this research study was to explore the experiences of FYs in care of the dying. The ‘Priorities for Care of the Dying Person’3 was used as a conceptual framework. This
framework allowed the exploration of experiences against a reputable and established national source, to provide a unique insight into the experiences of FYs which may then help identify areas for improvement in training and clinical practice. The research questions for this study were: i) What are the experiences of FYs, ii) how do these relate to the five ‘Priorities for Care of the Dying Person’\textsuperscript{3}, and iii) how can any findings inform under- and post-graduate medical education curricula?

**Methods**

**Ethics**

Ethical approval was granted by the Hull York Medical School (HYMS) Ethics Committee. This included the method of invitation, obtaining consent, data use, storage and dissemination. As the project only involved NHS staff, NHS Research Ethics Committee review was not required\textsuperscript{19}, but institutional approvals were gained prior to recruitment.

**Design**

Semi-structured group interviews were used to enable the participants and researchers to discuss complicated subjects and explore FYs’ experiences, perceptions and reasoning.\textsuperscript{19,20} Due to the practical necessity of scheduling around clinical commitments, some participants elected to contribute via individual interviews instead. Individual interviews allow for a more in-depth exploration of issues\textsuperscript{19} and can be used alongside group interviews\textsuperscript{21} (p213) Therefore, a pragmatic mixture of group and individual interviews was used to maximise the opportunities for FYs to contribute. Interviews were peer facilitated and the strengths and weaknesses of this is discussed in the limitations section.

As the ‘Priorities for Care of the Dying Person’\textsuperscript{3} was used as a conceptual framework to generate the topic guide, framework analysis was used. An inductive approach was exercised whereby the five priorities\textsuperscript{3} were pre-selected as key themes\textsuperscript{22}. A topic guide for the group and individual interviews was developed using the current literature and the document ‘Priorities for Care of the Dying Person’\textsuperscript{3}. It was then tested in a pilot group interview before use which allowed the refinement of stem questions. The topic guide consisted of open questions regarding FYs’ experiences of care of the dying to stimulate discussion, followed by stems based upon ‘Priorities for Care of the Dying Person’\textsuperscript{3}. These stems and prompts (see Table 1) were used for all interviews to reduce interviewer bias and enable transparency, whilst still allowing for an inductive response based on participants’ narrative and feedback.

**Study setting and participants**

FYs from across the North Yorkshire and East Coast Foundation School, which covers five sites (York, Hull, Scunthorpe, Grimsby and Scarborough), were invited to participate via convenience sampling
through email, social media and snowballing. No participant relationship was sought prior to study interviews.

Participation was voluntary. Consent, information and short demographic data questionnaires were completed. Participants were offered light refreshments and a certificate for participation.

Data collection

Eight group interviews and twenty-one individual interviews were conducted between January and March 2016 and were all audio-recorded. The interviews were largely conducted by one author (JP) and MR/SG/GF each conducted at least one group interview. Group interviews contained between two and five participants and were facilitated by a single researcher (JP/MR/SG/GF) who introduced their role at the beginning of the session; no observers or other individuals were present. HYMS facilities were used at each of the five listed hospital sites, and sessions were conducted outside of participants’ working hours. Individual interviews were held over the phone or over videoconferencing facilities. No repeat interviews were conducted. The researchers were all female; three were FY2s on the Academic Foundation Programme in Medical Education (JP/MR/SG), overseen by a Senior Lecturer in Medical Education holding a PhD in Medical Education (GF) and a Professor of Palliative Medicine (MJ). From a reflexive standpoint, it is worth acknowledging steps taken to minimise researcher bias, namely the use of standardised stems and prompts (see Table 1), an agreed framework, and data analysis steps as described below. Transcripts were not returned to participants for feedback. Participant validation was not used as different experiences may have occurred between the time of interview and transcription and due to the excessive burden of time this would impose on busy participants. No participants withdrew from the study.

Data analysis

The procedure for data analysis included verbatim transcription, familiarising with the interview through reading the transcript, open coding, developing the framework, charting and interpreting the data. Transcripts were coded using an agreed framework, with comparison across the transcripts. The results were coded and data were managed using NVivo qualitative data analysis software (Version 11). A combined approach was used; whilst the five ‘Priorities for Care of the Dying Person’ were used as a conceptual framework and as pre-selected themes, coding was inductive and subthemes were found under each priority. Care was taken to include contradictory views during the coding process. Participants were not involved in checking the findings. All authors contributed to interpretation of the findings including MJ who is a senior clinical academic in palliative care, involved in under- and post-graduate palliative care education in HYMS. In this paper, the results section will be restricted to presenting the data, then the discussion will be used to present the analysis of the findings in the light of other relevant literature.

Results
A total of 47 (14%) FYs participated out of 335 (see Table 2 for demographic data) (mean age 25.7 years, range 23-38). There was an even split between FY1s and FY2s. Participants gained their medical degree from 17 medical schools, of which two were outside the UK.

Thematic saturation was reached. Thirteen main subthemes arose from the five overarching themes. These are shown in Table 3.

Unsurprisingly, given the topic guide used the ‘Priorities of Care of the Dying Person’ as a frame, the five main themes directly mapped onto each priority. However, the 13 subthemes were not confined by those topics and were included to minimise reporting bias. An inductive process of exploring participants’ discussion allowed for further subthemes to be uncovered. In this paper results are therefore presented using the conceptual frame provided by ‘Priorities for Care of the Dying Person’.

Other themes further exploring education and training will be presented in another paper by the authors. Each of the five priorities are defined and then explored in turn with themes and illustrative quotes from participants. Quotes from participants in group interviews are labelled with their ‘G’ (group) and ‘P’ (participant) number. Quotes from individual interviews are identified by their ‘I’ (interview) number. No participant demographics are linked to these in order to preserve anonymity.

Recognition that the patient is dying

“The possibility that a person may die within the next few days or hours is recognised...”

Participants generally found it difficult to recognise a patient was dying, but found that this became easier with experience.

“...it’s difficult to recognise kind of the signs, such as things like agonal breathing, which we get told about in medical school but haven’t seen yet.” G7, P3

“...it was challenging initially... recognising that they are deteriorating... at the moment I think with experience I am getting a bit better, I wouldn’t say I’m the best yet but getting better.” I16

Participants also discussed differences between specialties when recognising a patient was dying; surgical specialities were highlighted as an area where this was particularly poor.

“I think in my surgical job patients that did end up on palliative care pathways it tended to be much closer to the point of death than on medical [jobs]...” G6, P4

There was also some exploration about whose role it is to recognise when a patient is dying. Participants questioned if it was the role of the FY or the responsibility of a more senior doctor or a more experienced nurse.
“...it’s usually the Consultant who says, okay, you know, this person is dying or even my, my SHO [senior house officer*] and stuff... I just depend on... the opinions of those around me who have that experience and who... can kind of read the situation better than I can.” I9

*Senior house officer is an unspecific term which may include any doctor at FY2 level or above.

This was sometimes accompanied by a fear of uncertainty.

“I think the nurses are quite good at recognising ... they tend to express that, which is usually a good thing, erm, but I, it’s one of the things that always scares me... there’s always that kind of, oh but what if they’re not dying?...” I15

However, as FYs gain experience they may be more likely to prompt other team members to consider the diagnosis.

“...it’s never us that has to say end of life, so, but it’s still important to be able to recognise it so we can like prompt people to maybe start thinking about it...” G5, P1

Conversely, it was also apparent that sometimes it can be clear to the FY, but others may not accept that the patient may be dying.

“sometimes... it’s obvious where things are going but then there’s a, there’s almost a reluctance to accept it, ... those times I feel maybe I’ve recognised it, erm, but then, the decision isn’t made that quickly and that makes me doubt... is it because I’m getting this wrong” I21

The responsibility of an FY in recognising dying was sometimes unclear, and where this was recognised, there may have been a reluctance to accept it by others in the team. It may be beneficial to clarify FYs’ roles regarding recognition of dying, and to reduce the disparity between specialties in recognition that a patient is dying.

Communication with patient, family and other staff

“Sensitive communication takes place between staff and the dying person, and those identified as important to them.”3 (page 1)

Communication was extensively discussed by participants including both communication with the patient and the family, and communication between involved staff, with positive and negative examples of each.

(i) Communication with patient and their family

Some FYs were surprised to find it was their role to break bad news or communicate care plans to the patient and family.
“...everything I do for the first time I feel like out of my depth, but I never, I didn’t envisage having to have, having to take that sort of initiative in my F1 year, especially so early in my very first job”

This responsibility was sometimes due to practical issues, for example, being the only doctor available. They found it very hard without the necessary knowledge to provide the quality of information they wanted to communicate to patients.

“There's been occasions when there's questions I would love to have been able to answer and I just couldn't... I find it hard to deal with personally because I feel as if I've let them down by not doing the job that I would want to do for them...”

Value was attributed to communication with the family, which also made their role easier.

“...they're just really worried about, you know, their sick mum or dad and, and all of a sudden they have a doctor coming in going ‘well we'd like to discuss, you know, end of life, we'd like to discuss DNAR ['do not attempt cardiopulmonary resuscitation' order]’... Yeah, I think if, if you've got the family on board, you've got the family on your side life's a lot easier...”

This also brought pressure, as these interactions were seen as critical.

“...it’s quite intimidating because... they always remember the discussion with the doctor who told them that their loved one is going to pass away [die] and they are really critical kind of doctor-patient/doctor-relative moments that you really don’t want to mess up and it’s like really really scary ...”

However, when communication was sensitive and effective, participants found it could be a valuable part of their role.

“...it’s quite rewarding though I think... when you pick up on that and you do have these good like communication discussions with the family and they, even though it’s horrible to give that sort of information they were, felt so much better informed about what was going on...”

Just as the role of FYs was sometimes unclear in recognition of dying, there was also uncertainty about their role in addressing patients’ and their families’ expectations, which could be practically challenging, but potentially rewarding.

(ii) Communication with the team

Written and verbal communication within the multidisciplinary team were both reported as crucial. Multiple examples were given, but good communication at handover and documentation in the clinical record was particularly highlighted.
(a) Handover

At the beginning and end of some shifts, doctors have the opportunity to communicate to their colleagues written and verbal information about patients of whom the following doctor needs to be aware. It was noted as particularly important to include information about deteriorating patients and expected deaths in that handover process.

“...even at handovers...with the stroke ward... Even if people weren't necessarily for end of life... they were quite good at making strict escalation plans... they were quite good at setting out ‘this is the limits of what this person should be and it was all discussed with them’, with the patients, but it was quite a good, and so it meant handovers and things over the weekend that they, it was also quite clear.” G3, P1

Doctors may start a shift and suddenly find themselves responsible for the care of a dying patient or communication with their family. Therefore, communication between the team is highly important.

“...it’s really important that it’s that the on call doctor knows who the patients are that are expected to die because sometimes you get asked to see relatives of the patients that you don’t know... there wasn’t a specific area on our handover for expected deaths... there is something in there as well about handing over expected deaths, plans, and a little bit of background information for those patients to the on-call team.” G7, P3

Effective handover of patients who are expected to die may better prepare FYs when they begin a shift.

(b) Documentation and terminology

Participants described the importance of accurate and specific documentation of all aspects of patient care, ensuring access to relevant information from the patient’s notes.

“...so a lot of it is not just communication with the whole team but putting that communication into words in the documentation so it can be passed between different teams that don’t have chance to communicate verbally.” G7, P1

However, participants described a lack of clarity about the manner and content of documentation.

“...it’s not something...we’re really taught either, I never remember having tutorials on how to document end of life care and what. You know, we did in oncology, all the anticipatory medication but nothing about documentation or anything.” I2

Additionally, it could be confusing for different staff when terminology was inconsistently applied or not explained further.

“...sometimes it confuses the nursing staff as well because if, if somebody’s got a DNR [‘do not attempt cardiopulmonary resuscitation’ order] in place and they’re for ‘ward level care’, I think
sometimes that can be misinterpreted as end of life as well when actually they’re not end of life, they’re still for full and active treatment, but you’re just not going to take them to ITU [intensive treatment/care unit]…” G6, P2

Effective and proactive communication with the patient, family and team, involves accurate documentation (including discussions with patient and family), effective handover and appropriate use of terminology. There should be proactive support for FYs when they are required to have difficult conversations with patients.

Involvement of the patient and family in their care

“The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.”3 (page 1)

Participants felt strongly that patients should be seen as individuals and should therefore be involved in decisions.

“I think it’s important … for people to remember that not everyone has the same wishes and we can’t make assumptions about people.” I9

Some FYs, however, noted that this cannot always happen due to the patient’s capacity or level of consciousness.

“And in terms of end of life as well, I think only two of the patients… that I’ve ever looked after at end of life were kind of like responsive enough to be involved in their own decision.” G5, P1

Sometimes the patient’s lack of capacity led to the teams relying more heavily on input from families.

“…I feel like we don’t really get the wishes from the patient themselves because most of our patients are quite elderly and cognitively impaired so… they can’t always communicate what they want, so most of the time we speak to the family I think, to get that from the families and from their friends and if they are close to them and that’s when we find out, okay, you know, is this what this person would want or what would they prefer or, you know, would they prefer to die in a hospital, would they prefer to die at their own home or in a care home or?” I9

As families may be expected to be more involved in those situations, there was an emphasis on the delicacy of such conversations. There was a dilemma about the involvement of families in decision making, as this was sometimes an uncomfortable role for the FY.

“…some people turn it around on to the relatives and say … ‘What would you want them to do’, it’s, it’s really not that fair because then they do kind of feel like ‘well I want them to stop treatment, maybe that’s why they died and it’s my fault, maybe I shouldn’t have said that’... ask
them... but then you kind of need to make, make them feel that you're the one in control and you’re just involving them, you’re not making them make the decision.” I19

Involving patients is positive where capacity allows. Advanced planning could be considered. Involving families is beneficial but requires careful consideration to not make them feel overburdened.

Support for the dying person and their family

“The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.”

The discussion around support included comments which overlapped with issues raised about communication. Several FYs felt support was largely provided by nurses and palliative care teams and time can be a challenging factor.

“...So in a way you never know whether people want to be left alone or whether they want to talk through things or not, the nurses would always like to give that option but you don’t always have the time to do that...” I19

It was noted that it may be difficult to know how to best support family members, partly because of the variety in individuals’ reactions.

“...I think it’s more dealing with people who’ve got different kind of reactions and grief responses, as I say grief reactions and things within a family and trying to ..., explain things appropriately ... but normally you're having to do it all in the same conversation, it's quite difficult to get the time to be able to have all those conversations separately with all those different people...” G3, P1

Different cultural, linguistic and faith backgrounds also challenged FYs’ ability to provide appropriate support.

“...And how best to kind of support them, erm. Erm, if you can learn more about kind of, erm, different tools for like death in different cultures, somethings there’s a lot of other people coming in with different religions and from different countries, you know, important, they see death in different ways and they want things done in certain ways...” I19

Providing appropriate support can be a challenge for FYs due to individual factors and time constraints, and may be better signposted elsewhere by the FYs.

Planning and carrying out good care of the dying

“An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.”
Examples were given by FYs of poor planning.

“... it’s not done well at all... especially on the weekend... if the team on Friday, they know that a patient’s going to be end of life over the weekend... they need to at least document into the notes that if this patient is deteriorating they’re for end of life care.” I13

There were also examples of where this was done well.

“...once you’re aware that a patient is dying, it’s been agreed, I think that the management is, is very good in the hospitals...” I18

Many participants noted the usefulness of the palliative care team when co-ordinating and delivering plans around end of life.

“...if you have easy access to the palliative care team that makes things a lot easier...” G4, P1

However, it was also clear that sometimes due to the speed of deterioration, or delayed recognition of dying, it can be difficult to allow for proper planning.

“...when they deteriorate in surgery there’s less of that kind of being able to plan for things and it’s more reactive rather than proactive, which is what I found with medicine.” G5, P2

There were also comments that the role of the FY is more to deliver the plan, rather than make the decisions.

“My job is more to carry out the management plan, I was not involved in decision making, I was involved in prescription of the end of life drugs and actually writing those things out...” G4, P2

FYs commented that up to date prescribing guidelines or appropriate protocols are not always accessible, thus indicating organisational issues which need to be addressed.

“...it does vary from trust to trust but at the time the Trust guidelines weren’t up on to our system so I had to go on to Google.” G1, P2

Therefore, palliative care team support and timely recognition of dying were important for allowing proper planning, but barriers such as sudden deteriorations, inaccessible resources, and the limitations of the role or knowledge of an FY may affect the FYs’ experience. Up to date guidelines for prescribing should be made available.

**Discussion**

In this review of FYs’ perspectives of caring for the dying, experiences were found to map to the five ‘Priorities for Care of the Dying Person’ expected of healthcare staff. However, within that experience, consistent with findings from the *End of Life Care Audit (EOLCA)*, both good and bad examples of care
and some areas for improvement were identified. Good experiences were characterised by an integrated team with excellent communication, documentation and handover. Clear plans for ceiling of care, documented discussions with patient and families, with proactive recognition of dying, particularly out of hours and weekends, prevented persistence with futile and often invasive treatments, and allowed appropriate care of the dying. Where care was poor, this was linked with late recognition or persistence with futile treatment, poor communication within the team or with the family, lack of understanding of and engagement with the patient or family’s wishes, waiting too long to seek the patient’s view (until they no longer had capacity), and inadequate support and management. Where the five priorities were not met, it is unsurprising that this reflected negatively in the FY’s experience. It was clear that not all FYs feel comfortable recognising patients who are dying or communicating with them, as previously described and that there are associated learning needs. Despite recommendations that a senior clinician is involved in recognising dying, the EOLCA identified that for a quarter of patients (24%), this did not happen. The data highlight the importance of senior support for FYs in this regard, which is echoed elsewhere for juniors further along in their training. Where senior clinicians remain actively involved in the care of the dying, better care is provided by the whole team who are supported in doing so. Where seniors “abdicate”, then decision making and care is left to the most inexperienced and poorly supported member of the team. Medical students and post-graduate trainees need systematic and experiential training about care of the dying as part of this support. Models exist but are variably implemented. The palliative care team were identified as an important source of support, which is reinforced elsewhere. Clinical, practical, and emotional support for all doctors caring for dying patients have been identified by the British Medical Association as important. Therefore it is crucial that this support is also provided for the most junior, least experienced doctors – the FYs.

Poor FYs’ experience was also linked to delayed recognition of dying. Delayed recognition of dying is common. One centre’s audit found that for 87% of dying patients, recognition occurred less than 72 hours prior to death, whilst EOLCA found that for half of all cases, recognition occurred less than 34 hours prior to death. Qualitative research has also identified a culture barrier to accepting death as an acceptable outcome. It is important that recognition occurs as early as possible, to deliver good care, and improve FYs’ experience of this important part of their job.

It is notable that several FYs used the term “end of life” interchangeably with “care of the dying”. “End of life care” is used in UK guidance to mean when an individual is expected to die within 12 months, whereas care of the dying is referring to patients who may die in days/hours. Whilst many principles overlap between the two, it would appear that there is a need for FYs and educational resources to be clear with this terminology. This research was not intended to explore the experiences of those caring for “end of life care” patients, who are expected to die within 12 months, but throughout it has been apparent that there are issues regarding terminology in this area. Recognition of dying may be delayed, and adequate palliation of symptoms and other concerns in people not imminently dying prevented if “palliative care”, “end of life” and “care of the dying” are perceived to be synonymous.
**Limitations**

The three main authors (SG/JP/MR) for the study were all FY2s at the time of research. The experiences of these three FY2s may have subconsciously influenced the facilitation of the interviews. However, their role may also have reduced the power differential between facilitator and participant, and there is less chance of peers misinterpreting the discussion\(^2^0\) (page 97). There were advantages to being medically trained in terms of familiarity with the language and concepts discussed, but on the other hand, some participants may have felt constrained by this peer-facilitated setting discussion\(^2^0\) (page 98), and there may be limitations around perceived lack of neutrality or doubts of confidentiality.

The research was conducted as a combination of both group and individual interviews.\(^2^1\) Fewer group interviews and more individual interviews were conducted than initially expected, largely due to participant availability as busy FYs with different working patterns. There was a relatively large sample size, and similar themes were found across both group and individual interviews, both of which help negate any impact of mixing the methods. With interviews, there is no participant interaction, and this may have had implications on themes which were discussed, but does allow for more in depth discussions of topics.\(^2^9\)

One limitation was the time constraints of the study period and the length of interviews, as there was a rich depth to both and further questions could have been asked to explore the topics.

The research was conducted at one foundation school (NYEC), but graduates from 17 medical schools participated. There was variety of teams and hospitals, and duration of experience (6 to 18 months) which will have affected FYs’ experiences. Whilst recall bias may have affected the accuracy of the events described, the experiences of the FYs remain valid. In the context of the aims of the study, the perceptions of the FYs are more important than a factual account.

Inevitably, research volunteers may be those with strong views and experiences in the area, either positive or negative. However, the broad range of 47 participants (see Table 2), would indicate wide representation of FYs at NYEC.

**Clinical and training implications**

To improve the five aspects of ‘recognise,’ ‘communicate,’ ‘involve,’ ‘support,’ and ‘plan and do’\(^3\), recommended areas concluded from the exploring the experience of FYs are listed in Table 4.

*Insert Table 4 here*

**Conclusions**
Using the ‘Priorities for Care of the Dying Person’ as a framework, these data highlight both good practice and areas for improvement. Experiences of care of the dying varied in quality depending on several factors. Good experiences tended to be in circumstances where the five priorities were being addressed by the whole clinical team. Gaps where the five priorities were not met can be addressed through training, support, and alignment with the five priorities to then aim to improve the experience of care for patients, families and the FYs caring for them, and to instil principles of good care of the dying in these doctors to take with them throughout their career.

### TABLES

**Table 1** – Stems and prompts related to the ‘Priorities for Care of the Dying Patient’ used for group and individual interviews

<table>
<thead>
<tr>
<th>Topic stem</th>
<th>Prompts</th>
</tr>
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</table>
| Recognising the dying patient           | Was it recognised that the patient was dying?  
Who recognised that the patient was dying?  
When was it recognised?  
Was this acted upon?                      |
| Communication                           | Was the situation communicated with the patient and their family? If so, how and by whom?  
How did the team communicate with each other?  
How did you feel about your communication?  
Did the patient understand?  
Were there any conflicts?                  |
| Involving the dying patient in their care | Was the patient aware of the situation?  
How were they, if at all, involved in their own care?                                |
| Supporting those close to the patient   | Thinking about the patient’s relatives, can you tell me what role you think they have/had?  
Did you involve the family in the care?  
Did the family need any support before or after their relatives passing? |
### Developing a plan for the patient’s care and treatment

<table>
<thead>
<tr>
<th>Was a plan for care/treatment made? How?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was it timely?</td>
</tr>
<tr>
<td>Was a ceiling of care agreed? If so when?</td>
</tr>
</tbody>
</table>

---

**Table 2 – Demographics of 47 participants who contributed**

<table>
<thead>
<tr>
<th>Demographic factor</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Mean = 25.7 years (range = 23-38 years)</td>
</tr>
<tr>
<td></td>
<td><em>Not disclosed = 2 participants</em></td>
</tr>
<tr>
<td><strong>Medical school of graduation</strong></td>
<td>Hull York Medical School = 14 participants</td>
</tr>
<tr>
<td></td>
<td>14 other UK medical schools = 30 participants</td>
</tr>
<tr>
<td></td>
<td>2 non-UK medical schools = 2 participants</td>
</tr>
<tr>
<td></td>
<td><em>Not disclosed = 1 participant</em></td>
</tr>
<tr>
<td><strong>Grade</strong></td>
<td>Foundation Year 1 (FY1) = 24 participants</td>
</tr>
<tr>
<td></td>
<td>Foundation Year 2 (FY2) = 23 participants</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Female = 27 participants</td>
</tr>
<tr>
<td></td>
<td>Male = 20 participants</td>
</tr>
<tr>
<td><strong>Site</strong></td>
<td>Hull = 15 participants</td>
</tr>
<tr>
<td></td>
<td>York = 15 participants</td>
</tr>
<tr>
<td></td>
<td>Scarborough = 3 participants</td>
</tr>
<tr>
<td></td>
<td>Scunthorpe = 8 participants</td>
</tr>
<tr>
<td></td>
<td>Grimsby = 6 participants</td>
</tr>
</tbody>
</table>
Format of participation

- Group interview = 26 participants
- Individual interview = 21 participants

Table 3 – Themes explored under the framework of the ‘Priorities for Care of the Dying Person’

<table>
<thead>
<tr>
<th>Priority/Theme</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognition that the patient is dying</td>
<td>• Experience</td>
</tr>
<tr>
<td></td>
<td>• Differences between specialties</td>
</tr>
<tr>
<td></td>
<td>• Role of FY</td>
</tr>
<tr>
<td></td>
<td>• Reluctance to accept</td>
</tr>
<tr>
<td>Communication with patient, family and other staff</td>
<td>• With patient and their family</td>
</tr>
<tr>
<td></td>
<td>• With team</td>
</tr>
<tr>
<td></td>
<td>o Handover</td>
</tr>
<tr>
<td></td>
<td>o Documentation and terminology</td>
</tr>
<tr>
<td>Involvement of the patient and family in their care</td>
<td>• Capacity</td>
</tr>
<tr>
<td>Support for the dying person and their family</td>
<td>• Culture</td>
</tr>
<tr>
<td></td>
<td>• Palliative team</td>
</tr>
<tr>
<td>Planning and carrying out good care of the dying</td>
<td>• Palliative team</td>
</tr>
<tr>
<td></td>
<td>• Speed of deterioration</td>
</tr>
<tr>
<td></td>
<td>• Role of FY</td>
</tr>
<tr>
<td></td>
<td>• Protocols/guidelines</td>
</tr>
</tbody>
</table>

Table 4 – Recommended areas concluded from the exploring the experience of FYs

Recommendations for consideration by the UK Foundation Programme Office, Academy of Medical Royal Colleges and members of LACDP:

- Clarity of FYs’ roles regarding recognition of dying
- Reduce disparity between specialties in recognition that a patient is dying
- Effective and proactive communication with the patient, family and team, which includes accurate documentation (including discussions with patient and family), effective handover and appropriate use of terminology
- Proactive support for FYs, especially when they are required to have difficult conversations with patients
- Involvement of patient and family in decision-making where capacity allows (consider advanced planning)
- Ensure support is available for those important to the patient
- When planning, think holistically about the patient and engage the palliative team wherever needed
- Ensure up to date guidelines for prescribing are available
References


24 - QSR International Pty Ltd. NVivo qualitative data analysis software version 11, 2015.


29 - Stokes D, Bergin R. "Methodology or “methodolatry”? An evaluation of focus groups and depth interviews". QMR. 2006;9(1):26-37.