End of Life Care in Staffordshire: Health Professional Perspective

Project Report

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Acknowledgements

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Health professionals' views and experiences of discussing end-of-life care in acute and primary care settings

Abstract

Background:

End-of-life care refers to the final year of a person's life. End-of-life care in hospital settings has been suggested to be sub-optimal (e.g., Al-Qurainy et al., 2009). The aim of this study was to explore health professionals' views and experiences of providing end-of-life care in Staffordshire and how this could be improved.

Methods:

Sixteen health professionals working in primary care (three general practices) or acute care (one NHS acute hospital trust) participated in a semi-structured interview. Interviews were audio-recorded, transcribed and analysed using thematic analysis.

Results:

Three themes emerged from the analysis as follows:

(1) Having the conversation earlier – to make the decision that the patient is entering their end-of-life and to initiate the conversation with patient and family at an earlier point.

(2) Personalised and holistic journey of care – to build a relationship with patients and allow them and their family the time to make an informed choice about their wishes.

(3) Delivering on patients' wishes – suggestions for how to improve the delivery of end-of-life care locally, including how to share and record patient wishes, and to deliver care that can meet those wishes.

Conclusion:

Participants highlighted the complex and challenging nature of end-of-life care. The importance of patient wishes was emphasised and suggestions for how to improve end-of-life care locally, to better deliver on patient wishes, were identified. The development of a local strategy/pathway may help to support this and to provide clarity about expectations and legal implications as well as roles and responsibilities.

Keywords:

End-of-life care; palliative care; health professionals; qualitative research; hospital

Introduction

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."
Dame Cicely Saunders (1918 - 2005).

End-of-life care usually refers to the final year of a person's life. The ambition is to help people to die with dignity, through good planning and good care (General Medical Council, 2010). Despite being a key part of medicine, end-of-life care has received less attention (Lancet, 2012; Singer and Bowman, 2002). Professionals and public bodies have been calling for actions to improve medical decision-making near the end-of-life over a number of years (Froggatt and Payne, 2006; Rudberg, Teno, and Lynn, 1997). Despite ongoing efforts to improve end-of-life care, there are still unmet needs (Ventura, Burney, & Brooker, 2014).

Providing end-of-life care within the hospital setting appears to be challenging. There is evidence from the last 10 years that quality of end-of-life care within the hospital setting remains sub-optimal (Al-Qurainy et al., 2009). This is supported by the National Survey for Bereaved People (2015) that found, whilst there is more good care than bad care[1], 69% of relatives rated hospital care as outstanding, excellent or good, compared with the respective figures for care homes (82%), hospice care (79%) and care at home (79%).

Research with patients and families about end-of-life care **in hospitals** suggests that patients receive poor management of symptoms and that family members can find it difficult to engage with health professionals in making decisions about care and management of end-of-life for their loved ones (Robinson et al., 2014). Various studies have identified communication issues as a fundamental challenge in end-of-life care, both within the hospital setting and more generally (e.g., Robinson et al., 2014; Richards et al., 2012; Gott et al., 2011; Glogowska et al., 2016). It has been suggested that a lack of communication between patient and health professional can lead to inappropriate treatment at the end of a patient's life (Glogowska et al., 2016).

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[1] 75% (of 49,000 respondents) rated the overall quality of end-of-life care for their relative as outstanding, excellent or good; 10% rated care as poor.

The nature of the acute hospital environment can present challenges for caring for dying patients. Robinson et al. (2014) highlight, with the multi-bedded rooms and high patient turnover of hospitals, it may be unhelpful to make direct comparisons with other settings (such as hospices) in terms of standards of care for dying patients. Gott et al. (2011) also identified the difficulty in 'standing back' (i.e. the opportunity to pause, stand back and think about it) within the acute hospital setting as a key barrier, and that professional hierarchies restrict the input that junior/nursing staff can have into decisions.

That services remain 'fragmented' also presents challenges (Davies et al., 2014). Issues around continuity of care in hospital and after discharge have been highlighted (Richards et al., 2012). Patients at the end-of-life may be admitted to hospital due to difficulties in finding an alternative solution, for example, a lack of planning which may have enabled them to remain at home if they wished (Glogowska et al., 2016).

There appears to be an emphasis on the importance of planning and patients' personal wishes about their end-of-life care. The end-of-life strategy in the UK acknowledges that individual preferences may vary and identifies the following as constituting a 'good death':

- ➢ Being treated as an individual, with dignity and respect;
- ➢ Being without pain and other symptoms;
- ➢ Being in familiar surroundings; and
- ➢ Being in the company of close family and/or friends (Department of Health, 2008: p9)

Increasing attention has been directed at **advance care planning** (ACP) since it was recommended by the UK strategy (Mullick et al., 2013). **ACP** is the process of discussing and recording a patient's wishes around goals of care for patients who may lose capacity or the ability to communicate in the future (Brinkman-Stoppelenburg et al., 2014).

Brinkman-Stoppelenburg et al.'s (2014) systematic review reports that ACP is often found to decrease life sustaining treatment, increase use of hospice and palliative care and **prevent hospitalisations**; it should be noted that most papers in that review were from US (81%), with differences in healthcare systems and cultural contexts to the UK. The authors concluded that ACP could potentially improve end-of-life care but highlight

that the methods/**tools used are varied** and the benefits are unclear (Brinkman-Stoppelenburg et al., 2014). This echoes Mullick et al's (2013) finding that evidence on the benefits of ACP is mixed but that more recent evidence suggests it can facilitate the delivery of care that is more in keeping with patient wishes and can increase patient and family satisfaction with care.

However, completion rates for ACPs are generally low and vary between countries and patient group (Godfrey and Hackett, 2015). Various challenges with ACP have been identified and previous studies have highlighted a difference between the theory of ACP (i.e., to help facilitate patient autonomy and document their wishes) and how it is implemented in practice (e.g., Mullick et al., 2013; Robinson et al., 2012). For example, Robinson et al. (2012) examined professional experiences of ACP in dementia and palliative care in the North-East of England and concluded that implementing ACP presented a **significant challenge with professional, organisational and legal factors issues all interacting**. They called for professional training to target these areas, alongside the standardisation of ACP documentation and clarity over roles and expectations of different professional groups. Robinson et al. (2012) also raised concerns about whether current service provision could meet patient wishes. Appropriate dissemination of ACP decisions has also been identified as a challenge given that (with the exception of lasting power of attorney) there is no central register of ACPs within the UK (Mullick et al, 2013).

Previous studies have tended to investigate end-of-life care in specific conditions/patient groups, rather than across acute and primary care. To our knowledge, no research has been conducted locally (Staffordshire) that focusses on health professionals' views and experiences of end-of-life care. This study therefore aims to address this by exploring health professionals' accounts of providing end-of-life care in Staffordshire, to inform local dialogue and improve local delivery of end-of-life care.

Method

Semi-structured interviews were conducted with 16 health professionals working in primary and acute care in Staffordshire (West Midlands, England) who have experience of providing end-of-life care. Nineteen participants expressed an interest in the study, however three were unable to participate. Ethical approval was obtained from the University ethics committee and Health Research Authority (IRAS Project ID 230859). All participants provided written informed consent prior to the interview.

Participants

Doctors were recruited from primary and acute care using purposive sampling to capture the views of health professionals working in varying roles and with varying years of experience. In the first instance the Medical Director and the Clinical Commissioning Group (CCG) contacted doctors in acute and primary care settings, respectively, to inform them about the research and invite to contact the researchers to express an interest. The participants (6 male and 10 female) were aged between 27 and 63 years and had been working in their role for between 1 month and 30 years. A mixture of consultants (n = 11), hospital doctors, including a core medical trainee (n = 2) and general practitioners (GPs, n = 3) took part, representing a variety of specialisms including, palliative care, critical care, cardiology, neurology, paediatrics and frail elderly. Two of the palliative care consultants worked across acute and hospice care and thus provided experiences of both settings.

Data collection

Individual interviews were conducted using a semi-structured interview guide. The interview guide was developed and refined with a steering group, which included consultants and GPs involved in end-of-life care in the local area. Interviews took place at the participant's workplace or the University according to participant preference. The researchers had no prior relationships with the participants.

After participants had been asked to describe their role, the interviews explored their views and experiences of providing end-of-life care. Specifically, participants were asked to explain how they find out information about the patient's wishes, what challenges they face in relation to discussing end-of-life care and what support might improve this conversation and communicating wishes with relevant services. They were also asked about their views on the current balance of quality of life versus

prolonging life, as well as advance care planning locally. Interviews lasted between 15 and 60 min, were audio-recorded and transcribed verbatim for analysis.

Data analysis

The data were analysed using thematic analysis (Braun and Clarke, 2006). The qualitative software package QSR NVivo 11 was used to manage the analysis process. To minimise potential bias in the interpretation of the qualitative data, two researchers were involved in the analysis and writing up process.

Results

The analysis of interview data identified three themes:

1) Having the conversation earlier
2) Personalised and holistic journey of care
3) Delivering on patients' wishes

Theme 1: Having the conversation earlier

This theme explores the difficulties of discussing end-of-life care in both healthcare settings and the wider society; whilst recognising that, the often-difficult conversations about end-of-life care wishes and plans need to happen earlier, when people have capacity.

Generally, given the years of experience within the sample, most of the participants felt comfortable discussing end-of-life with patients and their families. They spoke often about having developed their own routine/technique over time and with experience. Nevertheless, they acknowledged that **breaking bad news 'is never easy'** [Critical Care Consultant] and that 'the first steps are always the hardest' [GP1].

Participants highlighted the **complex and emotive nature** of the topic and emphasised that it can be **very difficult to predict outcomes** as every case is different:

> *"Although I might have seen sort of people with such-and-such Cancer, or people with heart failure before, every person is different, every family is different" (Consultant in Palliative Medicine)*

Participants also mentioned that it could be **difficult to reach agreement within the medical team** about when someone was approaching end-of-life:

> *"Sometimes our colleagues from other specialities from which we receive patients would say 'no we think we should continue and try this, try that', so the first challenge is often to get agreement about the fact that a patient is actually reaching the end of their life and that is before you approach families and patients". (Critical Care Consultant)*

Some participants explained how discussing end-of-life care raised **fears of failure** in a range of ways: getting a prediction wrong, of interfering and/or contradicting other staff, and of legal implications to their decisions.

Further worries about how the patient and family might react to such conversations were also talked about at length. Participants often spoke of risks around being sued or having a complaint lodged against them/where they worked.

Indeed, talking to patients about end-of-life was described as a 'brave discussion' or 'courageous conversation'. Participants expressed, from their experience, how some staff are afraid of having the conversation and thus avoid it:

> *"… some people just want to avoid the conversation altogether and pass it onto another person. But the problem is that it just gets passed on, and passed on, and passed on, and passed on and nobody actually sits anybody down and has an open conversation." [Palliative Care Consultant1]*

> *"The conversation itself might be difficult but I kind of feel it is my responsibility to bring it up, because who else is going to?" [GP2]*

> *"It is not right or fair to continue to do the easy thing." [Paediatric Consultant1].*

The Paediatric Consultant went on to explain:

> *"Patients come to me having had a lot of input from colleagues over a long period of time and no-one has had the brave discussion. The one that needs to be had, which is that sometimes it is kinder and more loving to withdraw care than it is to press on". [Paediatric Consultant1]*

Participants also recognised the fears of some patients to bring up the conversation:

> *"They are obviously frightened of actually raising it because the doctor may say 'yes, I think you are probably going to die in the next twelve months' and dealing with that information that they have just been given." [GP1]*

Participants highlighted **the need for conversations about end-of-life care to happen earlier**. Some participants suggested that health professionals, in both acute and primary care, need to be **more confident** to have conversations earlier:

> *"I think we should be a lot more confident about having that discussion before we even get to that point because just talking about your end of years shouldn't be a scary conversation." [GP2]*

> *"I think we are getting better at it [starting the conversation earlier] but we still have a long way to go." [Consultant Cardiologist1]*

The implications of not having the conversation early enough, were also reported by participants as highlighted in the following quotes from three different specialisms:

"… there should be that conversation at some point of how you want to live your last years and how you want to die. I don't think we are giving that right to people, we are afraid of having those conversations, even as doctors, because we are still human beings and we are depriving people of the right to choose how they want to die and that's a right." [A&E Doctor1]

"The problem is when they don't recognise that, or they recognise it but too late then that family loses that opportunity to have quality time with their child" [Paediatric Consultant2]

"I see that often, especially in cancer patients where there is time to discuss end-of-life options in a timely manner. The oncologists, the GP and everybody is so focused on the life prolongation treatment, like chemotherapy, radiotherapy or whatever, that the end-of-life topic is really only approached when it's almost too late to have a sensible discussion with a patient to find out what the patient really wishes." [Critical Care Consultant]

As the quotes above suggest, some participants felt there was a focus on prolonging life over quality of life. All participants were asked their views on **the current balance of quality of life versus extension of life**. Many highlighted that there is not a straightforward answer because of the subjective nature of 'quality' in life and the difficulty in predicting outcomes:

"I think things like saying 'I think the quality of life is very poor' is a very difficult thing to say because quality of life is a subjective view. Your view of quality of life depends on your religious views; your intellectual views; your cultural views; all sorts of things set your quality of life - your experience of life. So, what you think is a poor quality of life, I might think is quite good or vice versa". (Consultant Neonatologist)

*"We can't really put ourselves in the shoes of a patient whose life is having visitors, watching TV and reading a book. That is a good quality of life for that person and we are thinking well we can't walk to the shops so… I don't think we know and **I think it has got to come from the patients".** (Consultant Cardiologist1)*

Some (including palliative medicine, cardiology, gerontology, palliative care) felt that overall the right balance has not necessarily been achieved, that doctors could be

'rose tinted'/overly optimistic at predicting outcomes and that ultimately there was more of a focus on prolonging life:

> *"Well that's a tricky one. No probably I don't think we do, I think we are overly focussed on the prolongation of life" (Consultant Cardiologist2).*

> *"I think it probably swings a bit more that we are over-estimating what we can achieve and that we are probably pushing for too many tests and too much treatment when we should have focussed more on comfort and sort of achieving little goals". (Consultant in Palliative Medicine)*

In contrast, other participants (including GP, A&E, Neonatal) felt that, overall and taking into consideration all the complexities involved, the balance was good:

> *"I think we've pretty good at not trying to extend someone's life irrespective of the quality. I think we are pretty good on the whole. Focusing on someone's quality of life". (GP3)*

It was also highlighted that this could vary by specialism and by role/level of contact with the patient. Those working in intensive care, for example, were referred to as pessimistic about outcomes:

> *"It depends who you speak, intensive care physicians are unduly pessimistic and we often have to stop them from trying to turn patients off because we can see the long term results that that some people do make a good recovery but you have to give them a long time to do that" (Consultant Neurosurgeon)*

> *"We see first-hand what happens if you carry on for too long – the suffering that you inflict on the patient and that is something that we see in front of us every day and often find it distressing therefore we are often more proactive when it comes to actually accepting that the patient is reaching the end of their life". (Critical Care Consultant)*

This participant also discussed "how close you are to the patient" as being important, they went on to explain:

> *"The nursing staff often feel we should stop when the intensive care doctors don't feel that yet because we obviously are not that close to the patient as it is the bedside nurse that is physically at the bed side all the time. Therefore, we often say we can still try a bit longer; we can still try this or that; and the doctors that only come occasionally are even more remote or further away from the actual suffering in front of them, they tend to push even longer sometimes than we do". (Critical Care Consultant)*

This part of the interviews also raised questions about how 'success' is measured – and many implied a shift in focus from prolonging life to ensuring their death (and life) is dignified is required:

> *"Sometimes we can't cure everyone and that is not because I am a crap doctor, … sometimes I just cannot succeed but where I can succeed is ensuring that the child's death is dignified: that their symptoms are well controlled and that they are able to achieve what they are able to achieve, however small those wishes might be – enabling that to happen" (Paediatric Consultant2)*

An area that appeared particularly complex in terms of the balance of prolonging life versus quality of life related to **frail elderly**. It was highlighted that the 'default position' is to attempt resuscitation unless there is known to be a Do Not Resuscitate (DNR) in place and this was felt to be inappropriate in the case of some frail elderly:

> *"We have got it completely wrong on end-of-life care just by having resuscitation attempts as the default position if the wishes are not known for everybody. I am not speaking about the fifty-year-old with cardiac arrest. I am speaking about bed bound and severely frail old nursing home patients where it is absolutely inappropriate to only think about resuscitation if the heart stops – that destroys the complete dignity" (Critical Care Consultant)*

Examples were given of care homes ringing for ambulances for residents who were taken ill overnight and it was explained that, when a DNR is not in place, the paramedics legally have to attempt to resuscitate:

> *"By law have to start resuscitating them which is a highly unethical thing to do, but they have to". (Critical Care Consultant)*

> *"I think some of it is the care homes feel they will be sued for negligence for not sending people back (to hospital)". (Consultant Geriatrician)*

Some participants spoke of the ageing society and called for routine conversations about end-of-life care and what patients' wishes might be. It was felt that would also allow time for patients to think through their options, discuss with families, and make plans while they still have capacity.

> *"It is really important to capture it when they are of sound mind. For me, that is a challenge, having a conversation with someone who is clearly going into cognitive decline and I always sort of come away feeling I wish I could have had the conversation earlier" (GP1)*

More generally, discussing the 'taboo subject' of end-of-life care in wider society and the need to make such conversations the 'norm', were also considered by the health professionals:

"I just wish it was more part of our general culture as a society so that it wasn't a hospital thing, that it wasn't a doctor thing; that people talk to each other about it." [Consultant Cardiologist2]

Theme 2: Personalised and holistic journey of care

This theme captures the importance of relationships, emotions, timing and pace when planning, delivering and documenting the journey of care for the patient, wider family and the professional.

Participants explained the importance of **building rapport and trust where possible**, with each patient, to allow them to discuss their wishes.

"I think for most patients it is very difficult to have these very important, very intimate discussions, when they don't know the healthcare professional at all. … for lots of people, it's about having a bit of a personal relationship and then they will come out with what's really important to them" [Consultant in Palliative Medicine]

"The families trusted me enough to cry on me and to tell me what they really thought". [Paediatric Consultant1]

Continuity of care was also described as important for the professional and patient in ensuring a compassionate and informed approach to an individuals' end-of-life care.

"So, for me it is sides of a triangle which consists of integration, continuity of care and co-ordination of care. If we can get those three things right I think we will get somewhere." (GP2)

In keeping with relationships, participants mentioned holistic care and ensuring that care was centred around the individual, rather than the condition or medication. This included acknowledgment, understanding of and sensitivity towards the patient's beliefs and wishes.

"I think we get too fixated on end-of-life being about medication – it's not just about medication it is about the people who are involved in the journey with that person." [GP2]

"Practice wise, I have learnt a lot – that palliative care is not just about a body part or an organ like it is in the hospital, it is about the whole body

and a holistic approach. You need to have an open approach to everything." [Core Medical Trainee]

Furthermore, some participants explained the importance of building a relationship with the family as well as the patient.

"When you treat end-of-life care you don't treat only the patient, you treat a binomial, you treat patient and family, so you have to take both into consideration." [A&E Doctor]

Timing and pace

Timing and pace of conversations about end-of-life care were discussed frequently. One issue reiterated by participants was the **lack of appropriate time and space** to have these conversations within an acute setting. Some felt that patients might not absorb all the information in a hospital setting and that community settings might be more appropriate.

"…you might have an agenda on what you want to say but you can only say as much as the parents are ready to hear" [Consultant Neonatologist]

"Well one problem that we often have is time pressure. Often if you want to do a good job you need time because you need to adjust your pace to the patient or the families' understanding of the situation" [Critical Care Consultant]

They were mindful of trying to find 'the right time' to speak to patients and/or their families about end-of-life care:

"I have a template of the discussions in my own mind. I decide at the head whether I am going to have them depending on how the parent feels on that day and how the conversation opens up. It is intuitive. Sometimes it is definitely not the right day to have that discussion and you can tell. Sometimes it is the right time." [Paediatric Consultant 1]

Whilst acknowledging the varying timing and pace at which patients and families can absorb information, participants also spoke of the importance of timing for the professional, ensuring they were also emotionally ready to have the conversation. When discussing the challenges of discussing end-of-life care one participant commented:

"Sometimes from my side as well obviously there are days where I feel more capable of talking about things. There's other days where I feel you know sort of less inclined to tackle something sort of head on, where I

would like to avoid conflict a bit, because it's not a great day for me either." [Consultant in Palliative Medicine]

Another challenge identified here was around having conversations with families about **organ donation** and the time pressured nature of those conversations, whilst also considering the family's needs.

Planning for a personalised journey

In terms of planning for a personalised journey of care, from the participants involved in neonatal/paediatrics, there was a strong sense that **advance care plans (ACPs)** are used to help them have conversations with parents about their wishes for their child's end-of-life care:

> *"There's a children's advanced care pathway that we would use and go through that in detail and that is a document that you will keep revisiting as the situation changes". [Consultant Neonatologist]*

> *"We are quite different from adults in that actually we use our document (purple pages/our wishes document) to be able to have those conversations where possible and as early as possible" [Paediatric Consultant2]*

Other participants were aware but not personally involved in doing ACPs with patients and spoke more about referrals to the local hospice/palliative care teams:

> *"[those who] still have full cognition and what is happening to them and that is usually the situation where we would refer them to appropriate services such as the Macmillan team, palliative care team and their general care by that stage will probably be largely under the care of the oncologists. [Consultant Neurosurgeon]*

> *"Over here we have got teams who do it. I have never been asked to do it myself. We have got a specialist research nurse who does the advanced care planning discussions with the patients". [Core medical trainee]*

From participants' perspectives, there was potential for ACPs to help initiate/guide and record conversations about wishes for end-of-life care. Other advantages included that they could help inform the medical plan based on the patients' wishes:

> *"Think they can be useful when completed fully and taken the time to talk through an ACP. Can help to inform medical plan when completed in detail" [Palliative Care Consultant2]*

> *"I think it just reduces a lot of stress and anxiety and uncertainty. At that part of your life, nothing is certain, but you want as much certainty as*

possible, you want to be comfortable with what your expectations are".
[GP3]

Participants also identified a range of disadvantages/challenges with ACPs, including that it can sometimes be an awkward or uncomfortable process for patients:

"…the patient I have got in mind did just say that her GP kept trying to make an appointment to go through the paperwork. She didn't want to go through the paperwork. She felt that her GP was trying to sign her off and she wished it hadn't happened" [Consultant Cardiologist1]

The length of the ACP document and the time required to complete it properly were also highlighted. Another issue raised was fear of inflexibility with ACPs and that patients wishes and health needs might change. There was some concern that formalised plans such as an ACP may not be flexible enough to take such changes into account. However, it was also highlighted that an ACP is not a protocol, but a guide. Participants explained that whilst they would be useful tools to inform medical decisions, ACPs would not make decisions for them:

"I think to care for the patient would, again, be a clinical judgement because advanced care planning will only tell you about what the patient wishes but sometimes you also have to work according to the clinical setting and what their need is and what they would benefit with". [Core medical trainee]

Another consideration that participants identified here was the importance of the language used when having conversations with patients and their families about end-of-life care. The need to ensure language is appropriate to a lay audience rather than the medical profession was highlighted:

"I don't know if we should say 'planning for our future care?' Is it advanced care plan… but not making it so scary?" [GP2]

One GP spoke of how de-medicalising end-of-life care can help open up conversations:

"…I think it [the end-of-life conversation] actually breaks the ice a bit because the patient goes 'yes, I know I can't…' They have a way of saying it, so it will be things like 'oh doctor I know I am not going to be around forever' and it is great because you kind of de-medicalise the

*whole end-of-life thing and you have made it more about a sort of phase
or process rather than the COPD or the heart failure. It just then becomes
easier to manage that." [GP1]*

In terms of the language used and planning for a personalised journey of care, one consultant explained how living and dying should be planned for simultaneously and not thought of as separate dimensions:

*"… we use this thing called parallel planning. We plan about end-of-life,
but we also plan about living - living and symptoms, because actually they
both happen at the same time." [Paediatric Consultant2]*

Theme 3: Delivering on patients' wishes: suggestions for improvements

This theme explores suggestions for how to improve the delivery of end-of-life care locally. A large part of this was around communication and sharing information about patient wishes. Another key aspect related to how to implement these wishes as a system, to deliver the end-of-life care that respects patients' wishes as far as possible.

Sharing information: Communicating patient wishes

The importance of having **a record of the patient's wishes that is readily available and easy to access** was emphasised. Participants highlighted that, at present, this is not the case within the system itself and that the onus would be more on the patient, their family or carers to make those wishes known:

*"As an emergency physician, I can tell you most of the times the
information is not easy to access if it is there, and unless the patient
brings it himself, or the family or the Carers are quite aware of it, you don't
know where to find it, you don't know how to access it." [A&E Doctor)*

As such, there were calls for more advanced care planning/documentation of some description:

*"What we would basically need would be more advanced directives –
people thinking more about this at a time when they can think clearly
about these things and communicating their wishes and their beliefs to
family members or even writing them down and setting up an advanced
directive - that would be helpful for us". (Critical Care Consultant)*

The type of information that participants would want to know here related to what sort of interventions/treatments they would want, who they would want to have contacted,

their attorney/who is responsible for their affairs, along with where they want to die. Having information about their religious/cultural beliefs was also mentioned.

> *"Probably what sort of interventions or treatments they do or don't want when they come towards end-of-life care. Do they want me to treat infections vigorously and aggressively? Probably that's the most important. … I presume everyone wants to die without pain and with dignity, so that's a given. I suppose, how little intervention they want or how much intervention they want when it comes to towards the end."*
> *(GP3)*

It was also reported that ACPs do not need to be completed by a health professional and the potential to train others to assist patients in completing them was raised.

How to share patient wishes was identified as a challenge for the system and there was wide reference to things being 'slow' e.g. if a conversation was had at clinic, it would then need to be typed up etc. Crucially, in the absence of such information, the focus would be to '*carry on, carry on and carry on*' and treat patient (A&E Doctor). In terms of 'knowing where to look' for this information, questions were raised about who would 'hold' this information and what it might look like.

The potential for the patient to own the document was discussed as this would give clear guidance to paramedics if they were called to attend – how to make the document as visible and accessible as possible appeared to be essential.

Participants felt that the document should be accessible to anyone involved in providing care/treatment to the patient. A key challenge raised here was that primary and secondary care have different systems and that information is not shared between them:

> *"The IT system used by the community is completely different from the IT that is used by the hospital and one can't see the other." (Consultant Cardiologist2)*

As the following excerpts illustrate, this was felt to have contributed to a fragmented system:

> *"People have tried to invent other things… the problem with that then is it fragments the system because you have then got, for example … patients being looked after by five different people or organisations or whatever, and they are not actually joined up, which doesn't help the patient.*

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Everybody has their own way of looking at things and has a single approach". (GP1)

"We need really a single agreed care plan for a patient which not only is shared…held by the patient…but is easily shared with the all the partners and stakeholders and really the way to do it is to have an electronic record". (GP1)

There were calls for this to be addressed and for **the systems of primary and secondary care to be connected**. The transition between hospice and hospital was described as difficult and it was reported that explicit documents would be helpful (Palliative Care Consultant2). There were different views on whether paper or electronic copies would be most useful and often a combination of the two was suggested with the patient having a copy with them at home (to help paramedics/ambulance know of wishes), as well as a copy with GP/on file which should then be accessible to all those involved in providing end-of-life care to that individual. There was also a suggestion of implementing something similar to the pregnancy folder notes that are intended for the patient to carry with them at all times, to ensure that care plans/records and related documents are kept together and remain with the patient wherever they may be.

Delivering end-of-life care: Meeting patient wishes

Another aspect of this was around how the system could implement patients' wishes. There was a sense that **things are improving** in relation to delivering end-of-life care locally, and two participants specifically stated that end-of-life care is the *"most important thing we do"* in health care. A GP continued to explain that:

"End-of-life is the bit that you can really deliver universal care to your patients and the carers and the family wherever you are." [GP1]

However, as will be explored, throughout all the interviews there was a clear sense that there are improvements still to be made:

*"I think in lots of ways the system has recognised that it [end-of-life] is an important part of healthcare. I think it is going in the right direction, we just have to keep the momentum and continue to make sure that we **train everyone**, and everyone has got access to **communication skills training,** that people are supportive when they are sort of having to make difficult conversations, and yeah in a hospice, again especially in a hospital setting, but pretty much everywhere, **that the focus on what's important to the patient** stays." [Consultant in Palliative Medicine]*

As the quote above highlights, the need for education and training related to providing end-of-life care, and communication skills in particular, was emphasised. As mentioned earlier in the 'being brave' theme, most of this sample felt confident discussing end-of-life with patients and families however there was a clear sense they had built this up over time and experience (rather than through their medical training). Participants talked about a need for health professionals, and younger professionals in particular, to be more confident at having difficult conversations. There was a suggestion that this is important particularly considering the recent shift towards an ageing population and the complexities involved around frail elderly. There was frequent mention of 'advanced communication' training and it was highlighted that there was a waiting list for that.

Peer to peer training/shadowing/workshops to share experiences and techniques was also suggested, in comparison to more formalised training which participants highlighted was often selected based on their own preferences/interests. Participants also spoke positively about the local palliative care teams and the expertise and support they can provide:

> *"We find our palliative care teams to be hugely helpful in educating us and supporting us." (Consultant Cardiologist1)*

However, it was also emphasised that there is a need **to go beyond having conversations** about patient wishes, to actually put mechanisms in place that will enable their wishes to be delivered:

> *"There is no point saying we will do what we can to keep you at home and then you **find that there is not enough district nursing support; there isn't enough palliative care nurse input and it means that although they had a discussion that they** wouldn't be re-admitted, they keep coming back in, so who is there to stop them being re-admitted – what mechanisms are we putting in place?" [Consultant Geriatrician]*

> *"Probably get people to where they want to die if possible, but that is often fraught with hazards because they'd love to be brought to the hospice – the **hospice hasn't any beds and can't take them – they die in hospital".** [Consultant Geriatrician]*

As above, a lack of space to provide end-of-life care was identified. Participants called for more hospice places. In comparison, one [cardiologist] suggested having a special palliative care ward within the hospital, because whilst there are palliative consultants there are not palliative care beds. There was acknowledgement that resources are tight and often the focus in hospitals is on beds for those patients who they can help to survive or those who are going forward with organ donation.

There were also suggestions to focus on **improving discharge** in terms of planning and speed, rather than avoiding hospital admissions. As the following participant explained, they believed that admissions are often appropriate for palliative care patients – for example, if they need to have a scan/test/infection treated:

> *"But I think that where the hospital is then lacking is about getting them out quickly. … From my point of view, rather than focussing too much on admission avoidance, I would focus more on sort of a quicker discharge"*
> *[Consultant in Palliative Medicine]*

Related to this, another improvement put forward was to expand who is able to prescribe medication at home:

> *"Be able to prescribe medication when visiting a patient at home. Bureaucracy of the system means only a GP can prescribe in the home".*
> *[Palliative Care Consultant2]*

A recurring suggestion was to have a **co-ordinator** to ensure that someone has overall responsibility to make sure 'everything runs smoothly'. This designated person would co-ordinate all services involved to meet the needs of the patient. Therefore, it would not just be end-of-life discussions that would be patient-centred (as explored earlier), but the care would be too. It was emphasised that there are already huge demands on their time and resources and there was also a sense that having a co-ordinator would give clarity about roles and responsibilities:

> *"Coordinate the various services that are going to be involved in a persons' end-of-life care and make sure that whoever needs to be involved is involved so that each of them can perform their role and make sure that everything runs as smoothly as possible. So I think coordinating those that need to be involved." [GP3]*

> *"My personal view is that's the essence of working together and contributing from your, what you bring to the table really. But I think the*

*point is who is going to collate that. You have all contributed but who is
going to hold it." [GP1]*

Who might be best placed to perform this co-ordinating role was not clear cut. For
some (including one of the GPs), the GP was described as well-placed, but this was
not always the case as highlighted below:

*"This thing of who fills it in, who takes responsibility is a question that we
will need to be address. … The only way you will resolve it is you get all
the stakeholders in to a room and go what we are trying to do is agree on
a single care plan, advanced care plan, and what we are trying to
establish is who is the best person to lead that and coordinate that. My
personal view is that I don't think it's the GP. [GP1]*

There was a call for more guidance at a strategic level, either locally or nationally, to
provide further clarity around some of the challenges health professionals face in
delivering end-of-life care. Ultimately, the following quote sums up what participants
felt end-of-life care should be about: patients dying with dignity, without pain, and
according to their wishes where possible:

*"End-of-life care – the outcome is that the patient is going to die, and you
want them to die painlessly and with dignity and in accordance with their
wishes as far as possible." [GP3]*

Summary and discussion

From interviews with doctors working in acute and primary care in Staffordshire, it is clear that end-of-life care is challenging and complex. This research adds to a growing body of evidence which highlights the challenges we need to overcome to improve care at the end-of-life (e.g., Davies et al, 2014; Robinson et al, 2012; Glogowska et al, 2014). Participants in this study highlighted that end-of-life care is an emotive topic with medical, social, legal and ethical considerations. With the present context of an **ageing population** and advancements in medicine and related technology, end-of-life care has become more important, demanding greater discussion and clarity around how to manage these complex issues.

'Being brave': having difficult conversations

The need for health professionals to 'be brave' **- to have difficult conversations and make difficult decisions earlier** was evident. Participants acknowledged the challenge, but also the importance of a proactive approach so that patients are given the right to choose and are able to make decisions about their wishes whilst they have capacity. There was frequent mention of such conversations happening 'almost too late', when patients are no longer able to make their wishes known and/or that quality time for the patient/to spend with families may have been lost. There have also been suggestions that a proactive approach to communication with patients could reduce hospital admissions in the last three months of life (Korte-Verhoef et al., 2014). Whilst predicting when a patient is within their final year of life (i.e., should be receiving end-of-life care) is undoubtedly difficult, it is important to do so in a timely manner as this can impact the support and resources available to them (Mitchell et al., 2015).

Within this theme, **fear of failure** was identified as a key issue. This fear was multifaceted and appeared to relate to not being able to save everyone, getting predictions wrong, interfering/contradicting other members of staff, anxiety about how the patient and/or their family might respond and patient complaints or litigation. Most of those interviewed reported feeling comfortable with having such conversations and talked about having built up their confidence and technique over time. However, it was also highlighted that every case, every patient and every family is different and so there is also a need to be able to interpret and adapt to each case individually. Particularly for younger members of staff, a need for **more confidence** to have such conversations earlier was identified. Davies et al (2012) highlight that 'training' should

address confidence and fear as well as the development of skills. The authors contend that this could be most effective through workplace learning; our participants also mentioned shadowing, peer-to-peer training, workshops delivered by the palliative care team as well as the more formal advanced communication training.

Managing the balance between focusing on prolonging life and quality of life appeared particularly challenging for participants. Opinions were varied. There was a feeling amongst some participants that there was too much emphasis on prolonging life, whereas others felt the balance was about right, or that some specialisms (e.g., those in intensive care) could be too pessimistic in predicting outcomes. Indeed, they highlighted that this can vary across specialisms and how close their contact with the patient had been. It was suggested that nurses who may have spent more time with the patient may recognise that they are nearing the end-of-life sooner than consultants who can be quite removed from individual patients. This is important given that nurses tend to have limited input into such discussions and decisions (Gott et al., 2011). Furthermore, with the subjective nature of a patient's quality of life along with the 'inexact science' of predicting outcomes, participants often felt that such decisions should come from the patient themselves and/or their families.

The importance of patient wishes: patient-centred conversations

Participants emphasised the importance of patient wishes and the **potential for advance care planning** was something that had potential to facilitate this. Participants' knowledge and experience of ACP with patients varied within the sample. For those involved in paediatrics and neonatal care, it appeared that ACP in the form of 'wishes documents' and 'purple pages' were well used to facilitate conversations with parents of terminally ill children in a timely manner. There certainly seemed to be a sense from the interviews that health care can learn from the actions in paediatric health care. In adults, it appeared that ACPs would happen with the hospice/the palliative care team rather than acute staff or GPs more generally.

There was some concern that completing ACPs may be uncomfortable for patients and that they may appear inflexible. There must be opportunities to review and revisit because patient wishes as well as health needs may change over time (Glogowska et al, 2016). There were also calls from participants to amend the language used to make it easier for patients to understand – e.g., planning for future care, rather than advance

care plans. Other considerations included the length of the document and who completes it with the patient (not necessarily a health professional). The potential for appropriately trained volunteers could be explored (e.g., Brighton et al., 2017). Although it has also been suggested that more complex aspects may be better carried out by professionals with more specialist skills and experiences (rather than generalists) (Robinson et al., 2012). It should also be made clear to patients what aspects of ACPs are legally binding. Our participants tended to highlight that ultimately, decisions would depend on medical opinion and available resources alongside patient wishes, whereas a DNR order would be followed.

An area that requires further exploration locally is around **who is best placed to have (ongoing) end-of-life conversations** with the patient/family/carers and where these conversations should take place. Our participants emphasised that having a relationship with those affected generally helps and suggested that the hospital setting may not be the best place for such conversations. This supports previous research by Robinson et al (2014) that suggested effective communication with health professionals within this setting is difficult, particularly when giving bad news, as busy staff could also be perceived as unavailable by patients and their families. Our study highlighted that the timing must be right for patients, but also for health professionals because it is an emotionally demanding discussion for all involved. For the conversation to be effective, both sides need to feel ready and prepared.

Davies et al. (2014) focused on professionals' experiences of delivering end-of-life care for people with dementia and concluded that understanding the barriers involved could help to develop a dementia specific palliative care pathway. Participants in our study talked about frail elderly as a particularly complex group in terms of providing care towards the end-of-life and ethical and/or legal implications. In the absence of patient's wishes being known, it was highlighted that, if called, paramedics are legally bound to attempt resuscitation which some described as unethical practice. As such, there were **calls for discussions about advance care planning (including DNR orders) to become part of routine appointments as people age** so that they have time to consider their options whilst they have capacity. Indeed, previous studies, such as Robinson et al (2012), highlight the challenges around timing and when to initiate such discussions with patients with dementia in particular.

Another aspect that requires attention is **how to share ACPs** across the different strands of care. Some participants involved in this study (but excluding the palliative care staff and those involved in paediatrics/neonatal) highlighted that they would not necessarily know where to look to see if an ACP was in place and that the paperwork can be slow. That information cannot be shared across primary and secondary IT systems needs to be addressed. Participants talked about a 'fragmented system' and the need for a single agreed care plan that is held by the patient and shared with all those involved in delivering their end-of-life care. It was regarded as important that the patient holds the document, so that if a paramedic was called, the information would be available to them. Something akin to the pregnancy notes folder that patients carry at all times was suggested.

Whilst much emphasis was placed on patients' wishes, participants also stressed that there is **a need to go beyond having conversations** and obtaining patients' wishes to improve end-of-life care. Participants identified a range of issues that could prevent end-of-life care being delivered as a patient might wish and called for mechanisms to be put in place to improve the system. This echoes findings of Robinson et al (2012) larger qualitative study that found that the majority of professionals interviewed (95 participants – health professionals in dementia and palliative care in the North East of England) were uncertain as to whether existing service provision could meet patients' wishes.

In our study, a lack of resources was often identified as a barrier; **a lack of time and space in the acute setting** were seen as major obstacles both in terms of having conversations and looking after end-of-life patients. It was highlighted that patients can end up in hospital when the necessary support is not available to keep them at home (e.g., district nurses or palliative care nurses) or when there is a lack of places at local hospices. **Hospital discharge** was another aspect of care that participants felt should be improved for end-of-life patients, in terms of planning and timing. Aspects mentioned here included that only GPs are able to prescribe medication at home as well as a lack of hospice places available. Participants were very **positive about the local palliative care teams** though the lack of palliative care beds was highlighted – for participants, the priority in the acute setting often seemed to be on treating those

who were not nearing end-of-life. Mechanisms such as these must be addressed to help achieve the ambition to provide dignified end-of-life care for patients.

Throughout the analysis an important question recurred around how we assess success/failure in terms of care for those nearing end-of-life – some suggested that a shift is required, from prolonging life to ensuring death (and life) is dignified. What this would mean for how care is provided during patients' end-of-life, and particularly the frail elderly, requires further attention. The development of a local **strategy/pathway** may help to support this and to provide clarity about expectations and legal implications as well as roles and responsibilities. Arguably, it would be important to gain patient perspectives to help inform this as well.

Strengths and limitations

This study had a number of strengths. Firstly, it included doctors from a range of specialisms as well as GPs, in comparison to other studies that tend to focus on one specialism/patient group. Secondly, the sample size is good for a qualitative study using thematic analysis. Finally, the use of semi-structured interviews allowed participants to talk openly and in their own words about their views and experiences.

There are also limitations to acknowledge. Firstly, selection bias is a consideration but from the range of opinions gained we are confident we have not been too limited by this. Secondly, not all relevant health professionals were represented (e.g., there were no nurses). Finally, patients were not included in this study.

Conclusion

Delivering end-of-life care is a complex emotive area, with medical, social and legal considerations. In the context of an ageing population and advances in medical options for prolonging life, the issue has gained prominence and become more complex. The need for health professionals to 'be brave' in terms of making difficult decisions and having difficult conversations earlier came through clearly. Participants acknowledged that this is challenging and emphasised the importance of a proactive approach so that patients are given the right to choose and make decisions about their wishes whilst they have capacity, where possible. The difficulties around the subjective nature of quality of life and in predicting outcomes was highlighted within the quality of life versus prolonging life debate. Here, participants emphasised the importance of patient wishes and saw a role for advance care planning (of some description) to help patients and families to think about and discuss what their wishes might be. This would also then help health professionals in working with patients to plan and deliver their personalised and holistic journeys of care.

Participants also highlighted a need for changes to the system to enable end-of-life care to be delivered in a way can meet patients' wishes, including how to record and share patient wishes across different sectors of care. Further discussion and clarification around roles and expectations in planning and delivering end-of-life care is required, particularly in relation to frail elderly and those unable to articulate their wishes. The development of a local strategy/pathway may help to support this and provide clarity about expectations and legal implications as well as roles and responsibilities.

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