**Resuscitation decisions at the end of life: medical views and the juridification of practice**

**Abstract**

**Background:** Concerns about decision making related to resuscitation have led to two important challenges in the courts resulting in new legal precedents for decision-making practice. Systematic research investigating the experiences of doctors involved in decisions about resuscitation in light of the recent changes in law remains unexplored.

**Aim:** To analyse the practice of resuscitation decision making on hospital wards from the perspectives of doctors.

**Design:** The data presented in this paper was collected as part of a wider research study of end of life care in an acute hospital setting.Data collection comprised ethnographic non-participant observation on two acute hospital wards and eight semi-structured interviews with doctors caring for patients thought to be approaching the end of life. Data were analysed using a constructivist grounded theory approach.

**Results:**  Discussions and decision making about resuscitation present many challenges for those involved on acute medical wards. The data highlight the potential for multiple interpretations of legal precedents, creating misunderstandings that may impact patient care in less positive ways.

**Conclusions:** This paper provides unique insights into how doctors respond to the changing medico-legal culture and the subsequent effects on patient care. It demonstrates how the juridification of medical practice can occur. It highlights the potential benefit of a structure to support clinicians, patients and relatives in discussing and navigating decisions around care at the end of life in line with the patient’s wishes and preferences. Recommendations for future research are made and legal ramifications are discussed.

**Background**

Cardio-pulmonary resuscitation (CPR) was first introduced to medical practice in the 1960s 1. While the initial presumption and practice was that CPR should be performed on any patient to suffer a cardiac arrest, for patients dying of terminal conditions it became apparent that resuscitation was neither beneficial nor appropriate 2. In the UK, DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) forms were designed to document resuscitation decisions and ensure that patients were not inappropriately resuscitated 3. However, in recent years there have been growing concerns about the way in which resuscitation decisions are made, often without informing or involving the patient or those close to them 2. Since 2001 there has been professional guidance published jointly by the BMA, Resuscitation Council (UK) and Royal College of Nursing (previously named the ‘joint statement’) 4. These decisions have traditionally been made by the medical team on grounds of likely medical futility5 and there was no legal obligation for the doctor to inform the patient or their family that a DNACPR notice had been completed 2. However, the General Medical Council (GMC) guidance on decision making maintains that in all situations doctors should work in partnership with the patient 6. The GMC has provided specific guidance7 about the provision of treatment and care for patients who are reaching the end of their lives, in which it states: ‘*As with other treatments, decisions about whether CPR should be attempted must be based on the circumstances and wishes of the individual patient. This may involve discussions with the patient or with those close to them, or both, as well as members of the healthcare team’* 7. And ‘*If a patient lacks capacity, you should inform any legal proxy and others close to the patient about the DNACPR decision and the reasons for it*’ 7.

In 2014 the Court of Appeal handed down judgment in *R (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors* 8 and in doing so clarified the duty of clinicians to consult with competent patients when making DNACPR decisions. The Court ruled that by introducing DNACPR notices into patients’ notes, Article 8 of the European Convention on Human Rights (ECHR), which guarantees respect for private and family life, is engaged. Since DNACPR decisions would potentially deprive certain patients of life-sustaining treatment, there is a presumption in favour of involving them in those decisions. Furthermore, where CPR is considered futile by doctors, then patients must be informed and told they can seek a second opinion where necessary.

The ruling created a new legal precedent that doctors should discuss resuscitation with patients, relatives or both before signing DNACPR forms unless there is a reason to believe this would cause patients physical or psychological harm 9. A failure to do so would potentially breach a doctor’s common law duty to consult his or her patient in relation to the decision to treat or not to treat, as well as breaching a patient’s human rights. Prior to this judgment, though it was considered good practice to include patients and families in this decision, it was not required by law and the decision was up to the medical team.

In 2015, a further case, this time relating to a resuscitation decision for a patient who lacked mental capacity, was heard by the High Court. In *Winspear v City Hospitals Sunderland NHS Foundation Trust* 10, the Court referred both to the *Tracey* case and the Mental Capacity Act 2005 (MCA) when it held that, unless it was not practicable or appropriate to do so, decision makers should consult with relatives and carers of patients who lack mental capacity prior to making a DNACPR decision as part of the best interests decision-making process under the MCA11. Adopting the reasoning in *Tracey*, the judge in *Winspear* found that clinical futility was not a sufficient reason for withholding a resuscitation decision from a patient’s carer. Furthermore, the judge highlighted that ‘best interests’ is about more than clinical judgement and normally requires consultation with those close to the patient.

The legal position following the rulings in *Winspear* and *Tracey* is that when making resuscitation decisions, healthcare professionals must consider the duty to consult and that a failure to do so may breach a patient’s right to respect for private and family life guaranteed by Article 8 of the ECHR and a doctor’s common law duties. Both judgments emphasise, too, the concept of inherent human dignity for patients with and without mental capacity.

Though concern has been raised about resuscitation decision making at the end of life, much of the commentary about end of life decision making has come from stories and anecdotes in the press and national reports. Evidence from relatives has shown that while conversations about resuscitation can be carried out in a sensitive manner, some relatives have experienced vague and ambiguous discussions and have felt pressurised to give their opinion without a clear explanation of the implications of the decision 12. Systematic research investigating the experiences of healthcare professionals, patients and relatives directly involved in end of life care and how such practice occurs on a daily basis in light of the recent changes in law is lacking. The data presented in this paper was collected as part of a research study of end of life care in an acute hospital setting. Data collection for this research project took place between June 2014 and May 2015 and the data reflect direct observation of healthcare practice and physicians’ perspectives and behaviour in light of the new legal rulings. The aim of this paper is to investigate the reality of resuscitation decision making on hospital wards from the perspectives of doctors. We shall suggest that the relationship between law and clinical practice is a delicate one, where nuanced decisions are required and where legal dictate may not always achieve the desired result, and we shall use data captured during our study to illustrate this.

**Methods**

***Design, Setting & Participants***

Data collection for this research study commenced in June 2014 shortly after the Appeal Court ruling in the *Tracey* case. The data provide accounts of doctors’ views on the case, the experiences of relatives and patients as well as observations of the effects of this judgment on clinical practice. This study took place on two acute medical wards in a district general hospital in the north of England. NHS research ethics approval was obtained prior to data collection (Reference 14/NE/0104). Ethnographic methods of non-participant observation and individual in-depth interviews were used.

*Ward Observation*

In total, 280 hours of observation was conducted on two acute medical wards. Observation focused on the practice of end of life care on the wards and thus included discussions about resuscitation. Observation included clinical practice on all days of the week, in and out of hours. Field notes were made to record observations. For the ward observation, all patients, relatives and healthcare professionals were eligible to participate and they were informed about the study through information leaflets, posters on the wards and by meetings held with healthcare professionals working on the wards. Consent for observation was verbal and on an opt-out basis. The researcher gained verbal consent from staff prior to observing their practice. In turn, staff members gained verbal consent from patients and relatives prior to any observation of practice involving them, such as ward rounds and discussions about care.

*Individual Interviews*

When selecting participants for interview, purposive sampling was used to compare participant’s accounts in order to identify similarities, contradictions and variant ideas in the data. All participants were chosen after considering the data collected so far, aiming to target those who had experience of end of life care and with the purpose of answering questions or expanding on areas of interest. The focus of the study was end of life care on acute medical wards in general; this necessarily included resuscitation decisions but resuscitation was not the main focus of data collection. While healthcare professionals and relatives were asked directly about their involvement in resuscitation decisions, patients were instead asked about their involvement in decision making related to their care. Because of this, the majority of the data related to resuscitation decisions comes from doctors and relatives. Thirty-six individual interviews were conducted with patients (9), relatives (11) and staff members (16, eleven of whom were doctors). For formal individual interviews, written consent was gained from all participants. Interviews were digitally recorded and transcribed verbatim. On a few occasions, relatives declined participation in a formal recorded interview but expressed their desire to speak with the researcher there and then and for the researcher to take notes during the discussion. These interviews were titled ‘informal individual interviews’ and verbal consent was gained prior to and at the end of the interview.

*Data Analysis*

Thematic analysis of observational field note data and interview data was informed by analytic techniques drawn from constructivist grounded theory 13 and shaped by the authors’ overarching commitments to symbolic interactionism 14. Analysis involved simultaneous data collection and analysis. Coding and re-coding of all data provided a way of labelling and examining the perspectives and actions of the research participants. It facilitated the identification of recurrent ideas, discordant results and of understanding different processes occurring in the data. Focused coding led to the development of key themes within the data. All data was anonymised.

**Results**

The key themes to emerge from the data were: 1) Informing or involving – whose decision is resuscitation? 2) Challenges in making DNACPR decisions 3) Consequences for patient care.

***Theme 1: Informing or involving - whose decision is resuscitation?***

The doctors interviewed recognised and described their experiences of the way in which decision-making practice, including decisions about resuscitation, had changed in recent years.

|  |  |
| --- | --- |
| Quote 1.0 | *“So, not that long ago, there’d be an awful lot less communication, for instance, with relatives, families, stuff like that. The sort of, environment in terms of, you know, care plans, DNACPR forms, etcetera, has changed a lot. So I think there’s a lot more expectation on us, that we are very pro-active in terms of communicating with relatives, family, and discussing things with them”.* Interview with Consultant27 on Ward A |

Furthermore, there was recognition from some doctors that failing to inform and involve patients and relatives in decisions about resuscitation could lead to distress and upset.

|  |  |
| --- | --- |
| Field Notes  1.0 | *One of the junior doctors said a patient was given a DNACPR form and was then discharged to a nursing home without anyone telling the family about the form. The family later found out when one of the staff mentioned it in passing. The doctor said that they were very upset, not because the patient had been given a form (they actually agreed with that decision), but because no one had taken the time to tell them.* Field Notes Ward B |

Some relatives described conversations with doctors about whether or not a patient should be resuscitated. Some agreed immediately with the doctor’s opinion not to resuscitate.

|  |  |
| --- | --- |
| Field Notes 1.1 | *Relative10 said that she and her mum had never had a specific discussion with the doctors about resuscitation. She knew her mum would not want it. She explained that it was more like the doctors said it would not be effective and she and her mum agreed. She was happy with that as was her mum. She explained that her mum was elderly and frail and didn’t feel she needed to discuss it further.* Field Notes from informal interview with Relative10 on Ward B |

However, other relatives expressed distress and anxiety following discussions about resuscitations.

|  |  |
| --- | --- |
| Field Notes  1.2 | *The patient’s daughter described being shocked when the doctors talked about her mum’s deterioration and about resuscitation. She said she couldn’t cope, and that it came out of the blue. She had phoned her brother as she didn’t know what to do. She said she hated the thought that they were giving up on her mum…………… She explained that the doctors asked her if she had ever discussed resuscitation with her mum, and she was very surprised. She said to me that maybe some people talk about that but not us. It’s not us.* Field Notes on Ward B |

This relative’s response suggests that her distress may have resulted not only from the shock of her mother’s deteriorating health, but from a sense that she was in some way responsible for making the decision about whether or not her mother should be resuscitated.

On Ward B measures had been instituted to help ensure that resuscitation decisions were made with the involvement of patients and/or family members.

|  |  |
| --- | --- |
| Quote 1.1 | *“I was involved in a DNACPR audit, we’ve introduced a new check list, which they do on ward B at the moment, for anyone who’s got a new DNACPR. We found out that 50% of the patients who had a new DNACPR had not been discussed with the family………………..and I was completely horrified”.* Interview with Consultant 12 on Ward B |

It appeared that though doctors acknowledged the need to involve patients and/or their families in resuscitation decisions, there continued to be occasions when this did not occur. The following field notes were made during a consultant ward round.

|  |  |
| --- | --- |
| Field Notes 1.3 | *The patient had had a stroke in the past and needed full nursing care. She had been admitted with a chest infection and Consultant37 told her she was improving on IV antibiotics. With the curtains drawn around her bed he asked her how much she could do for herself and she said not much. Consultant37 bent over and said they would try and get her home later that week. Then he talked about continuing antibiotics but there being the possibility of her getting unwell again. He said if that happened and her heart stopped he didn’t think resuscitation would work and therefore they would just focus on keeping her comfortable. She nodded but seemed a little unsure of what he said. He said okay, and told the junior doctor that the patient would need a DNACPR form. As we left the bedside I looked back and the patient was frowning and looked anxious.* Field Notes Ward A |

Consultant 37 may have felt that, given the limited time for his ward round, this kind of information and decision making was good enough; or perhaps that the question of whether or not to resuscitate the patient was so clinically straightforward that it needed little discussion or opportunity for the patient to deliberate. However, if the patient did have decision-making capacity, she should have been more informed and involved. And if she lacked capacity the MCA calls for a best interests process to be carried out when making decisions.

The data analysis also suggested that following the judgment in *Tracey*, doctors continued to hold varying perspectives about what such ‘involvement’ required.

|  |  |
| --- | --- |
| Quote 1.2 | *“So there was, you know, there was that judgment of the High Court with that lady in Cambridge, and a lot of what I’ve heard, and I think I like to keep quite abreast of it and I read quite a lot of papers and read about it. Still a lot of my information is just second hand, and I think what it needs is someone to clarify what that judgment actually means, cause I’m not certain our interpretation of what that judgment is, is correct. I don’t think I know my, you just hear things from people, and I’m not certain that’s the correct interpretation. And so I think that’s providing uncertainty”.* Interview with Consultant 24 on Ward A |

Some doctors felt that patients and/or their relatives should simply be informed of the decision which had already been made by the doctors. The following field notes were made after a conversation with two junior doctors:

|  |  |
| --- | --- |
| Field Notes 1.4 | *The first junior doctor said he had no problem with signing it [DNACPR form] and then speaking to the family. He commented that it was a medical decision. I asked them both if they thought it should be a medical decision given how strongly patients and family seemed to feel about it. The second junior doctor said yes, because they [patients & families] didn’t know enough about it to understand.* Field Notes Ward A |

Both junior doctors suggested that resuscitation was a medical decision to be made by the doctors. The strength with which they presented their views seemed to highlight an implicit tension about whose decision this was: the doctor’s or the patient’s (or the relative’s). Though the second junior doctor felt that patients and families were not able to make the decision, his comment could be interpreted as implying that if patients and families had more information i.e. were better informed by staff, had access to relevant resources and literature, or perhaps if society as a whole were better informed about resuscitation, they might be able to understand and be more involved in the decision.

In contrast, in the following quote Consultant 35 maintained that a correct understanding of the *Tracey* case meant that it was not enough just to tell patients and relatives about a resuscitation decision:

|  |  |
| --- | --- |
| Quote 1.3 | *“And the onus now, or my understanding of that court case was the onus now is much more on involvement of patients and relatives rather than the very sort of paternalistic ‘I have made this decision’. Cos it’s [resuscitation] still a medical decision but you’re meant to seek their views. And I think one of the risks of making those decisions, so for example, if relatives aren’t around or the patient is too poorly and you make a decision, and then you retrospectively discuss it, I’m not sure that’s in keeping with the spirit of the law. You are meant to involve them not tell them. Because you want to seek their views and their opinions and their previously expressed wishes, and all of that stuff. I don’t think it fits with if you make the decision and retrospectively discuss it with them, I don’t think you are discussing it, I think you are retrospectively telling them”.* Interview with Consultant 35 on Ward B |

One junior doctor felt that confusion about what it means to involve families properly and the fear of complaints had meant that ‘involvement’ had sometimes been interpreted by doctors as having to ask the family to make the decision:

|  |  |
| --- | --- |
| Field Notes 1.5 | *The junior doctor said he thought that the doctors were all really afraid of a complaint. They’d been told that if a patient had a DNACPR and the family didn’t know about it and then the patient arrested, they might complain. Or if a patient went home with a DNACPR and the family found out they might complain and even the consultants weren’t immune. He said there was a culture of fear and no one wanted to get a complaint. Because of this he said that patients and family members, who may not be adequately informed, end up making the decision about resuscitation.* Field Notes Ward B |

This junior doctor felt that families who were poorly informed of the facts of resuscitation could end up making bad decisions. His comments implied that the result of such practice was poor decision making and poor care (inappropriate resuscitation) for the patient; but he also implied that if families were properly informed, they could be involved in making good decisions. It was apparent that many doctors felt ongoing apprehension and confusion about what constituted good practice in the light of the *Tracey* decision:

|  |  |
| --- | --- |
| Quote 1.4 | *“I don’t know, I go through cycles of thinking, what’s right and what’s wrong, to be honest. I think, to some extent, just playing devil’s advocate, what is wrong with everybody just being for resuscitation? Unless they are clearly palliative…………..For everybody else, why do we have to, just call the [cardiac arrest] team. That’s why we’ve got a cardiac arrest team. So, I know that’s not the right thing, but just sometimes I think, well why don’t you just call the team?…..and then make a decision depending on what’s happening at that time. I think, I don’t know, I think that, I think previously we probably were just filling out too many [DNACPR] forms without having the right conversations and talking to patients and families about the implications…..and I think that was wrong. And I think it’s almost swung too far the other way though”.* Interview with Consultant 28 on Ward A |

The Consultant questioned whether changes in decision-making practice had gone too far, with doctors now feeling unable to make clinical decisions without the permission of relatives. While doctors often agreed with the importance of involving patients and their relatives, they described many challenges to doing this in practice.

***Theme 2: Challenges in making DNACPR decisions***

On Wards A and B, doctors described feeling under pressure to have discussions about resuscitation with all patients soon after their admission. They often acknowledged what a sensitive topic resuscitation could be and the difficulty in having such discussions with patients and relatives whom they had never met before:

|  |  |
| --- | --- |
| Quote 2.0 | *“If somebody is clearly dying it’s easy to have that conversation [about resuscitation]; it’s absolutely right to have that conversation. If somebody is very frail, and you want to put limits of care, it’s right to have that conversation, I just find the timing difficult. I would prefer to have that conversation after I’ve known them for a while, known their relatives for a while”.* Interview with Consultant35 on Ward B |

While doctors might prefer to take time to build rapport with the patient, owing to the rapid transition of patients through the hospital, this was not always possible. Furthermore, there was the risk that a patient might deteriorate before the doctor made a decision. Therefore, such a discussion had to be timed appropriately so that the patient was unwell enough to recognise their potential for deterioration, but not so unwell that they could no longer make the decision:

|  |  |
| --- | --- |
| Field Notes 2.0 | *One junior doctor said she didn’t want to bring it up too early and scare them, but didn’t want to leave it so late that she missed the boat and they weren’t able to say what they wanted.* Field Notes Ward A |

When patients lacked mental capacity to be involved in decisions about resuscitation, many doctors described the importance of involving those close to them in the decision. Yet Consultant 24 also described the difficulty involving relatives in decision making in time-pressured ward environments where relatives may not be present when decisions were being made, especially in the middle of the night.

|  |  |
| --- | --- |
| Quote 2.1 | *“It’s easy sitting here saying these things, but I think I do try and do it, but if it’s the middle of the night, and the person is likely to die and they need an escalation of care decision, and it’s in the best interest of the patient, if I can I’ll communicate it with that patient. If there’s no one around to talk about it, I’ll make the decision in the best interests of the patient and we can discuss at a later point, it’s still a medical decision. And I think currently I’m still doing that, whether I gonna get, someone’s going to complain, I don’t know. I think that’s the right decision. Whatever else is going on, whatever hearsay is going on, whatever high court said, if you’re doing what’s in the best interests of your patient and you’re making sure that they are as informed as they can, then I don’t think you’re going wrong. But I think there’s a lot of uncertainty”*. Interview with Consultant 24 on Ward A |

This quote from Consultant 24 highlights the confusion surrounding the phrase ‘best interests’. Consultant 24 uses this phrase to describe making a resuscitation decision on his own in the middle of the night. Yet this description is not in line with the ‘best interests’ process described in the MCA, in which those close to the patient should be consulted where practicable and appropriate. Even when discussions did take place between patients, relatives and doctors, a further challenge was highlighted by interviews with relatives and observation of practice. That is, the potential for misunderstandings about resuscitation decisions. The use of euphemisms by doctors, which has been well documented in the medical literature 15, was seen to cause confusion about decision making related to resuscitation.

|  |  |
| --- | --- |
| Field Notes 2.1 | *Consultant 27 said they would focus on keeping her comfortable and ‘wouldn’t go jumping on her chest’. He said that this would not be effective in her case. The patient agreed. Once back in the corridor Consultant27 and the junior doctor explained that on her last admission the medical team had discussed resuscitation with the patient and then completed a DNACPR form. Later her family saw it in the notes and were very upset. The patient had said she didn’t remember discussing it.* Field Notes on Ward A |

The phrase, ‘jumping on her chest’ had been used as a way of describing chest compressions (a core component of CPR). Yet, Consultant 27 did not question the patient’s understanding of the phrase. During an interview with a relative on ward A, the Relative 8 described her own uncertainty about the decision had been made about her father’s care following a discussion with a doctor.

|  |  |
| --- | --- |
| Quote 2.2 | *“When they said that we had to prepare for the worst and just hope for the best. And that he couldn’t go into intensive care because his body wouldn’t cope with it. And they were doing the best they could but really we had to prepare for the worst, and if we could, if he needed it they would give him something to ease him. Emm….and I said to my Mam, I said “so does that mean like a do not resuscitate?” And she said well, she said “well that’s what it sounded like””.* Interview with Relative 8 on Ward A |

Some doctors also recognised the potential for confusion and misunderstandings following the discussion of resuscitation even in spite of their best attempts to make the situation clear.

|  |  |
| --- | --- |
| Quote 2.3 | *Consultant28 said he found speaking to relatives and patients about resuscitation hard. He said he knew what he had said but had no idea what they had taken from it. He explained that he was so used to having these sorts of conversation, but that didn’t stop him thinking what have I done? I don’t want to upset them.* Field Notes on Ward A |

It appeared that the *Tracey* case had a profound impact on resuscitation decision-making practice. Doctors were expected to speak with the patient if able, or their relatives prior to making a decision, yet having the time to have these discussions with every patient and/or their relatives posed difficulties. Their time was limited and owing to fixed visiting hours relatives were often not present when resuscitation decisions were being made. The experiences of relatives and doctors highlight the potential for misunderstandings about resuscitation decision making. Equally, sometimes practice appeared to be driven by a fear of complaints, which will be further outlined in the final theme.

***Theme 3: Consequences for patient care***

In light of the confusion and variation in practice related to resuscitation decision making, the data highlighted some possible consequences for patient care. Consultant 28 described his reluctance to complete DNACPR forms and alluded to his own concern about the risk of complaints. The consequence highlighted is the potential for delays in decision making.

|  |  |
| --- | --- |
| Quote 3.0 | *“A lot of us are worried about doing them [DNACPR forms] without having conversations with families, and it’s not always possible to have those conversations, and if there’s any doubt, whereas in the past we probably just would do a DNACPR form and that whole thing of it’s a medical decision, fine, I’m making a medical decision based on, and justifying it like that has gone. And I think that, for that reason, and because of the fear of it coming back at you……in those situations where previously you probably would just do a form, we’re now not”.* Interview with Consultant28 on Ward A |

One junior doctor described a patient case which illustrated the potential for delays in decision making when relatives were not present to involve in the decision.

|  |  |
| --- | --- |
| Field Notes 3.0 | *The patient had been deteriorating and she had stopped eating and drinking. The junior doctors had asked the Consultants about a DNACPR, but they wouldn’t sign one until the doctors had spoken to the family.* Field Notes Ward B |

In an interview, Junior doctor14 explained the above patient’s situation in more detail:

|  |  |
| --- | --- |
| Quote 3.1 | *“But the difficulty was the patient didn’t have any close family or close friends who are able to visit the hospital. No family member, apart from a distant niece, who didn’t want to visit her in hospital anyway and said she wasn’t very close to her. And it sounds like she had one or two friends locally, but they were too frail and couldn’t reliably be contacted, and couldn’t attend the hospital…………….. So we ended up just keeping her in hospital, and we weren’t really sure what we were doing with her……………… So she sat there for quite a while, and stopped eating and became low in mood. …………….And we also wouldn’t fill in a DNACPR form because we wouldn’t do that, the consultants wouldn’t do that until there was a discussion with the family, but there was no family. So they weren’t happy doing it until we’d really exhausted every possible avenue with other people. And then she arrested, and it was a very messy arrest, and yeah. The CPR went on for a good few minutes, and then we decided to stop………………… But we ticked every single box, in terms of doing things correctly, in that we didn’t fill in a DNACPR until there was an appropriate discussion”.* Interview with Junior Doctor14 on Ward B |

It seemed that patients without family or friends dying in hospital could be described by the term ‘disadvantaged dying’ 16, because of the likelihood of delays in decision making about resuscitation and potential for adverse effects on their care. This term was first used by Seymour *et al.* to highlight the disadvantages in care experienced by older people in the UK and seems applicable to the area of resuscitation decision making as well 16. When patients deteriorated suddenly and unexpectedly, doctors described varied practice in resuscitation decision making.

|  |  |
| --- | --- |
| Quote 3.2 | *“But I think people are now very anxious about doing DNACPRs without discussing them with families, and I think juniors are very anxious about, you know, even my juniors with a patient they knew and they knew I thought was dying, they still felt obliged to proceed with trying to resuscitate her………………. Because, I’m sure, because of anxiety over what would happen if they stopped”.* Interview with Consultant12 on Ward B |

The Resuscitation Council guidance states that in an emergency, doctors are to act in the patient’s best interests to provide good care, which may mean signing a DNACPR form before a discussion with the patient or family can take place 4. Yet, the data suggested that for junior doctors, with limited experience, making a sudden decision about resuscitation could be very difficult.

|  |  |
| --- | --- |
| Quote 3.3 | *“I think because we haven’t got the experience to say, this intervention won’t work, it’s not appropriate for the patient. I think….some junior doctors get to a point when they feel maybe like they shouldn’t escalate things…..and I would rather learn that as I get older rather than learn it the hard way and have someone die when I should have escalated it. And I think…………..it’s better to do a lot more than to have wished you’ve done in the first place, and I think it might be you can always explain that to a family. So if someone ends up having CPR who maybes wasn’t meant to have CPR….it’s a lot easier to explain to a family that we acted in the best interest at the time, than I think the family wanting you to do CPR and CPR not being done”.* Interview with JuniorDoctor4 on Ward A |

Our data seem to suggest that if a dying patient without a DNACPR form suffered a cardiac arrest they were more likely to receive resuscitation if no senior doctor was present. And even if the consultant had told junior doctors not to resuscitate a patient, but a DNACPR form had not yet been signed, the junior doctors still felt under an obligation to proceed with resuscitation if the patient suffered a cardiac arrest. These findings emphasise the importance of pro-active decision making, so that a patient’s wishes are clear in the event of sudden deterioration.

One junior doctor described her perception of variation in expected practice for junior doctors on different wards:

|  |  |
| --- | --- |
| Quote 3.4 | *“I don’t really do any discussions with families about end of life or around end of life, or DNACPRs [on ward A], that’s….whereas on the other ward that’s what you do. You do that at least like once or twice a week”.* Interview with Junior Doctor 25 on Ward A |

Junior Doctor 25 explained that, in contrast to the ward she had worked on previously, on Ward A Consultants tended to take responsibility for discussions about resuscitation and end of life care. It appeared that there was variation in what was expected of junior doctors across different wards. It seems possible that this could lead to confusion about the junior doctors’ role and impact on their confidence in making decisions.

However, there were also occasions when doctors purposely delayed discussion about resuscitation. One junior doctor chose to delay discussing a DNACPR form with a patient. He explained that she had already had many discussions that day about her inability to cope at home:

|  |  |
| --- | --- |
| Field Notes 3.1 | *The junior doctor said he had decided not to push discussions about DNACPR because he didn’t want her to feel as though everyone was writing her off.* Field Notes Ward B |

Consultant 35 talked about the importance of prioritising the care of the individual over and above making a specific decision at a given time:

|  |  |
| --- | --- |
| Quote 3.5 | *“I think that some of the stuff that comes out, actually if I disagree with it I won’t necessarily toe the line absolutely. So if I think it’s wrong to have a discussion with somebody about resuscitation because it’s the wrong time to do it, I’m not going to be forced into having it at that time. Because that I think, would be I think all of those things have to be done in the context of the person in front of you and the situation that it is”.* Interview with Consultant 35 on Ward B |

These doctors both highlighted the importance of keeping the patient’s feelings, or what they presumed the patient was feeling, central in the decision-making process even if this might, in some cases, lead to intentional delays in decision making. But delay in discussion could lead to inappropriate and unwanted resuscitation/poor patient care at the end of life.

What is becoming increasingly apparent is that the kind of discussion required for the ‘involvement’ of patients and/or relatives in resuscitation decisions is anything but simple. It requires careful explanation of the patient’s clinical condition and the rationale for the discussion; the ability to engage sensitively with patients and relatives, listening to their wishes and views while also explaining that they are not responsible for the decision; it may require engagement with patients and relatives who disagree with the medical opinion and careful consideration about how to care for patients and relatives in the face of disagreements about the best course of action. Despite the complexity of these discussions, the need for timely and well-informed dialogue, enacted in a sensitive and empathetic manner with clarification of understanding on both sides and opportunities for further discussion is essential.

**Discussion**

***Limitations***

The methods of data collection and sampling in this study have clear limitations. First, this study was conducted in two wards in one hospital in northern England. While it could be presumed that other acute medical wards in hospitals will face similar issues related to resuscitation decision making, this may not be the case. Second, while the study included a large volume of observational data around end of life care, interviews were conducted with only small numbers of doctors and therefore they are likely to provide only some of the many perspectives that may be held on this issue. Third, the focus of this study was not resuscitation but the wider topic of end of life care on acute hospital wards and therefore many interviews did not address the topic of resuscitation at all. Instead ‘resuscitation’ was discussed if and when brought up by participants. Fourth, while the new legal judgments will affect all UK acute medical wards, the effect may vary in different healthcare settings and cultures. Thus, some of the issues explored in this paper may be different to those encountered on other wards. Nonetheless, this paper presents an analysis of the views of medical staff, and provides a sense of some of the challenges this issue raises for those involved in resuscitation decision making.

***DNACPR decisions and their wider implications***

The *Tracey* judgment recognised DNACPR not simply as a decision about a treatment, but as a decision with much wider implications for the patient’s final days of life, their dignity and quality of life 5. The *Tracey* case also recognised that shared decision making demonstrates respect for the patient and their relatives, and ‘lies at the heart of good clinical care’ 5. Therefore, resuscitation decisions are not about pitting the patient’s autonomy against the doctor’s paternalistic views, but rather are about ensuring the patient is well cared for in line with their goals of care.

It seems sadly ironic that a legal precedent intended to ensure greater involvement of patients and relatives and greater respect for a patient’s dignity and quality of life should lead to delays in decision making and the potential for poor care. It could be argued that some decision making described in the data failed to reflect the principles established in *Tracey*, *Winspear* and GMC guidance. Though patients may deteriorate unexpectedly, necessitating a rapid best-interests decision about resuscitation, the GMC guidance is clear that, in general, healthcare professionals ought to involve patients in all aspects of healthcare decision making. Yet, in the data, ongoing ambiguity over whose decision resuscitation was and therefore how such a decision could or should be taken, led to varied involvement of patients and relatives. It has been suggested that in modern healthcare a ‘*procedural understanding of responsibility’* is increasing, with the result that legal discourse is becoming more pronounced in practice, and moral and ethical discourse has diminished in significance 17. ‘*When the moral approach to dealing with conflicts is replaced by judicial interaction, the nature of communication changes profoundly. Professionals are forced to take a defensive stance’* 17. This was seen to occur in the data. Though some doctors’ accounts suggested that they continued to act according to their beliefs about what was best for the patient, others openly acknowledged that their fear of complaints led them to delay decisions they would have otherwise made. On some occasions it appeared that moral debate and discussion about the right course of action, in line with the patient’s putative views and wishes, were lacking and instead the rationale for practice focused on how choices and decisions could be made with the least risk of complaint.

***The ‘juridifcation’ of medical practice***

It would appear that there is a process of ‘juridification’ of medical practice occurring. In other words, there is a proliferation of laws and legal regulation in health care. The concern is that this might lead to a narrowing of professional autonomy and a removal of professional discretion, which might adversely impact on good care at the point of delivery 18. Professor of Law, Mary Donnelly, has suggested that, “*As matters stand, the law has delegated certain tasks to the healthcare profession. Yet the applicable legal framework provides little indication of what is expected and the law has shown relatively little interest in how the task is carried out. This failure is likely to contribute to healthcare professionals’ disinterest in, and dismissal of, the ‘legal’ concern for protecting patients’ rights”* 19. In another context, Montgomery and Montgomery (2016) have warned about radical moves ‘*away from English law’s traditional respect for clinical expertise*’ 20. They go on to say that, ‘*If such a step is to be taken, courts need to be wary of being seduced into believing that the oversimplifications that legal processes require accurately reflect the complexities of clinical judgements’* 20. Foster and Miola (2015) agree with this sentiment. However, they argue that the law *should* be the final arbiter of ethical issues, and they call for the law to recognise this as its key role and engage in ethical debate 21.

In the current medico-legal culture, we suggest that our data highlight the importance of encouraging and supporting ethical discussion and decision making in clinical practice. While legal precedents provide vital assistance to clinicians making decisions about resuscitation, these should not be applied without careful thought given to the issues surrounding each individual case. In a busy and fast-paced NHS, the importance of such discussions must be emphasised and prioritised in practice. From the data, it seemed that a structure to support clinicians, patients and relatives in discussing and navigating decisions around care at the end of life in line with the patient’s wishes and preferences might also be helpful.

***A new way forward for resuscitation decision making?***

In 2014, the results of a systematic review of DNACPR decisions and documents were presented at a meeting of patients and clinicians, commissioners and regulators 22. It was agreed that there was a need for greater involvement of patients and relatives in decision making and a need to view resuscitation decisions within the broader context of the patient’s goals and wishes for their care. A national Working Group was set up to develop a new approach to DNACPR decisions. The result, is a new process called ReSPECT: Recommended Summary Plan for Emergency Care and Treatment 23. ReSPECT has been introduced into some areas of the UK over the last three years alongside formal research evaluation 23. And while it is still being rolled-out and evaluated, it has been advocated as a structure that will both normalise and facilitate discussions about treatment and care at the end of life between patients, clinicians and relatives. Such a process, which grounds decision making about treatment within the patient’s wishes and goals of care, may well be helpful in guiding decision making. Yet questions remain about the actual impact such a process will have on patient care. In the absence of robust evaluation, it is not clear who will have these conversations and when; what training professionals require; whether it becomes a proactive process rather than one that happens acutely in emergency situations led by junior doctors; and how time will be created to enable these conversations to take place in surgeries, clinics and on hospital wards. The biggest question is whether this decision-making process will make decision making any easier for doctors and patients. There is clearly a need for an education package for healthcare professionals in order to ensure a clear understanding of the purpose of the ReSPECT document. Yet, we propose that the education and training needed is not limited to the ReSPECT document, the topic of resuscitation, or to healthcare professionals alone. The Independent Review of the LCP highlighted the need for societal training about the importance of discussing openly death and dying and issues related to advance care planning. It argues, and we agree, that without public engagement and societal understanding, the quality of end of life care will remain inconsistent 12 24. As well as engagement about end of life care, patients and relatives need to understand the reality of the patient’s clinical condition. Without this, patients and relatives may not see the necessity to engage in these issues for themselves. In addition, *shared* decision making requires that all those involved in a particular decision are accurately appraised of the situation.

Many questions remain unanswered and the importance of ongoing research to evaluate the impact of new processes will be vital to ensure optimal patient care.

**Conclusions & Recommendations**

This paper highlights important challenges for doctors involved in making resuscitation decisions in light of the *Tracey* and *Winspear* cases. It is the only ethnographic work to have considered the experiences of doctors involved in resuscitation decisions on acute wards in UK hospitals in light of these two recent legal judgments. It provides unique insights into how doctors respond to the changing medico-legal culture and the subsequent effects on patient care. This paper suggests the potential benefit of a structure to support doctors, patients and relatives in discussing and navigating decisions around care at the end of life. The complexity of decision making towards the end of life surely mandates a multifaceted approach which includes training of healthcare professionals as well as societal education and engagement. Furthermore, this paper raises concern about the ‘juridification’ of clinical practice and the implications of this. It highlights the importance of ethical discussion and debate by clinicians about their everyday decision-making practice and how this is being influenced by changes in the law and the potential impact on patient care. It also raises questions about the ethical role of law in clinical decision making.

**Declaration of conflicting interests**

The authors declare that there is no conflict of interest.

**References**

1. Kouwenhoven WB, Jude JR, Knickerbocker GG. Closed-chest cardiac massage. Journal of the American Medical Association 1960;**173**:1064-7.

2. Fritz Z, Fuld J. Ethical issues surrounding do not attempt resuscitation orders: decisions, discussions and deleterious effects. Journal of Medical Ethics 2010;**36**:593-97.

3. Fritz Z, Malyon A, Frankau JM, et al. The Universal Form of Treatment Options (UFTO) as an Alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders: A Mixed Methods Evaluation of the Effects on Clinical Practice and Patient Care. PLOS ONE 2013;**8**(9):1-10.

4. Resuscitation Council UK. Decisions relating to cardiopulmonary resuscitation 3rd edition, 2014.

5. Samanta J. Tracey and respect for autonomy: will the promise be delivered? Medical Law Review 2015;**0**(0):1-10.

6. GMC. Consent: patient and doctors making decisions together, 2008.

7. GMC. Treatment and care towards the end of life: good practice in decision making., 2010.

8. R (David Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors [2014]: EWCA Civ 822.

9. Fritz Z, Cork N, Dodd A, et al. DNACPR decisions: challenging and changing practice in the wake of the Tracey judgment. Clinical Medicine 2014;**14**(6):571-6.

10. Winspear v City Hospitals Sunderland NHS Foundation Trust [2015] EWHC 3250 (QB)

11. Mental Capacity Act section 4(7), 2005.

12. Department of Health. More Care, Less Pathway. A Review of the Liverpool Care Pathway England2013 [Available from: <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf>.

13. Charmaz K. *Constructing grounded theory*. London. Thousand Oaks, California: Sage Publications, 2006.

14. Rock P. Symbolic Interactionism and Ethnography. In: Atkinson P, Coffey, A., Delamont, S., Lofland, J., Lofland, L., ed. Handbook of Ethnography. London, Thousand Oaks, : SAGE Publications, 2001.

15. Herbert A. The Role of Euphemisms in Healthcare Communication. Journal of Healthcare Communications 2016;**1**(2).

16. Seymour J, Witherspoon R, Gott M, et al. Messages from research. In: Owen T, ed. Dying in Older Age Reflections and experiences from an older person's perspective. London: Help the Aged, 2005.

17. van Heijst A. *Professional Loving Care. An Ethical View of the Healthcare Sector. Volume 2.*: Peeters, 2011.

18. Bærøe K, Bringedal B. Professionalism discretion and juridification: social inequality in health and social citizenship In: Sinding Aasen H, Gloppen S, Magnussen A-M, et al., eds. Juridification and Social Citizenship in the Welfare State: Edward Elgar Publishing Ltd, 2014.

19. Donnelly M. *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism*. Cambridge: Cambridge University Press, 2010.

20. Montgomery J, Montgomery E. Montgomery on informed consent: an inexpert decision? Journal of Medical Ethics 2016;**42**:89-94.

21. Foster C, Miola J. Who's in charge? The relationship between medical law, medical ethics, and medical morality? Medical Law Review 2015;**23**(4):505-30.

22. Fritz Z, Slowther AM, Perkins GD. Resuscitation policy should focus on the patient, not the decision. British Medical Journal 2017;**356**:j813.

23. ReSPECT. Recommended Summary Plan for Emergency Care and Treatment <http://www.respectprocess.org.uk/> [Available from: <http://www.respectprocess.org.uk/>.

24. Auckland C. Muddying the waters of end of life decision-making: Tracey and the encroachment of law on clinical judgment. Elder Law Journal 2016;**264**:1-9.