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“Do Not Attempt Cardiopulmonary Resuscitation” (DNACPR) in the community:

The experience of ambulance clinicians.

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Abstract

Background. Ambulance clinicians must make time-critical decisions concerning treatment and resuscitation. Little is known concerning the impact of the presence (or absence) of Do-Not- Attempt- Cardiopulmonary-Resuscitation (DNACPR) decisions in the community.

Aims. To investigate ambulance clinician’s experiences of DNACPR documentation and views concerning potential future changes.

Methods. Multi-methods study comprising semi-structured face-to-face interviews ($n=10$) and on-line questionnaire ($n=123$).

Findings. Ambulance clinicians report a statistically significant increase in numbers of community DNACPR forms. Most state they have not had formal DNACPR education and experience difficulties making clinical judgements in patients at the end of life, reporting inappropriate cardiopulmonary resuscitation (CPR) attempts and poor communication among stakeholders.

Conclusion. Assessment of patients near the end of life with (and especially without) a DNACPR is challenging for ambulance clinicians. There is a need for 1. education about resuscitation recommendations to be integrated into training and 2. a national approach to decisions and their documentation.

Introduction

Nearly half of deaths (45%) in England and Wales occur at home or in care homes (ONS, 2015). Ambulance services are often called to people close to death for sudden crises, worsening symptoms, or anxious caregivers, especially when community care provision is lacking (Ingelton et al, 2009). Clinicians then need to make time-critical decisions concerning resuscitation if no decision has been documented in advance.

Cardiopulmonary resuscitation (CPR) is the default treatment unless a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) is in place, or **under conditions unequivocally associated with death** or a paramedic assesses that death is imminent due to terminal illness (Joint Royal Colleges Ambulance Liaison Committee, 2016). National policy recommends that patients at risk of cardiac arrest are identified, with decisions made in advance as to whether attempted CPR would be appropriate and desired. The decision is recorded on dedicated DNACPR documentation and applies only to CPR: all other appropriate patient treatment and care should continue (Resuscitation Council, 2014). In the absence of an integrated DNACPR policy in England, many regions have introduced shared policies and standardised patient-held **DNACPR** forms that are recognised across care settings. **Yet there remains considerable variation in the portability of DNACPR decisions between organisations and across the community / acute care interface (Freeman et al, 2015)**, with multiple forms in use in some areas (Clements et al, 2014).

DNACPR forms are part of a complex process: understanding what outcomes would be valued by the patient, clinical judgement whether attempted CPR would be successful, sensitive explanation of the clinical recommendation to patient and family followed by effective documentation across the healthcare system. For some time this has been common practice in hospital, where around 80% of those who die have a DNACPR in place (Aune,2005; Fritz et al, 2013). However, the literature reveals that DNACPRs are not routinely completed (Cohn et al., 2012, Perkins et al. 2016), patients sometimes remain for resuscitation inappropriately (NCPOD, 2012) and DNACPRs are frequently misunderstood **by healthcare professionals. Furthermore, they have been associated with less likelihood of receiving**

some treatments, reduced levels of monitoring activity and less urgent escalation to senior support (Fritz et al, 2010; Mockford et al, 2016).

Existing evidence base.

Three databases were searched; CINAHL, Medline and PubMed for their relevance and accessibility (National Institute for Health and Care Excellence (NICE) 2017). The databases were searched combining the MESH terms/key words 'ambulance OR paramedic* AND do not resuscitate orders*'. Twenty-eight abstracts were identified and four had relevance. As a consequence of limited articles relating to the prevalence and use of DNACPRs in the community or how they are interpreted and used by ambulance clinicians it is key to first determine any existing gaps in understanding.

The aims of this study were to:

1. Investigate the experiences of community DNACPRs
2. Views concerning potential future changes to community DNACPRs

Methods.

A modified sequential explanatory design was used (Cresswell & Plano Clark, 2011); a qualitative interview study identifying major themes was followed by a larger-scale quantitative on-line survey to establish generalisability, with data integrated during analysis and interpretation.

Participants.

Interviews

Paramedics, ambulance technicians and care assistants who had worked in the East of England Ambulance Service Trust (EEAST) for a minimum of 2 years were invited to participate in the interview through an invitation letter sent to ambulance stations. From 19 expressions of interest the research team purposively sampled by seniority and years of experience, with ten participants agreeing to interviews. Individual interviews took place at participants' homes or places of work: one focus group was held. Participants were given a £30 voucher in recognition of their time. The semi-structured interview schedule used open questions, providing a consistent framework while allowing participants to speak reflectively. Interviews lasted 25 to 60 minutes; the focus group 75 minutes.

Questionnaire

All 350 ambulance clinician delegates enrolled at the inaugural “Innovation for Pre-Hospital Emergency Care” (IPHEC) conference were emailed a link to an anonymous on-line questionnaire prior to the conference. Most response categories were fixed, with free text comments also invited.

Ethical considerations

Ethics approval was obtained from the University of Cambridge Psychology Research Ethics Committee and Warwick University Biomedical & Scientific Research Ethics Committee for the qualitative and quantitative studies respectively. Research and Development authorisation was obtained from E EAST.

Data Analysis

Interviews were audiotaped, transcribed verbatim and anonymised. Field notes recorded insights and questions generated during interviews and a reflective diary maintained. Data analysis followed the five key stages of Thematic Analysis; familiarization, identification of a thematic framework, indexing, charting and interpretation (Richie and Spencer, 1994). Analysis was undertaken by SM, with emergent themes discussed at regular meetings with ZF and SB.

Initial descriptive statistical analysis of survey data was followed by multiple linear regression (MP). Specifically, the proportion of respondents was regressed against log of number of times DNACPRs were seen per month and occasion (today, 5 years ago, 10 years ago) and the interaction between them. Log was used as the relationships appeared linear on this scale with approximately constant variance. Evidence of interaction is evidence for changes in frequency of DNACPR over time. 95% confidence intervals were used.

Results

Recruitment – see Table 1

Table 1: characteristics of Interview participants and questionnaire respondents

Interviews (10 total)				
Gender	7 male	3 female		

Profession	Paramedics (7)	EMT (2)	ECA (1)	other
Questionnaire (123 total) response rate 123/350 (35%)				
Profession	Paramedics 80(65%)		Other 29	Student paramedics 14 (11%)
Years of Experience	11+ years (35%)	8-11 years (19%)	0-3 years (10%)	students
Region	Southeast (72%)	Elsewhere in England and Wales (28%)		

Prevalence of DNACPRs

Questionnaire respondents were asked how frequently they saw patients with a community DNACPR. There was a statistically significant increase in frequency noted over time from 0.12 a month (i.e. about once every 8 months) ten years ago (95% CI [0.09,0.17]), to 0.40 (about once every 2.5 months) 5 years ago (95% CI [0.30,0.55]), to today: 3.5 times a month (95% CI [2.7,4.7]) (see Figure 1). Note that the data were aggregated for analysis. The responses of individuals over time were not analysed using repeated measures techniques; it was felt that ignoring correlation in responses would be reasonable given other sources of variation like change of workplace, changing level of experience and role.

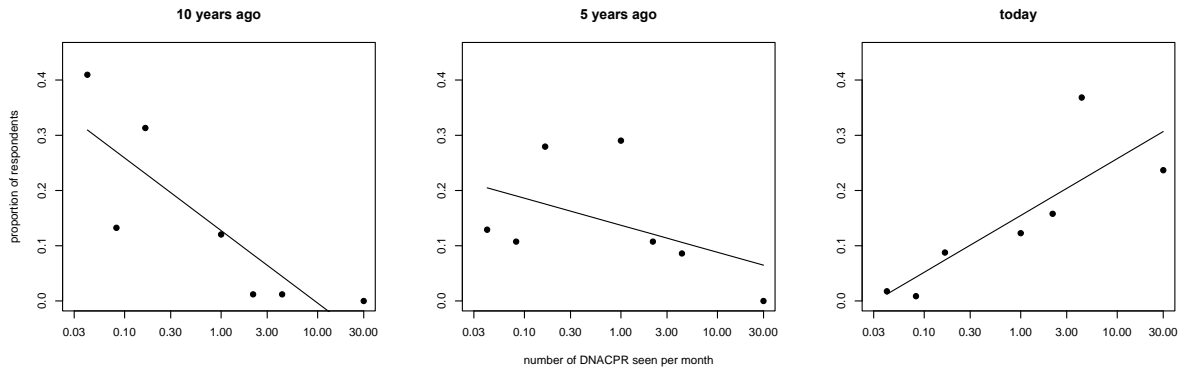


Figure 1. How frequently questionnaire respondents saw patients with a community DNACPR. Regression lines plotted for emphasis (R Core Team, 2016)

Thematic analysis of interviews and relationship to questionnaire findings

Four themes were identified: challenges interpreting DNACPR forms and patient’s wishes; making clinical judgements; the influence of stakeholders on decision-making; and education.

Challenges interpreting DNACPR forms and patients’ wishes

A third of questionnaire respondents believed that a DNACPR was helpful in determining whether a patient should be transported to hospital and what treatments should be given to a patient who had not arrested (Figure 2). They reported that the main reasons for calls to patients with a DNACPR in place were: relative anxiety (48%), transfer to hospital (34%), provision of comfort care (12%) and patient anxiety (6%).

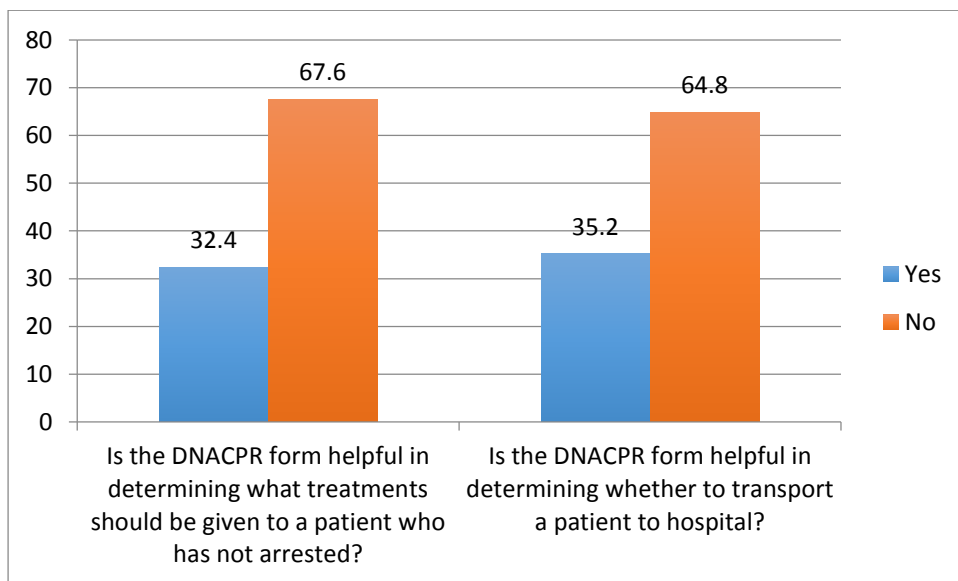


Figure 2.

Interview participants agreed that DNACPRs made resuscitation decisions much easier and allowed them to consider options other than taking the patient to hospital.

Yet at times there was uncertainty concerning how DNACPR affects other aspects of care:

“Some paramedics on crews won’t treat people aggressively if they’ve got a DNACPR in place, others will say ‘Do Not Attempt Resuscitation’ it’s not ‘Do Not Treat this Pneumonia.’”

Respondent 9.

Incomplete information added to ‘an already stressful situation’, leaving ambulance clinicians hesitant to make decisions and uncertain whether their decisions were in the patient’s best interest:

“In an end-of-life situation, it would make me ask the question what does the patient want? ... we’re not quite getting it right, but is that because it doesn’t say on the DNACPR ‘I don’t want to be transported to hospital, I want to die at home?’” Respondent 3.

2) Making clinical judgements

Most questionnaire respondents (86%) had been in situations where they had delivered CPR but wished that they had not; most (72%) also had been in a situation where they wished that a DNACPR had been in place.

Qualitative responses described how ambulance clinicians felt under pressure from relatives, at times performing CPR in the knowledge that survival was improbable and could go against the patient’s wishes:

“It’s just easier to just start 20 minutes, do what you have to do, fill out the paperwork you have to do rather than not starting and then the family kicking up a fuss”. Respondent 5

This participant described concern about the legal implications of their decisions, fearing complaints if they went against a relative’s wishes:

“Being slightly brutal I need to protect myself, and if I stopped and a relative made a complaint and said, ‘why didn’t you carry on?’ then I think from that respect I’d probably do everything I can”. Respondent 2

3) The influence of stakeholders on decision making

The ambulance clinicians spoke of their experiences with stakeholders including General Practitioners (GPs), care home staff and Accident and Emergency staff. Conflict between professionals was frequent and resulted in competing interests requiring negotiation:

“GPs I find really obstructive with DNACPRs, I went to a patient who had cancer [...]he’d had a sudden decline...I went to the GP...and said, “You need to go and see this chap, I think he’s going to die today, so you need to get around and do a DNACPR”. And the GP was like, “Oh I don’t like those conversations.” Respondent 6

Many participants struggled with the ‘snap-shot’ approach to DNACPR decision making in Accident and Emergency and described a perceived lack of willingness to continue resuscitation. This participant illustrated:

“Well quite a lot of the time you think, oh well, why are we doing this? And then all of a sudden, you’ll get a return of circulation. But I think the heart-breaking thing is, you put in all that work, and then you think, oh I’ve got to take them to hospital ... and they just look at you as if to say what the hell, and then they sign the DNACPR form in resus”. Respondent 5.

Most participants raised concerns about the variation between care/nursing homes. These ranged from awareness of issues relating to end-of-life care at an individual level to inadequate protocols and poor information-sharing systems.

“Some care homes are quite good, every person in their care if it’s appropriate will have one in place ... every folder has got a set place for it right in the front so it’s easy for us to see as well which is brilliant”. Respondent 2

“Nursing/care homes are appalling. They will only ever produce a photocopy of it with no clue of where the original is and half the time they won’t have it ... what are we supposed to do?” Respondent 6

4) Education

Very few interview participants had received formal DNACPR education, learning being largely informal from colleagues or online sources. The expectations between the patient’s wishes and the training culture created personal conflict:

"It's drummed into us from when we do our training we need to try and preserve life".

Respondent 1

"They wanted to die in the care home, so we just made them comfortable for 40 minutes and let them slip away. But it was going against all my training and to me against the grain to let somebody slip away". Respondent 3

At the end of the questionnaire, free-text comments were invited in response to "What would you like on a form about resuscitation that would make decisions easier for you? " Several respondents indicated that they would wish to have more information on the patient's wishes, more broadly than just CPR.

"What are the parameters of the DNACPR and what treatment they do want? It should not just be about withholding treatment. It should be about what treatment people want - especially those under end of life care for illnesses such as cancer"

"Patients' hospital wishes if they become unwell: to stay at home or go to hospital?"

"Specific treatment that they want withheld or not - IVs, BVM, Intubation, oxygen, pain relief etc. Transport preference - hospice or home treatment".

In addition, and perhaps unsurprising given the context of the study, there were calls for more education and for a nationwide form.

Discussion

Use of DNACPRs in the community appears to be rising; this change has been reactive rather than planned, and there are possible problems with a form intended for hospitals being adopted in the community (Freeman et al, 2015). Pre-hospital practitioners are sometimes in the invidious position of having to balance the needs of the family and a patient who has had a cardiac arrest without clear guidance. Current education errs on the side of interventions to preserve life which pre-hospital practitioners sometimes feel uncomfortable delivering when their clinical judgment suggests that the burden of treatment outweighs any potential benefit.

Education

National education of both health care providers and the public is required to ensure that communication around resuscitation and other treatment plans are consistently understood. This might include policies and procedures that are readily available to staff and the public; education of the public about what outcomes can be expected from treatments (including CPR) in different situations; coordination among stake-holders; and education and training in resuscitation decision-making in health providers annual updates. There is currently no scenario on resuscitation orders in the Resuscitation Council (UK) Advanced or Immediate Life Support courses: perhaps this could be introduced.

Stakeholders' problems with sharing data

Although there are regional examples of one form successfully being used across many healthcare settings these are not common, and do not address the problem of patients who move regions. Several respondents mentioned the need for a national form. Electronic records or a central repository such as 'coordinate my care' (Public Health England, 2015) and other forms of Electronic Palliative Care Coordination Systems (Petrova et al., 2016) may also be useful.

Towards a solution? ReSPECT

The Resuscitation Council (UK) has led on the development of the **Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)** (Fritz, Slowther & Perkins, 2017) a new approach to resuscitation and other treatment decisions. ReSPECT was designed with multiple stakeholders, including ambulance clinicians, to address many of the problems outlined here. ReSPECT puts resuscitation decision-making within a context of overall goals of care, and provides universally recognised documentation of clinical recommendations for an emergency. ReSPECT has been made nationally available (www.respectprocess.org.uk) and is being adopted in several regions. A web-education app is available to all health care professionals on this site, along with other educational resources.

Increase in Frequency of Use

We report a substantial increase over recent years in the number of DNACPRs being seen by prehospital practitioners. While many of these DNACPRs may have been written in hospitals and

transferred with the patient into the community, DNACPRs are also being initiated in general practice; some nursing homes are now having discussions about resuscitation decisions routinely when residents are admitted (Ampe et al, 2015). The intention is to avoid unwanted or inappropriate resuscitation attempts, and to make conversations about DNACPR with patients and their relatives more routine rather than waiting until a patient has deteriorated, when they are often too ill to participate meaningfully in a conversation. However, there has been a failure to communicate this intention to the public, which has led to concern articulated by some media that ‘asking patients to make such a decision when they may have many years to live will prompt concerns that the NHS is writing them off’ (Borland, 2015). In several regions, forms have been developed which cross all care settings: Treatment Escalation Plan (TEP) (Sherman et al., 2017), and the ‘deciding right’ approach in the north east of England (NHS England, 2014) are two examples. Both Wales and Scotland now have national forms, which facilitate their initiation and use outside the hospital setting. These initiatives may have led to the significant increase in DNACPRs seen in the community over the past 10 years.

Delivering CPR when they don’t want to

Many respondents identified occasions when they wished they had not delivered CPR. Several reported situations where they felt they had to carry out futile CPR, knowing the patient would not receive further efforts at the hospital. Multiple factors influenced decision-making including the location of arrest, whether a DNACPR form was available and if it has been discussed with relatives.

Compliance with relatives’ wishes over the patients has been identified in previous studies (Murphy Jones & Timmons, 2016; Yayas, Rutsohn & Ibrahim., 2003). Family members may have phoned the emergency services for support, often because they were anxious about their relative’s symptoms, despite knowing their family member did not want CPR. Once present, however, the service personnel often feel obliged to start CPR which can be very distressing for all involved. Our study suggests patients and families are not routinely made aware of the limited information clinicians have access to, or know the importance of ensuring the DNACPR form is available when they call an ambulance.

Misinterpretation and education needs

Our findings support the conclusions of others that ambulance clinicians do not feel confident in their knowledge of ethical issues surrounding appropriate CPR decisions (Wiese et al, 2011), with insufficient education and policy guidance (Norby & Nohr, 2012). The absence of specific training contributed to participants' lack of confidence. Whilst the majority of our respondents did not think that the presence of a DNACPR form would affect other treatments for the patient, it was concerning a third of questionnaire respondents conflated a DNACPR decision and other medical decisions; this was also reported in the interview data where respondents reported other staff misinterpreting DNACPR to mean 'do not treat'. Part of the reason for this reported and observed misinterpretation of the specificity of DNACPRs may be that less than half of respondents reported receiving any formal education on resuscitation orders.

Limitations

The questionnaire was not extensively validated; however, the potential to elaborate with free text boxes allowed respondents to add nuance to their answers.

The nature of the recruitment for the questionnaire (at a conference) and for interviews (via flyers) means that there was likely to have been a selection bias towards those interested in education and resuscitation; it is likely that these results overestimate the level of understanding about and education on resuscitation decisions. The interview sample was not geographically representative, with all participants coming from one ambulance trust. A higher proportion of questionnaire participants came from south east England. In Scotland, there is a national approach to resuscitation decisions, and in the north east the 'deciding right' approach encourages more advance care documentation.

Conclusions

Our findings highlight how resuscitation decision-making - from the initial conversation to ensuring smooth implementation across care settings - involves a series of complex tasks. Each requires appropriate training to ensure resuscitation decisions are appropriately communicated and implemented. This study identifies a need for education about resuscitation recommendations to be

integrated into training of all prehospital workers, and highlights the need for a national approach to resuscitation decisions and their documentation.

Keywords

- DNACPR
- Resuscitation orders
- Paramedic
- Treatment Plan
- Do-Not-Resuscitate
- Decision making

Key points

- Ambulance clinicians have seen an increase in in number of DNACPR orders being seen.
- Resuscitation decision-making involves a series of complex tasks to ensure they are appropriately communicated and implemented.
- Education and training in resuscitation decision-making should be incorporated into annual updates.
- A national approach to resuscitation decisions and documentation is recommended.

DNACPR Reflection Questions

- Reflect on conversation you have had with another healthcare professional regarding an end of life resuscitation decision. Now reflect on how you managed the incident.
- What information do you need on a form to not commence CPR?
- What considerations need to be taken into account before instigating a conversation regarding resuscitation preferences?

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