CPR decision-making conversations in the UK: an integrative review

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ABSTRACT

Objectives: Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) discussions with patients and their caregivers have been subjected to intense ethical and legal debate in recent years. Legal cases and national guidelines have tried to clarify the best approach to DNACPR discussions; however, there is little evidence of how best to approach them from the patient, family or caregiver perspective. This paper describes published accounts of patient, family and caregiver experiences of discussions about advance cardiopulmonary resuscitation (CPR) decision making.

Methods: An integrative review of the UK literature between 2000 and 2016 including qualitative and quantitative studies was conducted. Worldwide, 773 abstracts were identified, and 20 papers from the UK were included in the final analysis.

Results: Patient, family and caregivers prefer discussions to be initiated by someone trusted, and wishes for family involvement vary depending on the context. Timing of discussions should be individualised, though discussions earlier in the illness are often preferable. Discussions held in the acute setting are suboptimal. CPR decisions should be part of a wider discussion about future care and adequate communication skills training is important.

Conclusions: The findings of this review are at odds with the current statutory framework and potentially challenging for medical professionals who are working in a stretched health service, with pressure to discuss DNACPR decisions at the earliest opportunity. With increasing focus on person-centred care and realistic medicine, patient narratives must be considered by doctors and policy makers alike, to minimise harm.

BACKGROUND

Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decision making has been the subject of much ethical debate, legal dispute and uncertainty in the last few years. Cardiopulmonary resuscitation (CPR) is a treatment that was developed originally to save the lives of younger people dying unexpectedly from primary cardiac disease and it was never intended to be given to patients who are dying of irreversible underlying disease.

However, CPR is often misunderstood as a procedure that can restore cardiopulmonary function and prolong life, irrespective of the underlying cause of the cardiac arrest.

Public perception of CPR has been influenced by the media, as it is often portrayed as more effective and less harmful than in reality. This can influence care decisions made during serious illness and at end of life (EOL). Not only this, but there are many reasons why patients, family and caregivers (PFC) may find talking about death and dying difficult, for example, fear of: loss; their own mortality; being a burden on or upsetting family and friends and denial.

It is well documented that medical staff find initiating DNACPR discussions with patients difficult due to fear of causing distress, time constraints as well as fear of complaints. However, there is genuine potential for harm when communication about CPR and DNACPR decisions is inadequate. Numerous reviews in the UK have found deficiencies in considering, discussing and implementing DNACPR discussions, resulting in either futile or inappropriate CPR attempts, poor or delayed discussion of DNACPR decisions and inappropriate withholding of other treatments. This has also been highlighted in vulnerable patient groups such as those with learning difficulties, where a poor understanding of the Mental Capacity Act (2005) by healthcare professionals as well as inappropriate or poorly documented DNACPR orders has been noted.

Across the four countries in the UK, recent legal cases, which are outlined in box 1, have brought the DNACPR decision-making process in to the spotlight. It
has been updated, including updated decision-making frameworks in an attempt to clarify the meaning of this new terminology so healthcare professionals can address this complexity (box 2).

Although discussions about EOL issues and anticipatory care planning (ACP) can be challenging, changing the focus of these discussions from specific treatments (such as CPR), to discussions around goals of care, acceptable health states for patients and valued life, might be more acceptable. A UK-wide initiative, the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process, complements the process of ACP. It focuses on incorporating personalised recommendations for a person’s realistic care and treatment choices in future emergency situations, where they are unable to make or express choices, of which DNACPR decision making is one aspect. Shifting the focus from specific decisions about CPR, to making personalised plans on broader emergency care and treatment choices, may help tackle some of the difficulties clinicians face with DNACPR decision making and communication.

It seems unfortunate that many lessons and policy-changes on DNACPR decision making in the UK have come from cases highlighting deficiencies or poor practice. Medical staff often rely on communication skills training, which is based on perceived best practice from studies examining subjective views of people who may not have actually experienced discussions about CPR. Instead, communication skills training should be informed primarily by evidence from the lived
Anticipatory decisions about cardiopulmonary resuscitation (CPR) are best made in the wider context of advance care planning.

If the healthcare team is as certain as it can be that a person is dying, CPR should not be attempted.

Even when CPR has no realistic prospect of success, there must be a presumption in favour of explaining the need and basis for a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decision to a patient or to those close to a patient who lacks capacity.

Where there is a clear clinical need for a DNACPR decision in a dying patient for whom CPR offers no realistic prospect of success, that decision should be made and explained to the patient and those close to the patient at the earliest practicable and appropriate opportunity.

Where a patient or those close to a patient disagree with a DNACPR decision a second opinion should be offered.

Agreeing broader goals of care with patients and those close to patients is an essential prerequisite to enabling each of them to understand decisions about CPR in context.

A decision to delay or avoid communication of a decision to a patient must be based on that communication being likely to cause the patient physical or psychological harm. A decision to delay communication of a decision to those close to a patient without capacity must be based on that communication being either not practicable or not appropriate in the circumstances.

All decisions must be clearly documented in the patient’s notes.

A DNACPR decision must not be allowed to compromise high quality delivery of any other aspect of care.

CPR decision-making conversations, which we knew encompassed diverse epistemologies and methodologies. Thus, an integrative review was chosen for its inclusivity, which enabled the analysis of studies using qualitative and quantitative designs. The six main steps are shown in box 3.

**Data sources**

**Search strategy**

The research team worked in collaboration with a librarian to identify appropriate search terms. The search was then conducted by the librarian and the results fed back to the research team. Queries regarding inclusion and exclusion criteria were discussed contemporaneously throughout the search period. The search was conducted in the following databases: Medline, Health Management Information Consortium (HMIC), Embase, CINAHL, PsychInfo, Web of Science, Scopus. English language papers which were published between 1 January 2000 and 15 November 2016 were included in the search. The initial search included papers from all countries, recruiting patients from all settings (ie, hospital, community, nursing home, hospice), with all diagnoses (including frailty) and family members or caregivers. Papers focusing on health professionals’ experiences of CPR conversations were excluded, unless the paper included the views of patients and carers. The search terms can be found in box 4.

**Data evaluation**

After de-duplication, a total of 773 abstracts were identified. These were divided equally between the three researchers (CH, JL, EC). Abstracts were screened for eligibility according to the following inclusion criteria: Papers were included if (1) the research was conducted

**METHODS**

**Design**

We conducted an integrative review of the UK literature to summarise past empirical work and identify the scope of existing best practice. 14 The aim of the project was to identify research on participant experiences of CPR decision-making conversations, which we knew encompassed diverse epistemologies and methodologies. Thus, an integrative review was chosen for its inclusivity, which enabled the analysis of studies using qualitative and quantitative designs. The six main steps are shown in box 3.

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in the UK, (2) written in English, (3) published between 2000 and 2016 in a peer-reviewed journal, (4) primary quantitative or qualitative research, (4) included patient and carer experiences of DNACPR/CPR discussions (hypothetical and retrospective).

Data extraction and synthesis

A flow diagram of the search results can be found in figure 1. Of the 773 abstracts identified, 20 full text articles matched the criteria for inclusion. The full text articles were collated and appraised for quality using appropriate tools from CASP,15 SIGN guidelines 16 or Medscape.17 A coding system of 0–10 was applied to the papers. A score of 8–10 was considered high quality, 4–7 moderate quality and below 4 was poor quality.

The 20 papers in the final set were read by authors EC and CH. The data extracted were: CPR-related aim, country of origin, evidence of ethical review, setting, participants, design/methods, research tools, main CPR-related findings and study limitations. Themes were identified for each article and collated in a master document. At this point, data extraction and themes were cross-checked and a detailed analysis was conducted to extract, reduce and categorise subthemes,14 using the constant comparative method18 used in qualitative research. Themes and subthemes were discussed at regular research team meetings and iteratively refined. A conceptual framework was developed (figure 2).

RESULTS

Characteristics and quality

Twenty papers were from the UK and included in the final review. The papers are summarised in the online supplementary material. Of the 20 papers, eight were based on actual experiences of discussions as compared with nine which were hypothetical that is, what
patients, family members and caregivers would want for discussions about CPR. Three studies recruited participants with and without actual experiences of discussions. A qualitative design was adopted in 13 papers; four were quantitative and three used mixed method designs. Some studies were about ACP more broadly, of which the CPR conversation is a part. The setting for 10 of the studies was in hospital, 7 in the community, 1 in hospice, 1 in a care home and 1 using a variety of settings.

In terms of quality, 11 papers were classified as high quality and 8 were of moderate quality. No papers were classified as having poor quality. It was not possible to critically appraise one paper using the tools described above.

**Synthesis**
The main DNACPR-related findings from each paper are included in the online supplementary material. Analysis revealed themes in the following areas: (1) Involvement in discussion; (2) Optimal timing and setting; (3) Information and communication. Figure 2 presents a conceptual map of the findings.

**Involvement in discussion**
Who should initiate discussions?
Overall, the studies concluded that patients were willing to have a conversation about CPR or ACP and that doctors were perceived as best placed to have the discussion. Initiating the discussion was discussed in 6 of the 20 studies. Pollock et al’s 21 case studies with patients showed that both patients and health professionals can initiate conversations about ACP, but an existing relationship is required, and patients rarely do initiate these conversations. In addition, there was no documented ACP discussion in 9 of the 21 case studies. Pollock et al also found that it was often General Practitioners (GP) who initiated discussions. This is encouraging, since the findings show that patients valued having the discussion with someone they trusted, who was known to them.

Figure 2 Conceptual map of the findings. CPR, cardiopulmonary resuscitation.
In Seamark et al’s (2012) study, patients with chronic obstructive pulmonary disease (COPD), who had recently been admitted to hospital for an acute exacerbation, described that a consultant or specialist nurse could initiate a discussion about CPR, but they would not necessarily have the personal relationship that the patients desired. Similarly, Vandrevala (2002) found that older adults living in the community, when asked about EOL decision making, felt that doctors were the right person to give a clinical diagnosis, but not necessarily to discuss sensitive issues. Reasons given for this included doctors’ non-acceptance of death as a reality, the focus on cure within Western medicine and that doctors do not want to upset them so may water down the information provided. Conversely, Seamark (2012) noted that patients may avoid discussions as they are seen as potentially distressing and emotional. Ray et al (2012) highlighted the need for health and social care workers to have advanced communication and mentoring skills to build trust and facilitate ongoing conversations around planning for death and dying.

Who should be involved in discussions?
The participation of family at the discussions was largely viewed as positive. For example, Gorton et al (2008) showed that 87% of general outpatients would like their relatives to be involved in their decision about resuscitation status, if they were unable to hold a discussion due to critical illness. Likewise, Ackroyd and colleagues (2007) found that most patients with cancer in this study wanted their family involved. In the care home setting, an intervention to improve ACP for this included doctors’ non-acceptance of death as a reality, the focus on cure within Western medicine and that doctors do not want to upset them so may water down the information provided. Conversely, Seamark (2012) noted that patients may avoid discussions as they are seen as potentially distressing and emotional. Ray et al (2012) highlighted the need for health and social care workers to have advanced communication and mentoring skills to build trust and facilitate ongoing conversations around planning for death and dying.

When describing their views on Family Witnessed Resuscitation (FWR), patients felt that relatives would be responsible and able for decision making if they became incapacitated and that this would increase the chances that their wishes were met. In some cases, it was described as appropriate to hold a discussion with the family alone. For example, a case note review of patients admitted to an acute ward conducted by Cohn et al, found that 30 of 43 discussions were held with relatives alone due to ‘poor comprehension’ of the patient (including confusion, delirium and dementia).

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to hospital. Johnson et al (2008) suggested that distributing a leaflet about DNACPR during the first admission or day care visit to the hospice was appropriate, but had to be followed up with a discussion. Cox et al (2007) also highlighted the importance of postdiscussion support, particularly when discussions had been distressing.

There was agreement, particularly in more recent studies, that discussions should not be conducted during an acute admission to hospital or at diagnosis. However, they should occur earlier in the illness trajectory rather than later. For example, Ray et al (2012) suggests that EOL discussions for patients with motor neuron disease (MND) need to begin early in the disease progression and continue throughout the course of the disease. In this way, discussions can enable people with MND and their family members to reconstruct normality, to include dying as part of life and enable the development of a sense of control over care in an uncontrollable disease. Seymour et al (2004) suggested that discussions should not take place too close to death, but Pollock et al’s (2015) case studies revealed that this frequently happened. Reasons included lack of opportunity to have a discussion earlier and issues around communication. Pollock et al (2015) described a case, where, despite the presence of long term illness, DNACPR was completed 3 days before death. This is because the patient did not want to engage in ACP when he was well, despite efforts made by professionals.

Two studies noted the potential vulnerability of patients at EOL. Seymour found that patients worried about making the ‘wrong’ decision if they responded when they were ill. Ackroyd et al (2007) suggested that as a result of being ill and vulnerable, discussions about CPR need to be handled sensitively and important information may not be well received or understood when discussed during admission.

This is supported by Cox et al (2007) who reported that discussions should be conducted when patients are feeling well, so they can take in the information and act on it. Seemark et al (2012) found that patients with COPD were usually admitted with an acute exacerbation, which limited the opportunity for discussion about EOL. Further to that, relatives and patients may be at different points in the process and thus have different needs.

Setting

Only two papers mentioned the optimal setting for the discussion. Seemark et al (2012) suggested that discussions were best conducted by the GP, in the surgery, in the time period after acute admission. Similarly, Cox et al (2007) found that there were fewer negative comments about conversations when they had taken place in the outpatient department as compared with the ward—which was perceived as too public.

Information and communication

Delivery and content

Discussions should be individualised, empathetic, honest, straightforward and balanced. The use of vague language was found to be frustrating for patients in Pollock et al’s study. Good communication skills and consideration of the levels of education and literacy are required.

Conversations should aim to deliver information on risks involved in CPR and the low chances of success and should aim to elicit patient preferences and goals, as opposed to process decisions about care. This should include gaining a shared understanding between clinician and PFC of prognosis and quality of life—which was seen as a key factor in the decision making process.

Fritz et al (2015) and Obolensky et al (2010) both support a move from away from the DNACPR form to consider treatment more generally as is illustrated in Fritz et al’s paper about the development of the Universal Form for Treatment Options (UFTO)—a two-page form which is universal, simple, contains guidance about treatment options, resuscitation decision and has the potential for patients’ wishes to be incorporated. Patients in Obolensky et al’s (2010) study found discussing a ‘Treatment Escalation Plan’ (TEP) caused no excess anxiety and patients reported feeling ‘looked after’ ‘reassured’, and it enabled them to ‘to face reality’ and ‘put things in to perspective’.

The delivery of information in a written format (leaflet) was not considered useful in a study with relatives of patients with a stroke. In fact, relatives reported seeking information in other ways. Likewise, Johnson et al (2008) found that a leaflet on DNACPR policy was not effective in isolation and had to be followed up by a discussion, but it was acceptable to patients in the context of their illness understanding.

DISCUSSION

The results of this review identified that there is a lack of empirical research on the preferences of PFC regarding discussions around DNACPR. The findings show that some preferences of PFC are at odds with the guidance and statutory decision-making frameworks which guide clinicians in the UK. For example, there is a desire by PFC for discussions about CPR to be held by someone with whom they have a strong or established and trusting relationship. In several papers, this was the GP. However, by law it is now a necessity to discuss DNACPR decisions at the earliest practicable and appropriate opportunity, meaning that more and more discussions about CPR are being held with patients at, or soon after the point of acute admission to hospital, by doctors the patients are unlikely to have ever met. Although many DNACPR discussions are held in the community, it is unrealistic to expect every discussion to be held by a patient’s ‘known/trusted’ GP. The very nature of the decision-making process is
that these discussions are often triggered by an acute deterioration, followed by an admission to hospital. Not every disease trajectory allows for a predictable deterioration and clearly signposted opportunities for ACP discussions; however, work is ongoing to clarify best approaches for each trajectory. The literature highlighted that for most illness trajectories, an earlier discussion was preferable than later, and leaving discussions too close to death is suboptimal.

These PFC views add important evidence to the clinical opinion that there are potential opportunities for discussions about future care preferences which are being missed. There is evidence in the literature that PFC advocate a move towards CPR discussions becoming part of a wider discussion about realistic care and treatment options that includes a patient’s broader life values and goals of care. PFC prefer these discussions to be held in non-acute or outpatient/community settings, by someone known, when the person is more ‘well’ and less ‘vulnerable’. This finding would support the implementation of recognisable processes which can be used to facilitate such discussions in any care setting (eg, ReSPECT process http://www.respectprocess.org.uk). Such initiatives encourage specialists and generalist services to structure outpatient clinics to enable and facilitate discussion about future preferences for care as a core part of their review process. Electronic palliative care summaries may facilitate communication between specialist and generalist services and sensitive communication with patients on admission to hospital.

Adequately resourced advanced communication skills education, for all generalist and specialist clinicians with opportunity to support these discussions, is a necessity. The fact that some PFC feel doctors are not always the best people to discuss sensitive issues with, should encourage and empower nurses and Allied Health Professionals (AHPs) in care homes and the community, to take forward these discussions with their patients. Community teams could use

| Table 1 Bridging some of the expectations: challenges and opportunities |
|--------------------------|--------------------------|--------------------------|
| **PFC preferences**      | **Challenges**           | **Opportunities/Shape of future care** |
| ► Initiation of discussion by someone trusted with an existing relationship | ► Continuity of care | ► Proactively seeking out opportunities in community by GPs and nursing teams (eg, posthospital discharge) |
| ► Not necessarily just doctors—role also for nursing and AHP teams | ► Shared care of patients—who’s role is it? | ► Proactive use of tools in hospital and community (such as the SPICT tool) to identify patients who would benefit from ACP discussions, followed by targeted outreach by familiar medical/nursing team |
| ► Time pressures/workloads | ► Challenges of best timing of ACP discussions within disease trajectories | ► Improving electronic communication between primary and secondary care teams regarding existing ACP/DNACPR discussions: use of electronic Palliative Care Summaries (such as the eki) |
| ► Need for ACP/DNACPR discussions in acute environments often by teams not familiar with patients | ► Proactively seeking out opportunities in community by GPs and nursing teams (eg, posthospital discharge) |
| ► Most want family involved | ► Time pressures, communication challenges | ► Development of support roles in acute settings following ACP discussions and to identify follow-up conversations needed |
| ► Some fear burdening family members | ► Difficulty knowing who to involve, where, when to discuss | ► Integration of ACP screening questions at specialist outpatient clinic (eg, chronic disease/oncology) where frequently patients have established trusted relationships. |
| ► Family not always available when discussions take place | ► Development of support roles in acute settings following ACP discussions and to identify follow-up conversations needed |
| ► When? Timing of discussion needs to be individualised and early in illness | ► Space and environment limited | ► Initiating ACP discussions can be enabling for patients/families, especially in diseases such as MND |
| ► Where? Not during acute admissions, dislike of busy wards (vulnerability impacts on decision making) | ► Challenges of PFC expectations/fear of difficult conversations | ► Incorporation of ‘What (and who) matters to me’ section in to any ACP created with helpful descriptions such as ‘Would always prefer/not wish’… Mr/Mrs X, Tel…. to be involved in decisions about my care’ |
| ► Delivery: Individualised, honest, straightforward, empathetic language. Avoiding vague terms. Consider level of education/literacy. Include discussion about QOL | ► Basic communication skills training not always sufficient | ► Development of a consistent approach to communication skills training dealing with issues around ACP/DNACPR conversations embedded within medical and nursing education curricula; from undergraduate/preregistration level and throughout generalist/specialist careers. Greater understanding and embedding of health literacy approaches and resources within acute and community care settings |

ACP, anticipatory care planning; AHP, Allied Health Professional; DNACPR, Do Not Attempt Cardio-Pulmonary Resuscitation; MND, motor neuron disease; PFC, patients, family and caregivers; QOL, quality of life.
this evidence in support of proactively following up patients after discharge home following acute admissions, as described by Seamark et al (2012).27

As well as revealing some significant differences between PFC views and current practice, the findings also provide a rich opportunity for educators, policy makers and healthcare professionals to try to find ways of bridging some of these gaps between expectation, resource and reality. Table 1 summarises the opportunities and challenges of bridging such PFC expectations. We have provided suggestions for incorporating our findings in to practice and how the shape of future care in the UK might change. Undoubtedly incorporating change within a healthcare system with limited resources will create challenges both for primary and secondary care teams, but a deeper understanding of why change is happening and the potential benefits in terms of person-centred care is often helpful.45 Quality Improvement Methodology including the Plan, Do, Study, Act (PDSA) model for improvement is a fast and effective way of introducing change and is strongly advocated for use within the NHS.34 46

The Chief Medical Officer for Scotland set out her vision for the future of healthcare in her report Realistic Medicine, that we need to find ways to encourage clinicians to put the person receiving healthcare at the centre of the decision-making process and create a personalised approach to their care.47 The PFC experiences presented in the this review, along with the opportunities and challenges they present, must shape the way we manage these potentially challenging discussions in the future. Patient and family experience of ACP discussions should be evaluated alongside the introduction of any regional or national ACP process, to inform best practice approaches to communication.

Strengths and limitations

International papers were excluded due to the specific nature of the legal and statutory framework for discussing DNACPR in the UK, as outlined in the introduction to this paper. In so doing, findings from those studies may have been missed. Of the 20 papers included in the final review, nine papers were on hypothetical views about CPR decision making as opposed to actual experiences. This highlights the need for prospective primary research with patients and their families who have been involved in discussions about ACP and DNACPR. The studies were conducted in a variety of community and hospital settings which is a strength. However, only one study recruited participants from a care home which is a limitation. There was also good representation from patients and families. In terms of study design, there were no randomised control trials and only one case-control study which is a limitation. The qualitative papers exhibited a good range of methods, including ethnographic observation in one study, but often the number of participants was small and therefore the result not immediately generalisable.

CONCLUSION

The findings from this integrative review of the literature on PFC experience of CPR decision-making discussions are at odds with the current legal state in the UK and are potentially challenging for health professionals, who are required to discuss DNACPR decisions at the earliest opportunity. The educational elements needed are comprehensive, for example, advanced communication skills training, which commences in undergraduate training, and extends to higher specialist medical training, as well as ongoing training and regular review at consultant level. There is also evidence to suggest that the empowerment and extension of the role of nurses and AHPs is necessary to meet the preferences of PFC, particularly around initiating discussions about future care needs and wishes and planning future care. The views of these UK PFC should form a critical part of the evidence base for the person-centred approaches of future care planning policies, both at local and national levels. For healthcare to genuinely move towards a ‘realistic medicine’ approach, we need to acknowledge and balance the wishes and experiences of patients with the resources, legalities and processes of our healthcare system.

Acknowledgements  The authors would like to acknowledge the work of Alison Bogle, Health Management Library, National Services Scotland. Thanks to Dr Beci Evans who was involved in extracting data from a subset of papers.

Contributors  CCH, EC, JAS and JL designed the project. CCH, JL and EC reviewed the abstracts and extracted data from the papers. EC and CCH reviewed the papers for quality. EC and CCH drafted the final manuscript. All authors approved the final draft.

Funding  Funding for the project was received from the Scottish Government. The posts of JAS and EC are supported by Marie Curie.

Competing interests  None declared.

Patient consent  Not required.

Provenance and peer review  Not commissioned; externally peer reviewed.

Data sharing statement  There are no unpublished data.

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REFERENCES

Review


3 Fritz Z, Slowther AM, Perkins GD. Resuscitation policy should focus on the patient, not the decision. BMJ 2017;356:j813.


10 British Medical Association (BMA) RCU, Royal College of Nursing (RCN). Decisions relating to cardiopulmonary resuscitation. 3rd edn, 2016:35.


18 Miles MB, Huberman M. Qualitative data analysis: an expanded sourcebook. 2nd ed: SAGE Publications, 1994.


45 Ahmad NE, Kreel J, Lawrie, M H. Person-centred care: from ideas to action Bringing together the evidence on shared decision-making.


51 LeighDay. High Court rules doctors should consult on DNR orders for disabled patients. 2015 https://www.leighday.co.uk/News/2015/November-2015/High-Court-rules-that-doctors-should-consult-on-DN2017
