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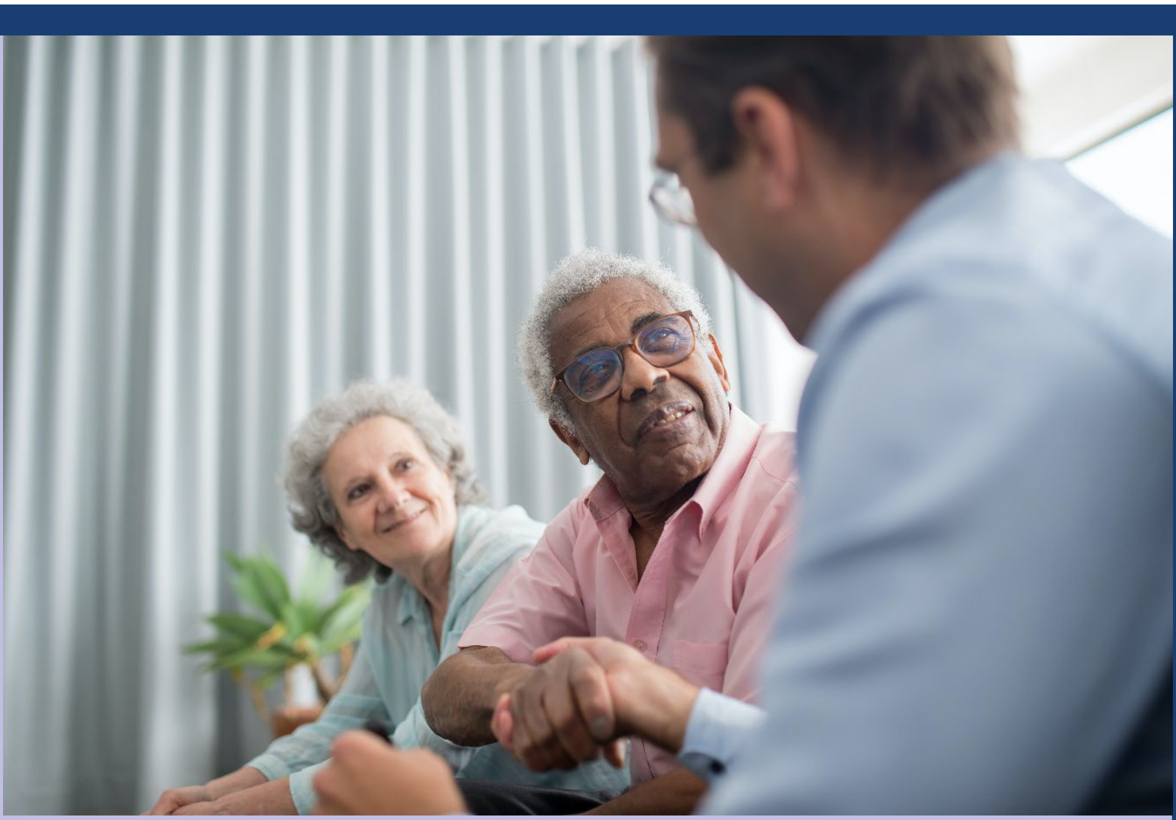

Executive Summary

Improving discussions about resuscitation in COVID-19

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Please note that this report has not been peer-reviewed.

Background

Outcomes following cardiopulmonary resuscitation (CPR) are often poor, and most frail older people who undergo in-hospital CPR do not survive to go home.[3] A decision not to attempt resuscitation (DNACPR) can prevent futile and undignified medical interventions. Following a Court of Appeal decision in 2014, clinicians must inform patients or their relatives (if a patient lacks capacity) if a DNACPR decision is made.[2] DNACPR decisions were a source of criticism and complaints before the coronavirus pandemic. However, COVID-19 presented multiple challenges to best practice, including the speed at which patients deteriorated and restrictions on face-to-face interactions between clinicians, patients and relatives. Numerous reports from regulatory bodies, including the Care Quality Commission (CQC), detail poor practice around DNACPR decision-making and communication during the 2020-2022 COVID-19 pandemic, whilst academic literature shows that more DNACPR decisions were made in 2020 during the pandemic than in previous years.[1,2]

Aims and methods

This qualitative research aimed to understand the experiences of people who discussed DNACPR with a clinician on behalf of their relative during the pandemic. Thirty-nine relatives took part in semi-structured interviews using telephone or video conferencing software. A patient and public involvement and engagement group (PPIE) was commissioned to refine the research scope; develop the interview topic guide, and guide analysis. Data were analysed using Framework Analysis.

Results

Three main themes were identified from the data: (i) Knowledge and understanding about DNACPR; (ii) Communication around DNACPR discussions; and (iii) Impact of DNACPR discussions. The issue of visiting restrictions was important across all three themes. Being separated from relatives at the end-of-life was highly distressing for those interviewed and impacted on the quality of communication with clinicians.

Theme 1: Knowledge and understanding about DNACPR

We interviewed people with a range of knowledge and understanding about DNACPR. Those with better understanding reflected on their experiences more positively. A frequent misunderstanding was the relative's role in DNACPR decision making. Although DNACPR is a decision made by the medical team (when CPR is felt to be futile – which represents the majority of DNACPR decisions made), relatives often felt they were being asked to make the decision. Some reported being asked to give permission for a DNACPR to be in place.

> *‘[the doctor] said, ‘well, it’s likely that he’s got COVID and it’s unlikely that he would survive this, if it is COVID. So, what would you like to do?’ And I then spoke to my husband… we made the decision that he probably wouldn’t*

> *be…he shouldn't be for CPR given how far advanced his Parkinson's was, his own quality of life and the fact that none of us were going to be able to come and see him.'* Participant 11

Participants described frustration when they were asked to be involved in decision-making about DNACPR, and then their wishes were overruled. Those with a limited understanding confused DNACPR with other types of medical treatment. Some believed that DNACPR was a mechanism for rationing care in an overwhelmed health service. Participants felt that having more information about DNACPR would have improved their experiences. Some recommended that public education about DNACPR should be improved.

Theme 2: Communication around DNACPR discussions
The ability of clinicians to lead DNACPR discussions was critical to all participants. Many described discussions about DNACPR as rushed, and felt they were not given the opportunity to ask questions. Some felt they were being coerced into agreeing with a DNACPR. Others described how, as general communication about their relatives' condition was so poor, they felt the discussion about DNACPR came without adequate warning.

> *'The ICU consultant brushed all my concerns aside … He tried to convince me absolutely, he didn't say, oh, there is an option … He had made up his mind that my husband would not be resuscitated and that's what he tried to convey. That my input was very minimal, there was no opening to ask any questions.'* Participant 2

However, participants also reported more positive experiences. Here, clinicians had adequate time to spend on the discussion about DNACPR. The process and rationale were explained well, and relatives were given the opportunity to raise concerns and have questions answered. Participants also reported that communication within families was important. DNACPR conversations were easier when participants clearly understood their relatives' wishes. Some participants reflected that normalising conversations about DNACPR in everyday life would be helpful.

Communication of DNACPR decision-making across care settings was felt to be poor. Repeated discussions about DNACPR caused distress and gave the impression that recording of discussions was poor.

Theme 3: Impact of DNACPR discussions
Discussions with healthcare professionals about DNACPR were considered to be significant events, even pivotal moments, for our interviewees. Participants often described feeling a burden of responsibility from being involved in decision-making and expressed the guilt associated with this. This was particularly significant for

those who felt clinicians had asked them to decide on DNACPR. However, people who were simply informed of the medical decision not to offer CPR were often left feeling overlooked.

> *'It was probably one of the hardest things I've ever done in my life, you know, giving permission for your mum not to be resuscitated and basically saying that if this happens, she's going to die, know what I mean, that's as hard a decision as you will ever have to make.'* Participant 24

DNACPR discussions were also viewed as an important opportunity by some participants. Involvement in conversations around DNACPR left people feeling that the clinicians had listened to them, and allowed them to better understand their relatives' condition, treatment, and illness trajectory. This was also an opportunity to explore other aspects of advance care planning, such as the preferred place of care and death. Many described a sense of relief when DNACPR was discussed, and plans made for what would happen when their relative deteriorated. A key feature of these positive experiences appears to be that the relative understood the patient's wishes, the patient's wishes were respected, and the discussion between relative and clinician incorporated the wider aspects of advance care planning and allowed time for explanation and questions.

Research implications

Participants recommended ways in which discussions about DNACPR may be improved. These were in the following key areas:

- **Education about CPR and DNACPR**: Many recommended that efforts be made to increase public understanding of DNACPR. Our data suggest that this should include clarity around the role of relatives in DNACPR decision-making.
- **Public understanding and discussion about death and dying**: Many participants described a need to 'normalise' conversations about dying. Participants valued having a clear understanding of their relatives' wishes around DNACPR, suggesting that communication within families and communities is essential.
- **Improving communication of DNACPR across care settings**: This is expected to negate the need for repeated discussions about DNACPR. This also implies that these discussions and decisions should be properly recorded onto systems.
- **Improving clinicians' communication around DNACPR**: Clinicians need sufficient time to speak to relatives about DNACPR decisions, respond to questions and consider advance care planning. Clarifying the role of the relative in the decision-making process is an important issue that may not be appreciated by clinicians.

Highlighting the personal impact of relatives' involvement in DNACPR discussions during the pandemic, draws attention to tensions between current clinical guidance and the legal framework. Best practice dictates that DNACPR should be discussed by a medical professional well known to the patient as part of advance care planning. However, during the pandemic, the majority of DNACPR discussions occurred during an acute admission and were led by hospital doctors who are obliged to discuss DNACPR at the earliest opportunity. Furthermore, the legal framework requires clinicians to inform patients and relatives about resuscitation regardless of the patient's wishes, even when resuscitation would be futile and unlikely to be offered on clinical grounds.

Conclusions

During the COVID-19 pandemic, discussion of DNACPR has been a source of enduring distress for many relatives. This research raises questions about the current approach to DNACPR decision-making, including how the legal framework impacts on clinical practice. Co-ordinated action at individual, family, care system and population levels has the potential to enhance relatives' experiences of DNACPR discussions. Better public understanding of DNACPR, early discussion in families, more time and communication skills training for clinicians, may all be helpful.

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