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Do not resuscitate orders in the time of COVID-19: Exploring media representations and implications for public and professional understandings

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Context:: During the COVID-19 pandemic, the UK press featured headlines that heightened concerns around Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders, particularly the use of 'blanket' DNACPR orders applied to older people in care settings. The portrayal of DNACPR may impact professional and public understandings with implications for end-of-life care.

Objectives:: To explore the portrayal of DNACPR orders in the general and academic press and consider implications for public and professional understandings and practice.

Method:: Academic papers and articles published in the general press during the first wave of the COVID-19 pandemic in the UK were retrieved. Those pertaining to the use of DNACPR orders were analysed thematically.

Results:: Analysis of 179 media articles and 11 professional commentaries identified mixed understandings of DNACPR as indicated within three themes: rationing of acute services, championing autonomy in DNACPR decisions, and communication and trust. The call to 'protect the NHS' marginalised palliative and social care services with DNACPR constructed as a rationing tool. This led to ethical challenges around autonomy, DNACPR decisions, communication and trust.

Conclusions:: Media coverage of DNACPR orders was contentious and raised questions around the value of life and quality of dying, particularly for vulnerable individuals. DNACPR orders were conflated with frailty, futility and rationing of acute services and the marginalisation of palliative care. Nevertheless, media outputs stimulated advocacy and support for human rights and autonomy. However, it is unclear what the legacy will be for public and professional understandings of advance care planning and the quality of dying.

Keywords: Resuscitation orders, Palliative care, Autonomy, COVID-19

Introduction

In early 2020 images worldwide, particularly Northern Italy, displayed a devastating COVID-19 impact on critical care resources and mortality rates. As the COVID-19 pandemic hit the UK in March 2020 there was increased apprehension regarding acute care capacity. COVID-19 necessitated rapid decision-making around escalation or de-escalation of care and resulted in a striking number of headlines around DNACPR orders.

Prior to the pandemic efforts to raise awareness of DNACPR orders aimed to promote autonomy and dignity at end-of-life.^{1,2} However, DNACPR decisions can be contentious, particularly where they

undermine family or individual wishes.³ There is also evidence that DNACPR orders can prohibit treatments (such as antibiotics), resulting in poorer patient outcomes.⁴ At the same time, decisions are not always reviewed, particularly when patients move between services.⁵ In 2016 a further decision tool, the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)^{3,6}, was developed as a means to explore preferences for escalation of care, including DNACPR wishes in patients at risk of sudden deterioration. The ReSPECT tool and DNACPR orders were crucial but controversial in efforts to support patients at risk of rapid deterioration in the context of COVID-19.

On the 20 March 2020 the UK government introduced the Coronavirus Act⁷ as an emergency response to National Health Service (NHS) workforce

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management and supporting health needs of those with COVID-19. This was augmented by further guidelines from the National Institute for Health and Care Excellence (NICE)⁸ and the British Medical Association^{9,10} which acknowledged that hastened decisions around care were required in the face of rapid deterioration from COVID-19. NICE guidelines recommended that the ReSPECT tool and the Rockwood Clinical Frailty Scale (CFS)⁸ aid decisions around the escalation of treatment and resuscitation decisions. The guidance also reflected international practice that recognised that in the context of COVID-19 and rapid deterioration, physicians had no alternative but to adopt a unilateral approach to decision-making around patient best interest.¹⁰

In April 2020, during the early stages of the pandemic, The Guardian newspaper reported that a General Practitioner (GP) in Wales had issued a blanket DNACPR order on all older residents of a care home¹¹ resulting in general outrage. This was one of many critical media reports on using DNACPR orders during the COVID-19 pandemic. Media outputs have the potential to capture public understandings and generate sensemaking, particularly in times of crisis.¹² It is not clear how the media portrayal of DNACPR orders will impact awareness and understanding of advance care planning and resuscitation decisions, nor what this means for those facing existential questions around death, dying and end-of-life care. This study, therefore, aims to explore how the media portrayed DNACPR orders during the early months of the COVID-19 pandemic and to consider the implications for public and professional understandings and practice.

Methods

A documentary analysis enabled a thematic exploration of content.^{13,14}

We examined articles in academic journals and UK news media with the aim of

- (1) Exploring media representations of DNACPR practice about COVID-19.
- (2) Examining the implications of media outputs on public and professional understandings of DNACPR orders.
- (3) Identifying the potential impact of the current discourse on future practice.

The search strategies covered the first wave of the pandemic in the UK from 1 March to 11 May 2020 when the first lockdown eased. FW searched academic databases, including Web of Science, CINAHL, and Medline, to capture academic outputs, including any primary research or commentary. JB searched the Nexis news database, including broadsheets, tabloids and local newspapers. The

search terms and limits are detailed in Table 1. Articles with content relating directly to DNACPR in the context of COVID-19 were retained, with repeated or irrelevant reports being rejected. The selection process is detailed in the PRISMA diagram¹⁵ in Fig. 1.

Thematic analysis followed the six steps proposed by Braun & Clarke.¹⁴ Papers were read for familiarisation then a selection was coded individually by the authors and entered into an Excel database for comparison. As coding continued, themes were identified during the regular review. Themes were refined and defined through an iterative process involving inter researcher reflections. Braun & Clarke's¹⁴ 15-point checklist of criteria for good thematic analysis was used to maintain the quality of the process. The checklist facilitated researcher reflexivity in ensuring emotive headlines were unpicked for meaning rather than driving analysis.

Results

A total of 1402 articles were identified in the initial searches. The final selection of papers comprised 179 media articles and 9 articles from academic journals. Thematic exploration suggests that many ethical and moral discourses were played out in the media.

Table 1 Search strategy for academic papers and news articles

Database	Search terms	Limitations
Web of Science	Coronavirus OR COVID-19 AND DNACPR OR Resuscitation orders OR DNACPR OR ReSPECT OR Advance care planning OR Emergency palliative care planning OR Treatment escalation plans	UK Jan 2020–6 May 2020 Published in English Commentaries and editorials included
Medline	All search terms as above	UK Jan 2020–6 May 2020 Published in English Commentaries and editorials included
CINAHL	All search terms as above	UK Jan 2020–May 2020 Published in English Commentaries and editorials included UK Jan 2020–May 2020 Published in English Commentaries and editorials included
Nexis	COVID OR Coronavirus AND Resuscitate OR Resuscitation OR DNACPR OR DNACPR OR 'Advance Care Planning'	UK 1 March 2020–11 May 2020 Published in English Newspapers, weblinks, newswires, press releases, web-based publications, news transcripts, magazines or journals, news, aggregated news sources or legal news

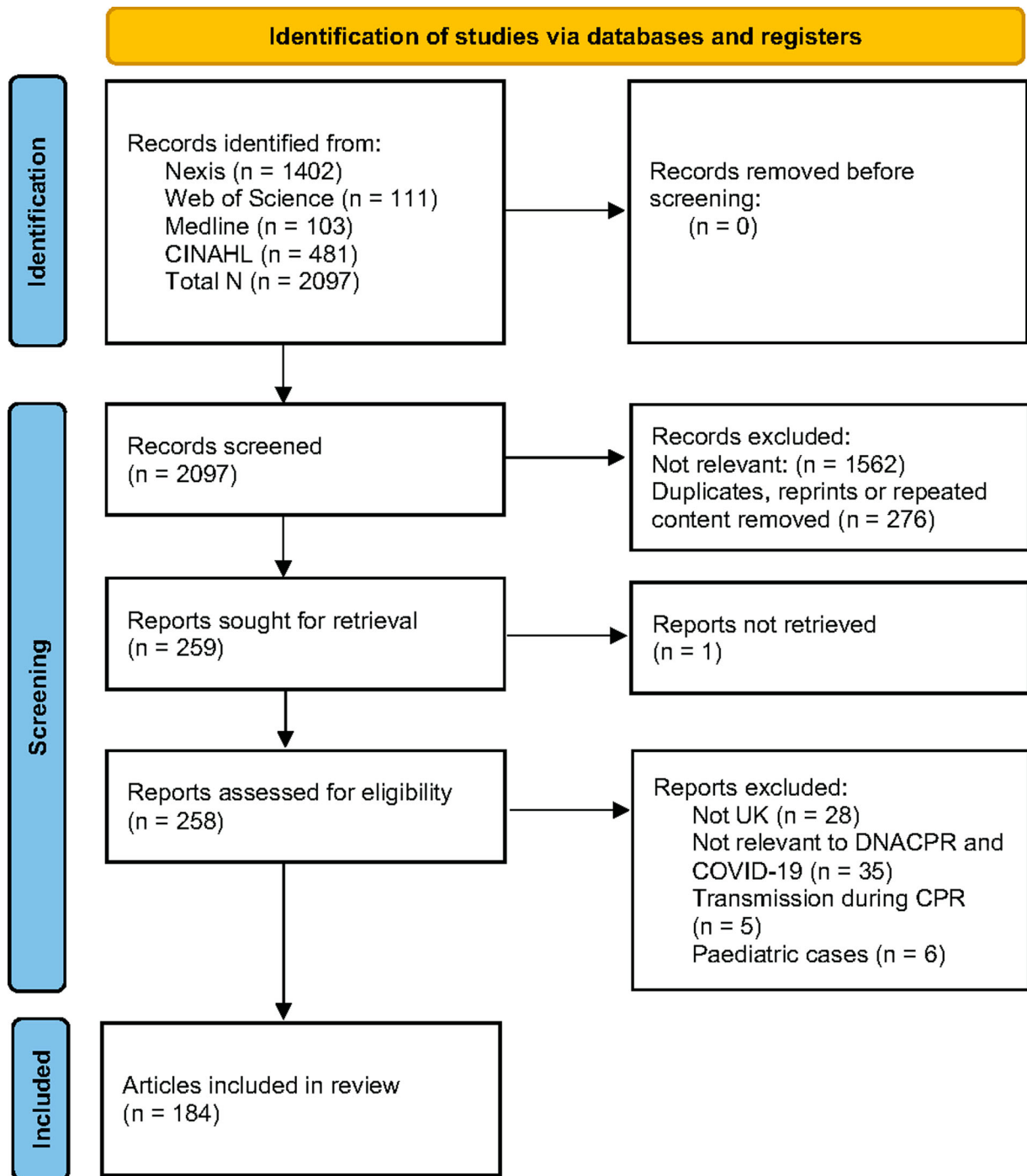


Figure 1 PRISMA Diagram detailing the identification of papers

These were grouped into three themes: rationing of what were seen as priority services, the undermining of autonomy in DNACPR decisions for vulnerable groups, including older and frail individuals and those with learning disabilities, and the need for communication and trust between vulnerable groups, services and professionals. Examples of data relating to each theme from news articles are presented in Table 2 and data from academic commentary in Table 3.

Rationing acute services

During the first wave of the pandemic, reporting indicated that DNACPR orders provided a means to

ration access to acute care, including intensive care beds, ventilators and oxygen supplies. There were reported incidences of vulnerable individuals (particularly in care homes), being asked to sign agreements not to be taken to the hospital should they become ill with COVID-19. The overarching message was that they should avoid hospital admission. One report of a letter from a GP stated ¹⁶

The letter informs patients that doctors from the surgery want to complete a ‘do not resuscitate’ form for them.

Table 2: Examples of data from news articles relating to each theme

Theme	Supporting data	Source
1. Rationing of acute services		
Clinical frailty as rationing	The NHS scoring system, developed by the government-sponsored National Institute for Health and Care Excellence, reveals that any patient over 70 years old will be a borderline candidate for intensive care treatment. A patient aged 71–75 would automatically score four points for their age and a likely three on the 'frailty index', taking their total base score to seven points. The Alzheimer's Society has asked for a review of the NICE guidelines, and for them to make clear that 'cognitive frailty is not discriminated against when having to make life or death decisions'.	Foster, P, Staton, B. & Rovnik, N. (2020) Doctors to make life-and-death choices using points system; NHS. Scoring tool; Age, frailty and underlying conditions will be considered as pandemic peak approaches. Financial Times. 13 th April 2020 Craig, I. (2020) Older people being pressurised into signing 'Do Not Resuscitate' orders, claim charities. South Wales Argus. 8 April 2020.
DNACPR as rationing	"Completing a DNACPR will have several benefits ... scarce ambulance resources can be targeted to the young and fit who have a greater chance." Doctors are being urged to ensure elderly and nursing home patients have a 'do not resuscitate' order in place where appropriate to help ease the burden on the NHS in the wake of the coronavirus outbreak. A GP stated that the lack of medical options for older people meant the job of GPs would be to 'provide palliation. We are already making sure they have 'do not resuscitate' orders in place and discussing end-of-life pathways with them."	Busby, M. (2020) Welsh surgery apologises over 'do not resuscitate' instruction; GPs' practice backs down after bid to focus resources on those more likely to survive COVID-19. Guardian. 31 March 2020. Gregory, A & Wheeler, C. (2020) Decide now whether you want to be resuscitated, elderly told; GPs are being urged to ensure that care home patients have 'living wills' in place, to ease pressure on the health service. The Sunday Times. 2 March 2020.
Avoidance of hospital admissions	One care home manager said ... that a GP had even told them none of your residents aged over 75 will be admitted to hospital. An owner of care homes in Scotland said: 'There are instances of ambulances taking residents to hospital and coming straight back, as well as huge discouragement by the authorities to hospitalise, a wish to keep them where they are and look after them where they are.'	Borland, S. (2020) Fury over elderly doomed to die. Daily Mail. 16 April 2020. Hurst, G. (2020) Coronavirus: Care homes become the hidden front line in Britain's fight against COVID-19. The Times. 12 April 2020.
Justification of rationing	Many medical treatments have always been 'rationed' - from intensive care to transplants-based on rational consideration of who is most likely to benefit. The problem with COVID-19 is that it will make these decisions starker. Decisions should be made about who gets treatment, but this is nothing new. Doctors are forced to decide every day how far to go to try and save patients. Access to intensive care is not an automatic right, and for some people, this is not a viable option regardless of coronavirus.	McCartney, M. (2020) Doctors must make tough decisions whether elderly coronavirus patients should stay at home. The Telegraph. 27 March 2020. Lintern, S. (2020) The truth about do not resuscitate orders; Health correspondent Shaun Lintern explores the difficult decisions facing families and doctors about death and the reality of hospital resuscitation. The Independent. 8 April 2020.
Justification of age as a factor in rationing	In this context, the decision to save the young before the old is, without question, right. Who comes first, the pensioner or the young parent? Faced with a very ill 30-year-old and less ill 80-year-old whose chances of survival may be similar should they be ventilated, doctors will have to choose who gets that chance. Most likely, they will choose the 30-year-old. Justice should teach us who should live if the choice is between someone who has had the majority of their natural life and someone who hasn't.	Toynbee, P. (2020) Coronavirus will force hospital chiefs to make some terrible choices; Our stripped-down NHS will not be able to cope when COVID-19 peaks, leaving it to officials to decide who lives and who dies See all our coronavirus coverage. The Guardian. 7 March 2020. Beadle, J. (2020) It's not easy, but it's time to look death in the face. The Journal. 11 April 2020.
The alternative to acute care	For patients who would be likely to die, even if resuscitation was successful and they were admitted to ICU, death would still be the likely outcome. Good palliative care in care homes is therefore a better option. ACPs offer an opportunity to consider options in patient care, including appropriate treatments, pain relief, location of care, and the presence of family and friends during the critical days and hours before death ... but we cannot know that if we do not talk more openly about what care means to us.	Nachiappan, A. & Wade, M. (2020) Elderly 'facing pressure over DNAR forms'. The Times. 6 April 2020. Paton, A & Goddard, A (2020) Doctors are now having the difficult conversations they always should have done. The Independent. 11 April 2020.

Continued

Table 2: Continued

Theme	Supporting data	Source
2. Championing autonomy in DNACPR decisions		
Evidence of the use of 'blanket' DNACPR Orders	<p>Peter Kyle, Labour MP for Hove, said care homes in his constituency were issuing DNAR notices 'en masse', saying that in one home, 16 of the 26 residents signed DNARs under instruction from a GP. He said all appeared to be planning as though residents over the age of 75 would remain in their homes if they contracted COVID-19 rather than being admitted to hospital.</p> <p>A care home in Somerset that looks after autistic adults said that it had been contacted by a local GP surgery about putting the plans in place for its residents. The chief executive of Voyage Care, the company, looking after the group, said that it had received several such notices and that there had been 'no consultation with families'.</p>	<p>Booth, R. (2020) UK healthcare regulator brands resuscitation strategy unacceptable; Care home residents in Hove, East Sussex and Wales have had 'do not attempt resuscitation' notices applied. The Guardian. 1 April 2020.</p> <p>Yeomans, E. (2020) Coronavirus: 'Do not resuscitate' offer from GP for 11-year-old with rare cancer. The Times. 12 April 2020.</p>
Condemnation of 'blanket' DNACPR Orders	<p>Age Scotland chief executive Brian Sloan said care home residents must have 'fair and equal access to medical treatment', following anecdotal reports of GPs telling facilities to adopt 'do not resuscitate' protocols and some hospitals refusing to admit care home residents over 75.</p> <p>The Health Secretary is set to ban the use of 'blanket' Do Not Resuscitate agreements to protect elderly people from being abandoned to die from coronavirus. Matt Hancock has told the Care Quality Commission to tell care homes to tear up any agreements that would stop residents from getting access to full healthcare if they choose it.</p>	<p>McArdle, H. Coronavirus in Scotland: 'devastating effect' on care homes exposed – as figures suggest true COVID death toll now over 1000. Herald Scotland. 16 April 2020.</p> <p>Bartlett, N. (2020) Coronavirus: 'Blanket' Do Not Resuscitate agreements to be banned to protect elderly; Matt Hancock will try and tackle the growing backlash against the treatment of care home residents by promising a 'right to say goodbye' so that families can pay a final visit to loved ones who are dying from coronavirus. Mirror. 15 April 2020.</p>
Not being informed about DNACPR	<p>Her mother was 'happy to take a phone call from anyone' but would rarely remember the discussion ... The family found the form by chance among her mother's medical correspondence.</p> <p>A dementia-stricken 78-year-old was discharged from the hospital to a care home, without her family being told. She also had a Do Not Resuscitate (DNR) notice along with the orders not to send back to the hospital if she caught coronavirus.</p>	<p>Feerick, K (2020) GP asks vulnerable pensioner to sign 'do not resuscitate' notice over COVID-19 fears; The family says they only became aware of the DNACPR notice when they discovered it in a pile of papers at the pensioners home in Dundee. Daily Record. 3 April 2020.</p> <p>Boyd, C. (2020) How many elderly Britons in care homes have REALLY been infected with coronavirus? Poll of care workers claims figure is around 40% – despite Number 10's insistence it is just 15%. Mail Online. 17 April 2020.</p>
Having a choice	<p>I know that not everyone feels this way but signing that letter offers a degree of comfort. For as long as I have the choice, I would much rather die in my own bed ... Whereas here, in the care home, I know my way around, I know the staff and they know me.</p> <p>I'm certainly not ready to die – but being aware of my position in the scheme of things has allowed me to make choices about the risks I will and will not take at present. It has also allowed me to reflect upon and have realistic expectations about what could happen if I fall ill. The following day pressure was put on her again to sign the DNR. 'The doctor told her that even if she disagreed with this, in the end it would be a doctor's decision.'</p>	<p>Soames, E. (2020) Two powerful voices on the care home corona hospital debate; This brutal ageism would have appalled my grandfather; Why should I deny someone younger a hospital bed? Scottish Daily Mail. 17th April 2020</p> <p>Farsides, B. (2020) How should we prepare for the death of loved ones?; With limited resources for fighting COVID-19, doctors must prioritise who they treat, writes ethicist. The Independent. 12 April 2020.</p> <p>Bain, M (2020) Trust apology for distress of pensioner asked to sign 'do not resuscitate' order. Belfast Telegraph. 8th April 2020.</p>
Talking about it now to have a choice	<p>If you can overcome your reluctance and embarrassment, and have this sort of conversation with your family, you might be surprised by the outcome. For many, the opportunity to share their fears and anxieties about the process of dying will come as a great relief. And finally, if you haven't said 'I love you' to those you value most in this world, do it now. Don't save it to your last breath, there may be no one to say it to.</p> <p>Although it may seem too hard, this is also the moment to explore decisions about end-of-life care. It is worth considering writing a living will. This sets out your wishes as to the treatment and care to which you will and will not consent in a medical emergency, when you are unable to communicate for yourself ... As challenging as this might be to think about, it is an important protection for you and your family at all times, but particularly during this pandemic</p>	<p>Dean, J. (2020) Now is the time to talk about death; The coronavirus pandemic puts end-of-life wishes into focus, says Dr John Dean. Western Mail. 17th April.</p> <p>Samuel, J. (2020) No final words, no funeral: grief will be frozen while the coronavirus has us in its grip; This is the age of smartphone bereavement. Families can no longer visit hospitals for fear of infection. A psychotherapist advises leaving no questions unasked. The Times. 4th April 2020.</p>

Continued

Table 2: Continued

Theme	Supporting data	Source
3. Communication & Trust		
Pandemic-related communication challenges	<p>Although the use of personal protective equipment (PPE) is necessary to reduce cross-infection, wearing masks and eyewear may further disorientate a confused patient in an unfamiliar environment. The use of PPE may also be challenging for patients who, for example, are hard-of-hearing and reliant on their ability to lip-read. There is, then, reason to be concerned that capacitous patients may be identified as lacking capacity following suboptimal capacity assessments, and best interests decisions may be made inappropriately on their behalf. This would undermine such patients' autonomy.</p> <p>Frontline staff are rushed, overwhelmed, working to their limits. It is clear that some DNACPR 'discussions' have been compressed into impersonal emails or letters or – even worse – not happened at all.</p> <p>Mr Zaman, who speaks Punjabi and Pothwari, self discharged from hospital on a Monday and his family said that in the three days he was admitted, the hospital did not arrange for an interpreter until just before he went home.</p>	<p>Parsons JA, Johal HK. Best interests versus resource allocation: could COVID-19 cloud decision-making for the cognitively impaired? <i>Journal of Medical Ethics</i>. 2020.</p> <p>Clarke, R. (2020) 'Do not resuscitate' orders have caused panic in the UK. Here is the truth; The idea that doctors are writing off vulnerable patients is wrong. Coronavirus has not changed our approach to CPR. <i>The Guardian</i>. 8th April 2020.</p> <p>PR Script Managers (2020) Family concerned about 'do not resuscitate' orders and patients not understanding what's happening. <i>Barking & Dagenham Post</i>. 15th April 2020.</p>
Impersonal communication causing distress	<p>'It made me feel worthless. 'I've lived with cancer for eight years and I want to live another couple of years. 'The doctor's sole purpose seemed to be to get me to agree to not being resuscitated should the need arise and to inform me that there was no guarantee that intensive care facilities would be available.'</p>	<p>Cooper, J. (2020) Outcry over 'do not resuscitate' letter. <i>The Western Mail</i>. 20 April 2020.</p> <p>Knox, D. (2020) Pensioner shocked at being asked to reject BGH resuscitation. <i>Peebleshire News</i>. 7 April 2020.</p>
DNAR may be the best choice	<p>At a certain stage of ill-health, the process of resuscitation can be harsh. It unnecessarily prolongs suffering rather than allowing someone who has suffered a cardiac arrest to slip away peacefully. In some circumstances, especially where the patient is extremely frail, resuscitation is the worst of all options. Hard though it is to accept, the prospect of death can come as a relief to some for whom there is no hope of recovery, and who are simply longing to be gone.</p> <p>The benefit of these forms is they can help avoid a frail patient spending their last hours being shipped off to a busy and alien A&E department for heroic, often very invasive, medical treatment if there is little chance of survival, and of ever having CPR performed on them in any situation. Instead, the patient can remain in familiar surroundings and be nursed and made as comfortable as possible with minimal suffering, hopefully with their family nearby.</p>	<p>Goring, R. (2020) Rosemary Goring: The idea that individuals automatically become obsolescent after a certain age is repugnant. <i>The Herald Scotland</i>. 8th April 2020.</p> <p>Anonymous (2020) Ventilators may not work on frail coronavirus patients – they should free them up for others. <i>The Independent</i>. 25th March 2020.</p>
Good communication examples	<p>'With condition of my wife, I appreciate the doctor's gentle approach and when I thought about it, which I had to, I realised that she probably wouldn't survive going into hospital.'</p> <p>'In the night, a lovely old lady was admitted – I had to listen to a consultant tell her he wouldn't be able to resuscitate her if she went downhill. I'll never forget the look in that man's eyes.'</p>	<p>McLaughlin, M. (2020) Hard questions ahead for relatives of those in care homes. <i>The Wiltshire Gazette and Herald</i>. 8th April 2020.</p> <p>Harris, S. (2020) Carol's warning after 24 h in red zone at the Vic. <i>Dunfermline Press</i>. 3rd April 2020.</p>

It reads: “In the event of a sudden deterioration in your condition because of a COVID-19 infection or disease progression, the emergency services will not be called and resuscitation attempts to re-start your heart or breathing will not be attempted.”

The letter adds that patients' 'best option' is to stay at home to be cared for by family, and by signing the form, 'scarce ambulance resources' will be sent to the 'young and fit who have a greater chance'.

It ends: 'We will not abandon you, but we need to be frank and realistic.'

Within the public debate over rationing there was a narrative that older people should 'do their bit' by agreeing to DNACPR and not taking up NHS resources (whether equipment or the time of medical staff) that could be used more effectively on others. Within this narrative, age appears to be an acceptable form of discrimination. Accusations of a 'cull', 'assisted dying', 'eugenics', 'euthanasia by the back-door' and 'turning care homes into hospices' were met with utilitarian arguments for doing the greatest

Table 3: Data from Academic journals relation to each theme

Themes	Author and journal	Title	Summary
Rationing of priority services Communication & Trust	Chidiac C, Feuer D, Naismith J, et al. <i>Journal of Palliative Medicine</i> . 2020. ¹⁹	Emergency palliative care planning and support in a COVID-19 pandemic	Identifies the impact of COVID-19 on palliative care resources. Recommends developing generalist capacity and service provision including palliative care teaching and sharing of skills particularly around communication in order to support and empower colleagues to introduce advance care planning conversations.
Communication & Trust Autonomy in DNACPR decisions	Greenhaigh, T.et al. <i>BMJ</i> 10.1136/BMJ.m1182 25 TH March 2020 ²⁴	Covid-19: a remote assessment in primary care	Commentary; advocates guidance for supporting remote consultations for COVID-19 symptom management and conversations around 'ceilings' of care. Argues that DNACPR and Advance care planning are required to prevent unwanted interventions.
Autonomy in DNACPR decisions	Hawkes, C. et al. <i>Resuscitation</i> 148 (2020) 98–107 ⁶	Development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)	Outlines mixed method approach to developing ReSPECT tool. Tool is timely with regard to DNACPR decision-making during COVID-19
Autonomy in DNACPR decisions Condemnation of 'blanket' DNACPR Orders	Lacobuci, G <i>BMJ</i> 6TH April 10.1136/bmj/.m1419 ²⁷	Covid-19 – Don't apply advance care plans to groups of people doctors' leaders warn	Refers to Joint statement of Royal College of General Practitioners, BMA, Care Provider Alliance, Care Quality Commission. GPs under pressure not to admit older people and refers to Welsh GP incident. Cites Royal College of Physicians recommendation that treatment should be given irrespective of background where it will help patient outcomes and not harm their long-term health and wellbeing. Argues that most commissioning groups have end-of-life care pathways in place which are based on NICE guidelines and medics should follow existing guidelines regarding advance care planning
Communication & Trust Autonomy in DNACPR decisions	McIntosh, L. <i>Age and Ageing</i> 2020, 49, 525–525 ²⁶	Can the COVID-19 crisis strengthen our treatment escalation planning and resuscitation decision-making	Commentary arguing that all medical inpatients should have treatment escalation plans which are discussed on admission 'at the front door' with opportunities to review. Refers to ReSPECT and advocates early discussion to enable patients to recognise severity of condition, and burden of intensive interventions, particularly during covid 19. Recommends such conversations are routine and supported by good communication skills.
Rationing of priority services	Moug, S. et al. <i>Geriatrics</i> 5, 30 2020 ¹⁷	Decision-making in COVID-19 and frailty	Argues that COVID-19 required rapid assessment as indicated by NICE guideline (NG159). Questions frailty assessment in decision-making and defines frailty as a spectrum not binary assessment, cautions that young adults may be wrongly defined as frail, and furthermore, frailty does not define futility. Advocates new multidisciplinary decision-making involvement

Continued

Table 3: Continued

Themes	Author and journal	Title	Summary
Rationing of priority services	Parsons, J,A & Johal, H,K. <i>Journal of Medical Ethics</i> 46. 447–450 ²⁸	Best interests versus resource allocation: Could COVID-19 cloud decision-making for the cognitively impaired?	Commentary that notes that NICE guidelines during COVID 19 advocated the use of clinical frailty scale in making decisions about care and treatment. However, practice was challenged by judicial review. Nevertheless, the COVID 19 pandemic put the NHS under pressure with regard to treatment decisions for vulnerable populations, particularly those who lacked capacity. Asserts that a utilitarian and paternalistic response may have underpinned decisions. Best interest decisions are challenged by the priority of rationing resources but also the context of the assessment of frailty. Assessment was made more difficult by delirium, the lack of a surrogate decision-maker if families not present, redeployment to staff from other specialities, lack of time to support decision-making and the emphasis on resource allocation. Argues that the emphasis on utilitarian and paternalistic response may continue into non-pandemic practice and challenges human rights for those lacking capacity or vulnerable
Communication & Trust	Selman, L., et al. <i>Journal of Pain and Symptom Management</i> . 2020 ²⁵	Bereavement support on the frontline of COVID-19: recommendations for hospital clinicians	Identifies the impact of COVID-19 on bereavement and loss, as well as the barriers to supporting the end of life during the pandemic (including, PPE, lack of time, no visiting, trauma for staff). Highlights that sensitive advance care planning communication is important and should be addressed early, involve families, and can improve bereavement outcomes.
Rationing of priority services Autonomy in DNACPR decisions	Singh et al. <i>Head and Neck</i> 2020 42:1144-1146 ²⁰	Navigating the impact of COVID-19 on Palliative Care for Head & Neck Cancer	Commentary, which argues that despite being a human right, palliative care is generally under resourced. The focus of pandemic has been on 'essential' critical care resources rather than on palliative care needs. For patients with head and neck cancer there is a need for discussions that capture patient wishes and also notes that despite diagnoses some will recover from COVID-19 yet prognosis generally is limited. ACP important and palliative care support should be available.

good (or least harm), such as maximising the years of life and number of lives saved.¹⁷

At the same time DNACPR orders became entangled with frailty assessments. Interpretation of the CFS within the NICE guidelines⁸ caused public concern. Scores were likely to be higher for older or disabled people leading to DNACPR decisions that precluded access to acute care resulting in accusations of discrimination and devaluing of vulnerable groups.¹⁸ The guidelines were amended to reflect

that frailty assessments should not be conducted in people under 65 years old. However, concern for those with mental health issues continued, causing Alzheimer's UK to campaign against cognitive frailty being a rationale for DNACPR.¹⁹

Within the media debate the rationing of acute care was justified by the routine rationing of treatments, including intensive care and transplant, to prevent unethical use of resources on those unlikely to benefit (see Table 2, Theme 1). However, the emphasis

on acute care led to reports of distress by people worried that they would be left on their own without treatment, resulting in increased calls to helplines for vulnerable groups.^{20,21} Several critical academic commentaries highlighted the disparity^{22,23} between acute and palliative care provision with some exhorting practitioners to refer to end-of-life care NICE guidelines and ensure palliative care needs were not overlooked given the initial focus on acute care.

Championing autonomy in DNACPR decisions

The initial wording of the NICE guidelines led to media reports of ‘blanket’ DNACPR orders applied to whole care homes or targeted at groups of vulnerable patients, including those with learning difficulties.²⁴ Blanket DNACPR orders were presented as a challenge to individual autonomy and were quickly criticised as being discriminatory by national charities representing patient groups.²⁵ Condemnation of blanket DNACPR policies by senior politicians, professional leaders and regulatory agencies closely followed in headlines. By mid-April 2020 the Health Minister had asked the Care Quality Commission to contact healthcare providers to review practice around DNACPR, particularly with regard to human rights and personalised care.²⁶

Academic commentaries pointed to the need for sensitive assessment and communication during the pandemic particularly in relation to DNACPR.^{6,27–31} However, the media provided instances where patients and families felt that their wishes were ignored or superseded, or were unprepared for discussions. In one report, families only learnt of DNACPR orders for elderly relatives in a care home after the orders were reviewed (See Table 2, Theme 2). Some individuals reported being ‘ordered’ or ‘forced to sign’ a DNACPR order or were told that it would be a medical decision in the end.³² Media articles highlighted the distress expressed by individuals, particularly if they disagreed and ‘wanted to live’.³³ Difficult experiences for families and healthcare staff involved in DNACPR decisions in the context of rapid deterioration with little preparation were also conveyed.³⁴

Medical staff also used news media to raise awareness around DNACPR orders and purpose, citing that CPR is brutal, and not always the best option with low survival rates.²¹ The distinction between cardiac arrest and dying was noted in these papers. Efforts by healthcare professionals, therefore, encouraged people to plan ahead for dying from COVID-19 (See Table 2, Theme 2). The benefits of advance care planning were cited as creating opportunities to say goodbye and exercise autonomy, and shield families

and medical staff from any moral distress and thus facilitate a ‘better’ grief experience for relatives.

Reports suggested that opportunities to make an autonomous decision or ‘choice’ about DNACPR was positively received by some patients and relatives as it enabled a sense of ‘control’ (See Table 2, Theme 2). However, reports originating in the care home sector suggested poor communication and an erosion of trust between care homes and GPs.²⁴ In the context of COVID-19 where hospital visiting was restricted, some people stated a preference for support at home, with their family present rather than a busy hospital environment. For people in care homes, being cared for by carers who knew them was expressed as preferable to the distress of hospital admission and care by strangers. Media reports, therefore, suggest that individualised and person-centred approaches to advance care planning were valued.

Communication & trust

Media reports highlighted the challenges of DNACPR conversations for healthcare staff, patients and families. It was acknowledged in the media and academic commentaries that environmental factors (remote communication, mask-wearing), redeployment and increased workload³¹ were challenging for staff. There were accounts of patients witnessing healthcare professionals’ distress at having DNACPR conversations (See Table 2, Theme 3). This was exacerbated when patients were not accompanied by relatives or were non-English speaking³⁵.

Reports captured the impact of remote communication on trust. Impersonal attempts at communication reflected in reports of letters or telephone calls to patients that they would not be resuscitated were received negatively and publicly deemed unacceptable by professional bodies (See Table 2, Theme 3). Patients reported feeling ‘shocked’ by the approach particularly when it clashed with their own perception of need.³³ It led to an erosion of trust as patients were reported to be tweeting and questioning whether DNACPR was in their best interest or was instead a consequence and questioning how doctors could be so certain that CPR would not work (See Table 2, Theme 3).

Examples of well-conducted conversations that facilitated informed decision-making about the escalation of care and what this might achieve resulted in reports of positive experiences (See Table 2, Theme 3). Patients and relatives were reportedly appreciative when staff sensitively discussed DNACPR. Academic commentaries similarly advocated early discussion around ceilings of care and sensitive communication^{27,29} and argued that the ReSPECT tool

was a timely intervention for shaping conversations about DNACPR and ceilings of care.⁶

Discussion

Media discourse around DNACPR during the COVID-19 pandemic in the context of considerable prognostic and potentially cataclysmic uncertainty has heightened debate regarding DNACPR orders and their role in advance care planning practice and ensuring autonomy and involvement in end-of-life care decisions. Prior³⁶ writes that ‘discourse is never inert’ and this review of professional and public discourse of DNACPR suggests that DNACPR orders occupy an uneasy positioning between advance care planning and palliative and end-of-life care at one end of a continuum and the management of acute care interventions at the other.

The call to ‘protect the NHS’ captured a media presentation of acute care versus no care dichotomy in which palliative and social care were marginalised, and DNACPR orders signalled abandonment. Frailty assessments were used to determine DNACPR decisions and acted as a paternalistic and utilitarian rationing tool. The pandemic has raised awareness of DNACPR orders and elevated concerns regarding their use as a means of restricting care and services for individuals and families, particularly those living with frailty or disability. The findings, therefore, highlight concerns around autonomy and human rights. They also intensify concerns regarding on-going inequalities, such as ageism,^{17,37} and potentially discriminatory end-of-life care practices at individual and system levels. Mogan et al.¹² found that media representations primarily portrayed older people as at-risk or passive in the coverage of COVID-19 in New Zealand, but those older people were nonetheless framed as deserving of support. This, in some ways, echoes our findings that vulnerable groups were constructed as being marginalised, but their rights were also championed.

Public concerns and human rights objections articulated in the media discourse may have heightened suspicion and distrust regarding DNACPR orders. One UK study³⁸ found that many hospital patients who had early DNACPR decisions during the COVID-19 pandemic received potentially life-saving treatment. However, it is unclear whether having a DNACPR order in the community precluded hospital admission. The discourse suggests that DNACPR as a standalone intervention presents a rather blunt instrument. Many hospitals adopted the ReSPECT tool as a means of planning for sudden deterioration, particularly as it encourages personalised communication with DNACPR being just one aspect.³⁹ The emergence of the ReSPECT tool and subsequent adoption by the Resuscitation

Council UK was timely; however, there is some evidence that currently practitioners use the tool as a proxy for DNACPR rather than person-centred decision-making.⁴⁰ There is solace in that the media focus has triggered ethical, professional, and legal inquiries to champion the rights of those deemed vulnerable, which has resulted in a Care Quality Commission investigation.²⁷ However, as well as calls to examine the purpose and practice of DNACPR orders during the pandemic, there is a need to ‘reimagine’ the role, resourcing and valuing of palliative care.^{23,40,41} This may include an exploration of the legacy of DNACPR media coverage on individuals and professional experience of advance care planning practice and how future patient-centred decision-making can be best supported.

Limitations

An in-depth discourse analysis approach was not used; therefore, some key texts may have been missed. However, the strength is that we amassed a repository of DNACPR headlines available at that time. The search pertains only to the first phase of the pandemic up to May 2020 and data from subsequent phases may provide additional useful material. The media representation of DNACPR orders may have exaggerated claims of poor practice, especially as stories were recirculated. It was not possible to verify the veracity of media outputs, rather the intention of the study was to consider the impact of media headlines. It is also recognised that the context is UK focussed; however, the discussion is supported by commentary from Europe and the US and suggests that the findings have relevance for international discussion.

As healthcare professionals, the researchers are unlikely to have the same interpretation as members of the public, patients and carers. It is recognised that this is an interpretive analysis, and it is unclear how news headlines have influenced public opinion in the short, medium or long-term. Further research is needed to establish this.

Conclusion

DNACPR orders continue to occupy an uneasy position in advance care planning. The conflation of DNACPR as a rationing tool undermines autonomy and yields the possibility for a discriminatory practice. Furthermore, the focus on acute care marginalised palliative care services having the effect that DNACPR orders were constructed as abandonment. It is salutary that the media coverage triggered ethical, legal and moral challenges and resulted in a Care Quality Commission investigation of practices. The impact of the pandemic headlines leaves an

unknown legacy in terms of how DNACPR orders and possibly the ReSPECT tool will be perceived by the public. Further research is required to explore this impact on the quality of dying and how best to support person-centred decision-making at the end of life.

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Disclaimer statement

Contributors: Joanne Bird's clinical practice focuses on caring for patients experiencing the long-term or Late Effects of cancer treatment. Within her clinics she see patients living with advanced cancer. As such her research interests involve the Late Effects of immunotherapy and patient and carer experience, patient-reported outcome measures and Advance Care Planning, particularly how this fits into long-term cancer care pathways.

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Data availability statement

The data that support the findings of this study are openly available in Figshare at <https://figshare.com/s/2b7ac8f7a1dff8117a38> reference number 10.15131/shef.data.16413288.

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