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Advance care planning for patients with COVID-19: a communication guide

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Abstract

In view of the high morbidity and mortality associated with COVID-19, early and honest conversations with patients about goals of care are vital. Advance care planning in its traditional manner may be difficult to achieve given the unpredictability of the disease trajectory. Despite this, it is crucial that patients' care wishes are explored as this will help prevent inappropriate admissions to hospital and to critical care, improve symptom control and advocate for patient choice. This article provides practical tips on how to translate decisions around treatment escalation plans into conversations, both face-to-face and over the phone, in a sensitive and compassionate manner.

Care planning conversations for patients with COVID-19 should be individualised and actively involve the patient. Focusing on goals of care rather than ceilings of treatment can help to alleviate anxiety around these conversations and will remind patients that their care will never cease. Using a framework such as the 'SPIKES' mnemonic can help to structure this conversation. Verbally conveying empathy will be key, particularly when wearing personal protective equipment or speaking to relatives over the phone. It is also important to make time to recognise your own emotions during and/or after these conversations.

Key words: Advance care planning; Ceilings of treatment; Communication; COVID-19; DNACPR; Escalation plan; Goals of care; Holistic; Resuscitation

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Introduction

The COVID-19 pandemic has been associated with significant morbidity and mortality. During the first peak (March–August 2020), 36% of patients who were admitted to critical care and 29% of ward-managed patients died within 28 days of admission (Docherty et al, 2020). A wide spectrum of disease severity has been observed, from acute respiratory distress syndrome requiring mechanical ventilation to asymptomatic carrier status (Meng et al, 2020). In addition, studies have demonstrated COVID-19 to be associated with rapid rates of decline. Cascella et al (2020) found that some patients developed tachypnoea, oxygen desaturation and >50% lung infiltration within 48 hours.

In view of the unpredictability and rapidity of disease progression, early and honest conversations with patients about goals of care is vital. This is the crux of advance care planning: the process of communicating and recording a patient's preferences and wishes for future care, should they lose capacity (Owen and Steel, 2019). Advance care planning discussions may include medical plans around resuscitation and treatment escalation plans, as well as patient-centred matters such as preferred places of care and death, spiritual issues and 'reconfiguring life in a new context' (Gold Standards Framework, 2018). These discussions are often revisited and repeated across the patient journey, representing a coordinated and collaborative process (Gold Standards Framework, 2018).

A key aspect of advance care planning is introducing conversations early into the disease trajectory. In the reality of COVID-19, this may be difficult to achieve as the clinical course can change abruptly and the first presentation may be when the patient is severely ill and in distress (Table 1). Advance care planning conversations will not be 'in advance' and clinicians may not have the opportunity to have complementary discussions with caregivers or relatives in the conventional way. Despite this, it is crucial that patients' care wishes are explored early in the treatment process. These discussions can prevent inappropriate or unwanted admissions to hospital and to critical care, improve symptom control, advocate

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Table 1. Challenges to advance care planning for patients with COVID-19
Difficulty prognosticating in a novel disease
Managing public perceptions that clinical decisions are based on the rationing of finite services to protect the NHS which was exacerbated by media coverage
Maintaining a personalised approach to advance care planning in the face of service pressures and limited choices such as preferred place of death
The loss of non-verbal cues as a result of personalised protective equipment, physical distancing regulations and visitor restrictions requiring bad news to be broken via telephone

adapted from Bradshaw et al (2020)

for patient choice, and prepare patients and their relatives for the possibility of death (Bailey and Cogle, 2018). Nguyen et al's (2021) survey of 100 chronically unwell older adults found that most felt advance care planning was more important now in than in the post-pandemic era. The fear of causing distress to patients is often cited as a barrier to timely advance care planning discussions. In contrast, evidence suggests that most people would wish to know if they are likely in their last year of life (Harding et al, 2013).

This article provides practical tips on how to overcome some of these challenges and translate decisions around treatment escalation plans into conversations, both face-to-face and over the phone, in a sensitive and compassionate manner.

Normalising the conversation

Although discussions around death are often daunting, in this COVID-19 era they have become more prominent in the national discourse (Brooke, 2020). Patients will be less surprised to have these conversations and may even anticipate them. Normalising them as part of routine practice can make them much less threatening, and can help to increase staff confidence in having these conversations (Brighton and Bristowe, 2016). For instance:

> **'These are some questions we are asking everyone at this time so that we know what is important to them if the situation were to change suddenly. Would it be ok to ask you a few questions?'**

> **'In my experience, these are some of the things that people in similar situations have found helpful to think about. I wonder if you would like to talk about this'**

Goals of care vs ceiling of treatment

The phrase 'ceiling of treatment' can be perceived as a judgement of a patient's worth and imply a limit to the care that might be provided, when in reality healthcare professionals do not stop caring for patients. In contrast, the phrase 'goals of care' focuses patients and healthcare professionals on which interventions might be effective in maintaining a quality of life that is acceptable to that individual. It draws attention to what is potentially achievable while reminding the patient that care will always continue.

A goals of care discussion may therefore encompass active treatment options such as full escalation (eg resuscitation, mechanical ventilation) or ward-based treatment (eg antibiotics, intravenous fluids), but it will also include broader, holistic measures. This is likely to involve elucidating a patient's personal values so that they can be maintained even when active treatment is withdrawn, such as living with minimal pain or being able to spend time with family.

It may help to begin these discussions with treatments that will be offered. Reassuring patients of these before focusing on treatments that may not be of overall benefit can make these discussions less challenging. Crucially, resuscitation discussions should only form one part of this holistic approach.

Table 2. A 'SPIKES' framework for discussing goals of care

Setting	Minimise interruptions What is the purpose of this conversation? Clarify with yourself before starting Compassion: they may not be able to see your face and are likely to feel scared and alone	For example, am I sharing the decision that resuscitation will not be performed or am I exploring the patient's priorities to guide decision making? *'Hello my name is …'*
Perception	What does the person know and expect about their illness, especially with regard to COVID-19? Start with open questions to gauge their level of understanding	*'What do you understand about your illness?'* *'What are you worried about?'* *'What have the other doctors explained to you so far?'* *'What do you think might happen if your condition worsens?'*
Invitation	How much do they wish to know? Opportunity to decline or nominate someone else to discuss on their behalf	*'Would you like me to explain what I think might be happening?'* *'Are you someone who likes to know what is happening in detail or someone who prefers small amounts of information as they arise?'*
Knowledge-share	Use everyday language Avoid vague terms such as 'poorly' – interpretations can range from a simple cold to dying Use 'I wish/ I hope … but I am worried' statements	*'This is what I expect may happen'* *'I wish I could say you will be fine but I am worried that things may change and if this were to happen suddenly, it would help to know what your wishes are'* *'I hope these antibiotics work in making your father better but I am worried that his condition is going to get worse'*
Empathy and emotion	Allow silence, acknowledge emotions Empathy has to be shown through words when body language is limited, eg on the phone, wearing personal protective equipment	*'I am so sorry this is happening; please know we will care for you no matter what happens'* *'It is normal to be scared/worried/ angry/ upset by what is happening'*
Summarise and signpost	What next? Who else could provide support?	*'We have talked about a lot today, is there anything else we haven't covered?'* *'Who would you like me to call to let them know what we've talked about?'* *'I am going to ask the palliative care team or chaplain to see you'*

Adapted from Baile et al (2000)

It can be useful to consider using a framework to structure the conversation such as the SPIKES framework, a protocol initially designed for disclosing bad news in oncology (Baile et al, 2000). Table 2 gives some suggestions.

Symptom control, such as managing pain and breathlessness, is not confined to supportive care but should occur alongside all treatments.

An example:

'We have tried to treat your dad's pneumonia with antibiotics and fluids, but I am worried that this is not working. We may need to change our focus from trying to cure this illness to making sure he is comfortable and not suffering'.

Discussions around cardiopulmonary resuscitation

A do not attempt cardiopulmonary resuscitation form is the documentation of a discussion to guide decision making in the event of a cardiac arrest or death. It is not a legal document. Every decision on cardiopulmonary resuscitation should be made following careful assessment of an individual's circumstances and 'blanket' policies should never be followed (British Medical Association et al, 2016).

Do not attempt cardiopulmonary resuscitation decisions can be conflated with end-of-life care and healthcare professionals can mistakenly withhold appropriate interventions (Fritz et al, 2017). It is important to proactively reassure patients that a do not attempt cardiopulmonary resuscitation form does not preclude other treatments such as antibiotics, surgery or critical care support (depending on individual circumstances).

Table 3 gives guidance on deciding and communicating resuscitation decisions.

Recognising one's own emotions

Brighton and Bristowe (2016) recognised that clinicians find discussing end of life care hard. Clinicians are trained to do the best for their patients and can often feel a sense of failure at not being able to provide the kind of care they would want for their own families (Macmillan, 2018). Take time to recognise this impact and share with peers and colleagues because they will be facing similar situations. It is important to remember that death is not a failure so long as the goal is to care and not just cure.

Phone conversations

Breaking bad news over the phone has become commonplace as relatives are restricted from visiting the hospital. Without the non-verbal cues from face-to-face contact, empathy and compassion can be harder to convey and need to be demonstrated verbally. Acknowledging emotions is necessary for patients and relatives to be able to absorb the information they need (Back et al, 2020). The following phrases may help:

'I am so sorry that due to this awful situation we cannot meet in person'

'Thank you, this is a really difficult conversation to have over the phone and you have been open and honest with me which can't have been easy'

'It is normal to be scared/worried/angry by what is happening'

Table 3. Guide for resuscitation discussions

Reason for do not attempt cardiopulmonary resuscitation decision	Communicating this decision	
Cardiopulmonary resuscitation will not be successful in the event of death from advanced, irreversible illness or a catastrophic event	Inform the patient in a compassionate manner unless they have expressly declined to know or are at risk of physical or psychological harm	Focus on wider goals of care and reiterate that other treatments/care will be offered *'We will treat you with antibiotics/ fluids/non-invasive ventilation but if your heart were to stop as part of the dying process, we will not attempt cardiopulmonary resuscitation as it will not work but rather allow you to die peacefully'.*
Cardiopulmonary resuscitation may be successful in restarting the heart for a period of time	Shared decision Explore individual priorities (best interests discussion or lasting power of attorney if lacking capacity)	*'It is possible that cardiopulmonary resuscitation might work in restarting your heart but there is a real risk that you may be left in a worse physical condition that you are in now. Is this risk something you might consider acceptable?'*
A patient with capacity does not want cardiopulmonary resuscitation	Patients have a right to refuse treatment, but the treating team must ensure that the decision is informed if cardiopulmonary resuscitation is expected to be successful	Explore their reasoning especially if resuscitation is likely to be successful *'Just so I know that I have understood what you are saying, would you explain to me your reasons for not wanting cardiopulmonary resuscitation?'*

Adapted from British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2016)

Conclusions

Advance care planning conversations are extremely beneficial to patients, their relatives and healthcare workers. In the context of COVID-19, the unpredictability of the disease trajectory requires that these conversations begin early and should be individualised, with active involvement of the patient. Focusing on goals of care rather than ceilings of treatment can help to alleviate anxiety around these. The authors recommend adopting a framework to structure your conversation and taking time to acknowledge the emotional impact it has on yourself and your patient.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

References

Back A, Tulsky JA, Arnold RM. Communication skills in the age of COVID-19. Ann Intern Med. 2020;172:759–760. https://doi.org/10.7326/M20-1376

Baile WF, Buckman R, Lenzi R et al. SPIKES—A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302–311. https://doi.org/10.1634/theoncologist.5-4-302

Bailey S-J, Cogle K. Talking about dying: how to begin honest conversations about what lies ahead. 2018. https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead (accessed 29 March 2021)

Bradshaw A, Dunleavy L, Walshe C et al. Understanding and addressing challenges for Advance Care Planning in the COVID-19 pandemic: an analysis of the UK CovPall survey data from specialist palliative care services. medRxiv. 2020. https://doi.org/10.28.20200725

Top tips

- Consider a structured framework such as the SPIKES mnemonic to aid in these discussions.
- Verbally conveying empathy will be key, particularly when wearing personal protective equipment or speaking to relatives over the phone.
- Focus on having ‘goals of care’ discussions, starting with which treatments are likely to be of benefit.
- Do not attempt cardiopulmonary resuscitation decisions are one part of a wider holistic assessment. They should be individualised and shared among the treating team and the patient.
- Make time to recognise your own emotions during or after these conversations.

Key points

- Since the COVID-19 pandemic has been associated with a rapid rate of disease progression, it is important to consider having early and open conversations around advance care planning.
- There are new and unforeseen challenges associated with advance care planning during a pandemic including: difficulty prognosticating in a novel disease, navigating conversations amidst public perception, and the impact that personal protective equipment has on non-verbal communication.
- A discussion around ‘goals of care’ discussion that encompasses broader, holistic measures may help to reassure patients that their care will always continue even if ‘ceilings of treatment’ have been reached.
- A structured framework may aid in these discussions, such as the SPIKES mnemonic.

Curriculum checklist

This article addresses the following requirements from the general internal medicine training curriculum:

- Able to deal with ethical and legal issues related to clinical practice.
- Communicates effectively and is able to share decision making, while maintaining appropriate situational awareness, professional behaviour and professional judgement.
- Managing end of life and applying palliative care skills.

Brighton L, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. Postgrad Med J. 2016;92(1090):466–470. https://doi.org/10.1136/postgradmedj-2015-133368

British Medical Association, Resuscitation Council (UK) and the Royal College of Nursing. Decisions relating to cardiopulmonary resuscitation: guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing. London: British Medical Association; 2016

Brooke L. Death cafes report surge of interest since COVID-10 outbreak. 2020. https://www.theguardian.com/society/2020/apr/13/death-cafes-see-surge-of-interest-in-online-events (accessed 29 March 2021)

Cascella M, Rajnik M, Cuomo A, Dulebohn SC, Napoli RD. Features, evaluation and treatment coronavirus (COVID-19). Orlando (FL): StatPearls Publishing. 2020

Docherty AB, Mulholland RH, Lone NI et al. Changes in UK hospital mortality in the first wave of COVID-19: the ISARIC WHO Clinical Characterisation Protocol prospective multicentre observational cohort study. medRxiv. 2020. https://doi.org/10.1101/2020.12.19.20248559

Fritz Z, Slowther AM, Perkins GD. Resuscitation policy should focus on the patient, not the decision. BMJ. 2017;356:j813. https://doi.org/10.1136/bmj.j813

Gold Standards Framework. Advance care planning. 2018. https://www.goldstandardsframework.org.uk/advance-care-planning (accessed 29 March 2021)

Harding R, Simms V, Calanzani N et al. If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis. Psychooncology. 2013;22(10):2298–2305. https://doi.org/10.1002/pon.3283

Macmillan. Missed opportunities, advance care planning report. 2018. https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf (accessed 29 March 2021)

Meng L, Qiu H, Wan L et al. Intubation and ventilation amid the COVID-19 outbreak: Wuhan's experience. Anesthesiology. 2020;132(6):1317–1332. https://doi.org/10.1097/ALN.0000000000003296

Nguyen AL, Davtyan M, Taylor J, Christensen C, Brown B. Perceptions of the importance of advance care planning during the COVID-19 pandemic among older adults living with HIV. Front Public Health. 2021;9(57):636786. https://doi.org/10.3389/fpubh.2021.636786

Owen L, Steel A. Advance care planning: what do patients want? Br J Hosp Med. 2019;80(5):263–267. https://doi.org/10.12968/hmed.2019.80.5.263