



# COVID-19: guidance on palliative care from a European Respiratory Society international task force

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This multi-national task force provides consensus recommendations for palliative care for patients with COVID-19 <https://bit.ly/31X83oZ>

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## ABSTRACT

**Background:** Many people are dying from coronavirus disease 2019 (COVID-19), but consensus guidance on palliative care in COVID-19 is lacking. This new life-threatening disease has put healthcare systems under pressure, with the increased need of palliative care provided to many patients by clinicians who have limited prior experience in this field. Therefore, we aimed to make consensus recommendations for palliative care for patients with COVID-19 using the Convergence of Opinion on Recommendations and Evidence (CORE) process.

**Methods:** We invited 90 international experts to complete an online survey including stating their agreement, or not, with 14 potential recommendations. At least 70% agreement on directionality was needed to provide consensus recommendations. If consensus was not achieved on the first round, a second round was conducted.

**Results:** 68 (75.6%) experts responded in the first round. Most participants were experts in palliative care, respiratory medicine or critical care medicine. In the first round, consensus was achieved on 13 recommendations based upon indirect evidence and clinical experience. In the second round, 58 (85.3%) out of 68 of the first-round experts responded, resulting in consensus for the 14th recommendation.

**Conclusion:** This multi-national task force provides consensus recommendations for palliative care for patients with COVID-19 concerning: advance care planning; (pharmacological) palliative treatment of breathlessness; clinician–patient communication; remote clinician–family communication; palliative care involvement in patients with serious COVID-19; spiritual care; psychosocial care; and bereavement care. Future studies are needed to generate empirical evidence for these recommendations.

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## Introduction

As of 30 June 2020, 10360882 coronavirus disease 2019 (COVID-19) cases had been confirmed with 507014 deaths due to COVID-19 recorded globally [1]. However, both the number of confirmed cases and COVID-19-related mortality are likely to be underestimated as not all cases and deaths due to COVID-19 are confirmed or recorded [2]. Patients may die at home, in the hospital, or in other facilities.

The importance of palliative care in this COVID-19 pandemic has been acknowledged [3, 4]. Despite its paramount need, providing high-quality palliative care during this pandemic is challenging. Patients may deteriorate quickly, healthcare resources are under pressure, isolation is required and family visits are restricted [5]. A case series of 101 hospitalised patients with COVID-19 referred for palliative care showed that most patients died within 3 days [6], and the need for “emergency” palliative care in COVID-19 has been suggested [7]. Worries have arisen about limited access to palliative care because of high demands worldwide in the pandemic [3]. Despite a number of guidelines and resources proposed by professional and other bodies [8, 9], neither evidence- nor consensus-based guidelines about palliative care in COVID-19 are available. In fact, a survey among hospices in Italy revealed that healthcare professionals lacked guidance on care for people dying from COVID-19 [10]. The COVID-19 crisis has been a professionally and personally challenging period for healthcare workers. Although the underlying principles of palliative care have not changed, the specific challenges of COVID-19 require specific guidance [4]. Therefore, the aim of the current study was to develop guidance on palliative care in COVID-19 patients through consensus, pending empirical evidence.

## Methods

We conducted a survey following the Convergence of Opinion on Recommendations and Evidence (CORE) process. The CORE process is a consensus-based approach to making clinical recommendations, which has been shown to yield recommendations that are concordant with those developed using Institute of Medicine-adherent methodology [11].

An *ad hoc* international task force was assembled, including European Respiratory Society (ERS) key opinion leaders in the field of palliative care and respiratory medicine. Invitations were sent to 90 experts (in palliative care, respiratory medicine, clinical care and research) identified by the task force members. A survey was created using SurveyMonkey software (SurveyMonkey, San Mateo, CA, USA), consisting of 14 questions, with the aim of providing consensus recommendations for clinical care. Each question consisted of three parts. The first part presented the question in a modified PICO (Patient, Intervention, Comparator, Outcomes) format. The second part was a multiple-choice question where the participant was asked to choose a recommendation for or against a given therapy: strong recommendation for; conditional recommendation for; no recommendation for or against; conditional recommendation against; or strong recommendation against an intervention (table 1). The third part was a free text box for comments. Three demographic questions were asked about each participant’s country, profession and field of expertise.

In the survey, we used the term “serious COVID-19”, defined as COVID-19 that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptom, treatment or caregiver stress. This definition was based on that of serious illness on Pallipedia [12].

The survey was administered from 2 to 11 June 2020. Several reminders were sent. Agreement of directionality was tabulated for each multiple-choice question. *A priori*, we defined that  $\geq 70\%$  agreement on directionality (agreement or disagreement) was needed to be able to provide consensus recommendations [13]. The proportion of respondents *per choice per* question was calculated and expressed as a percentage of the total number of respondents. A second round was conducted from 15 to

TABLE 1 Definitions of recommendations

<b>Strong recommendation for an intervention</b>	Should be chosen when experts were certain that the desirable consequences outweigh the undesirable consequences (or the converse for recommendation against). A strong recommendation is one that most well-informed patients would follow.
<b>Conditional recommendation for an intervention</b>	Should be chosen when experts were uncertain that the desirable consequences of the intervention outweigh the undesirable consequences (or the converse, for recommendation against). A conditional recommendation indicates that well-informed patients may make different choices regarding whether to have or not have the intervention.

18 June 2020 for the question not leading to consensus in the first round. Results of the first round were summarised for the second round. Free text comments were summarised by Dr D.J.A. Janssen and these summaries were checked with the data by Dr K. Marsaa.

## Results

### Respondents

In the first round, 68 (75.6%) out of 90 invited experts participated. Respondents were from 15 countries (Australia, and countries in Europe and North America) and most were physicians (table 2). Two-thirds had a background in palliative care and one half in respiratory medicine. The second round was completed by 58 (85.3%) of the 68 previous respondents.

### Recommendations

The 14 recommendations for palliative treatment and care are shown below. For each recommendation, a theoretical rationale is provided, followed by the results of the present survey. For some recommendations, barriers or concerns for implementation were mentioned (table 3).

#### *1) Advance care planning (discussion of goals and preferences for future medical treatment and care) should be routinely performed or reviewed by clinicians with patients and their loved ones at diagnosis of serious COVID-19*

##### *Rationale*

Advance care planning (ACP) enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate [14]. Early ACP discussions at the time of hospitalisation are suggested to avoid unwanted and burdensome life-sustaining treatments [15, 16].

TABLE 2 Characteristics of respondents

Characteristic	Respondents n (%)
<b>Total</b>	68 (100)
<b>Country</b>	
Australia	2 (2.9)
Austria	1 (1.5)
Belgium	3 (4.4)
Canada	1 (1.5)
Denmark	14 (20.6)
Germany	3 (4.4)
Ireland	1 (1.5)
Italy	3 (4.4)
The Netherlands	9 (13.2)
Poland	1 (1.5)
Portugal	9 (13.2)
Sweden	5 (7.4)
Switzerland	2 (2.9)
UK	8 (11.8)
USA	6 (8.8)
<b>Profession<sup>#</sup></b>	
Physician	50 (73.5)
Nurse	2 (2.9)
Allied healthcare professional	7 (10.3)
Researcher	16 (23.5)
<b>Expertise<sup>#</sup></b>	
Palliative care	46 (67.6)
Respiratory medicine	34 (50.0)
Critical care medicine	9 (13.2)
Geriatrics	3 (4.4)
Family medicine	3 (4.4)
Internal medicine	4 (5.9)
Other	6 (8.8)

<sup>#</sup>: respondents could report more than one profession and/or expertise.

TABLE 3 The barriers or concerns about implementation of recommendations reported by experts

Recommendation	Barriers/concerns
1) ACP should be routinely performed or reviewed by clinicians with patients and their loved ones at diagnosis of serious COVID-19	The disease evolves rapidly resulting in lack of clarity on the patient's condition preventing a possible long-term plan The often-rapid trajectory towards death Patients may be too ill to participate in ACP Patients may experience too much anxiety to participate in ACP conversations The family are not physically present
6) Staff taking care of patients with serious COVID-19 should receive training in optimising clinician-patient communication whilst wearing PPE	Practical concerns about implementing training during the pandemic
7) Staff taking care of patients with serious COVID-19 should receive training in online clinician-family communication (while using telephone or video conferencing)	Practical concerns about implementing training during the pandemic
8) Healthcare professionals trained in providing palliative care should be involved in cases where hospitalised patients with serious COVID-19 have persistent symptoms and concerns despite optimal disease treatment	Practical concerns Resource limitations, including limited availability of palliative care specialists
9) Healthcare professionals trained in providing palliative care should be involved in cases where patients with serious COVID-19 have persistent symptoms and concerns despite optimal disease treatment, and are being treated at home	Limited availability of PPE Limited resources available for patients at home or in care homes, including limited availability of palliative care specialists Risk of transmission of COVID-19
10) Healthcare professionals providing spiritual care (such as chaplains) should be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (irrespective of setting, so in the hospital, community or long-term care facilities)	Limited availability of PPE Limited availability of spiritual/existential care providers Patients being too breathless to talk
11) Healthcare professionals providing psychosocial care (such as psychologists and social workers) should be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (irrespective of setting, so in the hospital, community or long-term care facilities)	Limited availability of PPE Limited availability of psychosocial healthcare professionals Risk of transmission of COVID-19 to psychosocial healthcare professionals
12) Family members/loved ones should be invited and supported (e.g. being provided with PPE if indicated) to visit the dying patient with COVID-19 in person	Limited availability of PPE Visits are a source of distress for families and staff Risk of transmission of COVID-19 to visitors Lack of time between diagnosing dying and actual death
13) Family members/loved ones of deceased patients with COVID-19 should be offered bereavement support by healthcare professionals trained in palliative care or bereavement support	Limited availability of bereavement support

ACP: advance care planning; COVID-19: coronavirus disease 2019; PPE: personal protection equipment.

### Results

Most of the experts strongly (67.6%) or conditionally (29.4%) recommended that ACP should be routinely conducted or reviewed by clinicians with patients and their loved ones, at the time of diagnosis of serious COVID-19 (figure 1a).

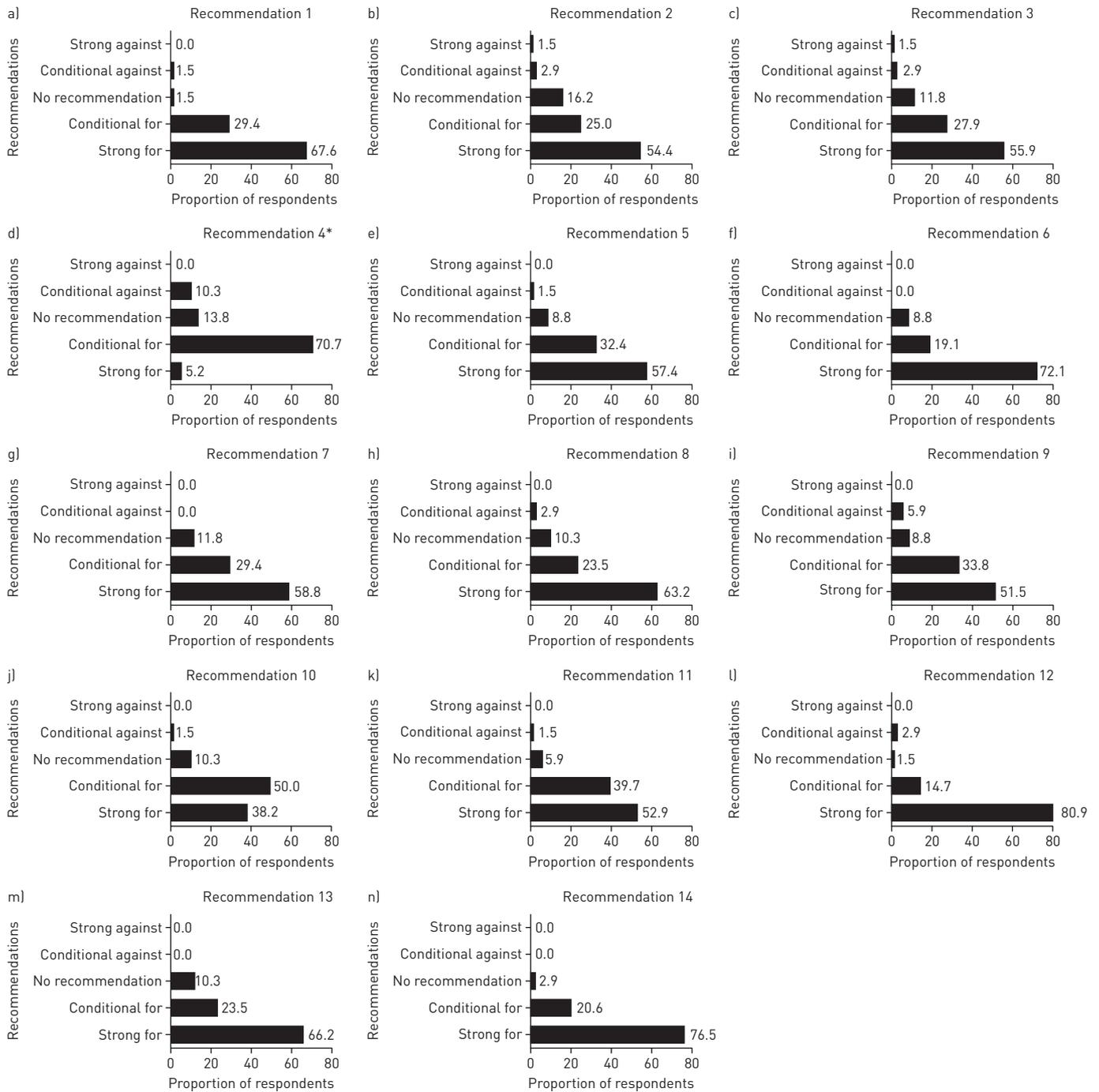


FIGURE 1 Experts' responses to the 14 questions. \*: results from the second round.

ACP was mentioned as “the first critical step to guide treatment for seriously ill patients”. A few experts suggested that ACP should be offered, but patient wishes should be respected if they declined. Some stated that whether ACP is offered should be dependent on the presence of comorbidities and the likelihood of a poor outcome. The need for and advantages of proactive ACP before the occurrence of COVID-19, especially in frail older patients, were also mentioned.

**2) ACP should be re-evaluated prior to discharge of recovered COVID-19 patients from hospital**

*Rationale*

Life-sustaining treatment preferences are likely to change, for example after a change in health status. While some patients are less willing to undergo life-sustaining treatments after a decline in functional

status, other patients are even more willing to undergo life-sustaining treatments [17]. For deliberate decisions concerning life-sustaining treatments, patients need information about possible outcomes and the likelihood of negative outcomes after treatment [18]. An intensive care unit (ICU) admission for acute respiratory distress syndrome associated with COVID-19 may have a lower chance of survival than an ICU admission for another illness [16]. So, a preference to forego ICU admission in cases of COVID-19 might not result in a decision to forego all ICU admissions. Therefore, evaluation of ACP before discharge of recovered patients with COVID-19 is warranted.

### *Results*

Most experts strongly (54.4%) or conditionally (25.0%) recommended that ACP should be re-evaluated prior to the discharge of recovered COVID-19 patients from hospital (figure 1b).

Experts mentioned that if patients recover, the serious illness might have influenced their preferences regarding life-sustaining treatments. Moreover, patients may be able to more fully participate in these discussions than during the acute illness. It was also suggested that re-evaluation of ACP after discharge by the family physician might be preferable.

### ***3) Patients presenting with serious COVID-19 and distressing breathlessness despite optimal treatment of underlying causes should be given low-dose opioids for the palliative treatment of breathlessness***

#### *Rationale*

Breathlessness is one of the most prevalent symptoms in hospitalised patients dying from COVID-19 [6, 15, 19, 20]. Opioids are widely used in palliative care with an evidence base effect for relieving breathlessness [21]. Nevertheless, there are no reported trials in COVID-19. A first case series of hospitalised patients with COVID-19 referred for palliative care showed that most patients were treated with morphine (median dose 10 mg in 24 h subcutaneously) and some received fentanyl (median dose 100 µg in 24 h) or alfentanil (median dose 500 µg in 24 h) [6]. However, effectiveness was clinician rated and data were not collected for individual drugs. Another case series of 30 hospitalised deceased patients showed that 76.7% of the patients used intravenous morphine but, again, effectiveness was not evaluated [19].

### *Results*

Most experts strongly (55.9%) or conditionally (27.9%) recommended that patients presenting with serious COVID-19 and distressing breathlessness, despite optimal treatment of underlying causes, should be given low-dose opioids for the palliative treatment of breathlessness (figure 1c).

Experts mentioned the need to treat breathlessness according to current palliative care guidelines, including opioids. They cited positive experiences of opioids for breathlessness in COVID-19. Some experts stated that effectiveness for breathlessness in COVID-19 should be confirmed in future studies, but agreed with the recommendation. Conversely, others cited the lack of evidence of effectiveness for breathlessness in COVID-19 as a reason to disagree or provide no recommendation for or against opioids. Experts stated the need for careful consideration of the individual situation, including the risk of adverse effects.

### ***4) Patients presenting with serious COVID-19 and distressing breathlessness despite optimal treatment of underlying causes should be given benzodiazepines for the palliative treatment of breathlessness***

#### *Rationale*

Clinical practice statements mention benzodiazepines as palliative treatment of breathlessness [22]. Nevertheless, a Cochrane review showed no evidence for benzodiazepines for breathlessness in patients with cancer or COPD [23]. The review suggested that benzodiazepines could be considered for palliative treatment of breathlessness when non-pharmacological measures and opioids fail, particularly in patients with distress and anxiety [23]. Data on effectiveness for breathlessness in COVID-19 are lacking.

### *Results*

In the first round, 11.8% of the respondents gave a strong recommendation for benzodiazepines for distressing breathlessness and 44.1% gave a conditional recommendation. As the predefined 70% threshold for consensus was not reached, the question was asked again in second round. In this round, 5.2% of the respondents gave a strong and 70.7% of the respondents provided a conditional recommendation for benzodiazepines for distressing breathlessness (figure 1d).

A few experts stressed the fact that there is a lack of evidence of the effect for breathlessness, while there is evidence of side-effects. Several experts mentioned that benzodiazepines should be taken into

consideration if patients were very distressed or anxious, when opioids didn't have enough effect, when opioids were contra-indicated, or in the last days of life.

**5) Patients with serious COVID-19 in palliative care and distressing breathlessness should be given oxygen therapy for the palliative treatment of breathlessness when their transcutaneous oxygen saturation is <90%**

*Rationale*

Oxygen therapy in patients with COVID-19 and hypoxaemia may help in reducing breathlessness in palliative care [15]. Oxygen therapy improves survival in patients with severe hypoxaemia. The evidence for a symptomatic effect on breathlessness is conflicting, but oxygen may relieve breathlessness in some patients with hypoxaemia [24].

*Results*

A great majority gave a strong (57.4%) or conditional (32.4%) recommendation for oxygen therapy for the palliative treatment of breathlessness when their transcutaneous oxygen saturation is <90% (figure 1e).

Free text comments showed some different opinions. Some stressed the importance of correcting hypoxaemia, without the primary aim of reducing breathlessness. Several suggested threshold oxygen saturations other than 90%, such as 85%, 88% and 92%. Others stressed that supplemental oxygen could be started if patients prefer, but discontinued if breathlessness was not reduced. Some experts highlighted the insufficient evidence for supplemental oxygen for symptom management at this threshold of hypoxaemia, whilst others presented anecdotal views that supplemental oxygen was often beneficial for breathlessness in patients with COVID-19 and hypoxaemia.

**6) Staff taking care of patients with serious COVID-19 should receive training in optimising clinician–patient communication whilst wearing personal protection equipment**

*Rationale*

Clinician–patient communication is a cornerstone of palliative care. Communication with patients with COVID-19 can be limited by wearing personal protection equipment (PPE). Healthcare professionals' experiences suggest that masks hide facial expressions and muffle voices, restricting the ability to show compassion [25].

*Results*

Almost all experts gave a strong (72.1%) or conditional (19.1%) recommendation for staff taking care of patients with serious COVID-19 receiving training in optimising clinician–patient communication whilst wearing PPE (figure 1f).

Expert experience indicated that PPE was a significant and dehumanising barrier to communication. They felt communication while using PPE was a critically important skill that had to be learned. New ways of showing empathy are needed along with guidance in these skills. One expert described tools developed to improve communication while using PPE, such as flashcards [26].

**7) Staff taking care of patients with serious COVID-19 should receive training in online clinician–family communication (while using telephone or video conferencing)**

*Rationale*

Family meetings for patients with COVID-19 are often held online to preserve PPE [27]. Communication and breaking difficult news remotely requires other communication skills in which healthcare professionals usually have no previous training. Healthcare professionals rely on in-person and non-verbal cues to facilitate difficult conversations [28], and may be reluctant to discuss sensitive topics during phone or video consultations [29]. Remote communication is more challenging for people with low literacy or few digital literacy skills, and people with sight or hearing impairment [29]. However, a report from the implementation of palliative care e-family meetings with trained clinicians showed the benefits of these meetings, including satisfied family members [30]. The key elements of remote communication skills have been published [31].

*Results*

Most experts provided a strong (58.8%) or conditional (29.4%) recommendation for staff taking care of patients with serious COVID-19 receiving training in online clinician–family communication (while using telephone or video conferencing) (figure 1g).

Experts reported the need for a member of the clinical team to communicate remotely with one designated family member or loved one daily. Remote communication skills are seen as essential, but clinicians are often not familiar with remote palliative care conversations.

The lack of evidence base for such training as well as practical concerns were mentioned (table 3).

**8) Healthcare professionals trained in providing palliative care should be involved in cases where hospitalised patients with serious COVID-19 have persistent symptoms and concerns despite optimal disease treatment**

*Rationale*

Patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment need optimal symptom management [15]. It has been suggested that symptom burden in dying patients with COVID-19 might be higher than usual in dying patients without COVID-19 [32], resulting in challenges for staff with no or limited experience in palliative care. Therefore, palliative care has an important role for patients with serious COVID-19 and strategies have been implemented to provide in-hospital palliative care [27, 33].

*Results*

The majority of experts strongly (63.2%) or conditionally (23.5%) recommended that healthcare professionals trained in providing palliative care should be involved in cases where hospitalised patients with serious COVID-19 have persistent symptoms and concerns despite optimal disease treatment (figure 1h).

Experts reported that expertise in palliative care is needed, with involvement of specialist palliative care clinicians varying according to the palliative care skills of the primary clinical team. Specialist palliative care could be invited by the primary clinical team for direct patient/family care, advice to the primary clinical care team, education and development of guidelines. The benefits of involvement of palliative care teams were mentioned, such as: multidisciplinary assessment; the ability to address aspects of care beyond disease treatment, including the management of complex symptoms, support of family and ACP discussions; and support for other healthcare professionals.

**9) Healthcare professionals trained in providing palliative care should be involved in cases where patients with serious COVID-19 have persistent symptoms and concerns despite optimal disease treatment treated at home**

*Rationale*

Home palliative care services can provide benefits such as better symptom control [34]. The Association for Geriatric Palliative Medicine (FGPG) recommends the availability of mobile palliative care teams for COVID-19 patients dying at home [35]. Data in COVID-19 are lacking.

*Results*

Most experts strongly (51.5%) or conditionally (33.8%) recommended the involvement of healthcare professionals trained in palliative care provision in patients treated at home with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (figure 1i).

Several experts mentioned that the need for palliative care involvement for patients at home was similar to that described in the hospital setting. Again, the need to involve specialist palliative care depends on the skills of the primary clinical team. The added value of involvement of palliative care professionals to address psychosocial and spiritual needs in the home setting was mentioned.

**10) Healthcare professionals providing spiritual care (such as chaplains) should be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (irrespective of setting, so in the hospital, community or long-term care facilities)**

*Rationale*

Spiritual care is an essential component of palliative care. Spiritual care supports patients and families in facing serious illness and in coping with poor or uncertain prognosis [15]. The COVID-19 crisis has led to fundamental uncertainty in communities, among patients, caregivers and loved ones, and among healthcare professionals. Part of this uncertainty extends beyond healthcare science and into our existential notions of life and death. A rapid review recommended the involvement of spiritual care providers in palliative care for patients with COVID-19 [33]. Attention should also be given to the spiritual care needs of those who are not represented by chaplains or people who are not religious, such as pastoral care workers [15].

*Results*

Most experts strongly (38.2%) or conditionally (50.0%) recommended that healthcare professionals providing spiritual care should be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (figure 1j).

Experts mentioned the need for spiritual or existential care beyond that which clinicians can offer, but also suggested that involvement should be dependent on the preferences of the patient and family. Existential care should not be limited to religious care but should include issues in relation to meaning more broadly.

**11) Healthcare professionals providing psychosocial care (such as psychologists and social workers) should be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (irrespective of setting, so in the hospital, community or long-term care facilities)**

*Rationale*

Psychological symptoms such as anxiety and agitation are highly prevalent in dying patients with COVID-19 [6, 19]. Psychosocial interventions in palliative care can relieve emotional and existential distress and improve quality of life [36]. A rapid review recommended that psychosocial care should be provided as part of the palliative care for patients with COVID-19 [33], although data in COVID-19 are not yet available [37].

*Results*

Most experts strongly (52.9%) or conditionally (39.7%) recommended that healthcare professionals providing psychosocial care should be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (figure 1k).

Comments provided were that the involvement of psychosocial care should depend on the needs of the patients and families and the existing skills within the primary clinical team.

**12) Family members/loved ones should be invited and supported (e.g. being provided with PPE if indicated) to visit the dying patient with COVID-19 in person**

*Rationale*

Because patients with COVID-19 are treated in isolation, family members/loved ones often have no or minimal contact, which may aggravate anxiety and other psychological distress. Moreover, families may be in quarantine or ill themselves [7]. The inability to say goodbye to a family member before death may increase the risk of complicated grief [38]. When family is allowed to visit, PPE might be needed. The value of remote contact between families and dying patients is unknown. Some authors caution against virtual contact between families and dying patients with COVID-19 because it can be too distressing [7]. Other authors do advise remote contact between patients in palliative care and family [39].

*Results*

Almost all experts strongly (80.9%) or conditionally (14.7%) recommend that family members/loved ones should be invited and supported to visit the patient dying with COVID-19 in person (figure 1l).

Most experts acknowledged the importance of a limited number of the closest loved ones being able to visit the dying patient for both patients and families.

**13) Family members/loved ones of deceased patients with COVID-19 should be offered bereavement support by healthcare professionals trained in palliative care or bereavement support**

*Rationale*

Family members/loved ones of deceased patients with COVID-19 might be at increased risk of complicated grief and post-traumatic stress disorder [38, 40]. Several risk factors may be present, such as: a rapid disease trajectory that might have hampered the preparation for death; less social support caused by social isolation; multiple losses due to COVID-19 in one family; feelings of guilt or (self-)blame; and the inability to undertake traditional grieving rituals [38]. Bereavement support is seen as a core component of palliative care. Support to families before and after the death of a patient can positively influence bereavement outcomes [40].

*Results*

Most gave a strong (66.2%) or conditional (23.5%) recommendation for bereavement support being offered to family members/loved ones of deceased patients with COVID-19 by healthcare professionals trained in palliative care or bereavement support (figure 1m).

Comments indicated that bereavement risk as well as the need for support will vary and some people will cope through their usual social or community support.

#### **14) Staff caring for patients with serious COVID-19 should be offered psychological support to cope with their experiences**

##### *Rationale*

During the COVID-19 pandemic, healthcare professionals are experiencing significant distress [41]. Healthcare staff caring for patients with serious COVID-19 may experience secondary traumatic stress; stress caused by observing suffering, and caring for patients dying alone [38, 41]. Challenging ethical decisions such as triaging limited resources may result in moral distress. At the same time, healthcare providers may face personal challenges, such as the decision to isolate themselves from personal support systems out of concern for spreading COVID-19 [38, 41]. During a crisis, attention for self-care may be limited. Adequate supervision and peer support may facilitate self-care, which in turn can overcome accumulated stress and grief in healthcare professionals [38].

##### *Results*

Almost all experts strongly (76.5%) or conditionally (20.6%) recommended that staff caring for patients with serious COVID-19 should be offered psychological support to cope with their experiences (figure 1n). Comments provided were that healthcare staff should have access to a range of support, depending on their needs. Debriefs within teams were mentioned as a possibility.

#### **Discussion**

This survey provides 14 consensus-based recommendations for palliative care in patients with COVID-19 in the hospital, at home or in other care facilities. Consensus was reached by international experts in different relevant fields, including but not limited to palliative care and respiratory medicine. Given the recent genesis of COVID-19, recommendations are based upon indirect evidence and clinical experience on: ACP; palliative treatment of breathlessness; clinician–patient communication; remote clinician–family communication; palliative care involvement in patients with serious COVID-19; spiritual care; psychosocial care; bereavement care; and support for healthcare professionals. In the absence of evidence-based guidelines, these findings provide consensus guidance for palliative care in COVID-19. The paramount role of palliative care in this pandemic is supported [3, 4], but also points to specific challenges and unanswered questions.

ACP was seen as “the first critical step to guide treatment for these seriously ill patients”, but the often-rapid disease trajectory, as well as physical absence of family or loved ones, were specific challenges to having these ACP conversations. So, preferably, ACP is initiated much earlier, especially in elderly, chronically ill patients or people with multiple comorbidities, to prepare patients and family for the moment when decisions concerning treatment of COVID-19 should be made. Future data concerning the long-term outcomes of serious COVID-19 are needed to support the process of ACP. Moreover, future studies should explore how to conduct optimal ACP in challenging circumstances like an admission for serious COVID-19.

Palliative treatment of breathlessness seems paramount in COVID-19. Currently, we rely on the commonly known palliative treatment options for breathlessness due to other causes, like opioids, supplemental oxygen in hypoxaemic patients, and benzodiazepines if other treatments fail and where breathlessness is associated with anxiety. Nevertheless, evidence of effectiveness, adverse effects and optimal dosage regimes for opioids and benzodiazepines in COVID-19 are absent. Other physical and psychological symptoms that are also frequently reported by patients with serious COVID-19 [6, 19, 20] were not included in the present study. Future studies should explore palliative interventions for breathlessness and other symptoms in COVID-19.

To overcome communication barriers in COVID-19, including the need to wear PPE and the physical absence of families and loved ones, healthcare professionals need new skills and experience. Fortunately, training and tools are being rapidly developed to facilitate communication with patients with COVID-19 and their loved ones [26, 30, 31, 42]. More experience as well as studies exploring the effects of tools and training are needed to optimally support communication skills in palliative care for patients with COVID-19 and their loved ones.

This study supports the value of involvement of healthcare professionals trained in providing palliative care in patients with serious COVID-19 with persistent symptoms and concerns, despite optimal disease treatment in the hospital and at home. The limited availability of palliative care specialists was mentioned as a concern. Nevertheless, not all patients will need to be seen by specialist palliative care clinicians, as

was also stated by several respondents. Indeed, non-palliative care specialists can be supported to adopt palliative care strategies, through training or consultation for example [42].

### Methodological considerations

These recommendations were developed following the CORE methodology, which has been shown to result in recommendations concordant with those developed using Institute of Medicine-adherent methodology [11]. Nevertheless, several limitations need to be acknowledged. First, although we were able to include experts from 15 countries, we had no respondents from Africa or Asia, but experts from some countries like Denmark, Portugal and The Netherlands were overrepresented. Second, most respondents were physicians; only two nurses and seven allied healthcare professionals participated. Relevant fields of expertise, like family medicine, internal medicine, geriatrics and clinical pharmacology were underrepresented. The wording of questions was unclear to some participants. For example, “healthcare professionals trained in providing palliative care” was interpreted by some respondents as specialist palliative care professionals, and by other respondents as including healthcare professionals with general training in palliative care. Further, defining the population of patients with COVID-19 in need of palliative care was challenging for the author group. We chose the Palliapedia definition of serious disease [12], but other definitions would have been possible. Nevertheless, this definition did not result in comments from participating experts. Finally, we had to limit the survey to 14 possible recommendations. Some aspects concerning palliative care in COVID-19, such as management of agitation, remain unexplored.

### Conclusion

This multi-national task force provides consensus recommendations for the palliative care of patients with COVID-19, concerning: ACP; palliative treatment of breathlessness; clinician–patient communication; remote clinician–family communication; palliative care involvement in patients with serious COVID-19; spiritual care; psychosocial care; bereavement care; and support for healthcare professionals. The fact that 13 out of 14 questions achieved recommendations >70% in the first round shows that there is a need to consider palliative care in the treatment of COVID-19 or similar diseases. Future studies are needed to provide empirical evidence for these recommendations.

The goal of consensus guidance is to standardise care, thereby improving outcomes and facilitating research. The suggestions in this document do not constitute official positions of the European Respiratory Society, or the institutions of the task force members. They should not be considered mandates as no suggestion can incorporate all potential clinical circumstances. The suggestions are consensus guidance that should be re-evaluated as evidence accumulates.

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