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Task force report

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COVID-19: Guidance on Palliative care from a European Respiratory Society International Task Force

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Take home message: Multi-national task force provides consensus recommendations for palliative care for patients with COVID-19.

Abstract

Background: Many people are dying from 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 increased need of palliative care provided to many patients by clinicians with 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 experts (75.6%) 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, 58/68 (85.3%) of the first round experts responded, resulting in consensus also for the 14th recommendation.

Conclusions: 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.

INTRODUCTION

As of June 30, 10.360.882 COVID-19 cases are confirmed with 507.014 deaths due to COVID-19 recorded globally.[1] However, both the number of confirmed cases and COVID-19 related mortality are likely to be under-estimated 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 be 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 three 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, 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.[8] 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 recommendations developed using the Institute of Medicine-adherent methodology.[9]

An a*d hoc* international task force was assembled, including the 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), consisting of 14 questions with the aim to provide 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 symptoms, treatments, or caregiver stress. This definition was based on the definition of serious illness on Pallipedia.[10]

The survey was administered from June 2 to June 11, 2020. Several reminders were sent. Agreement of directionality was tabulated for each multiple-choice question. *A priori*, we defined that at least 70% agreement on directionality (agreement or disagreement) was needed to be able to provide consensus recommendations.[11] 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 June 15 to June 18, 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 summarized by DJ and these summaries were checked with the data by KM.

RESULTS

Respondents

In the first round, 68/90 (75.6%) invited experts participated. Respondents were from 15 countries in Europe, North America, and Australia 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 58/68 (85.3%) 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 (ACP, discussions of goals and preferences for future medical treatment and care) should be routinely done or reviewed by clinicians with patients and their loved ones at diagnosis of serious COVID-19.*

Rationale: 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.[12]. Early ACP discussions at time of hospitalisation are suggested to avoid unwanted and burdensome life-sustaining treatments.[13, 14].

Results: Most of the experts recommended strongly (67.6%) or conditionally (29.4%) 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)

ACP was mentioned as 'the first critical step to guide treatment for these seriously ill patients'. A few experts mentioned that ACP should be offered, but patient wishes should be respected if they declined. Some mentioned 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, was 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.[15] For deliberate decisions concerning life-sustaining treatments, patients need information about possible outcomes and likelihood of negative outcomes after treatment.[16] An ICU admission for acute respiratory distress syndrome associated with COVID-19 may have lower chances of survival than an ICU admission for another illness.[14] So, a preference to forego ICU admission in case 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 recommended strongly (54.4%) or conditionally (25.0%) that ACP should be re-evaluated prior to discharge of recovered COVID-19 patients from hospital. (Figure 1B)

Experts mentioned that if patients recover, the serious illness might have influenced 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 mentioned 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 hospitalized patients dying from COVID-19.[6, 13, 17, 18] Opioids are widely used in palliative care with an evidence base effect for relieving breathlessness.[19] Nevertheless, there are no reported trials in COVID-19. A first case series of hospitalized patients with COVID-19 referred for palliative care showed that most patients were treated with morphine (median dose 10mg/24h subcutaneously) and some received fentanyl

(median dose 100 microgram/24h) or alfentanil (median dose 500 microgram/24h).[6] However, effectiveness was clinician rated and data were not collected for individual drugs. Another case series of 30 hospitalized deceased patients showed that 76.7% of the patients used intravenous morphine but, again, effectiveness was not evaluated.[17]

Results. Most experts recommended strongly (55.9%) or conditionally (27.9%) 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 mentioned positive experiences of opioids for breathlessness in COVID-19. Some experts stated that effectiveness for breathlessness in COVID-19 should be confirmed by 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 risk for 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.[20] Nevertheless, a Cochrane review showed no evidence for benzodiazepines for breathlessness in patients with cancer or COPD.[21] This Cochrane 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.[21] 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 lack of evidence for effect for breathlessness, while there is evidence of side-effects. Several experts mentioned that benzodiazepines should be taken in 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 below 90%.*

Rationale: Oxygen therapy in patients with COVID-19 and hypoxaemia may help in reducing breathlessness in palliative care.[13] Oxygen therapy improves survival in patients with severe hypoxemia. The evidence for symptomatic effect on breathlessness is conflicting, but oxygen may relieve breathlessness in some patients with hypoxemia. [22]

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 below 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 hypoxemia, 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 optimizing clinician–patient communication whilst wearing personal protection equipment (PPE).*

Rationale: Clinician-patient communication is a corner stone of palliative care. Communication with patients with COVID-19 can be limited by wearing PPE. Healthcare professionals experience that masks hide facial expressions and muffle voices, which restricts the ability to show compassion.[23]

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 optimizing clinician–patient communication whilst wearing PPE. (Figure 1F)

Experts experienced PPE as a significant and dehumanizing 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.[24]

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.[25] 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[26], and may be reluctant to discuss sensitive topics during phone or video consultations.[27] Remote communication is more challenging for people with low literacy or few digital literacy skills, and people with sight or hearing impairment.[27] 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.[28] Key elements of remote communication skills have been published.[29]

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 hospitalized patients with serious COVID-19 with 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.[13] It has been suggested that symptom burden in dying patients with COVID-19 might be higher than usual in dying patients without COVID-19,[30] 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.[25, 31]

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 hospitalized patients with serious COVID-19 with 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. Benefits of involvement of palliative care teams were mentioned such as: multi-disciplinary assessment; ability to address aspects of care beyond disease treatment including 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 patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment treated at home.*

Rationale: Home palliative care services can provide benefits such as better symptom control.[32] The Association for Geriatric Palliative Medicine (FGPG) recommends the availability of mobile palliative care teams for COVID-19 patients dying at home.[33] Data in COVID-19 are lacking.

Results: Most experts strongly (51.5%) or conditionally (33.8%) recommended 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. Indeed, spiritual care supports patients and families in facing serious illness and cope with poor or uncertain prognosis.[13] The COVID-19 crisis have 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 to involve spiritual care providers in palliative care for patients with COVID-19.[31] Attention is also needed for spiritual care needs of those not represented by chaplains or people who are not religious such as pastoral care workers.[13]

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 care that clinicians can offer, but also that involvement should be dependent on the preference of patient and family. Existential care should not be limited to religious care, but 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, 17] Psychosocial interventions in palliative care can relieve emotional and existential distress and improve quality of life.[34] Therefore, a rapid review recommended to healthcare professionals providing psychosocial care in palliative care for patients with COVID-19,[31] although data in COVID-19 are not yet available.[35]

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 needs of patients and families and the existing skills within the primary clinical team.

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

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 family before death may increase the risk of complicated grief.[36] 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 experienced as too distressing.[7] Other authors do advise remote contact between patients in palliative care and family.[37]

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 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 for complicated grief and post-traumatic stress disorder.[36, 38] Indeed, several risk factors may be present such as: a rapid disease trajectory which might have hampered 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.[36] 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.[38]

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 provided included that bereavement risk as well as need for support will vary and some people will cope with their usual social or community support.

14. *The international task force suggests that staff caring for patients with serious COVID-19 should be offered psychological support to cope with their experiences.*

Rationale: During this COVID-19 pandemic, healthcare professionals experience significant distress.[39] 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.[36, 39] 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 decisions to isolate themselves from personal support systems out of concern for spreading COVID-19.[36, 39] 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.[36]

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 dependent 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[3, 4] is supported, 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 the elderly, chronically ill patients or people with multiple co-morbidities, to prepare patients and family for the moment when decisions concerning treatment of COVID-19 should be made. Future data concerning 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 hypoxemic patients, and benzodiazepines if other treatments fail and breathlessness is associated with anxiety. Nevertheless, evidence for effectiveness, adverse effects and optimal dosage regimes for opioids and benzodiazepines in COVID-19 are absent. Other physical and psychological symptoms also frequently reported by patients with serious COVID-19[6, 17, 18] 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 physical absence of families and loved ones, healthcare professionals need new skills and experience. Fortunately, tools and trainings are being developed rapidly to facilitate communication with patients with COVID-19 and their loved ones.[24, 28, 29, 40] More experience as well as studies exploring 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. Limited availability of palliative care specialists was mentioned as concern. Nevertheless, not all patients may 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, for example through training or consultation.[40]

Methodological considerations

These recommendations were developed following the CORE methodology, which has been shown to result in recommendations concordant with recommendations developed using the Institute of Medicine-adherent methodology.[9] 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' were interpreted by some respondents as specialist palliative care professionals, and by other respondents also including healthcare professionals with general training in palliative care. Further, defining the population of patients with COVID-19 in need for palliative care was challenging for the author group. We have chosen the Palliapedia definition of serious disease[10], 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.

Conclusions

This multinational task force provides consensus recommendations for palliative care for 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 above 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.

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DISCLAIMER

The goal of consensus guidance is to standardize 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 reevaluated as evidence accumulates.

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Legend figure 1

Experts' responses to the 14 questions.

++ = Strong recommendation for…; + = Conditional recommendation for…; +/- = No recommendation for or against; - = Conditional recommendation against…; -- = Strong recommendation against…; * = results from the second round.

Table 1. Definitions of recommendations

Strong recommendation for the intervention	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.
A conditional recommendation for an intervention	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.

Table 2. Characteristics of respondents

		n (%)
Country	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	6 (8.8%)
	USA	6 (8.8%)
Profession*	Physician	50 (73.5%)
	Nurse	2 (2.9%)
	Allied healthcare professional	7 (10.3%)
	Researcher	16 (23.5%)
Expertise*	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%)

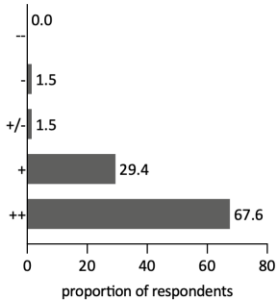
n=68; *respondents could report >1 profession and/or expertise.

Table 3. Experts' reported barriers or concerns towards implementation of recommendations

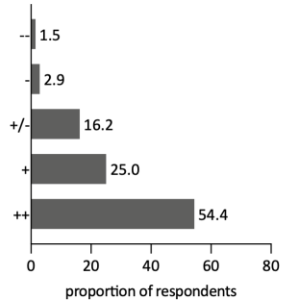
	Recommendation	Barriers / concerns
1	*ACP should be routinely done or reviewed by clinicians with patients and their loved ones at diagnosis of serious COVID-19.*	• The rapidly evolving disease resulting in lack of clarity on the patient's condition to allow for a long-term plan • The often rapid trajectory towards death • Patients being too ill to participate in ACP • Patients experiencing too much anxiety to participate in ACP conversations • Family not being physically present
6	*Staff taking care of patients with serious COVID-19 should receive training in optimizing clinician–patient communication whilst wearing PPE*	• Practical concerns to implement a training during 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 to implement a training during pandemic
8	*Healthcare professionals trained in providing palliative care should be involved in hospitalized patients with serious COVID-19 with 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 patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment 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 (for example being provided with PPE if indicated) to visit in person the dying patient with COVID-19.*	• Limited availability of PPE; • Visits being 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

Abbreviations: ACP= Advance Care planning; PPE= personal protection equipment.

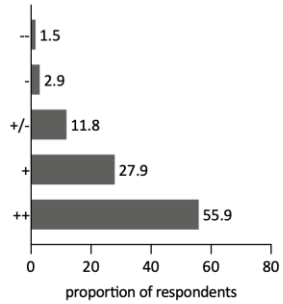
A Should advance care planning (discussions of goals and preferences for future medical treatment and care) be routinely done or reviewed by clinicians with patients and their loved ones at diagnosis of serious COVID-19?



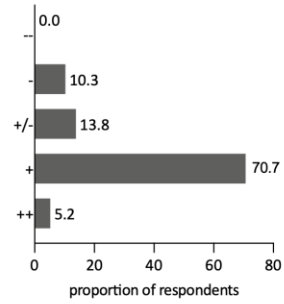
B Should advance care planning be re-evaluated prior to discharge of recovered COVID-19 patients from hospital?



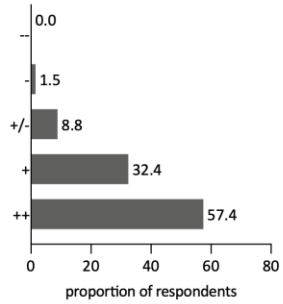
C Should patients presenting with serious COVID-19 and distressing breathlessness despite optimal treatment of underlying causes be given low-dose opioids for the palliative treatment of breathlessness?



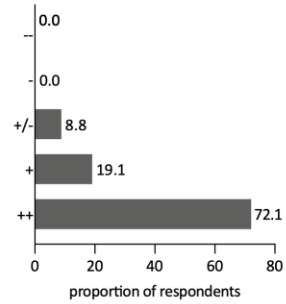
D Should patients presenting with serious COVID-19 and distressing breathlessness despite optimal treatment of underlying causes be given benzodiazepines for the palliative treatment of breathlessness?*



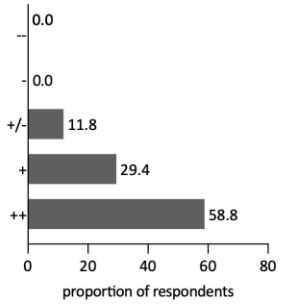
E Should patients with serious COVID-19 in palliative care and distressing breathlessness be given oxygen therapy for the palliative treatment of breathlessness when their transcutaneous oxygen saturation is below 90%?



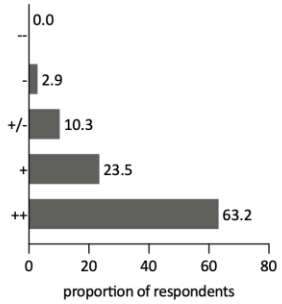
F Should staff taking care of patients with serious COVID-19 receive training in optimizing clinician – patient communication whilst wearing personal protection equipment?



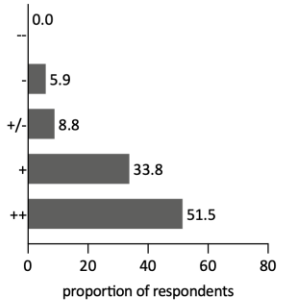
G Should staff taking care of patients with serious COVID-19 receive training in online clinician – family communication (while using telephone or video conferencing)?



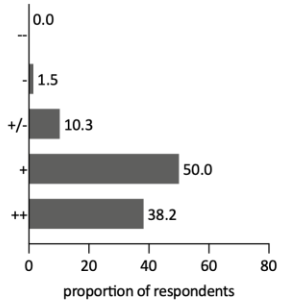
H Should healthcare professionals trained in providing palliative care be involved in hospitalized patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment?



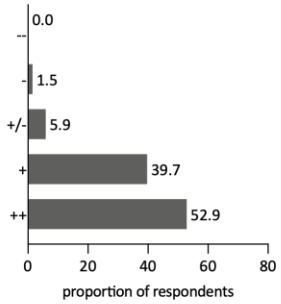
I Should healthcare professionals trained in providing palliative care be involved in patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment treated at home?



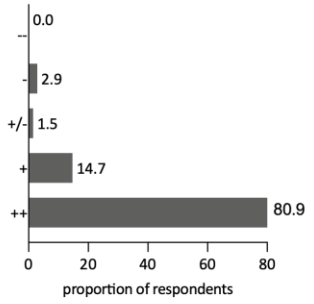
J Should healthcare professionals providing spiritual care (such as chaplains) be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (irrespective of setting, so in the hospital, community or long-term care facilities)?



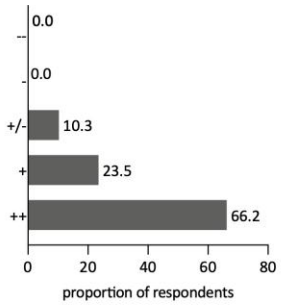
K Should healthcare professionals providing psychosocial care (such as psychologists and social workers) be part of the treatment team of patients with serious COVID-19 with persistent symptoms and concerns despite optimal disease treatment (irrespective of setting, so in the hospital, community or long-term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



L Should family members/loved ones be invited and supported (for example being provided with personal protection equipment if indicated) to visit in person the dying patient with COVID-19?



M Should family members/loved ones of deceased patients with COVID-19 be offered bereavement support by healthcare professionals trained in palliative care or bereavement support?



N Should staff caring for patients with serious COVID-19 be offered psychological support to cope with their experiences?