

## Review Article

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# National and international non-therapeutic recommendations for adult palliative and end-of-life care in times of pandemics: A scoping review

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## Abstract

**Objective.** The care of seriously ill and dying people is an important task, especially in times of pandemics and regardless of the patients' infection status. Before the SARS-CoV-2 pandemic, healthcare systems were not sufficiently prepared for the challenges of palliative and end-of-life care during a pandemic. The aim was to identify and synthesize relevant aspects and non-therapeutic recommendations of palliative and end-of-life care of seriously ill and dying people, infected and uninfected, and their relatives after one year into the pandemic to outline what actions, practices, and procedures were taken to deal with the pandemic and its consequences.

**Method.** A scoping literature review following the methods of the PRISMA-ScR. The electronic literature search was conducted in 09/2020 and updated in 02/2021 using MEDLINE (Pubmed), with no restriction of publication date and eligibility criteria. In addition, a manual search was carried out.

**Results.** A total of 280 studies met the inclusion criteria and three main aspects have emerged. The reduction of physical contact due to the risk of infection severely limited the work of palliative care professionals and solutions had to be found to maintain palliative and end-of-life care structures. This has been accompanied by strict visitor restrictions and the need to support patients, relatives, and enable contact. The third relevant aspect is the integration of specialist palliative care expertise into other clinical settings.

**Significance of results.** This scoping review demonstrates the need for basic palliative care training for every healthcare professional. It supports the importance of developing a national strategy for palliative care in pandemic times in every country, including the digitalization of the healthcare sector to offer telecommunication/telemedicine.

## Introduction

Even after one year into the current SARS-CoV-2 pandemic, the situation poses an enormous challenge to healthcare systems and societies around the world. In the beginning, medical care activities focused on the provision of intensive care beds for patients developing severe respiratory decompensation related to COVID-19 (Rosenbaum, 2020). Furthermore, the reduction of physical contacts in the society and recently vaccinating the population are currently the most important measurements to get the pandemic under control. Even though the development in Germany was less severe in comparison to other European countries, more than 80,000 people died of or with COVID-19 in Germany by May 2021 (RKI, 2021). Additionally, poorer care of non-COVID-19 patients has been described (“Corona Collateral Damage Syndrome”) (Ramshorn-Zimmer et al., 2020).

Palliative and end-of-life care aim to alleviate suffering and improve the quality of life of patients with life-limiting illnesses at the end of life and is now an integral part of many healthcare systems (Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, 2020). Early in the pandemic, the German Society for Palliative Medicine (DGP) published recommendations for the care of patients with COVID-19 (Nehls et al., 2020) and for the support of burdened, seriously ill, dying, and grieving people from a palliative care perspective (Münch et al., 2020). In addition, the DGP contributed to further recommendations on preclinical decision-making (Deutsche Interprofessionelle Vereinigung – Behandlung im Voraus Planen (DiV-BVP) et al., 2020) and prioritization of patients when resources are scarce [Deutsche Interdisziplinäre Vereinigung für Intensiv- und Notfallmedizin (DIVI) et al., 2020].

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There have also been a number of international publications on palliative and end-of-life care in pandemic times. Reports from patients, general practitioners, and nursing homes but also from palliative care providers showed that both the identification of individual preferences and the quality of care for seriously ill and dying patients varied greatly (Fallon et al., 2020; Janssen et al., 2020; Radbruch et al., 2020; Trabucchi and De Leo, 2020). For example, the lack of personal protective equipment (PPE), as well as strict isolation policies and visiting restrictions, led to great distress among those affected and those caring for them (Arya et al., 2020; Mottiar et al., 2020). However, creative and innovative initiatives emerged with the aim of maintaining palliative and end-of-life care for patients and relatives and making it possible under limited contact conditions, e.g., “Palliative Care Pandemic Pack” for non-specialists (Ferguson and Barham, 2020). Early in the SARS-CoV-2 pandemic, Etkind and Arya emphasized the pivotal role of palliative care in the pandemic including symptom management, training non-specialists, and participating in triage discussion (Arya et al., 2020; Etkind et al., 2020).

Overall, it has become evident that the healthcare system in Germany was not sufficiently prepared for the challenges of palliative and end-of-life care in times of a pandemic.

To increase the pandemic preparedness of the German health care system, the Network University Medicine, funded by the German Ministry of Education and Research, was created, comprising 13 large-scale projects covering surveillance, testing, evidence synthesis, etc. One of the projects focuses on Palliative Care in Pandemic Times (PallPan) to develop a National Strategy for the Care of Seriously Ill Patients and their Relatives with recommendations based on studies examining the current situation of dying patients in the pandemic and existing evidence. This scoping review is, besides a number of other studies, the basis for PallPan developing and consenting recommendations for palliative care in pandemics. It is intended to elaborate an overview and summarize the literature about what is already known.

As the pandemic situation is developing quickly and new evidence is emerging almost daily, the aim of this review was to identify and synthesize relevant aspects and non-therapeutic recommendations of palliative and end-of-life care of seriously ill and dying people, infected and uninfected, and their relatives after one year into the pandemic to outline what actions, practices, and procedures were taken to deal with the pandemic and its consequences.

## Methods

### Design

We conducted a scoping review following the PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) guideline (Peters et al., 2015). The decision for a further review was based on the wealth of new publications following the experiences after one year into the pandemic to incorporate the latest literature for the development of the previously mentioned National Strategy for the Care of Seriously Ill Patients and their Relatives. A scoping review was preferred to a systematic review to map the current literature on palliative care and pandemics rather than to appraise the evidence on a specific research question (Munn et al., 2018).

### Inclusion and exclusion criteria

The literature to be examined refers to recommendations for action, practices, and procedures on palliative and end-of-life care undertaken by providers and on system level in the context of pandemics. Both published and unpublished primary studies and reviews of quantitative and qualitative research results, editorials, letters, reports, statements, and guidelines were included. The review contains every type of recommendation for the care of adult critically ill patients with advanced end-of-life conditions and dying patients with or without infection and for the care of family members and bereaved relatives in pandemics. Studies on communication strategies for end-of-life care of critically ill patients were included, as well as publications on the use of telemedicine and its benefits in the context of palliative care in times of pandemic. Furthermore, studies on the psychological (and physical) burden of palliative care and primary care professionals (mental health of professionals) were taken into account.

All references dealing with pediatric palliative care, screening, and testing to contain or prevent outbreaks (e.g., in nursing homes) were excluded as they were not part of the planned recommendations. In addition, descriptive studies on infected (COVID-19-) patients and publications that did not include or were not applicable to the context of palliative care were excluded.

### Population

Publications focusing on adults aged 18 years and older dying (infected and not-infected) because of a severe, incurable disease, and their caring or bereaved relatives were included. In addition, all professional groups and institutions are involved in their care, both inpatient and home care, as well as specialist and non-specialist providers.

### Literature search

We searched the database MEDLINE (PubMed) on 30th September 2020 and updated the search on 11th February 2021. Relevant articles that were known to the authors were included. All references were transferred to Endnote.

### Search strategy

We developed the following search strategy using a combination of keywords and Medical Subject Headings (MeSH) terms related to palliative care in times of pandemic, which led to the combination of the following terms: *Palliative\*care\* OR palliative\*medicine\* OR residential\*facilities\* OR terminal\*care\* AND COVID-19\* OR corona\* OR pandemic\* OR pandemic\*preparedness\**. Search terms had to be included in the title/abstract. Only German and English literature was taken into account, with no restriction regarding the year of publication. Finally, a manual supplementary search was conducted on websites of international and national specialist palliative care associations, in newsletters and search engines (Google, Google Scholar).

### Data extraction/synthesis of results

Titles and abstracts of the identified publications were screened by three researchers (EL, DG, SG) relying on the established inclusion–exclusion criteria. Discrepancies were discussed between the three researchers and, if necessary, solved with the senior

author (CB). Afterward, all full texts were imported into the qualitative data analysis software MaxQDA and were appraised against the inclusion criteria by the three researchers and coded using a predetermined coding guide. The coding guide relies on key topics identified by clinical experts during a digital workshop. Since the results of the synthesis of the literature should primarily be used for the preparation of the recommendations of the PallPan project, we have decided to stick to the topics identified as most relevant for the planned recommendations by expert consensus. The eight key topics are (1) patient autonomy and decision-making, (2) communication with patients/families and strategies for the healthcare system itself, (3) symptom relief for patients infected with COVID-19, (4) enabling contact with relatives, (5) end-of-life care/dying support in pandemics, (6) care after death in pandemics, (7) maintaining palliative care and (8) integration of palliative care. In a first step, the literature was coded deductively according to the coding guide of the expert workshop, since these eight key topics were the basis for the recommendations for action. Whenever literature emerged that was not included in the coding guide but was still relevant, the coding guide was expanded inductively (e.g., telemedicine). 10% of the included articles were double-coded to ensure the reliability of the extracted results. Furthermore, each article was additionally assessed for recommendations for action or best practice examples that can be applied in palliative and end-of-life care. In a second step, a summary content analysis according to Mayring (2003) was conducted inductively, which led to a synthesis of the main aspects and challenges highlighted in the results.

## Results

### Description of studies

The search in MEDLINE (PubMed) yielded 427 studies. Additionally, 419 articles were added through manual search. After removing 152 duplicates, 694 articles were screened, and 192 articles were excluded according to exclusion criteria. A total of 502 articles were retained for full-text review, followed by the exclusion of further 222 articles. Overall, 280 articles were included in qualitative data extraction (Figure 1). They could be categorized in mainly special/fast-tracked articles (34%) and opinion papers/viewpoints/ commentaries/perspectives (19%), followed by reports/statement papers (14%), editorials (9%), and letters to the editor (6%). A total of 21 original articles and 9 reviews were included, 7 blog posts/website articles, as well as three interviews, one book section, and one protocol paper.

Overall, three main aspects and challenges could be identified through the analysis: **maintaining palliative and end-of-life care structures** despite limiting physical contact, **supporting patients and relatives, and enabling contact** and **integrating specialist palliative care into other settings**. The following sections reflect these themes in more detail. For this purpose, text passages with similar content have been summarized. Illustrative codes are shown in Tables 1–3.

### Maintaining palliative and end-of-life care structures

Due to the necessary reduction of physical contact, it was challenging for palliative and end-of-life care providers to maintain their daily work. In addition, in some cases, the numbers of infected patients have increased dramatically and parts of the teams have also been infected and were unable to work

(Blinderman et al., 2020; Lovell et al., 2020; Schoenmaekers et al., 2020). Therefore, services must be flexible, adapt, and change their organization and work schedules as needed (Nevzorova, 2020). Home visits must be limited to those who actually need care and cases should be shared with colleagues in order to make better decisions (Nevzorova, 2020; Valenti, 2020). Frequent testing of the staff is recommended (Szczerbńska, 2020) as well as designating one single professional who does in-person visits in the community setting (Tran et al., 2020). Furthermore, hospice and palliative care facilities should network locally to expand their services and offer them to all patients in need (Boufkhed et al., 2020; Münch et al., 2020). As multidisciplinary teams are common in palliative care, team members can to some extent step into other roles if necessary, to compensate for shortfalls (Feder et al., 2020). Another option in resource-limited settings might be, to shift certain tasks from highly trained clinicians to those with limited training, to save costs and resources, but basic training should be a requirement (Knights et al., 2020; Lopez et al., 2021). Healthcare teams can be supported by maintaining an adequate patient-to-staff ratio and ensuring frequent breaks (Mottiar et al., 2020). Providing and ensuring work-relevant information and the distribution of responsibility in order to keep additional workload low are essential (Hower et al., 2020).

Healthcare institutions should develop a response plan for pandemics (Boufkhed et al., 2021) like COVID-19 with the domains *staff, stuff, space, and system* to ensure high-quality palliative care delivery for patients and relatives and attend to the needs of non-palliative care professionals as they care for infected patients (American Geriatrics Society, 2020; Sese et al., 2020). Policies and protocols that impact physical and psychological safety (e.g., PPE, physically distanced workspaces, time for recovery from vicarious trauma, and compassion fatigue) should be regularly assessed and adjusted (Brown et al., 2020). In this context, it is crucial to ensure the availability (responsibility of individual governments) (Nyatanga, 2020; Valenti, 2020), training in and use of PPE for staff in all palliative care settings [Agar, 2020; Alhalabi and Subbiah, 2020; Bern-Klug and Beaulieu, 2020; Brown et al., 2020; Cohen and Tavares, 2020; Fausto et al., 2020; GovScot, 2020; Humphreys et al., 2020; Kluger et al., 2020; Mehta and Smith, 2020; Mottiar et al., 2020; Murray et al., 2020; Nevzorova, 2020; Rhee et al., 2020; Task Force in Palliative Care (PalliCovidKerala), 2020; Yardley and Rolph, 2020]. To achieve this, PPE should be stockpiled for palliative care providers in long-term care and community settings (Arya et al., 2020).

Alongside clinical staff, chaplains should continue to work and certified chaplain interventions should be offered where available (Bajwah et al., 2020; Bolt et al., 2020; Ferrell et al., 2020; Lawrie and Murphy, 2020). Therefore, if possible, a partnership with local spiritual counselors willing to visit patients face-to-face or virtually should be arranged (Schoenmaekers et al., 2020). Students (of social work) (Bern-Klug and Beaulieu, 2020) or volunteers who can provide psychological, psychosocial, and bereavement support by using digital technology or telephones can be employed (Cripps et al., 2020; Fausto et al., 2020; Cheng, 2021; Lopez et al., 2021).

In the home care setting, family caregivers should be empowered to participate in providing care and be enabled to manage care with remote advice and support from community palliative care services (WHO, 2018; Chidiac et al., 2020). Furthermore, they can be trained in the administration of medication at

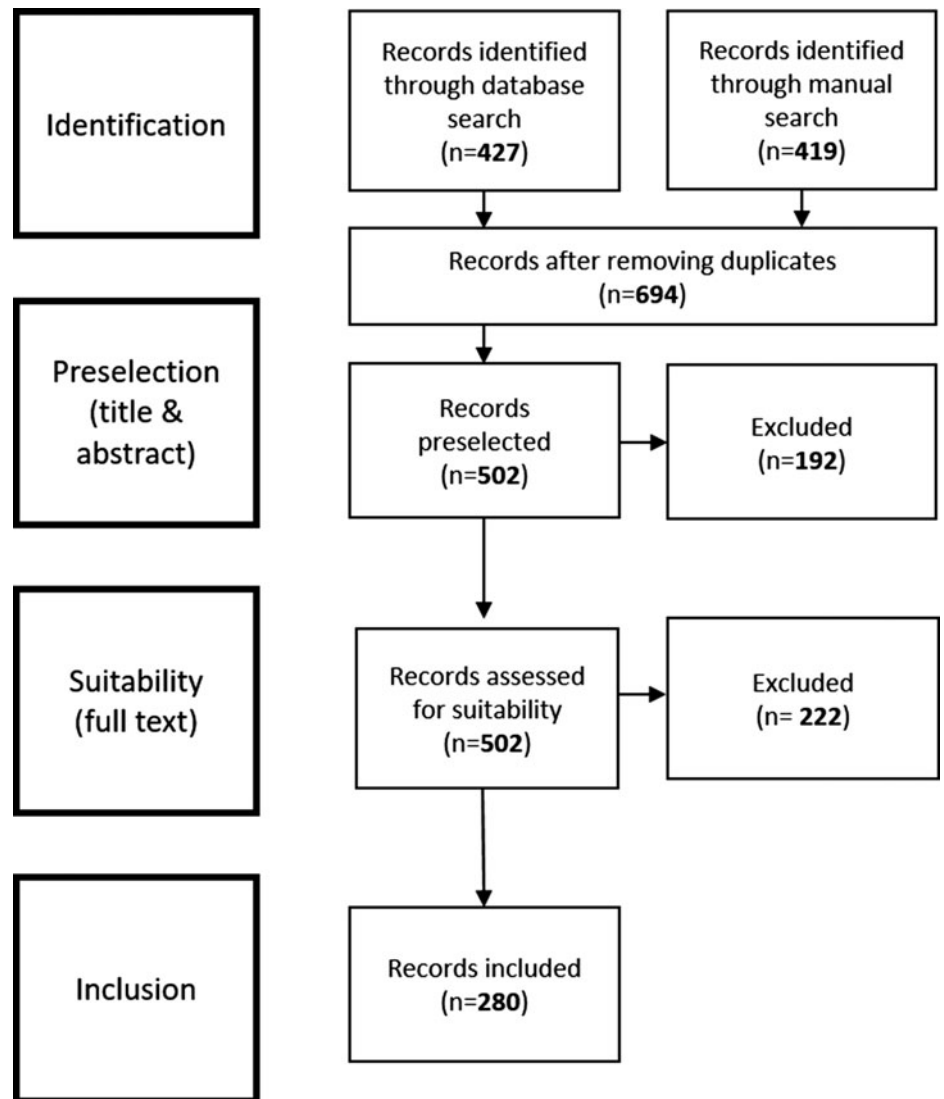


Fig. 1. Flowchart about the study selection.

home to reduce avoidable hospital stays (Chidiac et al., 2020; Mitchell et al., 2020; Schoenmaekers et al., 2020).

### *Mental health of healthcare professionals*

Staff should be offered special psychological support (Krishna et al., 2020; Szczerbińska, 2020) and regular supervision to prevent burnout (Downar and Seccareccia, 2010; Nouvet et al., 2018; WHO, 2018; Krakauer et al., 2019; Browne et al., 2020; Chidiac et al., 2020; Hendin et al., 2020; Hill et al., 2020; Humphreys et al., 2020; Janssen et al., 2020; Boufkhed et al., 2021; Varani et al., 2021). Peer-support (telephone or virtual) and informal debriefing to support teams' day-to-day work should be implemented (Brown et al., 2020; Mehta and Smith, 2020; Pattison, 2020; Schoenherr et al., 2020; Selman et al., 2020). "Palliative care provider groups" should be formed to supply mutual support and coverage if a team member becomes overwhelmed by the situation (Arya et al., 2020; Mehta and Smith, 2020). Increased collaboration can decrease feelings of loss of control and minimize trauma response in teams (Brown et al., 2020). Another important aspect is to recognize the hard work of staff in concrete ways (Bern-Klug and Beaulieu, 2020), ensure resilience (Etkind et al., 2020), and focus on wellness and self-care

(Hannon et al., 2020). Therefore, resources for self-care and coping should be created, formalized, and disseminated (Brown et al., 2020), including healthy food, enough sleep, social connections, and limiting news media (Kluger et al., 2020).

### *Supporting patients and relatives and enabling contact*

The restrictions on physical contact and the associated limitations on visits have led to great distress for all those involved. Therefore, patients and relatives must be supported and touch points need to be ensured as much as possible.

### *Physical face-to-face visits*

It is necessary to continue to allow physical visits, even if in limited form (e.g., only one person for a limited time after having determined that the relative has no symptoms or infection) (Estella, 2020; Lawrie and Murphy, 2020; Nevzorova, 2020). This is especially important for dying patients, as it has a great impact on the subsequent bereavement and processing of death (Hart et al., 2020; Janssen et al., 2020; Mercadante, 2020; Münch et al., 2020; Selman et al., 2020). Family members should be allowed to visit deteriorating patients (Guessoum et al., 2020;

**Table 1.** Illustrative quotes: maintaining palliative and end-of-life care structures

Subtopic	Author	Country	Code
<i>Maintaining palliative and end-of-life care structures</i>	Adams (2020)	USA (New York)	“Palliative teams should continuously monitor need and develop a surge plan for staffing and prioritization which might include utilizing outpatient and community providers and creating a plan for 24/7 accessibility. Some team members may be able to work from home, decreasing hospital exposure and preserving the work force. If asked to provide front-line hospital care, suggest admitting and managing patients who are on comfort care due to team expertise in symptom management.”
	Feder et al. (2020)	USA (Connecticut)	“Principle 4: Use a multidisciplinary team. Members of multidisciplinary PC teams are knowledgeable about the expertise and function of other PC team members and can, to some extent, step into each other’s roles as necessary. This “cross-training” is applicable to the current COVID-19 crisis and is already happening as clinicians’ usual roles are shifted to meet staffing and patient needs and to prepare for patient surges in hospitals.”
	Münch et al. (2020)	Germany	“Hospice and palliative care facilities should network locally to expand services and offer them to all patients in need.”
	Costantini et al. (2020)	Italy	“Governments must recognize the hospice and palliative care sector as an essential component of the healthcare system response to COVID-19.”
	Hannon et al. (2020)	Canada	“For the duration of the pandemic, the inpatient teams were split into two distinct teams (one covering the PCU and one the consult service, each with four physicians) to minimize the risk of infection and exposure among the entire team. Physicians were assigned to cover either service on a weekly rotational basis, with back-up physicians available in the event of increased workload, illness, or exposure.”
<i>Mental health of healthcare professionals</i>	Selman et al. (2020)	England	“We recommend that health care leaders and organizations take responsibility and ensure staff are prepared for the emotional consequences of their work and that resources, guidance, and training are in place to safeguard health care providers’ health. Self-care strategies and individual “resilience tools” such as mindfulness and reflective practice are insufficient; resilience should not become another responsibility of staff working in traumatic conditions but requires an organizational and systemic response. Organizations should actively monitor front-line staff, facilitate effective team cohesion, and implement strategies to support teams’ day-to-day work, including informal debriefing and peer support. Single-session psychological debriefing approaches should be avoided as they may cause additional harm. Leaders and organizations should also make professional sources of support readily available; this includes formal bereavement counseling, which can enhance awareness about vicarious traumatization and encourage adaptive coping strategies.”

Halek et al., 2020; Selman et al., 2020). If it is not possible, it should be explicitly explained to the caring relatives that the patient will be adequately accompanied by staff (ÖGARI, 2020). It should not be forgotten that hospice workers and volunteers are also a crucial part of the circle of visitors to support patients and families (DGP, 2020).

Appropriate visiting concepts, including safety measures, should be developed and used in the institutions (DGP, 2020; Münch et al., 2020; Murray et al., 2020). It is important to communicate in an open way what visitor regulations are in place and why. Therefore, institutions should provide information about their “pandemic policies” on their website and guide patients and relatives through internal processes and regulations (Hart et al., 2020; Münch et al., 2020). Furthermore, evidence-based interventions, like rapid COVID-19 testing, tracing, and isolating cases can be established to avoid infections in healthcare institutions and to enable contact (Curley et al., 2020; Murray et al., 2020).

### Personal protective equipment

A frequent recommendation to enable visits is to include the provision of PPE to relatives and the development and provision of

training on the appropriate use (Arya et al., 2020; Bear et al., 2020; Bern-Klug and Beaulieu, 2020; Eriksen et al., 2020; Estella, 2020; Hendin et al., 2020; Janssen et al., 2020; Kent et al., 2020; Kronen et al., 2020; Mercadante, 2020; Münch et al., 2020; Selman et al., 2020). Family caregivers should be considered when distributing PPE to protect themselves when caring for infected patients at home (Kent et al., 2020). PPE allows staff members to assist the patient during their last hours (Mottiar et al., 2020), which reduces the risk of patients dying alone in isolation (Abbott et al., 2020).

### Goals of care discussion/advance care planning

It is essential to be in contact with the family if the patient cannot express himself, e.g., with regard to goals of care discussions (Eriksen et al., 2020; Kluger et al., 2020). Goals of care discussions/advance care planning (GoC/ACP) and patient autonomy emerged to be an even more important topic during pandemic times.

The consensus of the synthesized literature is that GoC /ACP needs to be updated or created, especially for seriously ill people, to prevent triage discussions and to assign a specific contact person for each patient if possible. This is especially the case for

**Table 2.** Illustrative quotes: supporting patients and relatives and enabling contact

Subtopic	Author	Country	Code
<i>Physical face-to-face visits</i>	Nevzorova (2020)	Russia	“Unlike regular hospitals, hospices and palliative departments cannot completely prohibit patient visits. This would be inhumane — after all, many of them may simply not have another chance to see relatives. The only thing that can be done is to reduce the number of visitors to one person per day for each patient.”
<i>PPE</i>	Janssen et al. (2020)	Netherlands	“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. (...) 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 (...). Expert experience indicated that PPE was 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.”
	Janssen et al. (2020)	Netherlands	“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 (...). The inability to say goodbye to a family member before death may increase the risk of complicated grief. When family is allowed to visit, PPE might be needed.”
<i>Goals of Care discussion/ advance care planning</i>	Mottiar et al. (2020)	Canada (Ottawa)	“Establishing goals of care may present increased challenges in the context of a pandemic. Limitations imposed by isolation to limit infection transmission, PPE, and restriction of visitors may impact the communication skills that we are all accustomed to using and may lead to pressures that can impact goals of care discussions. In recent years, there has been considerable work on developing frameworks for discussing goals of care. The (...) frameworks share similar principles, and remain valid and unchanged in the setting of COVID-19.”
	Mehta and Smith (2020)	USA (California)	“Goals of care can be addressed using telemedicine to ease patient or caregiver distress and to prevent hospitalizations. Telemedicine has hidden advantages; video visits allow practitioners to see patients’ home environments—information that is unavailable in traditional clinic visits. However, we have also found that it can be difficult to rapidly establish trust with new patients. Being present, validating emotions, responding to questions, and using communication tools should continue to be implemented for virtual visits. (...) Before adopting this as the norm, health care professionals should remember that at least 1 randomized study of weekly palliative care teleconsultations vs usual in-person palliative care visits showed significantly more anxiety and higher distress in the telehealth group.”
<i>Communication in times of pandemics</i>	Nakagawa et al. (2020)	USA (New York)	“We incorporated COVID-19–specific language into our recently published “Three-Stage Protocol” and have successfully used this framework to navigate these difficult conversations. This approach was found to be useful for non-palliative care clinicians as well, including psychiatrists and ED clinicians, who received additional GOC training during the COVID-19 pandemic and provided positive feedback.”
<i>Telecommunication/ Telemedicine</i>	Hart et al. (2020)	USA (Pennsylvania)	“Videoconferencing is preferable to telephone calls and improves emotional connection through facial expressions and nonverbal communication.”
<i>Virtual visits</i>	Nakagawa et al. (2020)	USA (New York)	“Mitigate family absence at bedside, videoconferencing should be attempted whenever possible. Our experience has demonstrated that this is tremendously helpful for families, not only allowing them to grasp how sick their loved one is, but also for providing much needed contact.”
<i>Care after death/bereavement support</i>	Núñez et al. (2020)	USA (Pennsylvania)	“What can we do? One way is to have the funeral through Facebook, where singing and praying can be facilitated through a virtual platform.”

patients who are older or suffer from advanced chronic diseases and patients that live in community and nursing homes/long-time care settings (Abbott et al., 2020; Adams, 2020; Alhalabi and Subbiah, 2020; Arya et al., 2020; Bajwah et al., 2020; Battisti

et al., 2020; Bern-Klug and Beaulieu, 2020; Borasio et al., 2020; Brighton and Evans, 2020; Brown et al., 2020; Clarfield et al., 2020; Cooper and Bernacki, 2020; Desai et al., 2020; Estella, 2020; Fadul et al., 2020; Flint and Kotwal, 2020; Gillessen and

**Table 3.** Illustrative quotes: Integration of specialist palliative care into other settings

Subtopic	Author	Country	Code
Triage/ethic committees	Mercadante (2020)	Italy	“Palliative care physicians have to be involved in triage, responding rapidly and flexibly, need to provide symptom management, organizing shifting resources into the community to facilitate psychosocial and bereavement care, also adopting measures to deal with stress, using technology to communicate with caregivers.”
Primary care staff	Adams (2020)	USA (New York)	“We also suggest regular rounding in the ICU to support the staff and promote appropriate consultation.”
System level	WHO (2018)		“Realizing the urgent need to include palliation across the continuum of care, especially at the primary care level, recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care.”

Powles, 2020; GovScot and SPCPA, 2020; Hendin et al., 2020; Hopkins et al., 2020; Inzitari et al., 2020; Janssen et al., 2020; Kamal et al., 2020; Kent et al., 2020; Knights et al., 2020; Kotze and Roos, 2020; Kunz and Minder, 2020; Lawrie and Murphy, 2020; Michels and Heppner, 2020; Mohile et al., 2020; Moore, 2020; Moore et al., 2020; Mottiar et al., 2020; Münch et al., 2020; NHS, 2020; Núñez et al., 2020; Peate, 2020; Petriceks and Schwartz, 2020; Raftery et al., 2020; Rhee et al., 2020; Rosa et al., 2020; Selman et al., 2020; Sieber, 2020; Spicer et al., 2020; Szczerbińska, 2020; Task Force in Palliative Care (PalliCovidKerala), 2020; Ting et al., 2020; Wallace et al., 2020; Weinkove et al., 2020; WHO, 2020). If possible technical possibilities (e.g., telecommunication) can be used for GoC /ACP, to keep the risk of infection low for all involved (Mehta and Smith, 2020; Lopez et al., 2021).

Every inpatient should have a treatment escalation plan (control for patient, relatives, and healthcare workers) so that treatment decisions do not have to be made at short notice in a crisis (Downar and Seccareccia, 2010; Clarfield et al., 2020). Building a therapeutic relationship is very important (Mottiar et al., 2020) and patients have to be involved in decisions. If this is not possible, the clinicians should rely on relatives (shared-decision-making between team, patient, and relatives) (Eriksen et al., 2020; Feder et al., 2020; Gaur et al., 2020; Koffman et al., 2020; Milano, 2020; Santos et al., 2020). Already existing assessment tools should be used to support decisions and can be included in GoC/ACP discussions with patients as well (Fiorentino et al., 2020; Lapid et al., 2020; McIntosh, 2020). The patient's category status in the medical record should be updated accordingly (Hendin et al., 2020). Patients and relatives should be informed openly and honestly about the consequences and risks (infection/restricted visiting arrangements) that can result from a hospital stay (Singh et al., 2020).

Healthcare systems can cooperate with the home care setting to ensure that primary care providers create awareness of GoC/ACP and that all can offer basic palliative care goals of care and symptom control (Essien et al., 2020; Lopez et al., 2021). The crisis could offer a chance to discuss GoC/ACP more openly in the population and to increase death literacy (Lapid et al., 2020).

### Communication in times of pandemics

All rules of communication that exist in palliative care continue to apply (Gibbon et al., 2020; Santos et al., 2020; Schlögl and Jones, 2020). Additionally, a COVID-19 specific language should be used (Nakagawa et al., 2020) (e.g., “COMMUNICoVID” — How to communicate with families living in complete isolation) (Mistraletti et al., 2020) and it is strongly recommended to

encourage palliative care providers to honestly communicate the clinical uncertainty (e.g., of the COVID-19 trajectory) to families and patients. It is critical to provide transparent medical care, appropriate support, and counseling (Burke et al., 2020). Staff should be made aware of barriers resulting from communicating with patients in PPE (especially with masks/face shields) and trained in overcoming them (Arya et al., 2020) (e.g., pinning photos of their faces on the PPE to humanize themselves) (Brown-Johnson et al., 2020; Reidy et al., 2020).

### Telecommunication/telemedicine

Recently, communication has increasingly taken place via telephone and digital/virtual media to maintain palliative and end-of-life care. A few points should be noted when using electronic devices in healthcare. The equipment used has to be disinfected regularly (Cormi et al., 2020). Staff taking care of patients with serious COVID-19 infections should receive training in online clinician–family communication (Janssen et al., 2020) and needs training in online communication (e.g., Vital Talk COVID-19 communication guides) (Gray and Back, 2020). Contact with the family should be made at least once a day (Adams, 2020; Bajwah et al., 2020; Hart et al., 2020; Janssen et al., 2020; Münch et al., 2020), preferably by the same person, possibly by email, so that the relatives are informed about the situation (Milano, 2020). Videophone communication should be preferred if possible, especially when breaking bad news (Alhalabi and Subbiah, 2020; Hart et al., 2020). There are also patients or families for whom online communication is not suitable because they are too ill or they do not have the technical possibilities. They should rather be contacted by telephone or be prioritized for personal contact (Kent et al., 2020).

### Virtual visits

Virtual visits can be used, when face-to-face communication is not essential, to fit social distancing rules or when people are in quarantine. Virtual visits are very helpful when urgent decisions are necessary, but it is not appropriate to talk on the phone or when a personal visit would cause a delay or to prevent unnecessary use of PPE (Fausto et al., 2020; Hawkins et al., 2020). Virtual contacts should be facilitated and daily updates should be organized even when the patient is not able to talk (Krakauer et al., 2019; Abbott et al., 2020; Chidiac et al., 2020; Cooper and Bernacki, 2020; Curley et al., 2020; Farnood and Johnston, 2020; Guessoum et al., 2020; Hill et al., 2020; Knights et al., 2020; Mayland et al., 2020; Mehta and Smith, 2020; Münch et al., 2020; Nakagawa et al., 2020; Rosa et al., 2020; Selman et al., 2020; Ting et al., 2020; Yardley and Rolph, 2020; Pahuja

and Wojcikewych, 2021). This could be provided by additional staff (e.g., students, retired professionals) (Chidiac *et al.*, 2020). Therefore, structures for use of telecommunication should be set up (Feder *et al.*, 2020; Gibbon *et al.*, 2020; Kent *et al.*, 2020; Perrone *et al.*, 2020; Schoenherr *et al.*, 2020), while being cautious if it creates stress in actively dying patients (Fusi-Schmidhauser *et al.*, 2020; Selman *et al.*, 2020). Through virtual visits, consultations [including symptom control (Kent *et al.*, 2020) like monitoring opioid use (Adhikari *et al.*, 2020)] in clinics or medical offices can be reduced and thus lower the risk of infection (Perrone *et al.*, 2020). In general, it is important to humanize technology and providers should prepare the family prior to the conference for what they may see. Furthermore, naming everyone in the room and how they are connected, explaining how the patient is being monitored and have guidance on what to say is helpful. Regular reassurance and check-ins should be provided. Pitfalls of technology (setting expectations, having a back-up plan, considering a test call) and elements of physical and human contact (singing favorite songs, having the family watch elements of comforting care such as holding the patient's hand, sharing favorite stories) should be considered (Ritchev *et al.*, 2020).

There is emerging evidence on the utility of telemedicine in the provision of palliative care (Fadul *et al.*, 2020). However, adequate preparation and technical expertise are needed for an effective implementation into acute care settings. Palliative care and hospice teams will need to be proactive in identifying, implementing, and training on the most suitable remote platform to deliver services to patients and families (Creutzfeldt *et al.*, 2020; Fadul *et al.*, 2020). It is crucial to ensure good WIFI connection and communication technology infrastructure (Humphreys *et al.*, 2020; Münch *et al.*, 2020), to support and train staff in technology use (Hower *et al.*, 2020), and to organize information and data flow (Mody and Cinti, 2007; Behrens and Naylor, 2020; Boufkhed *et al.*, 2020; Brown *et al.*, 2020; Hanratty *et al.*, 2020; Hower *et al.*, 2020; Knights *et al.*, 2020). Governments should support digital education for aged care and on communication technology infrastructure, digital proficiency of staff and patients, and the provision of tech staff (Siette *et al.*, 2020). Furthermore, they should establish guidance (Rubinelli *et al.*, 2020), e.g., on balancing data security/privacy and use of communication technology (Hart *et al.*, 2020).

#### *Care after death/bereavement support*

Virtual bereavement counseling and support groups should be provided to relatives (Arya *et al.*, 2020; Hado and Friss Feinberg, 2020). This might help coping with remote send-offs such as funeral live-streaming and saying goodbye via video chat (Frydman *et al.*, 2020; Moore, 2020; Núñez *et al.*, 2020). Relatives could be encouraged to express grief online, via telephone, letters, or videos and/or have online funerals (Farrell *et al.*, 2020; Selman *et al.*, 2020). It is suggested to have a proper funeral after the pandemic or have a commemoration at home. Staff members can also provide an image of the deceased ones' faces to the relatives (with permission) for better coping with bereavement (Münch *et al.*, 2020).

#### *Integration of specialist palliative care into other settings*

The last but equally important aspect is the support of other clinical areas and settings by specialist palliative care teams. There is a necessity for palliative care to be available across different units, where patients at the highest risk reside (Arya *et al.*, 2020).

Palliative care delivery will frequently need to be undertaken by primary care teams under the guidance of specialist palliative care services (Davies and Hayes, 2020; Ferguson and Barham, 2020; Krishna *et al.*, 2020; Petriceks and Schwartz, 2020; Weinkove *et al.*, 2020). Every clinician with palliative care experience should be identified for providing (online) education sessions for primary care staff to coach symptom management and end-of-life care (Downar and Seccareccia, 2010; Knights *et al.*, 2020; Lai *et al.*, 2020; Mitchell *et al.*, 2020; NHS, 2020; Radbruch *et al.*, 2020; Selman *et al.*, 2020). Therefore, it is crucial to develop standardized order sheets and protocols, including order sets for end-of-life symptom management and continuous palliative sedation therapy for a particular use by non-specialist physicians (Downar and Seccareccia, 2010; Bowman *et al.*, 2020; Cripps *et al.*, 2020; Hannon *et al.*, 2020). The developed plans and palliative care assessments need to be clear and simple to understand to achieve maximum relief of symptoms (Fusi-Schmidhauser *et al.*, 2020). Involved allied healthcare workers like social workers and spiritual care staff can provide psychosocial support and bereavement counseling (Downar and Seccareccia, 2010; WHO, 2018; Etkind *et al.*, 2020). Furthermore, non-specialist staff in all different clinical areas has to be coached in primary palliative care communication skills (e.g., asking about hopes, worries) (Desai *et al.*, 2020; Gibbon *et al.*, 2020; Hannon *et al.*, 2020; Mottiar *et al.*, 2020; Murray *et al.*, 2020; Rajagopal, 2020; Sese *et al.*, 2020; Singh *et al.*, 2020).

#### *Triage/ethic committees*

Each hospital that does not have an ethics committee ought to organize one in case of triage. Complex triage decisions should never rest on a single person but involve an interdisciplinary team (e.g., existing of an intensive care physician, an internist, and a palliative care specialist) (Borasio *et al.*, 2020; Mercadante, 2020; Mills *et al.*, 2020; Obata *et al.*, 2020).

#### *Primary care staff*

There are special recommendations for primary care staff (including ICUs and emergency departments). For these teams, it is relevant to embed palliative care into their department and to organize regular rounds to support and promote appropriate consultation (Adams, 2020) and to screen for patients with palliative care needs (Adams, 2020; Fusi-Schmidhauser *et al.*, 2020; Gibbon *et al.*, 2020; Haydar *et al.*, 2020; Lee *et al.*, 2020). This includes peer education and support (Mody and Cinti, 2007; Brown *et al.*, 2020; Hado and Friss Feinberg, 2020; Hower *et al.*, 2020; Rim *et al.*, 2020) as well as engagement with institutional crisis response teams to ensure palliative care needs are incorporated into system-level response plans (Feder *et al.*, 2020; Münch *et al.*, 2020; Sese *et al.*, 2020; Pahuja and Wojcikewych, 2021). Pathways can be identified for rapid consultation and involvement of palliative care teams (Rosa *et al.*, 2020). The integration of palliative care into different settings and the involvement of specialists helps not only to provide essential care to patients but also to reduce the emotional burden of healthcare workers being at front-line (Nevzorova, 2020).

#### *System level*

Governments must recognize the hospice and palliative care sector as an integral component of the healthcare systems' response to pandemics (WHO, 2018; Costantini *et al.*, 2020; Laxton *et al.*, 2020; Mercadante, 2020; Salifu *et al.*, 2020) and the need for ongoing education and training offered to healthcare workers



(WHO, 2018). Collaborative relationships between generalist and specialist providers of palliative care have to be developed and better understood to inform national policy and to evolve recommendations for service delivery during future pandemics (Mitchell et al., 2020).

## Discussion

In this scoping review, the relevant aspects of palliative and end-of-life care of severely ill and dying people and their relatives during pandemic times have been synthesized. As an overall result, three central aspects have emerged through the analysis: maintaining palliative and end-of-life care structures despite limiting physical contact, supporting patients and relatives, and enabling contact and integrating specialist palliative care into other settings.

The principles of palliative care aiming to increase the quality of life, support the patients and their families and friends, and allowing dying in dignity still apply to humanitarian crises such as the current SARS-CoV-2 pandemic. However, the restrictions imposed by the pandemic on health care systems and thus palliative care are challenging for professionals as they need to accept that elements taken for granted before the pandemic are not possible anymore like unrestricted visiting, physical contact, or direct patient contact. Even more, the use of PPE, often felt as distancing to the patients, is now the basis for any patient contact. However, the pandemic also provides an opportunity for the development of palliative care. The need for palliative and end-of-life care becomes evident in a pandemic which is reflected in the first topic of this scoping review, maintaining palliative and end-of-life care structures despite limiting physical contact. Palliative care services and teams need to adapt to the current situation and partially find new ways of working. Health care providers and decision makers should support existing services rather than questioning them. Working under these constraints is demanding and many professionals suffer from mental health problems for which health care leaders and organizations need to take responsibility (Selman et al., 2020).

The second aspect, supporting patients and relatives, lies in the very heart of palliative care. Providing symptom management and support for dying people and their relatives should be paramount irrespective of the setting and the underlying disease or infectious status. Key issue and cause of severe distress is the reduction of physical contact accompanied by strict visitor restrictions in inpatient settings. Patients and relatives need to be supported and contact between them should be allowed wherever possible (Estella, 2020; Lawrie and Murphy, 2020; Nevzorova, 2020). At the beginning of the pandemic, the provision of sufficient PPE had been a major logistical challenge, especially in the home care setting (Nyatanga, 2020; Valenti, 2020). However, the recent experience in many countries shows that there are meanwhile sufficient amounts of PPE in all settings. Consequently, relatives should be provided with PPE for visits to their loved ones (Janssen et al., 2020). Virtual visits can be another solution (Fausto et al., 2020; Hawkins et al., 2020), but the situation must be assessed individually, as virtual contact can be perceived as a burden for severely ill or dying patients (Fusi-Schmidhauser et al., 2020; Selman et al., 2020). Especially in times of pandemics, open communication with patients and relatives is even more essential. This also relates to goals of care and advance care planning discussions to foster patient-centered care. The synthesized literature clearly underpins that they form an important basis

for remaining able to act in times of scarce resources. Triage discussions and treatment that is not wanted by patients can thus be avoided especially in seriously ill, older people, or people who live in nursing homes/long-time care settings (Moore et al., 2020; Selman et al., 2020; Sieber, 2020). These discussions and conversations should be honest and direct (Burke et al., 2020). Nevertheless, the general rules of communication in palliative care still apply (Gibbon et al., 2020; Santos et al., 2020; Schlögl and Jones, 2020). Therefore, it is important to also train other non-specialist staff on the basics of palliative care communication skills (Desai et al., 2020; Gibbon et al., 2020; Hannon et al., 2020; Mottiar et al., 2020; Murray et al., 2020; Rajagopal, 2020; Sese et al., 2020; Singh et al., 2020).

The third area covered by this review is the integration of specialist palliative care into other settings, to support other disciplines and identify patients in need of palliative care at an early stage. The call to integrate specialist palliative care even more into the health care system already existed before the pandemic. Basic knowledge on symptom management and communication is necessary in every health care setting caring for severely ill and dying patients. Specialist palliative care professionals need to further develop their advisory and teaching roles to foster the skills of other professionals and teach them palliative care principles. Primary carers (e.g., in ICUs and emergency departments) and palliative care teams in particular need to network and collaborate to ensure the best possible treatment for severely ill patients (Adams, 2020).

Overall, every aspect mentioned has to be adapted individually to the context of each setting in different countries. To support this and to be prepared for future pandemics, we need to learn from each other and from the developed solutions.

## Strength and limitations

A strength of this scoping review is the inclusion of a wide range of publications and aspects up to February 2021 in quite a dynamic time. Also, the qualitative approach of analyses of the publications' content helped to capture all relevant topics. Limitations are the lack of quality appraisal of the included publications and the limitation to English and German articles. In addition, only one database was searched, leading to a particular risk that allied health literature was neglected. As the review is part of a wider project with very strict time limits, we did not have the resources to conduct a full systematic review. As we were mainly interested in the various aspects of palliative and end-of-life care, we felt a scoping review would better meet our circumstances.

## What this study adds

This study adds an overview of relevant aspects and non-therapeutic recommendations in palliative and end-of-life care after one year into the SARS-CoV-2 pandemic. Only a very limited number of the included articles presented results from research studies. This is of course due to the limited time factor and the novelty of the global pandemic situation, but it also demonstrates that there are research gaps and enormous potentials to close them. Of particular interest are the long-term effects on the individuals involved, both patients and family members, as well as healthcare professionals.

## Conclusion

The results of the scoping review indicate that besides the integration of advance care planning in every clinical area and setting, the further development and expansion of digitalization in the healthcare sector is needed and must continue in order to be able to offer telecommunication and telemedicine. Using electronic devices in communication is helpful in non-pandemic times as well and will be increasingly requested. It also supports a lively exchange between professionals, patients and relatives, e.g., in goals of care discussions. Therefore, infrastructure must be provided, but staff must also be trained in specific “online communication skills”. In addition and especially in order to provide sufficient advance care planning, every healthcare professional should have basic knowledge of palliative care, which must be trained across all relevant clinical disciplines. Finally, a national strategy for integrating palliative care in pandemic times should be developed in each country.

## Author contributions

CB and STS obtained funding for PallPan. Concept and design of the review: CB, DG, EL, and STS. The analysis was carried out by DG, EL, SG, and MW. The synthesis was mainly performed by EL and DG. DG and EL wrote the manuscript with support from SG. SG, MW, STS, and CB critically reviewed the manuscript. CB supervised the project. All authors provided critical comments on drafts of the manuscript and approved the final manuscript.

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