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Preparedness and Capacity of Indian Palliative Care Services to Respond to the COVID-19 Pandemic: An Online Rapid Assessment Survey

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Abstract

Background: COVID-19 has been causing a high burden of suffering for patients and families. There is limited evidence on the preparedness of Indian palliative care services for the pandemic. **Aim:** This study aimed to assess the preparedness and capacity of Indian palliative care services in response to the COVID-19 pandemic. **Methods:** A cross-sectional online survey was developed based on prior evidence and international health regulations. It was emailed to the Indian Palliative Care Association members and investigators' professional networks in India. One participant per palliative care service was requested. Descriptive analysis was used. **Results:** Representatives of 78 palliative care services completed the survey. Three in four services had COVID-19 case definition and adapted their protocols for infection control (75%). About half of the services (55%) reported concerns about achieving appropriate hand hygiene in the community. More than half of the services (59%) had capacity to train nonspecialists for symptom control and psychological support. About half of the services reported that they had plans to redeploy staff (56%) and resources (53%) in the case of outbreaks. Two-fifths of the services used paper records to store an updated contact list of staff (40%) and did not have designated focal contacts for information update (40%). Staff anxiety related to personal infection risk and family care was relatively high (median score = 7 on a 1–10 scale). **Conclusion:** We recommend the following resource allocation to enable palliative care services to support the Indian health system in delivering essential care in this and future pandemics: (1) infection control, especially in the community; (2) training using existing clinical protocols to strengthen palliative care across the health system; and (3) redeployment plans.

Keywords: COVID-19, India, palliative care, pandemic, preparedness

Introduction

The symptoms and concerns reported by patients and families affected by COVID-19 include physical symptoms (e.g., breathlessness, cough, fever, and fatigue);[1-3] psychological symptoms associated with clinical uncertainty (e.g., fear and anxiety); and needs for spiritual, end-of-life, and bereavement care.[4]

Palliative care is an essential health service under the Universal Health Coverage, which improves outcomes for patients and families while saving costs.[5,6] World Health Assembly resolution 73.3 proposes palliative care as a core component to respond to the COVID-19 pandemic.[7] Evidence-based recommendations

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for the role of palliative care during a pandemic include patient symptom management, family bereavement care, and provision of training and support for clinical staff across the health system.[8] Palliative care also supports health services to conduct complex decision-making among patients with COVID-19 in resource-limited settings.[9,10] However, palliative care has been largely overlooked in public health emergencies such as COVID-19.[11,12] This is especially concerning in low- and middle-income countries.[13] For example, only half of the available African governments' COVID-19 case management guidelines include palliative care.[14]

Governments are required by the WHO 2005 International Health Regulations (IHR) to develop and test preparedness and response plans in the case of public health threats of international concern.[12] Despite the recognized importance of palliative care in public health or humanitarian crises response, the existing plans rarely include palliative care.[15]

As of December 10, 2020, 9,767,371 confirmed COVID-19 cases and 141,772 deaths were reported in India,[16] and COVID-19 continues to spread rapidly between states.[17,18] For example, in December 2020, Maharashtra state (central India) had the highest COVID-19-confirmed cases of 1,816,446 and 47,902 deaths. This state includes Mumbai, which is the largest city in India with more than 12 million citizens, and comprises the largest slum in Asia. However, Dadra and Nagar Haveli and Daman and Diu states (West India) had only 3352 confirmed COVID-19 cases with 2 deaths reported in the same month.[17] This pandemic has presented many challenges in India, including resource allocation, achieving optimal testing rates, population density, implementing infection control practices, and managing the health-care workforce.[19]

According to the 2015 Quality of Death Index report,[20] the capacity to provide palliative care in India is limited. Lockdown measures employed to minimize the COVID-19 transmission may have increased the palliative care needs of people with chronic and life-limiting illnesses.[21] Indian-specific guidelines are available for the supportive care and symptom management of severe COVID-19 cancer patients and their families.[22] However, preparedness and capacity within palliative care services to fulfill their essential role in the COVID-19 pandemic have not been assessed.

Our study aimed to assess the preparedness and capacity of Indian palliative care services to respond to the COVID-19 pandemic.

METHODS

Study design

We conducted a cross-sectional online survey using methodological guidance for such survey design and implementation.[23,24]

Sampling and settings

We used convenience sampling to recruit representatives of palliative care services. All members of the Indian Association for Palliative Care (IAPC) ($n = 1045$) working at 260 palliative care centers in India and of the professional network of the investigator (NS) ($n = 85$) were invited to participate by email, with a request for one response per palliative care service. Those expressing interest in participating received a survey link. Doctors, nurses, social workers, and administrators from palliative care services (including hospital, home, and hospice settings) in India were eligible to participate, as they were expected to have sufficient knowledge about the preparedness of their palliative care service to manage the COVID-19 pandemic.

Data collection tool and process

The survey questionnaire development is described elsewhere[25,26] and was developed using the IHR guidelines[12] and national and international studies on palliative care preparedness in rapidly spreading epidemics.[8,27] The survey was adapted to the Indian context by consulting local clinicians and academic experts and piloted from April 16 to 26, 2020, with 14 local palliative care providers. No necessary amendments were identified, and these responses were included into the final analysis. The questionnaire addresses: (1) description of the services (six items); (2) current COVID-19 situation in the service (seven items); (3) written procedures or guidance (four items); (4) measures in place to avoid contagion (twelve items); (5) communication and coordination (six items); (6) resources (nine items); (7) perceived effects on staff (five items); (8) perception of the risk (four items); and (9) preparedness to offer support (seven items). The majority of items were mandatory followed by open-text supplements (not mandatory). Response options were of multiple choice, multiple selection, 1–10 Likert scales, and open text. The full questionnaire is provided in Appendix 1.

The questionnaire was uploaded on the Google™ Form platform. Data collection was conducted online from April 16, to May 15, 2020. Reminders to complete the survey were sent out twice over this period.

Data management and analysis

Data were exported from the survey platform into an Excel spreadsheet and subsequently imported into statistical software IBM SPSS® (version. 26, Chicago, SPSS Inc.) for data analysis. We included all completed questionnaires for descriptive analyses. Categorical data were reported using frequency and percentage; continuous data were described by median and interquartile range (IQR). For open-ended responses, data were thematically coded.[28]

Ethics approval

This study was granted ethical approval by the Kasturba Medical College and Hospital's Ethical Committee (ref: KMC/KH IEC 286-2020). Data were collected and stored in India in line with the Indian data protection regulation.[29]

RESULTS

Participant characteristics

Of 1130 emails sent, we received 79 responses. All respondents completed the questionnaire (completion rate: 100%). We

included 78 responses in the analysis after excluding a single record from a service outside India.

The majority of respondents were medical practitioners ($n = 51$, 65%) from services primarily located in South and North India ($n = 29$, 37%, and $n = 24$, 31%, respectively) [Table 1]. The services provided care for a median of 1000 patients per year (IQR: 400–3000). Half of the services were hospital based ($n = 39$, 50%) and had beds (52%), with a median of 15 beds (IQR: 6–26). They were funded by either government ($n = 20$, 26%) or were a nonprofit charity ($n = 22$, 28%).

Current COVID-19 situation among services

Appendices 2 and 3 describe the COVID-19 situation within services. One-third of the respondents ($n = 24/78$, 31%) reported confirmed or suspected COVID-19 cases. Most of

these cases were among patients ($n = 17/24$, 71%) and had been identified by other medical divisions in the facility within which the participating palliative care service was located ($n = 18$, 75%) [Appendix 2]. Of the 24 services reporting cases, one-third were identified via telephone, email, or media communication between staff. For confirmed or suspected cases, most common actions were isolation of the cases (27%) and referral to COVID-specific facilities (24%). Social-distancing measures were put in place in almost half of the services following case identification (43%), including reduced care activities and quarantine [Appendix 3].

Perceived effect on staff and risk of infection

Table 2 presents perceived staff well-being and risk of infection. The respondents reported anxiety among staff, with respect to becoming infected with COVID-19 themselves (median: 7.5, IQR: 6–9), about caring for their children (median: 7, IQR: 5–8), and family care responsibilities (median: 7, IQR: 6–8). However, respondents reported only a moderate perceived risk of being infected by COVID-19 (median: 6; IQR: 4.25–8), or of the service closing (median: 6; IQR: 3–8) in the coming week.

Communication, coordination, and information systems

Table 3 presents the communication and coordination strategy to be used during the COVID-19 outbreak. The coding from open-text responses showed that those who were primarily informed about COVID-related issues were medical directors or superintendents ($n = 15$, 19%), frontline staff ($n = 14$, 18%), and/or facility managers or coordinators ($n = 13$, 17%). The triaging health-care staff ($n = 26$, 33%) or senior members of the services (e.g., heads of care team, senior officers, or service coordinators) ($n = 17$, 22%) were identified as those responsible for informing the service about confirmed or suspected COVID-19 patients.

Many services used 24/7 mobile hotline ($n = 59/78$, 76%) or WhatsApp ($n = 39/78$, 50%) to receive COVID-related information. More than half of the services did not have, or were unsure whether they had a designated focal point person for collecting and sharing up-to-date information ($n = 31$, 40%, and $n = 13$, 17%, respectively) [Table 3].

The vast majority of services had up-to-date lists of staff ($n = 69$, 88%) and patients ($n = 67$, 86%), but almost half reported challenges in keeping the records of relatives' visits ($n = 37$, 47%) and patients in the community ($n = 32$, 41%). Electronic records were used by half of the services to keep the contact list of staff and patients ($n = 37$, 47%, and $n = 33$, 42%, respectively). The majority of services ($\geq$83%) collected information regarding patients' symptoms, outcomes and treatment, and visits. This information system mostly relied on paper-based records. Around half of the services had limited information about relatives' visiting the services, with challenges in maintaining a list of contact details of relatives who visited the service ($n = 37$, 47%) or their visits' dates ($n = 39$, 50%) [Table 4].

More than two-thirds of the participants reported that they had an up-to-date inventory of personal protection equipment,

Table 1: Description of the 78 respondents

	n (%)
Region in India (categorized by states)	
South India	29 (37)
North India	24 (31)
West India	17 (22)
East India	8 (10)
Type of service categorized by funders	
Nonprofit charity	22 (28)
Public of governmental	20 (26)
Private	15 (19)
Mixed[a]	11 (14)
Missing	10 (13)
Type of service categorized by settings	
Hospital based[b]	39 (50)
Nonhospital based[c]	14 (18)
Missing	25 (32)
Services with beds	52 (67)
Respondent's current role (s)	
Doctor	51 (65)
Doctor and manager	12 (15)
Nurse	5 (6)
Social worker	5 (6)
Manager or responsible of the service	3 (4)
Other[d]	2 (3)

[a]Private and nonprofit charity (n=6); Public and nonprofit charity (n=4); Public, private, and nonprofit charity (n=1); Public and private (n=0), [b]Hospital based: Within hospital (n=19), within hospital and within community (n=3), within hospital and among inpatients (n=3), within hospital, within community, and among inpatients and outpatients (n=2), within hospital, within community, among inpatients and outpatients, home care (n=2), within hospital and among outpatients (n=2), within hospital and among inpatients and outpatients (n=2), within hospital, within community, and among outpatients (n=2), within hospital and within community and home care (n=2), within hospital, within hospital and home care (n=1), within community and among inpatients (n=1), [c]Nonhospital based: Within community (n=5), within community and among inpatients and outpatients (n=3), among inpatients and outpatients (n=2), within community and home care (n=1), within community and among outpatients (n=1), among outpatients and home care (n=1), among inpatients (n=1), [d]Other: Funder, chief executive officer, and counselor

Table 2: Perceived effects on staff and potential risks in the upcoming week (*n*=78)

	Median (IQR)*
Perceived effects on work staff	
Staff anxious about getting infected themselves	7.5 (6-9)
Staff anxious about the need to care for their own relatives	7 (6-8)
Staff anxious about the need to care for their children who may not be at school	7 (5-8)
Worried regarding potential issues for your interaction with the community if your service is known to manage a potential COVID-19 case	6 (4-8)
Perception of the risks in the coming week	
Staff are at risk of being infected by COVID-19	6 (4.25-8)
Service is at risk of closing because of an infection in the service	6 (3-8)

*On a scale from 1 (not at all) to 10 (extremely). IQR: Interquartile range

Table 3: Communication mechanisms in place to share information in case of COVID-19 cases (*n*=78)

	n (%)
Institutions or person who would inform the service*	
Health-care staff doing screening at the front line or exchanges on social media between staff	26 (33)
Head of care team, senior officer, or service coordinator	17 (22)
COVID-19 task team or department of infectious disease	9 (12)
Local district care team or health center	3 (4)
National Centre for Disease Control/National Hygiene Institute	3 (4)
Local authority, committee, or trustee	3 (4)
None reported	1 (1)
Missing	16 (21)
Person who would be informed in the service*	
Medical director/superintendent	15 (19)
Health-care staff/team members at the front line (e.g., physicians and nurses)	14 (18)
Hospital or facility management or health service coordinator	13 (17)
Head of nursing or palliative care, person in charge, or project manager	11 (14)
COVID-19 response team in the hospital or facility	9 (12)
Funder or trustee	2 (3)
None reported in the facility or hospital	1 (1)
Relatives	1 (1)
No information provided	12 (15)
Communication system (s) that will be used to receive information**	
Mobile phone available 24/7	59/78 (76)
WhatsApp	39/78 (50)
Telephone (in the service)	29/78 (37)
Email	26/78 (33)
Other[a]	3/78 (4)
Designated focal point person identified in the service responsible for collecting and sharing up-to-date information	
Yes	34 (44)
No	31 (40)
Unsure	13 (17)

*Data obtained from the analysis of open-text questions, **Multiple choices were possible, [a]Other: Memorandum (*n*=1); Telegram (*n*=2)

medication, and other supplies for patient care (*n* = 56, 72%, and *n* = 64, 82%, respectively).

Infection control measures in place and relevant guidance
The majority of services had a case definition for COVID-19 cases (*n* = 57, 73%) and a written procedure in the event of a positive case among patients (*n* = 61, 78%), relatives and visitors (*n* = 54, 69%), health-care staff (*n* = 61, 78%), and other staff (*n* = 57, 73%). Fewer (*n* = 34, 44%) reported that they had a written procedure for volunteers. Palliative care services had mostly adapted the existing policies or guidance to prevent or contain infection and provide bereavement care for relatives during the pandemic. Around half of the services adapted their policies and guidance both spontaneously in services and following the government instructions. Almost three-quarters of the services involved cleaning staff in COVID-related information sharing and training [Table 5]. Half of the services had a written procedure to manage staff's COVID-related stress (*n* = 40, 51%).

Table 4: Information systems available (*n*=78)

	Paper-based registry only, *n* (%)	Electronic record only, *n* (%)	Paper and electronic record, *n* (%)	None, *n* (%)	Other*, *n* (%)
Up-to-date contact list of					
All staff working in or for the service	32 (41)	26 (33)	11 (14)	7 (9)	2 (3)
All patients that attended or have attended the hospice or service	34 (44)	22 (28)	11 (14)	10 (13)	1 (1)
All relatives that visited or have visited the service	26 (33)	10 (13)	2 (3)	37 (47)	3 (4)
Patients visited in the community	19 (24)	12 (15)	4 (5)	32 (41)	11 (14)
System collecting information about					
Patients' symptoms	47 (60)	15 (19)	11 (14)	4 (5)	1 (1)
Patients' outcomes	42 (54)	17 (22)	8 (10)	10 (13)	1 (1)
Treatment given	41 (53)	20 (27)	11 (14)	5 (6)	1 (1)
Dates of patients' visits or stay	35 (45)	20 (26)	13 (17)	9 (12)	1 (1)
Dates of relatives' visits	22 (28)	11 (14)	4 (5)	39 (50)	2 (3)

*Other: Without further comments or detail/explanation

Table 5: Written procedures, policies, and recommendations in place (*n*=78)

	Yes, *n* (%)	No, *n* (%)	Unsure/don't know, *n* (%)
Case definition for confirmed, probable, and suspected COVID-19 cases	57 (73)	10 (13)	11 (14)
A written procedure for "what to do" in the case of COVID-19 case among the following			
Patients	61 (78)	16 (21)	1 (1)
Relatives and visitors	54 (69)	19 (24)	5 (6)
Health-care professionals	61 (78)	15 (19)	2 (3)
Volunteers	34 (44)	32 (41)	12 (15)
Other staff	57 (73)	15 (19)	6 (8)
Policies or procedures modified as a measure to avoid contagion			
Policy for visitors/relatives (number of visitors, hours, etc.)	65 (83)	10 (13)	3 (4)
Policy for operator protection PPE	66 (85)	10 (13)	2 (3)
Policy for patients' admission	47 (60)	24 (31)	7 (9)
Volunteer support policy	38 (49)	27 (35)	13 (17)
Policy regarding care of the relatives after the patient's death	40 (51)	28 (36)	10 (13)
If yes to any above, the modifications were made (*n*=68)			
Following the government instructions	18 (26)	-	-
Spontaneously	12 (18)	-	-
Both	37 (54)	-	-
Missing	1 (1)		
Recommendations/guidance if you or someone in your household becomes ill with COVID-19 symptoms	61 (78)	12 (15)	5 (6)
If yes to above, were the recommendations made (*n*=61)			
Following the government instructions	24 (39)	-	-
Spontaneously	8 (13)	-	-
Both	27 (44)	-	-
Missing	2 (3)	-	-
Cleaning staff included in information sharing and training regarding managing COVID-19	56 (72)	7 (9)	15 (19)
A written procedure to manage staff COVID-related stress	40 (51)	28 (36)	10 (13)

PPE: Personal protective equipment

Resources available and preparation for offering support

About one-third of the respondents expressed concerns regarding accessing infection control resources including disinfectant products (*n* = 25, 32%), hand sanitizers (*n* = 23, 29%), soap (*n* = 21, 27%), running water (*n* = 18, 23%), and electricity (*n* = 17, 22%). Their levels of concern were higher for access to infection control in the surrounding community [Table 6].

About one in five respondents reported that they did not have access to personal protective equipment (PPE) for use by palliative care (*n* = 13, 17%) or other staff (*n* = 16, 21%). More than 65% (*n* = 52) of the services could identify

isolation rooms for infection control. The majority (*n* = 65, 83%) reported that they knew how to safely dispose of highly infectious waste within palliative care facilities, but fewer people reported knowing how to do this in the community (*n* = 47, 60%) [Table 7].

Three in five services had palliative care protocols for symptom control and psychological support that could be shared with nonspecialists during the pandemic (*n* = 46, 59%). Of these, the vast majority (*n* = 39, 85%) reported that they had the capacity to train nonspecialists in using these protocols. Barriers to share their palliative care expertise were described by 23 respondents. The main barriers were logistic, such as funding constraints on delivery of their training, lack of trained personnel, and limited infrastructure resources (e.g., access to the Internet) [Appendix 4]. More than half of the services had redeployment strategies in place for staff (*n* = 44, 56%) or resources (*n* = 41, 53%) in the case of an outbreak [Appendix 5]. This proportion was lower for the redeployment of volunteers (*n* = 28, 36%). Two-thirds were aware of a plan to support palliative care patient triage in other health-care settings (*n* = 56, 72%).

DISCUSSION

In line with the recommendations on the response and role of palliative care services in pandemics,[8] Indian palliative care services have a number of core activities prepared to respond to the COVID-19 pandemic. This include adapted protocols or guidance to protect and care for staff (e.g., providing additional PPE), patients (e.g., symptom management), and relatives (e.g., bereavement care) during the pandemic. Serious concerns over the lack of essential resources for infection control in

the community were reported, which should be addressed in the preparedness plans. A communication and coordination system would help strengthen preparedness and response to an outbreak. This could include identification of a focal reporting person, communication pathway, and an up-to-date contact list of visitors and patients in the community. The majority of services had the capacity to support the broader health system by having plans for resource deployment and supporting triage of COVID-19 patients. Although the services perceived having capacity to train nonspecialists in palliative care, the sharing of expertise was sometimes impeded by logistic challenges.

The respondents reported a moderate level of psychological distress related to family care and self-care during the pandemic among staff, slightly lower but comparable to the surveys in Italian,[27] African,[25] and the Middle-East settings.[26] However, only half of the services had stress management procedures, which may impact the capacity to respond to a recurrence and continue providing care efficiently. With respect to palliative care staff's well-being, it should also be noted that the pandemic has been associated with excess non-COVID deaths.[30] Therefore, the additional workload and the associated stress may affect palliative care staff. It is thus vital to provide extra support and protection specifically to the people working clinically with COVID-19 patients.[4,31] Limited contact information about relatives and other visitors identified in this survey may also create anxiety and hamper infection control measures.

The Indian policy of national lockdown and quarantine measures may have increased the need for community-based palliative care due to travel restrictions and fewer hospital admissions.[19] However, this restriction requires investment in

Table 6: Concerns about access to resources necessary for infection control in the service or surrounding community (*n*=78)

	Facility		Surrounding community	
	Yes, *n* (%)	No, *n* (%)	Yes, *n* (%)	No, *n* (%)
Disinfectant products to continue providing care safely	25 (32)	53 (68)	46 (59)	32 (41)
Hand sanitizers (with 60% alcohol)	23 (29)	55 (71)	49 (63)	29 (37)
Soap	21 (27)	57 (73)	35 (45)	43 (55)
Running water	18 (23)	60 (77)	35 (45)	43 (55)
Electricity	17 (22)	61 (78)	33 (42)	45 (58)

Table 7: Personal protection measures available for staff working in the palliative care services (*n*=78)

	Yes, we have additional ones, *n* (%)	Not more than usual, *n* (%)	No, we do not have PPE, *n* (%)
PPE for palliative care staff	43 (55)	22 (28)	13 (17)
PPE for other staff	38 (49)	24 (31)	16 (21)
Hand-washing facility for all at points of entry	45 (58)	23 (29)	10 (13)
	Yes, *n* (%)	No, *n* (%)	N/A, *n* (%)
Isolation room identified in the case of infectious conditions like COVID-19	52 (67)	9 (12)	17 (22)
Knowledge of disposal of highly infectious waste in palliative care facilities	65 (83)	6 (8)	7 (9)
Knowledge of disposal of highly infectious waste in community	47 (60)	20 (26)	11 (14)

*Data obtained from the analysis of open-text questions and one respondent might have multiple answers. PPE: Personal protective equipment, N/A: Not available

adequate provision of water, sanitation, and infectious waste disposal in the community.

To the best of our knowledge, this is the first study to investigate the preparedness of palliative care services to respond to the COVID-19 pandemic in India. We used online survey method guidance to design and report the survey, which was developed from prior published similar research adapted to the Indian context. The number of participants' responses is reasonable given the time commitment for participation by services who are likely under additional pressures during COVID-19 pandemic. Despite this limitation, the data provide important information to guide further study and service planning. The use of mandatory questions for the majority of the questionnaire resulted in a 100% completion rate (although this may also have reduced response rate). However, the nature of the sampling available to the researchers meant that we could only contact individual IAPC members and not palliative care services. Therefore, some services may be represented more than once despite our data-cleaning and management procedures to de-duplicate. The web-based data collection method may have biased the sample toward those with a reliable internet connection.

Recommendations

We recommend the following for Indian palliative care services to prepare for the current and future public health emergencies: (1) improve access to essential resources including water, soap, and PPE for infection control in the community; (2) provide training using the existing clinical protocols to strengthen palliative care across the health system; (3) develop deployment plans (e.g., infection control resource deployment, staff stress management, and logistic support) to widen access to palliative care.

Conclusion

This study provides important data and insights into the preparedness and capacity of Indian palliative care services to respond to COVID-19 that can inform the preparedness and response to the current and future public health emergencies. Palliative care should be sustainably integrated into the wider health-care system to reach Universal Health Coverage and to support India's preparedness plans for palliative care provision.[11,15,32]

Conflicts of interest
There are no conflicts of interest.

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Appendix 1. Survey questionnaire

* mandatory items

Section 1: Information sheet and informed consent*

Section 2: Demographics of your service:

● Where is your service located (Mention the name of the city and state)?*

● The approximate number of patients seen per year*

● Type of hospice and/or service (tick all that applies):*

☐ Private ☐ Non-profit charity ☐ Government or public

☐ Within a hospital ☐ Within community

☐ Inpatient hospice ☐ Outpatient hospice ☐ Other, please specify….

● Do you have inpatient beds (applies both to hospital-based and hospice-based palliative care services) * ☐ Yes ☐ No

<u>IF YES</u>, Number of inpatient beds: _ _

● What is your current role (tick all that applies):*

☐ Doctor or medical officer

☐ Nurse

☐ Social worker

☐ Manager or administer

☐ Other _____

Section 3: Current COVID-19 situation in your service

● Did you have any suspected or confirmed cases of COVID-19 in your palliative care service or the hospital that your palliative care service is based?*

☐ yes, confirmed cases ☐ yes, suspect cases ☐ no (if no, continue to Section 4)

IF YES:

- **Who was positive (tick all that applies)?**

☐ patients

☐ family

☐ nurses

☐ doctors

☐ volunteers

☐ other staff

☐ others (specify) ….

- **If yes, where were the cases identified?**

☐ your palliative care service ☐ hospital that your palliative care is based

- **If yes, how many cases do you have (specify numbers for suspected, probable, confirmed)? …..**
- **How were they identified** (e.g. who informed you, which communication means (phone, email, etc.)? .....
- **What was done** (e.g. reporting, referral, containment measures, protection of and communication with staff and users, etc.)? .....
- **What were the consequences** (e.g. for your service, yourself, your interaction with the community, etc.)? .....

Section 4: Written response procedures (or Guidance)

● Do you have a case definition for confirmed, probable and suspected COVID-19 cases?*

☐ yes   ☐ no   ☐ don't know/Not sure

● Do you have a written procedure for "what to do" if you have a confirmed, robable and/or suspected COVID-19 case in your service among:*

	Procedure specific to COVID-19		
patients	☐ yes	☐ no	☐ don't know
relatives and visitors	☐ yes	☐ no	☐ don't know
healthcare professionals	☐ yes	☐ no	☐ don't know
volunteers	☐ yes	☐ no	☐ don't know
Other staff	☐ yes	☐ no	☐ don't know
Other please specify	☐ yes	☐ no	☐ don't know

● Do you have a procedure to support healthcare providers to manage stress associated with the presence of/exposure to COVID-19 patients?*

☐ yes   ☐ no   ☐ don't know

● Any comment or additional thoughts on policies and protocols for COVID-19 patients in your service…

Section 5: Measures in place to avoid contagion

● Did you modify any of the following policies or procedures as a measure to avoid contagion?*

1 Policy for visitors / relatives (number of visitors, hours etc.)	☐ yes	☐ no	☐ not sure
2 Policy for operator protection (Personal Protective	☐ yes	☐ no	☐ not sure

Equipment)			
3 Policy for patients' admission to the hospice	☐ yes	☐ no	☐ not sure
4 Volunteer support policy	☐ yes	☐ no	☐ not sure
5 Policy regarding care of the relatives after the patient's death	☐ yes	☐ no	☐ not sure
6 Other policy modified, please specify	.....		

- If you answered yes to any of the above: Did you change the policies following the instructions from health management or regional authorities, or did your hospice take them spontaneously?

☐ following the instructions   ☐ spontaneously   ☐ both

- Personal Protection Equipment (PPE) for:*

-palliative care staff: ☐ Yes, we put additional ones ☐ Not more than usual ☐ No, we do not have PPE

-other staff: ☐ Yes, we put additional ones ☐ Not more than usual ☐ No, we do not have PPE

Please specify which PPE are available ....

- Do you have in place any of the following measures to protect staff and patients: Hand washing facility for all at points of entry (soap and running water or hand sanitizers with 60% alcohol)*

☐ Yes, we put additional ones ☐ We already had them in place before COVID-19   ☐ No, we do not have such facility

- Isolation room identified in case of infectious conditions, like COVID-19:*

☐ Yes   ☐ No   ☐ NA (outpatient service only)

- Do you have guidance or protocol if you or someone in your household becomes ill with COVID-19 symptoms*

☐ Yes   ☐ No   ☐ Don't know

If YES, Please specify…..

- IF YOU ANSWERED YES TO ANY OF THE ABOVE: Did you change the policies following the instructions from health management or regional authorities, or did your palliative care service initiate them spontaneously?

☐ following the instructions   ☐ spontaneously   ☐ both

- Have all healthcare providers been trained in handling highly infectious conditions such as COVID-19?*

☐ Yes, trained before COVID-19 pandemic ☐ Yes, trained because of COVID-19 pandemic ☐ No, not trained

- Do you know how to dispose of highly infectious waste?*

- in the palliative care service ☐ Yes ☐ No ☐ N/A

- in the community ☐ Yes ☐ No ☐ N/A

- Was the cleaning staff included in information sharing and training regarding managing COVID-19?*

☐ Yes ☐ No ☐ Dont know/Not sure

Section 6: Communication and coordination

- How would you be informed if there is a confirmed or suspected case in your palliative care service?*

- Who will advise you? Who will be notified (position or job title)?*

- What communication system will be used for notification? (Tick all that applies)*

☐ Mobile phone available 24/7
☐ Telephone (in the service)
☐ Email
☐ WhatsApp
☐ Other.....

- Is there a focal point person identified in the palliative care service for collecting and sharing up-to-date information (about health recommendations, cases, protocols to use):*

☐ Yes ☐ No ☐ Not sure

- What communication means are in place to share COVID-19 or other urgent information with the below mentioned persons (Tick all that applies):*

☐ Text messages
☐ WhatsApp
☐ Phone call
☐ Email
☐ Other.....

- Do you have an up-to-date contact list of:*

- all staff working in or for the hospice or service (medical, administrative, cleaning staff, etc.?	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…

- all patients that attended or have attended the hospice or service	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…
- all relatives that visited or have visited the hospice or service	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…
- patients visited in the community	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…

● Do you have a system for collecting information about the below mentioned details:*

- Patients' symptoms	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…
- Patients' outcomes	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…
- Treatment given	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…
- Dates of patients' visits or stay	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…
- Dates of relatives' visits	☐ Yes, a paper-based registry ☐ Yes, an electronic record ☐ No ☐ Other…

Section 7: Resources

● Do you have concerns about access to*

	in your palliative care service?		in the surrounding community?	
running water	☐ yes	☐ no	☐ yes	☐ no
soap	☐ yes	☐ no	☐ yes	☐ no
hand sanitizers (with 60% alcohol)	☐ yes	☐ no	☐ yes	☐ no
electricity	☐ yes	☐ no	☐ yes	☐ no
accessing disinfectant products to continue providing care safely	☐ yes	☐ no	☐ yes	☐ no
Other, please specify…	☐ yes	☐ no	☐ yes	☐ no

● Do you have adequate material and facilities to dispose of highly infectious waste?*

- in the hospice (or service) ☐ yes   ☐ no   ☐ don't know/not sure
- in the community   ☐ yes   ☐ no   ☐ don't know/not sure

● Do you have an up-to-date inventory of:*

- protection material available for staff, patient and visitors (hygiene and sanitation materials, protection material like masks, etc.)

☐ yes   ☐ no   ☐ not sure

- medicines and other medical supplies available to care for the patients?

☐ yes   ☐ no   ☐ not sure

● Do you have the capacity to use technology instead of face-to-face appointment to provide some care remotely?

☐ phone call   ☐ video call   ☐ other

IF YES, please specify:
- which service can be provided remotely (e.g. psychological support, spiritual care, grief and bereavement, managing the end of life phase, etc.):

IF NOT, please specify:
- what are your limitations to use technology?

  ....

- what would facilitate your use of technology?

  ....

● In case of emergency, lockdown or quarantine, do you know how your palliative care service would have access to (e.g. Local/national authorities' stocks, private supplier, transportation, etc.):*

- food (for inpatient services only)   ☐ yes   ☐ no
- medicines and other medical supply   ☐ yes   ☐ no
- additional staff (e.g. if staff self-isolates or becomes ill)   ☐ yes   ☐ no

● Do you have education material about COVID-19 available?*

☐ Are there posters displayed where staff, patients and visitors can see them?
☐ Are they also available for the surrounding community?

Section 8: Effect on staff

- Do you observe that some staff suddenly did not come to work without justification?* ☐ yes   ☐ no   ☐ not sure
- In your opinion, how anxious are your staff about the need to care for their children who may not be at school?* From 1 to 10 (1 – not at all anxious; 10-extremely anxious)
- In your opinion, how anxious are your staff about the need to care for their own relatives?* From 1 to 10 (1 – not at all anxious; 10-extremely anxious)
- In your opinion, how anxious are your staff about getting infected themselves?* From 1 to 10 (1 – not at all anxious; 10-extremely anxious)
- How worried are you regarding potential issues for your interaction with the community if your hospice or service is known to manage a potential COVID-19 case?* From 1 to 10 (1 – not at all anxious/worried; 10-extremely anxious/worried)

Section 9: Perception of the risk

In the coming week ….

- How much do you think hospice/palliative care staff are at risk of being infected by COVID-19?* From 0-10 (0 no risk - 10 maximum risk you can imagine)
- How much do you think the hospice/palliative care service is at risk of closing because of an infection in the hospice or service?* From 0-10 (0 no risk - 10 maximum risk you can imagine)
- Do you have any security concerns for yourself or your staff?* ☐ yes   ☐ no
  IF YES, please specify…

Section 10: Preparing to offer support

- Do you have palliative care protocols for symptom management and psychological support that could be shared with non-specialist staff and/or COVID-19 response teams in other healthcare facilities:* ☐ yes   ☐ no
- IF YES, do you have the capacity to train non-specialist in using these protocols:
  : ☐ yes   ☐ no

  Optional: what are your limitations to share your expertise?   ....

  Optional: what could facilitate you sharing your expertise?   ....

- In case of outbreak COVID-19 or another highly infectious disease, do you have plans to redeploy the following in outside of the inpatient wards: staff and resources outside of the inpatient settings?*

Healthcare providers	☐ yes	☐ no	☐ don't know
Volunteers	☐ yes	☐ no	☐ don't know
Resources (material and supplies)	☐ yes	☐ no	☐ don't know

- Do you have plans to support other healthcare services in the triage of patients in case of COVID-19 outbreak?*   ☐   Yes ☐   No
- Additional comments: Do you think there are relevant information we have omitted to ask you?
- What are your biggest worries or concerns?

*Appendix 2. Description of the COVID-19 situation for palliative care services reporting suspected, probable or confirmed cases (n=24)

	n	%
Type of cases reported:*		
Confirmed	17	71
Suspected	7	29
Probable	0	0
Cases reported among*		
Patient	7	29
Patient, Nurse and Other staff	3	13
Patient and Relative	2	8
Patient and Nurse	2	8
Relative	1	4
Nurse	1	4
Physician	1	4
Patient, Physician, Nurse and Other staff	1	4
Patient, Relative, Physician and Nurse	1	4
Patient, Relative, Physician and Other staff	1	4
Other staff	1	4
Missing	3	13
Location of the cases identified:		
Another care services/divisions in the hospital where the palliative care is located	18	75
In the palliative care service	2	8
Missing (not specified)	4	17

* Multiple selection was allowed

Appendix 3. Ways of cases identification, actions done and consequences* (n=24)

	n	%
Ways of cases identification	**24**	
Telephone, email or social media communication between staff	8	*33*
Staff communication within or between services/local authorities	6	25
Clinical features of suspect cases	6	25
Test result of the suspect cases	2	8
Self-referral to services for testing	1	4
Regular outpatient clinic visits and assessment	1	4
Actions done	**55**	
Isolating the confirmed cases and quarantining the suspected cases	15	27
Referring the cases to COVID-specific facilities/services for testing or treatment	13	24
Reporting to relevant local authorities, head of department of managers	9	16
Staff wore PPE while providing care	6	11
Communicating with staff and users	4	7
Testing again the suspect cases to confirm	3	5
Contact tracing	3	5
Triage the suspect cases for testing, treatment or isolation	1	2
Referring dying patient to palliative care team	1	2
Consequences	**23**	
Restricted and reduced care activities, quarantine and social distancing measure in place	10	43
No specific consequences	3	13
Staff were alert due to worries regarding infection of staff and patients	2	9
Staff psychological distress (e.g. scared, worried, and retreated interaction)	2	9
Test results found negative	2	9
Suspected cases refused referral and went home for quarantine	1	4
Cases were cured	1	4
The services continue to offer care to patients and family members	1	4
Developing protocol to prepare for the future	1	4

This was an optional question. Data were obtained from the analysis of open text questions and one respondent might have multiple answers

Appendix 4. Protocols for symptom management and psychological support and capacity to train non-specialist staff and/or COVID-19 response teams in other healthcare facilities and the barriers (n=78)

	Yes n (%)	No n (%)	Missing n (%)
Protocol for symptom management and psychological support	46 (59)	32(41)	0 (0)
If yes, capacity to offer training for others (n=46)	39(85)	6(13)	1 (2)
Barriers to share expertise (n=23)*			**n**
Logistic: lack of funding, protocol, training, staff and resources			10
Not feasible for inadequate service provision			3
Busy clinical routine schedule			3
Refused by the trainee due to trainers' COVID-19 caring responsibilities			2
Staff motivation and willingness to learn			1
Hierarchy in the facilities			1
Lockdown regulation due to COVID-19			1
Lack of awareness			1
Rapidly changed COVID-19 related regulation			1

* Data obtained from the analysis of open text questions

Appendix 5 Plans to redeploy the resources and support other services in triage of palliative care patients for future infectious disease (n=78)

	Yes n(%)	No n(%)	Don't know n(%)
Plan for resources redeployment			
Healthcare providers	44 (56)	10 (13)	24 (31)
Resources (material and supplies)	41 (53)	13 (17)	24 (31)
Volunteers	28 (36)	16 (21)	34 (44)
Plan to support other services in triage of palliative care patients	56 (72)	22(28)	-