COVID-19 and palliative medicine: faith-based hospitals in India

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The impact of COVID-19 on Palliative Care services in faith based hospitals in India

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JJS, DM, SD, PJ, RAP, RP, AS, KB, LG and SM were involved in the initial planning and design of the study. JJS, RAP, PJ, SD and AS were involved in the conduct of the study. JJS, DM, SM were involved in the initial draft of the manuscript. SD, PJ, RAP, AS, KB and LG reviewed the manuscript and provided valuable input in the finalization of the manuscript. JJS is responsible for the overall content and will act as the guarantor.

Abstract

Objectives

Faith Based Organisations (FBO) in India provide health services particularly to marginalised communities. We studied their preparedness and delivery of palliative care during COVID-19 as part of a mixed-method study. We present the results of an online questionnaire.

Methods

All FBOs providing palliative care in India were invited to complete an online questionnaire. Descriptive analysis was undertaken.

Results

Response rate was 46/64(72%); 44 provided palliative care; 30/44(68%) were in rural or semi-urban areas with 10-2700 beds. Fifty-two percent (23/44) had dedicated palliative care teams and 30/44(68%) provided it as part of general services;17/44(39%) provided both. 29/44(66%) provided palliative care for cancer patients;17/44(34%) reported that this was more than half their workload.

The pandemic led to reduced clinical work: hospital 36/44(82%) and community 40/44(91%); with reduction in hospital income for 41/44(93%). 18/44(44%) were designated government COVID-19 centres; 11/40(32%) had admitted between one-2230 COVID-19 patients.

COVID-19 brought challenges: 14/44(32%) lacked PPE; 21/44(48%) had reduced hospital supplies and 19/44(43%) lacked key medications including morphine. 29/44(66%) reported reduction in palliative care work; 7/44(16%) had stopped altogether. Twenty-three percent (10/44) reported redeployment of palliative care teams to other work. For those providing, palliative care32/37(86%) was principally for non-COVID patients; 13/37(35%) cared for COVID-19 patients. Service adaptations included: tele-consultation, triaged home-visits, medication delivery at home and food supply.

Conclusions

FBOs in India providing palliative care had continued to do so despite multiple challenges. Services were adapted to enable ongoing patient care. Further research is exploring the effects of COVID-19 in greater depth.

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Introduction

India, with a population of 1.2 billion, had 10 million confirmed COVID-19 cases by 20th December 2020, although this is likely to be a significant underestimate(1). As the pandemic escalated in its cities, India declared a lockdown on 25th March 2020(2). High numbers of migrant and daily wage earners without employment returned to their home villages, disseminating SARS-COV-2 to rural areas where 69% of Indians live(3). Official statistics suggest the first wave of the pandemic peaked in late September 2020 and in March 2021 is seeing a second surge (4). Few studies of the impact of COVID-19 in rural India have been published.(5, 6)

Palliative care is an important component of COVID-19 management in India, with a position statement by the Indian Association for Palliative Care(7), a manual of palliative care management for patients with COVID-19, and ongoing interactive training being delivered online(8).

Faith Based Organisations (FBO) are characterized as having at least one of these traits, an affiliation with a religious body, a mission statement, a value base explicitly referencing religious or spiritual beliefs, a decision making, or governance process determined by a religious or spiritual community, or shared belief system.(9) In many countries FBO health facilities and hospitals frequently operate in rural areas, typically serving the poor and marginalised.(10) Many have established palliative care services using a public health approach.(11) Internationally FBOs have been important contributors to pandemic responses including during the 2015 Ebola epidemic.(12) Surveying FBO services can identify key challenges of providing palliative care for marginalised groups during COVID-19 and enable emerging solutions to be explored and shared. We identified hospitals providing palliative care services under two large Christian FBOs in India for the survey.

A collaborative of Indian and UK researchers and clinicians are undertaking a phased, mixed methods survey of palliative care provision. We report the first phase, an online questionnaire survey of Indian FBOs providing palliative care.

Method

Regular Zoom conferencing of the research team members from April 2020 enabled emerging issues to be discussed and important research questions were defined: How did FBO hospitals support palliative care delivery during the lockdown and subsequent course of the COVID-19 pandemic? What were the effects of the lockdown and pandemic on patients with palliative care needs? Were FBOs and their palliative care teams prepared for responding to the COVID-19 crisis? What was the impact of COVID-19 on good practice palliative care interventions? The mixed method design includes: an online questionnaire survey, key informant interviews with purposively sampled hospital palliative care team leaders and a survey of patients and relatives in selected sites.

The survey questionnaire attempted to gather information about the hospital, palliative care services, impact of COVID-19 on the hospital (services, supplies and finances), COVID-19 care provision and impact of COVID-19 on palliative care services and patients, challenges, adaptations and responses to care for the needs of patients and families.

The research questions, questionnaire and interview topic guide were reviewed by an advisory group of clinicians working in five Indian FBOs and suggestions incorporated. The final draft of the questionnaire was piloted by the advisory group. Institutional Review Board approval from Christian Medical College, Vellore and ethics committee approval from Emmanuel Hospitals Association (EHA) were obtained. An invitation with information sheet on completing the questionnaire (Google Forms) was sent to all FBO hospitals offering palliative care on databases held by EHA and the Christian Medical Association of India in September 2020. The results were downloaded, anonymised and descriptive statistical analysis was undertaken using SPSSv25.

Results

Of 64 FBO hospitals invited to participate, 46(72%) completed the questionnaire. Two hospitals not offering palliative care were excluded from further analysis. The 44 hospitals were spread across 15/29 Indian states representing different geographical regions of India (Table 1). Thirty of the 44 hospitals (68%) were in rural or semi-urban areas and 13(30%) in urban areas. They ranged in size from 10 to 2700 beds (median 100). Forty-two (95%) offered general medical services, 33(75%) general surgery and 32(73%) obstetrics and gynaecology and community medicine. Other services included: tuberculosis (66%), paediatrics (61%), HIV (50%), ENT (30%), dental (25%), oncology (18%) and ophthalmology (11%).

Twenty-three (52%) had dedicated palliative care teams and 30(68%) provided palliative care as part of general services with 17(39%) providing both; three did not specify. Although many palliative care teams were small and comprised one or two doctors and a small number of nurses, multidisciplinary working was in evidence with more than half having social workers and a substantial number with physiotherapists, counsellors and psychologists (Table 1). Whilst 29(66%) provided palliative care to people with cancer, only 15(34%) reported that this made up 50% or more of their palliative care work. Most provided palliative care to patients with non-communicable diseases (Table-1).

The lockdown led to a substantial reduction in general non-COVID-19 clinical work for 36(82%) and for 40(91%) it had reduced their community work. Even after easing of lockdown 34(77%) reported a continuing reduction in non-COVID-19 work, leading to a reduction in hospital income for 41(93%).

Thirty (68%) reported that they had adequate personal protective equipment (PPE).The rest did not have adequate PPE or were worried that they would not have sufficient supplies. Twenty-one (48%) reported that hospital supplies had been reduced during the pandemic with 19(43%) reporting that key medication supplies (including morphine) had been affected.

Eighteen (40%) hospitals were designated COVID-19 centres by the government (registered to admit patients or to provide testing). Eleven (32%) were already admitting COVID-19 patients and five were planning to admit them; 15(34%) were not and 13(30%) were undecided. The eleven already admitting patients had admitted between one and 2230 with between zero and 150 COVID-related deaths.

Twenty-nine (66%) reported that palliative care work had been reduced and in 7(16%) it had stopped altogether during the pandemic. Only one said that palliative care work had increased. Ten (23%) reported the palliative care team had been redeployed to support general COVID-19 related care. Of the 37(84%) still providing palliative care, 32/37(86%) reported that their principal palliative care work was with non-COVID-19 patients. Thirteen (35%) reported that the palliative care team cared for COVID-19 patients; for three this was their principal work. Only 2/13 with dedicated palliative care beds admitted COVID-19 patients to these. Nineteen of the 44 hospitals (43%) reported that patients had still been able to get active treatment for their underlying condition (e.g. chemotherapy for cancer patients),

16(36%) said that patients had not received usual treatment and 9(20%) were unsure or did not specify.

We asked the participants to provide examples of how they had adapted their palliative care service during the pandemic. Many had changed to telephone consultations for follow-up rather than seeing patients face to face, and avoiding out-patient visits if possible to prevent putting patients or staff at risk. Home visits would be triaged, making phone calls if possible before going to see patients. When they did visits in the community, they used PPE for protection.

Patients finding difficulty accessing the hospital meant that palliative care teams sometimes delivered medication to patients' homes and gave a longer supply than normal to ensure continuous availability. Some reported using their inpatient beds more frequently in this period because patients were not coping at home. Others in addition to clinical services provided food for patients and families who were in need.

Discussion

FBOs are recognized as important actors in delivering and sustaining community development, especially in the broader health sector. FBOs in India together with the WHO, UNICEF stepped up in the fight against the COVID-19 pandemic, to engage with communities under the guidance of the state government, and promote safety measures, advocate the well-being of the population at-risk and sensitize the communities against discrimination of health workers and those infected with COVID-19. (13)

While this survey wasn't comprehensive, the range of hospitals participating provides and illustrative picture of the need and supply of palliative care provision in India. Included were hospitals under the auspices of two of the largest FBOs in India (CMAI and EHA) and hospitals run by local FBOs from different geographical regions in India, small to large sized with different models of palliative care provision in different settings. The majority of hospitals were situated in rural or semi-urban areas, matching the Indian population distribution.

Though evidence points to a marked global disparity of palliative care access for cancer patients in rural and remote areas, most of the participating hospitals provided palliative care for cancer patients. The study also showed that palliative care was offered for a wide range of non-communicable diseases (NCDs) by FBOs in addition to cancer and this is significant

as recent studies point to deaths due to NCDs in India increasing whilst cancer makes up only 9%.(11)

During the pandemic lockdown period, palliative care and other hospital services had to reduce activity and a minority suspended some services altogether. Most FBOs charge for their services even if nominally,(10) apart from palliative care which is provided free of charge or at subsidised cost in some hospitals.(11) Any reduction in clinical work leads to reduced income and difficulties maintaining service provision. Community teams were restricted in their ability to work, reducing patient care. Hospitals also faced a lack of supplies, particularly medication, including morphine.

While some hospitals provided palliative care for patients with COVID-19, the majority continued to care for non-COVID patients. In some hospitals palliative care provision was reduced as staff were redeployed to other duties, out of necessity, though this may also suggest that providing palliative care for patients with COVID-19 was not yet seen as a priority. As with other palliative care services, changes in response to the pandemic included more telephone consultations,(14) in line with guidelines provided by the Indian Government.(15) Home visits were reduced with prior telephone assessments for triage. Some palliative care teams delivered medicines and were providing food for patients and families as a necessary extension to their normal services.

As far as we are aware, this is the first study of FBO palliative care response in India during the COVID-19 pandemic. A global survey of FBOs (n=52) to identify their response to the COVID-19 pandemic by the Christian Connections for International Health and the Joint Learning Initiative on Faith and Local Communities in April 2020 identified how the majority of FBOs were responding, coordinating, and modifying programs to respond to the COVID-19 pandemic, through community-based education, prevention and public health promotion.(16) During this pandemic FBOs and NGOs have been seen as highly committed and versatile, with their simple structures, operating at local level, being best placed to provide health services to people living in impoverished conditions, especially in rural settings. They have also been at the forefront of providing basic care and financial support to the most poor.(17)

A questionnaire can only provide limited insights into the functioning of palliative care teams and the effect of COVID-19. Ongoing key informant and patient/relative interviews are

exploring the challenges of the pandemic for patients and clinicians in more depth, including the psychological impacts on teams of working through the pandemic.

Conclusion

Most FBO Hospitals have continued providing palliative care despite the considerable challenges of the pandemic, expanding their services to include other humanitarian activities. Further research is needed to allow a fuller understanding of the challenges and solutions to providing palliative care for people in marginalised communities in India and other low and middle income countries as the pandemic progresses.

Table-1: Characteristics of Hospital and Palliative Care Service

Geographical distribution of hospitals across India

North	*North East*	*East*	*South*	*West*
Delhi 1	Assam 1	West Bengal 1	Andhra Pradesh 6	Gujarat 1
Himachal Pradesh 1	Meghalaya 1	Jharkhand 1	Karnataka 4	Maharashtra 2
Uttar Pradesh 6		Bihar 2	Kerala 6	*Central*
			Tamil Nadu 9	Chattisgarh 1
				Madhya Pradesh 1

Type of palliative care service delivered	**Number of hospitals (N=44)**
Community Palliative Care Service	26 (59%)
Outpatient Service	23 (52%)
Integrated Service	16 (36%)
Dedicated palliative care beds	13 (30%)
Specialist palliative care consult service	11 (25%)
Day therapy	5 (11%)

Palliative Care Team Members – Number of hospitals with each professional, range and median

	Hospitals	Range	Median if available
Doctors	38 (86%)	0-7	2
Nurses (Degree)	17 (39%)	0-8	1
Nurses (GNM)	33 (75%)	0 - >10	2
Nurses (ANM)	23 (52%)	0 - 10	2
Social Worker	27 (61%)	0-8	1
Physio	19 (43%)	0-1	1
OT	6 (14%)	0-1	1
Counsellor	17 (39%)	0-3	1
Psychologist	13 (30%)	0-1	1
Size of team		**1 - >20**	**7**

Who leads the team:	**Number of Hospitals N=44**
Doctor with specialist palliative care training	10 (22%)
Doctor with basic palliative care training	11 (25%)
Nurse with specialist training	2 (5%)
Nurse with basic palliative care training	3 (7%)
Dentist with specialist palliative care training	2 (5%)
Dentist with basic palliative care training	1 (2%)
Other doctor	5 (11%)
Other/Not specified	10 (22%)

(*Specialist defined as MD Palliative Medicine, MSc or National Fellowship Qualification)

Underlying condition receiving palliative care:	***Number of Hospitals N=44***
Stroke and Other Neurological conditions	30 (68%)
Cancer	29 (66%)
Disability	25 (57%)
Renal Failure	17 (39%)
Dementia	16 (36%)
HIV	16 (36%)
Advanced Respiratory Disease	16 (36%)
Heart Failure	12 (27%)
Liver Failure	11 (25%)
Paediatric	10 (22%)

Table 1: Characteristics of Hospitals and Palliative Care Services offered

References

1. Biswas RK,Afiaz A, Huq S. Underreporting COVID-19: the curious case of the Indian subcontinent. *Epidemiol Infect.* 2020 Sep 11;148:e207.

2. Dore B. Covid-19: collateral damage of lockdown in India. *BMJ.* 2020;369.

3. Ranscombe P. Rural areas at risk during COVID-19 pandemic. *Lancet Infect Dis*. 2020;20:545.

4. JHU. COVID-19 Dashboard by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU) Baltimore, Maryland: John Hopkins University Coronvirus Resource Centre; 2020

5. Kumar A, RajasekharanNayar K, et al. COVID-19: Challenges and its consequences for rural health care in India. Public Health in Practice. 2020;1:100009.

6. Singh S. Data on social and health vulnerability in rural India: A case of covid-19. Data in Brief. 2020;31:106020.

7. Damani A, Ghoshal A, Rao K, et al. Palliative Care in Coronavirus Disease 2019 Pandemic: Position Statement of the Indian Association of Palliative Care. *Indian J Palliat Care.* 2020;26(Suppl 1):S3-S7.

8. India P. ECHO on palliative care for healthcare providers treating people with Covid-19 (Pallicovid ECHO) 2020 [Available from: https://palliumindia.org/pallicovid-echo-palliative-care-healthcare-providers-covid19 (Accessed on 18 Jan 2021).

9. Haynes J. (2013) Faith-Based Organisations, Development and the World Bank. In:Carbonnier G, Kartas M, Silva KT. (eds) International Development Policy: Religion and Development. International Development Policy. Palgrave Macmillan, London. https://doi.org/10.1057/9781137329387_5.

10. Long K, Chandy S, Feeley III F, *et al*. Mission Hospital Responses to Challenges and Implications for their Future Role in India's Health System. *Christian Journal for Global Health*. 2020;7:19-36.

11. Munday DF, Haraldsdottir E, Manak M, *et al*. Rural palliative care in North India: Rapid evaluation of a program using a realist mixed method approach. *Indian J Palliat Care.* 2018;24:3-8.

12. Marshall K, Smith S. Religion and Ebola: learning from experience. *The Lancet.* 2015;386(10005):e24-e5.

13. WHO:Faith-based organizations across India step up the fight against COVID-19. https://www.who.int/india/news/detail/22-05-2020-faith-based-organizations-across-india-step-up-the-fight-against-covid19 (accessed on 22 March 2021)

14. Biswas S, Adhikari SD, Bhatnagar S. Integration of Telemedicine for Home-Based End-of-Life Care in Advanced Cancer Patients during Nationwide Lockdown: A Case Series. *Indian J Palliat Care.* 2020;26(Suppl 1):S176-S8.

15. Telemedicine Practice Guidelines. Government of India; 2020.

16. Global faith-based responses to COVID-19: Local, national, and international faith-based organizations and health care providers on the frontline of COVID-19 response. https://www.ccih.org/wp-content/uploads/2020/03/COVID-CCIH-JLI-Survey-Report.pdf (accessed on 24 March 2021)

17. Vilakati PN, Villa S, Alagna R, *et al*. The neglected role of Faith-based Organizations in prevention and control of COVID-19 in Africa, Transactions of The Royal Society of Tropical Medicine and Hygiene. 2020;10:784–86.

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The research questions, questionnaire and interview topic guide were reviewed by an advisory group of clinicians working in five Indian FBOs and suggestions incorporated. The final draft of the questionnaire was piloted by the advisory group. Institutional Review Board approval from Christian Medical College, Vellore and ethics committee approval from Emmanuel Hospitals Association (EHA) were obtained. An invitation with information sheet on completing the questionnaire (Google Forms) was sent to all FBO hospitals offering palliative care on databases held by EHA and the Christian Medical Association of India in September 2020. The results were downloaded, anonymised and descriptive statistical analysis was undertaken using SPSSv25.

Results

Of 64 FBO hospitals invited to participate, 46(72%) completed the questionnaire. Two hospitals not offering palliative care were excluded from further analysis. The 44 hospitals were spread across 15/29 Indian states representing different geographical regions of India (Table 1). Thirty of the 44 hospitals (68%) were in rural or semi-urban areas and 13(30%) in urban areas. They ranged in size from 10 to 2700 beds (median 100). Forty-two (95%) offered general medical services, 33(75%) general surgery and 32(73%) obstetrics and gynaecology and community medicine. Other services included: tuberculosis (66%), paediatrics (61%), HIV (50%), ENT (30%), dental (25%), oncology (18%) and ophthalmology (11%).

Twenty-three (52%) had dedicated palliative care teams and 30(68%) provided palliative care as part of general services with 17(39%) providing both; three did not specify. Although many palliative care teams were small and comprised one or two doctors and a small number of nurses, multidisciplinary working was in evidence with more than half having social workers and a substantial number with physiotherapists, counsellors and psychologists (Table 1). Whilst 29(66%) provided palliative care to people with cancer, only 15(34%) reported that this made up 50% or more of their palliative care work. Most provided palliative care to patients with non-communicable diseases (Table-1).

The lockdown led to a substantial reduction in general non-COVID-19 clinical work for 36(82%) and for 40(91%) it had reduced their community work. Even after easing of lockdown 34(77%) reported a continuing reduction in non-COVID-19 work, leading to a reduction in hospital income for 41(93%).

Thirty (68%) reported that they had adequate personal protective equipment (PPE).The rest did not have adequate PPE or were worried that they would not have sufficient supplies. Twenty-one (48%) reported that hospital supplies had been reduced during the pandemic with 19(43%) reporting that key medication supplies (including morphine) had been affected.

Eighteen (40%) hospitals were designated COVID-19 centres by the government (registered to admit patients or to provide testing). Eleven (32%) were already admitting COVID-19 patients and five were planning to admit them; 15(34%) were not and 13(30%) were undecided. The eleven already admitting patients had admitted between one and 2230 with between zero and 150 COVID-related deaths.

Twenty-nine (66%) reported that palliative care work had been reduced and in 7(16%) it had stopped altogether during the pandemic. Only one said that palliative care work had increased. Ten (23%) reported the palliative care team had been redeployed to support general COVID-19 related care. Of the 37(84%) still providing palliative care, 32/37(86%) reported that their principal palliative care work was with non-COVID-19 patients. Thirteen (35%) reported that the palliative care team cared for COVID-19 patients; for three this was their principal work. Only 2/13 with dedicated palliative care beds admitted COVID-19 patients to these. Nineteen of the 44 hospitals (43%) reported that patients had still been able to get active treatment for their underlying condition (e.g. chemotherapy for cancer patients),

16(36%) said that patients had not received usual treatment and 9(20%) were unsure or did not specify.

We asked the participants to provide examples of how they had adapted their palliative care service during the pandemic. Many had changed to telephone consultations for follow-up rather than seeing patients face to face, and avoiding out-patient visits if possible to prevent putting patients or staff at risk. Home visits would be triaged, making phone calls if possible before going to see patients. When they did visits in the community, they used PPE for protection.

Patients finding difficulty accessing the hospital meant that palliative care teams sometimes delivered medication to patients' homes and gave a longer supply than normal to ensure continuous availability. Some reported using their inpatient beds more frequently in this period because patients were not coping at home. Others in addition to clinical services provided food for patients and families who were in need.

Discussion

FBOs are recognized as important actors in delivering and sustaining community development, especially in the broader health sector. FBOs in India together with the WHO, UNICEF stepped up in the fight against the COVID-19 pandemic, to engage with communities under the guidance of the state government, and promote safety measures, advocate the well-being of the population at-risk and sensitize the communities against discrimination of health workers and those infected with COVID-19.(13)

While this survey wasn't comprehensive, the range of hospitals participating provides an illustrative picture of the need and supply of palliative care provision in India. Included were hospitals under the auspices of two of the largest FBOs in India (CMAI and EHA) and hospitals run by local FBOs from different geographical regions in India, small to large sized with different models of palliative care provision in different settings. The majority of hospitals were situated in rural or semi-urban areas, matching the Indian population distribution.

Though evidence points to a marked global disparity of palliative care access for cancer patients in rural and remote areas, most of the participating hospitals provided palliative care for cancer patients. The study also showed that palliative care was offered for a wide range

of non-communicable diseases (NCDs) by FBOs in addition to cancer and this is significant as recent studies point to deaths due to NCDs in India increasing whilst cancer makes up only 9%.(11)

During the pandemic lockdown period, palliative care and other hospital services had to reduce activity and a minority suspended some services altogether. Most FBOs charge for their services even if nominally,(10) apart from palliative care which is provided free of charge or at subsidised cost in some hospitals.(11) Any reduction in clinical work leads to reduced income and difficulties maintaining service provision. Community teams were restricted in their ability to work, reducing patient care. Hospitals also faced a lack of supplies, particularly medication, including morphine.

While some hospitals provided palliative care for patients with COVID-19, the majority continued to care for non-COVID patients. In some hospitals palliative care provision was reduced as staff were redeployed to other duties, out of necessity, though this may also suggest that providing palliative care for patients with COVID-19 was not yet seen as a priority. As with other palliative care services, changes in response to the pandemic included more telephone consultations,(14) in line with guidelines provided by the Indian Government.(15) Home visits were reduced with prior telephone assessments for triage. Some palliative care teams delivered medicines and were providing food for patients and families as a necessary extension to their normal services.

As far as we are aware, this is the first study of FBO palliative care response in India during the COVID-19 pandemic. A global survey of FBOs (n=52) to identify their response to the COVID-19 pandemic by the Christian Connections for International Health and the Joint Learning Initiative on Faith and Local Communities in April 2020 identified how the majority of FBOs were responding, coordinating, and modifying programs to respond to the COVID-19 pandemic, through community-based education, prevention and public health promotion.(16) During this pandemic FBOs and NGOs have been seen as highly committed and versatile, with their simple structures, operating at local level, being best placed to provide health services to people living in impoverished conditions, especially in rural settings. They have also been at the forefront of providing basic care and financial support to the most poor.(17)

A questionnaire can only provide limited insights into the functioning of palliative care teams and the effect of COVID-19. Ongoing key informant and patient/relative interviews are

exploring the challenges of the pandemic for patients and clinicians in more depth, including the psychological impacts on teams of working through the pandemic.

Conclusion

Most FBO Hospitals have continued providing palliative care despite the considerable challenges of the pandemic, expanding their services to include other humanitarian activities. Further research is needed to allow a fuller understanding of the challenges and solutions to providing palliative care for people in marginalised communities in India and other low and middle income countries as the pandemic progresses.

Table-1: Characteristics of Hospital and Palliative Care Service

Geographical distribution of hospitals across India

North	*North East*	*East*	*South*	*West*
Delhi 1	Assam 1	West Bengal 1	Andhra Pradesh 6	Gujarat 1
Himachal Pradesh 1	Meghalaya 1	Jharkhand 1	Karnataka 4	Maharashtra 2
Uttar Pradesh 6		Bihar 2	Kerala 6	*Central*
			Tamil Nadu 9	Chattisgarh 1
				Madhya Pradesh 1

Type of palliative care service delivered	**Number of hospitals (N=44)**
Community Palliative Care Service	26 (59%)
Outpatient Service	23 (52%)
Integrated Service	16 (36%)
Dedicated palliative care beds	13 (30%)
Specialist palliative care consult service	11 (25%)
Day therapy	5 (11%)

Palliative Care Team Members – Number of hospitals with each professional, range and median

	Hospitals	Range	Median if available
Doctors	38 (86%)	0-7	2
Nurses (Degree)	17 (39%)	0-8	1
Nurses (GNM)	33 (75%)	0 - >10	2
Nurses (ANM)	23 (52%)	0 - 10	2
Social Worker	27 (61%)	0-8	1
Physio	19 (43%)	0-1	1
OT	6 (14%)	0-1	1
Counsellor	17 (39%)	0-3	1
Psychologist	13 (30%)	0-1	1
Size of team		**1 - >20**	**7**

Who leads the team:	**Number of Hospitals N=44**
Doctor with specialist palliative care training	10 (22%)
Doctor with basic palliative care training	11 (25%)
Nurse with specialist training	2 (5%)
Nurse with basic palliative care training	3 (7%)
Dentist with specialist palliative care training	2 (5%)
Dentist with basic palliative care training	1 (2%)
Other doctor	5 (11%)
Other/Not specified	10 (22%)

(**Specialist defined as MD Palliative Medicine, MSc or National Fellowship Qualification)*

Underlying condition receiving palliative care:	***Number of Hospitals N=44***
Stroke and Other Neurological conditions	30 (68%)
Cancer	29 (66%)
Disability	25 (57%)
Renal Failure	17 (39%)
Dementia	16 (36%)
HIV	16 (36%)
Advanced Respiratory Disease	16 (36%)
Heart Failure	12 (27%)
Liver Failure	11 (25%)
Paediatric	10 (22%)

Table 1: Characteristics of Hospitals and Palliative Care Services offered

References

1. Biswas RK,Afiaz A, Huq S. Underreporting COVID-19: the curious case of the Indian subcontinent. *Epidemiol Infect.* 2020 Sep 11;148:e207.

2. Dore B. Covid-19: collateral damage of lockdown in India. *BMJ.* 2020;369.

3. Ranscombe P. Rural areas at risk during COVID-19 pandemic. *Lancet Infect Dis*. 2020;20:545.

4. JHU. COVID-19 Dashboard by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU) Baltimore, Maryland: John Hopkins University Coronvirus Resource Centre; 2020

5. Kumar A, RajasekharanNayar K, et al. COVID-19: Challenges and its consequences for rural health care in India. Public Health in Practice. 2020;1:100009.

6. Singh S. Data on social and health vulnerability in rural India: A case of covid-19. Data in Brief. 2020;31:106020.

7. Damani A, Ghoshal A, Rao K, et al. Palliative Care in Coronavirus Disease 2019 Pandemic: Position Statement of the Indian Association of Palliative Care. *Indian J Palliat Care.* 2020;26(Suppl 1):S3-S7.

8. India P. ECHO on palliative care for healthcare providers treating people with Covid-19 (Pallicovid ECHO) 2020 [Available from: https://palliumindia.org/pallicovid-echo-palliative-care-healthcare-providers-covid19 (Accessed on 18 Jan 2021).

9. Haynes J. (2013) Faith-Based Organisations, Development and the World Bank. In: Carbonnier G., Kartas M., Silva K.T. (eds) International Development Policy: Religion and Development. International Development Policy. Palgrave Macmillan, London. https://doi.org/10.1057/9781137329387_5.

10. Long K, Chandy S, Feeley III F, *et al*. Mission Hospital Responses to Challenges and Implications for their Future Role in India's Health System. *Christian Journal for Global Health*. 2020;7:19-36.

11. Munday DF, Haraldsdottir E, Manak M, *et al*. Rural palliative care in North India: Rapid evaluation of a program using a realist mixed method approach. *Indian J Palliat Care.* 2018;24:3-8.

12. Marshall K, Smith S. Religion and Ebola: learning from experience. *The Lancet.* 2015;386(10005):e24-e5.

13. WHO:Faith-based organizations across India step up the fight against COVID-19. https://www.who.int/india/news/detail/22-05-2020-faith-based-organizations-across-india-step-up-the-fight-against-covid19 (accessed on 22 March 2021)

14. Biswas S, Adhikari SD, Bhatnagar S. Integration of Telemedicine for Home-Based End-of-Life Care in Advanced Cancer Patients during Nationwide Lockdown: A Case Series. *Indian J Palliat Care.* 2020;26(Suppl 1):S176-S8.

15. Telemedicine Practice Guidelines. Government of India; 2020.

16. Global faith-based responses to COVID-19: Local, national, and international faith-based organizations and health care providers on the frontline of COVID-19 response. https://www.ccih.org/wp-content/uploads/2020/03/COVID-CCIH-JLI-Survey-Report.pdf (accessed on 24 March 2021)

17. Vilakati PN, Villa S, Alagna R, *et al*. The neglected role of Faith-based Organizations in prevention and control of COVID-19 in Africa, Transactions of The Royal Society of Tropical Medicine and Hygiene. 2020;10:784–86.