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Report of the WHO South-East Asia Regional workshop on expanding availability and access to palliative care

Colombo, Sri Lanka
11-13 October 2023





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Table of contents

1. Background and Objectives of the Workshop	5
2. Workshop proceedings	7
a. Session 1: Regional situation of palliative care and factors leading to success	9
b. Session 2: Multisectoral partnerships in palliative care	13
c. Session 3: Progress in palliative care in countries	15
d. Session 4: Key elements in palliative care service delivery	19
e. Session 5: Models of care and Innovations in palliative care	23
f. Observational visits to palliative care service delivery models in Sri Lanka	25
i. Palliative care unit, National Cancer Institute, Maharagama	26
ii. Santa Sevana Hospice, Maharagama; and Suwa Arana Hospice, Maharagama	26
iii. Divisional Hospital, Wethara; MO Health Office, Kahathuduwa	27
g. Session 6: Demystifying death and dying	29
h. Session 7: Country Roadmap for expanding availability and access to palliative care	33
3. Next steps	41
4. Annexes:	43
a. Message from Regional Director	43
b. Workbook	45
i. List of Participants	48
ii. Program	51
iii. Session details	55
iii. Working paper	61
c. Participants' feedback	121
d. Resource materials for further reading	124



1 | Background and Objectives of the Workshop

About ten million people in the South-East Asia region are estimated to be in need of palliative care, accounting for about 17% of the global needs. Close to 70% of the need for palliative care is due to non-communicable diseases (NCD) including cancers and stroke. With the anticipated rise in the burden of NCD and ageing populations, the need for palliative care is expected to continue to grow. Timely delivery of palliative care to needy persons reduces unnecessary hospital admissions.

World Health Assembly in 2014 passed a resolution urging Member States to work on strengthening health systems to integrate palliative care into continuum of care with emphasis to primary care and universal coverage scheme, to ensure domestic funding and human resources, and to include palliative care as integral component of ongoing education and trainings. Declaration of Astana on primary health care states that palliative care along with other components of health services must be accessible to all and recognizes palliative care as component of sustainable primary health care. Palliative care is a defining component of universal health coverage.



In the 2021 WHO NCD country capacity survey, less than half of the countries in SE Asia Region reported that palliative care was 'generally available'. A 2020 survey on palliative care situation in SE Asia Region found a significant variation in availability of services between countries in the Region. Home based palliative care was found to be available in small pockets across most countries. Provisions for patient's home visit by health workers in public health system, such as those in PHCs in Bhutan and through Saúde na Família in Timor-Leste are some exemplary initiatives. Availability of palliative care specific for children is sparse across the Region. Encouragingly palliative care is seen to be gradually extending its focus from cancer to wider group of conditions.

In this backdrop, it is clear that countries have to make available, and strengthen palliative care services to achieve Sustainable Development Goal 3.

Substantial effort is needed to make palliative care available and accessible to the people in need. This workshop was organized to support countries in bringing palliative care into priority at policies and strengthen the capacity to plan and implement programs for palliative care with the following objectives:

1. To support countries to review the current status of palliative care services and to identify gaps in access and availability.
2. To identify opportunities to enhance human resource, including the increased role for nurses, to improve availability and access to palliative care in community.
3. To support development of stepwise approach for expanding availability and access to palliative care and development of country specific plans.

2 | Workshop proceedings

Inaugural session



The workshop commenced with an inaugural session with address from the Regional Director, Dr. Poonam Khetrapal Singh, delivered by the WHO Representative to Sri Lanka Dr. Alaka Singh. The Regional Director highlighted the important achievements and exemplary initiatives in palliative care in the Region. Referring to the anticipated rise in burden of NCDs and ageing population in the region, the Regional Director expressed concerns over the expected increase in need for palliative care and stressed that the current efforts require to be scaled up further by addressing palliative care as part of universal health coverage (UHC), building human resource capacity, ensuring supplies of medicines and consumables, and implementing mechanisms for monitoring and evaluation.

Dr. Asela Gunawardana, Director General of Health Services and the chairperson of National Steering committee on palliative care, of the Ministry of Health, Sri Lanka welcomed all the delegates of the workshop. He shared the model initiative of community based palliative care in Kandy district in Sri Lanka and highlighted other important initiatives including training programs and partnerships for strengthening palliative care in the country.

Dr. Lakshmi Somatunga, Additional Secretary at the Ministry of Health, Sri Lanka extended her appreciations to WHO for selecting Sri Lanka as the venue for organizing of the workshop. She also highlighted on the priority to palliative care being given by the government of Sri Lanka as a result of which palliative care was beginning to encompass conditions other than cancers.

Dr. Cherian Varghese, Director a.i. Healthier Populations and Non-communicable diseases Department at WHO South-East Asia Regional Office (SEARO) shared that the situation of palliative care services in the Region has improved over the years. He emphasized the need for health care personnel to introduce palliative care gradually into patients in need, sooner after it is indicated, as opposed to near the terminal stage. He also emphasized the importance of focusing on broader symptoms management in the practice of palliative care in addition to management of pain; and for greater focus on community based palliative care.

The inaugural session was followed by themed technical sessions.

SESSION: 1

Regional situation of palliative care and factors leading to success



The objective of the session was to highlight the successful approaches in expanding access to palliative care and a review of the situation in South-East (SE) Asia Region. Dr. Eric L Krakauer, from Harvard Medical School, United States of America (USA) discussed on what seems to have worked well in improving access to palliative care in low- and middle-income countries. Dr. Bishnu Rath Giri, from WHO SEARO, briefly presented on the situation of palliative care in the region, and Dr. Suresh Kumar, from Institute of Palliative Medicine India discussed on the learnings from efforts in expanding palliative care in the Region. The session was chaired by Dr. Lakshmi Somatunga from Sri Lanka and Dr. Srivieng Pirojkul from Thailand.

The presentations were followed by a panel discussion on factors facilitating development of palliative care in the Region. The panel consisted of Dr. Suresh Kumar, Dr. Bishnu D Paudel from Nepal, Ms. Smriti Rana from India, Dr. Md Shahidul Islam from Bangladesh, Mr. TKA Nair from India and Dr. Udayangani Ramadasa from Sri Lanka.

Development of palliative care in Low- and Middle Income Countries – what has worked

Dr. Erik Krakauer highlighted that the medical argument for palliative care should begin with the scientific base that palliative care improves patient outcomes, by decreasing pain and other physical and psychological symptoms leading to better quality of life and sometimes, prolonged life. Integration of palliative care, including home care, into public health systems will also result in cost savings for the family and for the health systems.

Policies and plans on palliative care should be locally appropriate (clinically and culturally), practical, feasible, and acceptable. Most importantly the policies and plans must be implemented. In India, the recognition of palliative care by the medical council as a medical subspecialty led to creation of MD curriculum. National and subnational level policies can also be crucial in expanding palliative care, such as that seen in Kerala state in India. Policies should identify palliative care as responsibility of primary care clinicians as well as specialists in many disciplines.

Effective models of palliative care include nurses, social workers, and home-based components, and focus on communication, psychosocial support and patient or caregiver experience. Most patients in need of palliative care cannot travel, hence palliative care should be accessible in the communities and patients' homes.

Addressing the cost of care either via UHC approach or insurance is imperative.

Civil society organizations (CSO) can help greatly by pioneering new models, advocacy, and training in addition to funding. Sustainability has to be addressed on initiatives from CSOs.

Situation of palliative care in South-East Asia Region

Dr. Bishnu Rath Giri started with the global need for palliative care - each year 56.8 million people estimated to be needing palliative care, of which only 14% are currently receiving the required care. It was highlighted that all countries in SE Asia Region have palliative care included at policy level, commonly as part of cancer or NCD policy, eight countries have some form of government funding for palliative care, and seven countries have endorsed palliative care within listed primary health care (PHC) services. Four countries in SE Asia Region have palliative care generally available at PHCs and five countries have it in community or home-based setting. Some notable models of care in SE Asia Region

include community based palliative care model in Calicut, India; optimizing nursing staff for delivering palliative care at home in Sri Lanka; and home bound care delivered by health assistants at PHC in Bhutan among others.

For human resource development Bangladesh, India, Sri Lanka, and Thailand have subspecialty training courses, . Bhutan has included significant proportion of contents on palliative care in curriculum of health assistants, while short courses and fellowships are available in all countries.

Expanding access to palliative care – learnings from the Region

Dr. Suresh Kumar shared that the attempt to mainstream palliative care into PHC with proper policies in place has worked well in Sri Lanka. Thailand offers palliative care as integral element of national health service plan thus making it available in every hospital leading to a movement towards universal access to palliative care. This achievement is supported by policy and earmarked funding. Home bound palliative care from public institutions from primary to tertiary level is noteworthy in Bhutan. Civil society organizations have played vital role in Nepal in shaping policy, education, drug availability, and service expansion. Similarly in Telangana state in India, the government has leveraged well on the skills and expertise available with CSOs highlighting a successful collaboration between government and civil service organizations. The bottom-up approach in Kerala, India where palliative care programs have been integrated with community participation demonstrates a highly successful model.

He also highlighted that multisectoral actions are needed to facilitate access to palliative care. Inadequate universal health coverage, poor living conditions due to poverty, and poor formal social protection measures are the major barriers to expanding access to palliative care.



The participants of panel discussion stressed that empowering the policymakers with right information may facilitate development of policies crucial for expanding palliative care. Having policies for palliative care is important, but service delivery can start while waiting for policies and programs to take formal shape. Many a times the services have started out of personal interest of professionals. Partnerships between government and civil society is important. Political commitment is vital in strengthening palliative care.



SESSION: 2

Multisectoral partnerships in palliative care



The objective of the session was to discuss on the role of multisectoral partnership in improving access to palliative care. The opportunities that each sector bring in along with its participation and the modalities to leverage on their unique capacities were to be discussed. Dr. Bishnu Dutta Paudel from Nepalese Association of Palliative Care, Nepal discussed on the role of civil society organizations in developing palliative care in local and national context, Ms. Smriti Rana from Pallium India highlighted the role of partnerships and the importance of utilizing local knowledge in strengthening palliative care. Dr. Catherine Lalmuanawmi from Ministry of Health, Mizoram state, India shared the experience of implementing palliative care at sub-national level and the opportunities that were available to local governments to expand palliative care contextualized to local needs and resources.

The session was chaired by Smt. Sarita Nair from Ministry of health India and Dr. Gampo Dorji form WHO Nepal.

Role of civil society organizations (CSO)

Dr. Bishnu D Paudel highlighted that civil society organizations can play a very important role in many aspects of expanding access to palliative care. There are ample instances of civil society organizations establishing and operating palliative care facilities of various levels. CSOs can complement in improving services in public institutions by supporting in infrastructure, short term trainings, and provision of critical human resource. Another major area that CSOs can support is in facilitating care navigation and providing psychosocial support to patients and families. CSOs have another crucial role to play in advocacy and drive policy changes. In some countries national policy on palliative care have been the result of constant efforts from CSOs.

Partnerships in scaling up palliative care services

Ms. Smriti Rana stressed that partnerships are important at various levels for scaling up palliative care services. At community level partnership between other actors in the social development sector and local governance bodies helps in co-designing and implementing solutions. At subnational levels partnerships can facilitate in ensuring clarity in policies and in leveraging available training and budgets. Partnership with medical fraternity can be helpful in training and education, peer engagement and support for health personnel at different levels of care. At national level partnerships can help in evidence-based policy briefing and technical support. Partnerships at international level is necessary for knowledge exchange and technological support.

Opportunities in local governments while implementing palliative care services at subnational level:

Dr. Catherine Lalmuanawmi shared the experience from Mizoram state in India where the local government engagement has helped delivery of palliative care more effectively. The state has nine districts that provide home based care. The palliative care team distributes home based care kit. The kit consisting of essential medical care commodities is designed as per the local need. Handling of supply of narcotics are regulated with local laws. Local governments have been able to develop a more effective partnerships with the community, religious groups, and civil society organizations. The awareness activities are more contextualized and carried out in local language.

SESSION: 3

Progress in palliative care in countries

expanding availability and
access to palliative care

11-13 October 2023
Colombo, Sri Lanka



The objective of this session was to showcase the successful initiatives and the opportunities in the countries. This was thought to facilitate other countries to assess whether such successful models could be adapted in their own countries. The country presentations followed a group work in identifying successful examples that can be initiated to expand availability and access to palliative care in other countries. All the participating countries presented on these areas one after the other. The session was chaired by Dr. Anup Bastola from Nepal and Dr. Fahmida Alam from Bangladesh

Bangladesh

Dr. Wai Wai Mroy from Bangladesh shared that palliative care services are sporadic at various level of health care services in the country. National palliative care guidelines were developed in 2019, and training modules have been developed for doctors, nurses and paramedics. Training program for specialization in palliative care has been established. Compassionate Korail and compassionate Narayanganj are examples of community-based initiatives on palliative care. The initiative in Narayanganj aims to integrate palliative care into primary health care as a pilot project. In addition, there are scattered initiatives making patchy availability of hospices and tertiary level palliative care in the country. A national policy, adequate funding provision, and collaborating opportunities were felt as needs for accelerating provisions for availability and access.

Bhutan

Ms. Tshewang from MoH Bhutan shared that the country has provision for palliative care via routine health care services. Under the service with care and compassion initiative (SCCI), primary health care workers provide palliative care service at home of the patients in need. The national referral hospital provides home based palliative care in the capital city in an organized manner. The factors that facilitated successful implementation of home-based palliative care are service tailored to patient's needs for care at home, improved communication with patient and families, and the perception of improved quality of life. Reduced need for hospitalization and the cost effectiveness has further helped in garnering support for the initiative. Geographical factors hindering access, caregiver burnout, complexities in care coordination, and the growing demand for such services thus stretching the limited resources were cited as factors posing challenges.

India

Dr. Shalini Kelkar presented the progress in India. The national program for palliative care was launched in India in 2012. This made provisions for states to seek funds for establishing palliative care services in the districts. The strategic framework focuses on building capacity, community awareness and integrating palliative care into other related programs. Currently 708 districts are covered under the program. Notable initiatives include the home care vehicle in Telangana state, home based care kits in Mizoram, physiotherapy on wheels initiative in Chhattisgarh state.

Maldives

Ms. Aishath Lubana Labeeb from MoH Maldives shared that palliative care services are very limited in the country. Apart from tertiary level hospitals in Malé region and some atoll level facilities providing

some pain management, there are no other organized form of palliative care at institutional or national level. Some of the islands have facilities for home visit to bedridden patients. The country has plans to train doctors and nurses on palliative care and develop guiding documents.

Nepal

Dr. Anup Bastola from MoH Nepal presented on the progress in the country. Nepal has developed national strategy for palliative care in 2017. Nepalese association for palliative care, a civil society organization has been in forefront of palliative care activities. Bhaktapur cancer hospital, has established a dedicated palliative care service unit and provides community based palliative care. Guidelines for pain management in palliative care was published in 2012 and was revised in 2017. Specialty fellowship trainings are provided at Patan Academy of Health sciences. Short-term trainings to HCW is provided by the National health training center as well as BPK Memorial Cancer Hospital. Palliative care has not yet been integrated into the mainstream health care system. One time support of USD 750 is provided to patients with some selected chronic conditions. There is a need felt for establishing a network of palliative care providers. And for improving skills of HCWs to integrate palliative care into primary health care.

Sri Lanka

Dr. Lakshmi Somatunga from MoH Sri Lanka shared that the country has addressed palliative care well in its policies, standalone and within relevant areas of cancer and elderly policies. Ministry has developed a model of care delivery at various levels. Service standards have been defined and SOPs and guidelines are in place for coordinating care. Trainings are provided for nurses and doctors which range from basic to sub-specialty levels. Most part of cost of care is funded by government resources. Four districts have commenced palliative care services under ministry of health and some tertiary care teaching hospitals including the national cancer institute have palliative care services. Services are also available from the private providers and civil society organizations. Accredited training programs are available for nurses and physicians. Community based palliative care delivered by the cadre of public health nursing officers is functioning very well. A need is felt for expanding the initiative.

Thailand

Dr. Duenpen Horatanaruang from Thailand shared that the country has included palliative care into its national strategy. Multi-sectoral collaboration, quality improvement in services and training of critical workforce are the approaches adopted for palliative care service improvement. The country has integrated palliative care into mainstream health care services, and it is generally available across all levels of health care. Palliative care services are well organized at the level of community, primary health care and hospital levels. Most of the MOPH and university hospitals have palliative care services available. Home care is funded by the government. As per the country's assessment, accessibility of palliative care among adults is about 67%, while in case of children it is only 17%. Complete integration with other services, introducing digital health, reducing the hesitancy to provide optimum pain relief resulting from narcotic law are some of the challenges.



SESSION: 4

Key elements in palliative care service delivery



The objective of the session was to discuss on the most important elements in systems for palliative care services with focus on making symptom management as core function of palliative care services and community-based care as the primary approach for service delivery. Dr. Eric Krakauer, from Harvard Medical School, USA discussed on essential package of palliative care to prevent and relieve serious illness related suffering. Ms. Yangden from MoH Bhutan shared the experience from Bhutan on starting and sustaining palliative care. Ms. Kemachit Mookdadee from NCI Thailand discussed on the role of nurses as key resource for palliative care. Dr. Eshani Fernando, Director of National Cancer Control Program Sri Lanka shared the experience of implementing the model of shared care, leveraging nursing officers in delivering palliative care at home. The session was chaired by Dr. Shalini Kelkar from MoH India and Ms. Tshewang Lhaden from Bhutan.

Essential package of palliative care

Dr. Eric Krakauer discussed on the essential package of palliative care developed by the lancet commission on palliative care which was adopted by WHO in its palliative care guides. It consists of six components:

1. Interventions: for prevention and relief of pain, other physical sufferings, psychological suffering, social or spiritual suffering
2. Medicines: necessary to prevent or relieve specific symptoms of most associated with life-limiting health problems
3. Equipment: necessary for relief of at least one type of physical or psychological suffering
4. Social support: to ensure meeting most basic needs such as food, housing, transport to medical care and promote dignity.
5. Trained human resource and services at each level: Basic, intermediate and specialist palliative care training depending on level of care. Service standards defined for each level.
6. Standard Operating Procedures: for communication and referral between levels.

He stressed that these essential package and the necessary home visits should be covered by public health care financing schemes.

Community based palliative care

Ms. Yangden highlighted that community based palliative care improves quality of life of patients, caregivers and the ones that undergo grief and loss. Building community based palliative care requires securing support from stakeholders, need assessment and identification of community strengths to leverage upon, setting goals and planning by utilizing the learnings from existing successful models, implementation by starting with small scale and gradual increase, monitoring and evaluation with continued improvement from learning. A community-based Palliative care model will sustain when it is acceptable, affordable and adaptable. Government ownership is key to sustainability, engagement of other locally reputed institutions can add to ensure sustainability.

Role of nurses as key resource for palliative care

Ms. Kemachit Mookdadee emphasized that nurses are more likely to be present with patient near the

time of death than other health professionals. Nurses can deliver a number of common palliative care services including managing pain and other physical symptoms and attending to psychological needs. Nurses can also provide education to care givers and efficiently coordinate care. Primary health care personnel could be trained by competent palliative care nurses. They can play vital role in research, advocacy, and policy development.

Shared care and care coordination for delivering palliative care at home – leveraging nursing manpower

Dr. Eshani Fernando shared the experience from Sri Lanka where there is an exemplary model of palliative care delivery at home. This is backed up by relevant policies at national level, including inclusion of palliative care into essential health service package. The model of palliative care delivery ranges from community or home to tertiary level. The service standards have been defined for various level including community and home level. Referral mechanisms and SOPs have been developed for efficient care coordination and shared care.

Hospital nursing officers and public health nursing officers were provided palliative nursing care before placement for palliative care. The public health nursing officers coordinate referrals between higher level of care and district hospitals. They keep record of patients needing palliative care in the community and do periodic and on call home visits to provide care. Factors contributing to the success of this model include availability of policy, funding from government, availability of human resource and training facilities, defined service standards and SOPs.





SESSION: 5

Models of care and Innovations in palliative care



The objective of the session was to discuss the various models of palliative care services and innovations pertinent to the region. Models with focus on primary health care was the focus. Dr. Samadhi Rajapaksa from College of Palliative Medicine, Sri Lanka discussed on the models with community participation. Dr. Eric Krakauer, from Harvard Medical School, USA presented on the monitoring and evaluation systems in palliative care. Special consideration for including pediatric palliative care in service models was discussed by Dr. Srivieng Pirojkul from NCI Thailand. The final discussion in this session was on innovations in palliative care relevant to the region, presented by Dr. Mostafa Kamal Chowdhury from Banga Bandhu Sheikh Mujib Medical University, Bangladesh. The session was chaired by Ms. Aishath Lubana Labeeb from MoH Maldives and Dr. Sadhana Bhagwat from WHO Bangladesh.

Palliative care models with community participation

Dr. Samadhi Rajapaksa called attention to the fact that palliative care services should be delivered in a way that meets cultural, spiritual and economic needs of people. Home based care is cheap, acceptable to patient and families and respects the cultural values. Integrated community-based home care is perhaps the most effective model. Successful models will include components of addressing physical, psychological and spiritual needs, dignity and respect to patient, information, continuity of care, equity among other things. One such model is functional in Karapitia, Sri Lanka.

Unavailability of expertise, medicines, fund as well as cultural barriers and lack of awareness are some challenges for all models of care. Any model of care should be able to leverage on available resources.

Monitoring and evaluation in palliative care

Dr. Eric Krakauer discussed palliative outcome scale developed by King's college, London as one useful tool to evaluate the effectiveness of palliative care services. Various academic bodies have come up with quality indicators for palliative care services. Indicators included in WHO NCD country capacity survey can provide a general overview of palliative care service situation in a country. WHO has published a set of actionable indicators for assessing development of palliative care. These indicators have been classified as core (for comparative and in-country evaluation) and strategic (more relevant for countries at initial stages of palliative care development).

Innovations in palliative care

Dr. Mostafa K Chowdhury spotlighted some innovations that Bangladesh has introduced in scaling up palliative care service deliveries. Compassionate communities is a community led approach with support from health systems. Community participation, capacity building, and public awareness and promotion of palliative care are the core components. Neighborhood network in palliative care is another such model in Kerala India. Developing mid-level expertise – the palliative care assistants – has been seen to greatly facilitate access to home based palliative care. Volunteerism is a powerful way to increase access to palliative care, the means to ensure it varies from places. Technological innovations facilitate delivery of services. Use of smartphone for teleconsultation is a simple but widely used example. This can be leveraged further. Biomedical technological innovations such as electronic subcutaneous infusion device ease patient care greatly. Technology has also supported information management for palliative care. Use of artificial intelligence in palliative care remains to be explored.

Observational visits to palliative care service delivery models in Sri Lanka



The objectives of field visit were to provide the participants with an opportunity to observe the typical settings for palliative care service delivery at tertiary level health facilities, hospice, and community level; observe the expertise and human resource required; and the care coordination and organizing of service delivery in various models of care. The workshop participants were divided into three groups and each group visited and observed one among three different levels of care viz. tertiary care, hospices, or community level care. The following day, observations were shared among all participants which was followed by discussion.

Group 1: Palliative care unit, National Cancer Institute, Maharagama



The National Cancer Institute, Maharagama has dedicated unit for Onco-palliative care for cancer patients who were treated in the institute. It has five consultant, six medical officers and six nursing officers trained in palliative care services. The provision of palliative care is via a multidisciplinary team approach. Common symptoms managed at the unit include pain, breathlessness, weakness, nausea, constipation, diarrhea, and anorexia. It has a well-coordinated mechanism for referral and shared care including that with the primary health care. Palliative care data management is well organized.

The institution runs academic sub-specialty diploma training for doctors and nurses, and also carries out shorter term trainings and it is engaged in researches.

The cost of care is born mostly through government sources. Charities private donations contribute to part of care.

Group 2: Santa Sevana Hospice, Maharagama; and Suwa Arana Hospice, Maharagama

Both these hospices are close to the National Cancer Institute, Maharagama, run by civil society organizations.

Patients with cancer or other diseases in need of palliative care but having financial difficulty are managed in Santa Sevana Hospice. Common symptoms managed are pain, breathlessness, nausea, vomiting. Medical officers and nurses have received trainings in palliative care which are sporadic and occasional Care coordination with the NCI is efficient. Average duration of service received by a patient



is 6 – 8 months. Palliative care data management is paper based. The hospice is funded mostly by SL Cancer Society. Other NGOs and CSOs also contribute to the funds. There is no provision of home visit.

Suwa Arana Hospice is an initiative from Indira trust. This facility is being built as dedicated to children. At the moment, it only provides residential facility for those children on treatment. They have excellent psychosocial support services. Play and education is provided. Coordination with cancer hospital is efficient.

Group 3: Divisional Hospital, Wethara; MO Health Office, Kahathuduwa



Palliative care at the primary care level is provided from two agencies collaborating with each other – the divisional hospitals address the clinical issues relating to a patient, the Medical Officer of Health Offices facilitates coordination in the home visits by the Public health nursing officer (PHNO). PHNO is the person responsible for organizing palliative care at community level. These are nurses in health service with a minimum two years of experience who receive additional training in public health and two-months training in palliative care.

PHNO coordinates the palliative care of patients with cancer or other diseases referred from hospitals. The sharing of care is facilitated by a document. S/he makes home visits to follow up with these patients. The procedures performed included naso-gastric tube insertion, catheter change, medicine administration etc. PHNO reports to the Medical Officer in charge of the divisional hospital.

Workload related concerns and connection with other health workers making home visit.

SESSION: 6

Demystifying death and dying



The objective of this session was to stimulate thoughts on the concept of dignified death. The session divulged into the perceptions and the traditions relating to death in various cultures. The session highlighted the need for change in health care practices thereby facilitating earlier initiation of palliative care and the skills to convey to the family on possibility of limited benefit of certain medical interventions on patient with terminal illness and near end of life. The session was conducted as a panel discussion moderated by Mr. TKA Nair chair of Citizen India Foundation. The panelists included Dr. Suresh Kumar from Institute of Palliative Medicine, India, Ms. Fathimath Khumaira from MoH Maldives, Dr. Suraj Perera from NCCP Sri Lanka, Dr. Sadhana Bhagwat from WHO Bangladesh, Dr. Samadhi Rajapaksa from College of Palliative Medicine, Sri Lanka, and Dr. Cherian Varghese from WHO SEARO.

Dr. Suresh Kumar emphasized that many people do not feel comfortable discussing about death, thus it is not commonly discussed. Generally, people do not think about their own death. There are practices and traditions on responding to anticipated death in close family or community circle that vary between countries and societies. There are various beliefs about death in our region. He opined that discussion on death will help broaden our understanding about death and help build a system that promotes dignified death with sufferings reduced to the minimum.

Dr. Sadhana Bhagwat shared that life without pity and painless death, the essence of palliative care, are deep rooted in Hindu traditions. Death is thought to lead to rebirth thus it is considered as just one stage in the journey of the soul through various life forms until the attainment of 'moksha' (akin to salvation).

Dr. Suraj Perera shared that in Christian prayer services, there are prayers for good death, seeking for pain free and dignified dying. Closer to death, there is a sacrament of anointing of the sick, which is administered with a belief of providing the dying person spiritual strength. This helps the family in acceptance of death and thus ensuring dignified death to the dying person. At the point of death, prayers are done to offer the soul of the dying person to the god.

Dr. Samadhi Rajapaksa expressed that in Buddhism death is taken as a part of life and one of the most certain events. Buddhist philosophy promotes a way of life that will lead on to good death. It inculcates into people the realization that death can happen at any moment, and everyone should remain prepared for it. Dr. Srivieng Pairojkul added that in some places with practice of Buddhism, there is also a belief that being calm and focused at the time of death will lead the soul to heavenly abode. This belief has led to some people denying morphine to relieve pain near end of life, as it may obscure the thoughts. Advocacy from religious leaders and monks conveying messages that being in pain will anyway affect the heavenly journey has been effective in ensuring morphine acceptance in such scenarios.

Dr. Cherian Varghese pointed out that the health care team has to be able to anticipate death and accept it. They should also be able to help the family in accepting death. This is important to facilitate availing of good quality end of life care to the patient. It is difficult for families to accept death when the discussion happens very close to the time of actual death. So, the discussions must begin much earlier. Proper communication is important while conveying messages about death. It needs to be conveyed as coming from the team working together with the family to ensure proper care for the patient. Health personnel handling patients at end of life should be trained adequately so as to not be personally affected by the death of their patient. He also emphasized that health care providers should make efforts to simplify the process of dying for patients with terminal illness. Knowing the patient's social history is equally important as knowing the medical history. Often clinical experts find it difficult to make a call and let things go even when death seems inevitable. They may fail to convey to the family that the disease

is advancing, and good quality death should be ensured with palliative care. Change in this way of thinking and practice is required now.

Dr. Suresh Kumar brought out one notable example of tradition accepting death is seen in Pashupatinath (Aaryaghat) in Nepal, where a person near the end of life, is taken to the bank of holy river (Bagmati), the family awaits the person's death for days, with a belief that death near holy river helps in attaining salvation. The funeral rites take place once the death occurs.

He put forward the idea that visualizing one's own death is one way to help health personnel provide care in a way as to improve the quality of death of the patient that they are caring for. Practice of serious illness conversation, whereby the clinical team and the patient talk about the patient's goals, values and wishes serves an important purpose in planning care in advance. Attempt should be made to ensure good death to the patient. Good death should be defined in a local context since what is considered as a good death in one part of the world, or one society may be different from that perceived elsewhere. And good death may vary according to a person's wishes and perspectives, last wishes may be important component of a good death.

Dr. Suraj Perera remarked that discussions need to happen on what is an ideal situation of acceptance of death. Would a patient expressing his/her acceptance of it, and requesting for end-of-life care be one such situation? Discussions are also needed on what would be the pathway to achieve the ideal situation.





SESSION: 7

Country Roadmap for expanding availability and access to palliative care



The objective of this session was to develop a draft roadmap for improving availability and access to palliative care in countries by 2025. Each country groups engaged in an exercise to develop a stepwise approach to improve access to palliative care in their respective countries. The exercise was facilitated by a draft guide for the stepwise approach included as working paper for the workshop (annex B). The session was organized as an interesting interactive exercise, which was named as 'Marketplace'. The country roadmaps were presented in flip charts to the whole group and the individuals rewarded countries with the limited fund they were provided, in the distribution based on their individual assessment of the roadmaps. The session was moderated by Dr. Cherian Varghese. The following is the summary of country roadmaps presented:

Bangladesh

Bangladesh plans to ensure initiate and scale up palliative care services with the theme of "Palliative Care for All". The objectives are to:

1. Ensure easy availability and access to palliative care for all, and
2. Raise awareness through sensitization.

The country would begin with a rapid need assessment with stakeholder mapping and engagement.

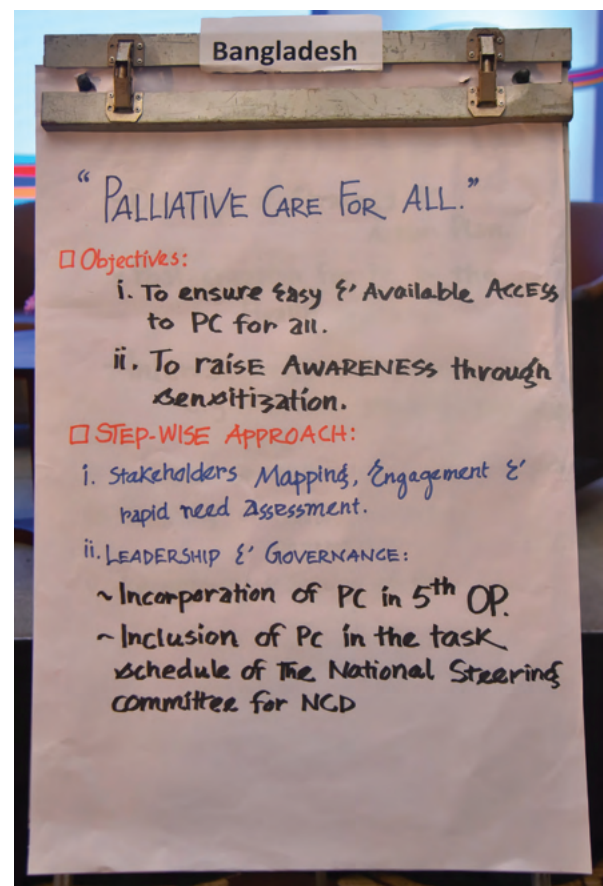
In order to improve leadership and governance, palliative care will be included in the fifth operation plan and in the task schedule of national steering committee for NCDs. Intersectoral collaboration will be promoted. Post would be created in government health system for personnel dedicated to palliative care.

Community sensitization would be carried out. Health workforce development would include doctors, nurses and paramedics. Provisions would be made for recruitment and training of palliative care assistants.

In the pilot phase, besides its regular services Banga Bandhu Sheikh Mujib Medical University will serve as the center of excellence for technical support, oversight, and highest referral. This would be followed sequentially by eight medical college hospitals, eight district hospitals, eight sub-district hospitals and eight union sub-centers. Tele-consultations will be used for ensuring mentoring supervision.

Pilot phase will also have provisions for availability of essential medicines and supplies, data integration into central MIS, systems for monitoring and evaluation and research.

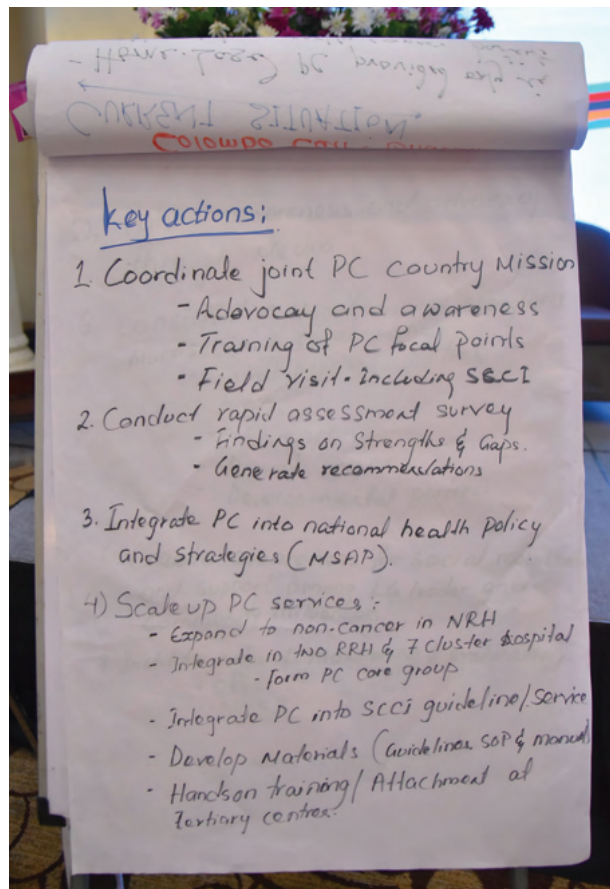
The pilot phase will then be taken up for nationwide scaling up with adaptations.



Bhutan

Bhutan plans to address the current state of cancer centric palliative care, and Thimpu-centered high quality palliative home care by introducing the following key interventions:

1. Rapid assessment of palliative care situation and integration of palliative care into national multisectoral action plan for health.
2. A national consultative workshop on palliative care to promote multisectoral collaboration
3. Scaling up of PC services by
 2. Expanding to other types of patients in addition to those with cancer
 - b. Expanding high quality palliative home care into the regional referral hospitals
 - c. Integrating palliative care into service with care and compassion guidelines
 - d. Hands-on training for primary care personnel in the tertiary care centers
 - e. Public awareness and advocacy through media
4. Social mobilization and support from local leaders and community influencers
5. Robust monitoring and evaluation via electronic patient information system and DHIS2



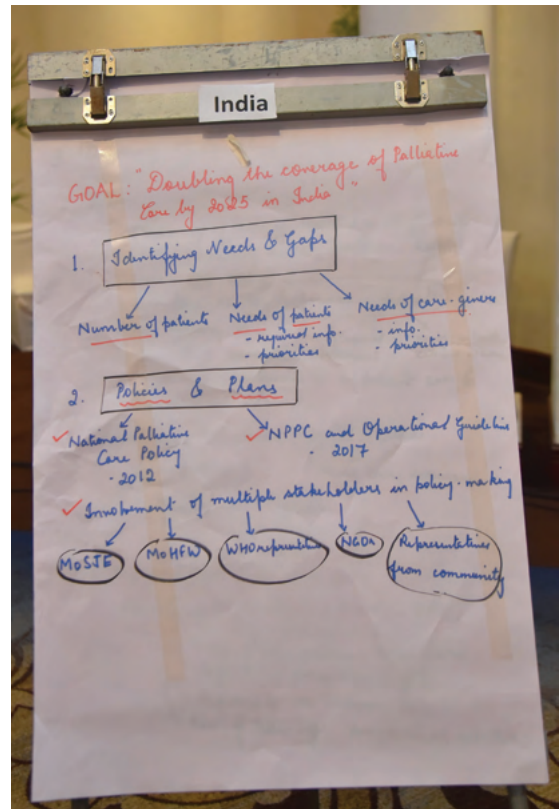
India

India aims to double the coverage of palliative care by 2025. This would be implemented via the following stepwise approaches:

1. Rapid need analysis
2. Multisectoral engagement leveraging on the policy provisions in national palliative care policy 2012 and operational guideline 2017.
3. Service provisions at all levels with clearly defined performance indicators:
 - a. Primary health care level:
 - i. Training of PHC workers, community health workers and Ashas
 - ii. Key performance indicators:
 1. Number of trained personnel
 2. Number of patients catered at home

- b. Secondary (district) level:
 - i. Palliative care outpatient services
 - ii. Palliative care in-patient services
 - iii. Palliative home care services

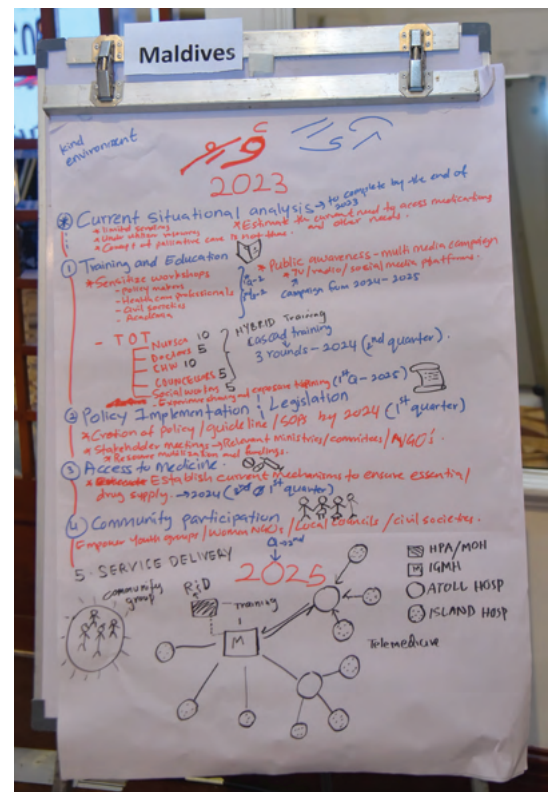
A team of palliative care personnel consisting of doctor and nurses will be made available
 - iv. Key performance indicators:
 - 1. Number of OPD patients
 - 2. Number of admitted patients
 - 3. Number of patients receiving home care
 - c. Tertiary care:
 - i. Specialist palliative care services
4. Ensuring availability of medicines and supplies at all levels
 5. Special focus for populations with special needs, such as children, those with dementia etc.
 6. Engaging the communities.
 7. Robust monitoring systems.



Maldives

Maldives plans to ensure initiate and scale up palliative care services by 2025 in the following steps and timelines:

1. Rapid assessment of current situation – by the end of 2023
2. Training of trainers from among doctors, nurses, counsellors, and social workers – by Q1 2024
3. Creation of policy, guidelines and SOPs - by Q1 2024
4. National stakeholder consultation - by Q1 2024
5. Ensuring availability of essential medicines and supplies for palliative care - by Q1 2024
6. Service delivery - by Q2 2024
 - a. IGMH (Indira Gandhi Memorial Hospital) as the nodal referral and training hub
 - b. Atoll hospitals would be trained and mentored by Indira Gandhi Memorial Hospital



c. Atoll hospitals would support island hospitals

Telemedicine would be extensively employed to ensure mentoring supervision of lower level facility by higher level facility

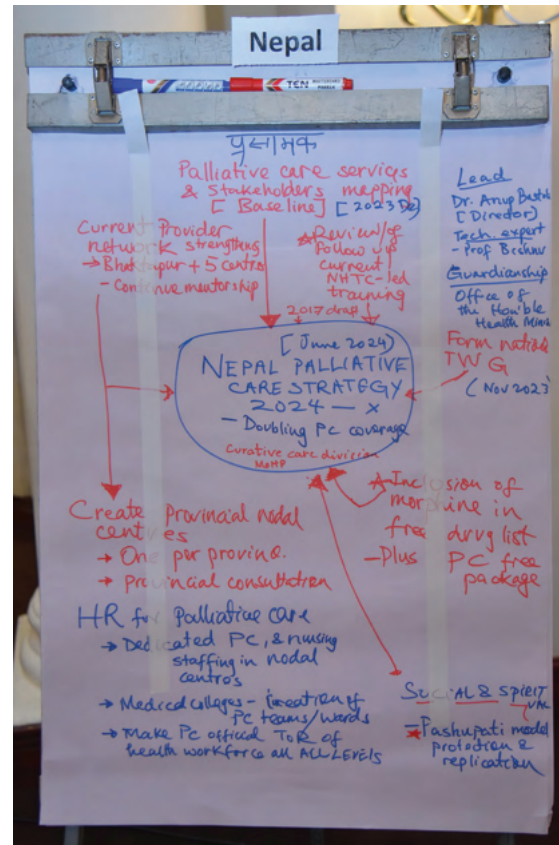
Nepal

Nepal targets to double the coverage of palliative care by 2025 with the following roadmap:

1. Base line rapid palliative care services and stakeholder mapping – by Nov 2023
2. Review and updating of Nepal Health Training Center led training
3. Strengthening of current service providers, creating the network of Bhaktapur cancer hospital and five other major centers (provincial nodal centers to be created)
4. Making provision of national technical working group for palliative care – by November 2023; and developing Nepal palliative care strategy 2024.

Among other things the strategy will make provisions for inclusion of morphine in free drug list and benefit package for palliative care services.

5. Human resource for palliative care:
 - a. Making provision for dedicated palliative care personnel in nodal centers
 - b. Making palliative care official ToR of health workforce at all levels
6. Including social and spiritual aspects in palliative care strategies: promoting and replicating the Pashupatinath model of dignified death and end of life care.

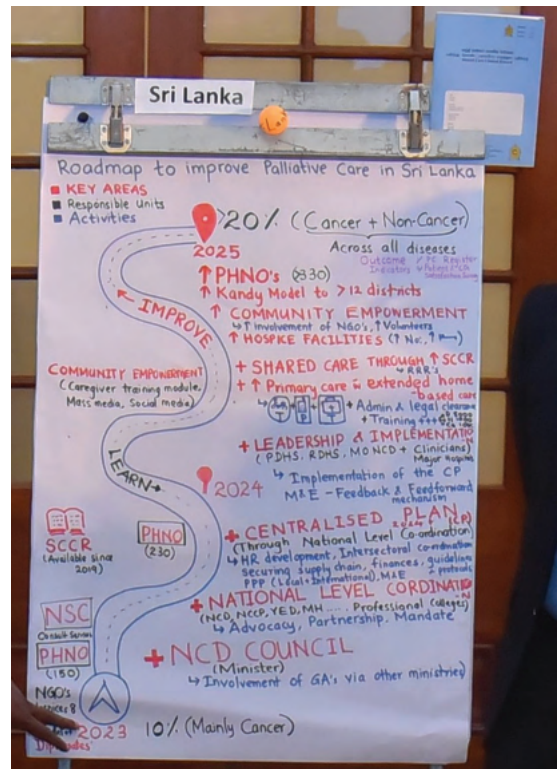


Sri Lanka

Only about 10% of those needing palliative care are estimated to receive services in Sri Lanka. Sri Lanka wants to achieve the coverage of 20% by 2025.

1. Status: The country has palliative care services at tertiary care hospitals, eight hospices, a model of community based palliative care in Kandy, specialist physicians and nurses trained in palliative care are available, there are 150 public health nursing officers providing community based palliative care, and the shared care mechanism is well organized. The national steering committee on palliative care is the central body in the ministry.
2. Palliative care is proposed to be included into NCD Council, that is headed by the minister of health with representation from other ministries. National level coordination mechanism will be established.

- National plan for palliative care will be updated in 2024 focusing on HR, intersectoral coordination, supply chain, clinical guidelines and PPP.
- Leadership in implementation will be ensured by creating a position for medical officer of NCD, and via clinicians in major hospitals.
- At primary care level, home based care will be extended via PHNOs with good transportation and communication facility. Doctors and nurses in primary care level will be trained on palliative care.
- Shared care mechanism will be further expanded. Shared care clinical record will be further refined. Number of hospices will be increased. Involvement of NGOs and number of volunteers will be increased.
- Kandy model will be replicated in more than 12 Districts, number of PHNOs will be increased to 330.
- Outcome will be monitored by using palliative care registers and patient and caregiver satisfaction surveys.



Thailand

Thailand's current coverage of palliative care is 66% for adults and 17% for children. The country plans to increase it to 80% for adults and 35% for children by 2025. Home based care is planned to be increased to 60% and advanced care planning to 70%.

- Policy change will be made to include palliative care at all levels of health care for all age groups.
- Palliative care quality will be improved at all levels of care. At tertiary care hospitals, other specialties will be provided with training on palliative care. Palliative care ward nurse system will be expanded. Primary care nurses and doctors will be provided with four-week training on palliative care.
- Palliative care workforce capacity building will be achieved via training by the academic division of MOPH.
- Referral networks and community based palliative care will be strengthened. Community based palliative care will be led by nurses.







3 | Next steps



Country dialogue: For countries in initial phase of palliative care development a national consultation engaging all significant stakeholders may be the first step to take stock of the situation and proceed to scale up services. The focal point for coordinating or leading the activities at ministry level should be identified.

Formulating policies: Where a deficiency of policy provision is felt, steps should be taken to address them. A country consultation can facilitate beginning of this process. The policies should adhere to palliative care as component of UHC with defined allocation of required resources.

Building capacity in palliative care with focus on primary health care workers: Palliative care needs to be included in the curriculum of medical, nursing and paramedical courses when not already done. In service training should be provided to health personnel at all levels. Existing available human resource, such as nurses and paramedics, need to be mobilized.

Defining standards of care for various levels: This can be adapted from countries such as Sri Lanka and modified for the country context. While doing so palliative care should be integrated into mainstream health care.

Developing local model based on local culture and practices: the model of palliative care should be suitable to local socio-cultural context, and it should also leverage on the local community strengths.

Dignified death, and optimal medical intervention: Clinical practice guidelines need to be developed and practice change be effected to facilitate dignified death and avoidance of medical interventions of limited benefit.

4 | Annexes

A. Message from Regional Director

Dignitaries, officials from the Ministry of Health from Member States, experts, colleagues, ladies, and gentlemen. Good morning and welcome to the workshop on expanding availability and access to palliative care.

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers.

About ten million people in the South-East Asia region are estimated to be in need of palliative care, accounting for about seventeen percent of the global needs. Close to sixty-nine percent of the need for palliative care is due to non-communicable diseases including cancers and stroke. With the anticipated rise in the burden of non-communicable diseases and ageing populations, the need for palliative care is expected to continue to grow.

It is worth emphasizing that timely delivery of palliative care to the needy person reduces unnecessary hospital admissions, thus preventing the diversion of health care resources by availing more cost-effective approach. Reducing sufferings is one of the core components in achieving universal health coverage.

South-East Asia region has prioritized and worked with Member States in strengthening palliative care. Palliative care is part of regional flagship on noncommunicable diseases and integration of palliative care into primary health care has been included in the implementation roadmap for accelerating prevention and control of noncommunicable diseases in South-East Asia.

All countries in the region have included palliative care in policies, mostly as part of cancer or NCD policy. Five countries have reported palliative care services being generally available at community or home-based settings and, in one country palliative care is in preliminary stage of integration into mainstream health care services. Palliative care is gradually increasing its focus from cancer to a wider group of conditions. Oral morphine is generally available in primary care facilities in four countries.

Some notable models of community based palliative care, such as the one in Calicut, India, are adapted and operational in member states. Provisions for patient's home visit by health workers such as those in PHCs in Bhutan and through Saúde na Família in Timor-Leste are some more exemplary initiatives.

Availability of health care personnel trained in palliative care is of fundamental importance in providing services. WHO and its collaborating centers are supporting the Member States' efforts in building human resource capacity through provision of short- and longer-term trainings, via virtual or hands-on modality. Bangladesh, India, Sri Lanka and Thailand have recognized medical postgraduate trainings in palliative care. Bhutan has recently included a significant component for palliative care in its curriculum for the training of Health assistants. Utilization of the available human resource in nursing for delivering palliative care at community is well implemented in Sri Lanka.

We have been advocating for a healthy and dignified life for all. With this workshop let's also intensify the conversation on dignified death. Bereavement support is also essential to help families to cope with their loss.

The demand for palliative care being huge, the current efforts must be scaled up significantly further. Countries must prioritize palliative care and work in expanding availability and access by:

First, identifying gaps in policy and plans and ensuring that palliative care is addressed as a part of universal health coverage by including in benefit packages and social welfare schemes, and that legislations are in place for facilitating access to narcotics and pain relief. It must be ensured that palliative care is integrated into mainstream health services at all levels and the focus be maintained in delivering palliative care services from community level.

Second, developing capacity for human resources training in various disciplines for all levels of health care services and building the capacity of existing health care personnel to provide palliative care. Guidelines and protocols must be developed for management of common symptoms and mechanisms for efficient referral should be established with provision for mentoring supervision of community level health facilities providing palliative care. Opportunities should be sought to utilize existing human resources including nursing and paramedical personnel.

Third, ensuring uninterrupted availability of medicines and consumables for palliative care by including them in the routine supply chain management at par with other health care commodities.

Fourth, implementing mechanisms for monitoring and evaluation with agreed set of indicators. Resources are available for identification of indicators relevant to country needs. The outputs of monitoring and evaluation exercises should feed back to improve the service delivery.

Member states in early phases of palliative care service development may consider taking a phased approach, beginning interventions from places with relative ease for implementation and gradually expanding to other areas with adaptations based on learnings from preceding phases.

I am hopeful that this workshop facilitates sharing of good practices and learnings from across countries in the region and will be helpful in further strengthening the countries' capacity to provide palliative care services to its people.

I wish you all a very productive workshop and a good stay in Sri Lanka. I look forward to receiving the outcomes of the workshop.

Thank you.

B. Workbook

South-East Asia Regional workshop on expanding availability and access to palliative care

PARTICIPANT WORKBOOK

Name:

Country:

Colombo, Sri Lanka

11-13 October 2023



Background and objectives

Background

About ten million people in the South-East Asia region are estimated to be in need of palliative care, accounting for about seventeen percent of the global needs. Close to sixty-nine percent of the need for palliative care is due to non-communicable diseases including cancers and stroke. With the anticipated rise in the burden of non-communicable diseases and ageing populations, the need for palliative care is expected to continue to grow. Timely delivery of palliative care to needy persons reduces unnecessary hospital admissions.

In the 2021 WHO NCD country capacity survey, less than half of the countries in SE Asia Region reported that palliative care was 'generally available'. A 2020 survey on palliative care situation in SE Asia Region found a significant variation between countries in availability of services in the region. Home based palliative care is available in small pockets across most countries. Provisions for patient's home visit by health workers in public health system, such as those in PHCs in Bhutan and through Saúde na Família in Timor-Leste are some exemplary initiatives. Palliative care specific for children is available sparsely across the region. Palliative care is seen to be gradually extending its focus from cancer to wider group of conditions.

It is estimated that globally only 14% of patients who need palliative care receive it; to achieve Sustainable Development Goal 3, working towards universal health coverage, countries have to make available, and strengthen palliative care services.

Substantial effort is needed to make palliative care available and accessible to the people in need. This workshop is being organized as an effort to support countries in bring palliative care into priority at policies and strengthen the capacity to plan and implement programs for palliative care

Objectives of the workshop:

1. To support countries to review the current status of palliative care services and to identify gaps in access and availability.
2. To identify opportunities to enhance human resource, including the increased role for nurses, to improve availability and access to palliative care in community.
3. To support adoption of guide for expanding availability and access to palliative care and development of country specific plans.

List of participants

South-East Asia Regional workshop on expanding availability and access to palliative care

Colombo, Sri Lanka
11 to 13 October 2023

Date: 12 June 2023

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Program

Day 1: 11 Oct 2023, Wednesday

Time	Session Details	Speakers / Moderators
09.00-09.10	Inaugural Session: Setting the scene, scope, and purpose	
	Inaugural ceremony	
	Opening remarks from RD read by Dr. Alaka Singh, WR Sri Lanka	Dr. Poonam Khetrapal Singh <i>Regional Director, WHO Regional office for South-East Asia</i>
	Remarks by officials from Ministry of Health, Sri Lanka	Dr. Asela Gunawardana <i>DGHS, Chair: National steering committee on palliative care</i>
		Dr. Lakshmi Somatunga <i>Additional Secretary (Public health services)</i>
	Scope and purpose of the workshop	Dr. Cherian Varghese <i>WHO Regional Office for South-East Asia</i>
09:45 – 10:15	Photo Session and tea break	
10:15 – 10:30	Introduction of participants	
10:30 – 12:00	Session 1. Global experience and regional situation of palliative care	Dr. Lakshmi Somatunga, Sri Lanka Dr. Srivieng Pairojkul, Thailand
10:30 – 10:45	Development of palliative care in LMICs - what worked?	Dr. Eric L Krakauer, Harvard Medical School, USA
10:45 – 11:00	Situation of palliative care in South-East Asia Region	Dr. Bishnu Rath Giri, WHO SEARO
11:00 – 11:15	Expanding access to palliative care - learnings from the region	Dr. Suresh Kumar, Institute of Palliative Medicine, India
11:15 – 11:30	Discussion	
11:30 – 13:00	Panel discussion (including Q and A with audience): <i>Factors facilitating the development of palliative care in the region</i> Panel: Dr. Suresh Kumar Dr. Bishnu Paudel - Nepalese Assoc. Palliative Care Ms. Smriti Rana - Pallium India Dr. Md Shahidul Islam - MoH Bangladesh Mr. TKA Nair - Trustee Citizen India Foundation Dr. Udayangani Ramadasa - Sri Lanka Med Assoc (Palliative and end of life care task force)	

Time	Session Details	Speakers / Moderators
13:00 – 14:00	Lunch Break	
14:00 – 14:30	Session 2. Multisectoral partnership in palliative care	Smt. Sarita Nair, India Dr. Gampo Dorji, WHO Nepal
14:00 – 14:10	Role of civil society organization in developing palliative care in national context	Dr. Bishnu Dutta Paudel
14:10 – 14:20	Partnerships in scaling up palliative care	Ms. Smriti Rana
14:20 – 14:30	Implementing palliative care programs at sub-national level – Opportunities in local governments	Dr. Catherine Lalmuanawmi, India
14:30 – 14:40	Discussion	
14:40 - 16:15	Session 3. Progress in palliative care in countries	
14:40 – 15:20	Country presentation (PowerPoint) 6-minute presentation and 4-minute discussion for each country	Dr. Anup Bastola, Nepal Dr. Fahmida Alam, Bangladesh
15:20 – 15:35	Healthy break	
15:35 – 16:15	Session 3 - Progress in palliative care in countries - Country presentations continued	
16:15 – 17:00	Group work 1 What are the notable examples of initiatives in countries that have potential for adaptation elsewhere, to address the gaps in access to palliative care. (To feed into group work 2)	Dr. Bishnu R Giri

Day 2: 12 October 2023, Thursday

Time	Session Details	Speakers / Moderators
09:00 – 09:15	Recap of Day 1	Mr. Pema Lethro, WHO Bhutan
	Session 4. Key elements in palliative care service delivery	Dr. Shalini Kelkar, India Ms. Tshewang Lhaden, Bhutan
09:15 – 09:30	How can health care systems be made ready to deliver palliative care with focus on managing symptoms?	Dr. Eric L Krakauer
09:30 – 09:40	Community based palliative care: how to start and sustain?	Ms. Yangden, Bhutan
09:40 – 9:50	Role of nurses as a key resource for palliative care	Ms. Kemachit Mookdadee, NCI Thailand

9:50 – 10:00	Shared care and care coordination - leveraging nursing manpower in delivering palliative care at home - what facilitates success?	Dr. Eshani Fernando, Sri Lanka
10:00 -10:20	Discussion	
10:20 – 10:35	Healthy break	
10:35 – 11:55	Session 5. Models of care and innovations in palliative care	Ms. Aishath Lubana Labeeb, Maldives Dr. Sadhana Bhagwat, WHO Bangladesh
10:35 – 10:45	Service delivery models with community participation	Dr. Samadhi Rajpaksa, Sri Lanka
10:45 – 11:00	Monitoring and evaluation in palliative care	Dr. Eric L Krakauer
11:00 – 11:10	Special considerations in palliative care models for children	Dr. Srivieng Pirojkul
11:10 – 11:25	Innovations in palliative care with relevance to South-East Asia Region	Dr. Mostafa Kamal Chowdhury, BBSMMU, Bangladesh
11:25 – 11:45	Discussion	
11:45-12:00	Briefing about field trip	Dr. Virginie Mallawaarachchi, WHO Sri Lanka
12:00 – 13:00	Lunch break	
13:00 – 17:00	Field Trip	
	Group 1: Palliative care unit, National Cancer Institute Sri Lanka, Maharagama, Colombo	Dr. Eshani Fernando / Dr. Lubis Kafi
	Group 2: Shantha Sevana Hospice, Maharagama; Suwa Arana, Maharagama	Dr. Virginie Mallawaarachchi / Dr. Priyangani Silva
	Group 3: Divisional Hospital – Wethara; Medical Officer of Health Office, Kahathuduwa, Colombo	Dr. Suraj Perera / Dr. Atreyi Gan-guli

Day 3: 13 October 2023, Friday

Time	Session Details	Speakers / Moderators
09:00 – 09:30	Field visit observations	Group facilitators
09:30 – 10:45	Session 6. Demystifying death and dying	Dr. Shalini Kelkar, India Ms. Tshewang Lhaden, Bhutan

09:15 – 09:30	<p>Panel discussion and Q and A session with audience: <i>Historical, socio-cultural and religions perspectives on death. How to Change the conversation?</i></p> <p>Panel: Dr. Suresh Kumar Ms. Fathimath Khumaira, Maldives Dr. Suraj Perera, Sri Lanka Dr. Sadhana Bhagwat Dr. Samadhi Rajapaksa</p>	
10:45 – 11:00 <i>Healthy break</i>		
11:00 – 13:00	<p>Session 7: Country roadmap for expanding availability and access to palliative care</p>	Dr. Cherian Varghese
11:00 – 11:20	<p>An approach to improving access to palliative care-prelude to the group work, Instructions for group work and marketplace</p>	
11:20 – 13:00	<p>Group work 2: Improving availability and access to palliative care-each country to develop a roadmap for 2025 (for presentation in the marketplace)</p>	
13:00 – 14:00 <i>Lunch Break</i>		
14:00 – 15:45	<p>Market place: win the funds for implementing your roadmap</p>	
15:30 – 15:45 <i>Healthy break</i>		
15:45 – 16:00	Closing	Dr. Cherian / Dr. Farrukh Qureshi

Session details

Day 1: 11 Oct 2023

Session 1: Global experience and regional situation of palliative care

Session objective: To highlight the successful approaches in expanding access to palliative care.

This session will focus on what approaches and interventions have resulted in a successful establishment and scaling up of palliative care services in low- and middle-income country settings globally. It will also dive into what are the successful models in the countries.

The session will start with presentations on global experience, regional situation, and regional experience. This will be followed by a moderated panel discussion on the factors contributing to the successful models within the region.

The session will help build a base for planning interventions to improve palliative care services in the countries. It will also put caution on what things are to be taken into consideration while planning for or adapting models for palliative care in individual countries.

Session 2: Multisectoral partnership in palliative care

Session objective: To discuss on the role of multisectoral partnership in improving access to palliative care

This session will discuss on the need for engagement of multiple stakeholders from the government, civil society and the private sectors in improving palliative care service delivery. The opportunities that each sector bring in along with its participation and the modalities to leverage on their unique capacities will be discussed. This session will help participants in identifying the key stakeholders in their own country and the ways to engage them in contributing to the plan for expanding access.

The session will have two presentations, one on the role of partnerships, and one exclusively on the role of civil society organizations. This will be followed by open floor discussion.

Session 3: Progress in palliative care in countries

Session objective: To showcase opportunities and successful initiatives in the countries

In this session country teams will present in brief the current situation of palliative care in their respective countries. Notable examples of success and opportunities for scaling up will be shared by the country teams. This will facilitate the other countries to assess whether such successful models could be adapted in their own countries, and what key aspects are to be considered when planning for adaptation.

The session will comprise of presentation from country teams followed by discussion. The discussion will start will inputs from one country (other than the presentation one) which will be randomly selected by lottery after the country presentation. The inputs from the randomly selected country team will include one notable practice and one possible approach to improve the services. The floor will then be opened for discussion.

Group work 1: Notable examples of initiatives

Session objective: To summarize the most important of the initiatives

This group work will help synthesize the best practices leading to success in the countries. Groups will be formed of participants from different countries. The groups will discuss within themselves on what were the notable examples of initiatives and what may have led to the success. Focus will be on the initiatives with potential for scale up and adaptation elsewhere.

To facilitate the process, groups will identify among themselves one moderator and one rapporteur. The groups will prepare a document summarizing the discussions and upload in the google drive link being shared.

Group works outputs from all the groups will feed into group work two where country teams will prepare a roadmap for expanding access to palliative care on day 3.

Day 2: 12 Oct 2023

Session 4: Key elements in palliative care service delivery

Session objective: To discuss on the most important elements in systems for palliative care services.

This session will discuss on some of the major basic elements in palliative care service delivery. The areas of focus will be on making symptom management as core function of palliative care services, community-based care as the primary approach for service delivery, having strong mechanism for care coordination and shared care and harnessing the nursing and other allied health care workforce in effective delivery of palliative care.

This session will help participants to identify if there are any major missing elements in existing palliative care services in their own country and in introducing and designing an appropriate intervention.

The session will have four presentations and will be followed by open discussion.

Session 5: Models of care and innovations in palliative care

Session objective: To discuss the various models of palliative care services and innovations pertinent to the region

This session will have discussion on the various models of palliative care which could be adapted in the countries in the region. Models of care with focus on primary health care will be the focus. Systems for monitoring and evaluation of services will also be covered. Special considerations in palliative care models for children will be discussed. And the session will finally discuss on innovations that are being implemented or are useful for the region.

This session will help participants in deciding on the models suitable for their own countries and the innovative approaches that could be incorporated into the roadmap for expanding access to care.

The session will have four presentations followed by open floor discussion.

Field visit

Objectives of field visit:

- To provide the participants with an opportunity to observe the typical settings for palliative care service delivery at tertiary level health facilities, hospice, and community level.
- To provide the participants with an opportunity to observe the expertise and human resource required for palliative care delivery at various levels of health care.
- To provide the participants with an opportunity to observe the care coordination and organizing of service delivery in various models of care including innovations and improvisation of available resources to best suit the local needs.

Groups:

Participants will be joining one of the three field visit groups in the afternoon on day two. Each group will visit one of the following sites:

Group 1:

Palliative care unit, National Cancer Institute Sri Lanka, Maharagama

Group 2:

Shantha Sevana Hospice, Maharagama;

Suwa Arana, Maharagama

Group 3:

Divisional Hospital – Wethara;

Medical Officer of Health Office, Kahathuduwa

Activities during field visit:

The following is a general guide on the activities during the field visit which may be adjusted as per the needs of the visit site.

- Walk through observation of Palliative care consult service
- Interaction with the health care providers will be the main modality of information exchange. The following could be the broader areas of discussion:

Common reasons for the patients to be seeking care

Most common symptoms requiring palliative care

Expertise availability and the trainings received

Medicines, consumables and supplies requirement and the supply chain management

Records and data management

Coordination higher or lower level of care and with other and referral management

Collaboration with civil society organizations

Communication with families and initiation of process of home visit

Engagement in education and research

Managing the funds and the challenges if any

The group would identify one member to share their observation details with the participants in the other groups in the main meeting venue on the next day.

Each group will have six minutes to present and four minutes for open floor discussion.

Day 3: 13 Oct 2023

Field visit observations

In this short session the members from each field visit group will share the observations made during the field. This will be a six-minute presentation by selected group members followed by an open floor discussion.

Session 6: Demystifying death and dying

Session objectives: To stimulate thoughts on the concept of dignified death

This session will have a moderated panel discussion on historical, socio-cultural and religious perspectives on death. This session will facilitate in bringing out the various aspects of dignified death in various cultures. The session will help participants in embracing the ideas for reducing suffering by avoiding medical interventions with limited benefit while allowing for more personal and family comfort. This is expected to help participants in planning end of life care with the patient and the family at the center.

Session 7: Country roadmap for expanding availability and access to palliative care

Session objectives: To develop a roadmap for improving availability and access to palliative care in countries by 2025.

This session will introduce the step wise approach to improving access to palliative care in the country. The approach is included as the working paper in this workbook after the session descriptions.

The country groups will then work in preparing a roadmap for improving access to palliative care in their countries. The roadmap will be presented in flip chart to all the other participants in what is named as marketplace.

Each participant will be provided with a fixed sum of funds prior to the presentations. Following the presentations of all the roadmaps, the participants will award the funds to one or more groups, other than their own country, in whatever proportion they deem appropriate.

The groups securing the highest amount of funds will be declared as winner.



South-East Asia Regional workshop on expanding availability and access to palliative care

WORKING PAPER

Colombo, Sri Lanka

11-13 October 2023





Table of contents

1. Introduction	67
2. What is palliative care	68
2.a. Definition of palliative care	68
2.b. Common signs and symptoms in palliative care	68
3. WHO's work on palliative care	69
4. Status of palliative care services in South-East Asia Region	70
5. Systematic approach to expanding availability and access to palliative care	72
6. The palliative care round table	73
6.a. Pillars to steady the table	73
6.b. Connectors for reinforcement	75
7. A Stepwise approach to enhance services and coverage for palliative care	77
8. Palliative care stories from South-East Asia Region	84
9. References	87
10. Annexes:	88
I. Considerations for providing palliative care and principles of common symptom prevention and relief	88
II. Tool to assess the status of palliative care	108



List of acronyms and abbreviations

AIDS	Acquired Immunodeficiency Syndrome
CBPC	Community-based palliative care
CBR	Community-based rehabilitation
COPD	Chronic Obstructive Pulmonary Disease
EPPC	Essential Package of Palliative Care
ESAS	Edmonton Symptom Assessment System
GPS	Glasgow Prognostic Score
HCP	Health Care Professional
HIV	Human Immunodeficiency Virus
IP	In-patient
KPS	Karnofsky Performance Scale
MD	Doctor of Medicine
MPI	Modified Prognostic Index
NCD	Noncommunicable Diseases
NLEM	National List of Essential Medicines
NPWD	Negative Pressure Wound Dressing
NSAIDs	Non-Steroidal Anti-inflammatory Drugs
OP	Out-patient
PC	Palliative Care
PHC	Primary Health Care
PiPS	Prognosis in Palliative Care Study
PPS	Palliative Performance Scale
SEARO	South-East Asia Regional Office
SPICT	Supportive and Palliative Care Indicators Tool
TB	Tuberculosis
TENS	Transcutaneous Electrical Nerve Stimulation
UHC	Universal Health Coverage
WHA	World Health Assembly
WHO	World Health Organization



Introduction

Availability and access to palliative care services are limited by many factors and there is a huge unmet need. This working paper presents a draft guide which covers the general principles and basis of palliative care service delivery. It presents the core components needed to strengthen palliative care in a country and proposed ten steps to expand availability and access to palliative care services. It is intended for national programme managers and health providers who are planning or implementing palliative care services. It would be useful for policy makers (at national/ state/ provincial levels) as well as mid-level managers at implementation level. Though the guide describes expansion of services in ten steps, there is no single best starting point for all settings. Some of the steps are complementary and could also be initiated at the same time, depending on capacity and national context.

What is palliative care?

a. Definition of palliative care

WHO defines palliative care as an approach that improves the quality of life of patients – adults and children – and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during a patient's illness and their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹

Palliative care aims to alleviate and prevent suffering by catering to patients' physical, psychological, social, and spiritual needs and supporting their families and care givers. By providing comprehensive and empathetic care, palliative care can improve the quality of life for patients and their families and lessen the burden of serious illness, provide financial risk protection for families, and may reduce costs for health care systems.²

Given the multifaceted nature of serious health-related suffering advanced illness and dying, it is essential to provide social, psychological, and spiritual support alongside medical care. This holistic care can be best achieved by a diverse team of individuals from various backgrounds within and outside the healthcare system. Palliative care providers work collaboratively with patients, their families, and local agencies to address physical symptoms, offer social, emotional, and spiritual support, and assist with daily activities.

b. Common signs and symptoms in palliative care

Patients with advanced and/or life-threatening illnesses suffer from various symptoms. The most common symptoms are fatigue, pain, depression, anxiety, confusion, breathlessness, insomnia, nausea, constipation, diarrhea, and anorexia. These symptoms may have different causes, such as the illness itself, treatments they receive, other health problems or medications they take. The basic principles of management of the most common signs and symptoms are given in Annex I.

WHO's work on palliative care

The World Health Organization (WHO) stresses the importance of integrating palliative care into all health systems, including primary care providers, generalists, and specialists with varying levels of training in palliative care. The WHO also recommends that patients have access to palliative care services at all stages of their illness, not just at the end of life.

In 2014, The World Health Assembly (WHA) adopted a resolution (WHA resolution 67.19) on strengthening palliative care as a component of comprehensive care throughout the life course.³ The resolution recognized that access to palliative care contributes to the realization of the right to the highest attainable standard of health and well-being. It also acknowledged that palliative care is an ethical responsibility of health systems and that it is the ethical duty of healthcare professionals to alleviate pain and suffering. The resolution noted the need for continuing education and adequate training for all hospital- and community-based health care providers and other caregivers. Additionally, the resolution emphasized the need for health services to provide integrated palliative care in an equitable manner to address the needs of patients in the context of universal health coverage. The resolution urged WHO and Member States to improve access to palliative care within health systems, with an emphasis on primary healthcare and community/home-based care. This can be achieved by implementing policies, training personnel in basic and advanced palliative care, making essential medicines and supplies available at affordable prices, and funding clinical services.

The WHO has developed guidelines and training programs to help healthcare providers integrate palliative care into their practices and improve the quality of care for patients with serious life-threatening illnesses.

WHO guidance for palliative care

1. Integrating palliative care and symptom relief into primary health care- A WHO guide for planners, implementers and managers²
2. Planning and implementing palliative care services: A guide for programme managers⁴
3. Integrating palliative care and symptom relief into paediatrics: A WHO guide for health care planners, implementers and managers⁵
4. Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide⁶
5. WHO Guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents⁷
6. Assessing the development of palliative care worldwide: a set of actional indicators.⁸
7. Quality health services and palliative care: practical approaches and resources to support policy, strategy and practice⁹

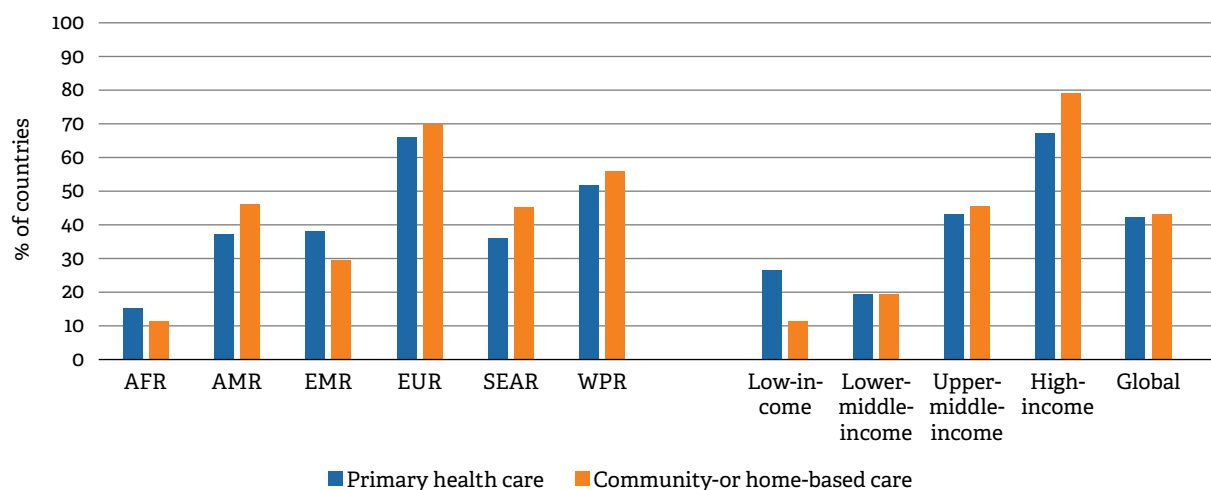
The need for palliative care has never been greater and is increasing at a rapid pace due to ageing of the world's population, increases in cancer and other non-communicable diseases, and the recent emergence of COVID-19. By 2060 the need for palliative care at the end of life is expected to double. Pandemics such as that due to COVID-19 can generate a need for integrated life-sustaining treatment and palliative care on a massive scale.¹⁰

Status of palliative care services in SEAR

WHO conducts NCD Country Capacity Surveys (NCD CCS) every two years to develop country capacity profiles, monitor progress, and identify gaps and unmet needs.¹¹

As per the NCD country capacity survey 2021, the South-East Asia Region reported 73% of countries having funding allocated for palliative care. Palliative care in 36% of countries of South-East Asia Region was reported as being 'generally available' (operationalized as *reaching 50% or more patients in need*) in primary health care setting and 45% of countries in community or home-based care setting indicating that palliative care availability in the Region is low, regardless of the setting in which it was provided.¹¹ The study did not assess the quality or comprehensiveness of palliative care.

Figure 1: Countries with palliative care reported as being “generally available” in a primary healthcare setting or community- or home-based care, by WHO region and World Bank income group



AFR: WHO African Region; AMR: WHO Region of the Americas; EMR: WHO Eastern Mediterranean Region; EUR: WHO European Region; SEAR: WHO South-East Asia Region; WPR: WHO Western Pacific Region.

Source: NCD Country Capacity Survey 2021

In 2021, the WHO Regional Office for South-East Asia also commissioned a situation analysis of palliative care in the Region’s 11 Member States where Government officials of the Member States and key informants involved in palliative care services responded to a semi-structured questionnaire and interviews.¹² The survey indicated that there were substantial differences in the level of palliative care provision among the countries in the Region. Few countries have dedicated programmes for palliative care while some have National cancer plan and NCD plans incorporating palliative care. Guidelines are available in majority of the countries. Palliative care is included in Primary health care in most countries and several countries have services based at hospital collaborating with hospice. Majority of countries have community-based/home care services though they do not cover all those who need the services. Service provision is highly variable with focus on cancer while non-cancer conditions are also taken into consideration to a lesser extent.

There are dedicated human resources at the Ministries of Health for palliative care in some of the countries. Provisions for palliative care specialisation (M.D. Palliative Medicine and Diploma) and incorporation of palliative care into undergraduate curricula for medical or nursing is present only in some of the countries. All countries have a National List of Essential Medicines (NELM) and reported that all items in the WHO List of Essential Medicines in Palliative Care are included in the NLEM. However, excessive fear of opioid side effects, addiction, and diversion have resulted in excessively restrictive opioid prescribing regulations, in all countries

Despite the presence of a national palliative care policy in almost all countries of the Region, face challenges in implementation due to inadequate trained human resources, misunderstandings about palliative care among health care providers and recipients and care givers. The analysis shows that the background of palliative care services, their drivers and the barriers to their development and mainstreaming are too complex to be tackled by a single strategy.

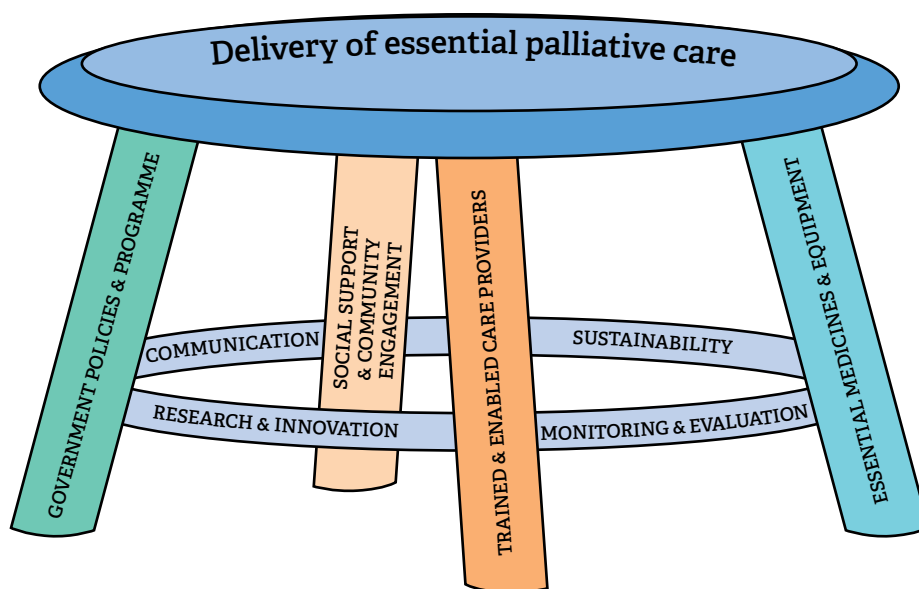
A systematic approach to expanding availability and access to palliative care

Availability and accessibility of palliative care services are essential to achieve universal health coverage (UHC). The South-East Asia, Action plan for the prevention and control of NCDs 2022 to 2030¹³ and the Implementation Roadmap for accelerating the prevention and control of NCDs in South-East Asia 2022–2030,¹⁴ recognize the need to enhance access to palliative care. The roadmap recommends enhancing policies, strategies, and plans, as well as increasing the availability of opioids.

The palliative care round table

A solid foundation is necessary to ensure the long-term effectiveness and sustainability of palliative care services. The foundation of palliative care is described using a round table which depicts the four essential pillars and the connectors to reinforce them (Figure 2). The round table also signifies that all pillars and partners are equal and will have to come together with the patient at the center of the programme.

Figure 2: The palliative care round table



a. Pillars to steady the table

i. Government policies and programmes

Government policies and resources are vital for palliative care service development. A dedicated national policy with adequate human resources and specific budget allocation is necessary and is a major pillar to keep the table steady. The policy should have provision for effective coordination between health care, social care, and community agencies. Including provision of palliative care services as a part of the national health policy is recommended to ensure collaboration with stakeholders, build the system's capacity to address patients' needs in palliative care, and strengthen human resources and training.

Governments should take policy-level steps to incorporate palliative care into the professional training of doctors and nurses, starting from the most basic levels. This is especially pertinent as there are minimal attempts to integrate palliative care into medical and nursing curricula in the region. Governments should provide the required resources and assistance to ensure seriously ill patients can access consistent psychosocial support, including trained counsellors and in-kind support such as food packages or cash transfers as needed. Governments should establish norms

regarding end-of-life care, rather than leaving this primarily to the healthcare or medical system. Such norms, guidance and Standard Operating Procedures will help to deliver palliative care with a strong backing and will make the providers more confident.

Formal healthcare delivery systems should focus on defining the roles and responsibilities of primary, secondary, and tertiary levels concerning palliative care. This could avoid duplication of services and capacity building at each level to achieve quality patient care and strengthen the referral chain.

Home care with supervisory/supportive mentoring is one of the components for service provision along with the services provided at primary health center, community, and hospital settings. Effective communication between healthcare providers at various levels is essential for successfully integrating palliative care into healthcare services. Mental health support to patients in need of palliative care and their caregiver should be provided. Team-based care (the need for inter disciplinary care) is required to support patients and their care givers.

While the development of the health system is essential, the urgent need for palliative care cannot be neglected. While improving the health system is a continuing challenge for most of the countries in the region, it is not acceptable to postpone the development of palliative care until the health system is functioning optimally. Such a delay perpetuates unnecessary suffering for millions of patients and their families who cannot wait for the health system to develop. Instead, a strategy to build care around what already exists in these communities must be developed to provide at least some relief and improve the quality of life for those suffering.

Palliative care is a crucial part of integrated, people-centred health services. Relieving serious health-related suffering, be it physical, psychological, social, or spiritual, is a global ethical responsibility. Thus, whether the cause of suffering is cardiovascular disease, cancer, major organ failure, drug-resistant tuberculosis, severe burns, or end-stage chronic illness, palliative care may be needed and must be available at all levels of care. In contrast to high-income countries focusing on integrating palliative care within the health system, low and middle-income countries face a dual challenge of inadequate health systems and a high demand for palliative care that remains largely unmet

Innovative financing mechanisms may be devised (funding through local support groups, corporate social responsibility support, public-private partnerships (with civil society organizations etc.) to ensure sustained palliative care services.

ii. Social support and community engagement

The second pillar is about involving nonhealth sectors and the informal care system by engaging the community. Government sectors such as social welfare and local government schemes should be brought into support palliative care. The term 'community-partnered palliative care' refers to the involvement of community members in planning, organizing, operating, and controlling palliative care services. The main focus is to make the community members take responsibility for making services available, rather than solely relying on healthcare professionals.

Community-centered palliative care aims to unite the formal and informal elements of care by bringing together health and social care providers with community support systems. The objective is to improve the effectiveness and efficiency of the system. This community-based approach places the person in need of palliative care at the center of the care process, recognizing that they are naturally situated at home or in their community, where they can be supported by family, friends, and neighbors. The broader community is responsible for providing social support to meet the patient's needs.

Governments can also work with civil society organizations to raise awareness about the importance of social care in palliative care and to provide training and support to caregivers and volunteers who provide social care services. The healthcare system and professionals should work to support this primary support system to minimize the patient's pain and suffering. Community engagement can take many forms, such as educational campaigns, fundraising events, volunteer programs, and partnerships with local organizations, all aimed at understanding the challenges faced by patients requiring palliative care and working together to provide them with the necessary support and resources.

iii. Trained and enabled care providers

The third pillar of palliative care involves integrating palliative care into all levels of healthcare services. It is crucial to ensure that patients receive comprehensive care focused on improving their quality of life. Healthcare providers should receive training on assessing and managing symptoms associated with serious illnesses and communicating about appropriate goals of care and end-of-life care with patients and their families.

A standardized curriculum with skills and competencies for different levels of health providers can be a big help to ensure that those who are trained will have some minimum standards.

Formal courses should be developed and widely disseminated. Basic palliative care should be part of the curricula of all health providers. Graduates and postgraduates in medicine and nursing should get posting in palliative care during their course to get a firsthand understanding of these services.

Web based courses can help to bridge the gap and also for continuous improvement in skills and capacity. Volunteers and lay providers have to be trained and locally relevant approaches can be used.

iv. Essential medicines and equipment

The fourth pillar is access to medicines and technology. Essential medicines and equipment should be available at all levels of healthcare. The initial stages of palliative care development are likely to place a special emphasis on the accessibility and appropriate use of opioids and other essential medicines and technology. All health systems should establish a system to monitor the flow of opioids from import or manufacture to use by the patient. Provincial & National governments must ensure a caring environment via informed decisions, including solid policies, access to essential drugs & availability of care devices. Access to opioids is important in the provision of palliative care. However, this needs not be the starting point. There are options to manage pain without opioids and also many other signs and symptoms are there to be managed. Steps to get access to opioids should be taken up and delivered as needed as per the national guidance and regulation.

Equating palliative care to opioid access is not helpful and lack of access to opioids should not be a reason to say that palliative care is not possible. Providers will get confidence as they start palliative care and use non opioids and simultaneously there should be efforts to get opioids to be used by trained providers.

b. Connectors for reinforcement

i. Communication and networking

Communication and networking are essential practices in primary palliative care. Palliative care services require skills in managing the complications of disease (and treatment), managing signs and

symptoms, providing psychosocial care for patients and families, and caring for the dying and the bereaved. Additionally, the palliative care team should also have skills in communication, decision-making and spiritual understanding. Understanding these roles and responsibilities helps a palliative care team function effectively, and helps inform training needs. All palliative care providers share a responsibility for communication and information transfer. There should be a smooth transfer of medical information between the different health professionals responsible for patient care. Where appropriate, this involves efficient exchange and sharing of medical records between community and tertiary-care teams. Providers need special focused training in management of both physical and emotional problems, as well as in communication.

ii. Research and innovation

Start with a few conditions, identify a model, and demonstrate sustained services. Learn and expand availability and access. Digital solutions are widely used and consider their application in supporting palliative care service provision. Teleconsultations can help. Dedicated apps can help to bring together providers and those in need. Implementation research can help to identify suitable models for different settings.

iii. Monitoring and supportive supervision

Develop a culturally appropriate and validated measurement tool that can easily be incorporated into practice. Measure outcome every month and every quarter and identify outcome indicators.

iv. Sustainability

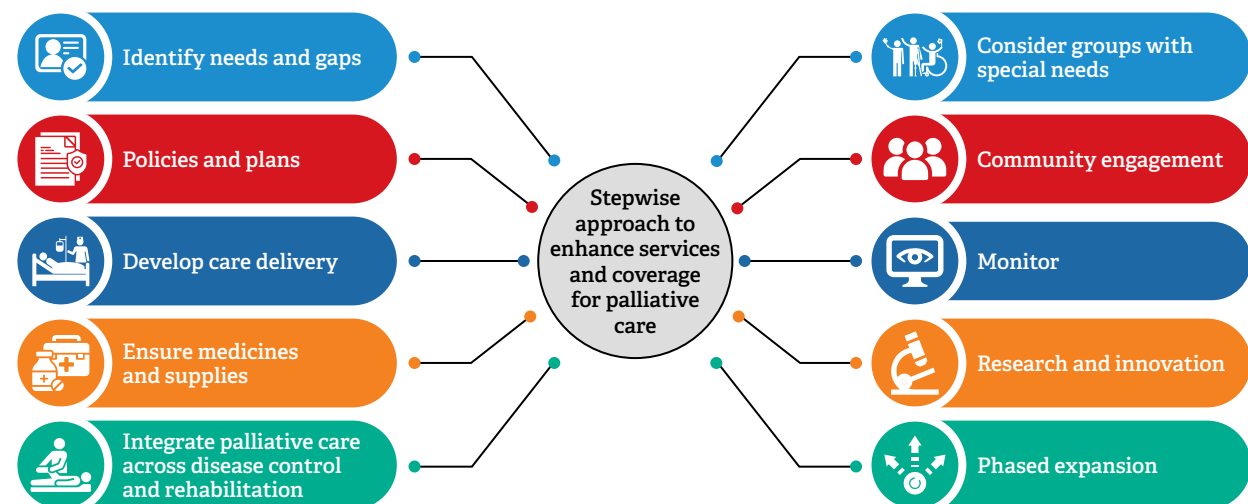
Government support and resources are key to sustainability. Palliative care by civil society organizations and volunteers also need to keep sustainability as a key element as once services are started, they should be continued. Involve the maximum possible stakeholders in the planning to develop capacity in the community. Establish good rapport with the communities and stakeholders. Provide factual information about palliative care to the stakeholders and potential lay person carers. Maintaining collaboration with hospitals, home-care organizations, NGOs etc. to ensure the continuity of care. Enhancing participation from different stakeholders to implement the action plan can facilitate sustainability.

A stepwise approach to enhance services and coverage for palliative care

A practical approach to expand the availability and access to palliative care in the countries would be to develop short-term national and subnational plans to maximize access within the current system while also devising long-term plans for improvements and corrections.

Though the guide describes expansion of services in a series of steps, there is no single best starting point for all settings. The steps presented in this manual are options to consider in the national context. Some of the approaches are complementary and could also be initiated concurrently, depending on capacity and context. The steps should be re-visited with the gradual expansion of programmes.

Figure 3: Stepwise approach to enhance services and coverage for palliative care



1. Identify needs and gaps

A multidimensional assessment of physical, emotional, social, spiritual, and cultural needs, values and preferences of patients and families is useful to understand the palliative care and gaps in the national context. Patients and/or their caregivers also have information and communication needs that need to be taken into account. It is important to determine the patient's values and priorities as a prerequisite to formulating the best plan of care.⁴

2. Policies and plans

Develop and implement a policy integrating palliative care into health care: National/subnational level consultations are crucial in developing a comprehensive approach to ensuring palliative care access. The aim of these consultations is to bring together important stakeholders from social welfare, healthcare,

civil society, religious groups, palliative care, and local self-government representatives to identify and address challenges and gaps in the provision of palliative care in their respective work areas or regions. The policies and plans should be made along with the involvement of social welfare, social justice, and other relevant departments. The following areas should be looked into:

- Include Essential Package of Palliative Care (EPPC) in health services
- Availability and official empowerment of trained human resources
- Budget for training, implementation, and evaluation
- Preparedness of the health care system to handle palliative care, the inclusion of palliative care in key performance indicators for primary health care centers, and the availability of specialized services in secondary and tertiary hospitals.
- Availability of social welfare schemes for patients needing palliative and long-term care
- Legislations that impact access to essential narcotics for pain relief and appropriate end of life care are essential components.
- Community engagement in palliative care
- Recommendations to include palliative care in medical and nursing undergraduate curriculums
- Referral criteria for PC patients must be developed and inter-disciplinary conflicts between health professionals need to be mitigated.



3. Develop care delivery

National teams should be formed to develop guidelines for clinical guidelines, capacity building, and community engagement. These teams should have representatives from various stakeholders, including social welfare, health, civil society, palliative care providers, and local or sub national governments. Such collaboration can ensure that the guidelines are comprehensive and address the needs of all stakeholders. Patients in need of palliative care may require support from different levels of palliative care services during the course of their care, and it is important that guidelines include referral pathways in place to ensure a seamless transition for patients and their families.


In most low-and middle- income countries, people in need of palliative care will have substantial challenges in terms of social and economic support. Thus, national palliative care delivery plans should bring in social sector support through government programmes for the economically deprived, as well as other social welfare measures.

National delivery plans for palliative care should be built around the existing informal and formal care systems in countries while considering the need to develop the health system in the future. In any country, the formal health care delivery system consists of three levels of health care, namely primary, secondary, and tertiary, which are operated by public, private, or voluntary sector

Following are suggested key measures to strengthen palliative care at different levels of the health care system.

Identification of the Target Population - to properly identify patients in need of palliative services who would benefit from the interventions available, so the limited resources are well utilized. It will also help in assessing the performance indicators.

Primary Health Care Level	1. Train primary health care staff and allied community workers in palliative care through algorithm-based protocols.
	2. Make palliative care a key performance indicator of primary health care functioning and include palliative care performance as a topic of discussion at regular monthly meetings.
	3. Develop home care services with community participation.
	4. Offer volunteer training programs in patient care and psychosocial support to the local community with the help of local civil society organizations.
Secondary level hospitals	1. Develop full-fledged palliative care departments at tertiary care centers with facilities to train healthcare professionals and look after patients referred for expert care from lower levels.
	2. Allocate health workers, including palliative care physicians and nurses, social workers, physiotherapists, and pharmacists.
	3. Develop training facilities for primary health care teams and community volunteers at district/provincial hospitals.
	4. Maintain a feedback system and review the feedback regularly to assess key performance indicators such as the number of patients registered in the out-patient, in-patient, home care, referrals made from primary health centers and referrals made towards tertiary care centers, number of training sessions conducted, and the number of patients accessing specialized clinics.
Tertiary level hospitals	1. Develop full-fledged palliative care departments at tertiary care centers with facilities to train healthcare professionals and look after patients referred for expert care from lower levels.
	2. Develop a multidisciplinary team with specialist palliative care physicians, nurses, social workers, psychologists, and other healthcare professionals to provide comprehensive palliative care services at the tertiary healthcare level.
	3. Establish inpatient and outpatient palliative care units with advanced facilities and equipment for managing complex symptoms, providing psychological and spiritual support, and offering end-of-life care.
	4. Develop specialized clinics for managing complex symptoms such as lymphoedema, chronic wounds, pain, dyspnea etc. as well as for providing advanced care for patients with cancer, heart failure, or neurological conditions.



4. Ensure medicines & supplies

This component refers to the availability and access to essential medicines for palliative care across all levels of the health system, with special emphasis on the use of opioids for the management of pain and other symptoms, supported by respective risk management strategies. The WHO list of essential medicines includes non-opioids and non-steroidal anti-inflammatory medicines; opioids analgesics; and medicines for other common symptoms in palliative care.⁸ The need of a robust supply chain management and logistic system is of utmost importance.

4a. Access to Oral Morphine and other opioids

Palliative care medications as outlined in the WHO essential palliative care medications list should be available to all those who need them. This is particularly important for opioids which are crucial for pain treatment and managing severe respiratory distress. Access to inexpensive immediate and sustained release morphine is necessary for a subgroup of palliative care patients. To achieve this, countries can work with International Narcotics Control Board (INCB), United Nations Office on Drugs and Crime (UNODC), WHO and civil society partners to address regulatory barriers and improve medication supply and management systems. There are good examples from low and middle income countries that can help.^{15,16}

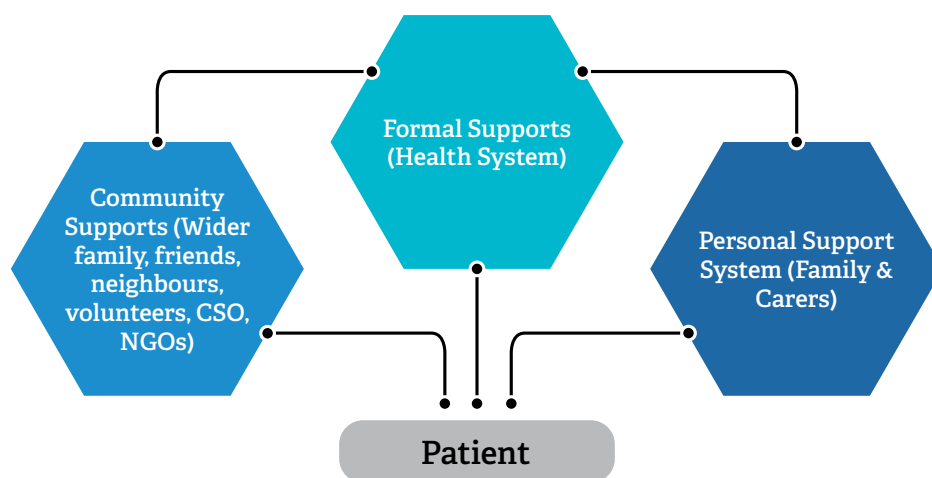
5. Integrate palliative care across disease control and rehabilitation

Include palliative care in all national policies and plans for non-communicable disease (NCDs), HIV/AIDS, TB, and other relevant health conditions. In a well-functioning system, there is also a need for interaction and integration between different levels of care.

There is no one-size-fits-all approach to integrating palliative care into different levels of care or types of services as it depends on existing services.

Another possible area of integration is community-based palliative care (CBPC) with community-based rehabilitation (CBR). These are two related but distinct approaches to care with many similarities. CBPC is an approach that provides end-of-life care and symptom relief to patients and their families in their homes and communities. It emphasizes patient-centered, holistic, and community-based care, with the active involvement of multiple agencies and community participation. The primary goal of CBPC is to enhance the quality of life for patients. It focuses on alleviating physical symptoms and ensuring comfort for individuals with life-limiting illnesses, while also recognising the significance of addressing the social and emotional needs of patients and their families. CBPC relies on the support of family members and the community to deliver care and provide support during the end-of-life period. CBR aims to provide healthcare and rehabilitation services to individuals with disabilities within their communities.

Figure 4: Overlap of different models of service delivery





6. Consider groups with special needs

Children are considered a group with specific palliative care needs. Palliative care for children represents a special field in relation to adult palliative care. Although palliative care for persons of any age has many similarities, palliative care for children represents a special area of care. It involves the active total care of the child's body, mind, and spirit, and involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. The role of the health providers is to both evaluate and alleviate a child's physical, psychological, and social distress.⁴

Provision of palliative care should also be laid out for groups with special needs other than children, to include individuals with dementia, members of the differently abled community, socio-economically marginalized communities, LGBTQ + community, and minorities, including sexual minorities. The marginalized people living with advanced illness face additional stressors due to their stigmatized identity, limited social and family support.



7. Community engagement

Involving the community as partners in palliative care allows strengthening the informal care systems through training and networking. Community involvement should be across all the steps of needs assessment, planning, implementation, resource mobilization, day-to-day management, and evaluation of the programme. Settings that may be poor in financial resources may have rich community resources that can contribute to palliative care services.

A suggested strategy to engage community in palliative care include

- identifying the status of the community, the willingness to participate in palliative care activities, and the barriers to community participation.
- Training and orientation for healthcare professionals to empower them to orient and educate caregivers/family members in providing home-based care. Trained HCPs can further empower community and family participation in continued care for the patient through structured care & support educational activities.
- Identifying the stakeholders and potential volunteers during the needs assessment activity
- Sensitizing programs for stakeholders and potential volunteers
- Training volunteers
- engaging the community in palliative care services
- supportive supervision to sustain the engagement
- Fundraising as the funding necessary to cover essential palliative care services usually exceeds the financial means.



8. Monitor

Include indicators for palliative care in health management information systems and other relevant programme monitoring areas. The WHO publication titled 'Assessing the development of palliative care worldwide: a set of actionable indicators'⁸ provides a foundation for countries to develop a range of

indicators to provide a more comprehensive assessment of palliative care provision that can be adapted to the national context.

- A good starting place for measurement is to examine the data that already exists and review how that can be strengthened.
- Keep monitoring as minimal as possible to lessen data burden.
- Ensure that monitoring is used for action and improvement. It is vital to consider how indicators will inform future policy and palliative care delivery.


Create basic information systems to monitor and evaluate actions at different levels of care. Build public understanding of palliative care. Ensure quality monitoring of service delivery. Measure population access to palliative care by diagnosis and social group. The indicators as depicted in Table 1 can be used.

All providers of palliative care should be committed to continuous improvement of quality of their services. Data collected from quality indicators is a primary source of information for improving services. When possible, palliative care services should be able to compare their quality indicator results with other similar services.

Table 1. Potential indicators to monitor palliative care

Indicator	Core	Strategic
Integrated palliative care services		
1. Number of specialized palliative care programmes in the country per population	√	√
2. Number of specialized palliative care programmes for paediatric population in the country	√	
Health policies		
1. Existence of a current national palliative care plan, programme, policy or strategy with defined implementation framework	√	√
2. Inclusion of palliative care in the list of health services provided at the primary care level in the national health system		√
3. Existence of national coordinating authority for palliative care (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care		√
Use of essential medicines		
1. Reported annual opioid consumption- excluding methadone- in oral morphine equivalence (OME) per capita	√	√
2. Availability of essential medicines for pain and palliative care at all levels of care		√
3. General availability of immediate-release oral morphine (liquid or tablet) at the primary care level		√
Education and training		
1. Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula	√	√

2. Specialization in palliative medicine for physicians	✓	
Empowerment of peoples and communities		
1. Existence of groups dedicated to promote the rights of patients in need of palliative care, their families, their caregivers and disease survivors	✓	✓
2. Existence of national policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care	✓	
Research		
1. Existence of congresses or scientific meetings at the national level specifically related to palliative care	✓	
2. Palliative care research on the country estimated by peer reviewed articles	✓	



9. Research and innovation

Research and clinical trials in palliative care should be facilitated to advance the knowledge and practice of palliative care in countries. Research aims at improving the level of scientific evidence to guide the care of people and decisions about the organization of health services. Use research evidence to inform clinical guidelines, focusing on evidence reviews. Form collaborations with academic institutions to strengthen the evaluation and use of available data on palliative care.



10. Phased expansion

There is no single approach to expanding coverage of palliative care services. It may be based on the existing resources and the needs.

A phased expansion can be supported by development of a national strategy for scaling up and integrating palliative care into the national health care system. Different activities (including inpatient care versus homecare, support of other teams, outpatient clinics and day-care hospital units) can be initiated and expanded gradually, based on feasibility and resources available. It is rational to allow the activities in the initial phases to be established along with enhancement of capacity of the palliative care teams and to use a stepwise approach for expansion.

Palliative care case stories from the WHO South-East Asia Region

a. Emergence of institution-based palliative care services in Bangladesh

Bangladesh's first major initiative in the area of palliative care was the institution-based palliative care programme in BSMMU.

- The Department of Palliative Medicine at Bangabandhu Sheikh Mujib Medical University (BSMMU) in Bangladesh has developed over the years. The department has expanded its services and outreach programs, including community-based initiatives. However, palliative care is still in its early stages in Bangladesh, and there is a need for more training and education for healthcare professionals, as well as improved policies and regulations for opioid availability.
- On 29 October 2019, the National Palliative Care Guideline was published.
- Successive workshops were conducted for doctors, nurses and paramedics and training manuals were made available to them.

b. Dawn of palliative care services in Bhutan

Bhutan's effort to support people living the last days of life can serve as a source of inspiration for those in areas which lack palliative care services.

Home-based palliative care in Thimphu:

- The Jigme Dorji Wangchuck National Referral Hospital (JDWRH) introduced the first home-based palliative care service in the country on 27 March 2018.
 - Entrusted three nurses with the task of providing home-based palliative care. These nurses are supported by a team of specialists (surgical oncologist, medical officer and nurse anesthetist), who take turns to make home visits.
 - Morphine SR and the fentanyl patch, which were not on the list of essential drugs before, were added.
- Progress through collaboration with relevant stakeholders
- Capacity building: National stakeholders in Bhutan worked with the IPM, which is a WHO Collaborating Centre, to develop the national training manual for palliative care.

c. Integration of palliative care services into primary health care in Kerala

- Kerala has been acknowledged as a successful model, not only in India but in the entire developing world, through its path-breaking work in Community Based Palliative Care.
- The Palliative Care movement in Kerala began with the Pain and Palliative Care Society in Kerala and grew quickly with the formation of the Neighborhood Networks in Palliative Care (NNPCs) providing home-based palliative care.

- The Kerala Model places a strong emphasis on community participation and volunteerism integrated with primary health care system especially through dedicated nurses under the overall leadership of local governments.
- The Goal of the Policy is to ensure that every person in Kerala has access to effective palliative care services of good quality with a focus on community-supported home-based care without getting exposed to hardships- financial, social, or personal.

d. Government–Civil societies organization collaboration to improve access to palliative care in Telangana

- The planning and implementation of palliative care services in Telangana has been remarkable in that it has been achieved through the joint efforts of the government and a CSO.
- It can serve as a useful model for others working in this area.
- In addition, as a parallel activity to bolster the palliative care initiative, the CSO took up the task of building the capacity and raising the awareness of district health officials, including accredited social health activists, auxiliary nurse midwives, staff nurses and medical officers, at all levels of the public health system. This facilitated the identification and referral of patients to the nearest palliative care unit.
- A survey and health profiling of all households in the community also helped in the identification of patients requiring palliative care.

e. Multi-agency collaboration builds palliative care services in Nepal

- The development of palliative care services in Nepal highlights the value of the contributions of CSOs and NGOs, both inside and outside the country.
 - These organizations have been working in the areas of advocacy and policy development, education, drug availability and the development of services.
- Under the purview of the National Strategy for Palliative Care, Nepal has been continuously expanding the coverage of services, training more and more personnel, and increasing the availability of morphine. The achievements in terms of boosting the availability of drugs have been particularly impressive.
- The Nepalese Association for Palliative Care (NAPCare)- a united and holistic effort would definitely be better than multiple players working in isolation
- A mobile application developed by NAPCare is in pilot phase for providing reach out to health-care workers with advice on palliative care.

f. Public health approach to palliative care services in Sri Lanka

- Sri Lanka has a long history of providing palliative care through different medical specialties, non-governmental organizations, and community groups.
- The government has taken steps to develop palliative care services systematically. Palliative care is now included in the National Health Policy and several other health policies, which have helped to develop palliative care services gradually over the years.
- The government sector provides specialist palliative care in 24 cancer treatment centers and several hospitals, and home-based palliative care services are provided by Public Health Nursing Officers.

- Non-governmental organizations also provide partnership for the palliative program in Sri Lanka, and seven hospices provide island-wide palliative care services.

g. Integration of palliative care into the health system in Thailand

- Thailand has a National Palliative care program that has grown well over the last few years.
- Inclusion of palliative care within the National Health Service plan is identified as the single most important factor enabling the system to work towards universal access to palliative care.
- Every hospital in the country has a palliative care service.
- Even a well-developed palliative care program at the secondary and tertiary institutional level will not be sufficient to meet the national demand unless it becomes part of a network of primary and community-based services.

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Annexes

- I. Considerations for providing palliative care and principles of common symptom prevention and relief
- II. Tool to assess the status of palliative care

Annex I. Considerations for providing palliative care and principles of common symptom prevention and relief

1. General considerations
 - 1.1. Communication
 - 1.2. Spiritual care and support
 - 1.3. Personal Care
2. Pain
 - 2.1. Pain assessment
 - 2.2. Differential diagnosis of pain
 - 2.3. Pain treatment
3. Respiratory system
 - 3.1. Cough
 - 3.2. Breathlessness/ Dyspnoea
 - 3.3. Tracheostomy care
4. Gastrointestinal system
 - 4.1. Halitosis
 - 4.2. Nausea and vomiting
 - 4.3. Anorexia
 - 4.4. Diarrhea
 - 4.5. Dysphagia
 - 4.6. Constipation
 - 4.7. Hiccups
 - 4.8. Stoma care
5. Urogenital system
 - 5.1. Urinary incontinence or retention
 - 5.2. Fistulae
 - 5.3. Indwelling urinary catheter

6. Nervous system
 - 6.1. Anxiety
 - 6.2. Depression
 - 6.3. Insomnia
 - 6.4. Delirium
 - 6.5. Fatigue
7. Skin Problems
 - 7.1. Pressure sores
 - 7.2. Fungating ulcers

1. General considerations

1.1. Communication

- If the patient has a severe physical symptom such as pain or dyspnea, it must be relieved before effective communication can occur.
- Optimum care requires a trusting therapeutic relationship, and trust is built through respectful, effective communication.
 - Expressions of respect and empathy are crucial.
 - Practice avoiding technical medical language and acronyms.
 - Speak slowly and pause frequently to enable the patient or family to speak.
- Every patient is different. It is necessary to explore:
 - The patient's living situation: Where and with whom does the patient live?
 - The patient's work and economic status;
 - The patient's or family's understanding of the illness, including diagnosis, treatment options, and prognosis.
 - The patient's fears, hopes, values, joys, and goals.
- Gently correct any misunderstandings about diagnosis, treatment options, or prognosis with the appropriate person:
 - Some patients wish to know everything themselves;
 - Other patients defer receipt of medical information and decision-making to one or more family members or friends.
- Based on clarification of the clinical situation and the patient's values, try to come to an agreement about the most important goal or goals of care.
 - Only agree to feasible goals (GOCs).
 - Sometimes, discussion of GOCs may require ongoing discussion, and further discussion may be needed whenever there is a major change in the patient's condition.

How to communicate with the patient and family?

- The patient needs to realize that that she/he is still wanted in this world, still deserves love and respect and under no circumstance should she/he ever be abandoned.
- Take care not to create any misunderstanding or to generate mistrust.
- The health care professional is there to listen to the patient, try and understand her/him and not to voice our opinions and force them upon her/him.

Dos and Don'ts in communication skill

Do's	Don'ts
1. Do have enough time for discussion with the patient	1. Don't be in a hurry
2. Do give timely reassurance whenever needed	2. Don't be a premature pacifier
3. Listen... listen... listen	3. Don't pretend that you are listening
4. Be attentive to verbal and nonverbal communication	4. Don't ignore what the patient says
5. Use simple words	5. Don't interrupt more frequently than needed
6. Have an open attitude	6. Don't use medical Jargon
7. Explain	7. Don't be judgmental
	8. Don't patronize
	9. Don't compare

Breaking bad news

Do's	Don'ts
S- Setting	Arrange for some privacy. Involve significant others if desired by the patient. Sit down at eye level with the patient. Allow adequate time including time for the patient to express emotions while you sit with the patient. Avoid interruptions (turn off mobile phone.)
P – Perception	Assess patient's perception. Finding out how much the patient knows. In particular how serious he or she thinks the illness is, and/or how much it will affect the future.
I – Invitation	Obtaining the Patient's invitation. Finding out how much the patient wants to know.
K- Knowledge	Giving knowledge and Information to the Patient. Objectives for the consultation - Diagnosis, Treatment Plan, Prognosis and Support. Start from the patient's starting point. Changing the patient's understanding in small steps and observing the patient's responses, reinforcing those that are bringing the patient closer to the medical facts and emphasising the relevant medical information if the patient is straying from an accurate understanding.
E – Emotion	Addressing the Patient's emotions with empathic responses. Acknowledge any shock and ask them what they are thinking or feeling. Listen and explore if you are unclear what the patient is expressing and then respond empathically.
S – strategy and summary	Patients will be looking to health professionals for help in making sense of the confusing information and in planning for next steps. Do not break bad news without having a plan for recommended next steps. Make a Plan or Strategy and Explain it. Preparing for the worst and hoping for the best

1.2. Spiritual care and support

- It is an essential component of providing palliative care and should be provided depending on the person and family.
- Spirituality is expressed through beliefs, values, traditions and practices.
- Actively listen to patient's fears, hopes, pain, and dreams. Explore the meaning and values in the patient's personal life. How does he see the illness and its associated difficulties. Explore religious faith.
- Be aware of one's own beliefs and biases. Make sure that they do not distort the communication with the patient. Be a compassionate presence in the patient's life.
- If possible, and if requested by the patient, arrange for an appropriate spiritual supporter with training in palliative spiritual care to visit the patient.

1.3. Personal care

- **Oral hygiene:**
 - Brush and rinse mouth at every 12-hour interval (more frequently if the patient is bedridden). Use a soft brush.
 - Soak dentures overnight if the patient is using dentures.
 - Apply moisturizer such as Vaseline to cracked lips.
- **Skin care**
 - Maintain daily hygiene (e.g., sponge bath, shower, wash, hair care, shave, trim nails).
 - Maintain clean environment (e.g., clean clothing, well-lit and fresh surroundings, and sterile bed linen).
 - Assess skin integrity, especially pressure points (e.g., sacrum, hips, heels, ankles, ribs, vertebrae, spine, shoulders, elbows, ears).
 - A patient with poor mobility needs 2–4 hourly change of position.
 - Pad bony prominences for protection (consider use waterbed or air mattress in some context)
 - Be aware of friction and shearing forces while moving the patient.
- **Nutrition**
 - Ensuring intake of fluids, and dietary fiber
 - Eating as much as the patient wants and as frequently as she/he wants
 - Nutritionally complete foods and dietary supplements as needed
 - Changing food consistency as needed
 - Nasogastric feeding when patient is unable to accept oral feeding
 - Prevention and management of oral thrush, nausea, constipation.

2. Pain

2.1. Pain assessment

- Pain is the most common symptom among patients with cancer and other serious illnesses. It often makes it impossible for patients to participate in activities of daily life, to sleep, to eat, or even to receive treatment for their illness. Relieving pain is an ethical responsibility of health care providers, and most pain can be relieved with basic knowledge and medicines.

- Pain can be quickly and easily assessed. The assessment should be done immediately if there is any evidence or suspicion that patient has pain.
- Some patients will deny pain out of respect for the doctor, so it is necessary to state clearly that you need to know the truth about pain to provide the best care.
- The essential, information about pain is as follows:
 - Location(s) of pain
 - Chronology: When did it start? Is it constant or intermittent?
 - Severity:
 - On a scale of 0 – 10, if 0 means no pain and 10 means the worst imaginable pain, how severe is your pain at its worst?
 - Does the severity remain constant, or does it increase and decrease?
 - Character: Describe your pain.
 - How does pain affect your daily life? Does it awaken you from sleep? Does it prevent you from walking or other activities?
 - Mediating factors: What makes it better or worse?
 - Previous treatments and their effectiveness.

2.2. Differential diagnosis of pain

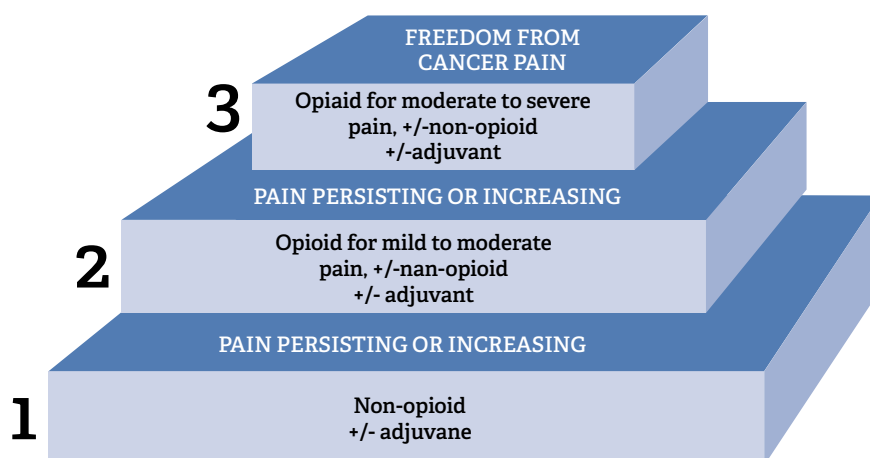
- Pain can have many causes, and it is necessary to consider the possible and most likely cause or causes (the differential diagnosis) to decide on the best treatment.
- Common causes of pain:
 - Tissue injury (for example, from cancer, infection, burn, traumatic injury). The injury usually is visible on visual examination or diagnostic imaging.
 - Nerve injury (for example, from tumor compression, diabetes, neurotoxic medicine, infection by varicella virus, or transection during surgery or traumatic injury).
- Mental health problems such as depression also can manifest as physical pain, and chronic physical pain can cause depression.

2.3. Pain Treatment

- Principles:
 - Believe the patient's report of pain unless you have clear evidence that the patient's report is not truthful.
 - Assure the patient that you want to provide pain relief that enables the patient to be comfortable.
 - Base your treatment plan on your differential diagnosis.
 - Treat the underlying cause of pain if possible and consistent with the goals of care.
 - Consider the possible adverse effects of any potential pain treatments.
 - Re-evaluate the patient frequently and adjust the pain treatment regimen as needed.
 - Use the oral route for pain therapy whenever possible, except in a pain crisis when intravenous or subcutaneous route is preferable.
- Pharmacologic Treatment
 - Use the three-step analgesic ladder as a general guide, but tailor the treatment to the patient's specific pain.

- Step 1: Mild pain often can be relieved with a non-opioid such as antipyretic analgesic or an NSAIDs when no contraindication exists.
 - Antipyretics must be used with care in patients with liver disease.
 - NSAIDs should be avoided in patients with renal disease or bleeding risk, and a proton pump inhibitor such as omeprazole should be given concurrently to reduce risk of peptic ulcer.
 - Adjuvant medicines (such as gabapentinoids, tricyclic antidepressants, and steroids) can be used alone or in combination with non-opioid analgesics for specific types of pain, especially pain from nerve injury (neuropathy).
- Step 2: Pain that is not adequately relieved with a non-opioid with or without an adjuvant medicine should be treated with “an opioid for mild-to-moderate pain.” This means either a “weak opioid” or a low dose of a strong opioid.
 - The opioid can be combined with a non-opioid and/or an adjuvant depending on the situation.
- Step 3: Pain that is not adequately relieved with Step 2 medicines should be treated with a strong opioid with or without a non-opioid and/or an adjuvant depending on the situation.
 - The correct dose of the opioid is the dose that provides adequate relief without unacceptable adverse effects. The number of milligrams is not as important as the comfort and safety of the patient.
 - Significant respiratory depression is extremely rare when standard opioid analgesic protocols are followed, and sedation always precedes respiratory depression.
 - Constipation, a typical adverse effect of opioid therapy, can be easily prevented or relieved with a stimulant laxative and/or an osmotic laxative.
- Pain that is constant or frequent be treated around the clock. For example, oral immediate-release strong opioids, that has a duration of action of 4 hours, should be given every 4 hours to maintain pain control.
- When an opioid is given around the clock, a rescue dose of opioid also should be made available in case there is a flare of pain. The rescue dose typically is calculated as 10% of the total opioid dose in 24 hours.
- If an opioid is needed, but opioids are not accessible at your clinic or hospital, the patient should be referred to a facility that can provide opioid therapy.

WHO analgesic ladder



- Nonpharmacologic
 - Radiation therapy can be an effective palliative treatment for painful bone metastases.
 - Other non-pharmacologic therapies that may help relieve some pain include:
 - Heat or cold therapy
 - Massage therapy

3. Respiratory system

3.1. Cough

Causes

- Seasonal allergy, upper respiratory infection
- Lower respiratory infection
- Aspiration
- Chronic pulmonary disease (asthma, COPD)
- Heart failure
- Smoking
- Chest malignancy
- Medicine (e.g., ACE inhibitor)
- Radiation pneumonitis
- Recurrent laryngeal nerve palsy

Principles of management:

- Assess for and treat a treatable cause (e.g., Bronchodilators, smoking cessation)
- Ensure a suitable environment – comfortable temperature, humidification, absence of allergens
- For productive cough– encourage the expulsion of secretions, physiotherapy, and postural drainage.
- Medicines: cough suppressants, expectorants
- Corticosteroids may help to control cough due to radiotherapy, tumour, or exacerbation of asthma or COPD.

3.2. Breathlessness/ Dyspnoea

- Dyspnoea is discomfort due to the body's inability to respond adequately to the brain's drive to increase respiration.

Causes

- Chronic pulmonary disease: asthma, COPD
- Pneumonia (pus in lungs)
- Heart failure (fluid in lungs)
- Pulmonary haemorrhage (blood in lungs)
- Tumour in lungs or airways
- Respiratory muscle weakness

- Pleural effusion
- Lung collapse
- Anaemia
- Metabolic acidosis
- Large ascites
- Anxiety

Principles of management: Relieve air hunger and resultant anxiety by treating the underlying cause and/or reducing the feeling of dyspnoea with opioid.

- Treat the underlying cause if possible and appropriate (e.g., diuresis for heart failure, bronchodilator for COPD exacerbation, antibiotics for bacterial pneumonia).
- Do not give anxiolytic as primary treatment. Relieving the dyspnoea usually relieves anxiety.
- Place the patient in the position she/he is most comfortable
- Fan to provide breeze on the face
- Relaxation/breathing techniques
- Teach patient to conserve energy and pace themselves during activities of daily living.
- Psychological support.

3.3. Tracheostomy care

- A tracheostomy is an artificial opening made into the trachea into which a tube is inserted to establish and maintain a patent airway.

Principles of management:

1. Routine care:

- Cleaning inner tube - thorough cleaning of the inner tube should be done with soap and water
- The inner tube to be removed and washed under cold running water. Soak it in a solution of normal saline to soften the secretions. Then clean it with soap and water and sterilise it by putting it in boiling water for 5 minutes. Then re-insert it and lock it.
- The outer tube should not be removed. Clean the tube plates thoroughly with gauze soaked in saline.
- Care should be taken not to allow the cleaning solution to enter the stoma while cleaning. It may be aspirated into the lungs.
- Train the patient to clean the tube by herself/himself using a mirror.
- Oral hygiene to be maintained
- Prevent entry of insects into tracheostomy tube.
- Prevent the entry of water directly into the stoma while bathing, swimming, and shaving.

2. Skincare

- Clean the skin around the tracheostomy site with gauze soaked in saline. Protect the skin with a gauze pad, which is cut in the middle so that it can be placed in between the outer tube and skin.

3. Suction

- As far as possible help the patient to cough out the secretions, postural drainage is helpful to bring out the secretions. Steam inhalation will help to loosen the secretions.

4. Humidification of air

- Place wet sterile gauze (soaked in tap water) on the tracheostomy tube. This helps in humidifying the inhaled air and filters the dust.

5. Changing the tie

- Tie is used to fix the tube in position. It should be changed by trained persons when dirty.

6. Speech therapy and communication.

- The patient is advised to take a deep breath, then close the stoma with finger and then speak. They may be provided with calling bell or paper and pen for communication.

4. Gastrointestinal system

4.1. Halitosis

- An oral health problem where the main presentation is bad smelling breath.

Principles of management:

- Meticulous oral hygiene, antiseptic mouthwash
- Clean and soak dentures

4.2. Nausea and vomiting

Causes

1. Emetogenic toxins: cancer chemotherapy, opioids, alcohol, Staph aureus food poisoning, emetogenic cytokines (due to infection or inflammation), hypercalcaemia
2. Gastrointestinal: gastroparesis, obstruction of intestine or other hollow organs, gastritis, release of serotonin due to cancer chemotherapy or radiotherapy to the abdomen.
3. Central nervous system: Increased intracranial pressure from tumour or bleeding or infection, anxiety, pain
4. Vestibular system: motion sickness, viral labyrinthitis, tumour of 8th cranial nerve

Assessment:

- Clarify if patient feels constant nausea or vomits without prolonged nausea. Vomiting without much nausea suggests functional or mechanical obstruction.
- Clarify when the symptoms began, what colour is the emesis, what makes the symptoms better and worse.
- Decide on the most likely cause or causes of the symptoms.
- Consider abdominal X-ray or CT scan only if the results might change management.

Management

- For gastroparesis: a pro-propulsant
- For malignant intestinal obstruction: consider a corticosteroid, somatostatin analogue if available and not too expensive, surgery, nasogastric tube, venting gastrostomy.
- For emetogenic toxin: a neuroleptic dopamine antagonist as needed or scheduled.
- For emetogenic chemotherapy or radiotherapy to abdomen: a serotonin type 3-receptor blocker with or without steroid and antihistamine.
- For gastritis: Proton Pump Inhibitors
- For increased intracranial pressure due to tumour: steroids, consider radiotherapy if indicated
- For anxiety: benzodiazepine (risk of delirium) or neuroleptic.

4.3. Anorexia

- The absence or loss of appetite for food is common in patients with chronic illnesses.

Causes

It is important to look for secondary anorexia which may be reversible.

For example:

- Dyspepsia
- Altered taste
- Malodour
- Nausea
- Vomiting
- Constipation
- Sore mouth
- Pain
- Biochemical abnormalities
- Drugs
- Radiotherapy
- Chemotherapy
- Anxiety and depression

Principles of management: Treat reversible causes

- Small but frequent meals, energy-dense food, limit fat intake, avoid extremes in smell
- Pleasant environment
- Presentation of food to the patient in a pleasing manner
- Listen to fears and anxieties of patient and family/carers
- Medication: Corticosteroids- short term improvement of appetite; Prokinetic.

4.4. Diarrhea

Causes

- Drugs-e.g., laxatives, magnesium antacids
- Antibiotics
- Infection
- Faecal impaction leading to spurious diarrhoea
- Acute radiation enteritis
- Cancer chemotherapy
- Secretory diarrhoea (e.g., AIDS, tumour)
- Surgical resection (short bowel)
- Steatorrhea: increase in fat excretion in the stools

Assessment

- Try to identify the cause(s). Review diet and medication
- Exclude constipation, infective cause, Clostridium difficile colitis, constipation with overflow
- Other investigations only if the result may affect management

Management

- Treat constipation if present
- If constipation, infection, and C difficile colitis excluded, consider antidiarrheal medicine or opioid
- Soften stool if there is partial obstruction
- If due to antibiotic therapy, stop antibiotic if possible
- Fluid and electrolyte support if consistent with goals of care
- Pancreatic enzyme if pancreas failure
- For severe, refractory diarrhoea, consider somatostatin analogue.

4.5. Dysphagia

Aim of management

- To enable swallowing without pain or aspiration
- To allow enjoyment of food and fluids

Causes

- Infection with Candida (thrush), virus (HSV, CMV)
- Cancer of mouth, throat, oesophagus
- Mucositis due to cancer chemotherapy
- Radiation stomatitis or esophagitis
- Neuromuscular disease or injury

Principle of management

- Treat presumptively for Candida or viral infection
- Treat pain
- Consult with oncologist or speech pathologist as appropriate
- Dietary advice
- Steroids may help with radiation injury
- Consider artificial nutrition (IV or nasogastric) if consistent with goals of care

4.6. Constipation

- Constipation can severely affect the wellbeing of the patient.
- Very common in seriously ill patients.

Causes

- Medicine (opioid, anticholinergics, ondansetron)
- Dehydration
- Reduced mobility
- Lack of privacy
- Hypercalcaemia
- Poor peristalsis due to tumour involvement of bowel, ascites, autonomic neuropathy (diabetes, spinal cord compression).

Assessment

- Obtain history: past and present bowel habits, laxative use, date of last bowel movement, current medications, any history of bowel obstruction or abdominal malignancy
- Abdominal palpation and auscultation
- Rule out bowel obstruction.
- Consider abdominal x-ray or CT scan if the result might change management

Management

- Prevention is the best management. In general, patients taking an opioid also should be given a stimulant laxative.
- Rule out faecal impaction with digital rectal exam.
- Treat mild constipation with osmotic laxative or low-dose stimulant laxative.
- Moderate / severe constipation usually requires treatment with stimulant laxative.
- Avoid anticholinergic medicines if possible.

4.7. Hiccups

Causes

- Gastric distension
- Gastro-oesophageal reflux

- Metabolic disturbances
- Irritation of diaphragm or phrenic nerve
- Brain tumour or metastasis

Management

- Hiccups often stop spontaneously. Treatment is only required if persistent and causing patient discomfort and distress.
- Try simple physical manoeuvres initially if possible and appropriate:
 - Sipping iced water
 - Breathing into a paper bag, particularly if the patient is hyperventilating
 - Interrupting normal breathing (holding breath)
 - Stimulation of the soft palate with a swab
- Medicines:
 - Neuroleptic as needed or scheduled
 - Steroids if due to tumour irritating diaphragm or phrenic nerve.

4.8. Stoma care

- A stoma is an opening that connects a body cavity to the outside environment.

Stoma management

The management of stoma patients in palliative care involves three principles.

1. Assessment of patients' general condition, application of knowledge of the different types of the stoma in planning and evaluating the outcome
2. Management of the stoma and stomal appliances
3. Providing physical and psychological care.

The four main contexts in which patients require stoma care are as follows:

- they are undergoing stoma surgery as a palliative strategy
- they have an established stoma whose action and management are now being affected by other palliative interventions
- they are in a terminal condition
- they have a fistula or a nephrostomy

Colostomy pouches are bags that collect stool from the colostomy. It is very important that the patients are empowered in managing the pouch system to have a good quality of life with a stoma. Proper care of the stoma includes learning how to empty and replace the pouch and watching for skin irritation.

Irrigating a colostomy

- Colostomy irrigation is a way to regulate bowel movements by emptying the colon at a scheduled time. The process involves infusing water into the colon through the stoma.
- Irrigating a colostomy allows more control over the elimination of waste because it stimulates the intestine to function at a regular time. It is generally done at the same time every day (more predictable outcome) or every other day. If you irrigate, you may need only a cover or pad over your stoma and may not need an ostomy pouch. Irrigation is not practised in children. Irrigation is done for colostomy, not for an ileostomy.

5. Urogenital system

5.1. Urinary incontinence or retention

Aim of management

- To maximize patient comfort and relieve anxiety

Causes

- Infection
- Medicines (opioids, anticholinergics)
- Autonomic neuropathy (diabetes, spinal cord injury)
- Constipation
- Anxiety
- Disease of the bladder

General principle of management of urological problems

- Assess for treatable causes
- Ensure adequate fluid intake
- Catheterization if necessary
- Careful perineal care
- Rapid and regular toileting
- Reassurance
- Treat for infection, constipation

5.2. Fistulae

Vesico-vaginal fistula management:

- Regular change of pads/cloth
- Antifungal vaginal suppository for thrush
- Barrier creams for skin
- Assessment for excoriation of vaginal tissue
- Psychosocial support (could affect intimate relationships and self-esteem of the patient)
- Consider supra public catheter or percutaneous nephrostomies
- Sitz bath

Note: women usually do not seek treatment until symptoms are severe thus requiring prompt attention

Recto-cutaneous or Colo-cutaneous fistula management:

- Bowel regulation
- Regular drainage of collecting bag before it gets to 3/4th of its capacity.
- Surgical consultation for possible resection or diverting colostomy if consistent with goals of care.

5.3. Indwelling urinary catheter

Management

- Cleaning from the umbilicus to mid-thigh daily once.
- For women, cleaning the vulval area and catheter 2 or 3 times daily with soap and water.
- Change Foley catheter at least every 3 weeks
- Increase intake of fluid to about 2- 3 litres /day
- Urobag should be kept below the waist level
- Keep the Urobag cap always closed.
- Empty bag when it is 3/4th full.
- Observe if urine is draining freely
- Secure the Urobag below the waist or leg while walking.
- Observe the colour and amount of urine

6. Nervous System

- Clinically significant anxiety and depression are common in patients with serious medical illnesses, and they are never normal, even in dying patients.
- Anxiety and depression frequently coincide.
- Any doctor with basic palliative care or mental health training should be able to diagnose and treat uncomplicated anxiety or depression.

6.1 Anxiety

Assessment

- Typical symptoms include:
 - Sweating
 - Dizziness
 - Dyspnea
 - Dry mouth
 - Headache
 - Hyperventilation
 - Muscle tension
 - Nausea
 - Palpitations or tachycardia
 - Tremulousness
 - Urinary frequency
 - Recurrent, unpleasant thoughts and fears
 - Expectation of catastrophe
 - Perception of environment as hostile and therefore need to flee / avoid treatment
 - Non-adherence to care

- There is a broad differential diagnosis of anxiety, and some of these conditions may be easily treatable:
 - Endocrine dysfunction
 - Drug-related
 - Cardiovascular disease
 - Respiratory disease
 - Immunologic disease
 - Metabolic disorder
 - Neurologic disease
 - Gastrointestinal disease
 - Infectious disease

Management

- Rule out or treat conditions mimicking anxiety, if consistent with goals of care.
- Reassurance / emotional support from social worker, psychologist, or trained community health worker or hospice volunteers.
- Explore patient's fears about illness and procedures. Clarify misconceptions.
- Pharmacotherapy:
 - Neuroleptic as needed or scheduled. Does not cause delirium.
 - Benzodiazepine as needed or scheduled. Often causes delirium in older or seriously ill patients.
 - Selective Serotonin Re-uptake Inhibitors (SSRIs), use lower starting dose than when treating depression.

6.2 Depression

Assessment

- Many symptoms of depression may also be symptoms of serious illness, but some symptoms are more specific indicators of depression:
 - Depressed mood
 - Lack of pleasure
 - Crying
 - Irritability
 - Feeling hopelessness
 - Feeling worthless
 - Feeling guilty
 - Non-compliance with care
 - Suicidal ideation
 - Excessive somatic preoccupation

Management

- Emotional support from social worker, psychologist, or trained community health worker or hospice volunteers.
- For patients who may live for more than a few weeks, consider treatment with:
 - Selective serotonin re-uptake inhibitor (SSRI).
 - Tricyclic antidepressant:
 - Many anticholinergic side-effects: orthostatic hypotension, dry mouth, confusion, constipation. Risk of cardiac toxicity at high doses.

6.3 Insomnia

Causes

- Physiological – wakeful stimuli, sleep during daytime
- Psychological – anxiety, depression, fear
- Unrelieved symptoms – pain, nausea, breathlessness
- Drugs – diuretics, steroids

Principles of Management

- Physiological – proper setting to induce sleep – dim light, quiet surroundings
- Psychological – allay anxiety by sharing, listening, anxiolytics, sedatives
- Treat symptoms – pain, nausea etc.
- Review and change drugs accordingly.

6.4 Delirium

- It is characterized by acute and fluctuating cognitive impairment.
- Delirium is a disorder of consciousness and attention combined with abnormalities of cognition and perception.
- Delirium can be of hyperactive, hypoactive, or mixed type

Predisposing factors

- Severe mental illness
- Poor functional state
- Primary or metastatic malignancy in brain
- Unfamiliar environment
- Sensory deprivation (hearing, vision)
- Psychological stress
- Metabolic imbalances

Principles of Management

- Provide environment and personal orientation.
- Manage patient in a quiet well-lit room

- Support and correct any sensory deprivation (use of glasses, hearing aids etc.)
- Ensure continuity of care by avoiding any potential disruptive interventions.
- Maintain hydration
- Allay fear and suspicion and reduce misinterpretation by using night lights, explaining every procedure and event in detail, and ensuring the presence of a family member or a close friend with the patient
- Hallucinations, vivid dreams and misperceptions may reflect unresolved fear and anxiety: facilitated discussion may be needed.
- Neuroleptics are most commonly used for symptomatic treatment of delirium.

6.5 Fatigue

- Fatigue is a common symptom experienced by patients with advanced diseases, including cancer, heart failure, and chronic obstructive pulmonary disease (COPD).

Causes

- Can be a consequence of underlying disease process (e.g., cancer) or because of treatment (e.g., chemotherapy, radiotherapy).
- Other causes include:
 - Anemia
 - Dehydration
 - Pain
 - Iatrogenic: opioids, benzodiazepines, post chemotherapy
 - Poor nutrition
 - Depression
 - Endocrine abnormalities

Principles of management: Initial management should consider reversible causes.

- Managing underlying medical conditions like anemia, electrolyte imbalances, and hypothyroidism.
- Patients can be advised to engage in light physical activity, such as stretching, walking, or yoga.
- Adequate sleep hygiene, including avoiding caffeine or nicotine.
- Providing nutritional support, like ensuring a balanced diet and staying hydrated. In some cases, enteral or parenteral nutrition may be necessary.
- Psychological and emotional factors like depression or anxiety can also influence fatigue.
- Medications should be prescribed by a palliative care specialist, and the risks and benefits should be weighed before prescribing.

7. Skin Problems

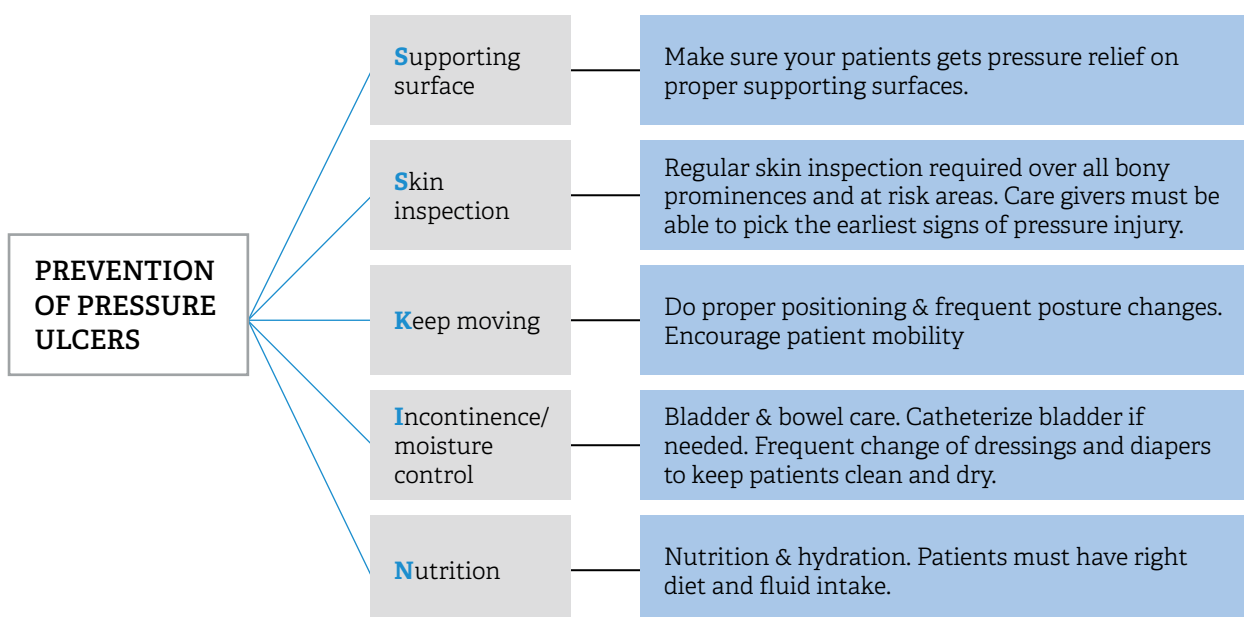
7.1. Pressure sores

7.1.1. A pressure sore is a type of injury that occurs when there is prolonged pressure on a specific body area, causing damage to the underlying tissue. In addition to pressure, friction and shear can also

contribute to developing pressure sores. These injuries typically occur in areas with frequent pressure (pressure points).

7.1.2. The risk of developing pressure sores is higher in individuals with certain risk factors, such as:

- older age
- lack of pain perception
- malnutrition
- urinary or fecal incontinence
- comorbidities that affect circulation
- decreased mental awareness
- use of external devices like casts.



7.1.3 Pressure sore care

- Wounds should be assessed daily for evidence of infection.
- Treating infection is necessary to promote healing.
- Use normal saline for cleaning and irrigating the wound.
- Remove dead tissues and scab.
- Avoid “wet-to-dry” dressings as this results in pain and removal of healthy granulation tissue with each dressing change.
- For wounds that may heal, use dressing with hydrogel to prevent pain and damage to granulation tissue while changing the dressing.
- For wounds that will not heal, dressing with petroleum jelly can be used.
- Nitroimidazole powder sprinkled on the wound and the dressing can eliminate bad odor.
- Treat any associated pain. Pre-medicate before dressing changes if they are painful.

7.2. Fungating wounds

- A patient with a chronic, non-healing malignant ulcer suffers physically, emotionally, socially, and spiritually.

Physical problems	Psycho-social problems
Malodor	Body image alteration
Exudate	Depression
Bleeding	Embarrassment, shame
Pain	Social isolation, rejection by relatives
Pruritus	Problem with sexuality
Infection	Fear
Nausea and anorexia	Anxiety

Principles of management:

1. Management of bad smell.
 - Thorough bathing will wash out exudates and decrease malodour.
 - Nitroimidazole powder should be sprinkled on the wound and on the dressing at least once daily, more often if needed.
2. Management of wet wounds: Change the dressing as soon as it is soaked.
3. Pain management
 - Adjust systemic analgesics. Give an extra dose of pain medication half an hour before dressing
 - To minimise pain during dressing, use of non-sticky, moist dressings (moisten with hydrogel or petroleum jelly).
 - Maintaining the wound in a moist environment.
 - Irrigation of the wound with saline rather than cleaning with a gauze swab will reduce pain.
 - Complementary therapies such as relaxation, distraction, or visualisation.
4. Management of maggots in wound:
 - If there are maggots, a piece of gauze soaked in turpentine can be held close to the wound. This will bring the maggots out so that they can easily be removed.
5. Management of bleeding
 - Wound bleeding is common in cancer wounds
 - Always mask the bleeding with dark coloured clothes
 - If dressings are not soaked while changing, bleeding may occur
 - Bleeding occurs when cleaning roughly
 - Using non-adherent dressings that maintain a moist environment, and cleaning by irrigation rather than swabbing, will reduce trauma and bleeding.
 - Gentle removal of dressing after soaking with saline or water is a good practice.
6. Nutritional support (if consistent with patients' goals of care):
 - Patients with chronic ulcers have an increased nutritional demand, and they require an average of 30 to 35 Cal/kg/day and 1.5g/kg of protein per day.

Annex II. Tool to assess the status of palliative care

Name of country:

Date:

SECTION I - National policy, programme, and resources

Person completing this questionnaire:

- **National programme manager/ Ministry of Health/Department of Health official**

Name:

Position:

Contact Information:

Address:

Email:

Phone:

Please cite any information sources consulted to complete this questionnaire:

1. Coordination and personnel for programme management

a. Is there a designated technical/professional staff (or desk, unit, branch, department) in the Ministry of Health (or equivalent), responsible for palliative care?

Yes

No

Comments, if any (max 100 words) _____

a.1. If yes, indicate the arrangement

b. What are the roles of the designated technical/professional staff entail? (e.g. political, technical etc...)

c. If not a full-time staff, then what percentage of this person's time is dedicated to support palliative care programmes?

Less than 10%

Between 10% and 50%

More than 50%

2. Programme for palliative care

a. Is there a current national palliative care plan, programme, policy or strategy:

*(National **plan** or **programme** refers to regulatory and official publications that are applicable to the whole country. These publications are usually endorsed by the national ministry of health/health authority and contain norms and standards for the development of palliative care, regulations relating to its service provision and in some cases guidelines for palliative care research. It should:*

- Have national scope
- Be designed to integrate palliative care in health care services
- Have an assigned budget and a responsible person

Yes (attach document)

No

Comments, if any (max 100 words) _____

b. Are there dedicated funds from the national health budget allocated for palliative care by the Ministry of Health or equivalent government agency;

Yes

No

Comments, if any (max 100 words) _____

b.1. If yes, is the funding specific for palliative care in any specific type of service (choose all that apply)

Secondary Care

Primary Care

Hospice

Home Care

Not specified

No allocated funds from national health budget for palliative care

c. Are there operational guidelines for palliative care services?

Yes (Please give detail _____; attach documents)

No

Comments, if any (max 100 words) _____

d. Which form of national palliative care plan (or programme, strategy) is/are available in your country?

If yes in any below, attach documents

	Available?	Period (started in which year)	Implemented?	Evaluated?	Comments
Stand-alone national palliative care plan (or programme, strategy)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	
National cancer plan (or programme, strategy) with a section for palliative care	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	
National Non-communicable Diseases (NCD) plan (or programme, strategy) with a section for palliative care	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	
National Human Immunodeficiency Virus (HIV) plan (or programme, strategy) with a section for palliative care	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	
Whole of government approach to palliative care (across ministries or departments of government)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In progress	

e. Is there any non-governmental funding for palliative care?

- Yes (Please give detail _____; attach documents)
 No
 Comments, if any (max 100 words) _____

f. If yes, what is the source of funding (select all that apply)

- NGO National
 NGO International
 Corporate Social Responsibility initiatives
 Other (specify _____)

g. How is the programme monitored?

h. Are there any reports available? If yes, provide the same.

3. Palliative care in health services

Inclusion of palliative care services in the basic package of health services

*(National health systems design, approve and implement a **basic package** of basic healthcare services for **Universal Health Coverage (UHC)**. This package is intended to meet the Sustainable Development Goal 3.8, through which all persons should be able to have access to quality essential health services without facing financial hardship. Inclusion of palliative care services in the basic package for universal health coverage is understood as **explicit mention on the UHC basic package to palliative care service provision** at the primary health care level)*

a. Have palliative care services been included in the basic package of health services?

- Yes
- No
- No basic package available
- Comments, if any (max 100 words) _____

b. Palliative care included in the list of health services provided at the primary care level in the national health system?

- Yes
- No
- Comments, if any (max 100 words) _____

4. Supervision

Existence of systems for auditing, quality evaluation, improvement, or assurance for palliative care services

*(**Auditing** is one of the main approaches to manage **quality assurance** in health care provision. Auditing systems seek to monitor and evaluate the quality of palliative care services that are being provided in your country. Quality auditing may be implemented in different categories, for example in structures, processes and outcomes. They can be, but are not limited to, formularies, protocols, standards and/or guidelines among others set to assess palliative care services' quality e.g. Patients' satisfaction surveys)*

a. Existence of systems of auditing, quality evaluation, improvement, or assurance for palliative care.

- Yes (Please give details: _____ National/Regional/Local audit? How frequently audited?)
- No
- No basic package available
- Comments, if any (max 100 words) _____

5. Reporting

a. Is there any national dataset (mandatory data collected at each service level that is reported at national level) for palliative care?

- Yes (Please give detail _____)
- No
- Comments, if any (max 100 words) _____

b. Are there multisector partnerships in palliative care at any of the levels below? (Tick all that apply) *multi-sector partnership means either Public-Private-NGO sectors partnership OR Civil Society Organization (+ professional organizations) partnering with government*

	No	I do not know	Yes
i. Policy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Details:
ii. Service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Details:
iii. Training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Details:

c. Existence of palliative care associations

Excludes those associations that promote palliative care or that have interest in palliative care but are not composed by palliative care professionals (i.e., national cancer association)

Is there any	No	Yes
i. National palliative care association	<input type="checkbox"/>	<input type="checkbox"/>
		Please provide details: Name, Year established
ii. Regional/Local palliative care association	<input type="checkbox"/>	<input type="checkbox"/>
		Please provide details: Name, Year established

d. Which are the agencies in the health, social welfare and the community responsible for delivering the services?

e. Which categories of people receive the care?

f. What is the extent of the care provided? (which domains of care are covered?)

g. How good is the quality of the care?

h. What is the cost of care?

i. What is the annual opioid consumptions in Morphine Equivalence per capita (from the latest available reported country consumption report to the INCB- International Narcotics Control Board)? _____ (Year: ____)

SECTION II - Educational programmes for palliative care

Person completing this questionnaire:

- **National Representative (Ministry of Health/Department of Health official)**
- **Palliative Care training institution focal point**

Name:

Position:

Contact Information:

Address:

Email:

Phone:

1. Coordination and personnel for programme management

a. Existence of an official process for the specialization in palliative medicine for physicians, accredited by the national responsible authority

(Official specialization in palliative medicine refers to any formal process (or schedule of training/ education) that provides official certification and accredits a higher level of competence to the physician working in the area of palliative medicine recognized by the competent authority e.g., Medical Regulatory Council)

No	Yes
<input type="checkbox"/> Yes	<input type="checkbox"/> MD or equivalent (master's level after basic medical graduation) <input type="checkbox"/> Diploma level after basic medical graduation <input type="checkbox"/> Others such as recognized fellowships (Detail:)
<input type="checkbox"/> No	<input type="checkbox"/> A process of specialization is in progress (Detail:) <input type="checkbox"/> A specialization done abroad is officially recognized in the country (Detail:) <input type="checkbox"/> We have a certification of competence in the country but not granted by the national competent authority (Detail.....) <input type="checkbox"/> There is no established, in progress, or recognized specialization process or diplomas to certify competency
<input type="checkbox"/> Comments, if any (max 100 words) _____	

b. Please estimate the number of palliative care physicians (currently working in your country) officially certified through a process of specialization recognized by your country's competent authority? _____

c. What does palliative care training in your country consist of?

	For Physicians	For Nurses	For Allied Health Professionals
i. Voluntary workshops or modules	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know
ii. Mandatory workshops or modules	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know
iii. Postgraduate modules not accredited by health professional regulatory authority	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know
iv. Postgraduate modules accredited by health professional regulatory authority	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Establishment in progress <input type="checkbox"/> Don't know

d. Who provides palliative care training in your country? (Please select all that apply)

Provider	No	Yes
i. Non-profit sector (e.g., charities, NGOs, voluntary organizations)	<input type="checkbox"/>	<input type="checkbox"/> Please give names and locations:
ii. Hospice organizations	<input type="checkbox"/>	<input type="checkbox"/> Please give names and locations:
iii. Primary health care organizations	<input type="checkbox"/>	<input type="checkbox"/> Please give names and locations:
iv. Secondary health care/specialist hospitals or organizations	<input type="checkbox"/>	<input type="checkbox"/> Please give names and locations:
v. Universities or academic institutions	<input type="checkbox"/>	<input type="checkbox"/> Please give names and locations:
vi. Others	<input type="checkbox"/>	<input type="checkbox"/> Please give names and locations:

e. Is palliative care education a mandatory part of curriculum in your country (included as compulsory teaching for all students in order to graduate) for:

i. Medical undergraduates?

- Yes
 No
 Establishment in progress

ii. Nursing undergraduates?

- Yes
 No
 Establishment in progress

iii. ANY Allied Health Professional undergraduate?

- Yes
 No
 Establishment in progress

f. Is there any training programme in palliative care aimed at general public/carers?

- Yes (Please give details _____)
 No
 Comments, if any (max 100 words) _____

g. Are there any training manuals in palliative care for your country?

- Yes, developed within country (Details and attach documents: _____)
 Yes, manual developed abroad but translated or adapted to national requirements (Details and attach documents: _____)
 No
 Comments, if any (max 100 words) _____

SECTION III - Palliative care services

Person completing this questionnaire:

- **National Representative (Ministry of Health/Department of Health official)**
- **Palliative Care Association Representative**
- **Palliative Care Practitioner**

Name:

Position:

Contact Information:

Address:

Email:

Phone:

Services offered

a. What are the health services where palliative care is provided?

- Medical school hospitals
- Cancer hospitals
- Secondary level general hospitals
- Primary health care

b. Approximately how many facilities or what proportion of these facilities have regular palliative care services?

c. In your opinion, what is the geographical spread of palliative care services in your country?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

Highly restricted to very few locations Widely available across the country

Comments, if any (max 100 words) _____

d. What is the total number of palliative home care teams in your country?

Comments, if any (max 100 words) _____

d.1 Is the above figure your personal estimate?

- Yes
- No - please give the source of the figure (.....)

e. In your opinion, what is the availability of home-based palliative care in your country?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

Highly restricted to very few locations Widely available across the country

Comments, if any (max 100 words) _____

f. What is the total number of inpatient palliative care units in hospitals (public and private) in your country

(Units= wards or departments within hospital that provide specialist inpatient care; they require highly qualified and multidisciplinary-palliative care trained teams, with at least one doctor and one nurse as a core

Comments, if any (max 100 words) _____

Is the above figure your personal estimate?

- Yes
- No - please give the source of the figure (.....)

Number and type of palliative care programs for children

(Palliative care services with programs specific to paediatrics includes free standing hospices and hospices for children that are a part of public or NGO hospitals, any kind of other hospices or home care teams, support teams in hospitals, palliative care units, inpatient units in hospices specific for children, etc.)

g. Number of adult palliative care services that care for children with palliative care needs _____

Comments, if any (max 100 words) _____

h. Number of palliative care services with palliative care programmes specific for children

- i. In inpatient hospices ____
- ii. In hospitals provided by palliative care team ____
- iii. In palliative home care programmes ____
- iv. In palliative day-care/outpatient programmes ____
- v. In other services or programmes (please specify)

i. Is palliative care integrated within the government health system (rather than separate service outside the mainstream health system)

- Yes
- No

If yes,

- a. Within Primary Health Care Yes No
- b. Within Secondary Health Care Yes No

j. Existence of palliative care for broad range of conditions: Is palliative care services provided for (tick all that apply)

- Cancer
- Non-cancer (Please provide detail _____ e.g., stroke, lung/ heart/ kidney, dementia, etc.)

To be answered by providers

k. What is the availability of medications of the steps of WHO pain ladder at the primary care level

	Always	Usually	Occasionally	Never	Comments if any
i. Strong opioid (Morphine, Pethidine, Fentanyl, Methadone)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ii. Weak opioid (e.g., Codeine, Tramadol etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
iii. NSAID (e.g., Ibuprofen, Diclofenac etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
iv. Paracetamol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

l. What are the available schemes in the formal social welfare system to support patients in palliative care?

m. What percentage of beneficiaries of the social welfare system are patients in palliative care?

n. What are the gaps?

SECTION IV - Access and availability of medicines and other products

Person completing this questionnaire:

- **National Representative (Ministry of Health/Department of Health official)**
- **Palliative Care Association Representative**
- **Palliative Care Practitioner**

Name:

Position:

Contact Information:

Address:

Email:

Phone:

a. Is there a list of essential medicines for palliative care?

- Yes (Please give details and attach documents _____)
- No
- Comments, if any (max 100 words) _____

a.1 If available, at what level of health care is the availability?

a.2. Is there availability of immediate-release oral morphine at the primary care level?

b. Are essential equipment for providing palliative care available?

- Yes (if yes, at what level of health care? _____)
- No
- Comments, if any (max 100 words) _____

b.1. What all equipment are available? Please specify

c. Has availability of medicines for palliative care improved, including in primary care settings?

SECTION V - Civil society organizations

Person completing this questionnaire: **To be answered by a civil society representative**

Name:

Position:

Contact Information:

Address:

Email:

Phone:

a. Are there civil society organizations in the country?

- Yes (If yes, how many organizations approximately?)
- No
- Comments, if any (max 100 words) _____

b. What is the role of the civil society organizations in providing palliative care?

c. Are there services related to palliative care that are provided by the civil society organizations?

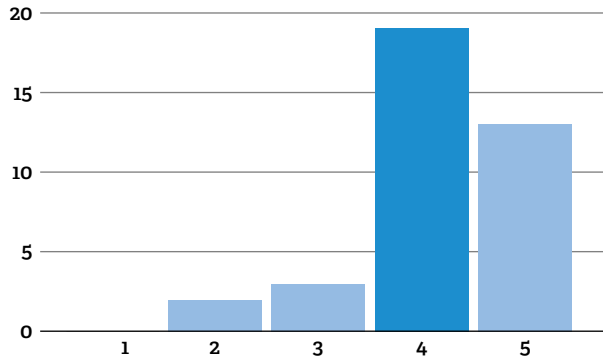
- Yes (If yes, What is the coverage?)
- No
- Comments, if any (max 100 words) _____

d. Do patient/community groups focused on patient rights exist? If yes, comment (100 words)

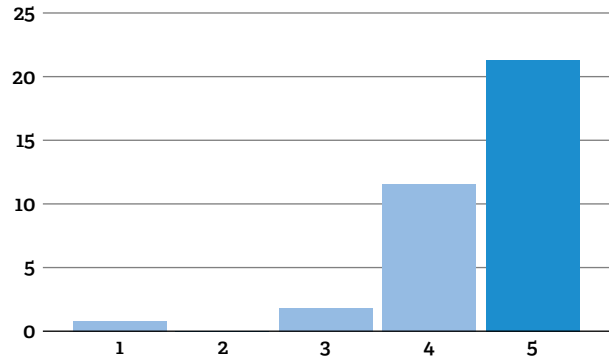
-----END OF ASSESSMENT TOOL-----

C. Participants' feedback

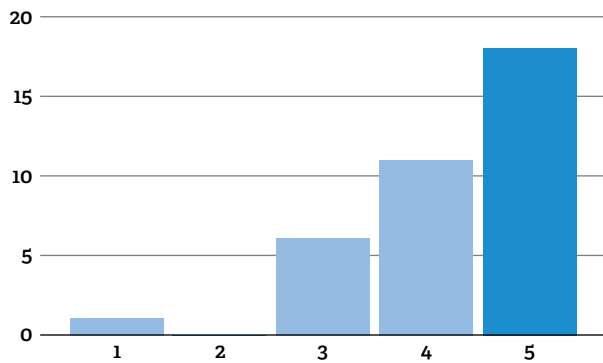
1. To what extent the objectives of the meeting were accomplished?



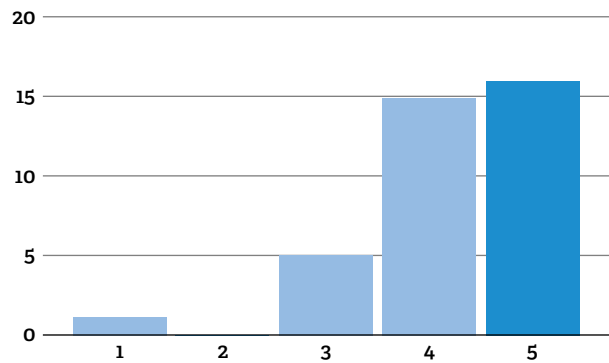
2. Whether the agenda items were relevant to achieve objectives?



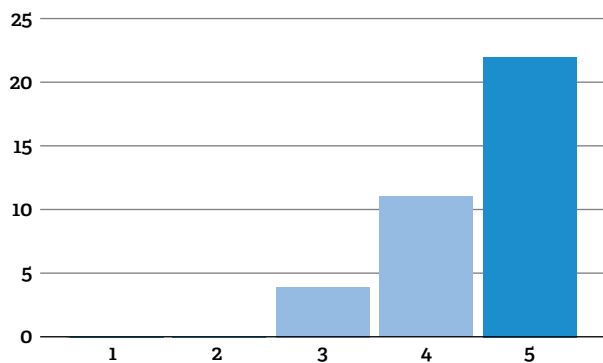
3. Were the outcomes of the workshop relevant to the needs of your country?



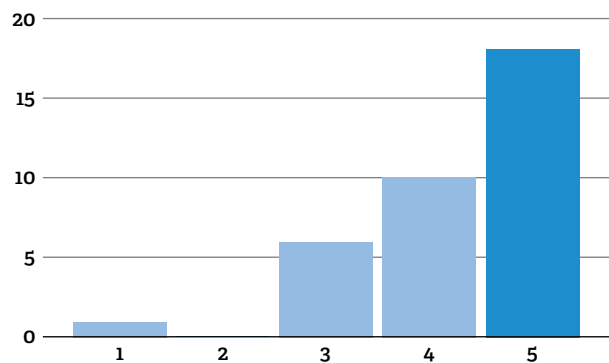
4. Were the working papers presented substantive to the needs of the workshop?



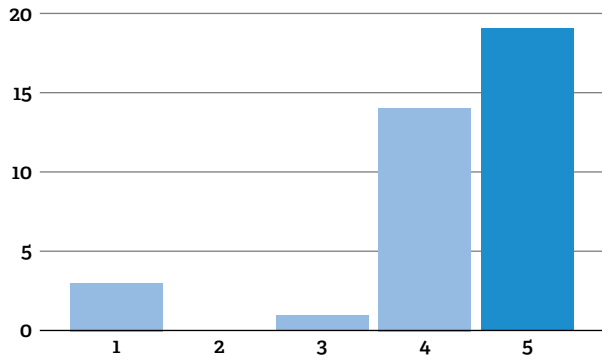
5. Was the WHO/SEARO staff technical support adequate in achieving your expectation?



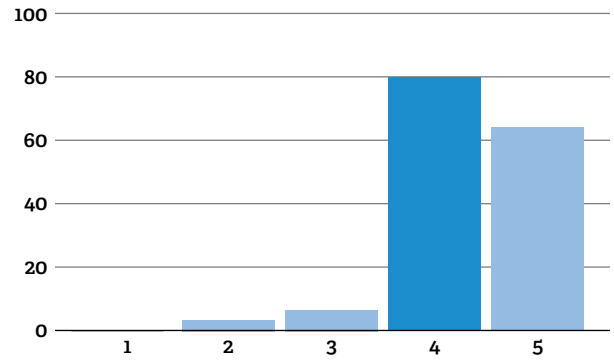
6. Were the resource person's technical support adequate in achieving the objectives?



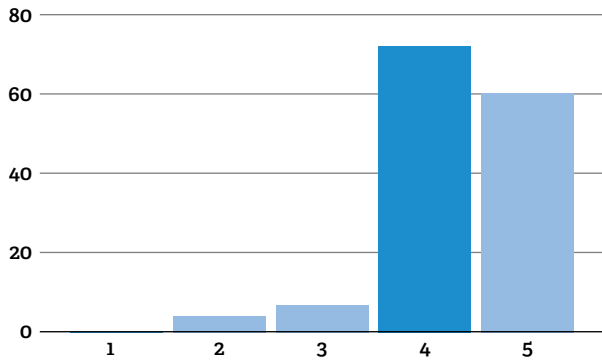
7. Did you find an opportunity to exchange information with other participants?



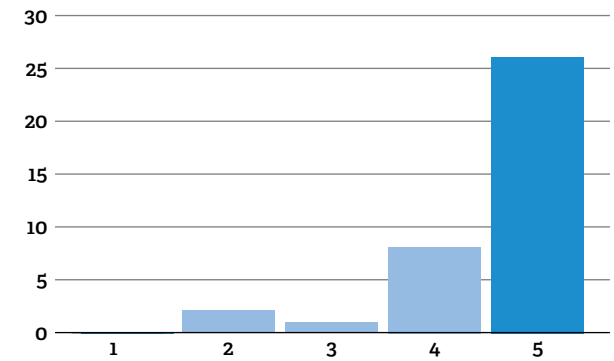
8. Was the field trip relevant to achieve the objectives of the workshop?



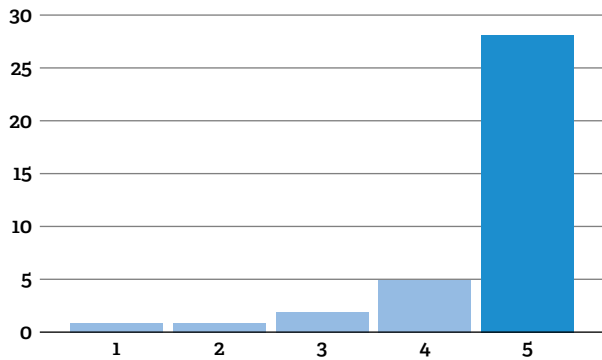
9. Are you in a position to integrate the outcome of this workshop to the national workplan?



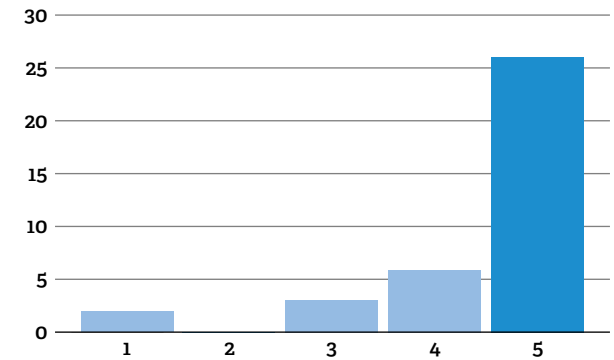
10. Conduct of the workshop



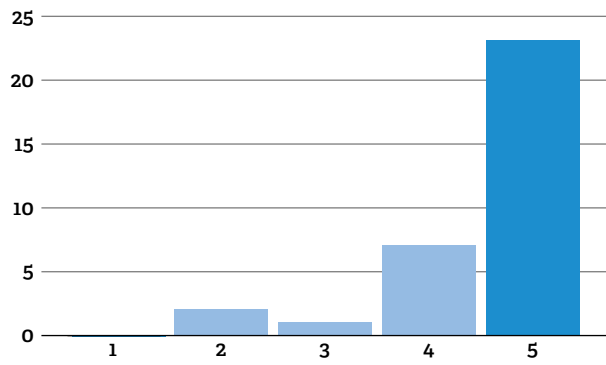
11. Workshop venue



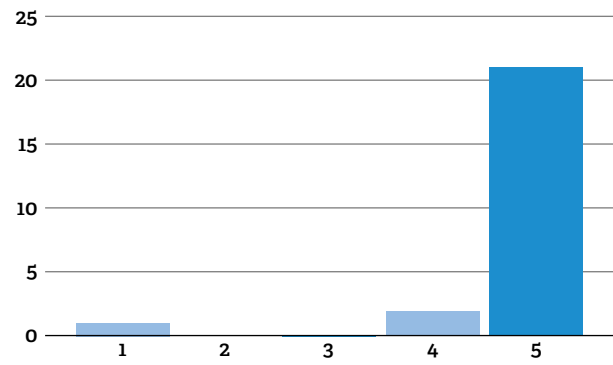
12. Seating arrangement



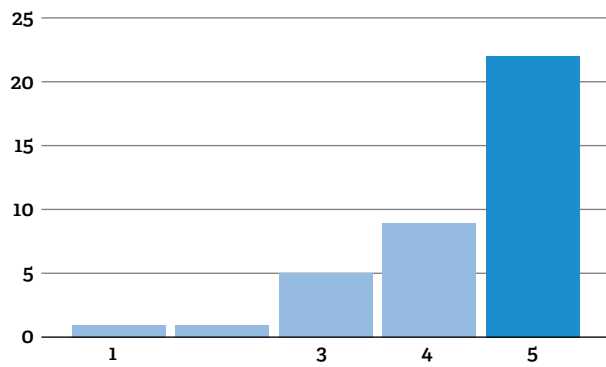
13. Transportation



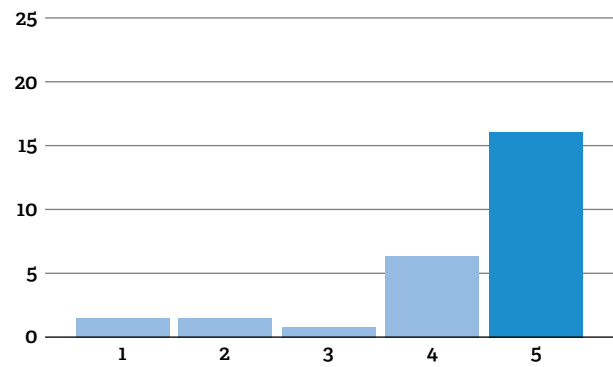
14. Accommodation



15. Meals



16. Secretarial support



D. Resource materials for further reading

1. World Health Assembly Resolution WHA 67.19: Strengthening of palliative care as a component of comprehensive care throughout the life course.
[EB Document Format \(who.int\)](#)
2. Planning and implementing palliative care services – a guide for program managers.
[Planning and implementing palliative care services: a guide for programme managers \(who.int\)](#)
3. Integrating palliative care and symptom relief into primary health care, a WHO guide for planners, implementers, and managers
[Integrating palliative care and symptom relief into primary health care \(who.int\)](#)
4. Why palliative care is an essential function of primary health care
[Why palliative care is an essential function of primary health care \(who.int\)](#)
5. Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises – a WHO guide
[Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises \(who.int\)](#)
6. Integrating palliative care and symptom relief into pediatrics – a WHO guide to health care planners, implementers and managers
[Integrating palliative care and symptom relief into paediatrics \(who.int\)](#)
7. Assessing the development of palliative care worldwide: a set of actionable indicators.
[Assessing the development of palliative care worldwide: a set of actionable indicators \(who.int\)](#)
8. OpenWHO course: Palliative care – Models of service delivery and symptom management.
[Palliative care: Models of service delivery and symptom management | \(openwho.org\)](#)



