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**DEVELOPMENT OF PALLIATIVE CARE SERVICES AND IMPACT OF COVID-19 PANDEMIC:
SITUATION ANALYSIS FROM FIVE ASIAN COUNTRIES**

Short Running Title: Palliative Care and pandemic situation analysis

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ABSTRACT:

Palliative care provides active holistic care for people with serious health-related suffering due to illness, especially near the end of life. In the Asia-Pacific region, there is variability in palliative care services and access to drugs, with a predominant focus on hospitals and cancer. The COVID-19 pandemic also disrupted the development and provision of palliative services. In this situation analysis, palliative services and the impact of the pandemic in five Asian countries (Bangladesh, Brunei, India, Myanmar and Thailand) are described. Overall, palliative care is an underserved specialty despite an obvious need for the services in each locality. While the pandemic significantly interrupted palliative services, palliative care providers adapted by developing guidelines and using teleconferencing. Overall, much work still needs to be done to improve palliative care in the region.

Keywords: Asia, Community, COVID-19, Palliative care, Service development

INTRODUCTION:

Palliative care is defined as the 'active holistic care of individuals across all ages with serious health-related suffering due to severe illness, especially those near the end of life' [1]. In the Asia-Pacific region, a survey found that there was some form of specialist palliative care service available in each country, with variable

access to essential drugs [2]. Progress in developing palliative care services in the region is quite difficult to monitor due to limited details, documentation and reporting of measures regarding the provision of palliative care [3].

One of the identified strengths of the region is the ability to develop successful community-

based models of palliative care despite limited resources [4]. However, there is limited use of validated tools to measure outcomes, confirm the actual costs required, and adaptation to the cultural context of death and dying for these patients. A systematic review showed that three-quarters of palliative care research from the Asia-Pacific originated from high-income countries, and were predominantly cancer-related [5]. Otherwise, published literature regarding palliative care in low-and-middle income countries, particularly non-cancer related diseases is lacking.

Many countries in Asia are densely populated, have an ageing population with chronic diseases and increasing cancer burden. The COVID-19 pandemic disrupted many health services, causing a dual challenge of providing cancer care while containing COVID-19 spread [6]. Palliative services continue to evolve despite the pandemic to provide a rapid flexible response for symptom management, psychosocial and bereavement care, and adapt to technology for communicating with patients and caregivers [7]. A survey of palliative services in the Asia-Pacific region during the pandemic identified that the main challenges faced in providing palliative care were access to face masks and the lack of guidelines, particularly management protocols for stress, advanced care planning and bereavement care for family members [8]. An international survey found that health professionals deemed palliative care as an

essential or urgently needed service during the pandemic [9]. For Asians and minority groups, there is a tendency for late presentations and referrals to palliative care, which is associated with worse outcomes [10]. Taking these factors into account, palliative care should be prioritised for service development in the Asia-Pacific region.

This paper describes the situation analysis of palliative services and the impact of the COVID-19 pandemic in five Asian countries: Bangladesh, Brunei, India, Myanmar and Thailand. Among these countries, only India had general palliative care provision, while the remaining countries (Bangladesh, Brunei, Myanmar and Thailand) only have isolated provision of palliative care [11]. The authors are involved in palliative services in each locality and the information described originated from discussions on palliative care service development care as part of a Fellowship in Palliative Care jointly organised by St Christopher's Hospice (London, United Kingdom) and the Institute of Palliative Medicine (Kerala, India), a World Health Organisation collaborating centre for community participation in palliative care and long-term care.

BANGLADESH:

Bangladesh is a country with 170 million people. There are no palliative services in the mainstream healthcare facilities or any state policies to support palliative care. A study of

patients with advanced cancer or acquired immune deficiency syndrome (AIDS) from Bangladesh found a high prevalence of pain (70.6%), of which 62.6% were reported as severe and more than a third continuing to have severe symptoms despite treatment. There is a significant burden of symptoms which necessitates the strengthening of palliative care [12]. A cross-sectional study of physicians showed that the majority had an average to high level of knowledge regarding palliative care. However, there were many misconceptions that needed to be addressed and resolved; this includes beliefs that palliative care excludes patients from other specialty consultations or curative treatments, and that it was only for older people, oncology patients and for the final six months of life [13].

While there is an estimated 600,000 people with incurable diseases in the country, there are only six palliative care programmes, which are all based in Dhaka, the capital city. A homecare outreach service has been set up by the Centre for Palliative Care of Bangabandhu Sheikh Mujib Medical University (BSMMU) in Korail, one of the largest slums in Dhaka. This community approach was shown to be effective, with recipients expressing satisfaction with the provided care, hope and dignity for life despite the physical, social, psychological and financial circumstances [14]. A cross-sectional study of cancer survivors from Bangladesh showed that patients receiving home-based palliative care

had improved social and emotional well-being, although physical health and symptom management could be further improved [15].

During the pandemic, the community home-based palliative services required training in COVID-19 precautions and communication skills during physical and social restrictions. Home visits were replaced with weekly phone calls, while the availability of medications and food parcels were ensured. Community sensitisation continued but was changed to an online format [16]. Unfortunately, the COVID-19 pandemic brought out the 'death-denying urban culture' in Bangladesh, with many people preferring to die in hospital rather than at home. This contributed to the saturation of health services, which already encounters difficulties as Bangladesh is one of the most densely populated countries globally.

BRUNEI:

Brunei is a small country with a population of approximately 445000 people. It has a rapidly ageing population and a high rate of non-communicable diseases. A study of older patients admitted to the main tertiary hospital in Brunei (RIPAS Hospital) found that approximately two-thirds had severe functional impairment and more than one-third had dementia [17]. Palliative services are provided in the tertiary hospital and a private oncology hospital, mainly for cancer patients. There are several challenges to implementing palliative

care in Brunei. Pain assessment and management needs to be improved, with multiple barriers identified before achieving a pain-free hospital [18]. While clinicians support the introduction of advance care planning discussions, cross-cultural adaptation of available tools is required [19]. There is also a need to have a national palliative and end-of-life care policy nationally [20]. Thus, there is much to be done to advance supportive care and symptom management, that needs to be planned across all health care settings.

During the COVID-19 pandemic, many services were temporarily halted including inpatient consultations, outpatient clinics and community visits for dependent patients [21].

This reduction in community services was complicated by an increase in sacral pressure injuries; some were so severe they led to osteomyelitis and required a prolonged admission to hospital for intravenous antibiotics [22]. The pandemic led to several new developments to provide patient support. Virtual consultations were introduced to bridge the gap caused by cancelled community visits [23].

A palliative care bundle was also implemented to ensure a consistent palliative approach was provided for patients towards the end of life in hospital [24]. Further effort is required to extend the range of palliative services and improve access for patients.

INDIA:

India is the seventh largest country by area and the second most populated country with 1.4 billion people. There is a large burden of suffering from terminal and life-limiting illnesses. Palliative care is mainly restricted to major cities and cancer centres, except for Kerala, where services are more readily available than other states. The Health Ministry data analysis by the Federation of Indian Chambers of Commerce & Industry found that only up to 2% of those with palliative care needs have access to the services [25]. Generally, there is limited access to palliative care, curative surgery or cancer-directed treatment for metastatic disease.

There are several advancements for palliative care in India. In 2012, India initiated the National program for palliative care (NPPC). The Indian Parliament amended the Narcotic Drugs and Psychotropic Substances Act in 2014, removing legal barriers to opioid access. In Kerala, a Neighbourhood Network in Palliative Care (NNPC) was developed, enabling improved access to home-based palliative services. This was a community-led initiative supported by multiple community groups, schools, universities, religious groups and non-governmental organisations, providing for the social, spiritual and emotional needs of a large number of people [26].

There are many barriers to improving palliative care in India. There is a lack of awareness or education by healthcare professionals and the

public. There is a need for educational campaigns to sensitise the public regarding palliative care. An effective curriculum and clinical skills training is required to upskill healthcare professionals, and correct the misconceptions and biased attitudes against the specialty. Policy makers also require improve awareness of the importance of palliative care and provide support with resources such as medications including opioids, equipment, finances and a staff for a multidisciplinary team. A holistic collaborative approach involving alternative therapy such as ayurveda, yoga, unani, siddha, homeopathy (AYUSH) and naturopathy should also be integrated to meet the cultural needs of the society [27].

During the COVID-19 pandemic, the majority of patients with life-limiting diseases such as cancer were unable to access treatment. The hardest hit patients were frail, older people that were unable to reach services in-person or virtually. There was limited personal protective equipment (PPE) provided for home-based palliative care; with the infection prevention control measures increasing costs and consultation times (including time to don and doff PPE). The positive impact of the pandemic was the adoption of telemedicine and the use of health technology to deliver care to patients. There was also increasing acceptance of novel approaches and alternative medicine systems, including AYUSH during the health crisis [28].

MYANMAR:

Myanmar is a low-income country with under-developed palliative care services. Palliative care was introduced in 2013 from efforts by healthcare professionals and civil governments to increase the capacity and quality of national healthcare, including palliative care. This resulted in the development of two stand-alone hospices and one hospital-based palliative department in the country. However, current political conflicts have affected the delivery of essential healthcare services, capacity building and provision of palliative care. There is limited interest and support from policy makers for palliative care. The socioeconomic crisis restricted availability of funds to invest towards palliative service development, education and research; affecting patient access to the already limited palliative services [29].

Despite the significant need, there is a general lack of awareness and knowledge about the specialty among the public and clinicians. Most consider palliative care as needed only at the very end of life or simply to provide pain relief. This limited understanding contributes to clinicians' reluctance to refer patients early or when required [30]. A study of Myanmar physicians found that generalists and specialists from both public and private sectors have limited skills to provide primary palliative care to patients. There was a focus only on physical symptoms, without considering the psychosocial and spiritual suffering of patients and families

[31]. While charitable organisations are willing to offer help for the needy, the poor palliative knowledge limits the provision of effective supportive care. Information, education and training programmes and research development in the field is greatly needed.

There is a national shortage of health workers, including nurses and social workers, affecting regular palliative care services. These services were further affected by the pandemic, as all healthcare professionals including trained palliative care nurses were required to cover general medical and COVID-19 wards. Their specialized skills and clinical experience were not utilized, while the additional duties caused extra burden and distress. Consequently, the overworked healthcare personnel were reluctant to contribute charitable palliative services in addition to their current workload [32]. The lack of career opportunities and progression also affected clinicians' interest in palliative care.

There are limited resources available to develop palliative services, with a dependence on donations from charitable organisations. Opiate medications such as morphine are restricted and only available in some tertiary hospitals. In Yangon General Hospital, the palliative care department was moved to extend the COVID-isolation wards, limiting clinical space for service provision. This was eventually closed during the pandemic due to inadequate staff and space. During the pandemic, the limited face-to-face

assessments and physical barriers in dealing with patients also made communication difficult, especially for patients during the end-of-life. Many patients died alone due to public health restrictions.

However, during this difficult time, telemedicine became more prominent and the palliative care team gained more confidence and experience providing palliative and end-of-life support to COVID-19 cases. There was an improvement in healthcare providers' knowledge in palliative care and an emphasis on family support and caregiver training in caring for patients. There was also an increased willingness and acceptance by the public to utilise and receive palliative care services [33].

THAILAND:

Thailand has a population of 71.6 million people, with an estimated 170000 people accessing palliative care services annually. While there is a national palliative care plan covering all regions in Thailand, palliative care centres are mainly based in secondary and tertiary care hospitals [34]. Palliative wards or hospices are limited. The palliative care budget comes from healthcare funds providing universal health coverage, with additional funds from other government agencies and donations. In suburbs or rural areas, while services are less developed, family caregivers, community volunteers and local organisations cooperate to support palliative care needs [35]. The

availability of clinical practice guidelines, access to medical equipment and palliative care courses are enablers in the country.

There are several barriers to palliative care in Thailand. There is limited opioid availability, home care services, and trained palliative care providers in certain localities. There is stigma and negative emotions associated with impending death situations affecting acceptance of palliative care in the community [36]. Application of living wills or advanced care planning remains difficult to implement, despite available laws to support this. The religious perspective of Buddhism prohibiting killing of living things may misconstrue the public's views of morphine administration and withdrawing life support as hastening death, with associated karmic consequences to the family making a decision for palliation [37]. There is also a need to identify the place of medical cannabis use for palliative care, as this has just been legalized in the country. The lack of palliative care teaching in medical and nursing school, as well as residency training may lead to negative attitudes and reluctance to refer to palliative care, resulting in consultations only at the very end of life [38]. There are also limited palliative care physicians outside teaching hospitals, with most palliative care tasks run by full-time nurses and part-time physicians. This will require policies to ensure an aligned career path in this specialty for doctors and nurses [39].

During the COVID-19 pandemic, clinical practice guidelines were developed on how to manage patients during such outbreaks. This included the use of telemedicine consultations to support patients and postal services to deliver medications. There was an increase in personal purchases of oxygen equipment, with a large number of home oxygen concentrators donated to hospital. However, the peak of the pandemic resulted in hospital bed capacities being overwhelmed, with palliative care services unable to cover all COVID-19 patients. Specialised trained staff in palliative care were also deployed to care for COVID-19 patients. Due to social restrictions, dying patients with COVID-19 infections were unable to access palliative services for symptom management. These restrictions also affected funerals or religious ceremonies, leading to unresolved grief. Many patients were lost to follow-up, particularly for those who had COVID-19 infections at the time of review.

Thinking ahead, there is a need to prepare a contingency plan for the next pandemic. Undergraduate palliative care, bereavement care and palliative nurse training should be strengthened. In the post-pandemic period, living wills and advanced directives should be promoted and destigmatized to facilitate these conversations. Community-based palliative care especially in rural areas should also be strengthened [40].

CONCLUSIONS:

This situation analysis of palliative care in these five Asian countries identified many similarities and recurrent themes. Palliative care is an underserved specialty, despite an obvious need for the services in each locality. The COVID-19 pandemic significantly interrupted palliative services, but providers adapted to these challenges such as developing guidelines and using teleconferencing. Overall, much work still needs to be done to improve the palliative care situation in the Asia-Pacific region.

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