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BUILDING AWARENESS AND SUSTAINABLE PALLIATIVE CARE: A PERSPECTIVE ON KEY CHALLENGES AND OPPORTUNITIES FROM BRUNEI

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ABSTRACT:

Palliative care improves the quality of life for patients with life-limiting illnesses and their families. However, integrating these services into healthcare systems remains challenging, particularly in resource-limited settings. This paper provides a perspective on challenges and opportunities from Brunei in building awareness and sustainable palliative care. Key challenges include limited access to trained specialists, fragmented care systems, low health and death literacy, and the need for culturally adapted approaches. Potential solutions to address these barriers include training community leaders such as village heads, establishing multidisciplinary interest groups, and piloting palliative care in high-need areas such as intensive care units. Integrating palliative care into medical education and healthy ageing initiatives may foster a long-term cultural shift in supporting palliative care. Proposed community awareness strategies emphasize the empowerment of informal caregivers and communities, using public libraries as information hubs, and storytelling from care recipients to destigmatize palliative care. To ensure sustainability, fundraising is critical, which may be achieved through organizing conferences and getting support from governments and corporate social responsibility programs. It is hoped that these reflections will provide useful insights for other countries aiming to develop palliative care.

Keywords: Community; fundraising; palliative care, participation

INTRODUCTION:

Palliative care is an approach aimed at improving the quality of life of patients with life-limiting illnesses and their families. Palliative care encompasses care at any stage of a serious illness and is not limited to end-of-life care. In contrast, hospice care specifically focuses on providing comfort and support during the terminal phase of an illness, usually when curative treatment is no longer pursued. The complexity of care for these patients requires a multidisciplinary approach [1]. A systematic review found that the elements of effective palliative care models include communication and coordination between providers including primary care, improved skills, and the ability to respond quickly to the person's changing needs and preferences over time [2]. Palliative care can be delivered across multiple settings, ranging from hospital or hospice based, as well as home-based palliative care [3].

Regardless of setting or patient characteristics, a systematic review found that all models of palliative care provided benefits to the patient and was associated with reduced total healthcare costs [4].

Despite these significant benefits, it is difficult to integrate palliative care into healthcare systems in the disease trajectory of those with serious illnesses. In the United States, there were several key barriers related to education, implementation and policies. There was lack of adequate education or training, inadequate palliative trained clinicians, difficulty identifying patients who require palliative care, fragmented healthcare systems, and inadequate reimbursement for palliative care provision [5].

These difficulties in establishing palliative care services occur worldwide. In 2011, globally, 58% of the countries had at least one palliative care service, but integration of palliative care was only achieved in 8.5% [6]. This increased to 70% and 14% respectively when the global survey was repeated in 2017 [7]. The World Health Organization non-communicable disease country capacity survey in 2015 showed that only 37% of countries included palliative care in their operational national policy for non-communicable diseases, with palliative care least likely to have funding available [8]. Projections of the global burden of serious health-related suffering that need palliative care by 2060 suggest that there will be an 87% increase in people dying with serious health-related suffering. This will increase significantly for low-income countries, among older people, cancer deaths and dementia [9]. Thus, it is important that countries take immediate action to integrate palliative care into health systems as an ethical and economic imperative.

A global initiative to provide palliative care leadership training is a six-month online course, the Fellowship in Palliative Care, jointly organized by the Institute of Palliative Medicine in India, St Christopher's Hospice in London, United Kingdom, Sanjeevan Palliative Care Project in Pondicherry, India and Bangabandhu Sheikh Mujib Medical University in Bangladesh. The curriculum covers palliative care concepts, skills and practical applications to enable participants to organize and start palliative care in their localities and is designed for clinical staff, program managers, coordinators, social workers, government agencies and professionals interested in establishing palliative care services [10].

In 2022, participants of the course were required to reflect on the following questions:

- *What were the five main barriers slowing down or blocking the establishment and/or*

expansion of palliative care services in your locality?
- *What are five possible ideas to help start or establish palliative care services in your locality?*
- *What are five possible interventions to improve the awareness and participation of the local community for palliative care?*
- *What are five possible options for fundraising towards palliative care?*

These questions are relevant, as it is important to identify barriers at the start of any program and find solutions to overcome them. Effective palliative care requires strong community advocacy and awareness [11].

Palliative care also tends to be short-changed when it comes to accessing funding through traditional mechanisms such as health budget allocations, hence a need to identify options for fundraising [12].

In this paper, the reflections on barriers and enablers for palliative care services, community awareness and fundraising ideas are described as it applies to Brunei, a small country in Southeast Asia with a population of 440000 people [13]. It is hoped that these considerations will form a useful case study that will seed ideas to initiate palliative care services in other countries.

Barriers to establishment or expansion of palliative care services in Brunei:

1. *Limited palliative care specialists and healthcare professionals with palliative care skills or expertise*:

The palliative care specialty is currently led by Consultant Oncologists instead of a palliative care physician. There are limited palliative specialists in the region and recruitment attempts have been unsuccessful. As of 2024, there are two nurses who completed postgraduate training in palliative care, but they are also involved in nursing management duties. There are no other doctors or allied health professionals with formal training or expertise in palliative care.

The Australian and New Zealand Society of Palliative Medicine recommends one full time equivalent (FTE) palliative medicine specialist per 100000 population [14], while the European Association for Palliative Care recommends two specialized palliative care services per 100000 people (one home care team and one hospital team) [15]. Thus, in an ideal situation, Brunei requires 4.5 FTE palliative specialists, with eight palliative teams in total. While recruitment is ongoing, currently, there are initiatives to teach the palliative care approach to other clinicians, focusing on pain management and advance care planning [16].

2. *Limited access to palliative care services*:

Palliative care services are predominantly Oncology-based at the Raja Isteri Pengiran Anak Saleha (RIPAS) Hospital, the main tertiary hospital and The Brunei Cancer Centre (TBCC). These are hospital-based specialty services mainly for oncology patients who develop complications or require symptomatic treatment. Patients are unable to access these services unless there is a referral from primary care or another treating clinician, and must travel to the main hospital for a consultation. Primary care and regional hospitals do not have developed palliative services. Community nurses based in hospital may offer outreach visits but only for patients known to the service.

3. *Lack of integrated palliative care*:

Working in silos affects care coordination, especially for those requiring palliative care. Oncology services are based in TBCC, and neurology services are also based in a different hospital, while acutely unwell patients, those who require other specialty input or radiological interventions need to present at RIPAS Hospital. On discharge, the follow-up remains with specialty services. Primary care is under-developed and caters for minor illness only. Patients with chronic diseases may be seen by multiple doctors, affecting continuity of care and limits advance care planning discussions.

There are several areas of potential collaboration between different specialties and allied health professionals that may be led by palliative care. For example, patients with chronic obstructive pulmonary disease and heart failure require an interdisciplinary approach [17]. Palliative patients require significant allied health professional input, such as for malnutrition and rehabilitation [18,19].

4. *Low health and death literacy*:

Despite the high rate of non-communicable diseases (NCDs), patients often have poor health literacy, health maintenance or illness prevention behaviors and limited self-management skills for chronic diseases, including asthma management and self-monitoring of glucose in diabetes [20]. A delay in seeking medical review may also result in faster health decline and an increased need for palliative and supportive care. In advanced terminal illness, family members occasionally bring patients to hospital unaware of the disease trajectory. This may lead to poor acceptance that there is limited medical intervention or treatment available to reverse the condition. For example, when those with advanced dementia or imminently dying patients stop eating, there may be requests for intravenous fluids, nasogastric feeding or oxygen. Further effort is required to improve health literacy among the public, particularly the NCDs and death literacy to improve awareness and acceptance of end-of-life care [21].

5. *Need to tailor palliative care approach to local and cultural views or practices*:

There is also a need to tailor the palliative care approach to local and cultural views or practices. For example, pain assessment requires a good history and descriptions of pain, which the Short

Form McGill Pain Questionnaire 2 (SF-MPQ-2) had to be adapted for use in older people in Brunei [22].

Similarly, tools from Western countries such as the Gold Standards Framework to identify palliative patients [23], and advance care planning discussions require cross-cultural adaptation and localised training for these tools to be implemented in our settings [24].

Ideas to establish palliative care services in healthcare institutions or country:

- *Palliative Care Basic Training for village heads*:

In Brunei, village heads are elected officials carrying multiple responsibilities, including ensuring efficient distribution of the monthly old age pensions, monitoring the social welfare of vulnerable people, such as poverty and social isolation, as well as assist in formalities and paperwork for community deaths. They are strategically placed to offer basic palliative care services and would benefit from basic palliative care training.

Permission is required from the Ministry of Home Affairs, which is supportive of initiatives for skill development. The training session can be held over a weekend, which includes case discussions and practical application of these concepts with the palliative care team.

- *Palliative Medicine interest group for healthcare workers*:

Before the COVID-19 pandemic, a palliative medicine interest group was held monthly. Topics and sessions were coordinated by a nursing lecturer in palliative care from Universiti Brunei Darussalam (UBD). Sessions consisted of a lecture followed by a workshop. These were well received and attended by healthcare professionals from different specialties, ranging from doctors, nurses, allied health professionals and academics.

The interest group should be resurrected and adapted to an online format. Lists of previous attendees can be used to invite people to participate. The online option also offers an opportunity to access experts or guest speakers from abroad and increase the number of participants.

The COVID-19 pandemic taught healthcare professionals and communities about the importance of palliative care, and the need to adapt services in hospital and the community during a pandemic [25-27].

In addition, some groups of patients were found to be vulnerable during a pandemic, such as those with NCDs or dementia, which can be identified to increase their awareness of palliative care services [28]. This requires healthcare workers to be trained first.

- *Incorporate palliative care into healthy ageing regional initiatives*:

Brunei has a rapidly increasing ageing population, which require services to be developed to improve the well-being and resilience of older people [29,30]. In the Asia-Pacific region, there are regional healthy ageing initiatives and policy discussions to manage this demographic change.

Brunei has developed Information Education Communication (IEC) messages for healthy ageing, which are the basis of health promotion materials. Several aspects of palliative care, such as advance care planning, rehabilitation to maintain function, mental well-being, quality of life (and death) can be introduced into the healthy ageing IEC materials in Brunei. This can be evaluated locally, and adapted for use in the region.

- *Introduce palliative care in areas of need*:

While the tertiary palliative care services in Brunei covers mainly cancer-related complications, there are other conditions that require palliative care, especially end-stage organ failures (cardiac, pulmonary, renal, hepatic and brain or advanced dementia). Unfortunately, these patients progressively decline and without advance care planning, may end up in the intensive care unit (ICU). A palliative service could be piloted in the ICU, offering outreach consultative services and palliative nursing support [31]. Patients can be proactively identified at ICU handover meetings for those who require palliative input and discharge planning. This pilot project will offer insights on how to subsequently introduce palliative care to other services.

- *Introduce palliative care into undergraduate and postgraduate medical education*:

When Geriatric Medicine was introduced in Brunei, core competencies related to the care of older people were introduced into the UBD medical and nursing curriculum. Lectures and tutorials were delivered by geriatricians from RIPAS hospital, with a geriatrics module incorporated into the undergraduate and postgraduate medical and nursing programs. A similar process can be done for palliative care so that palliative care concepts will be taught to medical, nursing and paramedic students, as well as Masters of Health students (consisting of Basic Specialty Trainees for Emergency Medicine, Internal Medicine, Surgery, Public Health, Primary Care, Intensive Care, Pediatrics, Obstetrics & Gynecology). After the pandemic, blended learning and the use of online modules opens further options for medical education, which can be applied to palliative care [32].

Ideas to improve awareness and participation of the local community in palliative care:

- *Empower village heads and 'death doulas'*:

Engaging and empowering communities through awareness raising is an essential cornerstone to develop palliative care [33]. Informal palliative care providers include village heads and 'death doulas', who assist with the logistics of dying arrangements [34]. They can advocate for the importance of palliative care and bereavement support for families of the deceased. Information regarding these services should be available and disseminated via community centers and public spaces. Training and education may increase empowerment of village heads and death doulas, such as an understanding of the expected trajectory of illness, advance care planning and bereavement counselling [35,36].

- *Community libraries as hubs for palliative care information*:

The public library network in Brunei can serve as hubs for palliative care information. Books on palliative care can be requested for libraries to purchase, which can be displayed in the front for a period of time. The libraries have meeting rooms to organize conversations and forums regarding palliative care.

- *National study of palliative care needs in Brunei*:

Collaborating with the local university to carry out this study will help identify and prioritize palliative care needs for the country. Participant information sheets distributed for subject recruitment contains information regarding palliative care. The study may also facilitate members of the public getting involved in giving opinions and feedback to shape palliative service development.

- *Socialize action plan for non-communicable diseases (NCDs) with an emphasis on palliative care*:

The Brunei National Multi-Sectoral Action Plan for the prevention and control of NCDs (BruMAP-NCD 2021-2025) includes developing and strengthening palliative care services [37]. This guidance should be socialized to healthcare professionals and the public, with information on palliative care available for all the sectors involved.

- *Share testimonials and stories from recipients of geriatrics and palliative services*:

Geriatrics and Palliative Medicine, RIPAS Hospital carries out satisfaction surveys of patients and relatives to identify potential areas of improvement. Feedback and stories on how the team helped them through difficult times may be shared anonymously with their permission as part of awareness raising activities.

Ideas to raise funds for palliative care:

- *Government support for associations*:

A palliative association may be set up to advocate for the need of palliative care in Brunei. The government supports non-governmental organizations (NGOs) that have a cause which contributes towards sustainable development goals. This support includes annual funding, provided Key Performance Indicators are met.

- *Research funds or grants*:

UBD offers research funds or grants, with a call for research proposal submissions each year. The selection committee is interested in novel research and ageing-related topics, in which palliative care fits well. Funds can be used to recruit staff, print information leaflets and equipment for palliative care, provided they are related to research.

- *Regional and international funding opportunities*:

There are also annual calls for project proposals for regional funding opportunities, which may be relevant for palliative care projects. The World Health Organization (WHO) and Association of the South East Asian Nations (ASEAN) have funding opportunities for ageing related projects, while the Organization of the Islamic Conference (OIC) supports health, social and development projects. These organizations may also provide technical expertise for the proposed project but a project evaluation report and deliverables are usually expected.

- *Approach banks and companies to support palliative care*:

Large companies and banks contribute funding support as part of their corporate social responsibility (CSR) to charitable causes. These companies have regular staff training sessions that NGOs may be invited to present. A sensitization program for palliative care falls within the remit of their staff development program, as palliative care and death affects everyone.

- *Annual conference on palliative care*:

A hybrid conference could be organized to update healthcare professionals on palliative care. Registration fees will contribute towards fundraising. Presenters may be invited from different specialties. Costs can be minimized through using hospital facilities and online meeting access, while printing and refreshment expenses will be offset by registration fees.

CONCLUSION:

Developing palliative services in Brunei must address systemic barriers, improve community awareness, and secure sustainable funding. A foundation for comprehensive palliative care services can be laid by leveraging existing resources, fostering cross-sectoral collaboration, and integrating culturally sensitive practices. It is hoped that these reflections will provide useful insights for other countries aiming to develop palliative care.

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