Palliative Care and Pain Management in a Resource-Limited Setting

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ABSTRACT

Palliative care is a vital component of healthcare that aims to alleviate the suffering of patients with life-threatening conditions. This specialized medical care focuses on managing symptoms, addressing social, emotional, and physical needs, and enhancing the quality of life for patients and their families. Palliative care addresses the patient's medical, psychological, and spiritual requirements, and can be used as the primary focus of care or in conjunction with curative therapies. Pain management is a crucial aspect of palliative care, involving the control or reduction of pain through medication, therapy, and other treatments. However, pain is a subjective sensation, making quantification and effective relief challenging. This review highlights the complex issues associated with pain management in palliative care, emphasizing the need for improved training and accessible pain management techniques, such as the widely recognized "Wong-Baker Face Pain Scale", particularly in resource-constrained environments like Nepal. The complex nature of pain management in palliative care compromises patients' quality of life, influenced by factors like chemotherapy and terminal illness. Addressing this issue is imperative, especially in areas like Nepal where there is a shortage of appropriate training among medical personnel. Encouragingly, initiatives like mobile health teams, smartphone apps, and the establishment of a Palliative Care Training Center demonstrate progress in improving end-of-life care.

KEY WORDS

Health personnel, Nepal, Pain management, Palliative care

INTRODUCTION

Palliative care is a complex field that addresses the suffering and discomfort experienced by individuals with life-threatening illnesses. Its primary goal is to enable patients to live comfortable, pain-free lives. Pain in palliative care is multifaceted, encompassing existential, mental, emotional, and physical components, requiring a comprehensive approach to understand and manage its intricate aspects.

Palliative care acknowledges that individuals with serious illnesses have diverse needs beyond physical symptoms, necessitating a holistic approach that fosters patient-centered, individualized, and supportive care.[1] This approach recognizes and addresses the various aspects of a person's well-being. In the complex field of palliative care, providing adequate pain relief to patients nearing the end of life is a significant challenge for medical practitioners. Pain perception varies greatly between individuals, requiring personalized pain management programs that involve careful assessment and ongoing adjustments, making it a dynamic and challenging process to oversee. Despite the development of instruments like the 'Wong-Baker Face Pain Scale', the subjective nature of pain remains a significant hurdle in accurate measurement and alleviation. This comprehensive analysis highlights the crucial need for improved training and accessible pain management techniques, particularly in resource-constrained environments like Nepal.

REVIEW

Pain management

Palliative care is the treatment and support of patients, who have a terminal illness with comfortable and painless living as their goal despite the often challenging circumstances. Nevertheless, controlling pain in patients who are under palliative care or those in their last few days of life is always a problem for doctors and other healthcare providers. Several factors contribute to the difficulties in managing pain, including:

1. The complexity of the patient's medical conditions
2. Individual differences in pain perception
3. Multiple concurrent complaints
4. Concerns about opiate addiction and side effects
5. Need for customized approaches

Effective communication between healthcare professionals, patients, and their families is crucial in tailoring therapies and addressing unique challenges. However, a large number of patients in the terminal phase of the illness remain without treatment for their symptoms, and this has a calculable effect on the patient's well-being. As a result of the variability in human beings' pain response, the experts in palliative care experience pressure in the proper handling of this issue. Inpatient healthcare consumers apply the WHO analgesic hierarchy and graphical pain intensity indicators, including the 'Face Expression Chart' and the 'Wong-Baker Face Pain Scale'.

The face pain scale remains a primary tool when assessing pain in patients who have limited capacity to verbally express themselves in patients with terminal illnesses. Expression-based pain rating scales have been employed in different specialties in medicine for some time now. One of the more famous such tools is the Wong-Baker FACES Pain Rating Scale, devised in the 1980s for pediatric patients and since adapted for adults. This scale employs the use of faces depicting various levels of pain in order that a given individual can be able to estimate his or her level of pain by pointing at the face figure. Face pain measures are used by palliative care practitioners under the broader framework of improving pain assessment and reporting among patients with communication impairment. The Wong-Baker FACES Pain Rating Scale has gained popularity in palliative care due to its:

- Visual presentation, making it accessible for individuals with varying literacy levels and cultural backgrounds
- Simplicity, making it easy to use for both patients and healthcare professionals
- Patient-centered approach, enabling individuals to communicate their pain in a unique and intuitive way.[2]

This scale is particularly useful in palliative care settings, where time and resources may be limited. The Wong-Baker Facial Pain Rating Scale effectively helps patients communicate the intensity of their physical pain to medical practitioners, using a combination of facial depictions, numerical values, and descriptive words. While ideal for use before medical procedures or during routine visits, its effectiveness diminishes in emergencies where patients may be unconscious or unable to articulate their condition.[3]

Pain assessment is crucial in palliative care, but its subjective nature makes it challenging to quantify. To guide treatment, it's essential to determine the pain's source, intensity, type, and distribution. However, in palliative care, this information is not always available. Several techniques can aid in pain assessment, including the Wong-Baker Facial Pain Rating Scale as shown in table 1, which is particularly useful in resource-constrained settings, such as developing countries like Nepal. This scale is simple, affordable, and visually based, making it accessible even in areas with limited medical infrastructure and diverse patient populations.

The Wong-Baker Facial Pain Scale's ease of use and cultural adaptability enable healthcare professionals to quickly assess pain levels, even in situations where language barriers or literacy issues may exist. This facilitates more effective and responsive pain management in high-demand healthcare settings, particularly in resource-scarce environments where its simplicity is a significant advantage.

Patients approaching the end of life have the right to a pain-free existence, making opioid analgesics essential for symptom relief. This aligns with the values of compassionate care, respect for dignity, and promotion of quality of life. Pain management is crucial to maintain dignity, improve comfort, and maximize the remaining time. It demonstrates a moral commitment to alleviating suffering during a vulnerable period.

The WHO analgesic ladder has been a simple and effective tool for reducing pain-related morbidity in cancer patients for over thirty years.[3] Opioids, particularly morphine, have been the most effective medication for managing moderate-to-severe pain in patients. Morphine, the first-choice drug for treating severe pain associated with serious illnesses like cancer, has revolutionized palliative care.[4] Nepal adopted a National Strategy for Palliative Care in 2017, outlining a ten-year plan to develop and integrate palliative care services into the healthcare system.[5] This strategy aims to ensure access to pain management and quality care for patients nearing the end of life.

Despite efforts, more needs to be done to educate doctors, improve public perceptions, and increase knowledge among policy-makers and healthcare workers about opioids. In

2015, Nepal's morphine equivalency was reported to be 0.27 mg per person, significantly lower than the Southeast Asia Region's 1.7 mg per person and the global average of 61.5 mg per person.[6]

Although the WHO emphasizes the importance of morphine, its availability in Nepal is inconsistent due to low production and supply chain issues, contrasting with the opioid overdose epidemics in developed countries. Legal restrictions, concerns about abuse, the stigma surrounding opioid use, and lack of knowledge among medical professionals contribute to the low supply.

Furthermore, barriers to access to opioids for the management of pain include challenges in pharmaceutical distribution and purchase besides limited funding. Local NGOs have made efforts to respond to this situation by influencing policymaking, raising awareness about the proper approach to the use of opioids, and reducing prejudice towards pain management and palliative care.[7] Improving the healthcare system and increasing the orientation of people to the problem can contribute broadly to the adequate and accessible provision of morphine to patients requiring it in Nepal.

Sustaining an appropriate amount of morphine to fulfill the need for palliative care in Nepal is very complex and contingent on polarity implications, enhancement in the health care structure, educational faculty, and removing stigma.[8] Some progress might occur in the future when all the regulatory barriers are solved, the healthcare system is developed, responsible opioid use is explained, and people with this disease are not discriminated against. To support longer-term changes, efforts should be made by agencies and ministries, physicians and nurses, NGOs, and international organizations. Continuous efforts and an approach towards the improvement of palliative care services in Nepal are needed to work towards aims towards equalizing the demand and availability of morphine.

Overview

Nepal, with a Human Development Index of 0.463, ranks 157th out of 186 countries in the 2012 UNDP (United Nations Development Programme) report, making it one of the least developed countries globally.[5] Despite adequate morphine and other analgesics in Nepal; however, palliative care services have had significant development in the last fifteen years. Nevertheless, the country struggles to deliver full-spectrum palliative care services for patients with cancer and those who have, at some time, received a cancer diagnosis due to the issues related to the lack of human resources, drugs, and specialized services.

This topographical feature and the remoteness of some of the areas make it challenging to guarantee the equitable availability of basic drugs, including opioids for the alleviation of pain. International Agencies have also noted that Nepal is among the countries with one of the lowest usage rates of controlled pain medicines due to limited funding, thus making the delivery of palliative care difficult. Patients' needs and preferences are varied and thus cannot be managed routinely and this has also contributed to the increase in the overall cost of provision of health care. Such peculiarities can be attributed to the absence of perfected uniform guidelines and metrics to implement them. The shortages in access and utilization of palliative care services and goods, especially in rural areas of Nepal, add to the difficulties experienced by caregivers and patients alike.[9]

METHODOLOGY

TThis review article identifies the significant challenges in pain management and the need for improved training and accessibility in pain management strategies, particularly in low-resource settings like Nepal. A comprehensive literature search was conducted using various databases, including PubMed, Google Scholar, and Directory of Open Access Journals. Relevant keywords such as palliative care, pain management, healthcare professionals, Nepal, low-resource settings, facial pain scale, and morphine were employed to retrieve data. The retrieved data were evaluated for strength and quality and then organized and synthesized to detect patterns, themes, and gaps in the existing literature. This methodology enabled a thorough analysis of the challenges and needs in pain management, informing strategies for improvement in low-resource settings like Nepal.

Prospective Difficulties in Providing Quality Palliative Care

There are some reasons why medical care providers may be hesitant to integrate person-centered philosophy in managing palliative pain. Large-scale training tends to provide solutions to specific matters related to care hence some caregivers might lack the confidence to address social, emotional, and spiritual aspects of care, which are important in comprehensive care. Furthermore, cases of time scarcity in caregivers' practice are another factor, as patient-centered care entails the integration of a biophysical, psychosocial, and spiritual assessment, patient-centered and individualized care plans, and communication – all of which take time than is available due to time constraints in patient care.[8]

Some may even challenge the efficacy of psychosocial and nonpharmacologic approaches to pain control and seek to replace them with pharmacological techniques that can be tried and true and easily measured. In low-resource environments, performers experience barriers to the acquisition of appropriate instruments and backing for detailed care that encompass people, time, and services such as counseling and religious help. Legal requirements for pain treatment, especially with opioid medication, can also affect healthcare choices. To overcome these barriers there must be a cultural reform where patients and families are educated about the benefits of holistic palliative care. This can be done through ceaseless running of education and training programs. Efforts towards the incorporation of holistic approaches into the framers of medical education and the support of medical professionals can go a long way in combating all forms of resistance.

Lack of awareness of the availability of palliative care leads the patients and their families to go for other treatments that are undesirable putting them in a worse health and economic state. In the case of a patient facing a terminal or chronic disease, the patient may decide to stop the therapy and go home or turn to charlatans who offer a cure instead of taking palliative care. This could be explained by their view on illness and treatment and therefore end up opting for traditional healers.

The geographic characteristics of the country also make it difficult to deliver palliative care since 83% of Nepalese territory consists of hills and mountains. In this respect, palliative care should become part of community health services to cope with this problem. The employed mid-level health workers including the health assistant and the healthcare worker are primarily involved in the provision of healthcare services to the communities in the rural areas although this workforce receives minimal training support and remunerations from the government.[11] These healthcare workers have an important duty in the provision of palliative care to the population.

Palliative Care: A Sociocultural Perspective

Palliative care in Nepal is characterized by holistic systems of delivering pain control with reference to socio-cultural and spirituality. Family is highly valued in Nepalese culture and, palliative care recognizes this and allows the caregivers, in addition to the patient, to handle the complexities of care.[12]

Culture and tribal customs remain important as to how patients and families make decisions concerning pain, and how they seek treatment. However, religion is an important component of the life of many Nepalese citizens, and in the same way, palliative care designates spiritual suffering, and spiritual care connected with the belief that there is a spiritual and physical duality of existence.[10,13]

Socio-cultural belief systems may influence how patients and families express concerns about pain, prognosis, and dying which sets the rationale for why making discourse of pain prognosis and end-of-life care requires tact. Nepal’s palliative care sometimes takes additional health care assistance in the community support through the community care structures which provide patients and families; economic and psychosocial support to improve the quality of lives of the patients and their families.

Holistic pain management is essential in palliative care, as it considers the existential and psychological dimensions of suffering, promoting peace, dignity, and acceptance. To deliver palliative care that is truly effective and culturally sensitive, healthcare providers must recognize and respect these sociocultural and spiritual elements, designing pain management strategies that align with these principles. By doing so, medical care becomes not only therapeutically effective but also meaningful within the context of patients’ cultures and spirituality.

Cost Considerations for Palliative Care

The Government of Nepal has recently introduced a health insurance system through the “Health Insurance Board (HIB)” that provides additional support for the treatment of insured citizens, including cancer patients who receive treatment support equivalent to US$ 855. However, numerous factors affect the financial aspects of palliative care in Nepal, where the healthcare sector faces financial challenges due to the country’s low income. The limited funding for personnel, supplies, and prescription drugs hinders the accessibility and availability of palliative care services, making it difficult for patients to access essential pain management medications due to financial constraints. Moreover, budgetary constraints impact palliative care facilities, limiting investments in infrastructure development, specialist facilities, and training programs.

Comprehensive coverage for pain management and palliative care could alleviate financial burdens for patients and their families. Charitable organizations often fund palliative care efforts, and their contributions could support patients who face additional expenses, such as travel, food, and lodging, as well as lost daily wages. Many patients are forced to sell their possessions to pay for medical care. The government provides financial support only to approved treatment facilities that adhere to established guidelines, ensuring quality of life, pain management, and support for patients nearing the end of life. However, this support is insufficient to meet the demands of the general public in Nepal who require palliative care, highlighting the need for increased funding and resources to address these challenges.

Palliative Care in a Low Resource Setting like Nepal

A cross-sectional study conducted by Thapa et al. among 336 healthcare professionals in Pokhara, Nepal, revealed that a significant majority (76%) do not adhere to specific pain management guidelines, with nearly 85% having never received pain training.[14] The study highlighted the need for proper training in pain management and medication dosing among healthcare professionals in Nepal.

Additionally, another study found that over 58,000 adults in Nepal required palliative care as of 2012, primarily in rural areas, emphasizing the urgent need for palliative care training among healthcare professionals and effective pain management in Nepal.[15]

According to Paudel et al. addressing the shortage of physicians in Nepal with training in pain management and palliative care requires skilled Nepali trainers.[4] This can be achieved through intensive training programs, either by sending Nepali clinicians abroad or inviting experienced foreign trainers to Nepal. Notably, research on the use of pain scales in Nepal is lacking, particularly in end-of-life care and palliative care facilities. The limited use of the Wong-Baker Facial Pain Scale in palliative care in Nepal may be attributed to cultural disparities, lack of education or experience among medical staff, or difficulties integrating standardized instruments in certain medical environments. Research and awareness campaigns can help explore the benefits of using these scales in palliative care, potentially leading to increased acceptance.

Palliative Care Initiatives in Nepal

Hospice Nepal, established in 2000 in the Kathmandu Valley, is the country's first recognized modern hospice institution. Since then, four major cancer hospitals have established palliative care sections and five hospices specialize in caring for cancer patients. Notably, organizations like Nava Kiran Plus, Blue Diamond Society, and Maiti Nepal provide care to patients with life-limiting illnesses, including HIV/AIDS, and support victims of human trafficking.

While most of these services are concentrated in Kathmandu, a few are located outside the valley. Green Pastures Hospital in Pokhara has offered palliative care since 2009, serving the underprivileged Western Region. The United Mission to Nepal has established hospitals in rural areas, providing comprehensive care, and the International Network for Cancer Treatment and Research (INCTR) has supported hospices through funding, training, and education. INCTR's projects include cancer awareness campaigns, cervical cancer screening programs, and expanding palliative care facilities in the Kathmandu Valley.

Although most palliative care needs are in rural areas, the majority of Nepal's palliative care services are concentrated in Kathmandu, according to the recently adopted national palliative care policy. Efforts are being made to ensure that healthcare personnel in rural areas receive appropriate training, acknowledging that different regions require tailored palliative care approaches due to Nepal's diverse topography. Palliative care teams are more justified in densely populated areas with higher needs. Interestingly, many Nepalese healthcare professionals have started using cell phones and apps for palliative care, particularly for cancer pain management. They utilize counseling apps, patient-caregiver communication platforms, and medication reminders to support patients.

A cross-sectional survey found that 96% of 97 palliative healthcare practitioners in Nepal were aware of the NAPCare PMG guidelines and used Android smartphones and apps to support cancer patients. While no single mobile app can fully address pain management complexities, digital interventions like NAPCare PMG offer valuable support for healthcare professionals and patients in low- and middle-income countries, enabling cost-effective remote patient care assessment and adjustment. The Nepalese Association of Palliative Care (NAPCare), a non-profit NGO established in 2009, aims to enhance palliative care services, raise awareness, and educate healthcare professionals about palliative care.

A forthcoming initiative in Nepal involves establishing a mobile Palliative Care Training Centre to consolidate recent progress and expand access to these essential services, particularly in areas where traditional centers may be challenging to establish. Additionally, localized language-based films highlighting the importance and benefits of palliative care have gained significant traction in the local community, leading to a notable increase in appreciation for palliative care. Consequently, rural Nepal is experiencing a modest surge in hospital admissions for patients requiring palliative care, reflecting the sustained commitment of Nepal's medical community and potential opportunities for enhancing care for terminally ill patients.

CONCLUSION

The current social and political transition in Nepal has resulted in progressive development in policies and services related to palliative care thus showcasing the relentless efforts of the medical fraternity in the country. Nevertheless, the situation concerning palliative care in Nepal is still quite grim, especially about the pain control of patients with advanced life-threatening illnesses. The existing services are inadequate to meet the high demand for palliative services within the country and the use of pain assessment instruments such as the Wong-Baker Facial Pain Rating Scale has not been effective in bringing the desired results. Some of the challenges that may be viewed as barriers include financial limitations and inadequate institutional capacity to provide adequate pain management education in low-resource environments.

However, improvements such as the Palliative Care Training Centre and local films have been made. Nepal is a rural developing country that has experienced a slight rise in admitting patients for palliative care, highlighting the efforts towards enhancing end-of-life care. The rising cancer rate in Nepal has led to an increasing need for palliative care, and the country has made significant strides in the last thirty years. Local opioid production has emerged as a crucial development in palliative care. International and national non-governmental organizations have played a vital role in expanding palliative care.

Despite government and organizational support, patients and their families still face significant financial challenges. A well-formulated drug policy can improve opioid availability and accessibility for palliative care patients. By combining this with capacity development and a comprehensive palliative care policy aligned with WHO guidelines, Nepal can reduce the unacceptable levels of serious health-related suffering. This review highlights ongoing challenges and the need for enhanced support, showcasing the progress made in assisting individuals in their final phases of life.

REFERENCES

1. Hackett J. The importance of holistic care at the end of life. *Ulster Med J*. 2017;86(2):143.
2. Medical News Today. What to know about the Wong-Baker pain scale. 2022. Available from: https://www.medicalnewstoday.com/articles/wong-baker-pain-scale
3. Kress HG, Aldington D, Alon E, Coaccioli S, Collett B, Coluzzi F, et al. A holistic approach to chronic pain management. *Curr Med Res Opin*. 2015;31(9):1743-1754.
4. Paudel BD, Ryan KM, Brown MS, Krakauer EL, Rajagopal MR, Maurer MA, et al. Opioid availability and palliative care in Nepal. *J Pain Symptom Manage.* 2015;49(1):110-116.
5. eHospice. National strategy for palliative care handed over to the government of Nepal. 2017. Available from: https://ehospice.com/international_posts/national-strategy-for-palliative-care-handed-over-to-the-government-of-nepal/
6. LeBaron V, Adhikari A, Bennett R, Chapagain Acharya S, Dhakal M, Elmore CE, et al. A survey of cancer care institutions in Nepal to inform design of a pain management mobile application. *BMC Palliat Care*. 2021 Nov 5;20(1):171. doi: 10.1186/s12904-021-00824-0. PMID: 34740339; PMCID: PMC8570036.
7. Gautam D, Adhikari S. Palliative care services for cancer patients in Nepal. *Palliat Care Soc Pract*. 2021;15:26323524211021105.
8. Magar A. Need of Medical Education System Reform in Nepal. *J Nepal Med Assoc*. 2013;52(191).
9. UNDP. Nepal moves one place up in human development ranks. 2022. Available from: https://www.undp.org/nepal/press-releases/nepal-moves-one-place-human-development-ranks-143r
10. Hindmarch T, Dalrymple J, Smith M, Barclay S. Spiritual interventions for cancer pain. *BMJ Support Palliat Care.* 2022;12(1):1-9.
11. Wasti SP, van Teijlingen E, Rushton S, Subedi M, Simkhada P, Balen J; Nepal Federal Health System Team. Overcoming the challenges facing Nepal's health system during federalisation: an analysis of health system building blocks. Health Res Policy Syst. 2023 Nov 2;21(1):117. doi: 10.1186/s12961-023-01033-2. PMID: 37919769; PMCID: PMC10621174.
12. Quinn B, Connolly M. Spirituality in palliative care. *BMC Palliat Care*. 2023;22(1):1.
13. Murray SA, Kendall M, Mitchell G, Moine S, Amblàs-Novellas J, Boyd K. Palliative care from diagnosis to death. *BMJ.* 2017 Feb 27;356:j878. doi: 10.1136/bmj.j878. PMID: 28242747.
14. Thapa P, KC B, Lee SWH, Dujaili JA, Gyawali S, Mohamed Ibrahim MI, et al. Managing Pain in Low Resource Settings: Healthcare Professionals' Knowledge, Attitude and Practice Regarding Pain Management in Western Nepal. *J Pain Res*. 2022 Jun 2;15:1587-1599. doi: 10.2147/JPR.S360243. PMID: 35677698; PMCID: PMC9169832.
15. Swarbrick EM, Pietroni MA, Munday DM. The Need for Palliative Care in Adults in Nepal: Projections Based on Modeling Mortality Data. *Indian J Palliat Care*. 2019 Jan-Mar;25(1):41-45. doi: 10.4103/IJPC.IJPC_177_18. PMID: 30820099; PMCID: PMC6388614.