



Providing End-of-Life Care in the Community: What Are the Challenges in Malaysia?

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A 72-year-old woman with metastatic lung cancer to bone and brain and with left external iliac vein thrombosis was under the care of a community palliative care provider. She experienced an acute pain crisis due to acute limb ischemia of the left lower limb. Goals-of-care discussions were held with the patient and her family; she prioritized symptom control and end-of-life care at home. The family and patient were aware of her short prognosis. Her complex pain was managed by the community palliative team, and her family was empowered to give subcutaneous injections. We illustrate a case showing the importance of community health services with palliative care support in providing symptom management and support to patient and family caregivers throughout the course of a life-limiting illness. It also highlights family caregivers' potential psychological distress in delivering subcutaneous injections in terminal care for a patient at home.

Key Words: Family caregivers, Subcutaneous injections, Community health services, Palliative care, Psychological distress, Terminal care

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INTRODUCTION

In Malaysia, palliative care has been incorporated into the local healthcare system since 1991. Hospital-based palliative care was first developed in 1995 and has been established well throughout the country, especially in recent years. Meanwhile, community-based palliative care services through hospices as home care programs were started in 1991 [1]. They were developed under voluntary organizations. It is thought to be more feasible to develop new community palliative care services with little bureaucracy involvement through non-governmental organizations (NGOs). Various NGO hospices are currently available. However, their services are mainly restricted to urban areas due to limitations of resources, personnel, and networks to reach out to distant locales.

A report on the Malaysian national palliative care policy

reported that only about 10% of Malaysians had access to palliative care services [2]. Access to palliative care is still very much lacking, especially in the community, as mentioned above [3]. Yang et al. [4] estimated that there will be an increase of 240% in the number of people needing palliative care by the year 2030 in Malaysia. Coupled with this statistic, a community survey conducted by Hospis Malaysia [5] showed that 61% of its respondents preferred to die at home and 53% preferred to receive end-of-life care at home. This finding echoes a population survey in Alberta by Wilson et al., which reported that 70.8% preferred to be at home for terminal care [6]. Family caregivers are recognized to have a vital role in achieving the goal of home death of a loved one. Nevertheless, this can be a challenging experience for family caregivers, particularly when it involves anticipatory subcutaneous injections at the end of life. Indeed, it is important for palliative com-

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munity care providers to address moral distress among family caregivers.

With increasing palliative care needs and a preference for care at home, there is an urgent need to establish comprehensive and accessible community palliative care services for both patients and their caregivers [7]. Here, we illustrate how a community palliative care team supported a patient with underlying metastatic lung cancer and describe severe complex pain management of acute limb ischemia by family caregivers with anticipatory subcutaneous injections and terminal care at home.

MAIN TEXT

A 72-year-old woman was diagnosed with metastatic lung cancer to bone and brain. She developed extensive thrombosis in her left external iliac vein and was started on an oral anticoagulant. After a discussion with oncologists, she decided to receive comfort care and was referred to a community palliative care service provider (Hospis Malaysia) based in Kuala Lumpur. At the first home visit, she was classified as Eastern Cooperative Oncology category 4 (i.e., unable to carry out any self-care and completely confined to bed or chair). She had nociceptive pain over the lower back and seizures that had been controlled with oral morphine and antiepileptics. In our discussion about her goals of care, she reiterated her wish for pain control and end-of-life care at home with our support.

Her symptoms had been under control for 3 months before she developed an acute pain crisis with a numerical rating scale (NRS) of 10 in her left lower limb. Her pain was unrelieved despite taking eight doses of oral immediate-release morphine (20 mg) over an 8-hour period (total dose: 160 mg). Our team made an urgent visit after receiving a distress call from the family. On arrival, we found her in severe pain with groaning and moaning. The character of the pain was indicative of neuropathic pain. On examination, her left foot appeared dusky. The skin was cool to the touch, with an absence of the left-sided dorsalis pedis, posterior tibial, and popliteal pulse. The clinical impression suggested acute left lower limb ischemia due to left external iliac vein thrombosis. Signs of opioid toxicity were not observed. The team proceeded to administer a total dose of 30 mg of subcutaneous morphine to alleviate

her pain. Her goals of care were revisited with the patient and her family, and they remained to be cared for at home with good symptom control. They were aware of her short prognosis. Family caregivers agreed to support their mother's needs with our guidance. She was treated with transdermal fentanyl (125 μ g/h) and anticipatory subcutaneous morphine (30 mg as needed). The family caregivers' anxiety was relieved by careful instructions on the administration of subcutaneous injections. Furthermore, our team assessed and confirmed their competence in delivering subcutaneous injections.

During our follow-up calls, the patient's pain was well controlled with NRS scores of 2~3 and required 1 dose of anticipatory subcutaneous morphine in a day. However, she deteriorated, with worsening neuropathic pain 2 days later. She had received a total dose of 180 mg of subcutaneous morphine over 24 hours from family caregivers, which had failed to relieve her pain. She also experienced two brief episodes of generalized tonic-clonic seizures. An emergency house visit was arranged. After an assessment, a total subcutaneous dose of morphine of 60 mg was given to relieve her pain. She was imminently dying. In addition to her transdermal fentanyl of 125 μ g/h, a continuous subcutaneous infusion of morphine (180 mg) and midazolam (10 mg) over 24 hours was started to achieve rapid adequate pain and seizure control. Subcutaneous midazolam (5 mg as needed) was prescribed for breakthrough seizures. Upon exploration with family caregivers, they had no technical issues in giving breakthrough subcutaneous injections to the patient, but they experienced anticipatory grief. Their anxiety and concerns about morphine overdose were acknowledged and addressed. They felt that pain relief and comfort were of utmost importance. We acknowledged their feelings and provided reassurance. Psychosocial support was given to address their anticipatory grief. Regular phone calls were made to family caregivers, who reported that her pain was under control and family caregivers had been coping well since our last visit. She passed on peacefully the next day. The family caregivers expressed gratitude for the guidance and service provided by our team, as they were able to fulfill the patient's wish to be cared for at home.

DISCUSSION

We illustrate a patient with complex pain related to acute limb ischemia that required opioid use and seizure management in her last days of life by family caregivers. The patient's autonomy and her wish to be cared for at home were respected by her family. Culturally, the family thought it was their filial duty to care for their mother at the end of life. However, her care was extended to administer anticipatory subcutaneous injections for symptom control by family caregivers. Continuous support from the community palliative care team to the patient and family was appreciated as a factor that enabled home death.

Continuous subcutaneous infusion (CSCI) via an ambulatory syringe driver is commonly used among palliative care patients in the hospital and community for symptom control when oral administration of medication is not possible [8]. The benefits of using CSCI with a syringe driver are (i) allowing parenteral administration of combinations of medications; (ii) ensuring reliable absorption; (iii) being portable and convenient when walking about, especially for those who are still ambulant; (iv) being less invasive than the intravenous (IV) route, making it feasible to perform in a home setting by reducing the anxiety and distress of family if an IV line dislodges with overt bleeding over the IV site; and (v) avoiding the need for multiple regular subcutaneous injections for symptom management, which causes pain at the site of injection [9]. The scenario is illustrated by our patient, who in her imminent dying phase needed CSCI of morphine and midazolam for ischemic pain and seizure. Her symptom management via CSCI with a syringe driver enabled the patient to achieve home death with optimal symptom control in her last few days.

Family caregivers need to be empowered to provide appropriate medications to achieve symptom control and terminal care to fulfill patients' wishes for home death. This may include the use of anticipatory subcutaneous injections, which is possible with support from a community palliative care service. Indeed, the practice of family caregivers administering as-needed subcutaneous injections has been embedded in some countries, such as Australia [10]. The value of family caregivers in providing care to dying patients should be acknowledged, as they are able to (i) improve the experience of a good

death by giving faster symptom relief, (ii) enhance personal fulfillment to support their loved one to die at home through reducing anxiety and frustration compared to standing helplessly bedside next to the patient during a symptom crisis, (iii) provide an opportunity for intimacy in caring for the patient and a degree of autonomy to both the patient and family caregivers, and (iv) reduce unnecessary emergency visits due to the symptom burden, thereby improving cost-effectiveness [11].

Despite the benefits of engaging family caregivers to provide care, various challenges should be considered, especially in managing complex symptoms. Family members' willingness needs to be explored first instead of being seen as the default role in care. Next, their competency to administer injections and capacity to respond to symptoms need to be assessed. Failure to recognize these potential issues could affect the care of patients due to overwhelming psychological distress in addition to their grief [10]. Family caregivers' distress can be minimized by providing sufficient information to alleviate their concerns, such as whether morphine hastens death [11]. Potential medication errors in anticipatory subcutaneous injections delivered by family caregivers (partner/spouse, children, siblings) can be minimized by (i) preparing prefilled syringes with different color labeling for specific symptoms by the community palliative team, (ii) informing family caregivers by providing them written schedules or diaries for the administration of anticipatory injections, (iii) reviewing the needs of anticipatory injections for symptom control by family caregivers through dairies by the community palliative care provider during home visits, and (iv) implementing a professional 24-hour support network by community palliative care providers via phone and in person with timely advice to treat symptoms appropriately with medications [12]. These safety precautions could help reduce the potential of family members delivering subtherapeutic doses and empower them accordingly.

The establishment of community palliative care services is important for enabling home deaths of patients, as illustrated herein. A community palliative care service requires a clinical team with palliative doctors and trained palliative nurses to provide (i) a comprehensive assessment of symptoms with effective symptom management, (ii) proactive identification of psychosocial issues with support for patients and families, (iii) timely responses to patients' needs via telehealth with 24-hour

access for emergencies [13]. Unfortunately, not all patients have access to community palliative care services in Malaysia [3]. The advantages of integrating community palliative care into the governmental healthcare system are (i) improving the geographical coverage for palliative care access, (ii) enhancing quality of life and care for patients and families, and (iii) improving cost-effectiveness in healthcare and hospitalization [14,15]. Hence, there is a desperate need to increase the delivery of community palliative care through governmental organizations to improve its accessibility in Malaysia.

CONCLUSION

In a nutshell, complex pain management with anticipatory subcutaneous injections can be delivered by competent family caregivers at home. This approach is feasible for terminal care in the home with continuous support from community palliative care services, and it enables them to achieve home death. Therefore, community development initiatives are needed, underscoring the need for policymakers to look into this urgent matter in Malaysia.

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CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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AUTHOR'S CONTRIBUTIONS

Conception or design of the work: all authors. Drafting the article: all authors. Critical revision of the article: YYL. Final approval of the version to be published: YYL.

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