Service utilization of a novel statewide domiciliary palliative care program in Malaysia

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ABSTRACT

Introduction: Palliative care is a human right and key to universal health coverage, yet remains inaccessible for many cancer patients. By 2030, Malaysia is expected to experience a 240% surge in demand for palliative care, with Sarawak, its largest state, projected to bear the greatest burden of unmet need. A novel statewide domiciliary palliative care (DPC) program was implemented to meet this growing demand across a culturally diverse and geographically dispersed region. This study characterizes the patterns of DPC service use during the inaugural year of this novel statewide program to inform future planning.

Materials and Methods: This retrospective cohort study included adults with advanced illnesses referred to DPC services at eight health clinics across Malaysia's largest state of Sarawak from July 1, 2023, to June 30, 2024. Descriptive analysis was utilized.

Results: A total of 113 patients with terminal illness were seen, the majority (89%; n=101) of whom had advanced cancer. The commonest cancer types were gastrointestinal (25%; n=28) and thoracic (17%; n=19). Median time from referral to first DPC encounter was 4 days (IQR 2–7). Median time to death was 28 days (IQR 11-53). Most patients (72%; n=82) received care in urbanized locations.

Conclusion: This study demonstrates the wide reaching implementation of DPC across a geographically and culturally diverse region, particularly to cancer patients. Opportunities for strategic growth include expanding rural outreach, strengthening engagement with indigenous populations, and community engagement to enable more timely, inclusive, and equitable access to palliative care.

KEYWORDS:
Palliative care; home care services; health services accessibility; neoplasms; rural health

INTRODUCTION

Palliative care is an essential component of universal health coverage and is recognized as a fundamental human right.[1] It is a crucial component of healthcare, yet global access remains strikingly inadequate.[1-2] According to the World Health Organization, an estimated 56.8 million people require palliative care services annually, and approximately 78% of this global need arises from low- and middle-income countries.[2] Of all people who require palliative care services, only an estimated 14% actually receive it.[1] This means that the vast majority of people experience unnecessary suffering towards the end of their lives.

Global inequities in palliative care delivery are largely driven by systemic barriers in low- and middle-income countries.[3] According Global Atlas of Palliative Care highlights that palliative care access in Malaysia remains fragmented, particularly at the community level.[4] Yang et al. projected a 240% increase in demand for palliative care in Malaysia by 2030, with the state of Sarawak anticipated to experience one of the greatest needs.[5]

Sarawak, Malaysia's largest state, is located on the island of Borneo and spans a vast geographic area of 124,450 km², with a population of approximately 2.9 million.[6] In rural Sarawak, patients travel up to 100 km to access the nearest palliative care service, often originating from remote areas without road access and requiring up to 2.5 hours of travel by boat.[7]

Given the frailty and symptom burden commonly experienced by people requiring such care, these logistical barriers highlight the urgent need for further decentralization and targeted expansion of palliative care delivery. Although community-based palliative care offers a scalable solution for rural and remote regions like Sarawak, such models have yet to be systematically implemented.

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Domiciliary Home Care services were first introduced in Malaysia in 2014, initially implemented across 160 selected health clinics.[8] At its inception, the program focused on providing nursing care and rehabilitation for patients with stroke, traumatic brain injury, spinal cord injury, cerebral palsy, and cancer. In 2016, its scope was expanded to include palliative care, namely domiciliary palliative care (DPC). This aligns with the Malaysian National Palliative Care Policy and Strategic Plan 2019–2030, which identifies the strengthening of community-based and primary care services as a core strategy for expanding access. This expansion is especially critical in Sarawak due to its widely dispersed geographical nature.

In 2023, eight public health clinics across Sarawak were selected for a statewide government DPC implementation program. The DPC program, aligned with global home-based palliative care models, enables patients to receive palliative care at home from 3-person teams comprising medical doctors, nurses and medical assistants who provide palliative services from public health clinics. Due to the state's unique landscape, catchment areas for public health clinics in Sarawak are not strictly delineated by distance. Instead, coverage is population-based with urban clinics serve smaller, densely populated zones, while rural clinics cover expansive areas encompassing multiple scattered villages. Patients are referred from hospitals and assessed holistically across physical, psychological, social, and spiritual domains, with specialist support as needed. Essential medicines such as morphine are dispensed, and patients are seen within three working days.[8] Admission criteria follow national DPC guidelines, including individuals with life-limiting illnesses and European Cooperative Oncology Group (ECOG) performance status of 3–4, or 1–2 if anticipated with rapid deterioration. The protocol defines that an initial visit should occur within 3 working days of receiving the referral, however the frequency of home visits is not specified and is appropriately based on clinical decision.

This study aimed to describe the patient demographics and key health service utilization data in the first year of this DPC implementation program. This will assist with a structured understanding of local healthcare needs and benchmarking against similar services to inform future directions of the DPC program.

MATERIALS AND METHODS

Study Design and Setting

This retrospective study included terminally ill adults receiving DPC from eight trained Sarawak health clinics (July 2023–June 2024), with ethical approval from Medical Research and Ethics Committee Malaysia (NMRR-24-01737-WNM (IIR)).

Study Setting

The eight selected health clinics across Sarawak participated in the DPC training program, representing diverse regional locations – Petra Jaya, Sri Aman, Midlayar, Siburan, and Asajaya Health Clinics in the southwest region; Sarikei Health Clinic in the central region, and Jalan Merbau and Bintulu Health Clinics in the northeast regions of Sarawak.

Data collection

Data were collected from local clinic databases using a standardized case report form and uniform data dictionary, reviewed by practitioners and verified by a senior author. Demographic variables (age, gender, ECOG status, primary diagnosis, Charlson Comorbidity Index (CCI) and health service utilization data (dates of referral, first DPC encounter, and death) were recorded. The interval from first DPC encounter to death was analyzed by diagnosis.

Statistical Analysis

Baseline demographic data were analyzed using descriptive statistics (medians, interquartile ranges, frequencies) with SPSS version 26. Complete data were available for all patients. Time intervals from DPC referral to first encounter and from encounter to death were analysed by clinic size based on average daily attendance, diagnosis, and ECOG performance status across the eight participating health clinics.

RESULTS

Demographics

During its inaugural year, 113 patients were referred to the DPC service. The median age was 69 years (IQR 59–76) with a balanced gender distribution (48% males). Malays comprised 50% of patients, followed by Chinese (23%) and Ibans (20%). Most had ECOG 3 (36%) or 4 (55%) performance status. Cancer was the primary diagnosis in 89% of cases, mainly gastrointestinal (25%), thoracic (17%), and head and neck cancers (14%). Non-cancer conditions accounted for 11% of referrals. The median CCI was 8.

Health Service Use

Referrals According to Serviced Population Size

Health clinics service classification is categorized based on their average daily attendance to clinic, ranging from Class 1 (population of >800) to Class 7 (population of <50).[10] The majority of referrals originated from Class 2 regions (50%) (population of 500 - 800), followed by one health clinic from each Class 1 region (population of > 800), Class 3 region (population of 300 – 500), Class 4 region (population of 150 – 300) and Class 5 region (population of 100 - 150) (Figure 1).

Timing of Domiciliary Palliative Care Service Provision in Relation to Geographical Location

The wait time from referral to the first DPC encounter varied across clinic classifications. The overall median wait time was 4 days (IQR: 2–7 days). The wait time was shortest for Class 3 region (median 2 days; IQR 1 – 4), and longest for Class 1 region (median 7 days; IQR 3 –9 days), followed by Class 5 region (median 6 days; IQR 4 – 10) (Table II).

Timing Between Domiciliary Palliative Care Service Provision and Death in Relation to Primary Diagnosis

Overall, patients died within 23 days (IQR 9.5–48 days) of first encounter. People with breast cancer, and neurodegenerative disorders survived the longest (median 29 days (IQR 19–78 days) and 27 days (IQR 20 – 85 days)) respectively. People with other cancers (hematological, genitourinary tract and melanoma) and end-stage renal failure (ESRF) had the shortest survival (9 days (IQR 4.5–27 days), and 9 days (IQR 2–22 days) respectively) (Table II).

Table I: Baseline Demographic Characteristics

Demographic Variable	Total Cohort (n = 113)
Gender, n (%)	
Male	54 (48)
Female	59 (52)
Age (years), Median (IQR)	69 [59- 76]
Ethnicity, n (%)	
Malay	57 (50)
Chinese	26 (23)
Iban	25 (22)
Bidayuh	4 (4)
Dayak	2 (2)
Non-Malaysian	1 (1)
ECOG, n (%)	
1	1 (1)
2	9 (8)
3	41 (36)
4	62 (55)
Primary Cancer Diagnosis, n (%)	
Gastrointestinal	28 (25)
Thoracic	19 (17)
Head and Neck	16 (14)
Breast	14 (12)
Gynaecological	8 (7)
Genitourinary	7 (6)
Other cancer1	9 (8)
Primary Non- Cancer Diagnosis	
End stage renal failure	3 (3)
Advanced COPD	2 (2)
Neurodegenerative disorder	7 (6)
Number of Referrals by Health Clinic, n (%)	
Class 1	
Petra Jaya	31 (27)
Class 2	
Sri Aman	19 (17)
Sarikei	16 (14)
Bintulu	11 (10)
Jalan Merbau	4 (4)
Class 3	
Siburan	13 (12)
Class 4	
Asajaya	15 (13)
Class 5	
Midlayar	4 (3)
CCI[2], Median [IQR]	8 [7 – 9]

[1]Other cancer – leukaemia, myelofibrosis melanoma, sarcoma, brain
[2]CCI = Charlson Comorbidity Index

DISCUSSION

This study describes the first-year outcomes of DPC service delivery in Sarawak and is the first to describe DPC implementation in Malaysia. Sarawak, the largest and most ethnically diverse in 30 different ethnic groups, faces challenges in equitable service delivery with only two palliative care physicians.[11] The DPC program has helped address these gaps, as community-based models effectively mitigate barriers from geographic isolation, limited healthcare infrastructure, and workforce shortages in rural and remote areas.[12] One of the recognized issues is lack of trained palliative care healthcare providers in the community.[13-14] This DPC program upskills clinicians from existing government-funded clinics to provide community-based palliative care which enables people to receive care in the home environment.

We observed that the volume of referrals to each DPC service was not necessarily related to the size of the population served by each clinic. The clinic with the largest number of referrals (Petra Jaya) was an outlier, accounting for over a quarter of all referrals. Its location in the state's capital, combined with its proximity to Sarawak's largest tertiary hospital likely contributed to this pattern, as it is also where both palliative care physicians are based. The authors postulate that referral trends may be more strongly influenced by community awareness of the service's availability rather than clinic population size alone.

The participating health clinics were located in urban areas with predominantly Malay (50%), Chinese (23%), and Iban (20%) populations, which does not reflect Sarawak's overall ethnic composition—Ibans (30%), Malays (25%), and Chinese (23%).[11] Indigenous minority groups were under-

Table II: Domiciliary Palliative Care Health Service Utilisation by Clinic Classification

Timepoint	Time Interval (days), Median [IQR]
Time from referral to first DPC1 encounter	
Class 1	7 [3 – 9]
Class 2	3 [1 - 7]
Class 3	2 [1 - 4]
Class 4	3 [1 - 4]
Class 5	6 [4 - 10]
Total	4 [2 – 7]
Time from first DPC1 encounter to death	
Primary cancer diagnosis	
Gastrointestinal Tract	28 [14 – 71]
Thoracic	21 [4 – 28]
Head and Neck	18 [11 – 99]
Breast	29 [19 – 78]
Gynaecological	22 [15 – 38]
Other	9 [2 – 22]
Primary non- cancer diagnosis	
Neurodegenerative	27 [20 – 85]
End stage renal failure	9 [4.5 – 27]
Chronic Obstructive Pulmonary Disease	89 [89 – 89]
Time from referral to first DPC1 encounter by health clinic	
Sarikei	0 [0 - 1]
Asajaya	3 [2 - 4]
Siburan	3 [2 – 4]
Sri Aman	3[2 – 6]
Bintulu	6 [5 – 9]
Midlayar	6 [4 – 10]
Petra Jaya	8 [3 – 9]
Jalan Merbau	9 [3 - 14]
Time from referral to death by performance status	
ECOG 1	39 [39 – 39]
ECOG 2	114 [31 – 136]
ECOG 3	29 [20 – 46]
ECOG 4	25 [8 – 45.5]
Total	28 [11 – 53]

[1]DPC: Domiciliary Palliative Care

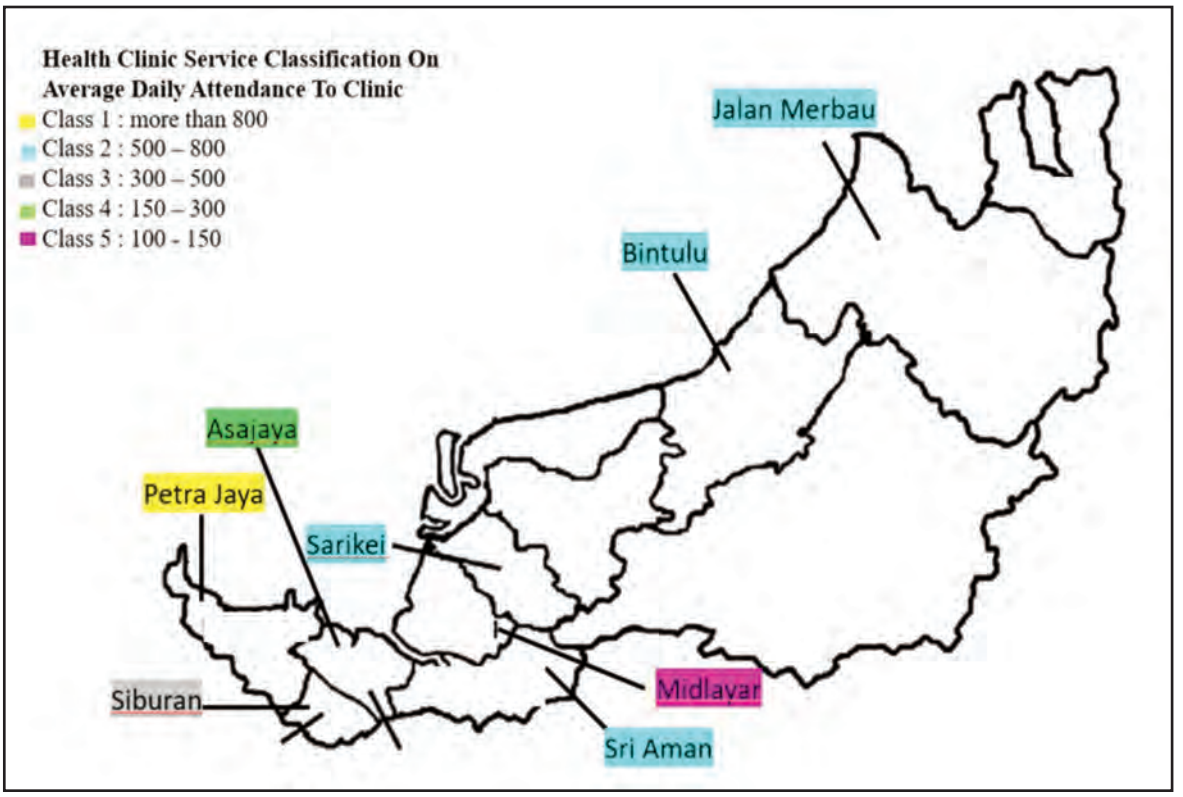

Fig. 1: Location of health clinics in Sarawak

represented, likely due to most referrals originating from urban areas.[12] In its first year, palliative care services may not yet be well established in rural regions, and clinics in these areas were not part of the initial implementation. These findings underscore the need to expand DPC services to rural clinics to enhance equitable access across communities.

Our findings showed that 88.4% of referrals involved cancer diagnoses, while only 11.6% were non-cancer. This aligns with Yip et al. and other studies showing most palliative care referrals in Malaysia and community settings are cancer-related.[13-14] Non-cancer conditions appear under-recognized, possibly due to limited awareness that end-organ failure also warrants palliative care.[15] As non-cancer illnesses often have prolonged, unpredictable trajectories, implementing validated tools such as the Supportive and Palliative Care Indicators Tool in health clinics may improve confidence and accuracy in identifying patients needing palliative care.[16]

Patients with non-cancer diagnoses, such as neurodegenerative diseases, had a median survival of 27 days, similar to cancer patients. While those with end-stage renal failure (ESRF) had the shortest at 9 days. ESRF referrals often follow dialysis withdrawal, reflecting limited prognosis and end-of-life care needs at home. Teno et al. reported that non-cancer patients generally have poorer functional status and outcomes, with lower-quality end-of-life care due to higher rates of life-sustaining treatments.[17-19] These findings underscore the need to strengthen DPC services for non-cancer patients through greater awareness at community and hospital levels.

Most patients (91%) had poor performance status (ECOG 3–4) and a high median CCI score of 8, reflecting frailty at referral. The median duration from DPC referral to death was 28 days, consistent with previous local findings.[13] Timely palliative care referrals allow for care that is tailored to patients' needs and delivered holistically, thereby optimising service provision in the community.[20] International studies show that early palliative care integration improves outcomes.[21] As the DPC service grows beyond its inaugural year, it will be important emphasise to the role of timely palliative care delivery.

In Malaysia, the Ministry of Health mandates that all health clinics provide the first DPC encounter within 3 days of referral.[8] However, our findings show variability, with response times ranging from 0 to 9 days, indicating challenges in meeting this target and highlighting the need for further improvement. It is expected that service delivery will increase significantly beyond this inaugural year. Service improvement efforts should focus on addressing the reasons for these slower response times and on how this may be improved, including the extent to which this is related to service demand and travel distance.

CONCLUSION

This study provides the first insight into DPC service delivery in Sarawak, a geographically vast and ethnically diverse state. Building on this inaugural year, key areas for growth include strengthening community engagement, expanding access for indigenous populations, increasing involvement from non-cancer diagnosis, and reducing referral to assessment timelines to ensure more timely, inclusive, and equitable palliative care access.

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CONFLICT OF INTEREST

The Author(s) declare(s) that there is no conflict of interest related to this work.

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ETHICAL APPROVAL

The study was approved by the Medical Research Ethics Committee Malaysia (NMRR ID-24-01737-WNM (IIR)).

PATIENT CONSENT STATEMENT

Patient consent was not required for this retrospective de-identified study.

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