NATIONAL QUALITY IMPROVEMENT PROJECT - MDS

Minimum Data Set (MDS)

Summary of FY2021 report

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On behalf of Singapore Hospice Council

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SINGAPORE HOSPICE COUNCIL
Living before Leaving

Summary and Key Findings

Introduction

Developed in 2017, the National Palliative Care Minimum Data Set (MDS) in Singapore provides information on the longitudinal trends in the demographic and clinical profile of patients being referred to palliative care. The findings inform quality improvement and service development by describing gaps in current palliative care services. This edition showcases results from Financial Year 2021 (FY2021) (April 2021 to March 2022), with key modifications to the data collection process and data analysis.

Methods

Participating institutions submitted de-identified patient-level data as in previous years. However, the data variable "Age" was revised to "Month and year of birth" to improve the accuracy of record matching. Prior to submission, institutions de-identified the data by masking the National Registration Identity Card (NRIC) numbers to its last 5 characters. Submitted data were thus by no means re-identifiable.

In palliative care, an individual patient may receive care from multiple services. Record matching was therefore necessary to link multiple referral records across institutions relating to the same patient for patient-level analysis. This year, the matching criteria was ±1 year for the data variable "Year of birth", tightened from ±2 years in previous years, and ±1 day for the data variable "Date of death". All data wrangling processes, including data cleaning, data merging, record matching, data validation, data verification and data analytics and visualisation, were performed with the R, Tableau Prep Builder and Tableau software, versions 4.2.2, 2022.1.1 and 2022.1.8.

This year, the focus was on improving data completeness and quality. De-identified datasets were cleaned after submission by each institution. Any missing data and duplicated records, if found, were verified with the respective institutions. Additionally, after record matching, the data underwent a data validation process to check each patient's data for consistency across its referral records. Any inconsistencies in the data, if found, were once again verified with the respective institution. Also, a new section on data quality was added and will remain in future editions.

Additionally, this edition also presents patient-level findings, in addition to service-level analyses as in past editions.

Key Findings

Overall, 20 institutions participated in the Singapore National Palliative Care Minimum Data Set (MDS) for FY2021 (April 2021 to March 2022). Based on aggregated statistics collected by Singapore Hospice Council, we estimate that the patients in the MDS represent approximately 95% of the patients referred to palliative care services in Singapore.

Penetration of specialist palliative care among patients at the end of life can be improved.

A total of 10,891 unique patients contributed 13,221 referrals records in FY2021, from April 2021 to March 2022. Within this cohort, 7,672 (70%) patients died. Inferring from the 24,292 deaths recorded in Singapore in 2021[1], the penetration rate of specialist palliative care among decedents was 32%. This rate is an underestimation as we were unable to account for patients who were referred in previous FYs and died within 2021.

There is no published data on the proportion of seriously ill Singaporeans who would require specialist palliative care annually. However, recent findings from this Lancet Global Health study projects that by 2060, annually, 53% of deaths in developed countries would suffer from serious health-related suffering and require palliative care.[2] Viewed in this light, our current estimated penetration rate of 32% has room for improvement to meet future palliative care needs.

To project for palliative care capacity needed within the next decade, we recommend national effort in estimating the population size of patients with serious health-related suffering. More research is needed regarding barriers and facilitators to increasing the penetration rate of specialist palliative care.

Palliative care starts late in the disease trajectory, especially for patients with non-cancer illnesses.

Overall, the median duration of palliative care before death was 22 days (interquartile range [IQR] 6-66 days). Additionally, we found a striking difference in the median duration of palliative care before death between cancer and non-cancer patients: 33 days (IQR 11-79 days) for cancer and 9 days (IQR 3-38 days) for non-cancer. This may be an underestimate as some patients may have been receiving generalist palliative care much earlier before referrals for specialist palliative care were made.

Internationally, a meta-analysis of 169 studies over 23 countries reports a weighted median duration of 18.9 days (IQR 0.1 day) from palliative care initiation to death.[3] Evidence suggests that to realize the full benefits of palliative care, continuity of care by a multi-disciplinary team is needed for at least 3-4 months.[4]

More needs to be done to bring palliative care further upstream in the disease trajectory. A systematic approach is needed to identify the population which would need palliative care. By going further upstream, longitudinal follow-up time for each patient will increase and palliative care resources will need to be expanded accordingly.

Access to specialist palliative care services is much lower for non-cancer patients, with significant variability in non-cancer caseloads across service types.

The majority (60%) of our MDS cohort had a cancer diagnosis, in contrast to cancer making up only 26% of all-cause mortality in 2021.[5] We also saw a wide variation in the proportion of non-cancer caseloads across the different service types: 16% in outpatient clinics, 30% in Inpatient Hospice Palliative Care Service (IHPCS), 33% in home hospice, and 44% among acute hospital inpatients.

Palliative care access disparities between patients suffering from cancer versus non-cancer illnesses is well-published in literature.[6–8] There is room for improvement with regards to palliative care access for non-cancer patients. We recommend examining non-cancer referral patterns in the outpatient clinic and IHPCS settings where this discrepancy is more pronounced.

Among patients who receive specialist palliative care, less than 50% die in hospitals.

For MDS FY2021, amongst patients receiving specialist palliative care, 46% died within acute hospitals, while 34% died at home and 17% within inpatient hospices. Among patients known to home hospice services, 65.6% managed to achieve home deaths.

In the recent Ministry of Health work plan seminar 2022, Minister Ong Ye Kung announced plans to help more people die at home, with the target of reducing deaths in hospitals from 61% to 51% over five years.[9] Local and international evidence suggest that receipt of palliative care increases the odds of achieving home deaths.[10–13] With future interventions to expand the reach of palliative care, more

out-of-hospital deaths may be achievable. However, not all patients may want to pass away at home due to various reasons. We recommend measuring goal-concordant place of death as a next step, for better patient-centred outcomes.

There is potential room for improvement with regards to waiting times for home hospice and inpatient hospice services.

After a patient's referral has been accepted by the home hospice and/or inpatient hospice, the average waiting time for assessment was 4.55 days (standard deviation [SD] 6.14 days) for home care and 3.59 days (SD 12.95 days) for IHPCS. There is also an outlier group of patients with longer waiting times than expected. Notably, 17.0% of home care patients, as opposed to 10.0% of IHPCS patients, were assessed more than 7 calendar days after being accepted by the community palliative care services. This is an area that should be examined in future quality improvement work.

Future

Insights from MDS have identified gaps and opportunities for quality improvement. With subsequent years of data import, longitudinal trends in patient profiles can be further studied. While the current MDS remains focused on structural and process indicators, we plan to expand and include patient outcome indicators in 2025.