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| **Service** | Territory Palliative Care Hospice |
| **PCOC Outcome Measure** | Recognising Terminal phase, patients dying outside the Terminal Phase |
| **Project Coordinator** | Amy Burrows, CNM, Shipsy Jose - CNS, Adam Whitby – CNS, Samantha Harrington - CNE, Charito Novio – RN |
| **PCOC Improvement Facilitator** | Tanya Pidgeon, *Improvement Facilitator (NT, SA & WA)* –<br>*E: tanya.pidgeon@uwa.edu.au*<br>Natalie Joseph, *Improvement Facilitator (NT, SA & WA)* –<br>*E: natalie.joseph@uwa.edu.au* |
| **Project Time Frame:** | September 2022 (completion date) |
| **Project Title** | Improving team confidence and accuracy in identifying the commencement of the Terminal phase of care |
| **Problem investigation and identification** | Territory Palliative Care-Top End (TPC-TE) is the Northern Territory's Department of Health specialist palliative care service. It is based on the campus of Royal Darwin Hospital (RDH).<br><br>TPC-TE includes a 12-bed palliative care hospice (PCH), an inpatient consult service into Royal Darwin Hospital, and a multidisciplinary community service. The community service supports patients at home, in aged care, and across rural and remote areas of the Top End NT. These areas encompass the suburbs of Darwin and Palmerston, and the remote communities in the East Arnhem, West Daly and Katherine/Big River regions, some 245,000 km2. TPC-TE also extends to service providers, including multiple Aboriginal Medical Services.<br><br>The PCH is the only specialized palliative care ward in the Top End of the Northern Territory. Medical expertise includes Consultant specialists, Registrars, Interns and RMO's. Nursing includes a Clinical Nurse Manager, Nurse Practitioner, Nurse Educator, Nurse Specialists, RNs and ENs. Allied health comprises of Social Workers, a Pastoral Care Coordinator, Occupational Therapist, and a Psychologist. A Physiotherapist and Dietician are available for hospice inpatients only. Allied health support covers patients in the Darwin/Palmerston region.<br><br>Patient admissions are referred from acute wards of both RDH and Palmerston Regional Hospital (PRH), nursing homes, GP's, and health services in the rural and remote regions. Care provided in hospice includes symptom management, end-of-life care, and respite.<br><br>PCOC was introduced to the PCH in 2015 and has been successfully integrated into the care systems. Since then, PCOC Patient Outcome reports are regularly reviewed to ensure that satisfactory patient outcomes are met. |
| **Problem Description** | The previous year's PCOC report (January to June 2021) indicated a significant number of patients dying outside the terminal phase – meaning when the person died their palliative care phase was either stable, unstable or deteriorating. A total of 28 patients (21.54% of total admissions for the period) were not identified as in the terminal phase prior to their death. This raised some |

questions on both PCOC implementation and patient outcomes; did this relate to staff training and confidence with initiating the terminal phase of care? Was the care, associated with the terminal phase, provided even though the terminal phase was not recorded?

The aim of the quality improvement project was to determine if the results were due to incorrect phasing (i.e. assessor competency – not recognising the terminal phase or inconsistencies in understanding the definition of terminal phase), or whether there were other factors that could explain this result. The priority was to determine if the quality of care delivered was appropriate and relevant to the needs of an actively dying patient and their families.

The PCOC report revealed that of the patients that died outside of a terminal phase, 82% were in the deteriorating phase (Table 1).

**Table 1. Patients Dying outside of Terminal Phase (January to June 2021 PCOC report)**

| Item measured | Number (%) |
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| Total number of patients dying outside the Terminal Phase | 28 (100%) |
| Patients who died in the Stable Phase | 4 (14.28%) |
| Patients who died in the Unstable Phase | 1 (3.57%) |
| Patients who died in the Deteriorating Phase | 23 (82.14%) |

**PCOC Evidence**

- PCOC Report (January to June 2021, Hospice Inpatient Setting)
- PCOC Report (January to June 2018, Hospice Inpatient Setting)

Review of patient's medical records/progress notes

**Interventions**

**Case Review**

Ten (10) cases where patients died outside of a terminal phase were randomly selected for the case review. Data from the selected patients' medical notes and PCOC scores were summarised using the *Case Review Template (Deaths outside terminal phase)*.

**Audit**

An audit of the medical notes of the 10 case reviews to determine if terminal care were provided for those patients who died outside of the terminal phase.

**Education**

Formal and informal education was utilised to explore the audit results and identify areas to improve. Formal education included staff attending available training courses such as the *PCOC Essentials Course* and *Fundamentals Webinar*, and providing opportunities for staff to attend PCOC workshops and conferences.

Informal education included mentoring (e.g.one-on-one conversations) to promote understanding of how accurate recognition of phase changes impact quality of care patients receive; this also helped identify that staff confidence in identifying terminal phase of care was a contributing factor.

**MDT**

Integration of PCOC in the weekly multi-disciplinary team meetings with a focus on appreciation of PCOC assessment in developing a relevant and responsive plan of care for patients in different

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| | phases.<br><br>**Developing an EOLC Pathway**<br><br>• Development of an EOLC Pathway to provide guidance in caring for patients as they approach the terminal phase is underway. |
| **Team/Staff Involved** | Amy Burrows, CNM, Shipsy Jose - CNS, Adam Whitby – CNS, Samantha Harrington - CNE, Charito Novio – RN |
| **Results** | Our case review revealed among the 10 in-depth randomly selected reviews, 70% (n = 7) were in the deteriorating phase and 20% (n=2) were in the stable phase (table 2).<br><br>The audit of clinical documentation revealed that **82% of these patients were in the Deteriorating Phase at time of death.** Based on the audit results, there was a delay in recording phase change by clinicians, as well as issues with data entry.<br><br>**14% died in the Stable Phase.** Studies have indicated that sudden or unexpected death can occur in 5-10% of in-patient palliative care units (Hui, 2015), regardless of the phase they are in. The audit results in Table 3 may further support this as the two patients who did not record an increase in RUG-ADL and a decrease in AKPS were also the ones who died in the Stable Phase. In fact, one of these two patients recorded a decrease in RUG-ADL and increase in AKPS that may be interpreted as a positive improvement in their clinical status.<br><br>Table 3: An audit of the medical notes revealed the PCOC assessment recorded did not capture the correct phase when terminal care had been delivered i.e. alerting the medical team, review of comfort medications (background and breakthrough dose demand), updating the family of patient's progress, and offering appropriate support.<br><br>**Table 2 Patients randomly selected to audit from the January to June 2021 PCOC report**<br><br>**Item measured** / **Number (%)**<br>Total number of audits conducted / 10 (100)<br>Patients who were reported dying in the Stable Phase / 2 (20%)<br>Patients who died in the Unstable Phase / 1 (10%)<br>Patients who died in the Deteriorating Phase / 7 (70%) |
| **Main findings** | Our clinicians tended to wait until patients became unresponsive before commencing the terminal phase of care despite indicators for the terminal phase including exceptional pathology findings, functional decline, and poor prognosis. In such cases, we have seen that the patient may not necessarily be unconscious but may nonetheless pass away within a few days, making it more appropriate to commence the terminal phase rather than the deteriorating phase.<br><br>Commencement of the terminal phase at the right time avoids risk such as bowel interventions and late recognition for spiritual intervention (a priest visit, for instance).<br><br>We identified factors contributing to the results. These included:<br><br>1. During this reporting period, there were new staff members who were new to PCOC and yet to complete the online course. Some have expressed they found the transition from deteriorating to terminal phase ambiguous; even some of the more experienced staff had to clarify when the phase needed to be changed. It was then agreed that when patients appear to be in their last 7 days of life that the phase should be changed to Terminal.<br>2. We have not found any substantial risk with not documenting the terminal phase however |

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| | 3. Minor risks like bowel interventions (as an example) can be avoided, and patients in the terminal phase can benefit from early recognition and referral for spiritual care intervention.<br><br>The current data input system (Caresys Clinical and Patient Management System) allows PCOC scores to be entered only once per day and is unable to capture multiple phase changes within a 24-hour period. |
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| **Outputs** | • Review Audit report<br>• Ongoing education sessions<br>• Hospice Staff Orientation Package<br>• Individual Patient's journey board features daily PCOC assessments<br><br>Inpatient Clinical Progress Notes (MDT case discussion) includes recent PCOC Phase, AKPS and RUG-ADL |

**Reference**

Hui, D. (2015). Unexpected death in palliative care: what to expect when you are not expecting. *Current opinion in supportive and palliative care*, *9*(4), 369. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4772866/