SUPPORTIVE CARE SERVICE: A MULTIDISCIPLINARY APPROACH TO MANAGING CHRONIC ILLNESS IN THE LAST 24 MONTHS OF LIFE

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KEYWORDS

Supportive care, Palliative care, Multidisciplinary care, Quality of Life, Chronic non-malignant life-limiting illness, Advance Care Planning

EXECUTIVE SUMMARY

This is a prospective observational study of 74 patients seen between April 2023-April 2024 in a new Supportive Care Service (SCS) managing patients with chronic non-malignant illnesses with a prognosis of 12-24 months. We will present outcomes including symptom burden and quality of life (QoL) measures, advance care planning (ACP) and advance care directive (ACD) completion, mean survival and eventual place of death. Our initial data shows improvement in symptoms and QoL as measured by the Integrated Palliative Care Outcome Scale (IPOS) and EQ-5D-5L questionnaire, high rates of advanced care planning discussion, and eventual death outside of acute hospital setting.

INTRODUCTION/ BACKGROUND

There has been increased recognition of the significant physical and psychological symptom burden associated with advanced non-malignant conditions. According to Australian Bureau of Statistics (ABS) data, 70% of deaths in Australia are due to non-malignant illnesses. However, only 25% of these patients receive palliative care input as per nation-wide Palliative Care Outcomes Collaborative (PCOC) data. In contrast, an Australian study of patients in the last year of life showed that specialist palliative care was provided to 68% of patients who died of a malignancy. This highlights a significant gap in palliative care service provision in Australia.

In 2022, the NSW Government allocated funding to the South-Eastern Sydney Local Health District (SESLHD) to address this gap through enhancement of community facing palliative care services. Extensive consultation with relevant stakeholders was undertaken within SESLHD to develop a model of care that would meet the needs of the patient cohort with chronic non-malignant illnesses, specifically: end-stage respiratory disease, liver failure, cardiac failure and neurodegenerative conditions. Renal failure and Motor Neurone Disease patients were excluded, as there are well-established palliative care services in SESLHD for these conditions. An exception was made when renal patients were not already known to the Renal Supportive Care Service and were too frail to attend their clinic appointments.

The model of care that emerged through consultation was a multidisciplinary, community facing hospital clinic with a target patient cohort with chronic non-malignant diseases (listed above) with an expected prognosis of 12 –24 months. Clinics were commenced at three hospitals within SESLHD between 2022-2024. This article will focus on one of these clinics: the Supportive Care Service at St. George Hospital, Kogarah NSW. The objectives of the service are to provide improved symptom management, support care in the community, prevent avoidable hospital admissions, increase advanced care planning, and facilitate smoother transition to end-of-life palliative care services. The team members include a Palliative Medicine Specialist, Clinical Nurse Consultant (CNC), Physiotherapist, Occupational Therapist, Social worker, Pharmacist, Dietitian and Speech Pathologist. The service is conducted via a hybrid model of telehealth, home visits and face-to-face clinic appointments. This study presents a description of the model of care, demographics and clinical profile of the patient cohort and early outcomes in the first 12 months of operation of the St. George Hospital Supportive Care Service.

HIGHLIGHTS

- Development of a new palliative care service
- Palliative care for patients with chronic non-malignant illnesses
- Greater engagement in advance care planning conversations
- Reduced symptom burden

- Improved quality of life

METHODOLOGY/ PROCESS

A prospective observational study was conducted using patient data obtained from the SCS over a one-year period from April 2023 to April 2024.

Data Collection

Demographic and clinical data were available through the hospital electronic medical record system, Powerchart. We measured symptom burden and quality of life with two tools, the IPOS and the EQ-5D-5L which were collected via the Quality Reporting Auditing System (QARS).

Data Analysis

Data was transferred from both QARS and Powerchart into an Excel spreadsheet to conduct descriptive analysis. IPOS and EQ-5D-5L data completed at the patient's initial appointment and at follow up were compared for improvement, decline or stability of symptom burden and quality of life.

RESULTS

A total of 128 patients were referred to the St. George Supportive Care Service between April 2023 and April 2024. Out of these, 54 patients did not meet the inclusion criteria and were referred to other outpatient or community services. Ultimately, 74 patients were reviewed by the service. The mean age of the patient cohort was 79.4 years and there was an equal split between male (n=37) and female (n=37). Majority of patients had a primary diagnosis of cardiac failure (39%); followed by end-stage respiratory disease (28%); neurodegenerative disease (16%); liver failure (10%); renal failure (4%); and other illnesses (3%) (Figure 1).

The Palliative Medicine Specialist had advanced care planning discussions with 100% of patients. This discussion was documented in the clinical notes in Powerchart and each patient was provided with a copy of the NSW Advance Care Directive. At the time of writing, 43 (58%) patients had completed an ACP or ACD and this documentation was uploaded into their medical record (Figure 2).

All patients had initial IPOS and EQ-5D-5L surveys completed, however only 12 patients (16%) completed follow-up surveys. The high attrition rate can be attributed to various factors: patient discharged prior to routine follow-up appointment; patient death; or referral to other palliative care services after initial review. Outcomes from the IPOS demonstrate that symptom burden either improved or remained stable for 85% of patients who completed an initial and follow up IPOS survey (Figures 3 and 4). For 82% of patients who completed an initial and follow up EQ-5D-5L survey, their symptoms either remained stable or there was improvement in their quality of life (Figures 5 and 6).

Of the patients seen by the SCS, 21 (28%) died during the 12-month period. The mean survival for these patients from referral to the service was 2.7 months. Of those patients, 10 (48%) died in a palliative care unit (PCU); 8 (38%) died at home; and only three (14%) died in an acute hospital setting (Figure 7). Not included in these figures are two patients who requested Voluntary Assisted Dying (VAD); one patient died at home following administration of the VAD substance, and one died at home of an unknown cause.

CONCLUSION

Our study describes a new model of care for palliative care service provision targeted at patients with chronic, non-malignant illnesses who have an estimated prognosis of 12-24 months. We present data from the first 12 months of operation of the St. George Supportive Care Service, including demographics, clinical profile and preliminary outcomes. While the sample size is small, the results so far demonstrate that early intervention by a multidisciplinary palliative care team leads to high rates of advanced care planning discussion and documentation, positive impact on patients' symptom burden and quality of life and reduces likelihood of death in an acute hospital setting. In the coming 12 months, our focus will be to improve rates of ACD/ACP documentation and collection of symptom and quality of life measures at follow up. Being a new service, we are actively engaging in outreach to other parts of the health system (e.g. primary care) to raise the profile of the service and increase referral rates.

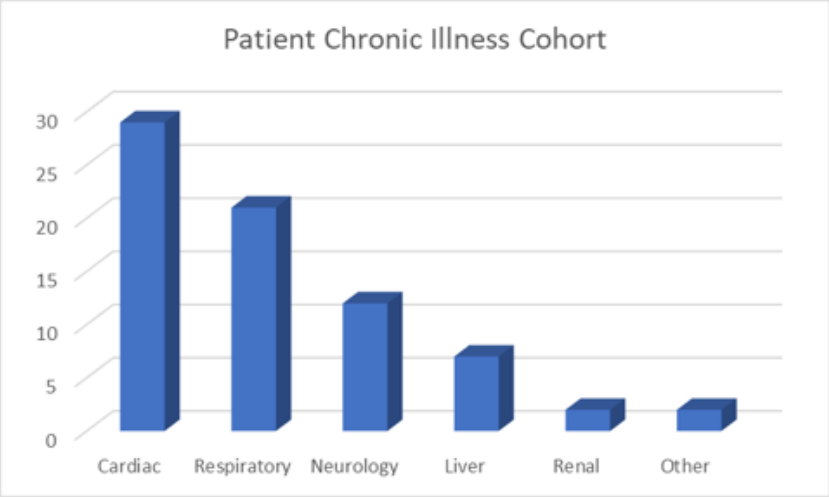


Figure 1 Non-malignant Disease Patient Cohort Numbers

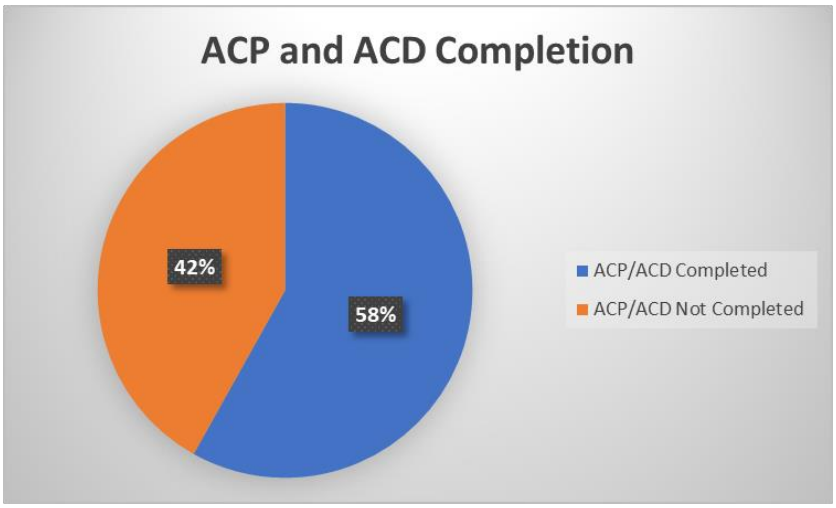


Figure 2 ACP and ACD completion rates for n=74 patients

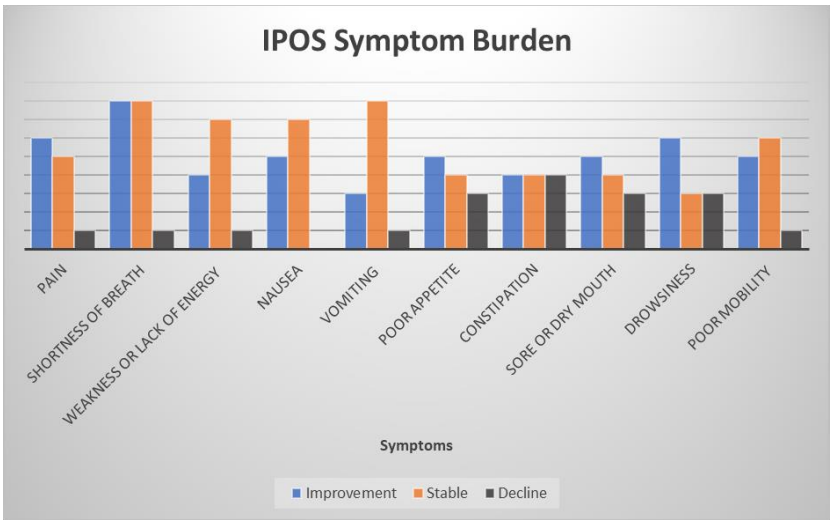


Figure 3 Breakdown of the IPOS survey demonstrating changes in patient symptom burden across several domains

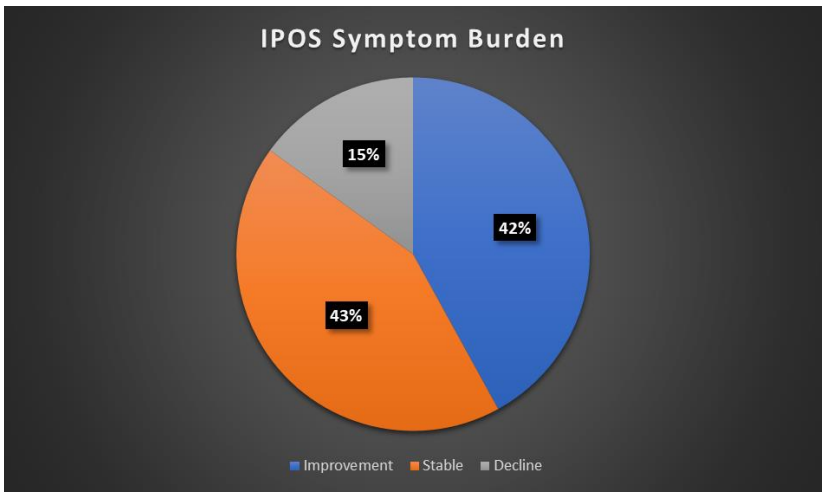


Figure 4 IPOS results comparing improvement; stability; and decline in patient symptom burden

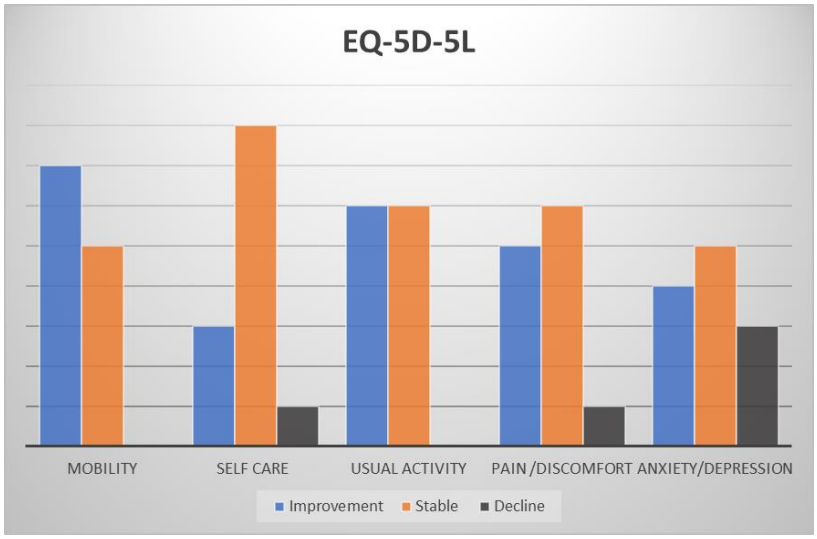


Figure 5 Breakdown of the EQ-5D-5L survey demonstrating changes in patient quality of life across several domains

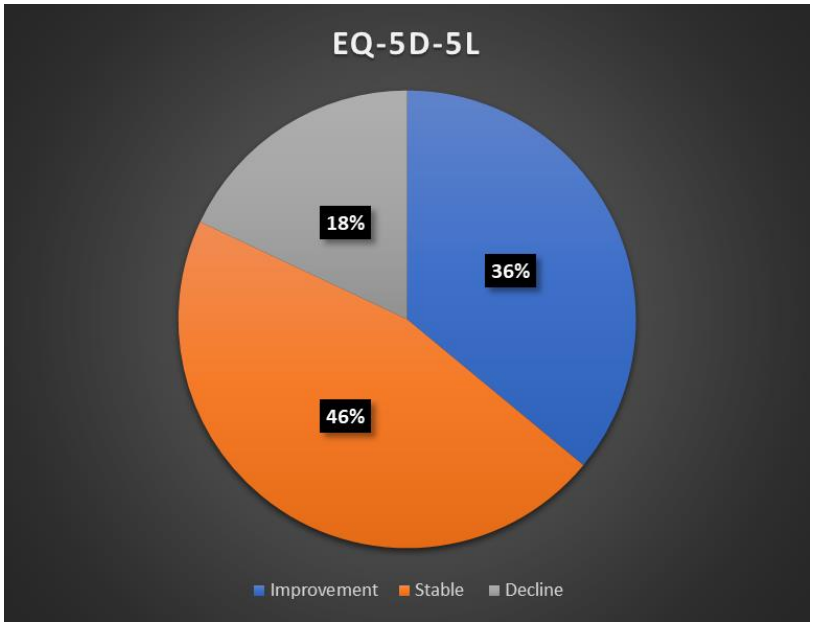


Figure 6 EQ-5D-5L results comparing improvement; stability; and decline in patient quality of life

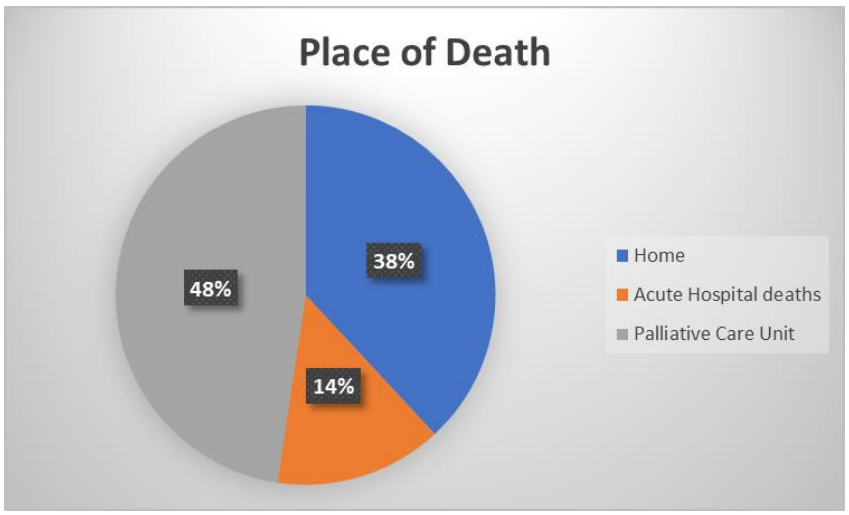


Figure 7 Patient place of death