

Research Poster Awards 2023



Dying at Home: enablers and barriers

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INTRODUCTION

According to the Grattan institute in 2014, 70% of Australians indicated a preference to die at home however only 14% achieved this.

Establishing some of the enablers and barriers to people being able to die at home will potentially optimise the chance that this can be achieved. This is especially relevant to Australian Health care providers as Australians are 50% less likely to die at home than people in the United States, New Zealand, Ireland & France (Swerissen et al. 2014).

The nurse-led multi-disciplinary Community Palliative Care service provides home-based care and support to people and families suffering from malignant and non-malignant life limiting diseases using a needs-based model.

OBJECTIVES

The aim of the current study was to investigate supports and interventions which enable patients who wish to die at home to do so, along with barriers that may lead to people dying elsewhere.

METHOD

A retrospective medical record audit of eligible Community Palliative Care patients who indicated a wish to die at home was undertaken.

All patients aged 18 years or above who were admitted to the Barwon Health community palliative care service between 1st July 2017 and 30th June 2018 were screened for study inclusion. This group was then reduced to the final study cohort, based on the following criteria:

- Indicated home as preferred place of death during their first three face-to-face consultations
- Died before 31/12/2018

People were excluded if they had been discharged from the service prior to their death.

RESULTS

Of one hundred and fourteen patients, 74% indicated a preference to die at home. Of these 66% achieved a home death, and most lived with a carer. Enablers for home death included family support, regular nursing visits and equipment. People who attended an Emergency Department in their last month of life, lived alone or were undergoing oncological treatment were more likely to die elsewhere.

Symptom burden was similar between the two groups, with fatigue, pain, confusion/agitation and breathlessness being most prevalent. Carer distress was more common in people who died at home.

DISCUSSION

Twenty nine percent of people eligible for the study expressed a wish to die at home and 66% did so. Whilst the number of people expressing a desire to die at home was lower than the 60-70% reported previously from population surveys (Swerissen & Duckett, 2014), the actual proportion of people who achieved a home death was considerably higher than the figure of 14% quoted in the same report. There are likely to be a range of reasons for the difference in desire to die at home between the study cohort and previous population estimates including the clear dichotomy between a real life scenario and a hypothetical construct. Having a supportive family was the most common enabler of a home death and people who lived alone (or with someone who was not able to provide care) were proportionally more than twice as likely to die in an alternative venue to home. Living alone but having carers available did improve the chances of a home death, however 64% of people in this situation still died in an alternative venue of care. The reality is, given deterioration that typically accompanies advancing disease, for some people without a dedicated carer, a home death may not be a safe or appropriate option.

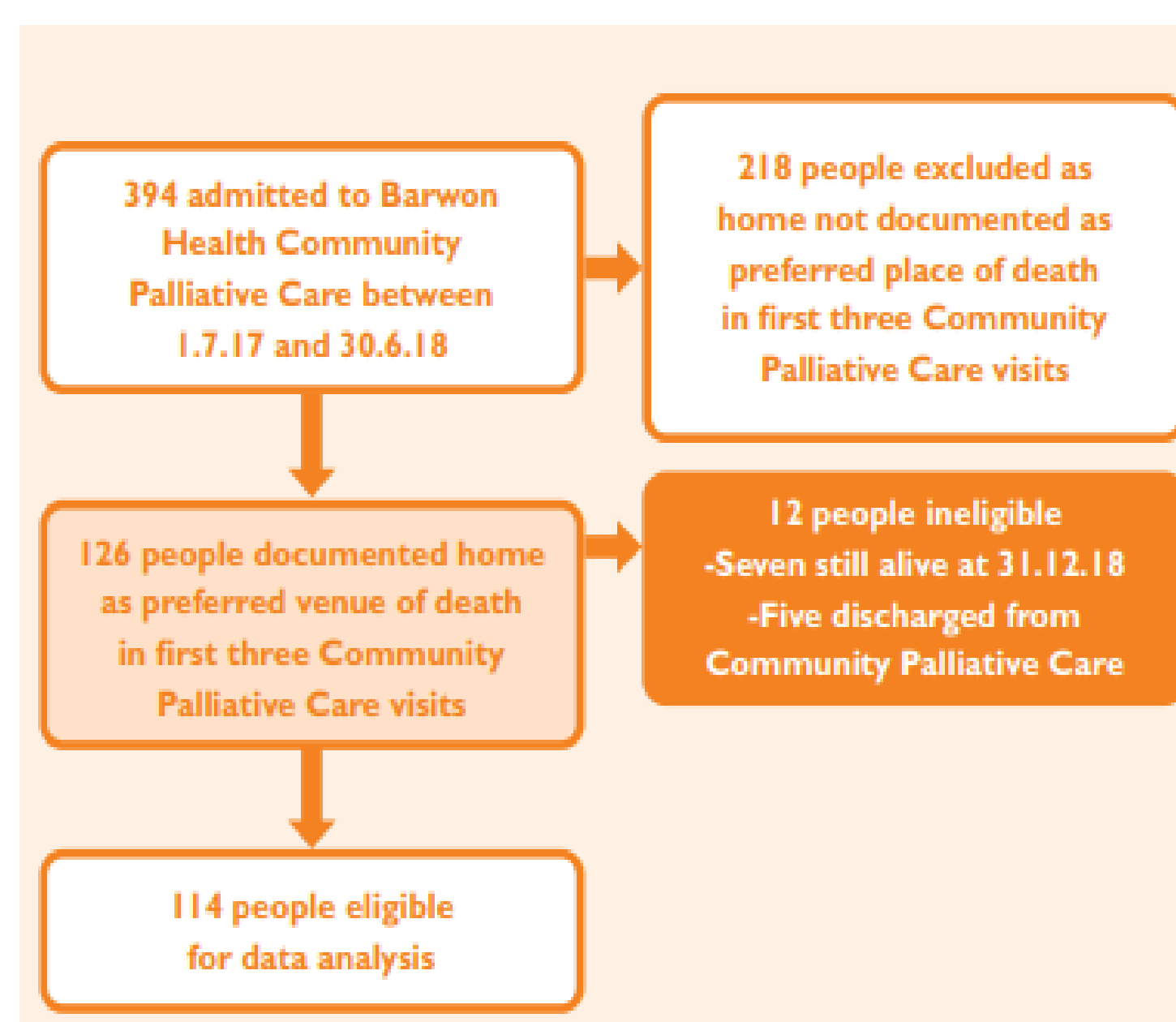
Differences were seen in the outcomes for people with malignant versus non-malignant disease. Eighty percent of those without cancer died at home compared to 59% of people with a malignancy. The nature of cancer management is likely to have played a role, as all patients with a malignant disease who received oncological treatment in the last month of life died in a venue of care other than home. This could be due to the fact that patients undergoing oncological treatment may have reversible symptoms related to their treatment and the appropriate action was to present to hospital. This group of patients were also more likely to present to an ED or be admitted to hospital.

Two common barriers for people dying at home were acute changes in condition and unstable or complex symptoms. One approach to try and manage unstable symptoms at home is the provision of anticipatory subcutaneous injectable medications which are kept, and administered in the person's home. This is established and routine practice amongst state wide CPC services (Safer Care Victoria, 2020) including Barwon Health. The administration of anticipatory medications, either by nursing staff or trained carers, was an important enabler of a home death in the current study with 92% of patients who died at home having anticipatory medications available compared to 56% who died elsewhere. There are a number of limitations to this study. People were excluded if they had not indicated a desire to die at home during one of their first three visits. While this timeframe was arbitrary, it was chosen as a fair reflection of the importance of these decisions for people with life-limiting illnesses and also to allow adequate time to put supports and interventions in place. It is acknowledged that sometimes this decision will be made later than the first three visits, and that people change their minds. While not the focus of the current study, future research investigating the decision-making processes around place of death and how this changes over time will be useful in progressing the development of structures to guide these important discussions.

CONCLUSION

In order to die at home people need people, however as shown in the current study they also need more than that. Many of the supports and interventions that assist people to die at home are, in broad terms, things that decrease the possibility of requiring a hospital presentation or admission. They include provision of anticipatory medications for expected and unexpected events, in home equipment to aid with function, multi-disciplinary tailored domiciliary health professional input and most crucially carer education, training and support.

Pair these supports and interventions with open honest discussions about the practicalities and possibilities of dying at home and we are giving our people the best chance of dying at home.



REFERENCES & ACKNOWLEDGEMENTS

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