

## **Title**

Supporting lay carers to provide breakthrough palliative symptom management

## **Background/introduction**

The aim of modern palliative care, whether provided by generalist or specialist service providers, is to support palliative patients to live and die within the setting of their choice, with optimal symptom control and a pattern of care that is supportive of patients' lay carers.

One of the most frequent reasons that community-based palliative patients have to be transferred to inpatient units is because their symptoms cannot be controlled at home. Palliative patients are inherently unstable and access to symptom control is required 24 hours a day but few patients have access to 24 hour professional care in the community. Effective symptom control often depends upon lay carers, who may be required to manage subcutaneous medications.

This study, funded by the Australian Government Department of Health and Ageing, reports the development, trial and evaluation of a Queensland-specific package that teaches lay carers to manage subcutaneous medications used for symptom control in community-based palliative patients.

## **Methods/strategies**

A package was developed for lay carers by palliative care stakeholders. It comprises an educational session, delivered by nurses, and a range of resources - demonstrative, audiovisual and written.

The package was trialled in 24 sites and was evaluated by lay carers and nurses.

## **Results/outcomes**

Lay carers and nurses rated the usefulness and relevance of the package and its components highly. After receiving education, lay carers' expressed confidence in managing subcutaneous medication.

In focus group interviews, nurses identified that there was 'no right time' to deliver lay carer education in terms of the palliative patient's illness trajectory and that timing was a clinical decision dependent on lay carers. Opinion was divided concerning whether it is safe and appropriate for lay carers to manage subcutaneous injections.

## **Conclusions/implications**

This study demonstrates that if lay carers are supported with education and resources, tailored to their needs, they can confidently, safely and competently manage breakthrough subcutaneous medications to relieve symptoms in home-based palliative care patients. This has important implications for families, services and healthcare systems across Australia.

Funding received from the Australian Government Department of Health for a three year period from July 2017-June 2020 will enable enhancement of the Queensland- specific resources in a project called **caring@home – symptom management for palliative patients**. The aim of this project is to improve the quality of palliative care service delivery across Australia by standardising and upskilling community service providers to train lay

carers to provide safe and effective breakthrough palliative symptom management to a loved one in their home. Project activities can be summarised as:

- Resource development: develop state and territory specific guidelines for handling medications, review and enhance existing Queensland specific lay carer resources, translate select lay carer resources into 5 languages, develop online education for community service providers, develop workshop content for community service providers in rural and remote areas
- Implementation / rollout: deliver workshops to targeted groups, communication and marketing
- Evaluation.