

# Development of a Carer package for safe administration of subcutaneous medications across the Grampians Region

## Background:

The anticipatory prescribing of injectable medications such as opiates and benzodiazepines for use in patient's homes is a unique aspect of the practice of community palliative care. The literature identifies that timely access to medication (including injectable medications) to manage symptoms is vital to providing high quality end of life care in the community (1). The symptom needs of palliative care patients can change rapidly due to a clinical deterioration, exacerbation of existing symptoms or the oral route no longer being appropriate. The inability to control symptoms at home is a frequent reason for unplanned admissions to hospital in the last days of life (2). Anticipatory prescribing of medication for common symptoms at the end of life has been shown to avert symptom crises, increase the amount of time a patient can be cared for at home and improve the likelihood of dying at home (3).

One of the challenges in regional and rural areas is lack of access to health care professionals to assist in the administration of injectable medications in the home setting. Carers in the Grampians region are given verbal education about administration of medications by injection in the home. There is currently no visual learning package available in Victoria to assist with education and support of carers in the administration of injectable medications in the home setting. Due to limitation of afterhours services available across the region, if family have difficulty with subcutaneous administration of medication for symptom control, they may need to take the patient to the emergency department. It was hoped that an education package including a DVD may support carers when administering injectable medications in the home.

Whilst the literature is clear on the benefit for patient's to be in the environment of their choice for end of life care, there is limited literature on the impact to the caregiver on administration of subcutaneous medications in the home environment for symptom control.

## Objectives/aims

This study aimed to evaluate an interventional media package that had been developed to enhance carer confidence in the drawing up and administration of injectable medications in the home environment.

## Methods:

Ethics approval was sought and obtained through Ballarat Health Services and St John of God Hospital Ballarat Human Research Ethics Committee. Each participating site ethics committee was contacted and approval obtained.

This study was designed to examine the feasibility of a brief DVD intervention for carers in the home setting. The study occurred over 3 phases:

1. Focus groups included previous caregivers and current health care professionals who reviewed a pilot DVD and action plan developed by Deakin Medical students and Grampians Regional Palliative Care Team (GRPCT). Feedback from these groups directed the redevelopment of a DVD and action plan.

2. Palliative care providers were invited to participate in the pilot. Four rural and regional palliative care services, one metropolitan community palliative care service and one inpatient palliative care unit agreed to participate. Education to palliative care nurses on carer intervention package was given at all sites that participated.

3. Current caregivers were identified when patients were prescribed injectable medications for home use. Caregivers were invited to participate in the study and consented. Pre and Post questionnaire's were given to current carers and evaluated the effectiveness of the intervention package.

## **Results:**

### ***Phase one - Focus groups:***

Ninety three bereaved carers were invited, and twelve consented and participated. A thematic analysis of the recorded carer focus groups highlighted five themes :

- Education and Training – This included the repetition of task, practical demonstration and the train the trainer method
- Medications – This included making decisions about which drug and what dose to give
- Language – Medical terms were used freely by carers
- Hospitalisation – Carers identified that their ability to give sub-cutaneous injections allowed their loved one to stay at home longer or in some cases die at home
- Ends to a means – Carers were not bothered by giving injections if it allowed their loved one to be cared for in their place of choice.

The need for clear consistent information was highlighted by bereaved carers, with some commenting that nurses used different terms for the same procedures, creating confusion. Bereaved carers felt having a DVD would have increased their confidence in caring for a person in the home setting. Bereaved carers liked the concept of a prompt card and a medication record. They felt that more information was needed, in different learning styles, and stated the combinations of video and prompt sheet achieved this. Carers discussed the availability of the video and suggested it be available either on a USB or DVD format. All bereaved carers felt this would give flexibility for carers to view the package.

Thirty health care professionals participated in reviewing the package and also felt it may reduce caregiver stress and increase confidence. Some felt that there was too much information for carers and the prompt card should be simplified. Preparing injections including drawing up caused concern for some health care professionals, as they felt this was not the role of the carer. For sites that did not have a 24 hour support service, they felt the DVD was an excellent tool to assist caregivers to assess, prepare and administer medications without support.

Information obtained from focus groups assisted in redeveloping the DVD, prompt card and medication record. A ten minute DVD was developed, and divided into four sections: Assess; Prepare; Give; Review.

Each carer package included a DVD, USB, prompt card and medication log sheet.

## **Phase 2:**

Palliative care providers were invited to participate in the pilot. Four rural and regional palliative care services, one metropolitan community palliative care service and one inpatient palliative care unit agreed to participate.

Education to palliative care nurses on carer intervention packages were given at all sites that participated. This included an information sheet explaining the process for data collection for the research, and ongoing support was given when required.

## **Phase 3:**

### **Study population:**

Current carers were recruited through four rural/regional and one metropolitan community palliative care services, and one inpatient palliative care unit. Eligible carers were those over the age of eighteen and were able to read and speak English.

### **Recruitment for intervention:**

Carers were identified when patients required injectable medications for home use. 27 carers consented to participate in the research over a three month period. 20 carers completed pre questionnaires and 16 carers completed post questionnaires. If a carer declined to participate in the study, standard education was given on administration of subcutaneous medications.

### **Outcome measures:**

The pre and post questionnaires recorded gender and age of participants. Participating staff were asked to record the UR number of the patient on the pre and post questionnaires so that correlation of data could be made.

The pre questionnaire was completed by the carer after initial education was given on the package. A self-addressed envelope was provided. The post questionnaire was completed one month later. If the patient died, four sites followed up with a bereavement visit and handed the questionnaire out at this time.

The pre questionnaire consisted of twelve questions measuring relevance, content, skills, stress, satisfaction, safety and usefulness of the package. The post questionnaire also measured relevance, content, skills, stress, satisfaction, safety and usefulness of the

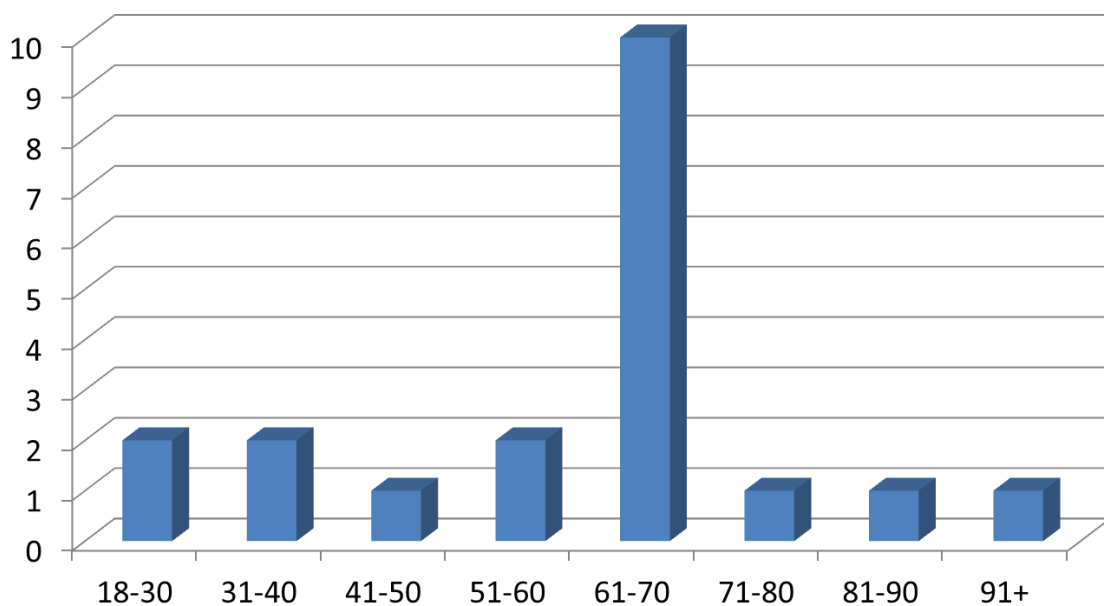
package, and also asked about preparation of injections, provision of symptom management and confidence in administration.

### Results:

27 carers consented over a three month period, 20 completed pre questionnaires and 16 completed post questionnaires.

Gender: 80% of participants were female.

Age of carers:



Carers were asked how many injections were given:

- None: 12.5%
- 1-3 injections: 31%
- 4-7 injections: 12.5%
- More than 7 injections: 44%

Carers were asked to rate their disagreement or agreement to questions on a 1-7 likert scale. Higher scores indicated higher satisfaction with the intervention, higher confidence, reduction in stress and improvement in skills.

All participants recorded a score of 4 or above on both pre and post questionnaires, demonstrating a positive outcome of the intervention. There was no significance difference between pre and post data from individuals relating to confidence, stress and improvement of skills. Variations occurred relating to the prompt card and medication log.

The prompt card was rated as extremely useful by 65% of participants on the pre questionnaire, but only 31% rated it as extremely useful on the post questionnaire. 57% of participants did not use the prompt card.

The medication log was extremely useful for 80% of participants on the pre questionnaire, but only 31% rated it extremely useful on the post questionnaire. 57% did not use the medication log.

The use of the DVD was consistent across all sites and 82-85% rated it extremely useful in pre and post questionnaires. One carer did not use the DVD and did not give any injections.

All carers felt the carer package had increased their confidence, reduced stress, and improved their skills. They felt the carer package was relevant to their needs and was a useful resource for injectable medications in the home setting.

Of the carers 55% provided comments on pre questionnaire, and 44% commented on post questionnaire.

#### **Pre questionnaire comments:**

- I have never had to inject any medications or care for someone before and feel this will give me clear knowledge and confidence to do so
- I found this information extremely helpful in giving me the confidence to give my husband his morphine and maxalon
- Takes the guessing away. Allows family to take control. Allows family to be with our loved one. Independently and confidently caring for our loved one
- I know I will be nervous the first time I give the injections but I am confident I will follow the correct procedure because of the information pack
- DVD excellent
- It will help relieve any anxiety I may have had in preparing and giving pain relief to my husband
- The DVD was put together very well - it was casual yet provided all relevant information. It is even useful for children to watch as it normalises the situation
- Very useful and well presented
- Prompt card good for reminding about key points. DVD/USB much more detail and repetition very helpful

#### **Post questionnaire comments:**

- I thought it was very well done. It gave me more confidence. I think having the visual there if required helped when I was stressed.
- It was amazing, it took a lot of stress out of the situation. Gave us control and the ability to manage my fathers symptoms as they arose.
- a great benefit to me and my wife in her final hours. We were able to promptly give her medications. Resounding success. My wife didn't want to go back to the inpatient setting for palliative care because she had to wait for medication for pain - this enabled me to provide the care at home and my wife to die at home.
- it was well done. Very easy to understand step by step. If you forgot something you could look it up. English is my 2nd language (Italian 1st) but very easy to understand.
- font larger on prompt sheet for older people would be beneficial. 100% great resource
- Pack has been very useful. I never thought i would be capable of drawing up injections - now I am very confident and this package has helped me be more confident.

- Thank you for the opportunity to be involved and to be able to help my husband
- I would like everyone to use this resource please as it is so easy to watch and made it easier
- As a RN I had the skills and knowledge to administer medications, but the package helped me support others who did not have the skills. It also enabled me to speak the same language. A very well prepared package, many thanks.

### **Discussion:**

Although this is not the first package to be developed for the palliative care market in Australia, it is the first to be trialed in Victorian metropolitan, regional and rural community palliative care services. Whilst the numbers recruited were small, the responses from carers demonstrated that the intervention assisted them in administration of medications and did not have a negative impact on carers.

### **Conclusions:**

This research clearly impacted on the wellbeing of carers who were caring for a person with a terminal illness. Carers commented that the package assisted in keeping a person at home, and reduced their stress and anxiety. Providing novel approaches to management of symptoms in the home setting may enhance carer confidence through the transition from hospital to home based care for terminal patients wanting to be cared for at home.

The package will continue to be available to all patients on a community palliative care program in the Grampians pending funding, and we would like to investigate whether there is a role for the package in acute services for families who wish to care for a person at home in the terminal phase, or a patient with a chronic illness who requires subcutaneous injections.

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