

# An educational package that supports laycarers to safely manage breakthrough subcutaneous injections for home-based palliative care patients: Development and evaluation of a service quality improvement

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## Abstract

**Background:** Palliative care services strive to support people to live and die well in their chosen environment, with optimal symptom control and a pattern of care supportive of laycarers. The likelihood of patients remaining at home often depends upon laycarers, who may be required to manage subcutaneous medications.

**Aim and Design:** This study reports the development, trial and evaluation of a package that teaches laycarers to manage subcutaneous medications used for symptom control in home-based patients. The package was developed by palliative care stakeholders and comprises an educational session, delivered by nurses, and a range of demonstrative, audiovisual and written resources.

**Settings/Participants:** The package was trialled across 24 sites and was evaluated by 76 laycarers (pre- and post-use) and 53 nurses (at study completion).

**Results:** Outcomes of primary interest were perceived global usefulness of the package and rated relevance of components. Laycarers and nurses rated the usefulness and relevance of the package highly – all means were above 5 on a 7-point scale. Also, laycarers were invited to comment on the package, and three focus groups for 26 nurses explored post hoc issues following package implementation.

**Conclusions:** In terms of the palliative patient's illness trajectory, consensus was that the time for package introduction depended upon each particular clinical situation and laycarer. Nursing opinion was divided concerning whether it is safe and appropriate for laycarers to manage subcutaneous injections. Nevertheless, this study demonstrates that the package supports laycarers to manage subcutaneous medications. This has important implications for families, services and health-care systems.

## Keywords

Palliative care, laycarer education, breakthrough pain, symptom management, homecare, subcutaneous injection

## Introduction

Australian palliative care services, like their international equivalents, strive to support patients to live and die well within the setting of their choice, usually home, with optimal

symptom control and with a pattern of care supportive of laycarers.<sup>1–7</sup> The likelihood of patients remaining symptomatically well managed at home often depends upon input

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from laycarers, mostly family members, who may be required to administer subcutaneous medications.<sup>8–11</sup> Australian bereaved laycarers report their ability to provide injections adds value to patient care; nonetheless, many report the need for education and resources to assist them in this quasi-professional role.<sup>4,7,9</sup>

Structured education programmes for laycarers result in positive patient and laycarer outcomes relating to symptom management.<sup>12–15</sup> Providing laycarers with the knowledge to understand the rationale of good symptom management adds to their confidence in administering the right drug for the right symptom at the right time.<sup>1,16</sup> This generates improved patient outcomes and decreases unwanted and inappropriate admissions to acute care facilities.<sup>17–19</sup>

There is some literature confirming the ability of laycarers to successfully administer pre-prepared syringes for symptom control, but there are few studies concerning the practice of also teaching laycarers to prepare injections.<sup>4,14,20</sup> There is resistance from some palliative care service providers about the appropriateness of teaching laycarers to prepare and administer subcutaneous injections.<sup>11,18,21,22</sup> This has been partly due to a perception that the task is too burdensome for family members, that is, it generates unnecessary stress and anxiety with possible negative consequences in bereavement.<sup>21</sup> In addition, there is organisational and individual uncertainty related to legal, jurisdictional and scope of practice issues for registered nurses and laycarers.<sup>17</sup>

This study investigated an intervention to improve laycarers' capacity to manage symptoms in palliative care patients requiring breakthrough subcutaneous injections. The intervention educated and supported laycarers to competently and safely prepare, store and administer subcutaneous injections; to monitor subcutaneous sites; to manage a medication administration record suitable for easy assessment by health professionals and to understand the uses of common medications used in palliative care.

## Method

The aim was to develop, trial and evaluate the effectiveness of a package, consisting of an education session and resources, that supports laycarers of home-based palliative patients to manage breakthrough subcutaneous medications used for symptom control. Ethics clearance was obtained from six Human Research and Ethics Committees.

### Legislative requirements

Early in this study, it was identified that many Australian community-based services and individual staff were unclear regarding the legal, jurisdictional and scope of practice issues related to the common palliative care practice of preparing subcutaneous injections and leaving them

in the home for subsequent administration by laycarers.<sup>22</sup> To clarify these issues and to progress the study, the Brisbane South Palliative Care Collaborative prepared a document entitled *Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland*.<sup>16</sup> This document has been endorsed by Queensland Health, Australia and complies with the *Health (Drug and Poisons) Regulation 1996*,<sup>23</sup> the *Queensland Powers of Attorney Act 1998*<sup>24</sup> and the *Guardianship and Administration Act 2000*.<sup>25</sup>

### The package

Production of the package was an iterative process guided by a multidisciplinary group of 14 specialist and non-specialist palliative care providers, academics and laycarers. The group met face-to-face five times to draft aspects of the package. These drafts were circulated until consensus about the final documents was achieved.

The education session development was informed by a literature search, consensus-based best practice with respect to subcutaneous medication use<sup>26</sup> and adult learning principles.<sup>27,28</sup> Agreed requirements of the session included:

- standardised information content, focusing on safety, competency and skills (inclusive of preparation, storage and administration of breakthrough injections) and able to be delivered by registered nurses to laycarers;
- suitable for delivery in a one-on-one format in the laycarer's home;
- able to be implemented across various health and geographical settings;
- various teaching material modalities to allow for individual differences in rates and style of learning.

A training manual was developed to guide nurses in the delivery of the education session. A suite of resources was developed for use within the education session and to provide laycarers ongoing support in their day-to-day management of subcutaneous medications. All the materials produced by this study can be accessed via <http://www.caresearch.com.au/caresearch/tabid/2145/Default.aspx>

### Package implementation

Specialist and non-specialist palliative care services across South East Queensland were approached to be involved in the study. All the registered nurses from consenting services received on-site training by research staff in all aspects of the package, including delivery of the education session, prior to recruitment of laycarers. Potential laycarers were identified initially by clinically registered nurses

**Table 1.** Laycarer inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
1. Deemed competent by the clinical nurse to administer and manage injections via a subcutaneous cannula for breakthrough symptom management if that need arises	1. Paid to provide care
2. Over 18 years of age	2. Previous experience or training in administering subcutaneous medications
3. Able to read, write and understand English language	3. Unlikely to be compliant with the project requirements

using the criteria listed in Table 1. These laycarers were later contacted by research staff to discuss the study and obtain written consent.

### Evaluation

The package was evaluated by laycarers and registered nurses. The outcomes of primary interest were the perceived global usefulness and relevance of package components. Laycarers completed two questionnaires: the first questionnaire was administered immediately after delivery of the education session (Time 1) and the second questionnaire was administered 4 weeks after laycarers had had experience injecting medications and using the resources (Time 2).

The first questionnaire rated the global usefulness of the education and resources as well as laycarers' perceptions of confidence with regard to aspects of their future delivery of subcutaneous medications. The initial section rated the education session in terms of relevance to needs, ease of understanding, potential usefulness in reducing stress, medication administration and satisfaction with the information. The next section rated confidence with preparing, labelling and administering injections; managing the injection site and symptoms and understanding of common palliative care medications. The final section rated specific aspects of the education and resources including the one-on-one session, written and illustrated information, demonstration and supervision components and the audiovisual resource.

The second questionnaire was similar to the first and asked laycarers to rank the usefulness of the resources that they had actually used after they had had experience injecting. All questions were answered on 7-point Likert-type rating scales where a higher score indicates a more positive response. Interpretation of the mean ratings and 95% confidence interval (95% CI) were based on a mean higher than 5, indicating a very positive response on average, and the lower limit of the 95% CI above 4, indicating consistent agreement among respondents about the high rating. Laycarers were also invited to write comments.

Nurses who delivered the education were asked to complete a questionnaire at the conclusion of the study. The questionnaire aimed to evaluate the package across content,

efficacy, safety and satisfaction domains. It was based on 7-point Likert-type scales with endpoints, strongly disagree, 1, and strongly agree, 7.

The first section rated overall aspects of the education session, including ease of delivery, quality of resources and appropriateness to the needs of laycarers. The second section concerned how well nurses thought the various issues had been explained. The third section rated the usefulness of specific aspects of the package for the laycarers.

At the end of the study, focus groups were held with a purposive sample of specialist and non-specialist palliative care nurses from participating sites. Focus group questions were informed by the findings from the registered nurse questionnaire. The purpose was to explore post hoc issues that had arisen after implementation of the package.

## Results

### The package

The education session comprised five major content areas. These content areas, the rationale for their inclusion and nurse actions associated with those areas are listed in Table 2. The education session required between 20 and 60 min to complete and was used to introduce the suite of resources developed for the study.

The resources are listed and described in Table 3. Resources numbered 1, 2, 3, 4, 5 and 9 were considered mandatory for use in the education session while resources numbered 6, 7 and 8 were non-mandatory and could be used at the discretion of the nurse and laycarer.

### Implementation

The study commenced on February 2009 and ceased on January 2010. The package was implemented across 24 sites (7 specialist palliative care services and 17 generalist services) in urban, regional and rural settings across South East Queensland, Australia.

### Evaluation by laycarers

Overall, 347 laycarers, who potentially may have been required to deliver subcutaneous injections in the

**Table 2.** Content areas, rationale for inclusion and associated nurse actions for the standardised educational session.

Content	Rationale	Nurse action
1. Safe preparation, storage and administration of subcutaneous injections through a cannula	<ul style="list-style-type: none"> <li>• Palliative patients are inherently unstable with respect to symptom emergence</li> <li>• Laycarers need to be able to provide timely subcutaneous medications for symptom management</li> <li>• Laycarers may run out of pre-prepared medications, so need the skills to prepare extra injections</li> </ul>	<ul style="list-style-type: none"> <li>• Teach laycarers to prepare, store and administer subcutaneous medications at a clinically appropriate time</li> <li>• Teach injecting skills according to the nurse's usual practice</li> </ul>
2. Use of non-sharp or needle-less system	<ul style="list-style-type: none"> <li>• Best practice to maximise patient/laycarer and staff safety by reducing incidence of needle stick injury</li> </ul>	<ul style="list-style-type: none"> <li>• Provide advice on best practice principles related to non-sharp or needle-less system as part of standard practice</li> </ul>
3. Insertion of a second Saf-T-Intima™	<ul style="list-style-type: none"> <li>• Subcutaneous cannulas can become blocked</li> <li>• Insertion of a second intima ensures that patients have access to timely symptom control, even when nurse is not available to change cannula</li> </ul>	<ul style="list-style-type: none"> <li>• Explain that nurse will insert two Saf-T-Intima™ when need to provide subcutaneous injections is apparent</li> </ul>
4. Flushing of static line with normal saline	<ul style="list-style-type: none"> <li>• Some subcutaneous medication doses are delivered in small volumes</li> <li>• Flushing ensures that the patient receives the complete dose of prescribed medications</li> </ul>	<ul style="list-style-type: none"> <li>• Teach laycarers to flush the Saf-T-Intima™ with a minimum of 0.3–0.5 mL of normal saline (unless otherwise indicated) after each breakthrough injection</li> </ul>
5. Competency of laycarers to safely prepare and administer subcutaneous injections	<ul style="list-style-type: none"> <li>• Nurses have a legal obligation to ensure that laycarers are taught to prepare and administer subcutaneous injection(s) safely and are competent to do so</li> <li>• Laycarers must be provided with appropriate training to safely assist with medication administration</li> </ul>	<ul style="list-style-type: none"> <li>• Check carer competency using competency checklist</li> </ul>

foreseeable future, were identified and 169 approached after the need for breakthrough injections was realised. Of these, 165 consented to participate and 76 returned questionnaires. The majority of consenting laycarers, 74% (123), were female, spouses, partners or daughters. Ages ranged from 18 to 76 years and over. The majority of laycarers, 49% (82), were aged between 46 and 65 years, 31% (51) were aged between 18 and 45 years, 19% (22) were 66 years or above and 4% (7) were over 76 years. In terms of geographical distribution, 81% of participants were recruited from urban areas, with smaller percentages from regional (16%) and rural populations (3%).

Time 1 questionnaire was returned by 76 laycarers, after the face-to-face education session, and Time 2 questionnaire returned by 62 laycarers, after experience with administering subcutaneous injections in the home. Mean ratings and 95% CIs for these laycarers are shown in Table 4.

Global usefulness of the education session was rated highly. Across both Times 1 and 2, means were greater than

6 out of a maximum of 7, indicating a high level of usefulness perceived before and realised after the experience of administering injection(s). In terms of laycarers' confidence, means were uniformly high at both times, indicating the benefits of the package in preparing laycarers for the task of subcutaneous medication management.

The potential and realised relevance of specific aspects of the package were also rated highly, as shown in Table 4. Aspects evaluated included the face-to-face education session, the written and illustrated information provided in the package, the demonstration and supervision while giving a subcutaneous injection and the DVD included in each package. Representative laycarers' comments are presented in Table 5.

In summary, the results show that the means of laycarers' responses were all equal to or above 5.9, indicating that laycarers found the package to be useful and relevant in enabling them to deal confidently with symptoms arising in the home-based palliative patient.

**Table 3.** List of resources and corresponding descriptions developed for use in the study. Resources numbered 1, 2, 3, 4, 5 and 9 were mandatory for use in the education session.

Resource	Description
1. Illustrated step-by-step charts	– Charts providing a visual guide for laycarers when preparing and administering subcutaneous injections
2. Practice demonstration kit	– Kit used, as a teaching aid, to facilitate learning the skills of opening ampoules and injecting – Kits included a cannula, inserted into stoma-type adhesive dressing that mimics a person's skin, plus glass and plastic ampoules, blunt drawing-up needles and syringes
3. Colour-coded medication labels	– Used for labelling pre-prepared syringes – Colour coding system adopts the Australian and New Zealand Standard – <i>User-applied labels for use on syringes containing drugs used during anaesthesia</i> <sup>29</sup> – Colour-coded labels help laycarers to distinguish between injectable medications, thus potentially reducing carer stress and medication injection errors
4. Fridge magnet	– Magnet composed of different colour patches consistent with the colour coding on the syringe labels. Names of patient medications able to be written on the appropriate coloured patch – Magnet acts as safety measure because it allows laycarers to check pre-prepared syringes, taken from the fridge, with medication names written on the magnet
5. Daily medication use diary	– Structured diary: carer documents every injection, inclusive of date, time, medication type, reason for administration and effectiveness – Diary allows health-care provider to monitor daily progress of symptom management
6. Medication booklet – 'Palliative subcutaneous medication administration: A guide for carers'	– Booklet concerns subcutaneous medication management – Content includes frequently asked questions, importance of symptom control, management of common palliative symptoms, commonly used subcutaneous medications and injecting processes
7. DVD – 'How to prepare and administer a subcutaneous injection: A guide for laycarers'	– 19-min DVD demonstrating subcutaneous medication preparation and administration, safe storage and disposal of medications and a trouble shooting guide
8. Lanyard	– For use by nurses – includes the colour-coded medication legend as well as the major content areas of the standardised education session for easy reference.
9. Competency checklist	– Checklist for nurses to confirm competency has been reached by the laycarer to safely prepare and inject subcutaneous medications. This is a requirement under the <i>Health (Drugs and Poisons) Regulation 1996</i> . <sup>23</sup>

### Evaluation by nurses

A total of 217 nurses from 24 sites were trained to deliver the standardised education; not all nurses subsequently delivered the education because their patients did not require breakthrough injections. Of those who delivered education, 53 returned questionnaires.

Nurses rated the education session highly for aspects such as appropriateness to the needs of laycarers, providing the necessary information to allow laycarers to safely prepare and administer subcutaneous injections. Similarly, they indicated that the issues relevant to subcutaneous injections of palliative care medications had been well explained, and the components of the package provided

useful resources for laycarers. Specific items, together with means and 95% CI, are shown in Table 6.

Three focus groups targeting three trial sites from different demographic areas, urban, regional and rural, were held with 26 nurses at completion of the project. In all the three groups, there were two issues that dominated discussion. The first was the question of when is the right time in the palliative patient's trajectory to deliver laycarer education regarding subcutaneous medication management. General consensus was that there is 'no right time' and that timing was a clinical decision dependent on individual laycarers. The second issue concerned whether it is safe and appropriate for laycarers to manage subcutaneous

**Table 4.** Laycarer evaluation of the package immediately after the face-to-face education session (*Time 1*) and four weeks after the experience of managing subcutaneous medications (*Time 2*).

Global evaluation of education sessions	Time 1		Time 2	
	Mean	95% CI	Mean	95% CI
<i>In relation to preparing and giving subcutaneous injections, the education package:</i>				
1. Is relevant to my needs	6.5	6.4–6.7	6.5	6.4–6.7
2. Is easy to understand	6.4	6.3–6.6	6.3	6.1–6.6
3. Is able to help to reduce my stress	6.3	6.1–6.5	6.1	5.8–6.4
4. Gives me the necessary skills	6.5	6.3–6.6	6.1	5.8–6.4
5. Provides me with satisfactory information	6.5	6.4–6.7	6.3	6.0–6.6
<i>In relation to preparing and giving subcutaneous injections, the education package increases my confidence to:</i>				
6. Prepare and label injections	6.2	6.0–6.4	5.9	5.5–6.4
7. Safely inject medication	6.4	6.2–6.5	6.4	6.1–6.6
8. Safely manage injection site	6.2	6.0–6.4	6.3	6.0–6.6
9. Manage symptoms	5.9	5.6–6.1	5.9	5.6–6.2
10. Understand common palliative care medications	6.0	5.8–6.3	6.2	5.9–6.5
<i>Rate the usefulness of specific aspects of the package</i>				
11. Face-to-face education session	6.7	6.6–6.8	6.6	6.4–6.8
12. Illustrated step-by-step guides	6.3	6.0–6.5	6.4	6.1–6.6
13. Colour-coded labels for syringes	6.6	6.5–6.7	6.5	6.2–6.7
14. Fridge magnet	6.2	6.0–6.5	6.2	5.8–6.5
15. Daily diary	6.4	6.3–6.6	6.5	6.2–6.7
16. Competency checklist	6.0	5.7–6.3	5.9	5.5–6.3
17. Medication booklet	6.2	5.9–6.5	6.4	6.1–6.7
18. Practical demonstration by nurse	6.7	6.6–6.8	6.8	6.7–6.9
19. Using demonstration kit	6.6	6.5–6.8	6.5	6.3–6.7
20. Supervised injection into cannula	6.6	6.4–6.8	6.7	6.5–6.9
21. DVD on subcutaneous medications' administration	6.1	5.9–6.4	6.1	5.5–6.8

CI: confidence interval.  
Ratings ranged from 1 to 7.

**Table 5.** Laycarer comments regarding the package.

We knew when the pain hit we were able to do something to try and relieve it immediately without having to sit waiting powerless for someone else to come and do it. I believe it gave me the confidence to keep him at home to the very end.

All the bits of the kits (were useful) even if they aren't all used by all caregivers. We all learn in different ways. Also, it's essential to have all that material to refer to if it is needed during a crisis for example when we say 'oops', what do we do next?

I felt it was a useful resource in reinforcing information received from nurses, to relay to other family members/caregivers in the house who may have been conflicted about us giving injections (drugs). This book could assist in allaying some of these concerns I found the step-by-step chart of immense value and support

medications. Opinion on this issue was divided – some considered it safe as well as necessary given palliative care resourcing constraints, while others held that it was simply too difficult for laycarers. Other recurrent issues included time pressures experienced by some nurses for the delivery of the one-on-one education session, the usefulness of the structured daily diary that allowed nurses to easily monitor medication effectiveness and frequency of symptom occurrence and the value of the colour coding system that contributed to laycarers' confidence that they were safely administering the right medication.

## Discussion

This study demonstrates that if laycarers 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 finding has important implications for laycarers, home-based palliative care patients, palliative care services and Australian health-care systems.<sup>11,13,26</sup> In terms of study limitations, the sample sizes and sample inclusion/exclusion criteria for laycarers

**Table 6.** Evaluation of package by registered nurses completed at the end of the study.

Global evaluation of education session	Mean	95% CI
<i>The standardised education package delivered by registered nurses to laycarers</i>		
1. Was easy to deliver	5.2	4.9–5.5
2. Provides opportunity to assess laycarer competence related to subcutaneous injections	5.5	5.2–5.7
3. Provides a framework for consistency in laycarer education	5.6	5.4–5.9
4. Is appropriate to laycarer needs	5.6	5.3–5.9
5. Provides quality resources	5.9	5.6–6.2
6. Provides necessary information for safe preparation of subcutaneous medications	5.8	5.5–6.0
7. Provides necessary information for safe administration of subcutaneous medications	5.9	5.7–6.1
8. Sufficient practice material in demonstration kit	5.7	5.4–6.0
9. Recommend continued use of the package after study completion	5.5	5.1–5.9
<i>The standardised education package adequately explained</i>		
10. Safe preparation and labelling of subcutaneous injections	5.6	5.3–6.0
11. Safe injection of subcutaneous medications	5.8	5.5–6.0
12. Safe management of the injection site	5.8	5.5–6.0
13. Managing symptoms	5.4	5.1–5.7
14. Commonly used palliative care medications	5.4	5.0–5.8
<i>Rate the usefulness of specific aspects of the package</i>		
15. Face-to-face education session	6.0	5.8–6.2
16. Illustrated step-by-step guides	6.0	5.7–6.3
17. Colour-coded labels for syringes	6.2	5.9–6.5
18. Fridge magnet	5.3	4.8–5.8
19. Daily diary	5.8	5.5–6.1
20. Competency checklist	5.6	5.2–6.0
21. Medication booklet	5.8	5.5–6.1
22. Demonstration kit	6.1	5.8–6.3
23. DVD on subcutaneous medications' administration	5.4	5.0–5.7

CI: confidence interval.

Ratings ranged from 1 to 7.

may limit the extent to which these findings are directly applicable across all palliative care service populations. Furthermore, this study is not applicable across countries due to differences in legal codes between countries.

Laycarers perceived the overall usefulness of the package as soon as they had completed their one-on-one education session. This perception was maintained after they had had the experience of symptom management using subcutaneous medications. They were satisfied that the package information was relevant to them and the content provided necessary technical skills to manage subcutaneous medications. Importantly, they felt confident that they could safely pre-prepare and inject subcutaneous medications. In addition, the package decreased their stresses surrounding subcutaneous injections, and they were satisfied that they could assist with symptom management. In summary, the package by allowing access to standardised, relevant information empowers laycarers to care safely for their loved ones at home.

Most Australian palliative care patients prefer to be cared for at home and many want to die at home.<sup>1,2</sup> In reality, only 16% of Australians are able to die at home, with the majority (54%) dying in hospitals.<sup>1,2,6,15,19</sup> One of the

most frequent reasons that community-based palliative care patients are transferred to in-patient units is because their symptoms cannot be controlled adequately at home.<sup>11,15,21,30–32</sup> The package reported here shows that laycarers can learn to manage subcutaneous injections, thus contributing to breakthrough symptom control in a timely and effective way. It is likely that use of the package can contribute to more patients being able to die in the environment of their choice, their home. Potentially, this will result in an improved quality of death<sup>9,15,18,21</sup> and decrease the cost burden to the health-care system incurred when distressed patients are unnecessarily transferred to acute care facilities.

Palliative care services are struggling to meet the increasing demand for palliative care.<sup>20,21,31</sup> This situation is worsening as the population ages and community acceptance of palliative care for people with chronic and non-neoplastic diseases grows. If the ability of laycarers to provide symptom management is improved by initiatives such as the package described here, then the capacity of professional palliative care staff, particularly nurses, to care for more people will be enhanced.

Registered nurses concurred with laycarers that the package was both useful and relevant. Nurses felt that the

education session was easy to deliver, adequately explained injecting issues and recommended its continued use. Nonetheless, delivery of the standardised education challenged some nurses, possibly because it encompassed practice change. Clinical opinion varied as to the appropriate time in the patient's palliative care trajectory to present the education session. Some commented on the clinical load imposed due to the time required to deliver the session depending upon the clinician and individual laycarers' abilities and learning styles. It was recognised, nonetheless, that with continued experience in education delivery, the time required to introduce the package would decrease.

Some nurses reiterated their concerns about safety issues related to laycarers managing symptoms and the burdensomeness of that task. However, given laycarers' high level of satisfaction with the package, it may be that nurses, and other health-care professionals, have been overprotective or gatekeeping in their attitudes to laycarers.<sup>11,17,21,22</sup> They may underestimate the resilience and motivation of laycarers when placed in the difficult situation of caring for a loved one at home.<sup>10,11,13,17,21</sup> Alternatively, it may be that the laycarers chosen for this study were psychologically robust individuals, given it was clinical nurses who initially screened laycarers' suitability for the study.

The issue of safe practice is pivotal to all health-care provision and was a fundamental consideration throughout the package development. To reinforce written medication information, a colour coding system, adapted from anaesthetic drugs safety Standards<sup>29,33,34</sup> and advocated by an Australian national labelling project,<sup>35</sup> helped laycarers to identify correct medications, and avoid errors, through the use of labelling pre-prepared syringes. The importance of the colour coding system was emphasised during the education session. Laycarers were taught that they could use the coloured labels on the pre-prepared syringes as a cue to help distinguish between medications, even when they were tired or distressed. All the pre-prepared injections were stored in secure containers in the refrigerator. The fridge door magnet incorporated the colour-coding system, thus further consolidating the colour prompt for the laycarer. The magnets were designed to be written on, so changes in medication could be easily updated by nurses or laycarers. The colour coding system was uniform across all package resources including the medication booklet and DVD.

Another safe practice measure was the diary provided to laycarers that encouraged the recording of every injection given as well as the effectiveness of the medication for symptom relief. This clinical tool proved to be of great value to both laycarers and visiting health professionals. In the focus groups, many nurses made reference to laycarers experiencing a sense of security in having a record of injection administration as pressures associated with the caring role often led to an inability to accurately recollect medical detail. Indeed, most laycarers chose to continue using the diary even after study completion. Nurses reported that they could easily interpret the information contained within

the standard diary and this helped them monitor medication effectiveness, progress of symptom evolution and patient condition.

The Australian National Palliative Care Strategy<sup>1</sup> of 2010 recognises that in order to meet future palliative care demand and provide equitable access to all Australians to the right care, at the right time and in the right place, new approaches to care and service models are required. The package presented in this study could be one element of a supportive model of care based on a partnership between lay and professional care providers to achieve optimal outcomes for home-based palliative care patients.

### Clinical trial registration

Australian New Zealand clinical trial registry 0835553.

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### Conflict of interest

The authors declare that there is no conflict of interest.

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### References

1. Australian Government Department of Health and Ageing. *The National palliative care strategy: supporting Australians to live well at the end of life*. Canberra, ACT, Australia: Commonwealth of Australia, 2010.
2. Gerrard R, Campbell J, Minton O, et al. Achieving the preferred place of care for hospitalised patients at the end of life. *Palliat Med* 2010; 25: 333–336.
3. Gomes B, McCrone P, Hall S, et al. Variation in the quality and cost of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALY-CARE study. *BMC Cancer* 2010; 10: 400.
4. Israel F, Reymond E, Slade G, et al. Carers' perspectives on injecting subcutaneous medications to palliative care patients at home. *Int J Palliat Nurs* 2008; 14: 390–395.
5. Zimmermann C, Riechelmann R, Krzyanowska R, et al. Effectiveness of specialized palliative care: a systematic review. *JAMA* 2008; 299: 1698–1709.

6. Shepperd S, Wee B, Straus SE. Hospital at home: home-based end of life care. *Cochrane Database of Systematic Reviews* 2011, Issue 7. Art. No : CD009231.110.1002/14651858.CD009231
7. Empeno J, Raming N, Irwin SA, et al. The hospice caregiver support project: providing support to reduce caregiver stress. *Palliat Med* 2011; 14: 593–597.
8. Johnson CE and Mitchell JK. Hospital and emergency department use in the last years of life: a baseline for future modifications to end-of-life care. *Med J Aust* 2011; 195: 267.
9. Stajduhar K, Martin WL, Barwich D, et al. Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nurs* 2008; 31: 77–85.
10. Grande G, Stadkdijar L, Toye C, et al. Supporting laycarers in end of life care: current gaps and future priorities. *J Palliat Med* 2009; 23: 339–344.
11. Eyre S. Supporting informal carers of dying patients: the district nurse's role. *Nurs Stand* 2009; 24: 43–48.
12. Aoun SM, Kristjanson LJ, Currow DC, et al. Caregiving for the terminally ill at what cost? *Palliat Med* 2005; 19: 551–555.
13. Docherty A, Owens A, Asadi-Lari M, et al. Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliat Med* 2008; 22: 105.
14. Lee L and Headland C. Administration of as required subcutaneous medications by laycarers: developing procedures and leaflet. *Int J Palliat Nurs* 2003; 9: 142–148.
15. Coyle N, Pain Management in the Home, *Curr Pain Headache Rep*, 2005, 9:231–238
16. Brisbane South Palliative Care Collaborative. *Guidelines for the handling of medication in community based palliative care services in Queensland*. Unpublished, 2008, <http://www.health.qld.gov.au/cpre/pdf/medguidepall.pdf>
17. Thomas K, Hudson P, Oldham L, et al. Meeting the needs of family carers: an evaluation of three home-based palliative care services in Australia. *Palliat Med* 2010; 24: 183.
18. Thomas K and Noble B. Improving the delivery of palliative care in general practice: an evaluation of the first phase of the gold standards framework. *Palliat Med* 2007; 21: 49–53.
19. Hudson P, Redmedios C and Thomas K. A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliat Care* 2010; 9: 17.
20. Roseman T, Hermann K, Miksch A, et al. The PAMINO-project: evaluating a primary care-based educational program to improve the quality of life of palliative patients. *BMC Palliat Care* 2007; 6: 1–6.
21. Bennet MI, Flemming K and Closs SJ. Education in cancer pain management. *Curr Opin Support Palliat Care* 2011; 5: 20–24.
22. Healy S, Israel F, Charles M, et al. Final report caring safely at home project: supporting carers of people requiring palliative care at home. May 2010, <http://www.caresearch.com.au/caresearch/tabid/2145/Default.aspx> (accessed 6 June 2012)
23. Queensland Health. Health (Drugs and Poisons) Regulation 1996 (reprint 1 October 2007), [http://www.health.qld.gov.au/health\\_professionals/medicines/default.asp](http://www.health.qld.gov.au/health_professionals/medicines/default.asp) (accessed 6 June 2012).
24. Queensland Health. Powers of Attorney Act 1998 (reprint 1 July 2011), [www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PowersofAttA98.pdf](http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PowersofAttA98.pdf) (accessed 6 December 2011).
25. Queensland Health. Guardianship and Administration Act 2000 (reprint 1 July 2011), <http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/G/GuardAdminA00.pdf> (accessed 6 December 2011).
26. Centre for Palliative Care Research and Education. *Guidelines for subcutaneous infusion device management in palliative care*. 2nd ed., The State of Queensland, Queensland Health, 2010.
27. Egle C. *Adult learning principles for facilitators*. Rural Health Education Foundation, 2007, [http://www.rhef.com.au/wp-content/uploads/userfiles/716\\_alp\\_lr.pdf](http://www.rhef.com.au/wp-content/uploads/userfiles/716_alp_lr.pdf) (accessed 6 December 2011).
28. Bugger E and Higginson I. Palliative care and the needs for education – do we know what makes a difference? *Health Educ J* 2006; 65: 101.
29. AS/NZS 4375:1996. User-applied labels for use on syringes containing drugs used during anaesthesia. Sydney, NSW, Australia: Standards Australia International Pty Ltd, 1996.
30. Bee PE, Barnes P and Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs* 2009; 18: 1379–1393.
31. Hillman KM. End-of-life care in acute hospitals. *Aust Health Rev* 2011; 35: 176–177, [www.publish.csiro.au/journals/ahr](http://www.publish.csiro.au/journals/ahr) (accessed 6 December 2011).
32. Gomes B and Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: a systematic review. *Brit Med J* 2006; 332: 515–521.
33. Australian and New Zealand College of Anaesthetists. *Guidelines for the safe administration of injectable drugs in anaesthesia*. Melbourne, VIC, Australia: ANZCA, 2009, <http://www.anzca.edu.au/resources/professional-documents/documents/professional-standards/pdf-files/PS51.pdf/view> (accessed October 2012).
34. AS4940:2002. Amendment 1. User-applied identification labels for fluid bags syringes and drug administration lines. Sydney, NSW, Australia: Standards Australia International Pty Ltd, 2003.
35. Australian Commission on Safety and Quality in Health Care (2012) *National Recommendations for User-applied Labelling of Injectable Medicines, Fluids and Lines*, ACSQHC, Sydney, 2012.

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