The Role of the Pharmacist in the Provision of Palliative Care

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## Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Explanation</th>
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<tbody>
<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>IT</td>
<td>Information technology</td>
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<tr>
<td>M</td>
<td>Mean</td>
</tr>
<tr>
<td>MMR</td>
<td>Medication Management Review</td>
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<tr>
<td>PCMMR</td>
<td>Palliative Care Medication Management Review</td>
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<tr>
<td>p/M</td>
<td>per million</td>
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<tr>
<td>PPCP</td>
<td>Pharmacy Palliative Care Portal</td>
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<tr>
<td>RE-AIM model</td>
<td>Reach; Efficacy; Adoption; Implementation; Maintenance</td>
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<tr>
<td>SD</td>
<td>Standard deviation</td>
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<td>UK</td>
<td>United Kingdom</td>
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1. Background

The demography of Australia is changing, the population is growing and the proportion of people in older age groups is increasing. As a result of greater longevity a larger proportion of Australians will eventually develop life limiting illness or succumb to the end stages of a chronic illness. Franks et al. examining usage in the United Kingdom calculated that the following palliative care services should be provided:

1. Pain control for 2800 people per million (p/M) population dying from cancer each year and for 3400 p/M people dying of non-cancer terminal illness;
2. Palliative home nursing for 700-1800 p/M with cancer and 350-1400 p/M with non-cancer patients with terminal illness; and 400-700 cancer p/M and 200-700 non-cancer p/M patients requiring in patient terminal care.

Lynn describes three trajectories of dying:

1. Slow decline with a rapid terminal phase (most cancer fits this trajectory);
2. Slow decline with periodic relapses and remissions (for example, organ failure); and
3. Generalised poor functioning and slow decline to death (for example, dementia).

How will Australia respond to the challenge of caring for people in these circumstances? Most people, when asked, indicate that they would prefer to die at home. Home represents familiarity, the presence of loved ones, and a sense of connection with ongoing life. In the last 50 years in Australia and many parts of the Western world however, the number of people who die at home has actually decreased. Now only 16% of people die at home. Around 20% of people die in hospices and 10% in nursing homes. The rest die in hospitals. Community pharmacists are among the health care professionals most likely to come in contact with people in need of palliative care or their carers, doctors and therapists while they are receiving palliative care in the community.

Effective palliative care mandates inter-professional collaboration. The extent to which allied health professionals are able to work collaboratively will determine the extent to which community based teams can provide timely support that responds to changes in the patient’s physical condition and his/her changing goals. The practice of collaborative health care can be challenging as each team member may have different “framework of understanding”. For example, a social worker may take a patient-centred approach where a physician may adopt a task-oriented approach. Such differences can make the already complex task of sharing information amongst team members more difficult and can ultimately detract from the quality of care. In order to improve the quality of care for palliative patients, palliative care education must move into a realm where theories and practice form a practical framework of care.

Pain and symptom management are central issues in palliative care. Health professionals aim to relieve pain but also support distressed people. The multi-faceted nature of palliative care requires professionals working with terminal patients to have a greater capacity for empathy, the ability to address psychosocial needs, a sophisticated knowledge of medical ethics, and excellence in communication skills. Although many of these skills are addressed in medical and pharmacy training, research indicates that many health care professionals are poorly prepared for the complexities of palliative care. The aim of this study was to design material that could facilitate the involvement of the community pharmacists in palliative care and enhance pharmacist involvement in medication management reviews for palliative care patients.

This project is framed within the Medical Research Council’s (MRC’s) framework for the development and evaluation of complex interventions. Complex interventions are those that include several components, in this case education of the pharmacists; multidisciplinary group practices; processes for engaging and rewarding involvement in palliative care; and patient confidence in the care offered. The evaluation of complex interventions is challenging because of problems in developing, identifying, documenting, and reproducing the intervention. A phased approach to the development and evaluation of complex interventions is recommended to help researchers define clearly where they are in the research process. Evaluation of complex interventions requires use of qualitative and quantitative approached as adopted in this research.
2. Objectives

Objective 1
To identify the needs of community pharmacy palliative care patients and their carers and families at different stages of their illness.

Objective 2
To develop an educational package for community pharmacists in order to provide enhanced care to palliative care patients.

Objective 3
To identify what barriers exist to community pharmacy involvement in palliative care and what supports are needed to facilitate involvement.

Objective 4
To identify specific needs in relation to medication management services and to develop medication management reviews that incorporate palliative care (PCMMR).

3. Methodology

3.1 Objective 1-Client and Carer Needs

3.1.1 Design
An in-depth qualitative design was used. Focus groups were the main source of information and these were supplemented by individual face-to-face or telephone interviews (when people were not able to attend a focus group meeting for a range of reasons including distance and caring or professional responsibilities).

3.1.2 Participants
One hundred and twelve people participated in either a focus group or an interview. The interviews and focus groups were undertaken with those professionals involved in providing services to palliative care patients together with carers and family members of patients living with a life limiting illness. The health professionals involved were accredited, community and hospital pharmacists; nurses in community palliative care, hospital, hospice and nursing home settings as well as those working with aged patients, children and adolescents; and Palliative care doctors and Palliative care doctors and GPs.

A total of 19 individual interviews and 16 focus groups were undertaken for the research. The participants were drawn from both metropolitan and regional areas across Australia – Western Australia, New South Wales, Queensland and Victoria, thus providing a cross section of views that may be reflective of particular practices in various parts of the country.

3.1.3 Materials
The interview schedules for each of the participants groups were developed using an iterative process. A subgroup of members from the project team formed the Focus Group Subgroup; all members of this subgroup had experience in conducting interviews. The subgroup developed the key questions, which were then shared with the rest of the project team. After extensive feedback, the questions were revised and updated, and the final drafts were sent to the Project Advisory Panel as a deliverable. The Focus Group Subgroup revised the questions to address the Expert Advisory Group's feedback. The final set of questions provided a schedule of the key issues to be addressed in each focus group (or interview) but was flexible enough to accommodate the natural flow of conversation and the inevitable pre-empting of questions by participants.
A core team of three highly experienced interviewers from the Focus Group Subgroup conducted the interviews and focus group sessions. The other three subgroup members played supporting roles.

3.2 Objective 2—Educational material

3.2.1 Design and Development of Content
We selected the topics and issues for the education package through a rigorous process which included (1) a comprehensive review of the literature and existing palliative care education materials; (2) interviewing pharmacists, nurses, Palliative care doctors and GPs, carers and other interested parties about community pharmacist involvement in palliative care, about what should be included in an education package and about how the package should work; (3) through an iterative consultation process with the experts on our project team; and (4) via feedback from the Pharmacy Guild Expert Advisory Group. The final result is an education package (portal) with four key modules each covering a range of salient topics and subtopics. After developing the topic outline, we worked closely with the educational design team to create a detailed list of learning objectives for each part of the package. We developed the objectives using Bloom’s taxonomy of learning objectives. The final learning objectives provide a standard to test against to ensure the package meets its objectives as a learning tool and as a reference point. We enlisted a group of expert content writers to create the content for the package. Each writer was provided with templates for the relevant sections. After each section draft was written, the section underwent a rigorous review process, with feedback sought from 3 to 7 expert reviewers for every section. The writers then revised the content in line with the reviewers’ feedback. Finally the project executive team approved the written content and it was passed on to a web-writer. The web-writer worked through the content to ensure it was appropriate for the internet and that it was written consistently throughout. Several sections did not gain the executive team’s final approval after the first round of review and revision; these sections were sent for a second round of review and revision until they met the team’s requirements.

3.3 Objective 3 & 4—Survey and Feasibility Trial

3.3.1 Survey Construction
In order to develop a valid survey instrument grounded in theory, we constructed the survey using Eagly, Mladinic and Otto’s attitude survey template, which is based on Zanna and Rempell’s tripartite model of attitudes. The model articulates that people’s attitudes are comprised of three distinct types of information: their knowledge and experience, their emotions, and their beliefs. Eagly et al.’s survey template has been used and published extensively, including in the palliative care arena. For instance, Cohen, O’Connor and Blackmore adapted Eagly et al.’s template to investigate nurses’ attitudes towards providing palliative care in nursing homes. They found that beliefs and emotions both independently predicted registered nurses’ attitudes, but knowledge did not. In other words, there was no evidence that providing these nurses with more information (and thus knowledge) about palliative care would affect their attitudes towards it; instead, the results suggested that in order to improve nurses’ negative attitudes, any education would need to target the nurses’ beliefs and feelings about palliative care. We adapted the survey template to make it appropriate for measuring community pharmacists’ attitudes towards providing palliative care.

We gathered feedback from the stakeholder advisory panel, the Project Advisory Panel and from pilot testing with several community pharmacists. We then refined the survey to make it more acceptable to the target audience. The survey is made up of five key parts. Firstly, the pharmacists were asked to rate their “attitude about providing services and supports for palliative care patients” using a 7-point scale ranging from -3 (“negative”) through to 3 (“positive”). In the Section 2, pharmacists were asked to report their beliefs about providing services and supports for palliative care patients.

The pharmacist could report up to six beliefs in his or her own words. The pharmacist then rates how positive or negative each belief is using a 7-point scale ranging from -3 (“negative”) through to 3 (“positive”). In Section 3 pharmacists could report up to six emotions they have about providing services and supports for palliative care patients, rating how positive or negative each emotion is in the same way. In Section 4, the pharmacist was asked to provide some personal information including his/her gender, location, how long they have been qualified and their experience in palliative care. Finally in Section 5, the pharmacist was presented with 20 knowledge statements about palliative care. For each statement the pharmacist was asked to indicate whether it is true or false or whether he or she is unsure of the answer. For example, one statement read, “Dexamethasone 16mg/day
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is a reasonable dose for treating decreased appetite and mood." Half of the statements were true and half were false.

There were two key differences between our final survey and the Eagly et al.’s original template. Firstly, the crucial attitude statement was changed from being a measure of a general attitude (e.g. towards palliative care) to be a measure about pharmacists’ attitudes towards personally providing services and supports for palliative care patients. Secondly, we reduced the number of available spaces for pharmacists to report their beliefs and emotions from 10 for each, to six for each.

To develop the statements for the knowledge section of the survey, experts from our research team suggested short true and false statements relevant to pharmacists’ knowledge of palliative care. We compiled the responses and sent the list containing 19 true and 24 false statements to the research team to rate the most appropriate for measuring pharmacists’ knowledge of palliative care. The survey research subgroup then selected the final 20 statements using these ratings and their own judgements to ensure the final set of statements covered the different domains of knowledge and were not repetitive.

3.3.2 Survey distribution

We used the website for the yellow pages online (www.yellowpages.com.au) to gather a random sample of pharmacies stratified by state. For each state we searched for “pharmacy” and the relevant state (e.g. “NSW”). We generated a random number between 1 and 9 (using www.random.org) to choose the starting point for each list. We recorded this first address and then every 7th address in an excel file. We posted surveys to the 1002 pharmacies identified using this procedure (Approximately 1/7 of the pharmacies listed in the yellow pages across Australia).

The surveys were addressed to “The Community Pharmacist” and the survey package included a cover letter, an information sheet, the survey itself, a complimentary tea bag, and a reply paid envelope. The survey was anonymous. We offered a $30 gift voucher for returning a completed survey. To receive the voucher, the pharmacist filled in an address slip at the bottom of the cover letter and posted it back with the completed survey.

We conducted two follow-up reminders using the phone numbers provided in the yellow pages. On the first reminder we asked pharmacists whether the survey had arrived and whether the pharmacist intended to return it. Pharmacists were also offered the option of returning the survey by fax or email if that suited them better. A number of pharmacists mentioned that they had misplaced the original survey, but would be happy to complete it if we resent it to them. In these cases a new copy of the survey was provided either by post, fax or email depending on the pharmacist’s preference.

3.3.3 Feasibility Pilot Study – Palliative Care Medication Management Review (PCMMR)

Twenty pharmacists completed a two-day palliative care training workshop; of which 18 took part in the pilot study. The study was conducted in metropolitan Perth and in the Albany and Bunbury regions. We worked with the clinical nurses at home hospice services in these locations. Figure 1 displays the study protocol. The clinical nurses identified eligible patients and completed a palliative care medication management review referral form. To be eligible for the study, patients must have been (1) receiving palliative care, (2) using five or more medications and (3) able to give informed consent to participate. The nurse’s referral was authorised by the hospice GP (or when there was no hospice GP, by the patient’s GP), and returned to the project team. The project team found a suitable accredited pharmacist (based on location and availability) to conduct the review and passed the referral on. Each accredited pharmacist could receive up to 10 referrals during the course of the study. A copy of the referral form was also sent to the patient’s GP and community pharmacist for reference (as members of the patient’s palliative care team) and to request basic medication records (e.g. prescription history) for the accredited pharmacist to conduct the review. Initially, the accredited pharmacists accompanied the nurses during one of the nurse’s regular visits to the patient’s home to conduct the review. However, it became clear that it was very difficult for the nurses to coordinate their home-visits with the pharmacists because it got in the way of the nurse’s need for flexibility (and as a result there was some reluctance from the nurses to refer patients). We changed the protocol so that instead of arranging to join the nurse on a home visit, the pharmacist contacted the nurse for any necessary information and then contacted the patient or carer directly to organize the visit for the review. The pharmacist visited the patient’s home and conducted the review. The pharmacist gave the patient a copy of the patient evaluation form to gather the patient’s views of the PCMMR and a reply-paid envelope to return the form directly to the researchers. To decrease any social pressure the patients may have felt to give positive responses, the evaluation form was completely anonymous and was not linked to the reviewing pharmacist in any way.
After the review, the accredited pharmacist wrote a report of recommendations and forwarded the report to the referring GP and the project team. The project team sent copies of the report to the rest of the palliative care team.

![Model protocol for palliative care medication management review](image)

*In locations with no hospice GP, the patient's GP will fill this role.

Figure 1: Model protocol for palliative care medication management review.

After the review, the pharmacists kept a diary of their ongoing contact with each patient. The follow-up period continued for a minimum of 4 weeks beyond the initial review. At the end of the follow-up period, we contacted a sample of the people involved in the pilot study (patients, carers, clinical nurses, hospice Palliative care doctors and GPs, Palliative care doctors and GPs, community pharmacists and accredited pharmacists) and invited them to take part in a follow-up exit interview about their experiences of the process. We gave those who participated in an interview a $30 gift voucher to thank them for their time. Pharmacists were remunerated at the standard rate for conducting a home medicines review (HMR) for the initial medication review. On completion of the study they were remunerated for the time spent beyond the initial review during the remainder of the study at a rate equivalent to conducting a second HMR. The referring Palliative care doctors and GPs were remunerated at the standard rate for referral HMR.

4. Results

4.1 Focus groups

4.1.1 Community Pharmacists’ Role in Palliative Care

Pharmacists clearly articulated a detailed and multifaceted role for themselves in the palliative care team. Pharmacists emphasised their ability to provide in-depth information and advice about symptom management, medications and their indications, their interactions, side effects, advice on medications that may no longer be needed, counselling the family on the use of medications, (including the practicalities of timing and administration, and maintaining a reasonable stock of medication for patients). Pharmacists also considered they could follow up patients after hospital discharge to ensure patients/carers had sufficient information about medications and were able to manage medications at home. They also saw their role as potentially providing extra information about medications to Palliative care doctors and Palliative care doctors and GPs and such a role became apparent in focus group discussions and interviews across Australia. For example:

...in the nursing homes, it's the GP that are, are running it and a lot of them don't really have the, the greatest knowledge of palliative care....so I think we could actually give them some advice on certain medications that we use, if we knew what we we're talking about. (Community Pharmacist Wollongong)

However, they did not see their role as being limited to medications and associated issues. They also perceived an important role in supporting patients and their carers by actively listening and offering advice, and by maintaining an ongoing relationship with the carer. They also considered that there was scope for their involvement in
supporting people with bereavement and loss in circumstances where they had an established relationship with the carer and his/her family. This focus on interpersonal support was especially important and was seen as a natural extension of their professional role, particularly where a longstanding relationship existed. This point was raised in a number of ways, but exemplified by a community pharmacist who suggested that if a community pharmacist has had a professional relationship over an extended period of time, he/she would not, in the patient’s ‘terminal moment’, be wanting to divest him/herself of the care.

It should be noted that although pharmacists did see an opportunity to provide interpersonal support, they also suggested that many pharmacists would need to develop better communication skills to fulfil this role (this finding is discussed further in Section 4.1.2 below on Pharmacists’ Needs and Supports). Pharmacists also suggested that they could play a role in sourcing items such as household aids. Finally, pharmacists felt that they were under-utilised as an accessible repository of community information, and given the appropriate support and recognition, they would be able to provide patients and families with useful information to address a much broader range of issues (for example where to go for financial advice or support services).

Although many pharmacists advocated a broader role in palliative care, some suggested that the best way for pharmacists to be involved in palliative care would be for some pharmacies to become specialised palliative care pharmacies:

> Or if, if there is a, for example, a system just like with Diabetes Australia wide which you know funds, supports certain pharmacies and for Diabetes supplies. And then you have other pharmacies for example that when a customer goes there for a, for a request, they usually say, “Oh go to that one, because that’s a Diabetes Australia Pharmacy. So if, if there’s like just a few pharmacies like that, say, you know, just specially for keeping, you know, palliative, more palliative care products and they’re registered for that, or even maybe subsidised more for that, then other pharmacies would, would know and say, if, if they have a customer with a request like that, they would be able to at least say, “Look, you know, we don’t keep it but this pharmacy, they is more specialised for these products and you can go there.” (Community Pharmacist, Perth)

Pharmacists suggested that as one of the most accessible health care professionals in the community they are central to a patient’s care, and as such their role could be extended significantly.

### 4.1.2 Needs and Supports for Pharmacists to become more involved in Palliative Care

The needs and supports that pharmacists considered they required to become more involved in palliative care were consistent across Australia and consistent between regional and metropolitan areas. Pharmacists placed surprising emphasis on the need to develop better communication skills – or as one community pharmacist described it “some kind of people skill” (Accredited Pharmacist, Melbourne). Pharmacists emphasised learning how to communicate when dealing with difficult questions, upsetting situations (such as when the carer brings back unused medications following the patient’s death) and implementing appropriate boundaries. For example:

> We [community pharmacists] don’t have that much, much knowledge in psychological help in what they go through and how they like, talk to them [patients/carers] and just not, not understand one hundred percent. It’s important, but we don’t know how to support them – how to communicate (Community Pharmacist Parramatta)

> I think that it, it’s easy, like I say, if someone brings in a script over the counter, for example…. Oxycodeone, it’s easy to dispense that, mention some side effects, but put that in the whole concept of palliative care, that, that prescription is part of, you know, this family has come in, they’ve got emotional concerns, they’ve got, you know, there’s a whole lot of other issues other, other than just handing that box over the counter. So I think pharmacists maybe sometimes find it hard to, to maybe confront that situation of the worried family member or even if the person who’s dying, has come in to pick up their own medication. So I think maybe they need some social skills and maybe… things to say to them which, which will somehow encourage or help them or strengthen them without sounding over patronising and saying, “Oh you know, they’ll be okay.” (Community Pharmacist Wollongong)

Pharmacists would also like to know more about palliative care medications, dosages, interactions and dose conversions. For example:

> I don’t think the majority of community pharmacists would have a, a too great a knowledge of the way drugs are used in palliative care. To be honest I, I remember when I, I, that my only real experience of
palliative care hospital was at Uni and I remember that things were used quite, quite differently than what they are otherwise, and I think that without looking it up in a book ... I wouldn’t know any of that off my head. So there needs to be a fair bit of education I would imagine. (Community Pharmacist Wollongong)

They also felt it would be extremely valuable to have a list of the essential medications to stock for palliative care patients and information about where to source the medications quickly. Pharmacists also wanted information about where they could find palliative care help and advice in an emergency (for example an emergency helpline for after-hours advice).

4.2 Educational Material

4.2.1 Pharmacy Palliative Care Portal

The pharmacy palliative care portal (PPCP) was designed as both an educational tool and information resource. It was clear from the focus groups that many community pharmacists favour experiential learning. To include interactive learning in the PPCP, we developed the Simulated Learning Space. This part of the PPCP consists of 12 simulated scenarios that require the pharmacists to draw on their knowledge to manage each situation and recommend a course of action. Each scenario touches on key issues across the four content modules of PPCP (demonstrating how the content of the education package is relevant to different situations) and emphasises the holistic approach involved in palliative care. The scenarios provide the ‘learners’ with an authentic task, encouraging them to test their skills at managing different situations that could arise in the pharmacy. The scenarios also model a process for pharmacists to work through the content in the portal and learn about different palliative care issues. For each scenario, the pharmacist watches a short video; the video stops at a situation that requires a response from the pharmacist. The pharmacist is asked to identify the main and possible peripheral issues presented, and use the available resources to prioritise and formulate a response and recommend a course of action. The pharmacist has the option of looking at the presenting prescription, looking at the dispensing history, asking the patient or carer questions, asking the doctor questions or looking up more detailed information in the content of the information resource. The question options have been designed to include both relevant and irrelevant questions. After devising a plan to address the situation, the pharmacist is able to “consult the experts”. They watch a video of a panel of experts discussing the key issues and the best course of action, and are then able to compare the experts’ responses to their own. Screen shots of four pages of the site are displayed in Figure 2 below.
Figure 2: Screen shots from PCPP.

The usability of the PPCP was evaluated using a tool developed by psychologists and available on-line at the Usability and User Experience Community. The evaluation was undertaken independently by three members of the project team and two others. The evaluators were required to assess the usability of the PPCP in relation to its functionality, format and presentation. Usability was scored on a scale of 0 to 4, where 0 = no usability problems and 4 = ‘catastrophic’ usability problems; thus the lower the score the greater the usability. The PPCP was displayed on a 20 inch computer screen and the evaluators given a tour of the resource by the web-developer. Questions were encouraged and evaluators were given the opportunity to explore the site following the presentation. The scores and evaluators comments were discussed with the usability expert and discussed with the web-developer for further comments. The group’s ratings were discussed with the web-developer following the completion of the evaluation and his comments sought on changes that could be made to the final product from the usability perspective. Those issues that were regarded as being more than a minor usability problem will be discussed in detail; 10 such issues were identified. The site was deemed to be user friendly and the changes required to the online version were relatively minor.

4.2.2 Pharmacist Survey

In total 250 completed surveys were returned. An additional 34 were returned by Australia Post because the pharmacy was no longer at the address given in the yellow pages, producing a final response rate of 26%. Given that pharmacists’ response rates are typically very low (for example Nation et al. reported a 10.3% response rate for their survey of pharmacists; this is deemed an acceptable response rate. Of the 250 completed responses, 114 were from females and 135 from males. The pharmacists ranged from 20 to 72 years of age, (M = 37 years, SD = 11.8). They had been qualified as pharmacists for between 0 and 50 years (M = 13.8 years, SD = 12.4), and working in community pharmacies for between 0 and 54 years (M = 14 years, SD = 11.3). The community pharmacies where the respondents worked employed between 0 and 12 additional pharmacists (M = 2, SD = 1.9). Table 1 provides a breakdown of the locations of the community pharmacies that the pharmacists worked in by State and Territory.

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</tr>
<tr>
<td>Western Australia</td>
<td>27</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>33</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>155</strong></td>
<td><strong>58</strong></td>
<td><strong>34</strong></td>
<td><strong>2</strong></td>
<td><strong>249</strong></td>
</tr>
</tbody>
</table>

Only 29 pharmacists reported having any training in palliative care, yet 121 pharmacists reported that they were currently providing services and supports for palliative care patients. Additionally 92 pharmacists reported having personal experience in palliative care (for example caring for a relative). A substantial proportion of the sample reported that they had not seen any palliative care patients in the previous 12 months (n = 48, 19%). Conversely, four pharmacists reported seeing 100 palliative care patients in the previous 12 months and one pharmacist reported seeing 500. Excluding these five pharmacists from the analysis, on average pharmacists reported seeing 6.7 palliative care patients over the previous 12 months (SD = 9.7).

4.2.2.1 Pharmacists’ attitudes towards providing services and supports for palliative care patients

Most pharmacists reported having a positive attitude towards providing services and supports for palliative care patients. Of the 232 responses to this question, all but 11 pharmacists rated their attitude on the positive side of the scale (95%). The remaining 11 unanimously rated their attitudes as neutral (5%). Given this skewed response the, pharmacists’ average attitude rating was summarised as positive (M = 2.3, SD = 0.82). We found no evidence that pharmacists were reluctant to be involved in the provision of palliative care.
4.2.2.2 Pharmacists’ beliefs about providing services and supports for palliative care patients

Pharmacists listed between 0 and 6 beliefs about providing services and supports for palliative care patients, \((M = 4.7, SD = 1.4)\). In total, the pharmacists reported 1159 beliefs. Despite their positive overall view of providing services and supports for palliative care, pharmacists rated some of their beliefs on all parts of the scale, with ratings ranging from -3 through to 3. We collapsed the more and less positive ratings, and the more and less negative ratings to calculate the proportion of positive and negative ratings overall. Pharmacists rated 21\% of their beliefs as negative \((n = 246)\), 4\% of the beliefs as neutral \((n = 45)\) and 75\% of their beliefs as positive \((n = 868)\), suggesting that while pharmacists were aware of negative aspects of palliative care the positives outweighed the negatives.

4.2.2.3 Pharmacists’ knowledge about palliative care

We calculated an overall score of each pharmacist’s performance on the 20 true and false statements as a measure of their knowledge and understanding of palliative care. The pharmacists’ scores were low, with scores ranging from 2 to 16 questions correct (10\% - 80\%), with an average score of 9.5 questions correct out of 20 (SD = 2.9). These 20 facts were selected because they were seen as essential for community pharmacists working with palliative care patients to know; the pharmacists’ poor performance highlights the need for palliative care education targeted towards pharmacists.

There was some evidence that the pharmacists were aware of their limited palliative care knowledge. More specifically, the pharmacists were asked to respond “unsure” for any statement that they could not answer. Overall, the pharmacists gave between 0 and 14 “unsure” responses \((M = 4.7, SD = 2.9)\). On average pharmacists’ were unsure about the truthfulness of 24\% of the statements, suggesting that they recognised the gap in their knowledge of palliative care.

These results illustrate that pharmacists have a good understanding about some aspects of palliative care. For example, 209 pharmacists (84\%) correctly rejected the suggestion that medication needs take priority over spiritual needs, and 203 pharmacists (81\%) recognised that medications may be used for different indications and at different dosages in palliative care. However, the responses highlight a number of areas where pharmacists lack knowledge about palliative care. For example, 156 pharmacists (63\%) reported being unsure about the evidence for combining drugs in syringe drivers, 165 (66\%) were unsure whether sleep reversal is a common experience for palliative care patients and 95 pharmacists (38\%) were not sure whether withholding opioids until the patient was in severe pain was a good idea. Finally, the results identify some common misconceptions about palliative care. For instance, the majority of the sample \((n = 226, 90\%)\) thought that all palliative care patients would experience depression, and 171 pharmacists (68\%) thought that the major focus of palliative care is managing pain at the end of life. These latter results support findings from the focus groups.

4.3 PCMMR Feasibility Pilot Study

In total we received 48 MMRPC referrals; 36 were from Perth, six were from Bunbury and six were from Albany. The patients ranged in age from 8 years to 85 years \((M = 65.7, SD = 14.5)\). According to the referral forms, the patients experienced between 0 and 7 of the common palliative care symptoms listed \((M = 2.3, SD = 1.8)\), and with 65\% of the sample \((n = 31)\) experiencing multiple symptoms. It is important to note that on a number of referrals the symptoms section was left blank; thus we cannot be sure whether the section was overlooked or whether those patients had none of the symptoms listed. As such, the numbers above provide a conservative estimate. In fact, it was common for the sections of the initial referral form to be left entirely blank, and this led us to shorten the form for the Perth referrals later in the project. The initial form was three pages long and had 12 sections to complete, and the revised form was two pages long with 9 sections. Only 7 referrals had something written in every section; the remainder had between 1 and 7 blank sections. On average, 19\% of the sections on the referral form were left blank \((SD = 14.9)\). However, it is not clear whether the information was being overlooked, whether it was not available or whether it was irrelevant for the patient. It would have been useful to have a box at the top of each of the section to be marked when a given section is not relevant for the patient or when the information required was not available. In total, 46 referrals included a list of the patient’s current medications; these referrals listed between 5 and 20 current medications, with an average of 10.5 medications per patient \((SD = 2.8)\) suggesting that most patients easily met the HMR eligibility criteria of taking five or more medications.

4.3.1 Medication reviews

Three patients died before their PCMMR could be scheduled, two patients withdrew from the study prior to their review due to deterioration in their health, and a further two patients withdrew before their review without stating a
reason. Another one referral did not provide sufficient information, leaving a total sample of 40 patients who completed the study.

Pharmacists were contacted based on the match between the patient’s and pharmacist’s location, and availability. Of the 18 pharmacists recruited for the study only 13 conducted medication reviews. Another two received referrals, but the patients withdrew prior to the review. The remaining three pharmacists did not receive (or accept) any referrals. The 13 pharmacists who did conduct reviews, conducted between 1 and 9 each (M = 3.1, SD = 2.3). One pharmacist withdrew from the study after conducting one review as they felt they were inadequately prepared. It should be noted on expert review, the case was deemed to be too complex for an HMR pharmacist.

It took between 2 and 30 days from the time the patient signed the consent form for the referral to be completed, the review conducted and the pharmacist to send their report to the referring doctor (M = 10.6 days, SD = 6.0). This timeline was much longer than we had anticipated. A number of reviews were delayed because the patient’s health deteriorated and the review was put off until their health improved again. However, there were also delays in the referral form being completed and signed off by the doctor, in finding a pharmacist to conduct the review, and in the pharmacist scheduling a suitable appointment with the patient. Some pharmacists also regretted that they had difficulties obtaining contact details for the patient.

Typically the medication lists provided on the pharmacists reports were longer than those provided on the referrals, \( M_{\text{Referral}} = 10.5 \) medications (SD = 2.8), \( M_{\text{Report}} = 11.4 \) medications (SD = 3.6). Although this is a small difference it was statistically significant, \( t(38) = 2.11, p = 0.04 \), suggesting that the PCMMR reports consistently included additional medications that the referrer was not aware of. Additionally, many of the PCMMR reports listed medications that were prescribed but no longer being used (M = 1.7 medications, SD = 1.7, Range = 0 – 7). Often these redundant medicines had been included on the referral list of current medications, supporting the idea that pharmacists can play an important role in assessing exactly what medications are being used.

### 4.3.2 Pharmacists’ recommendations

Pharmacists provided between 0 and 9 recommendations/issues per patient in their reports to the doctor (M = 3.6, SD = 2.0). In total, they made 145 recommendations.

We sent the reports to experts on the project team to rate their clinical significance. The raters were A = pharmacist, B = pharmacist, C = GP, D = pharmacist, E = pharmacist and F = GP. For each report, the experts were asked to consider the overall clinical significance of the report, providing a rating using a 7-point scale ranging from -3, “negative,” to 3, “positive”. After rating the overall clinical significance of the report, the experts were asked to rate the clinical significance of each of the recommendations individually, using the same scale. We also asked them to provide explanations of their ratings if they felt it was appropriate. We calculated a final rating for each report and each recommendation by taking the mean of the experts’ ratings for each part. The mean ratings for the individual recommendations ranged between -1.0 and 2.7, (M = 1.2, SD = 0.69). The majority of the mean ratings were positive; two were negative and six were neutral. Although the combined ratings of the reports were typically positive, there was a lack of consistency between the individual raters. For instance, one recommendation was rated -2 by one expert and 3 by two others. To generate a rough estimate of how similar the experts’ ratings were, we calculated correlations between each of the six raters. We found three significant correlations. First, rater E and A gave the most similar ratings \( r = 0.46, p < 0.05 \); rater A’s ratings were also correlated with rater B’s ratings although to a lesser degree, \( r = 0.24, p < 0.05 \), and finally rater B’s ratings were correlated with rater F’s ratings, \( r = 0.41, p < 0.05 \). These different relationships might suggest that the raters’ different experience and roles were leading them to evaluate the reports and recommendations in different ways. For example, while some of the experts may have rated “clinical significance” in terms of what recommendations were made and what was missed out, others may have rated in terms of whether the suggestions made would be useful to the doctor, or whether the changes would make a difference for the patient. These differences highlight that there are multiple outcomes from an HMR and a number of different ways of examining effectiveness.

### 4.3.3 Pharmacists’ interaction records

There was much less contact following the PCMMR than anticipated. Only three pharmacists returned diaries with interactions recorded in them at the end of the study, with the majority reporting that they simply did not use the diaries. Two pharmacists recorded details of the review in their diaries but because this information was not about follow-up contact, it was not included in the analyses.
Altogether, there were 17 interactions recorded in the three diaries; the interactions related to 13 different patients. The interactions took between 1 minute and 15 minutes (M = 6.3 minutes, SD = 4.7). Eight interactions were initiated by pharmacists (47%), and these were typically to check-up on the patient following the review or to provide additional information that was requested during the review. Seven interactions were initiated by palliative care specialists (41%) who discussed the report and recommendations with the pharmacist. Two reports were initiated by carers who asked questions of the pharmacist. Two interactions resulted in a change in medication—increasing the dose of pain medication for pain that was not well controlled—but otherwise the follow-up contact was mainly focused on sharing or requesting information. It was originally thought that a number of patients would require further interaction with the pharmacist during the follow-up period (post-review) and remuneration for this post-review contact was set as the cost of a follow-up review to adequately remunerate the pharmacist for their time. In light of the low level of contact during the follow-up period, and the variable time commitment, the appropriate level of remuneration for the follow-up component of the PCMMR still needs to be determined.

4.3.4 Patient evaluations of PCMMR

The forms for patients’ evaluations of the medication reviews had two parts. In part one the patients were presented with seven statements about the medication review. For example, one statement read, “I feel more comfortable about taking my medications”. For each statement the patient rated how much he or she agreed (or disagreed) using a 5-point Likert scale ranging from 1 “strongly disagree,” to 5, “strongly agree,” where 3 was “neutral.” In the second part of the evaluation, patients were asked to provide comments about the review.

In total, 25 evaluations were returned (of 40, 62.5%). The patients were generally very positive about the medication review with the mean responses falling between “agree” and “strongly agree” on the rating scale (see Table 2).

Table 2: Patients’ ratings of evaluation statements

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The pharmacist provided me with information about my medications</td>
<td>4.36 (0.86)</td>
<td>1–5</td>
</tr>
<tr>
<td>2. I was able to ask the pharmacist questions about my medications.</td>
<td>4.72 (0.46)</td>
<td>4–5</td>
</tr>
<tr>
<td>3. The pharmacist helped me to understand my medications better.</td>
<td>4.36 (0.91)</td>
<td>1–5</td>
</tr>
<tr>
<td>4. I feel more able to manage my medications.</td>
<td>4.20 (0.87)</td>
<td>1–5</td>
</tr>
<tr>
<td>5. I feel more comfortable taking my medications.</td>
<td>4.16 (1.03)</td>
<td>1–5</td>
</tr>
<tr>
<td>6. I felt comfortable talking to the pharmacist.</td>
<td>4.80 (0.41)</td>
<td>4–5</td>
</tr>
<tr>
<td>7. I would contact the pharmacist again to ask questions about my medication if I needed to.</td>
<td>4.64 (0.49)</td>
<td>4–5</td>
</tr>
</tbody>
</table>

The small ranges for statement 2, statement 6 and statement 7 highlight that all patients felt comfortable talking to the pharmacist, were able to ask questions of the pharmacist and were willing to contact the pharmacist in the future. For the remaining statements, some of the lower responses came with comments emphasizing that people felt they already understood their medications. These ratings may have been more a reflection that some patients were already very well informed rather than a reflection of unsatisfactory input from the pharmacist.

The final question on the evaluation asked patients whether they had any comments about the review. Of the 25 responses received, 18 provided comments (72%). The comments were coded into one of five pre-determined categories: (1) positive, (2) neutral, (3) negative, (4) providing information or (5) making a suggestion for improvement. In total, 15 comments (83%) were coded as positive. For example, one comment read “It was very comforting to someone actually sit down with me and go through my meds”. One comment was coded as providing information, as it simply provided a description of the outcome of the review and doctor’s subsequent intervention. One comment was a suggestion, “It would have been helpful to receive a post meeting letter reviewing the meeting and advising of further steps/options”. The final comment was coded as neutral. This comment read, “We don’t have any issues with our medications. We have been on the same ones for 15 months. We know if we have a problem we can contact a pharmacist.”

In summary, the medication reviews were a positive experience for patients and the majority left patients feeling more informed and better able to manage their medications.
5. Discussion

Objective 1:
To identify the palliative care needs of community-based palliative care patients and their carers and families at different stages of their illness.

The needs of people towards the end of life have been extensively outlined in the literature. People experience very different trajectories. Some people spend a long time in a relatively stable condition only to deteriorate dramatically in the final days of life. Others remain very ill for a long period of time before finally succumbing without a great deal of change in their condition. Most people die in hospital even though people consistently express the wish to die at home. It was evident from the data that pharmacists are already significantly involved with patients towards the end of life. Two specific issues were highlighted as essential to high quality palliative care; pain management and psychosocial care. The need for these exists notwithstanding the involvement of a specific professional group. Recognized reasons for failure to alleviate pain relate to the prescriber's knowledge of analgesics and their failure to tailor the regimen to the needs of the patient. This means that pharmacists, with their knowledge about medicines and an established relationship with the patient or carer, have a significant role in helping people to die in comfort and dignity. We note that 50% of the patients involved in our feasibility trial reported that they were experiencing pain before the involvement of the pharmacist. Associated with this is the potential for iatrogenesis in a population that often requires multiple drug treatments. In practice we found inconsistencies in the feasibility trial between the list of drugs the patient was prescribed at the time of referral for the PCMMR and the drugs that the patients had at their disposal. This confirms that this group of patients are at risk from adverse drug reactions by virtue of drug interactions and/or patients' lack of knowledge about their medications.

Pharmacists did not see their role as limited to advising on medications and associated issues. Death and dying are frequently associated with significant psychosocial morbidity for patient, carer and family. Pharmacists also identified as part of their role, supporting patients by listening and providing general advice when needed, and by maintaining an ongoing relationship with carers of the dying person. This was underscored by the fact that people are often familiar with the pharmacist and if been in contact with him or her on many occasions before the final phase of their illness.

The effect of a terminal illness may be exacerbated in circumstances where the professional advisors are not attuned to the need in these circumstances. A prerequisite is an established relationship between all those affected by the illness and experienced professionals with whom they may come into contact. This issue was highlighted in the survey of pharmacists in which only a minority of pharmacists reported having any training in palliative care, yet almost half the respondents claimed that they were currently providing services and support for palliative care patients. Additionally, a substantial proportion of pharmacists reported having personal experience of palliative care (for example, caring for a relative). A significant proportion of the sample reported that they hadn’t cared for any palliative care patients in the previous 12 months. In the focus groups respondents expressed a lack of understanding about palliative care by non-palliative care pharmacists. They reported that this lack of understanding and knowledge could lead to their colleagues feeling out of their depth. Although most pharmacists were aware that palliative care relies on a team approach, some were unsure about exactly what professional groups were contributing or indeed what formal role they might play in the care of patients who had been clearly identified as close to the end of life.

Findings from the focus groups indicated that carers usually had a close relationship with their community pharmacist and went to them for advice about medications and aids. Many carers articulated a 3-way relationship between themselves, their community pharmacist and their GP, indicating that they already regarded the community pharmacist as part of their palliative care team. The exit interviews at the end of the PCMMRs supported these findings and indicated high satisfaction with the reviews completed. The reviews provided education as well as knowledge. The carers and patients said they felt that the pharmacist had time whereas the GP often was rushed and needed to deal with many different aspects of care.

Recommendations:

1. Pharmacist education and training in palliative care needs to be increased, both at undergraduate and postgraduate levels. Pharmacists need to be well prepared to deal with the complex issues which arise amongst those patients whom they often already know and are now under palliative care. Up-to-date
knowledge of the indications, doses, route of administration and other aspects of pharmacology of drugs used in palliative care is required. Pharmacists need to be formally introduced to the palliative care philosophy and practice and they must be prepared to deal emotional needs of the patients and their carers, and be provided with coping skills to deal confronting situations which arise in palliative care. To achieve this representation needs to be made to a range of education providers, including Schools of Pharmacy, to address these needs.

Objective 2:
To develop an educational package for community pharmacists in order to provide enhanced care to palliative care patients.

In summary one might say that the primary role of community pharmacists in palliative care is to ensure the safe supply and use of medication and to act as a source of advice for patients. For this activity to be practised more widely the palliative care approach needs to be adopted and therefore taught to a wider group of pharmacists than is currently the case. We also note from the literature that effective palliative care is predicated on inter-professional collaboration. Palliative care requires pharmacists, physicians, nurses, social workers, psychologists, counsellors, occupational therapists, chaplains and, at times, psychiatrists to work together to create a supportive framework of care for patients and their families.

The extent to which allied health professionals are able to work collaboratively will determine the extent to which community based teams can provide timely support that responds to changes in the patient’s physical condition and his/her changing goals. The practice of collaborative health care can be challenging as each team member may have different “framework of understanding”. In the focus groups pharmacists placed great emphasis on the need to develop better communication skills – or as one community pharmacist described it “some kind of people skill”. Pharmacists emphasised refining communication skills when dealing with difficult questions, upsetting situations (such as when the carer displays emotional distress when they return unused medications following the patient’s death) and implementing appropriate boundaries. We noted that very limited or appropriate, tailored information is currently available to train community pharmacists in palliative care. In the focus groups and interviews there was consistency about what pharmacists thought they needed to learn to facilitate their involvement in palliative care. The key issues—symptom management, palliative care medications and communication skills—came up repeatedly. Each of these domains was therefore incorporated in the development of our Pharmacy Palliative Care Portal.

Pharmacists were very clear that they prefer experiential learning: learning by doing rather than learning by reading. Hence the incorporation of case studies with expert panel discussions in the PPCP. In terms of knowledge, the survey of pharmacists offered particular insights. Pharmacists were clearly aware of their limited palliative care knowledge suggesting that they recognised their limited expertise in palliative care, even in the medication management domain, a field in which they could legitimately claim mastery. Therefore a clear outcome of this study was the recognition that more involvement in palliative care will only be possible after formal induction in the philosophy and practice of palliative care, but also after updates on the indications, doses and interactions of drugs used to manage symptoms at the end of life.

The portal has the potential to be used to educate pharmacists in palliative care through a number of ways:

- As a just-in-time resource to assist pharmacists in reviewing patients’ prescriptions, providing advice on symptom management, and to provide drug information and patient education
- As a comprehensive self-directed educational package for continuing professional education
- As a foundation for undergraduate and postgraduate university palliative care curricula, or as an adjunct to formal undergraduate and postgraduate education.

We believe the PPCP will provide an excellent resource for those accredited pharmacists who engage delivering reviews to patients under palliative care. Incorporation of multiple choice questions (MCQs) related to material in the portal could be included in the suite of MCQs that are required to be completed by pharmacists as part of their initial accreditation assessment or as part of their reaccreditation.

Recommendations:

2. The PPCP needs to be formally evaluated as a resource for pharmacists in a number of practice settings. This evaluation should include the following: an assessment of the usability of the portal, frequency of use
of the portal (e.g., number of visits to the website, the bounce rate and pages visited) and its impact on the knowledge of pharmacists who access the resource (e.g., based on changes to self-assessment test scores).

Assuming that the results of the evaluation of the portal are positive then consideration will need to be given to the following:

- **Hosting and Maintaining of the Portal**
  - The PPCP will require continuous updating, which will require dedication of further funds. The upkeep of the PPCP will require a team approach; the team will require a project manager, content experts, reviewers and a web designer with Moodle® expertise.

- **Access to the Portal by Pharmacists, Other Healthcare Professionals and Education Providers**
  - The range of people who will have access to the portal needs to be determined; these may include community pharmacists, accredited pharmacists, hospital pharmacists, doctors, nurses, and academics.
  - At a minimum the PPCP should be available in all community pharmacies. Two possible options to achieve this would be to provide the portal free of charge or mandate that the portal is accessible in all community pharmacies and provide it on annual licence fee.

**Objective 3:**
To identify what barriers might prevent community pharmacy involvement in palliative care and what supports are needed to facilitate involvement.

A key prerequisite for high quality palliative care is a team approach with effective collaboration between doctors, nurses, pharmacists and those able to provide specialist psychosocial care. Therefore, a significant barrier to the involvement of pharmacists in palliative care relates to their acceptance as a contributor to the patient’s care. The feedback through the focus groups highlighted many of the current barriers to the involvement of the pharmacist.

Palliative care doctors and Palliative care doctors and GPs were ambivalent about engaging pharmacists without experience in palliative care, claiming that pharmacists would not be able to fully understand the patient’s and carer’s needs. Many pharmacists in the focus groups reported that trying to get more information about a patient from the GP was difficult. This reluctance to share information may have reflected a determination to preserve confidentiality or an attempt to limit the involvement of a professional who was not perceived as having a significant contribution to make. Some pharmacists did not feel as though they were part of the palliative care team—in part because they were not physically present on the team—but also felt that that other health care professionals did not really recognise or understand the pharmacist’s role in end of life care. Palliative care doctors and GPs who were interviewed stated that they did not see the value of MMRs generally and PCMMRs specifically. Palliative care doctors and GPs felt they were the key professionals caring of their patients and, if they needed support in any area related to medications, they would ask the pharmacist directly. Many Palliative care doctors and GPs in the feasibility pilot of PCMMRs did not participate or refer any patients. Communication between Palliative care doctors and Palliative care doctors and GPs and pharmacists needs to be improved and supported.

Nurses were also reported significant variability in pharmacists’ understanding of palliative care and especially their understanding of the urgency of the patient’s needs. Some nurses speculated that the variability was largely due to the pharmacists’ underlying attitudes and experience, or lack thereof, in palliative care. There were particular concerns around the experience of relatively young pharmacists. Nurses also noted that the palliative approach was not well understood even by experienced health care professionals and questioned how community pharmacists would engage given their lack of experience.

On the other hand carers in this study suggested that many non-palliative care pharmacists grasped and embodied some of the key principles of palliative care. For example, pharmacists seemed to intuitively understand the central role of the patient and the carer. They were aware of the need to support patients and their families at all stages of the patient’s illness. A key finding of this study was that pharmacists may underestimate their involvement and importance at the end of life because they perceive the skills they display as integral to their usual service, rather than skills that are specific to serving people in palliative care.

The results of the national pharmacist survey identified some common misconceptions about palliative care. We have already alluded above to the lack of training materials available to up skill practitioners appropriately. The Pharmacy Palliative Care Portal has been specifically designed to increase pharmacists’ understanding of palliative care.
care. The workshop, which was developed to prepare accredited pharmacists to participate in the PCMMR pilot study, was centred on case based problem solution session was also successful in significantly improving pharmacists’ knowledge and skills. However, such workshops are merely a starting point and there is a need for regular updates and mentoring. A key finding of this study is the need for continuing education. The survey also revealed that beliefs and knowledge significantly and independently predict attitudes to the provision of palliative care. This is a positive finding as we can work with these aspects via the PCPCP, up-skilling pharmacists and dispelling myths.

The need for timely medication reviews presents another barrier to the involvement of pharmacists in the care of palliative care patient as evaluated in the feasibility trial. It was hoped that the PCMMR model, with the palliative care nurse as the person identifying patients suitable for review and facilitating the initiation of a referral from the doctor, the referral process would speed up. However, this was not always the case. It took between 2 and 30 days from the time the patient signed the consent form for a referral to be completed, the review to be conducted and the pharmacist to send their report to the referring doctor. This timeline was longer than we had anticipated. Delays arose for a number of reasons: delays in the referral form being completed and endorsed by the doctor, delays in finding a pharmacist to conduct the review, and in the pharmacist scheduling a suitable appointment with the patient and, in a number of cases, due to the patient’s health deteriorating. These procedural and pragmatic factors are likely to impact on a wider extension of a scheme dependent on medication management reviews. Therefore one cannot conclude that PCMMRs are necessarily the best or only way to engage pharmacists. Significant human factors impact on the smooth operation of such a scheme. However, this is the only process that allows remuneration for formal in put in palliative care. This issue could be addressed by remodelling the way services are funded; either when tailoring patient medicine regimens or attending to the patient or carer’s need for advice or information. Hiring the pharmacist as a consultant could also be an option. Funding for any new model would need to be streamlined.

Finally, there were factors that were much more closely associated with the business of pharmacy. Pharmacists were concerned about stocking palliative care medications for a variety of reasons. Some were worried about stocking restricted medications in case they became a target for burglary. Others were loath to stock medications or supplements with a short shelf life or medications that were packaged in large quantities, believing that they would never dispense all the stock and would have to suffer financial losses. Similarly, pharmacists said if they stocked everything that palliative care patients might need, there would be limited scope to stock other items. Additionally community pharmacists were concerned that they had no way of knowing whether patients would require a particular medication, and hence they are not able to plan to either have the stock in the pharmacy, or to be able to access appropriate stocks quickly. Similarly, to provide a complete service to palliative care patients, pharmacists felt they would need to be familiar with and stock aids and devices specific to palliative care including catheters and specialised dressings. Pharmacists were concerned about the opportunity cost of being involved in palliative care. Time was a barrier also because of the need to invest time acquiring new knowledge. Community pharmacist also expressed concerns that a low level of exposure to palliative care patients made it difficult to maintain specific knowledge and skills. Therefore the demand for and materials required to participate in palliative care remained a significant barrier. Many pharmacists suggested that there could be pharmacies that specialised in palliative care. Patients, carers and nurses would be able to utilise the services of these specialised pharmacies and other pharmacists in the community would be aware of where to send people in emergencies.

**Recommendations:**

3. There needs to be systemic support for greater communication between pharmacists, palliative care doctors and GPs. Alongside education for communicating with carers and patients, there should be education for communicating with other health professionals in the palliative care team, particularly Palliative care doctors and GPs. The opportunities for inter-professional education based around case study reviews should be increased in an attempt to enhance communication between Palliative care doctors and GPs and pharmacists.

4. The benefits of the involvement of the community pharmacist and accredited pharmacist on the palliative care team needs to be clearly communicated and marketed to other health professionals. The pharmacist’s potential role needs to be delineated from that of the GP.

5. Education for palliative care should be ongoing and include professional development, top up training and mentoring.

6. Consideration needs to be given to the establishment of specialised palliative care pharmacies. This would help overcome supply and stocking difficulties and also ensure that community pharmacists involved have a positive attitude and a palliative care supply and stock plan. Reimbursement for investment, such as safe storage, needs to be considered as well as remuneration for palliative care services.
Objective 4: To identify specific needs in relation to medication management services and to develop medication management reviews tailored to the needs of palliative care patients (PCMMR).

Several key elements are required to engage pharmacists in palliative care through the MMR process. It requires pharmacists to feel confident and supported, to ensure that there is financial remuneration for the time invested and agreement in the local community that allows the pharmacist to make a contribution that could benefit the patient and their carers. As for the other recommendations, in detail these include: training as described in the workshop exercise above; consultation with the local medical practitioners and palliative care providers such that there is an agreement to request a PCMMR; a process whereby the required documentation is not held up by the need for detailed referral notes. Despite these arrangements the recruitment of patients to this pilot had a limited success.

We set out to recruit 150 people and despite project champions at each site we got less than a 1/3rd of this number. Some of these limitations were related to the time required to get multiple ethics committee approvals for our research project. However even when the study was in full flow there was failure to record data in the required format and some information could not be included in the final analysis. It is evident from the exit interviews that some medical practitioners refused to order a PCMMR, some nurses were put off by the paperwork and indeed three pharmacists in our cohort of 18 did not receive (or accept) any referrals. It was also evident that some referrals did not provide enough information to proceed with a PCMMR. This may relate to the misgivings about involving pharmacists as discussed above or it may reflect on the need for documentation and form filling which added to the bureaucracy of a remunerated and auditable process.

It is to be anticipated that some patients will not be referred in time because they die before their PCMMR is due or withdraw due to deterioration in health. It is also possible that a suitable pharmacist may not be available locally. The pharmacists involved in this study were trained and mentored by a specialist palliative care pharmacist. Unfortunately none had access to the PPCP as this was not available until later in the project. Within our trial with 18 pharmacists, only 13 conducted medication reviews. It may also take longer than anticipated to get the PCMMRs done for clinical reasons but also because of the delays in getting the signed and correct documentation to the relevant trained pharmacist.

Notwithstanding, the issues raised above, having the palliative care nurse identify the potential patients for review was an effective triage method. The final endorsement for the request was by a medical practitioner. As some doctors refused to refer patients identified by the nurse for review, having the nurse authorise the review would have increased the number of referrals received. Patients and carers consented to the PCMMR so we question whether it supports patient choice to have the review authorised only by a medical practitioner.

There were a number of issues that impacted on the pharmacist’s confidence in the review process. Administrative issues played a large part in causing frustration on occasion. This ranged from having to contact nurses for details that were omitted from the referral and unexpected delays in the review process. In some cases there was also confusion about where to lodge the pharmacist’s report. The format of the report was unclear and failed to indicate where to log details. As is commonly the case with HMRs, critical information was often missing on the patient referral forms including the patient’s current medications and laboratory test results. These issues are generic to the MMR process and not specifically related to PCMMRs. The pharmacist had to rely on the patient or the nurse for this information and often could not make recommendations without further information about diagnosis or medical history.

Some pharmacists felt that more training (top up training) was needed on specialist medications and some relied on other experts to offer suggestions or reassurance. One pharmacist did not feel they could add to the existing expertise on the palliative team. Some participants also felt that their involvement had minimal impact on patient care. Given that this was a feasibility trial, and that many of the pharmacists involved had little prior experience with palliative care patients, it is not surprising that they questioned their value to the team, however with more experience we would predict that this self-assessment of worth would change.

In general, patients and their carers reported that they benefitted from contact with a pharmacist through the PCMMR process. However it had been thought that patients and/or their carers, and the palliative care nurses and doctors would have engaged with the pharmacists more after their initial PCMMR. In fact the rate of post-review interaction was low, and almost half of the interactions (47%) were initiated by the review pharmacist. It was encouraging that 41% of the interactions were initiated by the general practitioners, pointing to an increase in pharmacist-doctor interaction in the course of the study. Two of the interactions were initiated by carers, who were seeking assistance with the patient control of their patients, which indicates an acceptance of the pharmacists’
expertise in this area. Whilst much of the follow-up interaction was focused on sharing or requesting information, this is to be expected in what was a feasibility of an innovative service. As a rapport develops between pharmacist and patient, and the pharmacist and other health care professionals, we anticipate that that frequency and level of post-review interactions would increase.

**Recommendations:**

7. Communication between health care professionals engaged in the medication management review process must be improved. Standards need to be established and implemented in regards to the format and quality of patient referrals and pharmacists’ review reports, to ensure effective and efficient communication. Investment in information technology (IT) solutions to improve both these phases of the medication management review process is strongly recommended.

8. Significant changes are required to the medication management review model to facilitate the widespread roll out of the PCMMR service. These changes should included modifications to the referral process to allow carers, nurses (with suitable remuneration), palliative care doctors and GPs to refer patients directly to a suitably credentialed accredited pharmacist. A remuneration model needs to include payment for both the initial medication management review and follow-up support. As PCMMR service matures it is anticipated that all those involved will develop a greater rapport that engagement of the pharmacist post the initial review will increase significantly. Follow-up is essential and the PCMMR service should be remunerated at a rate equivalent to two HMRs. Education should emphasise follow up.

9. Attitudinal barriers which limit GP willingness to refer patients for medication management reviews must be addressed both at a personal level and a professional level. Establishment of good personal relationships between pharmacists, Palliative care doctors and GPs will help foster greater collaboration, and this would be aided by the introduction of direct referrals from Palliative care doctors and GPs to accredited pharmacists. At a professional level inter-professional education activities which engage all healthcare professionals involved in the palliative care team need to be established.

**6. Conclusions**

Our review of the literature clearly demonstrated that community pharmacists are engaged with people under palliative care. Traditionally, community pharmacists ensure the supply and safe use of medication and the provision of advice to patients and their carers. However, their role often extends to psychosocial support of patients and their families. Still many community pharmacists feel that they are ill prepared to deal with patients under palliative care, citing lack of knowledge and the required communication skills as barriers to the delivery of more advanced care. This perceived lack of knowledge, both of the palliative care process and the medications used in palliative care, was also identified by palliative care nurses when interviewed about the role of the community pharmacist.

In the area of medication supply we discovered that patients and their carers were generally happy with the service provided by their community pharmacists, however, palliative nurses expressed concern about the availability of medications and a lack of urgency by community pharmacists to procure medications which not in stock. We also found that community pharmacists identified a number of barriers to stocking medications used in palliative, both logistical and financial. This issue needs to be addressed, and policies and procedures need to be developed and implemented to ensure all palliative care patients have ready access to their medications. Specialist palliative care pharmacies are one way of ensuring best practice in this area.

To address the need for education we developed the Pharmacy Palliative Care Portal, a comprehensive, web-based palliative care resource. The PPCP may be used as an information resource by community pharmacists in their review of prescriptions for palliative care medications, and to assist in providing advice on medication use and symptom control for palliative care patients. It may also be used as an education tool. The PPCP contains four domains; palliative care philosophy, communication skills, symptom control and medication use. It also includes 12 interactive cases, each of which may be used assist pharmacist develop their problem solving skills in the area of palliative care. The resource should prove invaluable to community pharmacists in the provision of pharmacy services to palliative care patients. We also envisage that the PPCP could become an important component of the palliative care curriculum of undergraduate and postgraduate pharmacy courses across Australia.

It is important to appreciate at this time that the use of the PPCP has not been evaluated in community pharmacists across Australia. Further, a decision as to who will host the portal is yet to be made. The PPCP will require
continuous updating, which will require a commitment of further funds. The upkeep of the PPCP will require a team approach; the team will require a project manager, content experts, reviewers and a web designer with Moodle® expertise. As all community pharmacists are likely to become engaged with patients under palliative care in some way, we believe access to the PPCP should be available in all community pharmacies. This could be achieved by providing access to the PPCP free of charge, or mandating that pharmacies have access to the PPCP through the national registering body, and sale of licences to use the portal. To encourage educational institutions to use the portal it is suggested that access to the PPCP should be provided free of charge.

The PCMMR feasibility trial aimed to examine whether the role of the pharmacist could be extended in palliative care through the medication management process. The PCMMR model adopted a collaborative approach in which palliative care nurses were used to identify patients suitable for the service and to facilitate referral by their GP. Whilst, we were unable to recruit the planned 150 patients into the trial, we were able to demonstrate that suitability trained accredited pharmacists could deliver a service which was seen to be beneficial by patients and their carers, the palliative care nurses and Palliative care doctors and GPs. The trial identified a number of areas which need to be addressed to facilitate the widespread roll out of the PCMMR service. These include the need for advanced training for accredited pharmacists wishing to participate in this area of practice, together with ongoing support and mentoring.

A revamp of the referral process which would allow both nurses (with suitable remuneration) and Palliative care doctors and GPs to refer patients directly to a suitably credentialed accredited pharmacist are essential to improve the uptake of the medication management reviews. There is need for standards for both patient referrals and pharmacist review reports to ensure effective and efficient transfer of patient information. We suggest investment into suitable IT solutions to facilitate the implementation of these standards. Uptake of the service will also be dependent on breaking down the barriers which limit GP willingness to refer patients for medication management reviews. This can be achieved on an individual basis through by pharmacist establishing a relationship with the GP and this will be helped by direct referrals. This should be addressed at a professional level through an increased focus on inter-professional education activities.
7. References
