# After-hours palliative care pilot projects

## health

## **Evaluation**

### **Overview**

In July 2009 the Department of Human Services (now Department of Health) appointed the Palliative Care Research Team at Monash University (Monash) to develop an evaluation framework for the after-hours community palliative care pilot projects, to assist in the evaluation of the pilot projects, and to provide recommendations for the recurrent allocation of funds.

In particular, Monash evaluated:

- to what extent the aims of the pilot projects were met
- to what extent the assessment criteria for the proposals were met
- to what extent implementation occurred in a sustainable manner
- initiatives that were transferable to other regions
- unexpected gaps and challenges that arose and strategies undertaken to address these.

## Background

Access to after-hours palliative care has been a requirement for all community palliative care services since 1997. The department's *Policy and funding guidelines* define business hours as normally falling between 7 am and 4.30 pm Monday to Friday, not including public holidays. All other times are 'after hours'. The guidelines also state that these policies and procedures should be included as part of a palliative care consortia-wide framework for after-hours palliative care.

Palliative care consortia were established in 2004 in all departmental regions. The role of the palliative care consortia is to:

- undertake regional planning in line with departmental directions
- coordinate palliative care service provision in each region
- · advise the department about regional priorities for future service development and funding
- in conjunction with the Palliative Care Clinical Network:
  - implement the service delivery framework
  - undertake communication, capacity building and clinical service improvement initiatives.

There was no clear agreement about the most appropriate after-hours care model for the state. In March 2009 the department funded two pilot projects to identify the models and elements of an after-hours service that could be rolled out to other services across the state. The pilot project period ended in June 2011.

#### Pilot project area 1 (PPA1)

PPA1 comprised services from Eastern Metropolitan Region Palliative Care Consortium (one service), Barwon South Western Region Palliative Care Consortium (one service) and Hume Region Palliative Care Consortium (five services).

PPA1's objective was to develop a regional framework for delivering after-hours palliative care services that were responsive to the needs of registered palliative care clients 24 hours, seven days a week. The service model used an existing telephone triage service based at Caritas Christi Hospice.



#### Pilot project area 2 (PPA2)

PPA2 comprised services from Grampians Region Palliative Care Consortium (four services) and Loddon Mallee Regional Palliative Care Consortium (seven services).

PPA2's objective was to develop an after-hours palliative care service model appropriate for rural areas. This included addressing issues such as ensuring the model was accessible and cost-effective, increasing client and family knowledge, and the ability to manage predictable symptoms by improving care planning, addressing staff safety issues and up-skilling non-palliative care trained staff.

## **Evaluation**

Prior to beginning the evaluation, approval was sought from 11 human research ethics committees responsible for the 18 participating palliative care service providers.

A process evaluation framework utilising a mixed-methods design was employed in the evaluation. Process evaluation examines the planning and implementation of the strategies and interventions, and their impacts and outcomes (Eagar et al. 2001). Sources of information included reviewing the project protocol, and documents and records, as well as conducting site visits, surveys/interviews/focus groups with stakeholders and consumers, and monitoring progress. Stakeholders who participated in the evaluation process included service provider management, service provider staff, palliative care clients and their carers, triage staff, project officers and project managers. In particular, data was collected in relation to:

- service providers (demographic and model implementation data and the views of senior staff)
- the experience of staff providing nursing care for clients and carers
- the experience of clients and carers
- the experience of staff providing a triage service
- the perspective of the pilot project officers and project managers.

#### **Evaluation activities**

The evaluation activities took place over six different areas of the pilot projects:

1. Individual service provider contributions included:

- VINAH baseline data from the 12 months prior to the pilot projects commencing (due to data collection issues it was not possible to compare this data with VINAH data collected during the pilot project period)
- Site-specific baseline data from a questionnaire completed by service managers
- a semi-structured interview with pilot project service managers (or other appropriate senior staff) about the impact of the project implementation at their work site, its outcomes, challenges and sustainability.
- 2. Clients and carers contributed their experience via:
  - questionnaires that explored their experience of after-hours service prior to the pilot project's commencement
  - nurse follow-up calls the day following after-hours service asked the client/carer's permission to complete a phone questionnaire about their experience following the implementation of the pilot project intervention.
- 3. Staff providing palliative care nursing participated in a baseline questionnaire and a post-pilot project questionnaire.
- 4. Triage staff (when an after-hours triage service was available following the implementation of the pilot projects) provided information about their experience of and satisfaction with the triage service.
- 5. Project managers and project officers were interviewed at the end of the pilot project period to explore their experience of undertaking the projects, their perceptions of the challenges and outcomes, and their views about sustainability and transferability of the models of after-hours care that they had implemented.
- 6. Project documents developed by the pilot projects were also examined.

#### Collaboration between Monash and the pilot project teams

Collaboration between Monash and the pilot project teams occurred on three levels:

- site visits by the Monash project officer to approximately half of the participating service providers
- regular working group meetings attended by the Monash project officer, the two pilot team project officers and the department project officer
- reference group meetings, chaired by the department, held six times during the pilot project period.

## **Evaluation outcomes**

The evaluation outcomes are presented according to the five key evaluation questions listed below. Where the outcomes differ for the two pilot project areas the questions are addressed separately for each pilot project. Where the outcomes were the same in both pilot projects they are addressed together.

#### To what extent have the aims of the pilot projects been met?

#### PPA1

PPA1's aims were to:

- 1. map, review and compare service components within the existing service system across the three regions
- 2. map and review client pathways for after-hours care across the three regions
- identify key strengths and innovative service approaches to inform collaborative planning, policy development and practice standards
- 4. identify any existing gaps and potential opportunities to address these, through pooling and mobilising interregional resources
- 5. collect and collate consistent data at all stages of the project and across all settings, including qualitative and quantitative input
- 6. using an action research approach within an inter-regional partnership identify, recommend, and where possible, facilitate collaborative, evidence-based strategies to optimise equitable client access to after-hours palliative care services.

The first three aims were achieved. This is supported by the documents published in PPA1's final report, which included process diagrams for each region, regional guidelines for providing after-hours services through the Caritas Christi Hospice triage service, interpreter guidelines, an ambulance contact flow chart and a management process in relation to addressing complaints.

The fourth aim was largely achieved prior to beginning the pilot project. The interview with the project officer and project manager confirmed their awareness of other gaps not specifically listed in PPA1's original proposal including: after-hours access to medications in rural areas; staff shortages and lack of palliative care trained staff; inconsistent software; and the low profile of palliative care in small rural services.

The fifth aim was met and is evidenced by the documentation provided that attempts were made to collect and collate data consistent with all stages of the project.

The final aim was met.

#### PPA2

PPA2's aims were to:

- 1. provide an accessible, cost-effective and equitable service through a nursing telephone triage service for the two rural regions
- 2. increase family and patient knowledge and capability to manage predictable symptoms after hours through standardising and implementing documentation and advance care plans across the region
- 3. address issues relating to staff safety in rural areas
- 4. up-skill non-palliative care nurses
- 5. develop treatment plans for the most common palliative care emergencies.

Significant effort and collaborative consultation went into meeting the first aim. At the end of the pilot project the pre-existing nurse triage service based in a local hospital had been refined and other palliative care services were linked in. In addition, after-hours nurse triage services were being trialled in two other local hospitals to which more than one service was linked.

Documentary evidence supported the work done towards achieving the second aim. The *Patient and carer manual* includes information and education material, process guidelines and checklists for staff to ensure each client and carer is assisted in an equitable and consistent manner.

Issues of distance, lack of mobile phone access, poor roads and inconsistent practices for making after-hours visits provided a considerable challenge to meeting the third aim. Interviews with service managers indicated that some services had refined and standardised their practice in relation to after-hours palliative care. This eliminated risks for nurses who had previously attended clients unofficially after hours or provided their private telephone number.

The fourth aim was met via the workshops, information sessions and the training session for nurses involved in providing triage services that were conducted during the pilot project. Documentation developed included telephone triage protocols for common emergencies and a CD with a self-directed learning package.

The final aim was achieved. Documentation developed included guides for clients and carers and care plans for staff, designed to prepare for predictable challenges. These documents were designed to allow flexibility for adaption to local service requirements and conditions.

#### To what extent have the assessment criteria been met?

The extent to which the two pilot project groups met the assessment criteria is addressed under the following points:

- the after-hours care model its planning, implementation, structure, components and delivery
- contextual factors relevant to the operation of the service model and the resources used
- the stakeholders their characteristics and perceptions of the after-hours care model
- level of community awareness of after-hours palliative care.

#### The after-hours care model – its planning, implementation, structure, components and delivery

#### PPA1

The focus of PPA1's work was to evaluate, refine and extend the uptake of an existing that which centred on a large after-hours nurse triage service located at Caritas Christi Hospice. The uptake of this service, prior to the implementation of the project varied across the participating consortia.

PPA1 was organised and supported by an active working group. Planning and implementation focused on:

- evaluating the service in those areas already using it, including the functioning of the triage service and indentifying gaps in the service
- working to extend the uptake of the service, particularly in the Hume Region.

PPA1 provided the following evidence that action was taken to address gaps:

- guidelines for interpreters to address the challenges of a multi-lingual population, especially in the metropolitan services
- a masterclass training program for palliative care triage nurses and updated triage guidelines
- streamlining the triage service to better accommodate the needs of differing areas by providing specific regional guidelines and process flow charts.

Evaluation data suggested that the main reasons for lack of uptake in Hume region were:

- poor communication between the triage service and local palliative care providers
- the perception that 'city people' did not understand rural conditions
- the perception that people receiving palliative care wanted to speak to staff they knew
- lack of compatible electronic databases making patient information transfer difficult.

Evaluation data confirmed that PPA1 attempted to address these difficulties by:

- facilitating meetings (by teleconference) between triage and service provider staff
- standardising client information forms
- establishing a process of faxing patient information and the outcomes of each triage service call.

Interviews with service managers and the triage staff questionnaires suggested variable success with these measures. Each group reported that the other should know more about their needs and challenges, and some respondents reported the new system to transfer data worked well, while others considered it created more work. However, respondents did acknowledge that in some areas an improved after-hours system was in place, eliminating earlier practices that risked nurse health and safety. Evaluation data showed that while there was little change in staff satisfaction with after-hours service provision there was a marked increase in staff perception of client satisfaction with the service provided.

Overall, data indicates that the PPA1 assessment criteria were met regarding the planning, implementation, structure, components and delivery of the model of after-hours care.

#### PPA2

The focus of PPA2's work was to develop a model of after-hours service provision that would be appropriate for a rural area where service providers are often understaffed both in terms of numbers and qualifications in palliative care. An after-hours triage service was available for one of the participating services prior to the pilot project, although several other services had some on-call access to nurses, usually only available to those people receiving palliative care who were considered likely to need after-hours care.

PPA2 was supported by a management group; however, there was some disruption to this as a result of staffing changes. Despite these challenges PPA2 was well planned and implemented. The PPA2 timeframe was difficult to maintain for several reasons including the need for significant project officer cooperation and collaboration with the service providers and the substantial flooding that took place in large parts of the project area in early 2011.

PPA2 developed a standard, legally appropriate set of protocols, guidelines and templates that were flexible enough to allow adaptation to a range of rural services. The capacity to connect with general health providers such as general practitioner (GP) groups and local hospitals was also important in establishing after-hours triage services.

While there were delivery challenges such as staff resistance to change, the need for multiple versions of documents, the culture of stoicism among clients, and the importance of contact with the staff well known to clients, data indicates that the PPA2 assessment criteria were met regarding the planning, implementation, structure, components and delivery of the model of after-hours care.

#### Contextual factors relevant to the operation of the service model and the resources used

#### PPA1

The contextual factors of the PPA1 model include a central after-hours palliative care triage call centre located in a metropolitan inpatient hospice servicing a wide range of palliative care providers over a large area of the state, which has been addressed in the previous section.

The resources used by PPA1, apart from a project officer (0.5 EFT), included funding for a delegated triage nurse, questionnaires, document production, preparation of the masterclass content and teleconference facilities for communicating with service provider teams. It is possible that a greater allocation of resources to more personal contact with service provider teams, especially those in rural regions, may have resulted in a greater impact on those services; however, there is no definitive data available in this regard.

#### PPA2

Contextual factors included a mostly rural area with two large regional cities, one pre-pilot project after-hours triage service and other on-call availability provided by local service providers. In most cases palliative care was provided as a small part of local healthcare services.

The resources used by PPA2 enabled a project officer (0.8 EFT) to undertake significant travel and make personal contact with local service providers and initiate genuine action research by participating services, with a goal to establishing local ownership, and to research and develop guidelines and manuals. This process was dependent on one person who empowered many local services to take on changes. While the process was laborious, resources were put to good use in terms of developing changes that are likely to be sustainable.

#### The stakeholders - their characteristics and perceptions of the after-hours care model

#### PPA1 and PPA2

#### Staff members

Data about the characteristics of pilot project service providers' staff members, including information about their involvement in after-hours service provision, showed that in both project areas there was a higher percentage of responses from staff working in rural areas. PPA2 staff reported that the service had improved as a result of the pilot project, although in both areas relatively low response rates made definitive conclusion difficult. A contributing factor was that the PPA2 model, which started from a lower base, resulted in more changes including providing access to an after-hours call service in some places that previously had none. Another pertinent consideration was that in both project areas, but particularly in PPA2, time constraints meant that follow-up questionnaires were distributed soon after the pilot projects' implementation. Perceived gaps in the service and suggestions for improvement remained similar in both pilot project areas across the baseline and follow-up questionnaires. There was some anecdotal evidence that call numbers were reduced in PPA2 as a result of improved client education and more comprehensive care planning during regular office hours. A more accurate assessment of real outcomes could only be achieved after six to 12 months.

#### Triage staff

PPA1 triage service nurses were generally more experienced and more qualified in palliative care than those in PPA2. This is not surprising considering the different contextual factors, in particular that the triage service in PPA1 was a dedicated palliative care service, whereas in PPA2 the triage services were of a general nature and mostly attached to small local hospitals. PPA1 staff reported the changes initiated by the project had resulted in some improvement in the after-hours care provided, while almost half of those in PPA2 did not think there had been improvement. Two factors may have impacted on outcomes in PPA2: lack of time for an impact to be observed (changes had only recently been implemented and a very low number of calls received); and most triage staff were not palliative care nurses and did not work with patients requiring palliative care other than to answer after-hours calls. Monash assessed it was too early to identify definitive outcomes for triage staff; however, the assessment criteria were met in terms of refining existing triage processes in PPA1 and in establishing new after-hours triage services in PPA2.

#### People receiving palliative care

The characteristics of clients and carers (pre-project implementation) were similar in both project areas regarding age, awareness of service contact details, use of the service in the previous three months, and type of advice received. PPA2 clients were more likely to have been less satisfied with the service and more likely to have experienced difficulty contacting the service. Contextual differences in large parts of the two project areas most likely explain these differences. PPA1 follow-up data indicated a high level of satisfaction with the service provided, similar to satisfaction pre-project. PPA2 data was not available due to the later implementation of project changes, widespread flooding at the time of collection and lower after-hours call numbers.

#### Level of community awareness of after-hours palliative care

#### PPA1 and PPA2

A number of factors (such as the timeframe and the availability of funding for evaluation, a larger participating cohort than was originally envisaged, and the early resistance of services to evaluation from outside their immediate staff and clients) precluded the option of approaching local community groups such as GPs and community centres about their awareness of the pilot projects and the impact on after-hours community palliative care options in their community.

Data from questionnaires reported that in both pilot project areas there was a high awareness among clients of the existence of some form of after-hours care and how to access it. Staff awareness of the pilot project and its implementation varied across all levels of staff, including at the senior staff level. Questionnaires indicated that almost one-quarter of PPA1 staff members were not aware of the pilot project compared with PPA2, which reported higher staff awareness of the pilot project. PPA2 data could be a result of the project officer's higher level of personal contact with staff and higher levels of staff involvement in developing local implementations. It may also reflect the different focus of the two projects: PPA1's focus was to enhance an existing triage service, whereas PPA2's focus was to initiate an after-hours service delivery model. The data suggests that both pilot projects met the assessment criteria for staff awareness.

#### To what extent has implementation occurred in a sustainable manner?

The evaluation did not establish whether the after-hours care models were financially sustainable primarily because most of the participating services did not identify exact funding amounts spent on after-hours care prior to the pilot projects beginning. The issue of sustainability was also investigated through the interviews with service provider managers (or key personnel), pilot project officers and managers.

#### PPA1

One service provider was very confident that implementation within their service would be sustainable because they considered the service had a simple, well-integrated system that was supported by good communication with the triage service provider. Other service providers reported that the new model was probably sustainable, noting that issues that may work against sustainability included staff shortages, ongoing funding concerns and the importance of maintaining a 'key contact' person in the triage service.

The project manager also identified funding issues (such as dedicated triage staff, back-fill for staff attending training and a designated triage service staff member to maintain records, deal with issues arising and maintain developing relationships between the triage service and the palliative care service providers) as a key factor in the sustainability of project implementation. In addition, the masterclass for palliative care triage staff required ongoing funding, and data suggested the program would be more sustainable if linked to palliative care nurse practitioner training.

#### PPA2

Three service managers interviewed were confident that the new model was sustainable because it had arisen from an identified need and the changes were well embedded into their service. Two service managers reported that the changes were unlikely to be sustained in their service because, in their view, the demand for after-hours services did not justify the additional work involved in the new system. Other managers reported the project was potentially sustainable; however, there were issues that needed to be addressed, including additional funding for ongoing education programs for service staff and ambulance officers. Ongoing palliative care consortia support was also considered vital to the sustainability of the new after-hours care model.

The project officer reported that the manner in which the pilot project was developed in each service was key to the model's sustainability, that is, significant emphasis was placed on empowering local staff to consider their particular needs, solve their own problems, and consult the project officer as required. Services participated in a workshop about introducing new practices into well-established services and a training handbook and CD was produced. Consortia support and endorsement of a five-year audit of documents to ensure the service kept pace with developing needs was noted as a factor in sustaining the model.

This data suggests that a champion within each palliative care consortia is an important sustainability factor, particularly in the early phases of model implementation and in ensuring appropriate reviews are undertaken.

#### Are the initiatives transferable to other regions?

#### PPA1

Service managers in PPA1 reported that the model was transferable to services in metropolitan and larger regional areas but would face difficulties in rural and remote services. They noted that new models are easier to introduce in a new service, whereas in longstanding services the introduction may involve changing existing practices. Rural and remote areas also face issues regarding the availability of training and backup, appropriate numbers of trained staff, and distance.

The project manager noted that services considering adopting this model (especially large ones) would require software compatible with the triage service provider, as well as good service management and accreditation. If the triage service was expanded to other palliative care service providers funding for dedicated triage staff and increased funding for after-hours by palliative care service providers would also be beneficial.

#### PPA2

Most service managers interviewed reported that the model was transferable to services of similar size and especially those in rural areas. The availability of triage training and documentation, which is sufficiently flexible to meet the needs of small services, was seen as important in enabling transferability. The lack of compatible software and some staff members' resistance to change were seen as inhibitors to transferability.

The project officer stressed that the single most important factor in ensuring successful transferability of this model was the presence of a champion prepared to spend time in the early phases building rapport with the service staff and empowering local ownership of the model.

#### What strategies have been undertaken to address gaps and challenges that arose?

#### **PPA1 and PPA2**

Both project area teams identified gaps in after-hours service provision prior to commencing the pilot project. These included: incompatible software; shortages of trained staff, especially in rural area; low GP participation; and lack of medication availability after hours (especially in rural areas). Most of these issues were beyond the scope of the pilot projects; however, PPA2 made progress with the medication issues, including GPs taking up care plans to ensure medication availability for predicable crises. Challenges identified included the following.

- Staff were resistant to change because some staff perceived the changes would bring more work for minimal benefit, while others perceived that existing practices did not require changing. A sense of working together and owning the new changes, brought about by efforts to meet with and understand the specific needs and circumstances of the individual service, was particularly evident in PPA2.
- There were gaps in staff and client education, which were addressed through the introduction of education packages and training processes.
- Communication between healthcare providers was an issue, although it was improved through standardising patient care plans and establishing patient data transfer protocols (such as between palliative care service and GPs and/or triage service providers). Standardisation of software would help address this issue and could involve significant practice change.

 1800 numbers cannot be accessed by pre-paid mobiles, potentially eliminating the capacity of some people receiving palliative care to access the after-hours call service. No immediate solution to this challenge was identified.

The evidence suggests that the two project areas addressed challenges both pre-existing and arising during the pilot project period in an appropriate manner. Some challenges require long-term attention by government and were beyond the capacity of the pilot projects to address.

## **Recommendations**

Monash did not identify one after-hours care model that would be appropriate statewide; however, the following recommendations were made:

- ongoing education of triage nurses and palliative care service providers about how to most effectively use the triage service
- provision of compatible software statewide, particularly for services utilising a central triage service (without this, an expansion of the central telephone triage service would be difficult)
- staffing levels to incorporate the visible presence of a person dedicated to maintaining good communication between the triage service and palliative care service providers (the general triage model would require this person to facilitate development in the early stages).

In summary, a central after-hours palliative care telephone triage service is most suitable for large service providers that have software compatible with the triage service provider, while a local general triage service model is most suitable for smaller rural services. Further evaluation of both models in 12 months' time would provide important supportive data.

## Appendix 1: Evaluation data

## People receiving palliative care - baseline data

#### Demographic data

| Response rate for each project area and location of patient baseline respondents |  |          |            |            |            |  |  |  |  |  |
|--|--|----------|------------|------------|------------|--|--|--|--|--|
|  | Total no. sent Total returned Response rate Metropolitan Run |          |            |            |            |  |  |  |  |  |
| PPA1   | 409  | 94       | 23%        | 57 (60.6%) | 37 (39.3%) |  |  |  |  |  |
| PPA2   | 271  | 73       | 26.8%      | 3 (4.1%)   | 70 (95.9%) |  |  |  |  |  |
| Age distribution of patient respondents  |  |          |            |            |            |  |  |  |  |  |
|  | Under 40   | 41–50    | 51–60      | 61–70      | 70+        |  |  |  |  |  |
| PPA1   | 2 (2.1%)   | 6 (6.4%) | 11 (11.7%) | 26 (27.7%) | 49 (52.1%) |  |  |  |  |  |
| PPA2   | 3 (4.1%)   | 1 (1.4%) | 11 (15%)   | 24 (32.8%) | 34 (46.6%) |  |  |  |  |  |
| Who is completing the  | Who is completing the questionnaire?                         |          |            |            |            |  |  |  |  |  |
|  | Patien   | t        | Carer      | ·          | Total      |  |  |  |  |  |
| PPA1   | 48 (51.6   | %)       | 45 (49.4%) |            | 93         |  |  |  |  |  |
| PPA2   | 44 (61.1   | %)       | 28 (38.9%) |            | 72         |  |  |  |  |  |

#### Awareness of after-hours service and frequency of use

| Do you know how to   | contact the after-ho   | urs service?   | ?          |            |                |         |          |                |       |
|--|------------------------|----------------|------------|------------|----------------|---------|----------|----------------|-------|
|  | Yes                    |                | No         |            | Unsure         |         | )        | Total          |       |
| PPA1   | 82 (88.2%)             |                | 3 (3.2     | %)         | 8              | (8.6%   | 5)       | 93             |       |
| PPA2   | 62 (84.9%)             |                | 6 (8.2     | %)         | 5              | (6.9%   | b)       | 73             |       |
| Have you used this a   | fter-hours service ir  | the past?      |            |            |                |         |          |                |       |
|  | Have used t            | he service i   | n the p    | oast       | Have           | e not u | sed the  | service in the | past  |
| PPA1   | 4                      | 8 (51.6%)      |            |            |                |         | 45 (48   | .4%)           |       |
| PPA2   | 3                      | 33 (45.2%)     |            |            |                |         | 40 (54   | .8%)           |       |
| If you have not used   | this after-hours serv  | vice in the p  | ast – w    | /hy not?   |                |         |          |                |       |
|  | Did not know           | about it       |            | Did not    | need it        |         |          | Other          |       |
| PPA1   | 1 (2.2%                | <b>b</b> )     | 44 (95.6%) |            |                |         | 1 (2.2%) |                |       |
| PPA2   | 2 (4.49%               | 6)             |            | 36 (87     | 7.8%) 3 (7.3%) |         |          |                |       |
| If you have used this  | after-hours service    | in the last tl | hree m     | onths – he | ow many        | times   | have you | used it?       |       |
|  | > once in one<br>night | Once           | •          | Tw         | Twice          |         | -5 times | > 5 ti         | mes   |
| PPA1   | 0                      | 25 (52.1       | %)         | 10 (20     | ).8%)          | 10      | (20.8%)  | 3 (6.3         | 3%)   |
| PPA2   | 0                      | 16 (45.7       | '%)        | 10 (28     | 3.6%)          | 7       | (20%)    | 2 (5.          | 7%)   |
| If you have used this after-hours service in the last three months – when was your last contact? |                        |                |            |            |                |         |          |                |       |
|  | In last week           | La             | st 2 w     | eeks       | In la          | st moi  | nth      | 1–3 months     | s ago |
| PPA1   | 9 (18.8%)              | 7              | 7 (14.6    | 5%)        | 11 (22.9%)     |         | 6)       | 21 (43.7%)     |       |
| PPA2   | 8 (23.5%)              | 5              | 5 (14.7    | '%)        | 7 (20.6%)      |         |          | 14 (41.2       | .%)   |

#### Reason for calling after-hours service, type and quality of service received

| The main reasons for calling the after-hours service (all applicable reasons recorded) |          |            |            |               |            |  |  |  |  |  |  |  |
|--|----------|------------|------------|---------------|------------|--|--|--|--|--|--|--|
| Pain Nausea/vomiting Medication Visit request or Other                                 |          |            |            |               |            |  |  |  |  |  |  |  |
|  |          |            | issues     | feeling worse |            |  |  |  |  |  |  |  |
| PPA1 (n = 48)  | 26 (54%) | 11 (22.9%) | 15 (31.3%) | 3 (6.25%)     | 10 (20.8%) |  |  |  |  |  |  |  |
| PPA2 (n = 35)  |          |            |            |               |            |  |  |  |  |  |  |  |

| What help did you receive when you rang the after-hours service (all recorded)? |                   |                  |                    |                   |                    |              |  |  |  |  |
|---|-------------------|------------------|--------------------|-------------------|--------------------|--------------|--|--|--|--|
|   | *Telephone        | Telephone        | Home visit         | Advice to go      | Advice to          | Other        |  |  |  |  |
|   | advice only       | advice in        |                    | to hospital       | contact GP         |              |  |  |  |  |
|   | -                 | total            |                    |                   |                    |              |  |  |  |  |
| PPA1  | 19 (40.4%)        | 20 (63.8%)       | 16 (34%)           | 10 (21.3%)        | 2 (4.3%)           | 1 (2.1%)     |  |  |  |  |
| PPA2  | 9 (25.7%)         | 20 (57.1%)       | 13 (37.1%)         | 10 (28.6%)        | 4 (11.4%)          | 1 (2.9%)     |  |  |  |  |
| *These patients only re   | ceived telephone  | advice and no o  | other service invo | olvement resultir | ng from contacting | g AH service |  |  |  |  |
| Did the after-hours se  | rvice help you m  | anage better?    |                    |                   |                    |              |  |  |  |  |
|   | Ye                | s                | ١                  | ۱o                | T                  | otal         |  |  |  |  |
| PPA1  | 46 (95            | 5.8%)            | 2 (4               | .2%)              |                    | 48           |  |  |  |  |
| PPA2  | 30 (85            | 5.7%)            | 5 (14              | 4.3%)             | 35                 |              |  |  |  |  |
| Did you have any diffi  | culties contactin | ig the service?  |                    |                   |                    |              |  |  |  |  |
|   | Ye                | S                | ١                  | lo                | Т                  | otal         |  |  |  |  |
| PPA1  | 1 (2              | %)               | 47 (               | 98%)              | 48                 |              |  |  |  |  |
| PPA2  | 4 (11.            | .4%)             | 31 (8              | 8.6%)             | 35                 |              |  |  |  |  |
| How would you rate y  | our satisfaction  | with the after-h | ours service?      |                   |                    |              |  |  |  |  |
|   | Excellent         | Good             | I Sati             | sfactory          | Poor               | Total        |  |  |  |  |
| PPA1  | 29 (60.4%)        | 17 (35.4         | l%)                | 0                 | 2 (4.2%)           | 48           |  |  |  |  |
| PPA2  | 22 (62.9%)        | 7 (20%           | 6) 2 (             | 5.7%)             | 4 (11.4%)          | 35           |  |  |  |  |
| Would you use the aft   | er-hours service  | again?           |                    |                   |                    |              |  |  |  |  |
|   | Ye                | s                | Ν                  | ۱o                | Т                  | Total        |  |  |  |  |
| PPA1  | 45 (95            | 5.7%)            | 2 (4               | .3%)              | 47                 |              |  |  |  |  |
| PPA2  | 32 (91            | .4%)             | 3 (8               | 5.6%)             |                    | 35           |  |  |  |  |

#### Carer satisfaction with the after-hours service

| How would you rate your satisfaction with the after-hours service? |                    |             |              |          |       |  |  |  |  |  |
|--|--------------------|-------------|--------------|----------|-------|--|--|--|--|--|
|  | Excellent          | Good        | Satisfactory | Poor     | Total |  |  |  |  |  |
| PPA1   | 29 (63%)           | 10 (21.7%)  | 5 (10.9%)    | 2 (4.4%) | 46    |  |  |  |  |  |
| PPA2   | 18 (53%)           | 10 (29.4%)  | 3 (8.8%)     | 3 (8.8%) | 34    |  |  |  |  |  |
| Did the after-hours se   | rvice help you man | age better? |              |          |       |  |  |  |  |  |
|  | Yes                |             | No           |          | Total |  |  |  |  |  |
| PPA1   | 43 (93.5           | %)          | 3 (6.5%)     |          | 46    |  |  |  |  |  |
| PPA2   | 31 (91.2           | %)          |              | 34       |       |  |  |  |  |  |

## People receiving palliative care – follow-up data

#### Patient/carer telephone follow-up questionnaire

| Reasons for                         | Reasons for seeking after-hours assistance |                     |                                 |             |                |              |   |              |   |  |                            |  |
|-------------------------------------|--|---------------------|---------------------------------|-------------|----------------|--------------|---|--------------|---|--|----------------------------|--|
|                                     | Pain                                       | Nausea,<br>vomiting | Breathlessness                  | Medication  | -, , ,         |              | agitated symptoms, constipation<br>advice, blood, unw<br>change |              | Died,<br>constipation,<br>blood, unwell | Wou<br>consciou<br>collap<br>psychos<br>hosp | isness,<br>ose,<br>social, |  |
| PPA1 –<br>%<br>response<br>(n = 59) | 32.2                                       | 18.6                | 10.2                            | 10.2        | 10.2           | 8.5          | 8.5   | 5.1          | 3.4 each                                | 1.7 e  | ach                        |  |
| PPA2                                |  |                     | ow-up data not<br>n early 2001) | possible du | e to low retur | n rate (most | likely du   | e to the imp | pact of wides                           | pread flo                                    | oding                      |  |
| Level of sa                         | atisfact                                   | ion with            | the after-hours                 | s service   |                |              |   |              |   |  |                            |  |
|                                     | Excellent Good Satisfactory                |                     |                                 |             |                |              | Poor  | oor Total    |   | ]  |                            |  |
| PPA1                                |  | 3                   | 33 (58.9%)                      | 18 (32.     | 1%)            | 4 (7.1%)     |   | 0 (0%)       | 1 (1.8                                  | 8%)  | ]                          |  |
| PPA2                                |  | n/a                 | a                               |             |                |              |   |              |   |  |                            |  |

## Staff providing palliative care data

| Did you consult a hea             | Ithcare professional wh                | en working after hours                  | ?                                      |   |
|-----------------------------------|--|---|--|---|
|                                   | PPA1 baseline – %<br>response (n = 30) | PPA1 follow-up – %<br>response (n = 18) | PPA2 baseline – %<br>response (n = 42) | PPA1 follow-up – %<br>response (n = 17) |
| Yes                               | 69.8                                   | 57.5                                    | 74.6                                   | 85                                      |
| If you get advice from            | healthcare professiona                 | I – which healthcare pro                | ofessionals?                           |   |
| GP                                | 43.3                                   | 50                                      | 64.3                                   | 82.4                                    |
| Medical specialist                | 43.3                                   | 44.4                                    | 38.1                                   | 47.1                                    |
| Senior nurse (from<br>my service) | 33.3                                   | 55.6                                    | 21.4                                   | 35.3                                    |
| Other colleague                   | 40                                     | 27.8                                    | 35.7                                   | 23.5                                    |
| After-hours triage nurse          | 43.3                                   | 50                                      | 19                                     | 11.8                                    |
| What are the reasons              | you have consulted wit                 | h other healthcare profe                | essionals after-hours?                 |   |
| Symptom control                   | 76.7                                   | 77.8                                    | 73.8                                   | 88.2                                    |
| Request for admission             | 50                                     | 44.4                                    | 66.7                                   | 82.4                                    |
| Medication query                  | 66.7                                   | 61.1                                    | 47.6                                   | 52.9                                    |
| Psychosocial<br>support/needs     | 23.3                                   | 5.6                                     | 2.4                                    | 5.9                                     |
| Client service coordination       | 30                                     | 22.2                                    | 26.2                                   | 17.6                                    |
| Have you ever had an              | y trouble getting in touc              | ch with other healthcare                | professionals?                         |   |
| Yes                               | 26.7                                   | 33.3                                    | 38.1                                   | 61.1                                    |
| No                                | 73.3                                   | 66.7                                    | 61.9                                   | 35.3                                    |

| Have you experienced any general problems in delivering after-hours services if you have to make a visit? |  |   |  |   |  |  |  |  |  |  |  |
|---|--|---|--|---|--|--|--|--|--|--|--|
|   | PPA1 baseline – %<br>response (n = 30) | PPA1 follow-up – %<br>response (n = 30) | PPA2 baseline – %<br>response (n = 42) | PPA1 follow-up – %<br>response (n = 18) |  |  |  |  |  |  |  |
| No problems<br>experienced  | 20                                     | 40                                      | 31                                     | 33.3                                    |  |  |  |  |  |  |  |
| Safety<br>(environment)   | 26.7                                   | 16.7                                    | 26.2                                   | 11.1                                    |  |  |  |  |  |  |  |
| Psychosocial<br>issues  | 50                                     | 20                                      | 21.4                                   | 16.7                                    |  |  |  |  |  |  |  |
| Distance  | 30                                     | 13.3                                    | 28.6                                   | 50                                      |  |  |  |  |  |  |  |
| Communication – phone   | 10                                     | 3.3                                     | 9.5                                    | 0                                       |  |  |  |  |  |  |  |
| Equipment problems  | 30                                     | 6.7                                     | 14.3                                   | 22.2                                    |  |  |  |  |  |  |  |
| Lack of back-up support   | 6.7                                    | 10                                      | 21.4                                   | 22.2                                    |  |  |  |  |  |  |  |
| Having to work next day   | 40                                     | _                                       | 35.7                                   | _                                       |  |  |  |  |  |  |  |
| Timing  | 13.4                                   | 3.3                                     | 4.8                                    | 27.8                                    |  |  |  |  |  |  |  |
| Care plan<br>incomplete   | 20                                     | 20                                      | 11.9                                   | 22.2                                    |  |  |  |  |  |  |  |
| Other (some<br>service visits not<br>made)  | 20                                     | 26.7                                    | 9.5                                    | 16.7                                    |  |  |  |  |  |  |  |

| If you have made a ho                   | ome visit after hours, ha              | ve you experienced any                  | v problems relating to p               | atient care?                            |
|---|--|---|--|---|
|   | PPA1 baseline – %<br>response (n = 30) | PPA1 follow-up – %<br>response (n = 30) | PPA2 baseline – %<br>response (n = 42) | PPA1 follow-up – %<br>response (n = 18) |
| No problems<br>experienced              | 26.7                                   | 26.7                                    | 31                                     | 33.3                                    |
| Medications not available               | 63.3                                   | 36.6                                    | 38.1                                   | 55.6                                    |
| Multiple/unclear medication orders      | 36.7                                   | 20                                      | 9.5                                    | 11.1                                    |
| Equipment not<br>available              | 26.7                                   | 16.7                                    | 16.7                                   | 7.2                                     |
| Patient information not available       | 13.3                                   | 13.3                                    | 21.4                                   | 11.9                                    |
| Time delays                             | 10                                     | _                                       | 21.4                                   | _                                       |
| Care plan<br>incomplete/unclear         | 16.7                                   | 13.3                                    | 14.3                                   | 7.2                                     |
| Safety issues                           | 6.7                                    | 6.7                                     | 9.5                                    | 2.4                                     |
| Move smart risks                        | 0                                      | 6.7                                     | 0                                      | 0                                       |
| Major crisis<br>situation               | 13.3                                   | 3.3                                     | 7.2                                    | 2.4                                     |
| Difficult patient or<br>carer behaviour | 23.3                                   | 3.3                                     | 7.2                                    |   |
| Other                                   |  | 23.3                                    |  | 11.1                                    |

## Triage staff data

| Three mos                        | Three most common reasons for after-hours palliative care calls |        |                 |                             |      |                            |      |              |                          |                             |                     |                  |                   |
|----------------------------------|---|--------|-----------------|-----------------------------|------|----------------------------|------|--------------|--------------------------|-----------------------------|---------------------|------------------|-------------------|
|                                  | P   | ain    |                 | sea /<br>iting              | (    | spirat<br>ory<br>blem<br>s |      | eral<br>/ice | Death                    | Anxiety<br>restlessr<br>ess |                     |                  | Other             |
| PPA1 - % response (n = 7)        | 1   | 00     | 1(              | 00                          | 7    | '1.4                       | 42   | 2.9          | 42.9                     | 28.6                        | 28.6                |                  | 14.3              |
| PPA2 – %<br>response<br>(n = 23) | 8   | 1.8    | 5               | 0                           | 1    | 3.6                        | 36   | 6.4          | 22.7                     | 45.5                        | 18.2                |                  | 27.2              |
| Three mos                        | t difficult   | pallia | ative ca        | re call i                   | ssue | s to ha                    | ndle |              |                          |                             |                     |                  |                   |
|                                  | Lack of<br>access<br>to pall<br>care data                       | aggi   | aller<br>ession | English<br>a seco<br>langua | ond  | Respi<br>probl             |      | Pain         | Anxiety,<br>restlessness | Death                       | Nausea,<br>vomiting | Genera<br>advice | Bowel<br>problems |
| PPA1 –<br>%<br>response          | 85.7  | 7      | 71.4            | 42.9                        | 9    | 28                         | .6   | 14.<br>3     | 14.3                     | 0                           | 0                   | 0                | 0                 |
| PPA2 –<br>%<br>response          | 36.4  | 3      | 31.8            | 27.3                        | 3    | 18                         | .2   | 45.<br>5     | 54.5                     | 13.6                        | 9.1                 | 9.1              | 4.5               |

## **Appendix 2: Literature review**

A literature review was undertaken to explore literature regarding after-hours palliative care models published in English from 2006 onwards. The review used the following search engines: Cinahl, Cochrane Library, Embase, Medline, Medline Plus, Ovid, Proquest Health and Web of Science; and the following keywords: after-hours, after-hours models, palliative care, policy, evaluation, assessment, community palliative care, needs assessment, community/community services, community palliative care services, terminal care, risk assessment, and various combinations of these.

#### Literature findings

The review suggested a scarcity of studies reporting on the establishment and evaluation of after-hours community palliative care services.

#### Models of after-hours services

While after-hours palliative care is acknowledged as having significant advantages, including being found to be important to people receiving palliative care (Borgsteede et al. 2006), and is seen as an important part of providing equitable care (Department of Health & Ageing 2004), Victoria does not have a specific government policy relating to particular models of after-hours care provision.

The United Kingdom model 'Palcall', which provides a 24-hour telephone call service for patients, carers and health professionals (Cambell et al. 2005), and a similar service in the Netherlands (Teunissen et al. 2007) were both found to be effective in improving patient care and support for carers and health professionals after hours. Carr, Lhussier and Wilcockson (2008) report the successful functioning of a 24-hour telephone advice line designed to transfer knowledge between specialist and generalist health professionals in the United Kingdom.

The Australian context has been broadly described as having two models of after-hours palliative care provision (Aranda et al. 2001): direct after-hours contact with a specialist community palliative care service; and triage through an inpatient palliative care facility or generalist triage service. A pertinent example of a centralised after-hours telephone support service provided by generalist nurses at a multipurpose service in a rural community has been reported by Phillips, Davidson, Newton and DiGiacomo (2008). This data supports the view that acceptable palliative care advice can be provided by generalist nurses in a cost-efficient manner when they are supported by appropriate protocols. Further studies relating to after-hours palliative care models are referred to in Tan, O'Connor, Miles, Klein and Schattner (2009).

#### Key factors in successful after-hours care provision

Communication was identified as the single most important factor in providing after-hours palliative care. The importance of good communication skills by those providing information, whether that be to people receiving palliative care or to other professionals, has been stressed (Carr et al. 2008). Communication between nurses and general practitioners (GPs) has been repeatedly emphasised and is key to the success of after-hours palliative care (Brumley et al. 2006; Kendall et al. 2006; Seow et al. 2008; Tan et al. 2009; Walshe et al. 2008). Solutions to the communication issue have been debated. The value of electronic hand-held client records has been questioned (Street & Blackford 2001). There is no doubt, however, that the issue of IT interface between service providers and call centres is an important and problematic issue requiring further investigation and funding (Phillips et al. 2008; Roberts et al. 2007).

GPs' involvement is seen as vital to the successful functioning of an after-hours palliative care service, especially in rural areas. Limited availability and access to GPs after hours has been mooted as a significant issue (Wilkes et al. 2004; Chan et al. 2007). A survey of people receiving palliative care indicated that access to GPs after hours was highly valued (Borgsteede et al. 2006). One Australian study of GPs (Rhee et al. 2008) showed that only one-quarter of those surveyed were involved in palliative care. Another study indicated that the average GP sees new patients requiring palliate care four to five times per year (Mitchell & Price 2001). This raises the issue of adequate education for GPs in palliative care. Efforts to address this matter include the Australian government-funded Program for Experience in the Palliative Approach (PEPA) (Department of Health and Ageing 2011) and a Dutch telephone advisory service run for GPs by GPs with a special interest in palliative care (van Heest et al. 2007).

Multidisciplinary teams or inter-disciplinary teams have been identified as important in providing communitybased palliative care, and especially in the adequate provision of after-hours care (Goldschmidt et al. 2005). GPs are an integral part of such teams (Ceichomski et al. 2009). In the Australian setting the introduction of Enhanced Primary Care Medicare Items, which renumerate GPs for time spent in participating in team meetings, in person or by phone (at which the care of patients is reviewed) enhances the possibility for communication to take place (Tan et al. 2009). Such discussions are also likely to enable more appropriate anticipatory prescribing, a particularly significant issue in rural and remote areas where access to GPs and pharmacies after hours is difficult or impossible (Tan et al. 2009; Walshe et al. 2008). Another significant role of the team is appropriate care planning during regular hours as this has been shown to reduce the need for afterhours palliative care by anticipating possible upcoming events. This process empowers the client and their carer to address issues without the need for an after-hours visit or a trip to the hospital emergency department (Hansford & Meehan 2007; Tan et al. 2009; Walshe et al. 2008).

When after-hours triage services have been provided the outcomes can be partly predicted by the skill of the triage nurse, regardless of whether they are a generalist nurse or palliative care trained (Aranda et al. 2001); however, triage training and providing appropriate protocols do have an important impact on the quality of after-hours service provision (Worth et al. 2006).

Other issues identified as having an impact on the quality and type of after-hours care provided are the importance of continuity of care to people receiving palliative care (Borgsteede et al. 2006), cultural issues (Phillips et al. 2008) and people receiving palliative care who live alone (Aoun et al. 2007).

#### Evaluation processes

The review identified little literature relating specifically to palliative care evaluation. While noting that quality of life is a key measure when assessing the value of palliative care service provision, Jocham, Dassen, Widdershoven and Halfens (2009) stressed the need for more high-quality evidence about the most appropriate ways to compare the relative merits of different models of palliative care service. Information transfer between service providers and team members is important and therefore the quality information transfer systems has been suggested as a key performance indicator of after-hours palliative care service provision (Burt et al. 2004). The development of appropriate systems frameworks to assess this performance indicator is essential. However, a range of other indicators have been suggested as appropriate measuring points for the quality of care provided including: the nature and extent of inter-professional collaboration (Bainbridge et al. 2010); the number of hospital admissions, emergency department visits and whether or not people die in their place of choice (Seow et al. 2008); and patient and family satisfaction levels. These indicators need to be evaluated in relation to: pain and symptom management; adherence to patient preferences; provision of life enrichment activities; the level of communication between professionals, the person receiving palliative care and their carer; and the availability of professionals known to the patient and family after hours (Norris et al. 2007).

#### Summary

The most important factor in the appropriate provision of after-hours community palliative care is the level and quality of communication. This applies both within multidisciplinary teams, and between team members, clients and their carers. GPs are an integral part of the team and they need to be involved in forward planning that anticipates possible crisis and caters for the potential need for medication after hours. The adequate training of triage staff and providing appropriate protocols for their use have been shown to be important. Finally, the quality of information transfer systems and of course client satisfaction are very important indicators of the quality of service provided.

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